



House of Lords
House of Commons
Joint Committee on
Human Rights

A Life Like Any Other? Human Rights of Adults with Learning Disabilities

Seventh Report of Session 2007–08

Volume II



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Oral and Written Evidence

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Joint Committee on Human Rights

The Joint Committee on Human Rights is appointed by the House of Lords and the House of Commons to consider matters relating to human rights in the United Kingdom (but excluding consideration of individual cases); proposals for remedial orders, draft remedial orders and remedial orders.

The Joint Committee has a maximum of six Members appointed by each House, of whom the quorum for any formal proceedings is two from each House.

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NOTE:

The Report of the Committee is published in Volume I, HL Paper 40-I, HC 71-I.

The Evidence of the Committee is published in Volume II, HL Paper 40-II, HC 71-II.

Evidence received by the Committee but not printed can be inspected at the Parliamentary Archives, email: archives@parliament.uk

Oral evidence

Taken before the Joint Committee on Human Rights

on Monday 25 June 2007

Members present:

Mr Andrew Dismore, in the Chair

Judd, L
Lester of Herne Hill, L
Onslow, E of
Stern, B

Nia Griffith

Witnesses: **Dame Jo Williams**, Chief Executive, MENCAP, and **Mr Andrew Lee**, Director, People First (Self-Advocacy), gave evidence.

Q1 Chairman: Good afternoon, everybody. This is our first formal evidence session on the inquiry we have just started into Human Rights for Adults with Learning Difficulties. We are joined for our first session by Dame Jo Williams, who is the Chief Executive of MENCAP, and Andrew Lee, Director of People First, the self-advocacy group, who is accompanied by Kevin Clifford. Welcome to you both. I am sorry about the late start. Andrew, do you want to make an opening statement?

Mr Lee: Yes, please. As I have said on previous occasions, I think of life as a person with learning difficulties as being taken to watch a football match where life is that football match and never being allowed to join in. People with learning difficulties have the same dreams, inspirations and aspirations as everyone else but we are held back from engaging in life. If you think of your most cherished moments in life, of the things that you still look back on and smile, I expect it is something that people with learning difficulties would get held back from doing. At the root of the barriers we face is an idea that we are less good and less worthwhile than other people. Doctors try to stop us from being born in the first place. One thing that comes to mind is the amniocentesis test for Down's syndrome that itself causes more spontaneous miscarriages than there are abortions as a result of parents discovering they are carrying a baby who will be born with Down's syndrome. When we are born, our parents are given negative views about our chances in life. They are encouraged to mourn the fact that they have abnormal children, and their disappointment stays with us throughout our lives. My parents were told I would never walk, would never talk, and would be a vegetable for the rest of my life. The extent to which society looks down on us contributes to the fact that throughout our lives people with learning difficulties do not get their human rights, and yet there is no public outcry, no-one up in arms about how little choice or control we have over our everyday lives. One of the most tragic things about the recent abuses in Sutton and Merton was that staff did not even know they were doing anything wrong. Another major factor, I am afraid to say, is money. People within the system who know how

unfair our lives are are simply used to the fact that there is not the money there to do anything about it. In order to be given the same chance in life as other people, people with learning difficulties need good, independent, individualised support, and that costs money. One thing that would make a big difference would be Lord Ashley's Independent Living Bill. I urge that this be passed as law by this Government. This would give disabled people, including people with learning difficulties, a legal right to the support we need to lead full lives. This piece of law would make the connection between human rights and the day-to-day lives of disabled people. With that behind us, our lives would have to improve.

Q2 Chairman: Thank you very much for that opening statement. We put out a notice to ask people various questions. Do you think we asked the right questions or is there anything else we should have asked about?

Mr Lee: I am pleased that the Easy Read call for evidence has been done in a way that is easy to understand and that the deadline for evidence was extended, as this is vital to people with learning difficulties being able to give their views. However, I think a lot of people will need support to see how what the call for evidence is asking for connects to their lives and experiences. A lot of people do not know what their human rights are and, for example, asking about human rights and public services such as housing will not mean much. What you are asking there is about people's experiences in group homes and supported living, and where they are treated unfairly, it would need support for a lot of people to realise that. I think the questions should have been more like those that *Community Care* magazine asked in their recent survey as part of their A Life Like Any Other campaign. Their questions were about the everyday lives, experiences and also aspirations of people with learning difficulties, so people with learning difficulties themselves could engage with the questions. The results of the survey were very telling and showed how far our lives are from those of other people, even down to the fact that some staff and carers have written beside answers given by people with learning difficulties,

rubbishing what they were saying. For example, someone wrote that they would like to be able to get a job or live independently, and the carer had written “not capable of this” next to it. I would urge this Committee to find out about *Community Care*’s research, if you have not already done so. Human rights abuses against people with learning difficulties happen every day on different levels. There are major abuses on the level of Cornwall and Sutton and Merton, but the reason I am not surprised about the big abuse is because they exist within a culture of disrespect and ultimately abuse: things like an individual wanting to go to a garden centre on his birthday and staff saying that there were not enough staff on duty for him to do this so he had to stay at home; a kitchen in a group home being locked at 8 p.m. every night so residents cannot make themselves a cup of tea after that time; a day centre saying they do not have the resources to communicate effectively with every service user; a self-advocate being told by group home staff that she cannot go out to her meeting—with a government minister, incidentally—until she had made her bed, then calling the police and reporting her missing when she went out anyway; an individual being told by respite home staff that she was not allowed any pizza along with everyone else because she was too fat at size 14; adults with curfews and if they miss the curfew, they get locked out.

Q3 Chairman: Why do think this is going on?

Mr Lee: Because it is being ignored; there are no consequences. The reason why these things have been allowed to happen is because of the way society views people with learning difficulties for what we cannot do instead of what we can. I think that a contributing factor alongside is the fear of letting people with learning difficulties take risks. Services are aware of the duty of care and are frightened of things going wrong. The effect of removing risk from life is removing the chance of a real life. The reason I think these things happen in the first place is the way services are set up, and a lack of money for real individualised support, where people with learning difficulties are lumped together in services and there is inevitably an element of warehousing and a lack of individual choice and control. The person should not be placed in a service. Support should go to them to enable them to live as they want to. This approach should save money in the long run, as the Office for Disability Issues Independent Living Review is setting out to prove, but in the short term it definitely involves a significant investment. Things will not change while we try to tinker with existing services, as has happened since *Valuing People*. We need entirely new structures of support.

Q4 Chairman: Jo, do you think that the Human Rights Act, the Disability Discrimination Act and the recent Disability Equality Duty have made any real difference to the way that people with learning disabilities are treated?

Dame Jo Williams: I think it is early days. Andrew has made some very powerful statements and supporting what he has to say by referring to

Cornwall and Sutton and Merton. We published a report earlier this year really reflecting on some very poor practice in the health service. That was called *Death by Indifference*. I think it is early days. The fundamental issue which I think Andrew has highlighted is that, in a variety of different ways, people with a learning disability are somehow regarded in a different way to the rest of society, and we certainly welcome this Committee’s concentration on this particular issue. We think that the legislation provides the right kind of framework but actually, we have yet to see people’s behaviour change, and that is about a cultural shift in the public sector and in public attitudes generally.

Q5 Chairman: Do you have any practical examples of where the human rights legislation has helped to improve the situation?

Dame Jo Williams: I do not think the legislation has been put to the test, and certainly one of the things that concerns us, for instance, with respect to Cornwall, is that actually there have not been any criminal prosecutions and there is an issue there about people with a learning disability being credible witnesses. So we have a lot of work to do. I would add that I think for many people there is a sense in which family carers and supporters are also prepared to put up with things that probably most of us would not put up with, and that is about very low expectations. That is, again, a significant issue that we have to address.

Q6 Chairman: Could I ask Andrew another question? When the Human Rights Act was originally published, a number of groups put out information on the Act and human rights in Easy Read. Do you think people with learning disabilities understand what human rights mean to them?

Mr Lee: Can you repeat the question?

Q7 Chairman: When the Human Rights Act started, information was put out by a variety of groups in Easy Read, and the question is, do you think people with learning disabilities understand what human rights mean for them?

Mr Lee: It was definitely important that Easy Read information was brought out on human rights. It meant that people with learning difficulties involved in fighting for a right became better informed and were better able to campaign. In any section of the population you find some people who are interested in politics and some people who are not. You cannot expect all people with learning difficulties to be interested in reading about rights and politics, just like I would expect the number of people without learning difficulties in this country who have read the Human Rights Act are in the minority. That does not mean that only a minority should have their rights met. People without learning difficulties have a better sense of what their rights are because, through sheer experience, they have come to expect a certain level of treatment in life.

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Q8 Baroness Stern: My first question is to Jo and after that I am going to ask Andrew a couple of questions. My question to you is about the parallel universes and the gap between the policy and the reality. You have already said a little about that but I wonder if you could say why you think there is still—and we are talking about six years now—such a gulf between the policy and the reality of what happens to people?

Dame Jo Williams: I think it is a very complex question and I do not think there are a number of things that I can just reel off and say to you, “If we fix that, it is going to make a difference.” There is something very fundamental about the way in which through history people who have been defined as having a learning disability have been treated, the institutional care that perhaps marked the way in which society looked after people until the Eighties and Nineties has left a legacy—there is no doubt about that. There is a huge level of ignorance, I think, amongst professionals. If I think about the people in the Health Service, we know through our work in MENCAP that they may not come across various conditions very often, but somehow there seems to be almost institutional discrimination. We believe that a person with a learning disability is of less worth, and we believe that has to be challenged through education and training, and actually, people becoming role models and exposure and involvement in work. Only one out of ten people with a learning disability are in active employment, so actually exposing people in the workplace is one of the ways in which people begin to change their understanding and behaviour. It is a very complex issue and I think we have a lot of work to do. The understanding of the legislation and the way in which people are able to use the legislation to protect their rights—I think it is early days. It is clear to me that we, perhaps my organisation and others, have to do more to work with people to help them protect themselves and protect their human rights.

Q9 Baroness Stern: Do you think human rights is a helpful way of changing the situation you have described?

Dame Jo Williams: I think it is part of a whole range of complex issues, and it is important to have the legal framework, but it is also, as I said earlier, very important to make sure through education that there is increased understanding. We have not talked about resources—I think Andrew touched on this—but actually, one of the things that we now know is that through medical advances children, babies, are living that would not have done possibly five or ten years ago, coming through into adult life with a range of very complex health needs as well as other needs. They do require significant resources, and their families need support. They are reaching adult life, again, with a significant amount on the public purse and the resources invested—and there have been additional resources—are not meeting that demand.

Q10 Baroness Stern: Do think that the Government’s stated commitment to the human rights of people with learning disabilities is actually taken seriously by all government departments?

Dame Jo Williams: I think there has been some progress. I would say that when *Valuing People* was published, there were not resources to support and back it, and some of the measures put in place to bring about change, like the partnership boards, have not been universally successful. In any given location there may be 20-plus partnership arrangements in that community. It is my view that actually, if we are to see significant change, people who have positions of power in public bodies, hospitals, police authorities, someone has to be a champion and understand the world of learning disability and speak up about it. It has to be embedded in everyday life rather than put into a separate group and as I say, through *Valuing People*, a partnership board with a learning disability.

Q11 Baroness Stern: Andrew, can I ask you, do you think that *Valuing People* has improved the way that people with learning disabilities are treated?

Mr Lee: *Valuing People* put choice and control on the agenda, and that was significant. Commissioners now know about the principle of independence, inclusion, choice and control. However, still there are front-line staff who do not know about the White Paper, and many people with learning difficulties as well. Most people who know about the principles agree that they are good ones, but the stumbling block for a lot of authorities and services has been around how to put them into place within existing frameworks and resources that they have. There has been resistance to change amongst service users and carers who have not been properly consulted or who fear that change is an excuse to save money without investing in real alternatives. Local authorities have been trying to save money by making eligibility criteria under Fair Access to Care tighter and tighter and denying support to all but those with the highest support needs. However well the principles of choice and control are understood, if there is no funding for services, then there will be no services to uphold those principles. We need a target for change with real teeth and we need policies for changing the entire framework of services for people with learning difficulties to enable Commissioners and service providers to create services that follow *Valuing People*. We also need the Independent Living Bill, which will give people with learning difficulties a legal right to support. Then, if government policy fails to establish the services we need, the courts of law can play their part in pushing for change.

Q12 Baroness Stern: Thank you very much. My final question is to you, Jo. The Government, as you know, have said they want to refresh *Valuing People*. What steps do you think they should take in the course of this refreshment to secure the rights of people with learning disabilities?

Dame Jo Williams: I think I have partly answered that question already, suggesting that some of the principles, some of the understanding, needs to be

mainstream, within local communities. I agree with some of the issues that Andrew has raised about how we begin to address people's entitlement to services. Andrew and I are part of a group called the coalition. We are tried to look very carefully and gather information about what is happening. We are hearing about cuts but we need real evidence. Potentially, once that work is completed, we will have a story to tell about how the resources are being used. I think there may be something for those who are the most significantly disabled, who might want to see an entitlement link to Disability Living Allowance. I think *Valuing People* has done a great many good things. It really has. I meet families, however, whose children, brothers and sisters, are profoundly disabled and they say that as a consequence of *Valuing People* and some of the other changes, where there really are some opportunities, they feel increasingly marginalised and often left to cope alone, without the support they need. So we are certainly, as an organisation, very concerned with those individuals and their families and we would wish the refreshment to really concentrate on supporting those individuals and their families as well as, as Andrew says, setting real objectives and targets.

Q13 Earl of Onslow: Dame Jo, first you, and then Mr Lee. We have an awful lot to get through so can we try and answer as concisely as possible, please. You have said that there is a funding crisis which threatens the stability and success of current government policy and the human rights of adults with learning disabilities. Do you think that securing the rights of people with learning difficulties is mainly a question of spending more money, or is it a question of organisation as to how it is done, or staff training? When Mr Lee was answering first, the things about which he complained struck me as just being bad behaviour, which should not happen in a normally run place. This comes into the point you raised just now about eligibility criteria; if you put the eligibility level so high, it could in theory reduce it to one person for the whole government budget. Could you possibly elaborate on those points?

Dame Jo Williams: The point that I would want to make about funding is that we are gathering information. The evidence that we have to date it is that the increase in the population of people with learning disabilities is about one per cent per annum. The current investment is not keeping pace with that. We believe that is because of medical advances. We are doing more work with colleagues and will want to feed our findings into the Comprehensive Spending Review over time. We are hearing about cuts in services that are affecting people's lives. There is some change there that actually may be the way the future is going, and that is where individuals themselves are given a budget to commission and purchase services, and that seems to be giving people a greater degree of control and independence, and I know the Government is looking at its policies in relation to that. Again, we need to make sure it is resourced. The second point to make is that you are absolutely right; fundamental to everything we have

been talking about this afternoon is people's attitudes. They need to be properly trained and their behaviour needs to be challenged. The legislative framework is there and gives the opportunity to challenge unacceptable behaviour. That is why it is so important.

Q14 Earl of Onslow: Who is not doing the challenging then?

Dame Jo Williams: It may well be the individuals themselves and it may also be their families, because of fear of change and being deprived of services, but actually, we also know that some professionals themselves who are in senior positions are not challenging poor practice and poor behaviour, and Cornwall is a classic example of that.

Q15 Earl of Onslow: You have said that the number of people with learning disabilities is increasing by one per cent a year. Does this mean—I assume it does—that over time, say over ten years, there will be ten per cent more people? Is the budget in any way keeping up with that?

Dame Jo Williams: No.

Q16 Earl of Onslow: Does the cost per person increase over inflation? Does this show that there is a need, just to stand still, that there should be a larger than inflation budget?

Dame Jo Williams: These are very good questions and I do not think I have the detail to respond to them adequately. They are certainly questions we are looking at. What I would say is, from our experience in MENCAP, we are now seeing young people, for instance, who may be dependent on medical interventions and techniques for their life, so for some families their homes are mini hospitals; it is that level of support and care. It is costing thousands of pounds per week.

Q17 Earl of Onslow: Mr Lee, would you like to add anything to what Dame Jo has said?

Mr Lee: Yes. If the Government is serious about stopping human rights abuses against people with learning difficulties, then it will simply cost money. If society decides that ultimately it does not care enough about people with learning difficulties to spend money on us, then society exists as a society where people are left out, marginalised and abused within our midst.

Q18 Earl of Onslow: This again is to Dame Jo. You have told us that sometimes more able people are denied services because resources are allocated to those with more complex needs. Do you think that striking a balance in this way is always wrong? If we assume there is no more money available, how can the current arrangements for distribution of resources and access to services be improved? I would bracket in with that that there has, for instance, been criticism of the Government's massive extra spending on the Health Service, but it has not been productive; that the productivity of the extra expenditure has not been nearly as much as the

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expenditure itself justified. Do you think there is room for improvement in, basically, learning disability treatment productivity?

Dame Jo Williams: I do think there are some questions about how the current social care system is working for people. I do not think everyone who is in receipt of a service is necessarily having a really good quality of life.

Q19 Earl of Onslow: Quality of life or quality of service?

Dame Jo Williams: Quality of life. The service, maybe through the regulator or the inspectorate, may be of a high standard but Andrew has made the point that people may be told when they can go out, what time they have to eat and what time to go to bed. People are looking for a different style of service, different expectations.

Q20 Earl of Onslow: To me, that means quality of service rather than quality of life.

Dame Jo Williams: The point I am trying to make—and perhaps I am illustrating it badly—is that actually, for many people quality of life is about making choices for themselves and freedom to act. Andrew's point about risk aversion in some providers of services is one that I would absolutely support. So we need changes to the way in which the system is working. We are looking now, as I have suggested, at different ways of individuals receiving money to take control of their own lives. I would also want to say that we have concentrated on social care and health but actually, in terms of working, for instance, people with a learning disability are significantly disadvantaged and opportunities, working with employers, giving people information and support to get into employment—actually, the people I know that are working in my own organisation and elsewhere, I know that that changes their lives significantly. We need increased flexibility so that people may need support for a longer period of time as they move into the working environment, and the current regulations I do not think extend perhaps as long as some people with a learning disability may require to make the adjustment into work.

Q21 Nia Griffith: If we could turn to the issues about independent living, what really are the main barriers to people with complex learning disabilities actually leading an independent life?

Dame Jo Williams: I know people who do have complex needs who can be supported to live independently but it requires significant flexibility and a great deal of imagination for the right kind of support to be put together and it is very difficult for people themselves without good support to access quality housing services, make sure that the right kind of personal assistants are appointed for them, but there are some very good examples of this. My organisation works closely with a sister charity called Golden Lane Housing where people are themselves tenants of properties, that actually with support, even with complex needs, people can have a very significantly enhanced quality of life.

Q22 Nia Griffith: What do you think actually makes a difference between people being able to do that and not? Is it to do with attitude and imagination of perhaps the powers that be?

Dame Jo Williams: It is partly that and it is also about aspirations too. This is one of the issues that is perhaps outside the remit of your Committee but I do think that one of the things we need to see changing with time is through young people's education. Andrew made the point that concentrating on the difficulty or the disability actually denies people those hopes and aspirations. Concentrating on ability and people's gifts opens doors for them and I think that is one of the cultural shifts that we need to see within education, and that is a long journey.

Q23 Nia Griffith: Andrew, I understand that sometimes it is the families who do not want a person with learning disabilities to live independently. What can we do in a situation like that, where perhaps a person wants something different from their family?

Mr Lee: Parents and families can be worried about us living independently because there is not the support around that we need. I think that advocacy is key for protecting the interests of an individual when those clash with what a carer wants, and there needs to be more recognition and funding for advocacy.

Q24 Nia Griffith: Sometimes we understand from some people that it is actually families or carers that stop people from having girlfriends or boyfriends. Why does that happen, do you think?

Mr Lee: People are stopped from having boyfriends and girlfriends for a number of reasons, all to do with us being regarded as not as good or as capable as other people. Some people want us to stop breeding in line with eugenics. Some people do not see us as adults and therefore as not capable of relationships. Some people think we will not be able to look after children. My ex-wife was told by her parents that sex was wrong because she had a learning difficulty and they had her sterilised. One of the factors in the breakdown of our marriage was the fact that we could not have children, which we desperately wanted. Society needs to realise that we are adults, with the rights of adults.

Q25 Nia Griffith: Why do you think it is that sometimes people with learning disabilities are stopped from having children?

Mr Lee: The way things work at the moment, people with learning difficulties are assumed to be bad parents unless they can prove otherwise. It is a case of guilty until proven otherwise. There are many bad parents without learning difficulties, yet it is we who are under suspicion. I think there should be parenting support for people with learning difficulties and it should start before a baby is born—this, incidentally, would benefit many people, not just people with learning difficulties, for example,

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teenage parents. Whenever professionals come into contact with parents with learning difficulties, they need to respect the fact that we have learning difficulties and explain things in a way we can understand. For example, if a doctor prescribes medicine for a child of a parent with a learning difficulty, they need to make sure they explain what the medication is and the dosage in a way that is accessible to the person with a learning difficulty. If a person with a learning difficulty has not understood what the doctor has told them and gives the wrong medicine, they would be viewed as bad parents and the child taken away, whereas if a person whose first language is not English were in a similar situation, it would be understood as an access need rather than

a parental issue. Some guidelines have just come out around support for people with learning difficulties and these should be put in place.

Q26 Chairman: Thank you. I think we are going to have to finish our session with you now because, unfortunately, we lost time at the beginning because of the vote. There may be other things we want to follow up with you in writing; if there are other things that come up, we may want to write to you to follow things up. Thank you for coming. I think you have been very helpful to us today and it has been a very good start to our session. Thank you.

Mr Lee: We wish you the best of luck with your work.

Witnesses: **Ms Eve Rank**, Commissioner, and **Mr Mark Shrimpton**, Assistant Director, Legal and Operations, Disability Rights Commission, gave evidence.

Q27 Chairman: We are now joined by Eve Rank, who is a Disability Rights Commissioner, and by Mark Shrimpton, who is the Assistant Director, Legal and Operations for the Disability Rights Commission. Welcome to both. Thank you for coming to give evidence this afternoon. Perhaps I could start off by asking Mark do you think that the introduction of the Disability Equality Duty has made any difference to the way people with learning disabilities are treated?

Mr Shrimpton: I am largely during this session going to be supporting Eve and I will expect her to answer most of the questions, and I think she has indeed got something to say. If that is okay with the Committee, I will pass over to Eve.

Ms Rank: Some local authorities do not know about the Disability Equality Duty. For example, last week I had alterations done to my bathroom, because my husband is disabled, and I am disabled a little bit for the next six weeks. I asked about the equality duty and asked if he was involved with people with learning disabilities and he did not know what it was. That is the Adaptations Manager. I also asked somebody from Bedfordshire social services this morning and they did not know. So in that context, I do not think anybody professional is not working for people with learning difficulties because professional people do not know about it. However, it has only just recently come into force, since December, so it is early days to tell whether it is working or not but it is great fun asking the people who I know if they know about it. I think it is really important that they do involve people with learning difficulties in their equality schemes. The one problem they might have is that they do not know how to do it, because it is the first time they have got to involve people, so they need training, and the only people to give this training to get people involved are the people with learning difficulties themselves, because they are the experts.

Q28 Chairman: When the Government reviews the *Valuing People* document later this year, what do you think the Government should do?

Ms Rank: I think they should involve people with learning difficulties to see what they think about the review of *Valuing People*. I think they also need to go back and have a look at what they were saying years ago, or what we were saying years ago, because I was part of the advisory group. Although *Valuing People* has done good things, there are still some gaps. For instance, it needs to look at employment for people with learning difficulties because that was one of the big areas, and there are still too many people with learning difficulties on Incapacity Benefit. There are some people in work but there need to be more. Also, there are some people with learning difficulties that are not on the Minimum Wage, that still get paid in shopping vouchers, etc. They also need to look at the issues, again, particularly around carers. The reason why I am saying this is because more carers with learning difficulties are coming on board as their parents are getting older. In *Valuing People* it highlights carers but it is not carers with learning difficulties. They have got a family carers network but who do people with learning difficulties go to? They do not have anything at all.

Q29 Lord Lester of Herne Hill: You told us in your evidence that advocacy services should go far beyond the independent mental incapacity advocacy service. What would holistic advocacy services do for a person with learning disabilities?

Ms Rank: There is a basic answer to that. It is supposed to advocate for people with learning difficulties, but I think what would help are things like peer support, Circle of Friends. I believe that there is not enough money to go round to give advocates, but sometimes people with learning difficulties can advocate for people, and that has been happening. I have known that to happen. I advocate for some of my friends, so I know it is happening, although I do know as well that organisations should also put their leaflets, etc, into Easy Read and to promote Easy Read, to also help with form filling, because benefit forms are not easy and somebody with a learning difficulty might want an advocate then. That would help. Also, for

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example, I know in Bedfordshire our lead Commissioner for learning disability dishes out money for Advocacy Alliance just on training, but there is no advocacy money. They should be given a budget that is spread out between training and advocacy, so I think the local authorities might have some responsibility there.

Q30 Lord Lester of Herne Hill: I do not know whether Mr Shrimpton wants to add to that?

Mr Shrimpton: No, I will leave it to Eve, thank you.

Q31 Lord Lester of Herne Hill: Thank you very much for that. You told us also about the importance of support from advocates to make a complaint. If an advocate is not available, is there any other way to help make it easier for people with learning disabilities to make complaints?

Ms Rank: For instance, again, if you have a complaint against social services—that is just an example—their complaints procedure is not easy, and it should be in Easy Read, because if we have the information but we can understand it, there is no point in giving it to us because it is absolutely useless. So I think, again, Easy Read to promote it.

Mr Shrimpton: Earlier on we were talking about the confusion about precisely what advocacy services are, and there are some lower levels that certainly are not advocacy. If authorities open up their process in the way that Eve has described, talking about Easy Read and promotion of the availability of those materials, mere assistance with the form filling can often be extremely helpful. That is not advocacy; that is purely an administrative task, but it can be enormously helpful in opening up systems.

Q32 Lord Lester of Herne Hill: That is also included in guidance and support by the Disability Rights Commission, as I understand it.

Mr Shrimpton: Absolutely, yes.

Q33 Nia Griffith: The Disability Rights Commission say that sometimes consultations are sham events, because people do not have enough time to respond. How can we make sure that such activities really do take into account the needs of people with learning disabilities, their views and opinions?

Ms Rank: We think planning. It should be planned properly. You must know that you have consultation out probably months in advance. For example, there was loads of consultation on the Mental Capacity Act; there was loads of consultation about that. There was a deadline, although I cannot remember what it was, but it was probably needed for next week or the week after. That is too quick. You need at least three months' notice. You would know when that is coming up, so authorities and organisations should plan consultations and get the Easy Read version out.

Mr Shrimpton: One of the issues that Eve mentioned on this question earlier on was that, in answer to how the Government or other authorities can make sure their activities are taken into account, the Disability Equality Duty is now there; they actually have a duty to do that, so it is something they should have

been actively pursuing and involving people with learning disabilities in their activities for the last six months.

Ms Rank: Yes.

Q34 Nia Griffith: What happens if a decision has to be made very quickly? What could be done then to make sure that we include people with learning disabilities?

Ms Rank: I think they should never be a quick timing, because with forward planning, as Mark has said, the Disability Equality Duty should come into force. I have had problems in past experience with consultations, especially, for example, if you have a day centre that may be closing and Joe Bloggs does not want to go to Fairfields day centre; he wants to go somewhere else, so they have this consultation day but the problem is they have already decided what they are going to do, so it is tokenistic; it is not consultation at all. They have just thought "We will go in there and say what we have got to say" and that is it. It becomes very tokenistic.

Q35 Nia Griffith: Can you perhaps tell us if there is any way that we can make it easier for people with learning disabilities to vote?

Ms Rank: The problem is that some residential care homes for people with learning difficulties actually take the voting cards away because they believe their residents do not understand the voting systems. I think it would be a good idea to monitor care homes to find out how many people with learning difficulties actually voted in the general election, and if they come back and say nobody has voted, you need to ask them why and if they say "Joe Bloggs won't understand", there is something that needs to be done. I think the Commission for Social Care Inspection should be able to monitor it within their inspections. Also, the Disability Rights Commission Learning Disability Action Group two years ago now did a pack on the right to vote. We have run a few training events, which were successful, so more people with learning difficulties did vote, because we did a mapping exercise. So there is the right to vote pack which you can get through the Internet. That could also be done through the Electoral Commission and people with learning disabilities should be able to work with the Electoral Commission, and the Social Care Inspectorate should be able to talk to them as well. On 10 July DRC is launching a campaign on how to get people with learning difficulties involved in becoming part of a political party, which will be launched here.

Q36 Earl of Onslow: As you know, the new Commission for Equality and Human Rights absorbs the Disability Rights Commission and various other bodies. As you also probably know, some people in the learning disability world have some reservations about this. The CEHR will have a disability sub-committee chaired by Lady Campbell. Do you think the new CEHR will be able to understand the human rights and equality issues facing people with learning disabilities? Should they have a learning disability action group like yours?

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Ms Rank: I am going to split that question into two parts. Your first question was whether I think the CEHR will understand people with learning difficulties. I personally think not, if they do not have anybody with learning difficulties on board, because I believe that if they do not have anyone with experience of a learning disability, they do not know, because they have not been in that position.

Q37 Earl of Onslow: May I suggest you are angling for a job? I am only joking!

Ms Rank: No. Also, in the fact of the Learning Disability Action Group, yes, because the reason why I am saying that is because there have been some changes. I cannot say the word. He has come up with a big word.

Mr Shrimpton: Colossal changes. When the group considered these papers at the last meeting in February, they considered they had made huge changes, not just in the sphere of the statutory sector and public delivery but also in the private business world, in the banking industry and other areas as well. The group's feeling was that, if its work was lost, not necessarily through the same membership, but if that focus was lost within the new Commission, then learning disability issues will fall off the agenda, without a shadow of a doubt.

Q38 Earl of Onslow: Have you met Lady Campbell?

Ms Rank: I know Jane. She is one of our Commissioners.

Q39 Earl of Onslow: Do you reckon she is strong enough to take it up and make sure it works?

Ms Rank: I have spoken to Jane and she said she wants to get a committee on board first and then she will let us know.

Mr Shrimpton: But I suspect more power she has behind her from, for example, what emerges from this Committee, the better.

Q40 Lord Lester of Herne Hill: I wonder whether you could take a message back to the Disability Rights Commission or the new Commission that if a consultation is a sham consultation, what they should do about it is to bring public law proceedings, or threaten to do so, because, as you know, it is unlawful.

Mr Shrimpton: Yes, thank you.

Q41 Lord Judd: The Department of Health has told us that they are working closely with the DRC on the independent inquiry into the very disturbing deaths of six people with learning disabilities highlighted by *Death by Indifference*. What do the DRC think are the lessons we can learn as a result of these deaths? What difference do you think it would make if people with learning disabilities train people who work in hospitals or care homes about human rights and equality?

Ms Rank: We think it would be a huge difference, because people with learning difficulties can do training around this area. I think that would make a huge difference. Training should also be mandatory, one of the things that they should do. We think there should be more refresher training for members of staff.

Mr Shrimpton: One of the things that Eve mentioned on the journey here today was that she did not think that individuals delivering this sort of care should receive a qualification unless they have been exposed to proper training, delivered by people with a learning disability. In terms of the lessons that were learned you mentioned a couple of things.

Ms Rank: One of them was to close the institutions. I know there are at least two institutions that are still open. When *Valuing People* came into force, that was something they wanted to close by the end of 2005, and yet there are still two open, and I think there are still two too many. Also, again, regulating care better. For example, I do not think that homes or hospitals should come off the social care inspection because they are good, because they tend to fall off that register.

Q42 Chairman: Thank you very much. We are going to have to go away to the House of Commons. The bell is about to go. Is there anything you briefly want to add, otherwise I think we are going to have to end the session. I am sorry it has been so curtailed.

Mr Shrimpton: There was one question I know you really wanted to ask about the Independent Living Bill and we have prepared answer, if you have two minutes. Eve thinks that there is a need to make big changes to health and social care so that disabled people can be equal citizens, and today only people with very high support needs get help from their council. Often they do not have a say in what kind of support they get and lots of people, as we know, do not get any support at all. People's human rights are suffering because of this. People with learning disabilities need rights to independent advocacy and to control when support workers come and tell them what to do. They need support to be parents and they need support to be carers. The Independent Living Bill would give people these rights. The reforms would save the Government money because more disabled people and more carers would be able to work and pay taxes. Also, more disabled people would be able to live in the community rather than in expensive and inappropriate residential locations. Finally, women's groups and carers' groups support the Bill because it will protect their human rights as well.

Chairman: Thank you very much. I am sorry it has been a bit curtailed but unfortunately we have had votes in the House of Lords and it takes our time away. Thank you very much. There may be one or two questions we want to follow up in writing with you when we have read the transcript. We will write to you if there is anything else. Thank you for your time this afternoon.

Monday 9 July 2007

Members present:

Mr Andrew Dismore, in the Chair

Judd, L
Onslow, E of
Plant of Highfield, L
Stern, B

Nia Griffith

Witnesses: **Ms Sonya Sceats**, Policy and Research Officer, British Institute of Human Rights; **Ms Anne Lofthouse**, Lead Officer for Service User and Carer Involvement in Learning Disabilities; **Ms Lindsey Dyer**, Director, Service Users and Carers, Mersey Care NHS Trust; and **Ms Joanna Perry**, Board of Trustees, Values Into Action, examined.

Q43 Chairman: Good afternoon, everybody. This is our second formal session in our inquiry into the human rights of adults with learning disabilities. We have been joined for the first of our panels today by Sonya Sceats, Policy and Research Officer, British Institute of Human Rights; Anne Lofthouse, who is the Lead Officer for Service User and Carer Involvement in Learning Disabilities; Lindsey Dyer, Director, Service Users and Carers, with the Mersey Care NHS Trust; and Joanna Perry, who is from the Board of Trustees of Values Into Action. Welcome to you all. Does anybody want to make any opening remarks or shall we go straight into questions? Perhaps I can start by asking Joanna: in 2005 you published a document called *One Law For All*, which came to the conclusion that the rights of people with learning disabilities were being pretty badly infringed. Do you think things have changed since 2005? Have there been any improvements?

Ms Perry: I think that in order to answer that question fully probably follow-up research should be done to see if there has been a change between the publication of that report and now. I know that a project that we carried out during and after the publication of that report included going out to self-advocacy groups, which are groups run and organised by and for people with learning difficulties, talking about their daily experiences and how their rights are affected in day-to-day life. We actually went out and spoke to people, asking questions such as the kinds of issues found in *One Law For All*, where people did not have control over their day-to-day life, quite serious infringements to their rights in terms of health—sterilisation and things that you have read about. I think it is fair to say that in the 50 groups that we visited there was very little awareness of the Human Rights Act among people with learning difficulties themselves and professionals. My tentative conclusion would be certainly not enough but we would have to measure how much, whether the principles have really been embedded for people with learning difficulties and professionals.

Q44 Chairman: So the conclusion is that the Human Rights Act has not made much of a difference?

Ms Perry: Probably, yes.

Q45 Chairman: Can I ask Sonya, do you think that people with learning disabilities understand what human rights mean for them?

Ms Sceats: I think Mersey Care will be able to speak more directly to that. The British Institute of Human Rights works on an organisation to organisation basis. Certainly over the last number of years we have worked with hundreds of disability organisations and the message we are getting from our partner organisations is that absolutely, human rights should be made accessible for people with learning difficulties and that when it is, there is a difference.

Q46 Chairman: I will ask Mersey Care that question then.

Ms Dyer: The short answer is yes. I think it is up to us to enable people with learning disabilities to understand human rights and to put it in a language and form that they can understand.

Q47 Chairman: How can we go about doing that?

Ms Dyer: As far as Mersey Care is concerned, we have tried to implement human rights since April 2001 across the whole of the Trust, not just in learning disabilities, because we think it is a set of values and principles that are quite a powerful lever for change. We have taken the view that service users and carers across the whole of our Trust, including people with learning disabilities, have the right to be involved in decisions which affect them, and that is absolutely everything that we do, so that, for example, we involve service users and carers across the whole of the Trust in appointing our staff, giving people the right to have a say about the people who come into their homes and their lives, and that includes people with learning disabilities. Across the whole of the Trust we have had about 160 service users and carers involved in appointing our staff, over a third of our staff to date, and we have had 16 people with learning disabilities who have appointed over 60 of our staff to date. That is just one example.

Q48 Chairman: Do you have any other practical examples of how people with learning disabilities using human rights knowledge can improve the way they are treated and make sure their rights are

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respected? You have talked about them actually hiring staff but in terms of how they are treated personally directly.

Ms Dyer: My colleague Anne is perhaps the best person to give you an example about health action plans.

Ms Lofthouse: We followed the Government White Paper *Valuing People* around trying to give people the opportunity to have a health action plan, and that has been from 2001. What we also realised is that people who are very vulnerable, with multiple disabilities and do not have any communication, are the most vulnerable at receiving health care or not receiving health care, particularly with the MENCAP report in mind. We have developed a photographic health action plan, and I will leave this with you so you can have a look at it. This was done with carers, because the person in here cannot give capacity to consent so it was with his father and his mother's consent and we used photography as a means of communicating his health needs, so how he has to have his medication, how he has to be protected in bed, how he needs to be positioned, how he sits in his wheelchair, how he is transferred. I will leave this with you because it is a very practical example. Another example on the other side is that we have advance statements, which is similar to an advance directive but is more encompassing. Again, we have done an Easy Read version—and I will leave these with you—where in our service we have over 16 service users who are able to give capacity when they are well to say how they would like to be looked after when they are unwell. Again, we have done it in an Easy Read format. The Trust has a different system for those who may be able to read. Again, I will leave these for you. So people can actually see and fill those in. It is interpreting all the policies that we do in Mersey Care and adapting them and changing them so that they are suitable for people with learning difficulties.

Q49 Chairman: Joanna, do you have any examples?

Ms Perry: Yes, the Rights For All project was led by a person with learning difficulties, a project worker, and we devised a workshop which explained human rights principles, how to take action, and explained concepts such as proportionality, which we all know are quite complicated, by the using phrases such as “using a sledgehammer to crack a nut”, using ways to make concepts more accessible to people, and we found that people really did understand the concepts and could take action using them. For example, a lot of people who we worked with would have examples when they were not allowed to see people they wanted to see. For example, they might want to go and see their girlfriend but it was during what the group home said was dinner time. “You can't go at six o'clock. You have to go after dinner time.” This is an example of where a policy might disproportionately interfere with someone's right to enjoy their private and family life. We helped them get the language together to talk to people who had control over their lives and to challenge these quite pervasive daily ways that people's rights were being interfered with. There are many examples of this.

There should be a lot more and it is absolutely possible for people to understand the concepts and make them real.

Q50 Earl of Onslow: I have been reading the Values Into Action evidence and listening to what you have to say about people not being able to see their girlfriends. This is the sort of behaviour that strikes me as something you just do not do, Human Rights Act or no Human Rights Act. This is how, if you are looking after people, under no circumstances should you do it. Ms Dyer also said—and she used a word which I found very interesting; she used the word “lever”. So fundamentally, would I be right in saying that is exactly what you, in the business of looking after people with human rights are doing, using the Human Rights Act as a lever to make sure that people behave properly, in a way that they should have been doing, should do and should always do, whether the Human Rights Act was there or not?

Ms Dyer: Can I answer that? In essence, one argument is should it all be common sense, and I think the difficulty is there is not one version of common sense. Everybody has their own version of common sense.

Q51 Earl of Onslow: It is not common sense. It is decent behaviour.

Ms Dyer: I was going to say that is one argument that I have heard. The point you are putting to me, I think, is about decent behaviour and standards of professional practice.

Q52 Earl of Onslow: Yes, exactly.

Ms Dyer: Unfortunately, again, I do not think there is one standard of professional practice that governs all professions which are involved in the care and treatment of people with learning disabilities. The advantage of the Human Rights Act is that it is something that everybody is entitled to, whether you are a service user, a carer, a member of staff, somebody with learning disabilities or their carer. Everybody is entitled to be treated with dignity and respect. I think it is an empowering Act and I also think it is an inclusive Act that everybody is governed by.

Q53 Baroness Stern: My question is to Lindsey and to Anne. You sent us a lot of documents, and I have to say I read them all and found them quite inspiring. We know that your work on the pilot and on your human rights strategy is at a relatively early stage. You told us that your questionnaire—and I am quoting here—“has the potential to be developed into a viable human rights assessment tool for some people with learning disabilities in a patient setting.” Could you say a little bit more and perhaps explain to us how using that questionnaire will lead to increased respect for the rights of people with learning disabilities?

Ms Lofthouse: All I can speak for is our service. We had quite a good foundation because before the Human Rights Act came into use we used principles that were from John O'Brien—I do not know if people are familiar with that. That was basically a

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rights-based approach. So I think the staff have been very familiar with that. Adding to that the tool that we have used, we have been able to just take a snapshot, because there was only a small number of people that we used to start this off, just to get a flavour of what was happening. We are going to alter it and improve it. We need to make it a bit more easy to read and we need to try and look at FREDA principles at the back of the document to try to put that into a different framework for people with learning disabilities.

Q54 Baroness Stern: Perhaps you should just say what the FREDA principles are.

Ms Lofthouse: The FREDA principles overarch the Human Rights Act and they stand for fairness, respect, equality, dignity and autonomy. They are quite difficult concepts for our service users to understand, so again, I am going to be working with the British Institute of Human Rights to come up with some descriptions so that the translation of those principles can be done in an Easy Read format but we do not lose the meaning of them. Then we are going to develop an action plan from this, and that will be integrated into the work that we do—not something separate but completely integrated into the work of that unit—and come back and do an evaluation, so everybody who leaves our unit will be asked if they would like to do a questionnaire four to six weeks after they have left the unit, and that will be our check to see if it is making a difference. That is our quality assurance framework. There will be a number of other action plans that mean from a service perspective that we need to also look at and that we have to check against. Does that answer your question?

Q55 Baroness Stern: How does the questionnaire make a difference?

Ms Lofthouse: For example, one of the questions is: “Do you feel safe when you are on this unit?” What we will do then is take that and, say, come back and check with other people, put some plans into place and identify where we think the areas that need to be improved are, and come back and check with other people and see if they also feel safe or unsafe. It is that circle of audit that we are hoping to use. Does that make sense?

Q56 Nia Griffith: Obviously, it is very encouraging that you have found that taking a human rights-based approach has led to real improvement but you mentioned both staff attitudes and clinical practice. Can you give us some practical examples of how you have seen improvements come through?

Ms Lofthouse: Yes, the Mental Health Act information. We have, again, put that into an Easy Read format so that our service users know their rights. Before it was read out to them, as it was presented in all the other mental health services, and again, people did not really understand what it was and it was left to individual staff to do the translating. Because we have now done it in a systematic way, where we have looked at that Act, they are now informed of their rights.

Q57 Nia Griffith: You talked about sophisticated evaluation procedures. How do you know that they are informed of their rights? What is the practical outcome? You put a lot of input in. How are you measuring the output and the actual results?

Ms Lofthouse: For example, because we have the rights in an Easy Read format, we also made a booklet about coming in and staying, and it was devised with our service users. They helped to design this booklet. I will leave it here for you to have a look at. One service user who came into our unit was very distressed. In the past he would have had to have been sectioned because of his distress level. We were able to give him this, go through it and tell him what happens when he comes into the unit and answer all the frequently asked questions about his rights and about being sectioned. His distress was completely resolved and he was able to come in without being sectioned. That is an example where we had the information available, it was done with our service users, so it was in a format that they understood. These service users had used our services and understood their needs and were able to safeguard their rights.

Q58 Chairman: Does this reduce the need for advocacy?

Ms Lofthouse: Possibly, but it is quite difficult for us to get advocates. I hope with the Mental Capacity Act now that there will be more advocates around but in the past I have to say it has been quite difficult for us to get them.

Ms Dyer: If I may, on that point, I think the Trust has a responsibility to enable our service users to effect their entitlement. There is also a need for independent advocacy. There is a need for both; it is not one or the other.

Q59 Chairman: What does Sonya think?

Ms Sceats: I would absolutely agree. The British Institute of Human Rights has done work for years now with advocacy organisations and I think advocacy organisations themselves would not want to think that empowering service users to claim their own rights in any way had an effect on their role, in diminishing it in any way, for example.

Q60 Earl of Onslow: With your friend FREDA, I rather got the impression that she was not being properly followed. If FREDA is not followed, why should the Human Rights Act be followed? They are both concepts of decent behaviour on how people should be treated, all of which I think everybody is essentially agreed upon. Why if you have this concept, which seemed to me absolutely right, should the Human Rights Act have any more influence than FREDA?

Ms Sceats: I think FREDA is a very nice concept, in a way. It is an attempt to translate into core principles what the Human Rights Act was always designed to achieve but it is the statutory force behind those principles which give service providers, for example, the confidence to be able to assert that if somebody is not being treated with respect . . .

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Q61 Earl of Onslow: It is the lever.

Ms Sceats: Exactly. I think there is a lot in your point about a lever. It is a very important lever. We have done all kinds of work, not only with the advocates but also service providers, who say, "This is a tool that we always needed in order to be able to say that certain things need to change for the better around here."

Q62 Nia Griffith: We understand from the Commission for Social Care Inspection that sometimes when there has been pressure on funding the money that should have been allocated and used for *Valuing People* is diverted elsewhere. Do you think there is a case for some form of ring-fencing for human rights training, keeping the funds specifically for it rather than letting them be dissipated into other things?

Ms Dyer: Yes, I think there is a danger of dissipation and, yes, absolutely, that money does need to be ring-fenced, but I think we also have to think about, as large organisations, where we make our investment and, if we are going to put human rights at the heart of everything that we do, which I think, as an NHS organisation, we are trying to do, and an NHS organisation should do, we have to be prepared to spend a percentage of our budget on that and that is important.

Q63 Nia Griffith: How do you respond to those who say there are better uses for the money?

Ms Dyer: I would respond from Mersey Care's point of view that we spent roughly a quarter of a million pounds on involving service users and carers, enabling them to effect their right to be involved in decisions which affect their lives. That is my salary, Anne's salary and payments to service users and carers. We make payments of about £55,000 a year to respect them. If you add that all up, a quarter of a million pound sounds a lot of money but it is not a lot of money on a budget of £190 million. It is less than half of 1%. My sums are not brilliant but I think it is less than half of 1%. If we are spending less than half of 1% to try and spend 99.5% cent more wisely, I think it is brilliant value for money.

Q64 Nia Griffith: Perhaps I could turn to Sonya Sceats now and ask, in the light of your experience with the Department of Health framework project, do you think we should have similar projects now rolled out with our other government departments?

Ms Sceats: Our project with the Department of Health was always meant as a pilot and we have absolutely got an eye to extending that learning to all kinds of other sectors. Concurrently with that project we have an education project that is running that is seeking to develop a teaching resource but also guidelines to assist schools to develop a whole school's approach to human rights, to bring human rights alive in the context of our schools. That is just one example of another area where human rights-based approaches have a lot to offer and I would say that there are many other sectors which could profit from this approach as well, and we would be very happy to be involved in those kinds of initiatives.

Q65 Nia Griffith: Are there any specific departments that could help to benefit people with learning disabilities if they had better training?

Ms Sceats: Education is one good example. Our education project is actually in partnership with the Ministry of Justice, interestingly, but you could imagine the relevance of that project also for DfES and other departments as well; learning disabled children in schools, for example.

Q66 Lord Judd: The DRC have told us that, although it is early days for the Disability Equality Duty, it will only make a difference to people with learning disabilities if local authorities specifically include it in the development of their equality schemes and training. How do you think that the introduction of the Disability Equality Duty will affect the way people with learning disabilities are treated?

Ms Sceats: The Disability Equality Duty is not something that the British Institute of Human Rights has special expertise in, so we would not offer evidence on that. The only thing I would say about the duty is that the really strong emphasis on properly involving disabled people is highly consistent with a human rights-based approach and I would love to see that extended across some of the other duties as well in the future.

Ms Perry: Equally, Values Into Action has not done work on the Disability Equality Duty either. Our knowledge is mainly with human rights, so I would not feel qualified to say anything on that.

Q67 Lord Judd: It sounds to me as though it is a pretty academic consideration for those of you who are in the front line. It is not a mainstream issue?

Ms Perry: A mainstream issue for services or for our organisations?

Q68 Lord Judd: For the way you go about your work, what you are trying to achieve.

Ms Perry: What is important about this is where you actually look at work that you are currently doing and see the evidence you can get for specific things like human rights or Disability Equality Duty and you have to unpick it to see how it might help.

Q69 Lord Judd: How many people do you think know that it exists?

Ms Perry: Not many. I agree with you on that. It is vital, especially with the Commission for Equality and Human Rights, that where the interface between equality duties and human rights come together, there is help for people themselves who are trying rely on their rights, as well as professionals who need to uphold their obligations, to understand how they fit together and how they can meet their obligations, make it real for people. I would like to give an example of how, as was mentioned before, a lot of the human rights issues we are talking about are matters of common sense. Sometimes for staff, in particular staff working directly with people with learning difficulties in institutional settings, especially in long-stay hospitals, sometimes in the institutional world common sense is not the law of

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the land, it is not what rules how people are treated. Sometimes staff need help to see how human rights obligations can help them problem-solve. There is one example of a man who liked to go out in the garden and he made a lot of noise and the neighbours were complaining about it. The response was to not let the man go outside again and to always be inside, which of course upset him even more and upset the people he lived with. We helped the staff use the framework of human rights, which puts everyone's rights on an equal footing, to see how his rights were equal to the neighbour's rights—he had the same rights as they do—and how to come to a compromise. The staff, at the beginning in workshops, were thinking, “Oh, human rights. That's just another thing we are going to have to deal with,” to seeing how it could be used to problem-solve some very difficult situations, and it can be used for anything from day-to-day stuff like that to life and death decisions.

Q70 Earl of Onslow: That is bad training of the staff concerned. They just should not behave like that. It is bad training of the supervisors. What was the person in charge, the matron, doing allowing it to happen?

Ms Perry: Luckily, what is happening is that long-stay hospitals are closing. The Department of Health itself would agree. This is Department of Health policy, that long-stay hospitals that house people with learning difficulties who have no need for medical treatment are being shut down, and in that process of shutting down, it is being recognized and taken on board that these are not acceptable situations. That is a move forward but I share your frustration completely that these things do happen.

Q71 Lord Judd: It is a battle for the culture rather than for the implementation of rules.

Ms Perry: Absolutely.

Q72 Earl of Onslow: Is it not also a question not only of the quality of the staff, if it is not very good, probably the quality of the people, who are not very well-paid, probably there are not enough of them, probably they are transient. That seems to me the problem. Would you recognize that as an accurate description?

Ms Perry: I think so, and I am sure that my colleagues can add to that but from the Values Into Action point of view, people with learning difficulties themselves need information, and they needed it in various formats. What our project did was active accessibility. It was not just an Easy Read version but actually getting out there and working with people and acting it out, and that is how you can learn. It is both sides of the coin, where people themselves see what it can do for them but service providers, like this service provider has learned how to use it to really improve their services.

Ms Sceats: You are absolutely right that sometimes these problems are due to poor resourcing, poor training and so forth but, as your colleague Lord Judd pointed out, what we are really talking about is the failure of the human rights culture to properly

take root so far. It is early days since the Human Rights Act has entered into force. We have a culture at the moment where our inspectorates who are now going in to inspect facilities are not using the language of human rights. We have a culture where those in charge at the top of these organisations, the Health Service and beyond, are not talking the language of human rights. We have a culture where our Department of Health is only now beginning to feel conversant with the language of human rights and so forth. There is a long way to go and we need to be thinking not just about the poor practice on the ground and the isolated instances but also about the system change that needs to go on if we are going to achieve a proper culture of respect for human rights that is pervasive across the country.

Q73 Lord Plant of Highfield: Could I ask you about the UN Convention on the Rights of Persons with Disabilities? This is the question to Values Into Action and the British Institute. I should declare an interest in relation to the British Institute in that it is a self-governing institute within the King's College London Law School, of which I am Dean. I need to register that interest. Do either of you think that the ratification of the new UN Convention, which the Government has indicated that it will ratify, would make any real difference to the way in which people with learning disabilities are treated in the UK and, if you think so, why do you think so?

Ms Sceats: I would absolutely say that the United Kingdom's signature already of that Convention and its intention, we hope, to ratify will send an incredibly strong signal not only to people with learning disabilities but disabled people more generally and to our community about the importance we set on the rights that belong to disabled people. Many people have traditionally seen disabled people through the kind of lens of charity and so forth and this Convention is sending a very strong signal that disabled people are rights holders. This is very important. Many people ask us in the context of our work at the British Institute of Human Rights why we need special standards out there when human rights are supposed to be universal, and our answer always is that there are some groups for whom rights have been overlooked and these kinds of specialised conventions are one very important way to redress that.

Ms Perry: At Values Into Action we welcomed the European Convention on Human Rights and its implementation through the Human Rights Act because it was universal and it does equally apply to all people, whatever group they belong to. That is not to say that disabled people may not need a particular bridge to universal rights and possibly the Convention will help build that bridge but it should never be forgotten that actually, all rights in the Convention are guaranteed for all people and the language of the Human Rights Act is vital to focus on the word “human” rather than any other label that might be attached to it. I would agree with Lord Ashley, who said in the House of Lords on 25 June that, in the light of the recent Lords decision that certain if not most—I am not directly quoting him,

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by the way; I am paraphrasing—most actions by non-public authorities running care homes would not be covered by the Human Rights Act, possibly this Convention would provide some much-needed help in ending what he did call an outrageous situation. If it can help in remedying what has been quite a narrow interpretation of the remit of the Human Rights Act, we would support that in that sense, but it is very important that the universal aspect of the Convention is highlighted.

Q74 Lord Plant of Highfield: The Government has indicated that it will not ratify until it is convinced that existing standards and procedures and practice and policy are compatible with the obligations under the new Convention. What is your sense of how far away we are from that? Are we a very long way away from that or are we quite close?

Ms Perry: On what we have said so far today, probably not; quite far away from it but I do not know.

Ms Sceats: I think there are some positive shifts. The independent living agenda, for example, is increasingly being viewed as part of the human rights agenda and that is something you can find resonating in the text of the UN Convention, and it is actually framing independent living issues around participation and so forth as a human rights issue, so I think we can see some convergence in our domestic agendas here and the spirit of the new Convention at the international level.

Q75 Lord Plant of Highfield: A second question, again, for Values Into Action and the British Institute. In a sense, it picks up something that Lord Onslow has highlighted several times now. Many of our witnesses have suggested that the problems faced by people with learning disabilities are caused by negative attitudes and a lack of understanding of learning disabilities. Given that, how far do you think that taking a human rights-based approach to the treatment of people with learning disabilities is going to change that?

Ms Sceats: I think there is something very fundamental about looking into the eyes of a learning disabled person and seeing there a human being who is a holder of human rights. We have seen in our work on an organisation to organisation basis the incredible shift that can occur in terms of practice when that kind of change in ways of looking at service users does occur. I think we have a long way to go but there are things to be positive about. Human rights, as was suggested, provides a very powerful lever for changing the power dynamics between service users and service providers.

Ms Perry: I would agree with that, and I think the key thing about the Human Rights Act and the Articles is that it spans life, it spans the important parts of one's life—education, life—and I think, especially in Article 8, the richness of life is there. So in terms of people having access to an ordinary life, it is an extremely important tool, both for people to understand and to use for themselves to win that life, but for people who are supporting that, whether it is people who might be supporting them in hospital or

supporting them in their job or supporting them in a group home, wherever it is that they are in their life. It is very powerful but a lot more work needs to be done to make it real and helpful for both sides of the coin.

Q76 Chairman: Could I ask a question of Mersey Care, as we are coming to the end of our session. Why do you think you were chosen for this project?

Ms Dyer: I think because we have a track record. As I say, we have been working for the last few years on involving service users and carers in making real and important decisions and I think because what we are trying to do through using a human rights-based approach is to actually enable our service users generally and people with learning disabilities in particular in this context to actually hold the Trust to account for what we do. I think that is the fundamental shift that the human rights approach potentially enables us to make.

Q77 Chairman: This is a similar question to the ones Lord Onslow was asking earlier on. Why are you so unusual? What makes you so unusual in the NHS? Why are the others not doing it?

Ms Lofthouse: I do not know. I think we have a chief executive who is very keen on human rights. We have Lindsey Dyer, who is a Director of Service Users and Carers, so we have the structure and the framework, which then allows those who want to develop pioneer things. We have a budget. Very important. You need resources. Every single one of these has not been a huge amount of money but it has required resources. You need people. We have a network of service user and carer leads and that is just part of my job. I have a few other roles as well, but you actually have structures within an organisation that allow that, and allow that development to go on, and are not afraid about what service users and carers might say about our organisation; instead of being defensive, actually embrace their comments and bring that into your action plan, so that the next year . . . In learning disabilities we have an annual away day for our service users and carers, a service governance day, and that holds us to account for what we have been doing. So they come back and tell us, and we go off and do our action plan for the next year, and I am held accountable. I have a carer who does my personal development plan each year, who is sat there with my manager, holding me to account. When you have that culture, and that enabling one, you have listed the profile of service users and carers into a partnership. We are working right from the grass roots upwards, which is how it should be, and that is where you get your best ideas from all the time.

Q78 Earl of Onslow: Being partly Scouser.

Ms Lofthouse: I am not a Scouser.

Ms Dyer: As Scousers, when the Trust was set up in April 2001 we have had seven different organisations coming together under the Mersey Care umbrella. They were very vocal and a lot of service users and carers came to consultation events, and what they

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said was, “If this is just another NHS reorganisation, if all you are going to do is change the label over the door, we are not interested. What we want is an organisation that will listen to us, will have more empathy and will work in partnership with us.” My Board took that on board—if a board can take it on board—and in a sense has provided the leadership and framework to enable this to happen.

Q79 Chairman: How are we going to spread this good practice throughout the NHS?

Ms Dyer: We do our best. We are available for conferences and seminars. Probably not a week goes by where I do not have some contact from another NHS organisation looking to learn from our experience. I think, in a sense, the NHS cannot rely on pockets of good practice and trying to spread good practice. Whilst I welcome being part of one of the pilot projects, I do not think that is enough. I think we have to mainstream the human rights-based approach within the NHS. We have a wonderful opportunity if we are going to have an NHS constitution. We have a wonderful opportunity in terms of we could be commissioning services by PCTs on a human rights-based approach. Every board could be like my board, and actually test every paper that comes to the board as to whether or not it is promoting a human rights-based approach. Every chief executive and member of the executive team, as my board, could have human rights-based objectives in their objectives. That is the kind of real cultural shift we have to make if we are going to make a real difference to people with learning disabilities, because learning disability services are part of bigger organisations.

Q80 Earl of Onslow: You see, it seems to me, that you would have done this without the Human Rights Act—and that is the point I am trying to get at—because you believe it to be the right way to look after people, the right way to treat people, the same as I do. So you could have done all of these things without the Human Rights Act.

Ms Dyer: I would have had a go without the Human Rights Act. I would not be so successful without the Human Rights Act because the Human Rights Act provides a framework; whether you are a service user, carer or a member of staff, it is a very clear framework that you can operate in. I do not argue with people now about whether people have the right or not. The issue for me is how do we do this, not whether or not people have a right, and it is having that fundamental right that makes all the difference for me.

Q81 Chairman: It presumably helps to get the money.

Ms Dyer: It helps get the money.

Ms Sceats: Can I just say something final on the framework, which is to say that it has been turned around in a very short time. It has been designed, piloted, produced, all in under a year, and we are absolutely committed, with the Department of Health, hopefully to be taking it into a second phase, to be getting more of the kind of learning that committees like yours are looking for in terms of the practical benefits that this actually makes for people. This is just the beginning and it is very early days and we have always seen it in that way.

Q82 Lord Judd: Would you not say the Human Rights Act was essential to recognizing that patients or people with learning disabilities are individuals with their own integrity and personality and not just people to be treated well by an enlightened service?

Ms Dyer: Yes, absolutely.

Ms Sceats: There are also the rights of staff as well. One of the other wonderful things about the human rights framework that we have been putting together in partnership is that there is an emphasis also on the rights of staff. That is not something that has been forgotten and that has allowed a resonance in there for people who otherwise would not have seen the relevance of this stuff to their own kind of practice in an organisation, say if they are not even coming into contact directly with service users. There is something in it for everybody, so to speak.

Chairman: Thank you very much. Is there anything you want to add that we have missed? Thank you for giving evidence, which obviously supplements what you gave us in writing.

Witnesses: **Ms Ruth Scott**, Head of Policy and Government Affairs, Scope; **Professor Tony Holland**, Health Foundation Chair in Learning Disabilities, Department of Psychiatry and **Ms Amy Forgacs**, Cambridge Centre for Participation; **Ms Philpa Bragman**, Director, and **Mr Shaun Webster**, Project Co-Ordinator, Change, examined.

Q83 Chairman: Thank you for coming to join us for our second session. We are joined by Ruth Scott, Head of Policy and Government Affairs for SCOPE; Tony Holland, who is the Health Foundation Chair in Learning Disabilities, Department of Psychiatry, and Amy Forgacs, Cambridge Centre for Participation, and Amy has her facilitator, Wendy; and Philpa Bragman, Director, and Shaun Webster, Project Co-Ordinator, Change. Does anybody want to make any opening remarks?

Mr Webster: If you do not understand me, I will

repeat myself. I want to tell you what parents have told me. I have been talking to parents with learning disabilities all over the country. Many parents have told us about the injustice and heartbreak they have suffered. They have had their children taken away by Social Services in unjust practices. They told me that when they asked for support, they did not get any until it was too late. We talk about communication; they told me that when social workers and other professionals come into their homes, they talk jargon. They talk about assessments.

*Committee suspended from 5.08 p.m. until 5.17 p.m.
for a division in the House of Lords*

Q84 Chairman: Would you like to continue, Mr Webster?

Mr Webster: We talked about assessments. They told me that when they have an assessment, they always look at things they cannot do, never things they can do. They want assessments at home and over a longer period of time. We talked about adoption. They told me that when their children are taken away, they are already upset. It feels like the children have died, and it made them mad. I talked to parents with learning disabilities about social workers not working together. I talked to parents with learning disabilities about Child Protection. They have no respect for parents with learning disabilities. Too often they do not listen and understand their learning disability. A lot of parents with learning disabilities do not know about their rights. They are told things that happen. A mum with a learning disability went to hospital to have a baby, but Child Protection was there, waiting to take the baby away, and she never got to bond with her son. This is a human rights issue. Sometimes, when parents with learning disabilities have two or three children, they have to pick which child to keep because Child Protection think they cannot cope. One lady told me that in the end she lost all her kids. Sometimes social workers are waiting outside the school gates to take their children away. This is a form of legalised kidnapping. This is against their human rights. Accessible information. I believe everybody needs to work in easy words and pictures because things need to be accessible. At Change we make sure everything is accessible just as all other leaflets and booklets. We have a word-to-picture team of people with learning disabilities who help us to make everything accessible. I think every organisation and work place should use these words and pictures. This would respect our human rights.

Q85 Chairman: Thank you very much. Perhaps I can ask a question to follow up on what you just said, Shaun. You talked about the jargon and the inadequate information that is available, particularly for parents. What do you think is the most important thing to have easy to understand information about?

Mr Webster: Everything has to be accessible. It cannot be just one thing, about benefits or about work. It has to be everything across the board. People with learning disabilities need to train professionals in those types of jobs to make things accessible, because it is all linked together.

Ms Bragman: Can I just add something? I think at the moment organisations have a different understanding of what "Easy Read" means. We have examples we have brought with us of Easy Read information that a lot of people with learning disabilities do not actually find easy to read and there is no code of practice. We in Change think it is very important that there are standards of Easy Read information. People with learning disabilities in Change have been training inspectors from the

Commission for Social Care Inspection in how to make information accessible, and we have worked with different authorities where we have trained the people that work in those authorities in how to make information accessible. We have worked with people with learning disabilities, so they can check whether the information is accessible or not, which we feel also needs to happen as the other side of that coin.

Q86 Chairman: Could you describe one or two good and bad examples for the record? That would be helpful.

Ms Bragman: I was hoping you would ask that. This is the Mental Capacity Act, which is in Easy Read, and, if you have a look, the pictures are in black and white, and the same pictures are used to illustrate different text. If you cover the writing with your hand, you should have a good idea from the pictures of what is going on. If you did this here, which is what we do in Change, it is very hard to tell. There is another one here which is produced by the Department of Health.

Q87 Chairman: Who produced that first one?

Ms Bragman: The Department for Constitutional Affairs. This is the Department of Health, which is photos, which does not reflect the text, and actually, this is produced by the *Valuing People* support team, but there is a photo with lots and lots of writing. What people have said to us is that the people that commission information to be made accessible often go for the cheapest and the quickest. They do not quite know what they are looking for and are really pleased when it has pictures. This is what we produce in Change.

Q88 Chairman: This is a good example?

Ms Bragman: This is a good example. We have our own standards, so people with learning disabilities say it is very important to have a yellow background, bold print and that the pictures tell a story.

Q89 Chairman: Why is a yellow background important?

Ms Bragman: Because some people with learning difficulties say the words jump around on a white background.

Mr Webster: I myself am dyslexic. If I see black writing on a white background, I cannot read it. It is not accessible for myself and for people like myself.

Q90 Chairman: So it is easier with a yellow background?

Mr Webster: Yes, a yellow background is a lot better.

Ms Bragman: This is good practice guidance for parents with learning disabilities that has just come out from the Department of Health.

Mr Webster: This is *You and Your Baby*. This is for first-time parents.

Q91 Chairman: It is a rather fat book. Does the size matter?

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Ms Bragman: No. It is a difficult thing. When you make information easier to understand, you do not want to make it intimidating but, if you are adding pictures, it is going to take more space.

Mr Webster: We did research on this with artists and writers. We all got together to make this accessible, because a lot of parents get this book for free but soon, when our books run out, the parents will have to pay for it.

Q92 Chairman: Do you want to add anything to the points that Shaun has made about what should or should not be in Easy Read, the problems that have arisen and any examples?

Professor Holland: I think I would expand it a bit to go beyond just the availability of written and picture material and argue that we should be looking to what is sometimes referred to as as a total communication environment. If you go into, say, group homes for people with learning disabilities who have problems with communication, you would expect that the staff are trained in the use of sign, if sign is what the residents use. You should expect that there are ways of presenting information about their lives, what people are going to do during the day. It goes beyond just written material, yet one problem is that that is not usually in the contract for organisations that are contracted to provide social care. It is not there. You have no say over how they might improve their communication.

Q93 Chairman: Amy, do you want to say anything about this?

Ms Forgacs: I was just thinking. I agree with the point that was made earlier about how all public services should make their information in Easy Read more accessible or what have you. I suppose the Disability Equality Duty would be one thing that says that people need to work with people who have learning difficulties to make information accessible, because if you are given a leaflet full of difficult words that you cannot understand, you will not be able to have the same kind of fulfilled life and you would not be able to do so much. I have an example of something that Speaking Up did with people with learning difficulties.

Q94 Chairman: This is a bad example you are holding up now, is it, or a good one?

Ms Forgacs: No, this is a good example of a book that was done with people with learning difficulties to make accessible on bereavement, called "When Someone Dies". It covers things like the kind of emotions that a person might feel when someone dies, and that it is okay and natural to feel those kinds of feelings. There is a pull-out mood chart, and the idea is for people who support people with learning difficulties to look through a book like that, if that individual feels that they want someone to support them.

Q95 Chairman: So basically the message I think you are giving us, Amy, is the same as Shaun was saying, that if these books are going to work you have to use people with learning disabilities to help write them?

Ms Forgacs: Absolutely. I would say that nobody knows how better to deliver information for people with learning difficulties than the people themselves who know what kinds of things people might need.

Q96 Chairman: Ruth, do you want to add anything at this point?

Ms Scott: No. I think everyone has covered it.

Ms Bragman: I just want to say that to make reports accessible that are really long and thick is quite an impossible job for people with learning disabilities. There is lots of information and we think it is important that people that are working in services have training by people with learning disabilities so that they make good accessible information but not that people with learning disabilities should be making absolutely everything accessible.

Q97 Lord Judd: Ruth, Scope has told us that in its experience many people with learning disabilities and communication impairments are not currently able to convey their needs and wishes because they lack access to a communication aid. For the record, can you describe for the Committee some of the additional barriers that people with learning disabilities and other impairments who do not use speech to communicate face in securing respect for their dignity with human rights, which matters as much to them as the rights of anybody else?

Ms Scott: It pretty goes much without saying that if you cannot communicate using speech you need to find some alternative way of getting your wishes understood, making decisions, communicating what you want, how you want to live. A lot of people we work with, because a lot of people have no speech at all, people suffering from cerebral palsy and other people, report to us that they have great difficulty in accessing the assistive and augmentative communication technology that is available in order to help them speak, such as providing an artificial voice that they can programme to speak for them. Scope have been talking about this for quite a long time and the Government did take some action in terms of supporting school-age children to access communication equipment, but unfortunately that project has now ended and there is nothing there to replace it. There is also very little evidence or information about how many people might benefit from communication aids, how many there are with communication impairment, full stop, and how many people have a communication impairment at the level at which they might require assistive technology to enable them to communicate their wishes. We are particularly concerned, obviously, in the context of human rights, that if people cannot communicate and cannot say what they want, they cannot indicate yes or no, it is almost impossible for them to have choice and control over any aspect of their life because all their decisions are going to be made for them. We believe that it is a really crucial human rights issue, particularly as to communication equipment because without that assistive technology people are essentially left gagged and unable to communicate even their most basic wishes.

Q98 Chairman: What you are saying is that we do not actually know how many people there are?

Ms Scott: The Government does not collect any statistics. We have done a literature review and produced some figures that we think are probably quite accurate but it would be great, obviously, if there were official statistics to confirm that. We estimate that probably 2.5% of the population have some kind of communication support need and between 0.4% and 1% of those would benefit from some form of assistive technology in terms of enabling them to communicate. That equates to between 200,000 and 500,000 people.

Q99 Lord Judd: And you are saying that what is particularly frustrating is that the techniques are proven and available but are not in reality made available because of resource problems and probably that includes staff as well as money?

Ms Scott: Yes. There are probably three main factors in terms of access to communication aids, one of which is getting an adequate assessment of need, people being properly assessed and saying, "This is what you want and this is how you would benefit". The second is getting hold of the equipment itself, some of which is quite expensive, and in general there are not that many people with learning and communication needs so because local authorities are supposed to provide this sort of equipment they do not in general prioritise three, four, five individuals who need very high cost equipment over the money that could be spent perhaps on lots more people for less expensive equipment. A third is that the ongoing level of support that people need to programme their equipment, to ensure that their equipment is upgraded and that people not only know how to use it themselves but people around them who support the user know how to use that equipment. There is a statistic that suggests that about 75% of hi-tech communication aids are abandoned by users because no-one around them has support to use it properly, which is a travesty.

Q100 Lord Judd: Tony, people have told us that independent advocacy services are vital, particularly for people with complex and profound learning difficulties. If we could not afford to pay for everyone to have an advocate is there anything else we could do to provide extra support to people with learning disabilities?

Professor Holland: I would start by arguing that in fact advocacy is important not just for people with severe and profound learning disabilities but also for people with mild learning disabilities and, say, mental health problems or who are in trouble with the law. I think there is a real issue here about the question of resources for advocacy services. I would imagine that if one could improve the general training of support staff, particularly around the whole human rights perspective, they would at least be some level of substitute for an advocate, but I think there are many examples where the absence of

an advocate is a serious problem in terms of helping people make their views and needs known, often in rather difficult and problematic situations.

Q101 Lord Judd: But in the absence of proper, adequate provision is there an immediate need to concentrate more on those with the most profound problems than to try and spread it across everybody?

Professor Holland: It is a difficult one for me because most of my own work is with people with milder learning disabilities, many of whom are in trouble with the law, and I see serious situations that arise where an advocate might help resolve and prevent such situations arising. I think I would argue that there is a need for advocacy across the broad spectrum of people with learning disabilities.

Q102 Lord Judd: Some of you have told us that there is a significant possibility that the Mental Capacity Act, which was introduced in 2005, will be interpreted in a restrictive way by staff and others. The Act does not come fully into force until later this year. What makes you think that it will be interpreted restrictively and do you think the guidance on the Mental Capacity Act published by the Government is adequate or inadequate? What do you think would be the effect of giving the Mental Capacity Act a restrictive reading on the rights of adults with learning disabilities?

Professor Holland: When the Scrutiny Committee of the joint Houses of Parliament examined the then Mental Incapacity Bill it was a very particular issue raised by many user organisations, this concern that once you move from the vagaries of common law to the particularities of statute it can be used in inappropriate as well as appropriate ways. Our concern for that really comes from a number of sources. One important one is that we evaluated the seven IMCA pilot sites in preparation for the Mental Capacity Act coming into force, and Speaking Up from Cambridge is one of those pilot sites. What the advocates told us was first that there was not a perspective among different professions, perhaps more so in my own profession of medicine than some of the other professions, that came at this issue from a human rights perspective, and, perhaps importantly, there is still not the view that is clearly stated in the Mental Capacity Act that you must start with the presumption of capacity, so you must make no presumption on the basis of someone's appearance, for example, but, secondly, that there were not the strategies in place or the attitudes that were encouraging working with people in a way that maximised their capacity, and this comes back to the whole issue of communication and availability of materials to help people who may have a problem understanding. Examples were things like the availability of material to help people understand that they were advised to have a blood test and that if you use visual material to help people understand invariably there are people who previously did not understand who now understand.

Q103 Lord Judd: What has come across to us as a Committee as we have been listening to witnesses is that there is an issue behind it all which is about the prevailing culture.

Professor Holland: Yes.

Q104 Lord Judd: Can you spotlight some real spark points by which by greater activity the culture could be changed?

Professor Holland: When it comes to what one might call more particular decisions in the context of the Mental Capacity Act, such as health treatment, people are becoming more informed about it and the Mental Capacity Act sets out quite clearly the process that should be followed. I think where it could be more problematic is much more in the routine day-to-day support and care of people. This may be particularly true of, say, people with cerebral palsy and learning disabilities around issues of choice of food or choice of activities or what they might wear, and that again is very much is captured in the culture that I think still is maybe seen as rather paternalistic and not supportive or empowering enough. We had an example when we evaluated the role of IMCAs in hospital settings, whereby when you interviewed doctors who had been involved, their attitude about the IMCA was not that it was the right of an individual to have an advocate in this particular policy but rather the doctor saw it as a sort of tool to help them solve a problem. That is fine, that it helped to solve the problems, but actually I would like to see doctors and others seeing it as a right that people who lack capacity in that context have an advocate who can help put the views of the person who lacks capacity forward, and that under best interests in the Mental Capacity Act there is an obligation to attempt to identify what this person wishes in this particular context. I think it is about care planning, it is about attitudes.

Q105 Lord Judd: And values?

Professor Holland: And values. It is about all these sorts of things on a day-to-day level.

Q106 Lord Judd: Thank you. Ruth, did you want to add anything to that?

Ms Scott: In the context of the Mental Capacity Act I wanted to make a short point about potentially the balance between national care standards and the duty under the Mental Capacity Act. Scope has been delivering some training schemes to staff who work in our services and a number of issues have come up from staff being trained about how these two pieces of legislation balance with each other. There is a sense within national care standards that the main focus of national care standards is around mitigating risk, around health and safety and around protecting people, and on the other hand you have got the Mental Capacity Act which says people have the right to make their own decisions and be supported to make their own decisions, and also have the right to make decisions that are perhaps not wise or that we would not necessarily agree with.

There have been a number of points that have come up where people say, "How do I as a member of staff in this service balance the right of this individual to make this choice, which I think might not be a brilliant choice but it is their right to make it, and my duties under national care standards to have a duty of care towards this person and mitigate risks that they might encounter?". A particular example that came up was of a guy who has quite complex physical impairments and a learning difficulty and has great difficulty in swallowing. Staff were very concerned that when he ate he was at risk of choking, and they were quite concerned that in terms of their duty of care to him they did not want to be responsible for killing him by giving him his dinner, so what they proposed was that they would feed him by putting a tube in his stomach, and he was absolutely adamant that that was not what he wanted, and so you ended up with a situation where he was able to give that very clear view that that was not what he wanted and yet staff were saying, "If we continue to allow him to eat in this way he is at risk of choking to death". That is something that we would really like clarification on in terms of guidance around mental capacity.

Q107 Lord Judd: If you were advising on what the clarification should be what would you say?

Ms Scott: I would say that we should go with the decision that he made, that that is what he wants to do and if he can understand the risks associated with that then that is what he should be able to do, but I think staff need reassurance that when they make that decision in the document they are therefore protected from potentially a backlash through national care standards which would say, "You were negligent towards this person". There were a number of other perhaps less life or death issues associated with it but that come up in similar ways around to what extent you have the right to impose your view of what is safe for somebody over their view as to what they want to do.

Q108 Lord Judd: So public and media education is central to all this, so that staff feel they will not be destroyed by the media for having been irresponsible or whatever?

Ms Scott: Absolutely. I think as well that in the CSCI inspectorates as well there has to be a human rights culture and an expectation that inspections—and I think this was a point made earlier—take into consideration the human rights perspective when they are inspecting services and that staff can feel confident that when they support a service user's decision and back that person up to make that decision they are not going to get problems afterwards when the national care standards inspectorates come round and say, "Why did you do that?".

Q109 Lord Judd: I have had rather a long innings but, Tony, could you just finish my questions by saying a word about staff perspectives, what is lacking and how improvements in this quarter could

really assist, and, just to come back to the point again, where guidance and training come into all this?

Professor Holland: I would like to say that I believe there is also very good practice out there, and I think we have to be careful not to see it all negatively. Where I think the practice is poor is where there is not an appreciation that when you are working with someone, you are supporting someone, you have responsibilities. It is trying to bring together your duty of support and care for that person on the one hand but respecting their autonomy on the other. The danger is that you see them as opposing whereas I see them as complementary in a way. The duty of carers is, of course, to enable people to make those decisions that they are able to make, and where we fail is where we do not provide those services and the right approach in supporting people to try and make decisions that they are able to make, but at the same time acknowledging that there will be some people who cannot make particular decisions and then your duty moves to a slightly different level. Your duty then is to work with that person and try and ascertain what it is they might like under these circumstances. It is very much trying to get over to staff the idea of a sort of partnership, and I think again the Scrutiny Committee here, when it looked at the Mental Capacity Act, was saying that this Act is not simply filling a gap in English and Welsh law; it is about a culture change. That is fundamentally what it is about. It is trying to say to all of us not only supporting people with learning disabilities, supporting people with dementia and so on; it is about how you work in partnership with them. I think it is going to be a very slow process. Like the previous witnesses, I think the human rights framework and the mental capacity framework provide the means by which to begin to argue that case through training.

Q110 Lord Judd: Amy, do you have anything you wanted to say about all this?

Ms Forgacs: I am not sure.

Q111 Nia Griffith: Chairman, I would like to put a question to Amy and to Philipa and Shaun if I may. We are sometimes told by the Disability Rights Commission that consultations are “sham events”, that people do not get the proper time to respond, and I want to know if you agree with that and how you think the Government or public authorities can make sure they do take into account everybody’s views.

Mr Webster: It can be a sham but if people come out to talk to us and everybody can get their questions in we will be able to do it one-to-one. If they come to CHANGE to talk to us about parents with learning disabilities, the best way to do it is to come out and talk to us, because if you do not it one-to-one it is very difficult to get your questions in.

Ms Bragman: Sometimes with consultations in CHANGE we get sent through questionnaires and

we do not have lots of people in CHANGE who can support people with learning disabilities to answer these questions and have time for people with learning disabilities to sit down and go through that process. In our experience, when there have been consultations, where people have come out to CHANGE and we have organised a number of people with learning disabilities to meet up, that has been one way of doing it. When we are thinking in CHANGE about how sometimes it is really hard for people with learning disabilities to get their voices heard, lots of people with learning disabilities around the country consult with other people with learning disabilities and become specialists in key areas, and sometimes that is not recognised, and so we also wonder whether there is a place for people with learning disabilities to get recognised and paid to be the expert, whether it is in employment or parents or health, and that they do the consultations and have a better understanding of the issues and then they can be their link into whatever consultation is going on.

Q112 Nia Griffith: Does Amy want to comment?

Ms Forgacs: Yes. I suppose one example of consultation with people with learning difficulties would be our Parliament model. We have a group of MPs who have learning difficulties who represent other people who have learning difficulties about any kinds of issues that they have within public services, like health and housing and transport, and the MPs themselves speak to the people they speak up for by meeting with them and listening to what they have to say before going into a Parliament event and putting people’s views across. I suppose the point I am trying to get across is that, as a result of people speaking up for each other, as well as the Parliament meetings we have a Cabinet which is linked to the Parliament where people can campaign to make things better. One successful campaign that was done was to do with a hydrotherapy pool which was about to be closed down. Lots of people really needed that pool to stay open and our MPs got up a petition to have the hydrotherapy pool kept open and as a result of doing that the pool was kept open.

Q113 Earl of Onslow: You have told us that if more information were made easy to understand people with learning disabilities would need less support to live independently. Can you give us examples of what you mean by this?

Mr Webster: Myself and other people with learning disabilities, when we get basic forms, gas bills, doctors’ forms, we struggle to understand them and that makes us want more support, but if the letters were in easy words and pictures we would need less support to live our lives. A lot of letters we get from benefits, doctors, solicitors, everybody are in jargon and then we need a lot of support to cope with that at home, because if you get a letter about a gas bill or a letter from social services it can panic you and you need a lot more support then. If you make them

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accessible that would not happen and it would save a lot of money. We would need a lot less support if everything was accessible, and that is what we need.

Chairman: As there is another division what I suggest we do is ask one or two questions informally now. Thank you.

Monday 22 October 2007

Members present:

Mr Andrew Dismore, in the Chair

Lester of Herne Hill, L
Onslow, E
Plant of Highfield, L

Stern, B
Dr Evan Harris

Witness: Mr Rob Greig, National Director for Learning Disabilities and Co-Chair of the National Task Force for Learning Disability, gave evidence.

Q114 Chairman: Good afternoon, everybody. Welcome to another of our open sessions on our inquiry into the Human Rights of Adults with Learning Disabilities. We are joined by Rob Greig, who is the National Director for Learning Disabilities and Co-Chair of the National Task Force for Learning Disabilities. So welcome, and thanks for coming at relatively short notice, I think.

Mr Greig: That is fine.

Q115 Chairman: Do you want to say anything before we start?

Mr Greig: If I could briefly just say two lines about my role, which is a kind of slightly strange role, perhaps, so you know the context in which it operates. As a national director, I am seconded into government with two lines at the top of my job description. One is that my role is to represent government to the field in relation to people with learning disabilities; that is not just the Department of Health, although I am based there. The other is to represent the field, that is people with learning disabilities and families, into government, which creates a tension occasionally, shall we say. Therefore, in a sense, it is with those two hats, the particular interest in the lives of people with learning disabilities, but also representing government, that I am here today to answer your questions.

Q116 Chairman: You are piggy in the middle and get the blame from both sides, presumably?

Mr Greig: On a good day, they think I am okay, but yes.

Q117 Earl of Onslow: You have to negotiate with yourself and agree with yourself, is that right?

Mr Greig: In part, yes.

Q118 Chairman: Perhaps I could start by asking you about what MENCAP told us, which was that despite the various commitments to human rights of people with learning disabilities in the *Valuing People* document, there is still a long way to go on delivering on that. Why do you think, six years on, there is such a gulf between the policy and what is actually happening on the ground?

Mr Greig: I think it is primarily because of the levers that are available to deliver the policy. The policy has widespread support in the country, but I think it is true to say that if you look at things like the performance framework and other ways that government uses to get people to comply with

policy, they are limited. Therefore, we have had to rely significantly upon persuading people that they want to make those changes. Obviously things like the Disability Discrimination Act, and, in particular, the Disability Equality Duty, add additional new important levers, but I would say that is the major reason.

Q119 Chairman: Do you think a rights-based approach can work? We get the impression it has not actually led to any real change so far.

Mr Greig: I think it has led to change, in the sense that the culture and the attitude of people in many services is changing, and certainly people are aware of what they should be doing differently. To specifically answer your question, I think it is the right approach, because getting people to understand that this is not something you do because you want to be nice to disabled people, but is actually their rights as equal citizens, and building that into working patterns, is the way forward. We have plenty of anecdotal information and stories as to where that has had a good impact, but we are still some way from it being a reality for the majority of people.

Q120 Chairman: Do you think we need more training and awareness raising for people with learning disabilities and people who work with them? Would that make a difference, particularly on human rights and disability discrimination?

Mr Greig: Yes, I think we need to approach it from two angles. One, which has actually been a fairly substantial strand of the *Valuing People* delivery programme, is actually promoting leadership and awareness of issues amongst people with learning disabilities and families, because in a sense, you have to crank up the demand from people to have their rights respected. I think we need to remember that we are talking about people who on the whole have not only had their rights denied for centuries, but have actually lived in an environment where they have been born and taught not to have great expectations in life, so we have to crank up the demand. But the other side is that we do have to take steps to make sure that people who manage and work in services place that agenda at the top as well. If I can just briefly give you a good example, we have been reasonably successful in promoting an increased take-up of direct payments amongst people with learning disabilities, to a greater extent, I believe, than other sections of society, in terms of

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the rate of increase. I think that is because we took a twin-track approach; on one hand of approaching managers and care managers, but we also invested a lot of time and energy and some money in developing materials for people with learning disabilities to help them understand what a direct payment is, how to demand it and so on. So we helped crank up that demand to put additional pressure on services to respond accordingly.

Q121 Chairman: Whose job is it to provide this training and awareness raising, do you think?

Mr Greig: Do you mean for self-advocates?

Q122 Chairman: Yes, who should be responsible for providing it? Is it the government's job?

Mr Greig: I think the government has an important role in providing frameworks and providing support for that to happen, but I do strongly believe that it is the responsibility of local services not to see people who use services as—the “opponents” is perhaps the wrong phrase, but to see people as actually partners they have got to help with. A quote I remember a few years ago from a director of social services, after I had had a similar discussion with him, he ended up by saying, “Yes, Rob, you probably have a point, I have a £45 million budget on learning disabilities, but I only spend £40,000 on promoting and supporting advocacy, yet I am saying we should have a user-based organisation, the balance is wrong”. I think he was right there. There is an onus, I think, on services providing training and information for people, so they know what they can demand back of services.

Q123 Earl of Onslow: You mentioned local services just now; is there a difference between the services provided, say, by Cornwall and the services provided by Surrey or the services provided by Hampshire, or is the standard of care more or less the same over the country, or is there a great difference between one local authority and another?

Mr Greig: There is a great difference between authorities. If I can just add to that, there are even great differences within authorities, because if we remember that the *Valuing People* agenda is a cross-government agenda, what you can often find, even amongst the better authorities, is some really innovative progress in one area, maybe around access to mainstream healthcare, but maybe not doing much around access to paid work. So you get, as it were, two dimensions of variability, but certainly, there is geographical variability. I think that comes back significantly to some of the stuff I said in my opening comments.

Q124 Lord Plant of Highfield: I would like to refer you back to your answer to the Chair's first question about the next steps document, *Valuing People "Next Steps"*. You stressed in your answer to the Chair that you thought that there were issues about effective implementation on the ground and so forth. I think we take that point, but is there anything that

you would like to see in the paper when it is published that would make a big difference, beyond what you expect, as it were, to see in it?

Mr Greig: It is obviously slightly difficult for me to answer in the abstract sense as I am involved in its development, but if I can just flag up three particular things I think would make a difference to implementation? The first is that there is a commitment, following on from the Cornwall inquiry, from the Secretary of State for Health to look at strengthening the performance framework for health and adult social care. I think that that would make a significant contribution, coming back to my original comments. We have already announced, in the CSR announcement a week ago, new public service agreement indicators around people having real jobs and access to real housing, so those are really good, I think we need to build on that. That is the first thing I would say. The second thing is that Learning Disability Partnership Boards, which *Valuing People* set up, are similarly variable across the country, but where they are working well, they are having a positive impact. I think if we can find ways of making all partnership boards as effective as the best, then we will begin to create that accountability to people and their families that is perhaps lacking in some of the areas that are less successful. The third area, I think, relates to the extent to which what I will call mainstream services fully take on board the inclusion of people with learning disabilities; or, to put it another way, the delivery of the Disability Equality Duty in a major way across areas such as employment, housing and healthcare, so that people with learning disabilities are demonstrably getting equal access and better outcomes. So I think I would flag up those three as my major hopes and aspirations.

Q125 Lord Plant of Highfield: But you think that the paper, when it appears, will flesh out the idea of from independence to interdependence in an adequate way, do you?

Mr Greig: I am confident that it will take us further. Coming back to my very opening line about my role, I guess I always have aspirations and hopes that are greater than may be realisable, because my particular interest in this role is people with learning disabilities, as opposed to balancing those interests with other people in society. But it certainly seems to me that the interests of people with learning disabilities have not had a fair crack compared to the rest of society, and therefore I hope and I believe that the document will take us some further steps forward, but still with a long way to go.

Q126 Earl of Onslow: A number of witnesses have told us there is a difficult balance to be struck between ensuring that adequate support is available for those with profound and multiple learning disabilities and high support needs, and those for whom a low level of support may avert a crisis. Do you think that local authorities' eligibility criteria for support is currently undermining the aims of *Valuing People*? It seems also that that question is

linked in with a great deal of detail to the supplementary I asked earlier on, if there are different counties with different qualities of control, and then you have told us within different parts of the same department; this becomes not only a more apposite question but also an infinitely more complicated one.

Mr Greig: If I may take that question in two parts, I think there are two issues I would like to comment on. The first is your specific question about further access to care and eligibility criteria. I obviously appreciate the financial difficulties that local authorities are under, but it seems to me that a decision by an authority only to provide services to people who are deemed critical is going to have medium to long-term financial impacts on them, let alone the impacts on the quality of life of the people themselves. Certainly, if authorities go down that route, there will be significant numbers of people who have traditionally been in receipt of support, to help them get lives as outlined in *Valuing People*, who will not be getting those services in the future. The other thing, though, I want to say, which adds to that, is I think it is important, when you think about services to people with more complex disabilities, that we do not think about developing separate services for them, which is sometimes what some people say. I think if you work from the assumption that, as I have heard some people say, "Oh, a person with a complex disability cannot get a job or have a home of their own", you immediately confine them to a more limited range of experience.

Q127 Earl of Onslow: Ghettoise.

Mr Greig: Absolutely, and my experience is back from when I used to work in services; whilst, to take my example, a job for somebody with multiple disabilities might not look like a job as you or I might expect it, nonetheless, it is a job, and it has a great impact upon their personal esteem, it impacts upon the people around them, it is worth pursuing. So I think we need to be clear, when we are talking to people with different levels of need, we do not have different aspirations, we look at different ways in which we can support people to achieve those aspirations.

Q128 Earl of Onslow: Does it not also follow from what you are saying that you cannot make a division, because the line of change is so imperceptible the whole way through? Somebody might be just like the late Robin Denison-Pender, who when he was at school with me was known as thick, and then it goes the whole way up from Robin Denison-Pender to somebody with very, very serious learning difficulties, and there is actually no boundary between that; does that follow?

Mr Greig: I would absolutely agree with you. The other thing that that, I think, emphasises is the importance of one of my earlier points, which is about the involvement and engagement of the mainstream services. If I can just hang on to the paid work example that I have used a couple of times, there clearly is a really essential role for disability employment advisors and Jobcentres Plus to be

actively engaged in supporting people with learning difficulties and disabilities into paid work. As people's learning disability becomes greater and their needs become more complex, then the degree of involvement from adult social services and specialist employment services become greater, and you will, not on the basis of some analysis of level of disability, but on the basis of analysis of the needs of the individual, reach a point where the balance of engagement may tip between the two parts of the service. You could say the same if you were talking about mainstream health or anything else.

Q129 Baroness Stern: We have had a number of witnesses who have talked about money. One of them, from People First, said if the government is serious about stopping human rights abuses against people with learning difficulties, it will simply cost money. Witnesses have also told us that there needs to be a more enthusiastic and consistent implementation by local authorities. Could you say something about how much difference a new policy statement can make without a significant increase in earmarked or ringfenced funding?

Mr Greig: There is no evidence that the places where there has been more significant abuse or denial of rights of people with learning disabilities are spending more money on services. That is what I would say is the starting point in answer to your question. So I do not think that money in itself, in substantial national terms, is a prerequisite to promoting human rights, preventing abuse and so on. I think it is much more to do with attitudes, with culture, with respect for people. Those negative attitudes will often come from people who have only ever experienced people with learning disabilities in a negative, passive role in society, if that makes sense; in other words, what we are facing is a major challenge to change centuries of society's attitudes to people with learning disabilities. It is only when society sees what people are really capable of that I think we will begin to make some major changes in terms of the behaviours that lead to the negative things that we are talking about. That is not to say that money is irrelevant, because clearly, in order to promote some of those changed attitudes, there is action that is needed around helping people get into paid work, have proper tenancies, live in their own communities; clearly one, I think, has to raise some fundamental questions about how the media depicts people with learning disabilities as well. I think the place where money comes in quite crucially is that there is a significantly growing population of people with learning disabilities.

Q130 Chairman: Is that due to diagnosis or the fact there are more people?

Mr Greig: There are, broadly speaking, three causes. It is not because of diagnosis. The three causes are firstly that people are living longer, because of medical advances in technology, and linked to the fact that that is greater numbers, that also means that people with learning disabilities are now actually facing challenges that older people face, in terms of health and support, in the way that people

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did not years ago, because they were not living that long, if you go back 30 or 40 years. Secondly, improved technology around birth means we not only have more disabled babies surviving into adulthood, but they survive with much more complex disabilities; so it is not just a question of the numbers, it is also an issue of the complexity of disabilities. It is my personal view that society, quite rightly, about 25 years ago, decided to invest in the technologies to allow premature babies to survive and disabled babies to survive, and perhaps there has never been the public debate and political decision to recognise the financial costs that then knock on into adult life, with those people who are now in their late teens and early 20s. The third one -- sorry, I went on a bit long on that point -- is that there is significant evidence of greater prevalence amongst certain south Asian communities which affects certain parts of the country. We are not clear exactly of the reasons why, but the evidence is clear that there is. If you add those things together, there is a numerical increase of around 1 per cent per year, but if you add the increased level of disabilities to that, the demands upon the public purse are significantly greater than that.

Q131 Dr Harris: Can I just follow up on one thing you said? I have seen research papers or at least published predictions of the cost of advances in neonatal care, and the fact that more and more premature babies and low birth rate babies with some brain damage are going to feed through in terms of costs. Are you aware that those who make policy around the budgets for adults with learning disabilities are aware of that data, has that been fed in, or are the two -- it is in the journals, is that not feeding through at all?

Mr Greig: The data has been fed in. For example, the Association of Directors of Social Services did a piece of work a couple of years ago which extrapolated some of the information they have got on children's registers into adult services over the next few years, and presented to the Department of Health, which then contributed to the comprehensive spending review discussions the impact of that. But I think it is fair to say that the level of detailed robust analysis that, for example, we have seen in relation to Wanless reviews in older people's services has not yet been done in relation to the impact of demand and cost in learning disability services.

Q132 Dr Harris: Because my understanding was there was a cohort study from 1995 called EPICure 1 which looked at all very premature births, and I think there is something called the Trent Neonatal Survey from the large Trent area of South Yorkshire and the East Midlands, which has been going all through the late 1990s to now. I know they are not adults yet, but clearly that is going to be predictive, because there is little mortality after the age of 12, as I understand it.

Mr Greig: If I can just refer you back to my previous answer, yes, that data is being considered, but that is only part of the equation. Another part is what I said

about there are increased demands from other sources such as the ageing population, and then issues around culture and ethnicity, but the other thing is how do you then also factor in the changing demands and expectations of people? You can factor in the future cost of services on the basis of doing the same in the future as we have done in the past, but one of the things relating back to the Chair's opening comments is I would not underestimate the extent to which expectations of people, their families and indeed staff who work in services have changed over the last few years. We are now looking at a completely different type and style of service, a completely different way of providing support, a completely different way of living. If you overlay that on to the population demands, it becomes a very complicated set of calculations, if you like, and it is that complex set of analysis that I am saying has not been done in great detail in the way the Wanless review did for older people.

Q133 Baroness Stern: It says in Community Care that you hinted that compromises have had to be made to keep some departments on board with the implementation of *Valuing People*. Are you prepared to do more than hint and actually tell us what were these compromises?

Mr Greig: With all due respect to Community Care, and I think the person who wrote that is possibly sitting behind me at the moment, that was a bit of a paraphrase of something I said at a conference speech a short while ago, where what I was doing was explaining that the process of developing a new policy like this is a process of dialogue and negotiation with government, where I would go and would say to—let me hang on to my job theme, for example, at the Department of Work and Pensions, “You really have to make it a really big priority to deal with this”; they say, “It is not a priority, but we will do something”, so we see what we get to in the middle. That was effectively what I was doing. What I would say, when the document does come out, which I hope will be in the near future, is that I hope you will see there is some significant progress with some other departments. For example, for the first time, the active engagement of the Home Office in doing some work around hate crime of people with learning disabilities, which is something that the original *Valuing People* document said nothing about.

Q134 Baroness Stern: Can you tell us a little bit about how difficult it is, what are the difficulties of selling it to central and local government and to others? What do they come up with?

Mr Greig: There are two problems, I would suggest, that are probably interlinked. The first one is that we are talking of a comparatively very small number of people, and even though the evidence of, for example, health inequalities may be very stark, and clearly is, because of the Disability Rights Commission report showing us that, when one looks at numbers compared to the population as a whole, and the numbers of people where you might be able to address health inequalities with some other

initiative, there is an imbalance there. That is where it comes into the human rights agenda, both in terms of the impact of action and the fundamental human rights question, as something that leads me to say that even if the numbers do not necessarily stack up, it is something that has to be done. That, I would say, is the first problem. The second problem, which is related to that, and to something I said earlier, is that people with learning disabilities are not a politically empowered group of people. On the whole, they tend not to vote. We did, at the time of the last election, do some political awareness-raising campaigning, with the Disability Rights Commission, to get more people to do that. On the whole, they are not politically organised. Families, on the whole, are exhausted from caring, and it is only a minority that have the energy to get involved in political lobbying. Therefore, the voice is not heard as strongly by politicians and others as it often is by other sections of society. I think if you put those two things together, then that is probably what makes it most difficult.

Q135 Baroness Stern: What should be done to stop it being marginalised?

Mr Greig: I think, with respect, it is back to one of your earlier questions to me about the validity of the human rights framework. The Disability Equality Duty is, in my opinion, possibly the single most important piece of policy and legislation that could impact upon the lives of people with learning disabilities, more so than the *Valuing People* policy itself, because it has that legal framework. The difficulty that I see at the moment is there is a low level of awareness of the Disability Equality Duty across the country. I am unclear as to why that is the case, and again, if I might just give you an anecdote, for the last year, every time I speak, I talk about it, it has been in our newsletters, on our website and everything. At the same conference that you quoted from in an article a few weeks ago, which consisted primarily of middle to senior managers in services, I asked how many people could give me a one-line explanation of the Disability Equality Duty, and what it meant, and put their hand in the air; about eight or ten out of 150 hands went in the air, and that is not untypical. So I think we have a major challenge of getting people in services, let alone people with learning disabilities and families, to understand the potential power that it holds for them.

Q136 Earl of Onslow: Of that eight or ten, how many could?

Mr Greig: Someone suggested to me that so few hands went up because they thought I might then pick on someone, so they did not put their hand up, but I did not test it out.

Q137 Lord Plant of Highfield: There have been a number of reports recently about pretty dreadful incidents affecting people with learning disabilities. There have been a number of deaths, certainly the MENCAP report, Death by Indifference, and there has been a range of poor care, sexual abuse, physical

abuse, or at least allegations of those things. So the National Task Force has criticised the government's response to the Disability Rights Commission report on health inequalities, and as I understand it, they are closely monitoring the government's response to the Cornwall, Sutton and Merton and the Death by Indifference inquiries. So what do you think are the key lessons to be learned by the deaths highlighted in the MENCAP Death by Indifference report and from the incidents in Sutton and Merton and Cornwall?

Mr Greig: Obviously, the independent inquiry has been set up, in following on from Death by Indifference, and that will go, I am sure, into some depth to identify those things. So if I may particularly draw on lessons from Cornwall, it seemed to me, and I presented this in a number of places, both publicly and privately, after the Cornwall report, that there were four big pieces of learning that we had to take from it. The first was it was clear that the local managers felt that they could give low priority to services to people with learning disabilities and get away with it. So there was something about the messages that managers and commissioners in both health and social care, but particularly NHS services, were hearing, that led them to believe that they could give low priority to those services and thus allow those things to happen. The second was, and I have already mentioned the regulatory framework, the performance framework, and the undertaking to take a look at that, that a chief executive said to me a few weeks ago, "If it is not counted, then it probably will not get done". There is an important issue about what we count and what we measure. The third one is that in all of those places of those reports, there was no culture of people in services seeking out, listening to and responding to the voices of people with learning disabilities and their families, which takes us back into the human rights agenda, so I think we need to fundamentally change that agenda. The fourth one is more explicitly a simple question of human rights, but also legal rights, because again, if we looked at what happened in Cornwall, much of that abuse took place in settings where people were supposed to have assured tenancies and housing rights, for example, and that was not the case. So I think if we add those four things together and take action on those, that will not be the end of it, but that will be at the core of the way forward.

Q138 Earl of Onslow: But none of these abuses are things which you should actually have to use the Human Rights Act for. These are abuses, am I not right, which are either—if you are properly brought up, you do not do it. If you know how to behave, you do not behave like that. Who is responsible, on these issues, for making sure that people basically behave properly?

Mr Greig: The responsibility for that: firstly, I think there is a personal responsibility on the individuals, I do not think we should let them away from that. I would say secondly, it clearly is the managers and the organisation that employs and manages them, and where that service is a commissioned service, I

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would say it is the commissioners. There is a trail here, which is why I am doing all of them. Also, it is the responsibility of the regulators to pick up on those things. I absolutely agree with you that these are things where one should not have to be bringing the legal framework to bear, but the reason why I think the legal framework is so important comes back to an earlier one of my comments: particularly if we look at Cornwall, one of the most distressing and worrying things was the fact that many of the staff did not believe and understand that what they were doing was wrong, so rather than be something that people would not do because they are brought up not to do that, one of the problems was because—I do not wish to get all philosophical and historical, but because society has dehumanised people with learning disabilities for centuries, there is still a significant chunk of society that believes it is okay to treat people with learning disabilities in a different way to which you would treat a non-disabled person, and that is what was going on in Cornwall. I suspect that was going on in the cases that were identified in Death by Indifference, and dare I say it, I suspect that was what was going on in many primary care services that the Disability Rights Commission took a look at in their report. The importance of the human rights approach is that over time, you will gradually create a culture where people understand that what they were brought up on, from attitudes of from when I was a child, and what I was taught, are not acceptable in modern society.

Q139 Dr Harris: I am going to ask you about rights in parenting. *Valuing People* and the recent DH and DfES good practice guidance made recommendations about the need to provide appropriate support for parenting for adults with learning disabilities, because we have heard that this is a particular problem, that there is a tendency to remove children. I was wondering whether you can say what has been done to implement that, that advice and best practice from those two documents.

Mr Greig: There have been two or three things taking place. One is there have been a series of conferences organised by an independent parents network which is supported independently, which I and other colleagues have participated in. The audience for that has primarily been professionals. Secondly, through the *Valuing People* network, it has been disseminated through a range of hundreds of network meetings across the country, and we have used those to disseminate it. Thirdly, it has been put out in paper and web form to all the various organisations which should get involved in it. I think an issue that we have to grapple with for the future is that it has probably been better disseminated through the adult side than it has through the children's services side. I think we need to focus more on the children's services over the next year or two.

Q140 Dr Harris: Do you have any metrics on it? Is there a way of measuring to what extent practice is changing as these initiatives are implemented?

Mr Greig: No, we do not. To refer back to, I think, the very first question from the Chair about the difference between rhetoric and reality, one of the challenges that we have is the desire to reduce the burden on local services for data collection. One of the consequences of that is that there are a number of things I would dearly love to collect data on, that because of that desire to reduce the data collection burden we are not able to collect data on.

Q141 Dr Harris: Is that not rather self-defeating? If you cannot measure your effectiveness, that might actually reduce your effectiveness? I know there is always a worry about collecting data, but I think most people object to collecting data that is not useful, or is unhelpful, or is relatively meaningless. I would have thought meaningful data is not something that should be sacrificed.

Mr Greig: I would agree with you, I was just describing the situation we find ourselves in.

Q142 Dr Harris: Can I talk to you about the hate crime issue which you mentioned just before? What is the position with regard to anything that you are aware that the Ministry of Justice is doing to tackle the problem in general terms, and if I could be more specific, to think about providing the same sort of coverage in terms of even new legislation that is being awarded to other "victim strands"; even as we speak now, for example, the incitement to hatred, for example.

Mr Greig: My understanding from discussions with colleagues in the Home Office is there are discussions taking place about definitions of who should be incorporated and when is a hate crime not a hate crime, and what does one do about incitement to hatred. In the pure definition of incitement, I am unaware of stuff that you would overtly describe as incitement of hatred towards people with learning disabilities, I think it is more subtle than that. Therefore, there is a debate about whether it is needed taking place, of which I do not know the outcome. What I do know, and I hope you will forgive me if I do not give too much detail, but potentially, it has to be signed off and agreed in the *Valuing People "Next Steps"* document over the next two or three weeks, is that I do think we can look forward to some cross-government action on that hate crime issue over the coming year.

Q143 Chairman: Could I just ask you about more general support for people who are victims of crime? When we were visiting the Keyring Project last week, we found a couple of people who had been victims of crime there. The process seemed to have been dealt with relatively well, but in the wider community, if somebody is a victim of crime, they get support from the Victim Support organisation; do Victim Support work with people with learning disabilities? Do they have people who have been trained specifically to work with people with learning disabilities?

Mr Greig: My understanding is they are increasingly doing so. Certainly, they have some staff in the senior part of their organisation who have

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experience in the learning disability field. There is an issue about the extent to which people get the range of different supports other people get; in a sense, that is no different from if you had asked about any other aspect of life, it is my point about the mainstream public services often are lacking in the skills and capacity to work with people with learning disabilities in part because historically they have not needed to, because people have been shut away and not lived lives with everybody else. One of the other problems in hate crime which relates to your question which we have identified recently -

Chairman: This is not necessarily hate crime, but just crime in general. One was a burglary, and one was an assault.

Q144 Dr Harris: I am interested in hate crimes, when you are ready.

Mr Greig: If I can put the two together, one of the problems is when people are subject to any type of crime, they often find themselves referred through protection of vulnerable adult procedures which may well be appropriate and should be pursued when need to be, but often, that is at the expense of them getting legal redress through the criminal justice system. In other words, there is a risk that sometimes, services including the criminal justice services see someone has a learning disability and think it is their learning disability that has to be dealt with rather than the crime. That is one of the factors of a recent hate crime survey that the *Valuing People* programme identified as something that needs to be addressed.

Q145 Dr Harris: The House of Commons Library tell me that on 27 February 2007, the CPS launched a policy for prosecuting disability hate crime. Are you aware of that? Do you think it deals with the issue of adults with learning disability in a satisfactory way, or is it mainly about other forms of disability?

Mr Greig: I think it helps. It perhaps could have been strengthened if there had been a greater degree of engagement from the CPS with myself and colleagues when they were writing it. There is more engagement now and we hope to build on what they have done in the future.

Q146 Dr Harris: My final question on this particular point about hate crime is: do you have any figures on the number of complaints, prosecutions and convictions using section 146 of the 2003 Criminal Justice Act, or any other way of measuring?

Mr Greig: No, we do not. I regret I am back to your previous question again, with a slight degree of difficulty, in that on the whole, there are one or two slight exceptions around the country, data collection around crime and hate crime does not specifically identify that a person has a learning disability, they are broader categories than that. So one of the problems that we experience, again, if you will forgive me for answering the question in anecdote form, is over the last couple of years I have met with

many chief executives of councils across the country to persuade them to include action on people with learning disabilities and hate crime in their community safety strategies. Almost without exception, they have not realised that it is a problem. The reason they do not realise it is a problem is that the data that is collected or presented to them does not identify people with learning disabilities as a distinct category. It is therefore a hidden problem, and finding ways of resolving that, which again is something we are talking to the Home Office about, is almost a prerequisite, because at the moment, the data is not collected to give the answer to your specific question.

Q147 Dr Harris: So would you agree with me that on this and other issues, there is a real question about government and agencies collecting the right data in order to evaluate where they are up to and whether their policies are working; would you say that is a fair statement?

Mr Greig: I would say that is a fair statement, yes.

Q148 Dr Harris: In terms of people who are accused of crime, there is obviously concern about their access to a fair trial, given the particular challenges that they face. There are a number of initiatives that I understand you might be able to talk about now that are being put forward. How much work have you done with the Justice Department or the Home Office on that particular problem; the need to have, for example, appropriate adults from the very beginning, and indeed continuing support through the prosecution, if there is one?

Mr Greig: It is not an area that I personally have done a great deal of work in, to be frank with you. One of the ways in which we have sought to take forward the *Valuing People* agenda, as it covers all of life, it is a very large agenda that we have to cover, is to support and encourage voluntary sector organisations, academics and so on, to take forward work in that area. So that is not an area that I have had a great deal of direct involvement in.

Q149 Dr Harris: I am now going to ask the question, more in hope than expectation: is there any data or any way of collecting data that can identify the number of people with learning disabilities in the system and the number of times they have been helped?

Mr Greig: There is data, to my understanding, through research studies and surveys. To my understanding, although I am not 100 per cent certain on this, there is no official data that is collected on that. I may be wrong on that specific point.

Q150 Earl of Onslow: The Prison Reform Trust informs us that those with learning difficulties are likely to serve longer sentences, as they are unable to engage in rehabilitation programmes effectively. Do you find this is true, and how much of this can be mitigated by better representation at their trial?

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Mr Greig: This is another example of what I was just saying to your colleague: the work of the Prison Reform Trust and others is my main source of knowledge and information on that. As you say, their information clearly shows that, and I have no reason to doubt it. It does seem that if eligibility for early release and parole is linked to capacity to complete and demonstrate study that requires a degree of intellectual capacity, then almost by definition, people with learning disabilities will not be able to achieve that early release. We have recently been doing work with the Health and Social Care in Criminal Justice programme, a Department of Health funded programme, to produce good practice advice for the criminal justice system on working with people with learning disabilities. They have agreed to take further action over the next year to roll that out, to help the wider criminal justice system understand some of these issues and to work with them more effectively.

Q151 Lord Plant of Highfield: In your report or document *The Story So Far*, you recognise the importance of advocacy. You have already mentioned it in your evidence, how important it is to have well-funded advocacy services to help to empower people to recognise their rights and to speak up for them. So what progress has been made on your 2010 challenges so far?

Mr Greig: Well, my understanding is that the level of spend on advocacy by local authorities has continued to increase; this is one of the pieces of information that is collected from local authorities through their delivery improvement statements. The commitment in Life Chances for Disabled People to develop user-led organisations is, I think, potentially quite an important and central part of providing the answer to that challenge. That policy commitment was about there being a user-led organisation based upon the Centre for Independent Living model in every area. Centres for Independent Living are, on the whole, excellent organisations or arrangements, but I think it is also fair to say that on the whole, they have not been very inclusive of people with learning disabilities. They have been primarily people from the physical disability movement. So I think one of the challenges we have for the future is to turn that around. The other area though, and this is perhaps something that *Valuing People "Next Steps"* may focus on, is that whilst funding of advocacy is important, it is also important that we help improve the quality of advocacy organisations. I do not just mean self-advocacy, I mean citizen advocacy and professional advocacy as well. There is occasionally a temptation for people to just think, "Oh, because it comes from advocates, it must be right and must be good". I think there is the same onus on advocacy organisations to demonstrate impact and effectiveness as there is in any other organisations. So what I am hoping is that we will be able to find a way of doing some work to improve the quality of advocacy, rather than just focusing on the issue of spend on advocacy.

Q152 Lord Plant of Highfield: Is that about the sensitivity of the advocate to the special needs of the person whose case is being advocated, or is it to do with the more general competence of the advocate, not so much the sensitivity to the specific issues of people with learning difficulties?

Mr Greig: I think it is both of those things. If I was then also just to briefly take it into issues of self-advocacy as well, I think it is also a question of helping self-advocacy organisations to be representative of wider groups of learning disabled self-advocates; for example, people from minority ethnic communities, people with particularly profound and complex needs. I think it is about being able to demonstrate, back to one of my earlier comments, the positive benefits and outcomes, not only from people with learning disabilities, but also for people like directors of social services of the investment they are making in it. I think if we can do that more effectively, it would be easier for people to argue to get more local investment in services.

Q153 Chairman: Last question from me: a big question, but preferably a short answer. We visited some projects last week, and basically, the question is: what are the main barriers to independent living? The answer I got from last week was in large part, it is the willingness of those in power, as it were, to allow people to take calculated risks; there was a cotton wool approach, I suppose, the fear that people might hurt themselves or get into trouble if they were allowed to actually exercise their own choice. That was the unofficial view I started to get from what people were telling me. What is your opinion?

Mr Greig: I would certainly agree that that is a major obstacle. I think it is back to two or three things I have mentioned already. I would also say the willingness and ability of mainstream services to fully engage with people with learning disabilities, because independent living is about having control over your lives and doing things you want to do. So if you cannot, in public service terms, get a decent tenancy from a social landlord, get a decent service from your job centre, or in commercial service terms, going to your bank and your shop, and interacting with a member of staff who is actually willing to do that, is actually a major obstacle. So I would flag that up as the second major issue. The third one, I would say, is the perhaps ambivalent attitude towards independent living from public services. One issue that interests me from a rights perspective is the question of the balance of rights and housing rights between people who are living in assured tenancies and people who are living in residential care. There has quite rightly been a degree of coverage about whether or not there is informed consent when people move from residential care into ordinary housing, which is part of independent living. I think there is equally a question about where the informed consent comes into play when people move into residential care in the first place. When you move into residential care, you lose rights to decide who goes over your doorstep, which staff support you,

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you have problems in earning enough money from a job to pay your residential care fees, and it is not at your behest when you move on to an alternative place to live. It seems to me that there is a big issue about how we actually ensure people give informed consent to moving into residential care when those changes in their rights come into play.

Chairman: That is an important point, it has something that has been flagged up with older people in healthcare. Thank you very much. It has been a very interesting session. I am sorry we slightly overran, we were a bit late starting, but it has been very helpful. I think our report will probably be early in the New Year. Thank you.

Monday 12 November 2007

Members present:

Mr Andrew Dismore, in the Chair

Judd, L
Lester of Herne Hill, L
Onslow, E
Plant of Highfield, L
Stern, B

Dr Evan Harris
Mr Virendra Sharma

Witnesses: **Mr Ivan Lewis**, a Member of the House of Commons, Minister for Care Services, Department of Health, and **Mrs Anne McGuire**, a Member of the House of Commons, Minister for Disabled People, Department for Work and Pensions, examined.

Q154 Chairman: Good afternoon, everybody. This is the last of our evidence sessions on our inquiry into the *Human Rights of Adults with Learning Disabilities*. We are joined this afternoon by Ivan Lewis, who is the Minister for Care Services at the Department of Health, and Anne McGuire, who is the Minister for Disabled People in the Department for Work and Pensions. Anne and Ivan, do either of you want to make any opening remarks?

Mr Lewis: Thank you very much, Chairman. I just want to say a few words and I think perhaps Anne wants to say a few as well. The context of this inquiry is very, very timely indeed. If we look at the different stages in society's approach to people with learning disabilities, the two key elements of that have been over the last 30 years. First, there was the closure of the long-stay mental handicap institutions and the accompanying dowries which enabled people to be supported to live in the community. I have to say, it is interesting when we talk of care in the community in a very negative sense, but I think this country can be incredibly proud of the way it closed those institutions and, on the whole, satisfactorily relocated people into the community. There are very different debates around the closure of psychiatric hospitals and some of the instances there where, frankly, people were left to fend for themselves in entirely inappropriate circumstances. On the whole, the closure of the long-stay mental handicap hospitals was a success and was of great credit to all those involved, and to this country more generally. You then want to move from simply recognising that people with learning disabilities are entitled to live within the community to also talking about equality of citizenship and the right to independent living. The seminal document in that respect, or policy shift, was in 2001 when we launched *Valuing People*. It was a very ambitious set of policies, genuinely cross-government, and was a real attempt to begin a process of equality of citizenship and independent living for people with learning disabilities. I think the evidence will demonstrate that there has been significant progress as a consequence of that policy document, that renewed commitment to the rights of people with learning disabilities and their families. It will also show there has not been anywhere near enough progress, and that is why when I got this job around 15 or 16 months ago I made a strong case for saying that we needed to renew *Valuing People*

because we needed to give it a new energy, a new passion, a new commitment in terms of changing what was happening for people on the ground. In a sense, the test of the government policy has to be the experiences of citizens we are trying to support in this case. They tell us, as I say, there has been a lot of progress but we also know that in many communities there has been a slowing down, frankly, of the progress that we wanted to see made in terms of *Valuing People*. I am currently working with Anne, and I have to say we have tried very much to work on these issues together. Anne is the Minister for Disabled People and does a tremendous job across government. Anne really gave me the green light to look at developing a new version of *Valuing People*, but also to recognise in that context that people with learning disabilities do have distinct issues and distinct challenges and it is all right to have, as we do have and we share, a passion about the disability rights agenda, and in a sense we are almost the leading ministers, along with one or two others, across government for driving this agenda forward, and it is appropriate to have a very, very distinct approach in many instances to the needs of people with learning disabilities. This hearing has come at an excellent time. We are in the process of finalising a document to go out for consultation, which will be a renewal of *Valuing People*, and it will be useful to test that draft document against some of the no doubt searching questions we are going to get from the Committee here this afternoon.

Q155 Chairman: Anne?

Mrs McGuire: Thank you, Chairman. To follow on from Ivan's comments, we recognise, certainly I recognise, that there has been significant progress but we all know that people with learning disabilities still face discrimination as well as significant threats to their human rights, and I welcome the opportunity to discuss some of these issues this afternoon. As the Committee will be aware, in the UK we signed the UN Convention on Disability Rights on 30 March this year and we are now working towards ratification of that Convention. Some countries have proceeded very quickly to ratification but I want to say to the Committee I think that ratification has to be meaningful. We need to ask ourselves not just whether legislation and policies are compliant, but how we can make the

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Convention real for disabled people within Britain and, indeed, across the world. We need to look at how we can make use of the Convention's Articles in the same way that we have done with our Disability Equality Duty, to use them as important levers for change. I want to also advise the Committee that I have set my officials the aim of securing ratification by the UK no later than the end of 2008. As the Committee will be aware, this Government has already strengthened and deepened the legal framework which outlaws discrimination against disabled people in employment, in education and in accessing goods and services. As we have already touched on, even with this robust framework disabled people still face complex and diverse threats to their rights; their views are often dismissed; their experiences are often undervalued, if not ignored. We cannot ignore the fact that there is bad practice and a negative attitude in relation to disability and perhaps particularly in relation to those with a learning disability. The Convention is a powerful statement that disabled people are fully entitled to the same human rights and fundamental freedoms as others, and we must take it and use it as a catalyst to bring about real change in the way Government understands and meets the needs of disabled people. I am under no illusion that making a reality of the new Convention in this way represents an enormous challenge but it is a challenge that we are committed to meeting. We need to build services around disabled people which support them in a way that they want to be supported and not expect them to live in a box that other people have created for them. The Office for Disability Issues is currently leading a project across government to assess how disabled people can be better supported to live independently at home and in the community. In closing my opening remarks, I want to say to the Committee that in respect of policies for people with learning disabilities our focus is very much in keeping with the spirit of the new Convention to embrace core human right values, not least dignity and self-determination.

Q156 Chairman: Thank you for that. We will have some detailed questions on the Convention later on. Perhaps I could ask a more general question first of all. We have got Ivan, who is the Minister for Care Services and responsible for *Valuing People*, and we have got Anne, who is the Minister for Disabled People. If somebody with learning disabilities wanted to raise a question about the Government's performance or a complaint, who would they go to?
Mr Lewis: I cannot imagine the circumstances where they could ever wish to raise a complaint about either of our performance, but it is a pretty good question.

Q157 Earl of Onslow: But you do not know the answer!

Mr Lewis: I actually think the creation of the Office for Disability Issues and the Life Chances Ministerial Group means that uniquely this agenda in terms of the rights of disabled people is being driven across government. Whilst I think we often

talk about joined-up government, but do not always achieve it, if we are frank in this room today, on this agenda we do have very good evidence to support the fact that there is a synergy and consistency between our policies and the renewal of *Valuing People* is very much being done consistent with the overarching commitments and principles in terms of disabled people. I guess the answer in terms of who has lead responsibility for the rights of people with learning disabilities in Government, it would be me. If you wanted to talk more generally about issues affecting disabled people as a group, as a whole, it would be Anne who would have lead responsibility.

Q158 Chairman: That is helpful. Obviously people with learning disabilities are particularly vulnerable, a relatively small group who may be disenfranchised and pretty excluded. How do you go around arguing their corner in Government?

Mrs McGuire: I think you are right to identify that those with learning disabilities are perhaps one of the most disadvantaged groups amongst disabled people. I know that some of the evidence you have heard from those with learning disabilities who advocate on their own behalf has highlighted some of those issues. Inside Government I think there is now a recognition of the various different layered disadvantages that those with learning disabilities have suffered, and are suffering. We are not just talking about disadvantage that has been there for the last ten, 20 or 30 years, we are talking about disadvantage and discrimination that goes back hundreds of years, in fact. I am sure we can all identify some of the evidence on that. Working with the Department of Health, with the Department of Innovation and Universities, with the new Department for Children, Schools and Families, I think for the first time we are coming together to give a cohesive approach to the work that we need to do together as Government to support those with learning disabilities, whether that be in education, employment or in promoting skills with a view to moving into employment. One of the advantages of the cross-Ministerial Group that Ivan alluded to, which is charged with implementing the *Life Chances* report, is that we can do that both as ministers and through our officials. There is a greater awareness than perhaps ever before. Of course, Ivan and I, and other ministerial colleagues, meet on a regular basis with representatives of the lobby who represent the interests of those with learning disabilities, whether that be Mencap or People First or one of a range of organisations.

Mr Lewis: If I can add to that very briefly. I think also, for the first time, in terms of the next Comprehensive Spending Review period we have just agreed the money but we have also agreed the performance assessment framework. There are specific proxies as part of the cross-government social exclusion proxies which are to do with people with learning disabilities on housing and employment. This is a major step forward because it says to every government department that one of our priorities is achieving together certain goals with regard to people with learning disabilities. Also,

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within my own Department, if I am very frank, there has been a struggle to get the NHS to take the needs of people with learning disabilities anywhere near as seriously as they should have done. If you look at the work of the National Director, Rob Grieg, who you have met, he has in some ways been a lone ranger within the Department. I think he has probably found me, having arrived, as an important assistant, but until I arrived he was very much a lone ranger. I just want to pay tribute on the record to the work that Stephen Ladyman did when he was a minister in this area because *Valuing People* was very much about his determination and vision. Beyond that, in terms of the access for people with learning disabilities to mainstream NHS services, there has not been anywhere near the attention that should have been given to the specific needs and experiences of people with learning disabilities. Secondly, the commissioning of specialist services for people with learning disabilities where the NHS has continued to be commissioning those services against a very medicalised model. Frankly, we have seen the consequences of both of those situations and both the independent inquiry established by Patricia Hewitt and the *Valuing People* refresh document that we will publish in due course have to address as a top priority both the question of access to mainstream health services, whether it be primary care or acute care, but also the question of the Health Service's continued role as commissioners of services against a very medical model, which I believe has got to come to an end.

Q159 Earl of Onslow: Can I ask a supplementary on that. Minister, my daughter is a GP in Cumberland and I asked her this exact question I said: "Is it true that there is a difficulty with people with learning disabilities" and she told me a story about two people with learning difficulties who had a child who came to see her. The NHS allocates to GPs about five minutes per person and it took her 20 minutes to even get to the stage of, I think it was, changing the nappy. This is the great difficulty. She loves her doctoring but it takes so much extra time. In your view, do you think the NHS hierarchy takes this sort of difficulty into account?

Mr Lewis: Of course, that then leads us into questions about GP remuneration and contract negotiations, and we all have our own views on those, my Lord.

Q160 Earl of Onslow: You have overpaid my daughter! She gets terribly angry when I say that.

Mr Lewis: I shall send her a transcript of your comments! There are two issues. Clearly if we are going to get very much further on the question of a focus on the needs of people with learning disabilities we are going to have to include that in a number of different ways, first of all in negotiations we have with GPs once the contract negotiations are resumed, so that is something that is going to have to be done, and secondly there is the whole question of what chief executives of NHS provider organisations regard as being important, and if it is not one of their priorities then, frankly, they are not

going to treat people with learning disabilities anywhere near as seriously as they ought to. Thirdly, there is the whole question of the relationship between the NHS and local government and, indeed, the voluntary sector, private sector, in local communities. We talk a lot about integration but for many of the groups of people, particularly this group of people, that whole relationship between social care so-called and the NHS is absolutely crucial. My answer to your question would be that, first of all, I think GPs have to consider what is best practice sometimes and make sure they do that best practice without a view to exactly how much in the QOF formula they are going to get as a consequence of it. Some of it is just best practice and the best GPs want to give equal access to their patients and recognise that some of their patients will need more attention and more time than others. You used the five minute argument, and I have not got the detail in front of me, I may want to challenge that, but, of course, there are other patients that GPs are dealing with who need far less time than the median. The best GPs are willing to recognise that different patients have different needs for different reasons, and inevitably some people will need more attention. I wish I felt the biggest single issue here was to do with a lack of time. I think there is a lack of knowledge and expertise, and I am not saying in relation to your daughter but amongst GPs generally.

Q161 Earl of Onslow: I asked this because it came up.

Mr Lewis: Also, I think there are certain things which are expected of GPs that I regard as being about best professional practice, not about whether you are going to be incentivised through contractual negotiations to do it or not. We need to be frank about that. Carers, by the way, are another area and we should remember that many adults with learning disabilities are still predominantly supported by carers or family members and there is a whole debate to be had about the relationship between GPs and carers.

Q162 Chairman: If we are looking at the issue of health, and I think you are right to look more strategically than just at the GP time taken, although that is important, we saw the DRC on an inquiry on health inequalities and they came to a pretty robust conclusion and said: "The term 'institutional discrimination' does not seem too strong to describe what is happening in some quarters", and I suspect from what you are saying that whilst you may not formally agree with those words you would understand perhaps where they are coming from. What would you say you are going to try and do to address that? I know you have got your independent investigation into some of these issues now but how can you respond to comments like that from the DRC?

Mr Lewis: The answer is there are a number of ways and I have tried to identify some of them. There are the contractual negotiations with GPs and their representatives. There is an understanding of what best practice is and spreading that best practice.

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There is the training of doctors and nurses, and we should remember that primary healthcare is not just about GPs, it is about a whole range of professionals. It is about senior managers in the NHS knowing that a part of the way they are going to judge but also incentivise in terms of their responsibilities are the experiences of people with learning disabilities. Frankly, there is also the fact that when appalling neglect, institutional or otherwise, takes place there are the consequences, because I never want it to be said, "That person had a dreadful experience in terms of their healthcare but the mitigating factor is the person had a learning disability". That is a complete anathema and unacceptable to me. The other issue is commissioning. The other question that has to be asked alongside that is that when there have been these abuses, mainly in specialist services, there have not been very many prosecutions stemming from those abuses. There is a whole variety of factors at play here and it would be very disingenuous to say one more than the other would make the difference. It is really about the Department of Health, and the NHS consequently, taking the needs of people with learning disabilities seriously and giving them a higher status in the future and, whether you are a GP or a senior manager, knowing that people with learning disabilities require a specific and distinct response and they have the same rights in terms of access to mainstream healthcare as any other citizen, and in terms of the provision of specialist services this notion that we have got to move away from the medical model, other than in circumstances where people have an illness or a health condition.

Mrs McGuire: That is where the Disability Equality Duty is also key, because it is about charging public authorities in the widest sense not just to look at their practice but to start to raise the issues of disability equality as part of the way in which they deliver services, and that covers the NHS as much as it covers police authorities and educational establishments.

Q163 Chairman: I think that is something we will want to come back to again. The answer you gave there, Ivan, was not very dissimilar from the answer you gave us when we were looking at this issue in relation to the treatment of the elderly within the hospital and care home system. That links through to me to the main thrust of what we were talking about then, which was the use of human rights as a lever to improve services. Do you see the Human Rights Act and human rights principles as a lever here to improve services and, if so, how are you using it in your negotiations with your colleagues across departments to help people with learning disabilities? Perhaps you can give us an example, if possible.

Mr Lewis: Obviously part of the new *Valuing People* focus that we will be publishing in the near future will be the whole reminder to people that this is about human rights legislation and the Disability Discrimination Act, and some of this is grounded very clearly in law. It is not just about doing the right thing, it is not just about best practice, it is also about

fulfilling statutory obligations. As I said to you the last time I appeared, I also have a concern that ministers are very clear that in the same way as just announcing a policy or an initiative does not change anything for people on the ground, simply having law does not always change people's experiences on the ground either. As long as we get the message right in terms of that combination of factors I think you are right. Mersey Care, and they have appeared here, have a very impressive approach and a significant part of that approach is based around starting off from the perspective of fundamental human rights. The new approach to *Valuing People*, the next stage of *Valuing People*, needs to emphasise to the deliverers as well as the policy-makers that much of this is grounded in the law.

Q164 Lord Plant of Highfield: Your answer there really brings me on to my first question. Many of the witnesses have said in the context that you are producing a further version of *Valuing People* that what is needed is not so much more policy or an elaboration of policy, they are strongly supportive of the policy and think you have got the policy right, the problem is implementation, persuading people on the ground, as you put it a minute ago. What sort of levers can you pull? How do you go from a widely supported policy to actually getting the implementation on the ground?

Mr Lewis: I will deal with that and then Anne might want to come in. There are a number of things. First of all, we now have substantive legislation that was not there previously. You have got to align the message you send to your regulators, whether it be CSCI or the Healthcare Commission, in terms of how they are judging public sector provision, so regulation, making sure that is consistent, understanding that if you are a senior person in an organisation part of the way that organisation will be judged is the way you treat people with learning disabilities, in this case. The fact that we have proxy targets for the first time around social exclusion which are about people with learning disabilities are a major step forward. In addition to that, empowering people and family members to know what their rights are and supporting them to develop the skills and confidence to challenge the system when the system is not delivering is crucial, whether it be forums or things like personal budgets and direct payments, so recalibrating the power in the system so you give a lot more power to people and their families who use services is another important way of changing things. We set up the Learning Disability Partnership Boards, which the Committee has heard a little of, and of course the view is they are incredibly patchy in their effectiveness and some local authorities are going through the motions. They have not disbanded them but they have very little influence over the development of either policy or delivery at a local level, so one of the things we have got to look at is what we can do in terms of the Learning Disability Partnership Boards. The new version of *Valuing People* is no change of policy whatsoever, and this is the whole point, we will be saying very clearly the

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policy was right and is still right, the consensus is still there. It is how do we use the levers that we have available to us at a national level to secure better delivery locally. The final point I would make is this whole debate around devolution and localism. If you look at the latest Comprehensive Spending Review settlement, the new arrangements between central and local government, there is a much greater level of devolution. With that comes a performance framework, clear requirements and obligations in terms of outcomes, and with that comes local area agreements, but in the end we have to be much clearer as ministers and as Government in every area of policy—this applies to the dignity of older people as well—what are the levers that we have and be very ruthlessly focused on seeking to identify what they are and, where appropriate, pulling them to maximum effect. The final responsibility and power ministers have is to say these things matter. A lot of the work that we have done around the dignity of older people is beginning to have an effect in that it is beginning to be debated and discussed and is in the media almost on a daily basis. Getting these issues debated and discussed, and people understanding how important and serious they are, and that it is not just about somebody else's family, it may end up being about your family or someone you care about's family, is crucially important.

Mrs McGuire: I think we have also got to recognise that legislation has been there now for a long time and it is about how individuals who deliver public services actually accept their part of the responsibility. I do not want to pre-empt the question on the disability equality duty, but what that does do is recognise that everyone who is involved in the delivery of the public service has a responsibility for ensuring that the rights and needs of disabled people are taken into account. If I could give you a specific example where a reasonable adjustment could be made in terms of a hospital, it might well be that they need to look, if it is an outpatient appointment, at how they manage that outpatient appointment. Do they change it to suit the particular commitments of a learning disabled adult and perhaps their parent or carer? What can be considered to be a reasonable adjustment? The whole concept of reasonable adjustment has now been with us for a long time. Ivan is right: we are not now defining new policy. What we are doing at every opportunity is highlighting to those who deliver our public services in particular, but also to those in the private sector who deliver jobs and various other services, that they have a responsibility to work with those with a learning disability as individuals and not categorise them, stereotype them or make assumptions about what they can and cannot do. That is where, I think, the human rights perspective is so powerful. As I say, I know from earlier evidence that that approach was supported by various organisations and their representatives.

Q165 Lord Plant of Highfield: But, picking up the point about localism that I have made, some of our witnesses have suggested that local authorities are

tightening up a very great deal on the criteria for eligibility and that means that a more and more limited group of people will have access to the best level of service that might be provided. Do you recognise that, and, if you do, how are you going to work with local authorities to ensure that the vision of *Valuing People* is not eroded by this tightening up under financial pressures of eligibility criteria? A more specific question following that general one is this. If the numbers are tightening up because of the tightening of the criteria the critical group is going to get into the eligibility criteria but the group of people immediately below that group, as it were, who could get very great value from services but whose needs are not as critical, are not going to get them under this tighter regime. Do you recognise that and what steps, if any, do you think you can take to ensure a reasonably equitable distribution between the critical group and the very needy but not critical group?

Mr Lewis: In the Comprehensive Spending Review settlement the Government has committed now to a process of public engagement and consultation leading to the production of a Green Paper next year on the long term funding of care in our society. I am delighted that the scope of that is beyond older people. I think this is a major advance, something that we fought for, and it recognises that social care, unlike the NHS, has always been means tested and therefore the challenge, in the context of a society which is changing—disabled people now have long lives and expect full lives, quite rightly, as well as the fact that we live in a society where people are living longer and have more complex and challenging conditions), is that as we look at that demographic change which is swirling around us we need to have a new settlement between the state and the citizen in terms of who is responsible for what when it comes to the funding of social care. That is the long term. As for the short term, I have spent my whole life in social care before I was elected to Parliament in 1997. I started off life as a young volunteer at the age of 14 working with people with learning disabilities, which is where I get some of my passion for this from. I set up a small voluntary organisation at the age of 19 looking at leisure and social opportunities for people with learning disabilities. I feel very strongly that we are not getting best value for existing resources. I think the community care legislation of the 1990s was very well intentioned indeed. I think it has led to unintended consequences of an over-complex and over-bureaucratic system with too much emphasis on assessing people and very little on doing anything once you have assessed them. We have got this whole stuff around eligibility criteria which means that we do not realise that our interventions need to be a lot more about early intervention and prevention. If a person with a learning disability is healthy, is working, is having a positive life, they are far less likely to become ill and to become highly dependent on the state and therefore, in terms of best use of existing resources, there is a lot more we can do. We will be announcing very soon a programme of reform, which we will be leading on for the Department of Health but which

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will be cross-government, on the whole way that we do adult social care in our country. I do not want to go into that too much but I want to be clear about the ingredients of that message. One is a much greater role for personal budgets so that people have a greater level of control themselves over the care that is provided to them and their families. Some people will need a large amount of help to make that a reality. Other people will need a minimum amount of help. Another is a shift to early intervention and prevention and away from a system which starts to respond to people once they have already deteriorated. We need a much closer level of integration between the NHS, local government, the private sector and the voluntary sector in every local community and a focus on the quality of commissioning. I do not just mean of commissioning by local authorities or by primary care trusts or by DWP. I mean the notion of joint commissioning in communities so that we are looking holistically at the needs, in this case, of people with learning disabilities. We talk of a world-class commissioning system. We do not have a world-class commissioning system. We never said it was world-class, by the way, but it is our aspiration. At the moment there are a lot of people who act as commissioners but who frankly are contract managers, who manage an existing market, who manage existing providers but who have not got the skills or the vision or the imagination to first of all get a very clear sense of what their population needs assessment is and, having done that, to really begin to re-engineer and recast services in an appropriate way. I also suspect that we have large amounts of money tied up in out-of-date services that people with learning disabilities do not need and do not want. There is a real challenge there about how we free up some of that resource in an imaginative way but also in a way that takes families with us. I think this is a really difficult one for people at a local level. If you are proposing major reform of traditionally provided services and you have thousands of people marching down your local street it is all right referring to the minister's contribution at an evidence session like this, but when certain politicians (who shall remain nameless) are presenting any change in the NHS and social care as cuts it makes it incredibly difficult to radically move services forward. I also believe we must do this reform very differently from the way we have done previous reforms. You need to win the hearts and minds of people on the front line if you are going to reform a system effectively, and therefore, rather than having a set of reforms that we impose top-down on people working in the social care system (and to some extent in the NHS) you need to try and find a way of reforming the system in partnership with those who are responsible for delivering it in the real world on the front line whilst never, never being afraid to challenge, as Anne said, the poorest of the practices, whether it is about the dignity of older people --- I had a go recently and said some nursing brings that profession into disrepute. Failure of accountability amongst NHS managers is completely unacceptable. It is about achieving this

delicate balance between wanting to win the hearts and minds of people on the front line and taking them with us but never being afraid to say that there are certain things which are entirely unacceptable and standing up for the rights of citizens who use services, and their family members in this case.

Q166 Chairman: It seems to me, Ivan, and we have had an amazing amount of evidence on commissioning issues, whether from people who have given evidence to us formally or when talking informally with people with learning disabilities or we have been out and seen for ourselves in those bodies, that there is a huge amount of really good work going on, often with relatively few resources. You can achieve an awful lot for people who are not particularly seriously disabled. It is like the greatest good for the greatest number argument, I suppose, in terms of a relatively small amount of money being spent relatively thinly and doing an enormous amount of good, and whilst we are inevitably focusing on people with serious disabilities who must have the help, we have to find a way of getting smart in the commissioning process. That is quite an inspirational statement. The real question is how you translate that inspirational statement into what happens on the ground.

Mr Lewis: Anne has some similar experiences, but, very quickly, the only person employed in the small voluntary organisation I ran back at the age of 18 or 19 (when I had a proper job and a life) was me and a half-time admin worker. This was about getting people access to social and leisure opportunities other people would take for granted—going down the pub, going to the theatre, the cinema, introducing people to the notion of relationships and friendships and acquaintances. The only cost was the volunteer expenses and my salary and that of the half-time administrative worker and the £30 a week it cost to rent a dingy basement room in a not very salubrious hotel somewhere in darkest Salford. The point I am making is not that volunteers should be used to do it on the cheap or that we should exploit people but that there is an awful lot we could be doing in the world of social care which is about alleviating loneliness and isolation, about building relationships between people, that does not need to cost billions of pounds in state expenditure. One of the sadnesses about the community care legislation of the early 1990s is that it has left us with a system where nobody appears to be responsible for things like how do you alleviate the loneliness and isolation of older people or people with learning disabilities? One of the things we will seek to address in the announcements we make in due course will be not saying that the state has a duty to provide people who are lonely with a friend, because that would be a disaster, but that surely the state, represented at a local level, in partnership with local communities, so it has to be a combination of statutory agencies, the voluntary sector and local communities, has a duty to look at its most vulnerable members and build various systems around those members which enhance their quality of life. Some of it is about statutory agencies like adult social care, like the

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NHS, like Jobcentre Plus, like the Learning and Skills Council, making sure that they fulfil their statutory obligations to everybody in an equal way (they do not do that at the moment in many cases) but some of it is also about communities having a different view of what a decent civilised aspirational community should be in a modern world.

Mrs McGuire: That is why we are so keen on our individualised budgets approach, because it is not about additional money or additional resources; it is about looking at the resources that are there and how, by reconfiguring them, you can not only give independence, control and authority to an individual disabled person but also improve their quality of life because they are in the driving seat, and certainly some of the early experiences coming back from those individualised budgets are very positive.

Q167 Mr Sharma: You have already picked up the question I was going to ask, but I had experience, before becoming a Member of Parliament only five months ago, of working in the disability field, particularly with learning disabilities. My main concern is that there is a lack of skills, which you have already identified, but also strict financial controls, so that when a needs-led assessment is done it is done keeping in mind how much money we have, and that is where this new criterion will affect a lot of people who are sitting on the margins. How are we going to improve the staff skills and the skills of those people who are going to decide it in the future?

Mr Lewis: We spend vast amounts of money on staff training in social care and I am still wondering whether we are clear about the outcomes we get for the money. We should recognise that 70-75 per cent of the provider organisations in social care are in the private sector or the voluntary sector; it is not in-house or direct provision. One of the things I want to do is ensure that in every locality the private sector and the voluntary sector are around the same table as the local authority in designing and developing the training programmes, because we are talking in those cases about the vast majority of the staff on the front line or their workers. We also need, of course, to raise the status of care staff who are poorly paid and often low skilled, and this is a major difficulty generally. No government is going to massively increase the salaries of those people overnight but there is a need to have a serious look at the inevitable consequence of a low-skilled, low-paid workforce when we are asking them to work with the most vulnerable sections of our society. I think Anne's point is really important. If you look at the implications of moving towards a model where the vast majority of people have their own budget, this will change the role of many social workers and social care staff because in a sense they will go back to doing what I hope most of them joined the profession to do in the first place, which is to empower and enable and support people, not simply assess them and tick boxes. Let us be clear: what I am articulating today is a vision about a considerable reorganisation of the way adult social care does its work up and down the country. I think there are

many unintended consequences of that well-intentioned community care legislation. It is almost as though people feel they have to do social care, like they do with the assessment criteria, with the same approach all over the country. It has become an industry which does things in the same way. I am not saying there are not real financial pressures because that would not be the case, but can people, hand on heart, say that we are getting best use for the existing resources? I am afraid I do not believe we are anywhere near getting it. We have had the Comprehensive Spending Review settlement. The department budget is spent largely through local government into its whole range of services, including adult social care,—and we should remember that that budget is not ring-fenced, by the way—but what will happen next is that we will be announcing very soon an amount of money the Department of Health has specifically for the reform of adult social care over the next three years, which is over and above the resources that go through local government in terms of the revenue support grant.

Q168 Earl of Onslow: Minister, I must say I have been very impressed by your complete grasp of this subject.

Mr Lewis: I am in trouble, obviously.

Q169 Earl of Onslow: I could almost call you an *über*-Blairite but perhaps it would be unfair.

Mr Lewis: It may not be very helpful either.

Q170 Earl of Onslow: What I am finding it difficult to come to terms with is the fact that although your diagnosis of the problem seems to be extremely good there also appears to be patchy local authority and local reaction. How do you balance the demand which you articulated for more locally-based solving of problems with imposing from the top a standard of behaviour of which we should all be proud?

Mr Lewis: Is that not the age-old question for politicians of all colours through history and have we not gone from one extreme to another in terms of this pendulum of central, Stalinist, rather *über*-Blairite control and devolution?

Q171 Earl of Onslow: I think we are much too centralist in practically everything.

Mr Lewis: The irony is that people have come to a conclusion that to achieve real change you need to empower far more the professionals on the front line in the localities. There seems to be a consensus around that. Equally, if you think about the amount of time that ministers spend dealing with the latest press release from Age Concern or Mencap or Help the Aged slamming the system for one failing or another, the obvious pressure on the politicians is to take some responsibility rather than say that this is a matter for local determination. I think we may be accused of abdicating responsibility, so we need a far more mature debate about the role of central government *vis-à-vis* the role not only of local government but also of local communities and local government's relationship with other statutory agencies. The great difficulty often, I feel, is that

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there are certain things that happen on NHS wards in nursing homes, in agencies of one kind or another, which to me are nothing to do with resources and nothing to do with the Government's "target culture" and everything to do with poor management and a lack of professionals taking responsibility. I am not prepared to stop challenging the system when I believe it is fundamentally failing in its basic obligations to older people or people with learning disabilities. In terms of older people, if it would not be good enough for my mother and father why should it be good enough for somebody else's mother and father? That is the message that I think we need to send out. You could also use this analogy, changing the words "mother and father" to "family": if it is not good enough for my family why should it be good enough for somebody else's family? Some of it is because these professionals and managers function in very high pressure circumstances in a very difficult context, but some of it is people not taking responsibility and not doing their jobs properly. Any Member of Parliament knows that many of the people who end up in their surgery are there because one public service or another has failed to take responsibility for sorting that person's problem out and instead has passed that person from pillar to post and treated them with complete contempt, as a number. That is why an *über*-Brownite policy, which we should welcome, is this notion of the personalisation of public services. Of course, the danger of the term "personalisation" is that it becomes another fashionable, meaningless expression, so we have to define it. What it means for me is that we have to move away from regarding people who use public services as part of a system of mass production, which I am afraid is the current culture, to a system which treats every individual in a highly personalised way. I will use an analogy which is controversial, *über*-Blairite or *über*-Brownite, and that is that very few people who are seriously ill would choose to go to the private healthcare sector for a solution. They are much better off in the NHS in my view, but why do people often choose—still a small minority in this country—to use the private sector? Largely for the customer care and the highly personalised nature of the service that the individual or the person that they love will get. That for me should not be above the capability of a modern public service, to offer not just the best clinical care but also the best personal and customer care that we can possibly seek to provide.

Q172 Baroness Stern: I am enjoying what you are saying very much. I want to talk about the Equalities Public Service Agreement, which I have read. I have it here and it is a most encouraging and attractive document, but my question to you really is about implementation. The implementation of documents like this is associated, I think, in many people's minds with designing a list of things you can measure. Somebody will no doubt be sitting somewhere in one of your offices now designing a list of things you can measure, and the local deliverer is the person who does the measuring or makes sure

the measuring comes out right in some way or other and ticks boxes, and then you implement this thing, which is an excellent thing. I want to ask you whether there is another vision you might have about implementing it which would have something to do with the Human Rights Act and the values and ideas in the Human Rights Act, and trying to tell the people who do the delivery about them, and then inspiring them to see this not as another tedious ticking thing from Whitehall (of which they already have so many) but as something that could lead them to give people some pride in their work and a strong sense of values. Have you got any ideas about how you might do that?

Mrs McGuire: The PSA on Equalities is part of an approach across all of these areas which is very much based on a human rights set of values. In talking about ending discrimination in employment, unfairness in receipt of services and unfairness in the lack of access to participation to public life, I think we are setting out fairly inspirational objectives and ones that may not be easily achieved by the tick-box exercise. Certainly Ivan and I, who do a double act in various forums across the country, and internationally as well, are very much giving out the message that we are not interested in tick-box exercises any more because you are right, Baroness Stern: they can be achieved pretty easily and then they become routine and then just part of the drudgery. This is not about the drudgery of life. This is about being evangelical about the rights of disabled people, particularly those with learning disabilities, to be full members of society. We need advocates, we need champions alongside us on that, and I have to say from my experience, which goes back slightly longer than Ivan's but comes very much from a similar background, that I am now beginning to see those changes, that people who are involved in public life and people who are involved in business, senior members of the business community, are now beginning to talk about learning disability in far more positive terms than, frankly, I could ever have anticipated 35 years ago when I was working with adults with learning disabilities. Yes, we do need to measure the achievements, we do need to look at ways in which we can assess our progress along the road, but we also need to inspire people. We are not doing this because it is a tick-box exercise. We are doing it because it is the right thing to do, and, to hark back to what Ivan said earlier, if it is good enough for my family then it should be good enough for everybody. That is where we are coming at on this, but it has to be an inspirational message and it has to be one where communities hear the advocates, such as Andrew Lee, who was at your committee a few weeks ago and who I thought gave very powerful evidence to you on how he perceived his life both as an individual and as a representative of those with learning disabilities. Certainly from my experience the picture that he painted was very much the picture that I used to have to work with before I was a Member of Parliament.

Mr Lewis: I agree entirely with all that. The other thing we need to do is recognise that there are some real pioneers out there, some radical forces for

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change who have been revolutionary in a sense for many years in the learning disability field. In Control is one of the latest manifestations of that, as is some of the work at Mersey Care and similar organisations. There is an organisation I am aware of called Partners in Policy Making, which seeks to give family carers a lot more confidence and assertiveness in challenging the system but in a sensible, constructive, positive way, not in an adversarial way. This is an area where there are lots of hazards. I think the danger is that pioneers are seen as a threat, not an opportunity, and the radicals are kind of marginalised and we need to find a way in the period ahead of encouraging and rewarding and incentivising people who are willing to challenge the norm. I think any organisation that is going to be successful needs to start off by being values-led, and everybody who works within it needs to understand what those values are and why they matter before you get on to talking about people's individual job titles or their individual roles and responsibilities. The best leaders and managers understand that. I have to say to you that I think there are far too many public sector organisations in this country where they do not have leaders and managers who understand that.

Mrs McGuire: And who also do not like the idea of risk.

Q173 Baroness Stern: Do you have a plan about this PSA, to try and have it implemented in the rather inspirational way that you have both described, and is it somewhere where we can read it and look at it?

Mrs McGuire: Is that a cunning plan?

Mr Lewis: What is this PSA? Does it specifically refer to, say, old people?

Q174 Baroness Stern: The Equalities PSA.

Mrs McGuire: It focuses on the pay gaps, on discrimination—

Mr Lewis: Do you mean across the board?

Mrs McGuire:— across the board.

Q175 Baroness Stern: Yes, but obviously we are interested in how it is implemented in relation to this inquiry into people with learning disabilities. They are in there and therefore I would like to know where the inspiration turns into doing.

Mr Lewis: The belief that we can transform the adult social care system in this country without waiting ten, 15, 20 years is one that I hold, and I think Anne holds, and that would obviously make a massive difference to people with learning disabilities. Our challenge in the period ahead, and we are talking about weeks, not years, is first of all to be absolutely clear about what that vision is, and, being absolutely clear about the vision, then to set about the task of ensuring that as many people as possible in positions of influence understand the vision, own the vision and see it as a shared responsibility to make the vision happen. I would say that in relation to adult social care in the assessment couple of years there has been a period of silence in terms of vision and sense of direction and leadership, and that period of silence is coming to a close. The challenge is that we

will be able to articulate the vision because in a sense today I hope we have been able to show you some of the ingredients of that vision, but then we need to ensure that organisations that can make the most difference, locality by locality, first of all share it and understand it and then inspire the people who work at every level of their organisation. It is no good the chief execs being good guys if the middle managers do not understand it, do not feel signed up to it, are not included in it and then the front-line staff are alienated. If any part of that chain is broken the danger is that you end up with unintended consequences, but I do think there is an issue beyond this about public sector passion in terms of when you go to work every day are you made to feel as though you have the power to make a real difference and are you encouraged to feel that about your job, or are you going to work every day feeling that you are having to fulfil a very functional set of responsibilities? That is the challenge in terms of the personalisation of public services going forward.

Q176 Baroness Stern: So I assume you do have a plan.

Mr Lewis: We do.

Q177 Baroness Stern: It sounds as if you have got a plan.

Mr Lewis: We do.

Mrs McGuire: But it will manifest itself in different ways. One of the PSA targets is choice and control in life. We are looking at developing our independent living approach. We currently have a task force due to report on an approach to independent living, and I know that it is an issue that has been raised on a regular basis in the House of Lords. In terms of issues relating to discrimination in employment, we are currently working with organisations through our disability employment schemes, et cetera, our Pathways to Work, to look at how we tackle those issues. Going back to what I said earlier, we need champions out there and there are champions. They do not always get the publicity they deserve but increasingly it is becoming part of the orthodoxy, I think, in conversation, certainly in the private sector, and Ivan is spot on when he talks about public service deliverers. One of the most positive discussions that I have heard, when we were talking about an individualised budgets approach, came from social workers who had been in the social work slot for a long time, and through the individualised budgets approach they were freed up to do some of the work that they had gone into social work to do, which was not about making decisions for people but about supporting people to make their own decisions. They had become reinvigorated and almost liberated in the way in which they were now pursuing their work, and if we could find a way of bottling it and sending it out across the country we might well do that.

Mr Lewis: In the north west, when the long-stay hospitals were closed down, the resettlement of people with learning disabilities, there was a network of people with a missionary zeal about the closure of those institutions but also the positive

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resettlement of those people into the community. We want the same missionary zeal amongst as many people as possible in terms of the right to independent living, and that in a sense is our next challenge.

Q178 Baroness Stern: I have another much less complicated question, and it is to you, Ivan. In your evidence you told us that CSCI, the Commission for Social Care and Inspection, considers that about 20 per cent of the funding from the Learning Disability Development Fund distributed to PCTs has been diverted to general NHS funds. Do you have a view about that and how can you exert your influence on funding that is meant to go for one purpose to ensure that it does?

Mr Lewis: Which particular fund is that because I need to be clear?

Q179 Baroness Stern: The fund is the Learning Disability Development Fund distributed to primary care trusts.

Mr Lewis: That will all be transferred to local authorities in the future on the basis that we should be focusing on a social model, not a health model, but also the evidence is that that is more likely to be spent on the purposes that it is meant to be spent on. All of that will become the responsibility of local government.

Baroness Stern: That is a very helpful answer. Thank you.

Q180 Lord Judd: Chairman, as this is my swansong may I just be allowed one comment? Having spent a great deal of my life in the voluntary sector, there have been several points in the last hour when I have wanted just to yell, "Hallelujah! Ivan will save", (and Anne as well), because it does seem to me that if the voluntary sector is about anything it is about vision, it is about risk-taking, it is about initiation, it is about challenging. I am, however, a little bit worried about the culture of crisis in the voluntary sector as a sub-contracting culture begins to take over, as just deliverers of the services, as they are, fostered sometimes from others of your colleagues saying, "This will be a cheaper way of doing it". I want to ask you a very specific question. You have been making very clear that a lot of the work being done in this area is being done by the voluntary sector, and indeed the private sector, and you will know that this Committee believes very strongly that service users will not be adequately protected unless they are considered public authorities for the purposes of the Human Rights Act. Recent law decisions have not helped in that respect. However, it would be helpful if you could tell this Committee exactly what you are doing to ensure that the duty to act compatibly with Convention rights of service users applies to both the voluntary and the private sectors.

Mr Lewis: I will just deal with the first point you made about the voluntary sector and its traditional role. Another very distinctive shift of emphasis by the new Prime Minister is celebrating the role of the voluntary sector to campaign, change and advocate politically (with a small "p") in communities, not

just be an extension of the state in terms of service provision. This is a very clear position of both the current Prime Minister and Ed Miliband, who was leading on these issues, and now Phil Hope, his replacement. The point you make is really important. On the question of what plans do we have, to be absolutely clear, the negotiations are ongoing with the Ministry of Justice. I am absolutely determined, as we as a Government are, to put that anomaly right. Parliament always intended that independent sector providers should be covered. The commitment here is that we are currently discussing with the Ministry of Justice the best way of doing that, so hopefully we will be in a position to make some public announcements on this in the near future.

Q181 Lord Judd: But surely in the meantime there should be a ruling that all contracts that are made must stipulate the Human Rights Act?

Mr Lewis: I tell you what we can do, and what I am looking at doing—you heard it first here—is making it absolutely clear as part of the legislation which is due to go through on the new regulator, you know, the merger of the Healthcare Commission and CSCI; it was in the Queen's Speech, that they need to regulate to the level and the standards that would be expected if the Human Rights Act were to apply to those providers. The interim measure would be to make it very clear to the regulator, through guidance or other means which we have not yet decided upon, that they must regulate independent voluntary sector providers according to the same level of standards that are required by the human rights legislation, but then the next stage is to continue to make it clear publicly that the Government's commitment is, as soon as possible, when the right legislation comes along, to make sure that this anomaly is put right.

Q182 Lord Judd: But surely in the meantime a very practical step is just to ensure that whenever a contract is made it is in black and white in the contract.

Mr Lewis: That is exactly what we are looking at at the moment, with both the regulator and the Commissions.

Q183 Chairman: The problem with that approach is that it cannot be enforced by the person that receives the services in the same way that it could if there was a direct applicability to the Act. I remind you that when I brought my 10-Minute Rule Bill in last year in response to the Second Reading, Vera Baird, who was at the DCA in those days, said that this would be sorted out by Christmas. Will it?

Mr Lewis: It depends when Christmas is going to be this year, I guess.

Q184 Chairman: 25 December is usually the date.

Mr Lewis: I think that the Government hopes to announce its position so it is absolutely clear, publicly and to parliamentarians, before Christmas.

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Will it be sorted out? I think it is highly unlikely. Will it be clear to everybody how we intend to sort it out? I hope it will be before Christmas, yes.

Q185 Chairman: It will certainly in relation to this lot because I am going to deal with the Bill, so there we are.

Mr Lewis: Right, okay.

Q186 Lord Judd: One last quick question. We have a rotation system in the Lords and I am about to be rotated off the Committee, and this is my very last question that I am ever going to ask. It is a very small, specific point. Can you tell us why there is no reference to human rights or any practical guidance on rights for commissioning authorities in the recent *Good Practice* guide issued by the National Director of Learning Disabilities?

Mr Lewis: No.

Q187 Lord Judd: Could you please draw this to his attention?

Mr Lewis: When we publish for consultation the revised *Valuing People* document I think that is where we need, in that document, to talk much more up front and clearly about the human rights elements of the whole agenda, so I will make sure that that document begins to put that right, yes.

Q188 Lord Lester of Herne Hill: These are questions to Anne McGuire. First of all, on the disability equality duty, it is almost a year old and we have had evidence from the National Director on Learning Disabilities and others about the low level of awareness of public authorities about the requirements of the duty. What steps are the Government planning to take to address the problem of low awareness?

Mrs McGuire: There are a couple of issues there. One is the awareness of the disability equality duty at a high level within public authorities, the publication of a disability equality scheme, et cetera. The Office for Disability Issues undertook some work in co-operation with the Disability Rights Commission and we certainly found that there was significant compliance with the disability equality duty. Indeed, if my memory serves me right, there were only about 60 public authorities that had not published the disability equality scheme and most of them were persuaded to do so before their names were published. We also have a bigger issue, and it harks back to some of the comments that Ivan made earlier about the cultural change. The disability equality duty is a radical change in the way in which public authorities are expected to work. To be frank with you, radical change does not happen overnight. We are talking about challenging, all the way through the system from the chief executive to the person on the front line, the way in which they operate. We are working through the Office for Disability Issues to ensure that that involvement is recognised and that that responsibility at all levels within the public authority structure is recognised, and, of course, one of the ways we have of doing this is to ensure that the chief executives, for example, are

responsible for the implementation in the same way as there are specified secretaries of state responsible at central government level for the implementation of disability equality duty. In the lead-up to the implementation of DED and since that time I have made it very clear that this is not a tick-box exercise, it is not something that you did on 6 December or 1 December last year and you put it to one side. It will be monitored, there will be action plans accepted, you will be judged by the implementation of your action plan. Previously we would have worked closely with the Disability Rights Commission. We obviously will work closely with the new Equality and Human Rights Commission to ensure that this is not going to be left on a pile somewhere.

Q189 Lord Lester of Herne Hill: Thank you very much. Given that it is radical and new and that a tick-box exercise will not do, could you provide the Committee—not now—with some indication in writing of exactly what you propose to do to promote awareness so that people get the full protection of the duty?

Mrs McGuire: Yes, I will do that and build on my answer.

Q190 Lord Lester of Herne Hill: Thank you very much. Could I turn to the Disability Rights Convention? First of all, given that we have plenty of existing law and practice under the Human Rights Act and the Disability Discrimination Act, how will ratification of the Convention help in the real world to make life better for adults with learning disabilities? What added value is there in it?

Mrs McGuire: First of all, we are having to go through our own law at the moment to make sure that we are compliant with the UN Convention. In terms of practice in spirit we are pretty compliant, but we also have to ensure that we are in fact compliant and can meet our responsibilities. I am not sure whether or not the Committee is aware that the level of awareness and support for the UN Convention amongst disability groups within the UK was astonishing, including from those organisations for all people with learning disabilities, because for the first time, I think, we saw the United Nations discussing disability in that strategic sense. While countries such as ourselves can say that we have a pretty robust legal framework, there are other countries in the world which in signing up to the Convention have to look now to their own law and practices. I was certainly buoyed up by the fact that the Foreign and Commonwealth Office and DFID would join with us to promote the UN Convention throughout other countries. Part of it is about raising the confidence of disabled people and those with learning disabilities that there is now an international recognition that they have rights as individuals. They are no longer just the passive recipients of what other people want to give them or do to them; they have individual rights and those rights have been recognised by the United Nations.

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Q191 Lord Lester of Herne Hill: Can I tell you then where I am coming to because I take your answer to mean that we have got plenty of existing law and you have not yet identified any serious mismatch at the moment between our existing law and the Convention? I may be wrong about that. If there is a serious mismatch I would be glad to know about it, but let us assume at the moment—and I have read the Convention and I know a bit about the existing law, that there is no serious mismatch—that we do not need to introduce new legislation to change our existing law and strengthen it. My puzzlement is this. We were the first country to ratify the European Convention on Human Rights in 1951, and we take great pride in that. What I do not understand is why this process is now going to take so long. Looking at your very helpful memorandum, you explain, for example, that we are now eight months since the original period for signature and you have said that there have been 117 signatures and there have been 76 signatories to the Optional Protocol which allows the individual complaints mechanism, and there have been seven ratifications of the Convention and three of the Optional Protocol. I cannot for the life of me understand first of all why we did not sign up to the Optional Protocol. You explain that in your memorandum in a rather curious way, if I may say so, because what you say is, “Traditionally the Government has not favoured accession to Optional Protocols that provide an individual right of petition to the appropriate UN Committee”. That is not really correct because we do indeed allow women to go to CEDAW, for example, and we are alone in the big countries in not doing it for the international covenant. I hope we will by Human Rights Day have that to announce. What I do not understand is why we did not even sign the Optional Protocol, not ratify it but sign it, and why you say it is going to take until the end of 2008 to ratify the Convention when, looking through it, the only bit I can see that would cause us slight difficulties—but please correct me if I am wrong—is Article 33, I think you have said in your memorandum, which is dealing with something pretty soft and it is national implementation and monitoring. Why can we not get a bit more energy into signing the Optional Protocol before Human Rights Day, and I know we cannot do that because the Convention is not ratified, but why can we not ratify the Convention, say, within a year of opening for signature instead of waiting for this very long period of time when I see no gap between the Convention and our domestic law?

Mrs McGuire: I am very reassured by that confidence, Lord Lester, that there is no gap. I indicated that I certainly do not see any gap in principle between the Convention and our current legal framework. Having said that, as I am sure colleagues are aware, we do take the signing of the Convention seriously and we do want to ensure that our legislation is compliant. If I could put it into some sort of context with other countries, yes, there have been countries that have moved very quickly to ratification, and indeed, I think Jamaica, on the day of signature last 30 March, ratified the Convention and signed the Optional Protocol, and that was for

them to do. We think the approach we have taken is the right approach, and certainly is one that I have explained to the NGOs, and indeed we are meeting with the NGOs from the lobby on 6 December. Can I also advise the Committee that in just over a year or a year and a half, whatever time it will be during 2008, when I hope we will be in a position to sign, in terms of ratifying conventions is not an inordinate length of time. The International Convention on the Elimination of All Forms of Racial Discrimination was two years and five months, and the Convention on the Elimination of All Forms of Discrimination against Women was four years and 11 months. In both of those cases there was consequential legislation but what I am saying to you is that we want to do it properly and when we ratify the Convention we will be able to say that we are compliant with the Convention. I appreciate the frustration amongst disabled people and their organisations, and it is a convention that I hope to continue to encourage them to feel confident that we are going to sign, but I think we need to make sure that we are properly compliant.

Q192 Lord Lester of Herne Hill: I am sure that is right, and may I say I welcome your change of language. You said at first the end of 2008 and then you said during 2008.

Mrs McGuire: I meant to say by the end of 2008.

Q193 Lord Lester of Herne Hill: But you have not identified any obstacle other than the need to proceed carefully. We agree with the need to proceed carefully, but unless you can come up with a practical obstacle I think you will get more pressure to do it. I quite understand about CERD and I quite understand about CEDAW but, as you rightly said, they required significant changes in our law. I do not think this does.

Mrs McGuire: We are discussing all of these issues with the other government departments in terms of their own legislation and I hope that the Committee will understand why we are doing it the way we are. If we need to make legislative changes I would rather be able to say that. At the moment, of course, I am not in a position to say whether or not there are new legislative changes or not but I am buoyed up by the opinion given by yourself, Lord Lester, on this matter.

Lord Lester of Herne Hill: I am probably wrong. Thank you very much.

Q194 Earl of Onslow: “We . . . need the Independent Living Bill, which will give people with learning difficulties a legal right to support. Then, if government policy fails to establish the services we need, the courts of law can play their part in pushing for change”. We have asked a number of our witnesses about independent living. We know that the Independent Living Review is due to report next year and has recently published research on the business case for support for independent living. If the review does not find a solid business case for

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further support would the Government be less committed to developing independent living for people with learning disabilities?

Mrs McGuire: Can I say to the Committee that we believe in the principle of independent living and I think my colleague, the Minister from the Department of Health, when she answered Lord Ashley's debate, said that quite clearly. Where we have a disconnect at the moment is that we do not think that we should legislate at this time on the right to independent living, and I appreciate that that is not a position that some organisations and some individuals feel comfortable in supporting, but we do think in our judgment that that is a sustainable position at the moment. One of the reasons why we pulled together our Independent Living Review Group was to in order to look across the board at all of the issues relating to independent living, including, for example, trying to come to an understanding about what independent living means and trying to get some sort of agreement on that to look at the ways in which it can be supported in individual circumstances. We have not closed the dialogue on independent living by any manner of means. We just at the moment do not think it is appropriate to legislate for the right to independent living.

Q195 Earl of Onslow: Presumably it is also graded according to the amount of disability that the individual person has. It must be, must it not?

Mrs McGuire: The definition of independent living?

Q196 Earl of Onslow: How much independent living you can give to somebody. It must vary. I may not understand the meaning of "independent living".

Mrs McGuire: I suppose it depends what the definition is. We underpin our thinking on this with independence and control and authority for decisions and, yes, obviously, in some situations people may need support to make some of those decisions but it does not take away their right to exist independently with that support and to have their rights recognised. That is why we thought it appropriate to pull together an expert panel made up from many disabled people who have a great deal of experience, not only in their own lives but also in the lives of other disabled people, to look at how we move this agenda forward. As I say, we have no disagreement with the principle. What we are not prepared to support at the moment is a legislative right and I appreciate that is a position that, as I say, some people will not agree with.

Q197 Chairman: I do not understand why because we all have the right to live independently. We do live independently. Why can we not give the right to people with disabilities? Is it simply a question of the cost involved in implementing it? Is that the reason?

Mrs McGuire: No, I do not think so. Part of the discussion that has taken place at the expert panel has been looking at the complexities around independent living, and perhaps the Earl of Onslow has touched on one as well in this discussion. All of our policies at the moment are driving towards

independent living, whether that be individualised budgets or giving people control over their lives in education and in employment. It is whether or not at the moment we would support enshrining the right to independent living in law. Our position is that we would not want to do that at the moment.

Q198 Chairman: But the law has to grapple with some of these relatively grey concepts in the context of the human rights law, and we talk about the right to family life. The right to live independently surely is not much of an extension beyond some of the basic human rights we have already signed up to.

Mrs McGuire: But it also depends what we mean in terms of independent living. Of course there will be a cost element to that. It is whether or not that right is impossible, how you judge that right to independent living. These are issues we still have to work through in terms of discussion with disabled people themselves, although in principle, as I say, we do not disagree with the concept.

Q199 Earl of Onslow: Is it not possible to do what I think everybody would like? Is it not possible to do this by policy rather than legislation?

Mr Lewis: We are doing it.

Mrs McGuire: That is what we are doing.

Q200 Chairman: The real problem is that unless it is an enforceable right on the part of the person with the disability, unless they can have access to the advocacy service to help them achieve those rights, how are we going to progress the issue of independent living, which we all see as a desirable object?

Mrs McGuire: But we are progressing it.

Q201 Chairman: It comes back to our earlier discussion with Ivan, does it not? We can have these wonderful policy statements which we all agree with, but you have to be able to enforce them on the ground.

Mr Lewis: No, no, come on; there are people in my community who are living independent lives, as you might define that, who only 20 years ago were locked up and had been for 30 or 40 years in mental handicap hospitals. I think it is completely unfair to say policy has not got us very far. It has got us a tremendous distance. The question is—

Q202 Chairman: I am sorry; I think you misunderstood the point. The point I am making in the end is that that is fine and we very much appreciated what you had to say about that, but surely the implication of that is that in the end if we are serious about people with learning disabilities (or indeed other disabilities) having equal treatment under the law, being treated fairly, surely they must be able to enforce that.

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Mrs McGuire: But that is what we are doing through policy, Andrew.

Q203 Chairman: Yes, but what happens when policy fails? That is really the thing we want you to explore.

Mr Lewis: Who is going to judge that and at what point? The other thing is, why is the Committee not debating the right to integrated or mainstream education for all children—

Q204 Chairman: We may get on to that.

Mr Lewis:— because it is the logical extension. If you believe everybody with a disability has a right to independent living you should also surely believe from a philosophical point of view, and we could debate the resources you need and all the rest of it—

Q205 Chairman: Maybe we will go on to that; you never know.

Mr Lewis: Can I say one thing on this question? To be honest, I think in a sense we have always got, as members of the Committee have got, this constant dilemma about what should be in law and at what stage you say that we need to let policy take its effect and at what point we say policy has failed. That is a constant challenge and choice the policy-makers have had to make through history and will always have to make. We do not believe that putting it in law at this stage is right. Do we say for ever it is not the right thing to do? Of course we do not say that. I also want to say something really important about this. I think there is a lot of sloppy language being used out there which is causing people to have negative experiences. What I mean by that is that I believe totally in the right of everybody to independent living. However, not one person in this room is independent. Andrew, you said, “We are all independent”. We are not. We are all interdependent—on friends, on family members, on workmates, on neighbours and on colleagues. I know it is not totally directly in response to this question.

Q206 Chairman: There are choices and respect.

Mr Lewis: Hold on. It is a massive part of the sloppiness of some of the problems with not dealing with things like loneliness and isolation, not funding voluntary organisations on social and leisure activities for people. Professionals want to make people independent, right? Sometimes that means leaving people who appear to be living in the community independently but are having awful lives as a consequence of a sloppy understanding and then a sloppy delivery of what independent living is about. Independent living is not making people independent because none of us is independent. We are all interdependent and we should not forget that.

Mrs McGuire: In terms of choice and respect, Andrew, we already have choice and respect built into our legal framework, our practices. We have spoken about disability equality duty and the way in which we are trying to support people making individual choices. We had a long discussion about the PSA targets, which is again very much about

allowing people to make choices and have respect. It is not that we are doing nothing on the issue. Policy is being implemented which—

Q207 Chairman: I certainly did not want to give the impression that I thought you were doing nothing, because we said earlier on we were very pleased to hear the things you said. The question is, this has to be the next stage.

Mr Lewis: I really want to say this, and I know it is not the Committee’s brief, but if society is going to have a debate about independent living for disabled adults you cannot start there. You have to start with the way that disabled children are treated in the education system and by our society. That is massively important in this whole debate. It is not a cop-out but it is a really important point.

Q208 Earl of Onslow: The point really is about leadership at the level of those who are providing the help for these people, is it not? It is a question of leadership and policy, at least in my view, rather than legislation. If you can make the people who provide it have that standard of leadership, in other words, they have got to be the brigade of guards in the social services rather than—

Mr Lewis: But many people believe that you will never ultimately get enough of the system to take that view unless you enshrine in law the power to say, “I have this as of right”, and therefore if you do not like it or you are not very good at your job or your organisational policies are wrong or the way you put them into practice is wrong we can go to court and say, “I have a right to that and if you do not deliver it you are in breach of the law, not just not very good at your job”. That again is a constant debate that we have to deal with in this whole policy arena, do we not?

Mrs McGuire: But we understand the strength of feeling there is out there on the issue. I hope that this afternoon Ivan and I have demonstrated that the way policy is developing is consistent with a move towards independent living to support individual disabled people to exercise rights, to have choice, to have control, to have independence in their lives, which is consistent with the human rights and social model approach to disability.

Q209 Earl of Onslow: I think really, the question, does the Government accept that without access to effective advocacy or support for self-advocacy some adults with learning difficulties will never be able to stand up for their rights, follows on to the next question: if so, what steps does the Government propose to take to increase access to effective advocacy services? I understand from where you are coming.

Mr Lewis: There is a really important issue though here, Lord Onslow. The position is that there are different forms of advocacy. There is supporting people with learning disabilities to develop the confidence and the skills to advocate for themselves. There are professionals advocating for people, so professionals acting as advocates. There are carers and family members, both as groups and as

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individuals, being supported to advocate strongly to get people what they need and deserve, and then there are volunteers who, every day of the week, without giving them a title, are out there championing their friend or their neighbour or their workmate who is not getting what they deserve. Then in a more legalistic sense there is the appointment of independent advocates. For example, you know the controversial Mental Health Bill that has just gone through. There is a lot of controversy about the Government initially not putting into that independent advocacy but the Government accepted amendments, I think, from your place to that effect, so all I want to say on this advocacy debate is that first of all it is crucial that there is proper advocacy for people out there who are vulnerable and do not yet have the equality of citizenship, but, secondly, we need to be very clear that there are different ways of going about it. Some of the most exciting things I have seen in my career have been individuals with learning disabilities who were told could not speak for themselves being given the chance to develop the skills and the chance for the first time in their lives to say what they want and what they need, and you would be amazed at how able so many people are at articulating very clearly what they want and need. It is just that in the past nobody has ever listened to them and that has been the problem. And, by the way, that is the same issue for many family members and carers who sometimes have not been treated by professionals in a very positive way.

Chairman: Certainly we would agree with that on the basis of our experiences during this inquiry. I just bring you back to the previous question about independent living. Let us move on.

Q210 Mr Sharma: I think the buzzwords were “choice in Parliament” and also “independent living”, but all that is when people get all the information in a language they understand. It is most important that these people understand what their rights are. Unless they know them they will not be able to demand those rights. Can you explain why almost a year has passed and the Government has not yet published an Easy Read version of the UN Convention on the Rights of Disabled People?

Mrs McGuire: I can assure the Committee that that Easy Read version is in the process of being published and I take the point that it has probably taken slightly longer than best practice would have allowed us to do. Can I also say to the Committee that Easy Read translation is not always straightforward and we do have to be careful that we do not make assumptions about what Easy Read is and we have to ensure that Easy Read is genuinely easy read. I remember one of your earlier witnesses saying that in some situations Easy Read in fact was not easy to read at all. Some of the concepts, some of the language, some of the ideas in the UN Convention have to be very carefully worked on. I should say, however, that as an issue of practice we are trying to ensure that there is simultaneous publication of an Easy Read version and the principal version of any documents and, of course,

we also use IT to ensure that we get the information out as quickly as possible in various formats. Where we actually did have a delay in publishing an Easy Read version was on the welfare reform consultation, the Green Paper consultation, not the one this year, the one two years ago, and what we did in those circumstances was that we extended the consultation period for those organisations and for individuals with learning disabilities. We had a two-week delay in getting the Easy Read version out but we compensated for that at the other end of the consultation, so we did not expect people to respond in three months minus two weeks. We are very aware of the issue of improving information for disabled people and the Office for Disability Issues has established five principles of communication, some of which I think you have identified, that it has to be clear in terms of language, it also has to be provided through a range of formats and channels and it has to be sure that it meets the user’s needs. There is nothing worse than a piece of information that is no use to you at all. The other issue which is important is for authorities to identify who is responsible for the information and who is responsible for making sure that that information is kept up to date, so we are working very closely with public authorities on that five-principle approach.

Q211 Mr Sharma: Can you give any timescale when that will be out?

Mrs McGuire: On the Easy Read version of the UN Convention?

Q212 Mr Sharma: Yes.

Mrs McGuire: I will confirm that with the Committee, if that is acceptable, and I will ensure that the Committee also get a copy.

Q213 Mr Sharma: Let us hope it will be easy for us to read as well. Is there a cross-government strategy in place on Easy Read information on rights, like HRA, DDA and the Mental Capacity Act?

Mrs McGuire: I think I would probably be less than honest if I said that there was a strategy. There certainly is an increasing awareness of the importance of alternative formats and that is something that the Office for Disability Issues is working on. Certainly we have encouraged departments, where they are publishing information and documents, to look at alternative formats. I think I also would be honest in saying that departments are certainly more aware now of the need for that, not least because of, dare I say it, the disability equality duty, which was implemented last year, and of course under the Disability Discrimination Act they do have to look at different ways in which goods and services can be accessed by disabled people, but as to whether or not you would call it a strategy, I am not sure that I would give it that name just now. There certainly is an improvement.

Mr Lewis: I would just like to say beyond this narrow discussion today that if we are going to successfully tackle health inequality, ie, encouraging people who are excluded on the whole from

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communities, to change their attitude, their behaviour, their approach to their own health, if we are going to tackle social exclusion, we have to completely have another look at the way we seek to send messages to people and communicate with people. If you use the same materials, the same literature, the same language as you use across the board, you will never ever be able to get to the very people we most claim to want to support in terms of health inequality and social exclusion. I think this is a major challenge for public bodies and public authorities. Let us think of some of the documents we get to read as Members of both Houses, I get to read as a minister, but, more importantly than that, members of the public who are most at the margins of their communities, for one reason or another, get to read, are we even thinking about doing things differently in the messages that we send to them? The answer is, we are not thinking anywhere near as imaginatively and as innovatively as we need to.

Mrs McGuire: And in reality public authorities are failing in their duty if they do not ensure that, for example, information given to a tenant with learning disabilities about anti-social behaviour is not given to them in a format that he or she can understand. It would not necessarily be by a letter through the door. It might be by a visit rather than a piece of written communication, and it is about practice changing and not making assumptions. Ivan is right: we have so got a long way to go on this particular issue.

Q214 Earl of Onslow: I presume that both of you as Ministers have had written for you turgid speeches which you have had to deliver.

Mr Lewis: We have written a few ourselves over the years. I think the difficult bit is to try and always remember, if you are going to publish a document or put your name to a document, the people who are going to be expected to read it. This is the constant battle, I think, for us at our level, but also, I think, for Members of both Houses, even if they do not have ministerial responsibilities. If the message is not clear and simple and articulated in that way, the people that you are trying to influence—you might be trying to inspire them; the word has been used, or you may be simply trying to get a message to them on a very factual basis—will not that message. If you do not start from the position, will the person or the group of people understand it, you are in trouble, and I think a lot of governmental and public sector publications unfortunately do not get that right.

Q215 Baroness Stern: Can I ask you some quick questions about parents' rights? A number of people have told us that parents with learning disabilities are routinely separated from their children and I am sure you know that. Do you agree with us that unless such a removal is considered justified and proportionate in the circumstances this could lead to a real risk of a breach of the rights of the child and the parents to respect for family life as guaranteed by Article 8 of the European Convention?

Mr Lewis: I would say two things: absolutely yes, but also we must never get into a situation where political correctness means that a social worker decides that a child should remain with parents simply because those parents have learning disabilities. Let us get the balance right. The answer to the first question is absolutely yes, but let us never allow a child to be abused or neglected because some social worker says, "The new policy is we never remove a child from a parent who happens to be defined as having a learning disability".

Q216 Baroness Stern: But I did say "justified and proportionate in the circumstances".

Mr Lewis: And the answer is still yes.

Q217 Baroness Stern: What are you doing to ensure that local social services departments, particularly children's services, know about your *Good Practice* guidance on support for parents with learning disabilities and what their duties are under the Human Rights Act?

Mr Lewis: A significant part of the new *Valuing People* document is going to be on parents who have learning disabilities.

Q218 Baroness Stern: The last question is to Anne. I think I know what she will say but I will give it a go. As Minister for Disabled People do you think that a healthcare provider would be compliant with the requirements of the statutory Discrimination Act if it failed to provide educational and other information for new parents with learning disabilities in an accessible way?

Mrs McGuire: In an inaccessible way?

Baroness Stern: No. Would it be compliant if it failed to provide them in an accessible way? Sorry: let us start again.

Chairman: Take the double negatives out.

Q219 Baroness Stern: Okay; let us take all those out. Do you think a healthcare provider would be failing to comply if it did not provide this information for new parents with learning disabilities in an accessible way?

Mrs McGuire: I would say probably, but I think that is an issue that perhaps we should take an alternative opinion on. My view is that they would probably be in breach without—

Q220 Baroness Stern: Perhaps if you have another view you would let us know.

Mrs McGuire: No, no. I am always careful in the presence of so many good legal minds not to give a definitive answer on a legal question, but my instinct would be that they would be in breach.

Mr Lewis: It would be good to get some straight answers from lawyers from time to time to help us with some of these difficult decisions. Can I say one thing that parallels this on carers? We have not touched very much on carers. There is an increasing number of carers of adult sons and daughters with learning disabilities, and I just want to say on that first of all that the Prime Minister will be announcing in the spring a new deal for carers which will look at

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carers of adults across the board. Very recently we announced a significant new investment in terms of supporting parents of disabled children but also looking at the question of the transition from being a disabled child to becoming a disabled young adult, and there will be a lot more resource in the system specifically for that. Finally, the Prime Minister has set up a standing commission chaired by Philippa Russell, who is a well known campaigner for disabled people's rights but who also has a son with learning disabilities herself, and its job will be to look at the long term challenges that carers will face in our society over the next 20 or 30 years.

Q221 Chairman: One last question from me. We talked earlier on about the Mersey pilot and so on. I was just wondering when you were going to evaluate them and disseminate the good practice that is emerging.

Mrs McGuire: Individualised budgets?

Mr Lewis: Is this the human rights stuff?

Q222 Chairman: Yes, the IHR partnership thing.

Mr Lewis: I cannot tell you today. We will write to you and give you the information.

Q223 Chairman: Thank you very much. I think it has been a very interesting session. We are probably on the same wavelength. The real question is obviously implementation happening on the ground. For those who like to know, that is the last of our evidence sessions on this inquiry. We will be producing our report in due course and we anticipate publishing it in Easy Read as well.

Mr Lewis: Excellent.

Mrs McGuire: If the Office for Disability Issues can give you any support in doing that, Chairman, we would be delighted to do it.

Chairman: Thank you very much.

Written evidence

Memorandum from Trust, Caring & Nursing Agency

In response to your request I hope this sincerely helps in understanding possibly the experiences and thoughts of organisational carers who care for those with learning disability at home.

Primarily, we are contracted by NHS trusts/ education board to provide care/learning support to those with learning ability at home and at college. We have several long term service users over the last 8–10 years.

On discussing this with them at a review meeting this morning—Our staff carers confidential experience of this is these service users are ruled by their family members, they get to make few major decisions for themselves, are rarely consulted on these decisions and carers feel that in family's attempt to do their best for a service user by providing a safe and secure environment, they actually inhibit the service users progress and development. Our staff feel the service users families have developed habits of "survival" in trying to ensure the best for their relative but also for their own lifestyle. Participation within the local community is usually down to when a relative has time free to accompany, due to other commitments, or can afford the funds for a carer to accompany—which is very seldom. If you are talking about those service users who are able to attend college, this appears to have become a new form of daycare where it may take someone with a learning disability up to five years to complete a course. During this period carers state the service users do develop a sense of self and motivation to try new things, however they tend to walk straight back into the family environment each day, which may be one of the reasons why progress takes so long.

We have sadly seen the outcome of reduced funding in this sector over the years, to a point where direct payments are no good for a service user who needs to develop a long term relationship with a care support worker to encourage their development. Many who do work on a "private basis" with such service users, tend to be unwilling to work after teatime, or weekends—times when this support is most needed, to help SU to develop socially and develop relationships. We have also had great difficulty as an agency, in getting appropriately trained individuals during these time periods for the funds on offer.

Therefore I suggest there is a basic structural problem where the infrastructure and culture are conflicting constantly with each other. Having a right to develop relationships is conditional between 9–5pm, as with good quality care support or learning, which does not suit all families. The 9–5 culture is probably one of the greatest blocks we can see in this.

As you know, supporting someone with a LD is a vocation, not just a job—we have found there are very few good quality individuals today who have this "vocational stickability". Many are looking for career progress rather than a satisfying job. This I feel is a main issue in setting up long term support services and helping to develop the human rights for those with learning.

With regards to rights:

Service users can be described as a "customer" and citizen—like any other. So what rights do we all have—and the response to this is basically—very little—yes we have a right to emergency treatment, an education and to feel socially included, however, we are also responsible for ensuring we go for the treatment, go to the college and make the attempt to socialise—those with learning needs require support to do these things, therefore they are more vulnerable than most. We do not know the answer to these questions except that more support services are needed to develop these skills and it needs to be family orientated rather than person orientated. As you know there are many service users families who do receive benefit support to ensure their sibling is cared for, however some relative can feel this is a payment for them as they receive little other financial support for their own lifestyle. These relatives have also developed a home culture that is habitual and can be hard to break so I feel the issue of advocacy has never been more important.

Wil Coyle, Director

11 April 2007

Memorandum from Find a Voice

Find a Voice was set up with the specific aim of helping children and adults with language and communication needs. Many of these people also have learning difficulties.

We believe that everyone who has the ability to use a communication aid should have the right to obtain one, free of charge and that anyone needing speech and language therapy should be able to access it. Often carers and families have tremendous difficulties in finding:

- What is available and what and who can help them.
- Speech and language therapists with experience in communication aids.
- Funding for aids.
- Training in writing in symbols for Person Centred Planning.
- Training in use of IT to open up possibilities for people with learning difficulties.

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- Software for carers to produce daily schedules, messages etc.
 - Advocates who know the difficult procedures and systems to apply for grants from multiple sources to obtain full funding for aids.
 - Communications aids you can “try before you buy”.

With our help Keith obtained £9,000 funding and is now able to use his aid at meetings, on the train and to order a Chinese take-away. He can access services and is actively participating in the life of the community.

According to the European Convention on Human Rights the State is required . . . *in certain circumstances* to take positive steps to secure the enjoyment of those rights. We believe that access to speech and language therapy and communication aids should be one of those circumstances and that the State should fund these aids and increase speech therapy instead of cutting back on the service.

John was 45 and had never been able to express clearly where his pain was. His elderly parents had never been able to communicate with him. After receiving his aid, with our assistance, he was able to get effective pain relief and “talk” with his parents for the first time.

Article 8 has been interpreted by the European Court of Human Rights as including a right to participate in the life of one’s local community. The Court also recognises that the States are under an obligation to facilitate such participation. Find a Voice maintains that the human rights of adults with learning difficulties are currently not being respected and that provision should be made to supply communication aids together with funding for insurance and maintenance and that speech therapy should be a right.

Money is being wasted where some people with learning difficulties have been provided with inappropriate communications aids, which are then left at the person’s home unused. Find a Voice has a library system whereby aids can be lent and tried before commitment to a certain type of aid but we cannot lend aids indefinitely and the person requiring the aid and their carers/families are devastated when they learn they cannot keep it. Also it is difficult for families and carers to find or afford insurance and maintenance. The State should find ways to provide blanket cover for these.

The opportunities that can be opened to people with learning difficulties when they can be provided with a communication aid are endless—they can “talk” to their friends and family, they can begin to think about employment, participate in meetings and provide input to their own life plans, gaining self respect and dignity. Providing speech therapy could mean that their learning difficulties could be eased.

Currently Find a Voice tries to meet the needs of people in Kent but we regularly receive enquiries from all over the British Isles and ideally there should be Find a Voice Centres all over Britain.

May 2007

Memorandum from Winchester and District Mencap Society

RESPONSE FROM ADULTS WITH A LEARNING DISABILITY

Experiences of using services like health, education, housing and welfare benefits:

- Health- fair.
- Education- good.
- Benefits- if you can get them they are good. If you don’t get them and can’t get a job, it is very hard.

Chances for personal relationships with:

- Partners (boyfriends, girlfriends, husbands or wives)- not fair. People treat you funny. Some won’t let you have a relationship. People against us getting married.
- Your family- ok.
- Children- N/A

Help given to make and have these relationships:

- Varies much. Some people have good experiences; some feel they have very few chances or encouragement.

Taking part in the local community:

- Go into town, shopping. Some people are rude.

Support to access local community:

- Sometimes. Could be better and easier to access. Public could be friendlier and more accepting.

Can the *Convention on the Rights of Persons with Disabilities* help people with a learning disability to have their rights?

- It can encourage people to give us our rights.

How easy is it for people with a learning disability to have a say in decisions which affect them?

- Sometimes hard because not enough responsibility is given to them, especially in the working world. Often treated like children. Easiest people to talk to are parents.

How easy is it for people with a learning disability to make a complaint about a service?

- You can tell someone in authority or a parent, but you are not often taken seriously or believed.
- It's hard to get people to listen.

What would help people with a learning disability get their human rights and any examples you have of when this has been done well?

- Being able to get jobs and prove themselves.
- "The doctor helped me."

Answers provided by a group of young aged between 18 and 45, with learning disabilities living in Winchester, Hampshire.

4 May 2007

Letter from the Sunlight Development Trust

I work for Sunlight Trust and am supporting the development, to eventual independence, of shout out, a self advocacy group for adults with learning disabilities in Medway. Shout out commenced in June 2006 and the management committee will imminently be voted in following lots of work on the constitution for the group.

The group took part in discussing the above consultation at their last meeting. Unfortunately, time ran out before all the issues were discussed but I trust the following points can be included in the overall response you receive.

On their behalf the collated response follows:

GOOD HEALTH CARE

Explaining information about hospital tests/procedures/operations is not good. Accessible information is not given.

Waiting times, if long, can be more difficult for someone with learning disabilities than without.

EDUCATION

Still remember being bullied at school and "nobody doing anything about it".

"Not having teachers believe in me at school."

"People didn't bother, take extra time, to help me eg with reading, because I have learning disabilities".

Not enough opportunity to take "proper" exams eg GCSE.

HOUSING

"No choice of who I live with" ie when living in small group home.

Limited choice of housing when living independently.

WELFARE BENEFITS

Not enough choice, or even being informed about, direct payments.

PERSONAL RELATIONSHIPS

Being told not to have babies because “you can’t look after it”.

Being discouraged from having girlfriends/boyfriends by parents/carers.

Sometimes difficult to keep contact with family members and friends because of being dependant on carers/ parents making the arrangements.

“Staff shortage and sickness affects your social life.”

Paula Crill,
Community Development Manager

Memorandum from the Compass Advocacy Network

Compass Advocacy Network are a user led organisation providing services and advocacy support to people with a learning disability in Northern Ireland. We promote the empowerment of people with learning disabilities and promote the human rights legislation to all our members. We provide training on human rights issues both internally and externally and support our members in accessing their entitlement to various services.

We assist our members to access public services such as healthcare through the provision of support to enable and empower them to speak up for themselves with confidence. We also provide direct representation to members and speak up on their behalf to ensure that they receive the best services possible. At present in our geographical area, most people with learning disabilities are accessing some form of mainstream healthcare although they are still referred to specialist treatment hospitals for certain conditions. Very few of our members are accessing mainstream education with most people attending special schools. We have enquired of parents/carers why this is the case and it would appear that financial resources has limited the choices offered to parents and they have not been furnished with the appropriate information which would enable them to challenge from a human rights perspective. There also appears to be a lack of appropriate learning support offered to people with learning disabilities to enable them to access mainstream education. Again we feel that this comes down to a lack of financial resources within the education sector.

With regards to access to housing, most of our members live at home with family, residential settings or supported living developments. Very few have access to their own home in the community due to a lack of support package to meet their needs.

Most of our members do receive welfare benefits and have been able to secure these benefits by having assistance from social workers who have completed the forms etc.

People with learning disabilities should be able to access mainstream services but barriers remain, mostly attitudinal barriers and through a lack of education and training this looks like being a long time before change will occur. We have commenced this change process by offering user led disability equality training and trying to change the attitudes of our local community. By promoting a positive image of people with learning disabilities and placing value on their contribution to society we are helping to adjust mind sets and hopefully commence the trend of people with learning disabilities being fully integrated and included in their community.

People with learning disabilities do form good relationships with people and again this is something we encourage. We bring together people from all sections of the community and unite them in a common purpose and goal which is improving the lives of people with learning disabilities. Relationships that form can be in place for many years and really enhance the quality of life for both the person with the learning disability and those without.

We operate two social firms and through these firms we encourage our members to participate in community life. They are actively working with local communities and providing services to the local community which show the valuable contribution they can make. We also encourage partnership working with local community associations and groups and the relationships formed through the social firms can become stronger increasing our members social capital and social networks. We feel that social inclusion is about being innovative and creative with projects to involve all of the community and integrate everyone together. Local councils and government agencies could do more to assist with social inclusion. Examples being, firstly their information is not accessible. They claim that people can phone in and ask for information in alternative formats but if the person can’t read the information telling them to phone in the information is worthless and invalid. Secondly they need to provide their staff with proper disability equality training and explain the DDA so that staff can adapt their style as opposed to expecting the person with a learning disability to adapt.

We feel that the convention on the rights of persons with disabilities could promote the rights of people with learning disabilities by providing training on human rights and also providing accessible information. The convention could also lobby and campaign for changes in existing laws to be reflective of human rights

legislation. In Northern Ireland the law is so out of date that the human rights bill cannot be fully implemented due to clauses in the Mental Health Order etc. The convention could lobby and campaign to have this deficit in law removed and allow full entitlement to the human rights legislation.

We feel that people with learning disabilities can make their voices heard in decisions affecting their lives if they have the right support to do so. As an advocacy organisation we provide such support and feel that this support is worthwhile and valued. It would be ideal if funding existed for organisations like ourselves to provide independent advocacy services to enable individuals to access their full entitlements in life. We support our members in making complaints and again most complaints systems are not accessible. We interpret and assist our members in the making of complaints and assist with communication when face to face meetings are called for regarding complaints. Advocacy Groups have a very clear role in assisting people with learning disabilities to speak up for their rights but statutory agencies must support advocacy groups to enable them to continue as funding streams remain scarce. Advocacy must remain independent of service provision and only then can it offer an unbiased view. We feel strongly that more work could be completed on human rights with people with learning disabilities but it is going to take a financial commitment from government to do so.

May 2007

Letter from Sussex Partnership NHS Trust, Community Team for People with a Learning Disability

Here are the points that we would like to be considered.

1. Discrimination in many areas if you need support; under funded and charged twice because you need someone with you; and
2. lack of fairness in accessing housing benefit if you need 24hr care.

Housing benefit is paid at a rate set by the government, very low. Prohibiting access to general housing.

A disabled adult under 25 can only access in the region of £70 pw to rent a property. Anyone who needs extra space because of a carer in the house will probably not have it funded, thus excluding severely disabled people from accessing appropriately sized mainstream housing.

Severely disabled people enjoy accessing the community just like anyone else, but not only are they excluded from many settings due to poor access, they have to pay for themselves and for a carer to gain entry.

Local authorities are continually financially squeezed and either cannot or do not make funds available to employ appropriate levels of care, and are certainly unlikely to fund a carer's expenses so that they can share in activities (incl. Holidays) with the person they care for.

These matters reflect how people with a learning disability continue to be excluded from accessing community-based resources, not only through stigma, but also by lack of the financial means that would help realise a more inclusive society.

Christopher Ball

Community Nurse Manager/Team Co-ordinator

17 May 2007

Memorandum from the Brandon Trust

INTRODUCTION

Brandon Trust is an independent charity supporting people with learning disabilities in a whole range of community situations. Further information about the organisation can be found on the Web-Site www.brandontrust.org This submission is made by Steve Day (Assistant Director—Organisational Development); although I have prepared this statement as an individual employee of Brandon Trust it is done so within the values base of the organisation. As an independent charity we would welcome further impute within the context of any parliamentary Joint Committee consideration on the rights of people with learning disabilities.

This submission is written because there are a number of key areas in which people with learning disabilities still have issues which make true community inclusion problematic. In highlighting the areas below it is recognised that the relationship between these issues and the Human Rights Act 1998 is sometimes on the margins of direct correlation, nonetheless, in all cases these are very specific areas in which people with learning disabilities experience extreme difficulty in exercising their rights as citizens. The list is not exhaustive and as such is representative of a number of a continuing anomaly's related to this group of Disabled People.

THE VALUING PEOPLE CONTEXT

There have been a significant number of changes in the last few years which have brought greater awareness of the issues related to people with learning disabilities. It is only comparatively recently that both “rights” and “opportunities” have co-existed to enable people with learning disabilities gain inclusion into basic social policy (such as housing, employment, individually assessed and sourced social care and support).

The Government White Paper, Valuing People (2001) and subsequent impute of the national team supporting this initiative should take some of the credit for this change in perception. We also recognise that initiatives such as Direct Payments, In Control, Individual Budgets, Self Directed Support, Supporting People and growth of the Third Sector have all contributed to furthering the broadening horizons for people with learning disabilities. There is now an urgent need to revise the aims and objectives of Valuing People to give their crucial national focus for learning disabilities the kind of pro-active agenda which would see the issues laid before the Joint Committee on Human Rights receive the attention they deserve.

BRANDON TRUST: CURRENT WORK

Brandon Trust currently support 1,500 people with learning disabilities throughout the South West of England. Over the last 12 years it has been involved in a number of different projects which have their roots in the dismantling of the old “Health” Institutional response to, what was once termed, the care of the “mentally handicap”, a term loaded with prejudicial perception and still used in some formats today. Brandon Trust works with a significant number of people with high support needs using individual support plans and person centred approaches radically different to the old structural provision of previous decades. Our recent current work in Cornwall is specifically about enabling people to have individual community support, where until recently they had been the subjects of an institutional response unfit for purpose.

EVIDENCE: MITIGATING AREAS

In promoting a community based approach to enabling people with learning disabilities find ways which they, as individuals, can develop their own particular lifestyles we have identified six specific areas which mitigate and impact on the four key principles of Valuing People—Rights, Choice, Independence and Inclusion. It is these mitigating “areas” which are now drawn to the Joint Committee’s attention:

- *The Right to Further Education:* The transition from child based services to adult services can often be problematic; it is exasperated by the lack of inclusive “design” within Further Education in terms communication systems, structure of course work, and accessible entry into “specialist” subjects. The Government Web-Site states that “Universities and higher education colleges have an obligation to make provision for disabled students.” Such “provision” is often only basic and takes little account of people with special needs. People with learning disabilities can undertake vocational qualifications which are capability assessed. There are some very good pieces of work being undertaken in this area but when it comes to academic study there is a wilful lack of special resources within the Further Education system. Adults with learning disabilities have little or no opportunity to undertake coursework on mathematics, history, philosophy, geography, subjects which are the stuff of ideas, ultimately driving choice, independence and inclusion. A right to education is a core requirement of the Human Rights Act, it is a key objective within the Valuing People White Paper yet there is little evidence within the Further Education system that a broad curriculum of learning is available to people with learning disabilities.
- *The Right to Employment:* Access to employment for all citizens is a key objective of Government. According to law employers are tasked with making “reasonable adjustments in the workplace” to allow Disabled People access to a wide variety of employment. At Brandon Trust we take the view that there are many people, some with significant and profound learning disabilities, who could access part-time work if “reasonable adjustments” involved individual job carving and skills matching. Brandon Trust currently employs 37 people with learning disabilities out of a total workforce of 1,300 people. It is not unreasonable to believe that we could double this number by carving out particular pieces of work which relate to the skills of “matched” individuals. A number of organisations, particularly retailers such as Tesco, have done good work in this area. However, overall the number of adults with learning disabilities in permanent employment remains small.
- *The Right to Housing:* The Supporting People project was launched in April 2003 and has involved 1.2 million “vulnerable people” being able to make the link between individual housing and support and care services. This was a very welcomed initiative despite the initial take up by people with learning disabilities being marginal. The initial slow start for people with learning disabilities was largely due to the Fair Access to Care Services protocol which all Local Government Adult Community Care Departments are bound into. This results in only those people with learning disabilities who are identified as having substantial or profound need being able to take-up Community Care funding—the “care” component of Supporting People. The 1.8 billion worth of initial Supporting People finance has been eroded; currently in 2007 there is a seeping away of Supporting People finance and no likelihood of this position reversing. Housing is key to people

with learning disabilities being able to break free of institutional group living services. In turn Supporting People was/is a key component in making individual housing and individual care and support a reality for adults with learning disabilities. Other initiatives such as Individualised Budgets and the whole In-Control agenda offer ways forward; Supporting People provides a mechanism. The right to a decent standard of housing is still an uncomfortable battlefield of beliefs and contains little in the way of an accessible and quantifiable strategy by which to make this a reality.

- *The Right to Access*: Although access to buildings and other public areas has significantly improved in recent years due to legislation, problems still remain. In April 2007 Brandon Trust staged a première of a short film, *My Unique Life*, made by and for people with learning disabilities at the Watershed Arts Centre in Bristol. It was a successful event with over 200 people attending. The Watershed had good access and worked with us to ensure people with physical disabilities had a positive experience. However, parking for people in specially adapted vehicles within the immediate vicinity of the Arts Centre was lamentable poor. A new underground Millennium Car Park has “disability reserved parking” within the car park itself; however, this is not accessible to specialist wheelchair vehicles using tail-lifts due to a height restriction. Immediate on-street parking is extremely limited. The nearest multi-storey car-park to the Watershed is too far for those people with profound physical disabilities using specialist adapted wheelchairs. Whilst many people were able to attend *My Unique Life* at the Watershed, some missed out simply because parking arrangements were insufficient. This kind of issue is still common place. At the time of entering this submission, Brandon Trust has received no reply to a letter dated 8th May 2007 to Bristol City Council Parking Services.
- *The Anomaly of Direct Payments*: In the UK the origins of the Direct Payments initiative has its roots in the Disability Rights campaigns which took place during the middle of the 1990’s. The concept of Direct Payments sprang from Disabled People asserting their desire for financial control over the support services they required. The Community Care (Direct Payments) Act came into effect in April 1997. One of the key drivers to the change agenda with respect to Direct Payments is that in April 2003 new powers came into force requiring councils throughout England to offer Direct Payments to all people being assessed for community care services. Direct Payments is a welcomed initiative, however, although Direct Payments is one of several new initiatives to give people with learning disabilities greater power over their own lifestyles, this initiative also defuses quality of support in a number of important aspects. To take one example; people who accept a Direct Payments package lose the right to be supported by individuals who are registered under the General Social Care Council (GSCC). At a time when all domiciliary workers are about to be required to register with the GSCC, Direct Payment support workers have no such requirement. This is an anomaly because very often the only difference between two sets of domiciliary support is the funding stream itself. People have a right to expect that their support staff have the same level of expertise, training and monitoring as support staff employed elsewhere in the Care Sector. Direct Payments has the potential to offer people with learning disabilities a real stake in the way they individually receive and manage services, nevertheless it is crucial that such a move retains people’s rights to quality support.
- *The Opportunity of the Mental Capacity Act to empower*: The Mental Capacity Act 2005 comes into force this year. Brandon Trust welcomes the clarity brought about by this piece of legislation. The five main principles of the Act provide an opportunity to empower people: (1) Assume a person has capacity unless proved otherwise. (2) Do not treat people as incapable of making a decision unless all practicable steps have been tried to help them. (3) A person should not be treated as incapable of making a decision because their decision may seem unwise. (4) Always do things or, take decisions for people without capacity, in their best interests. (5) Before doing something to someone or making a decision on their behalf, consider whether the outcome could be achieved in a less restrictive way. In the search to enable people with learning disabilities to have meaningful experiences in relation to their Human Rights the new Mental Capacity Act provides a useful framework for empowering people to take up their rights. The assumption of mental capacity is key; if this is applied in housing, employment, education and public accessibility then positive change will be generated.

My hope is that this submission to the Joint Committee on Human Rights will be helpful in quantifying some of the issues related to people with learning disabilities in this country. As stated elsewhere in this submission the extension and further development of the national Valuing People Team would enable any recommendations which result from your deliberations to have active follow through. Brandon Trust would also be very willing to take a positive role in the further development of these issues.

Steve Day
Assistant Director (Organisational Development)

18 May 2007

Memorandum from RESCARE

Our RESCARE submission of evidence for consideration by the Parliamentary Joint Committee on the Human Rights Inquiry into the Human Rights of Adults with a learning disability as reflected in our Response to the ODI Consultation Document. "Equality for disabled people: How will we know we are making progress?"

Run by families for families of people with severe and profound learning disabilities, we represent through our affiliated groups, individual and family membership, thousands of such caring families and their dependent sons, daughters and relatives. It is on their behalf and in the context of their multiplicity of needs that our response is submitted.

People with learning disabilities do need life long care, support and protection to a varying degree according to the extent of their disability, a human rights requirement that needs a wide spread of service provision commensurate with, and reflecting their vulnerability.

THE OFFICE FOR DISABILITY ISSUES CONSULTATION DOCUMENT.

'Equality for disabled people' does, we feel, have to go beyond just the physical, blessed as they are with the intellectual ability to act in their own best interests in making choices, and for whom the cause has surely been won.

Equality for the disabled requires an holistic service model approach, which recognises the diversity of needs to be met far beyond just the physical into the area of severe learning disabilities. This requires a range of service options commensurate in meeting the multiplicity of needs for those who are without capacity, and having the age of a young child. Such adults and their families are being disadvantaged and marginalized by changes in services that fail to fulfil the overall vision of 'Valuing People'.

For example: It cannot be right or proper that for such people and their families "Equality for disabled people" means just the right only to an imposed "Supporting Living" environment without being provided with positive information in respect of the various options specified in the Governments White Paper, 'Valuing People' and its Statutory Guidance, these being *"small scale ordinary housing, supported living and village and intentional communities as well as residential care. None must be ruled out."* (See Annex's A & B).

Of increasing concern is the practice of a cherry picking dissection of the Government's White Paper 'Valuing People' to the omission of its range of options in what is becoming a "one size fits all" imposition in Education, living environments, and support services, leading to a crisis led service with a denial of any effective and meaningful choice for people with learning disabilities and their families.

When the widespread abuse in the Cornwall authorities supported living service first came to light in 2004, through the concern and persistence of five determined families, Domini Gunn, the Audit Commission's Supporting People Inspection Co-ordinator said in Conference *"Some people would never be able to achieve independent living—I know its blasphemy but we need an open and honest debate over what's appropriate"*.

Mencap's reports: "Families at breaking point" and the recent "Death by Indifference" are further evidence resulting from the overall contradiction between the Government 'Valuing People' policy intention, and the practice of closure with loss of support and respite services being pursued by statutory authorities at local level. The White Papers message was clear *"The role of public services is to facilitate choice not frustrate it"*.

Families, (70% doing the caring in the family home) were encouraged as 'Valuing People' (2001) gave recognition to the family role saying *"Caring for a family member with learning disabilities is a lifelong commitment, which continues even when the person is living away from the family home . . . statutory agencies do not always properly recognise the extent of carers contribution or its value . . . They need to be treated as valued partners by local agencies, not as barriers to their sons or daughters greater independence"*.

In education discrepancy also arises between government policy, which is supportive of special schools, and the practice of unwarranted closure being carried out by local authorities.

The Department for Education and Skills (DfES) has said, *"Inclusion is not an agenda to close special schools"*.

The Department of Health circular "Social Care for Adults with Learning Disabilities" in 'Links with the family' said *"the most important life long stable relationship for many people with a learning disability is the relationship with their families, and it is important that this should be maintained"*.

Regrettably people with what is simply a learning difficulty (their description) but who fortunately enjoy the intellectual ability to express their case, albeit with some support, although well meant, are unfortunately creating the impression that their ability can be extrapolated as being representative across the whole spectrum of learning disabilities which is not the case. Unfortunately they are allowed to exert a disproportionate influence which has diverted attention away from the needs of those with severe life long, permanent learning disabilities who by any rule are without capacity from birth, and for whom the normal age of majority is meaningless.

Delivering real choice as per "Valuing People" is the key to meeting real needs in the real world.

Our Society RESCARE is about choice, the key principle of “Valuing People”.

- Choice in education including properly resourced mainstream, special day and residential schools.
- Choice in housing including small scale ordinary housing, supported living, and village and intentional communities as well as residential care.
- Choice in support services including day centres and respite care.
- Choice overall in the implementation of ‘Valuing People’ in full including the above.
- It is not a case of one type of provision versus another but a comprehensive service with each option having a part to play.
- It is not a case of one family versus another but a united voice reflecting respect for the choice and wishes of each family who after all know their own dependent relative best.

We commend as essential the implementation in full of the Government’s White Paper, *Valuing People: A new bold strategy for Learning Disabilities for the 21st Century* with its eleven “Objectives for Learning Disability Services” given immediate effect including No 6 “Housing: To enable people with learning disabilities and their families to have greater choice and control over where and how they live”. (See Annex C).

With regards to the ODI Question “How will we know we are making progress?” For our dependent relatives the ultimate goal is not and cannot be an academic exercise but a goal that is surely and simply one of care, satisfaction, contentment and individual well being leading to the happiness and protection of society’s most vulnerable and dependent citizens, and that of their caring families whose love and life long commitment is firmly interwoven in serving the best interests of their dependent sons, daughters and relatives.

Should you wish we would be pleased to expand on any aspect of our submission.

We hope that our submission is helpful and we thank you for the opportunity to comment at this important time in the lives and affairs of our sons, daughters and relatives so disabled.

Richard S Jackson
Honorary Chairman

15 May 2007

Supplementary Memorandum from Rescare

Your Press Release on the 29 March 2007 calling for evidence outlined a range of National and International Acts, Conventions and other human rights instruments for people with learning disabilities that the State is required not only to refrain from interfering with any individuals human rights but also, in certain circumstances, to take positive steps to secure the enjoyment of those rights.

It has to be accepted that the initial interpretation in activating and using the protection of these Human Rights instruments is beyond many thousands of their intended beneficiaries with severe learning disabilities, and for whom adulthood is meaningless. For them, as has often been proven and accepted, their next of kin caring family members are their natural substitute decision makers and first line of defence whose important role as Deputy in the Mental Capacity Act 2005 should be emphasised and not declared by the States representatives as being rarely used.

With regard to employment, and the value of Sheltered Workshops and other places of possible employment the scheme being proposed in New Zealand is worthy of consideration and brought to our notice by our daughter organisation RESCARE New Zealand namely under “Victory for disabled workers rights”. This introduces the right for disabled people to be paid according to their ability and not where they work and has been won by the passing of the “Disabled Persons Employment Promotion (Repeal and Related Matters) Bill”. The repeal means that sheltered workshops will have to pay everyone they employ at least the minimum wage, unless individual workers have an exemption.

1 August 2007

Memorandum by Diane Ferguson, Advocacy Project Worker, Hambleton & Richmondshire Advocacy

I enclose information which are my own views formulated during my role as an advocate for people with learning disabilities. I believe these views represent the majority of those people I support. I work with approximately 30 people.

EXPERIENCES OF

Health

Health facilitation as recommended in *Valuing People* has ensured GPs and hospitals have a good knowledge of learning disability issues. Their practices have changed to accommodate a more person-centred and individual approach. Many PCTs are struggling at present financially. Learning Disability specialisms; speech therapy, physio, communication aids, are not being funded locally. Learning Disability Partnership Boards are finding it hard to link with health partners. There are some inequalities in healthcare, mainly health screening and preventative care.

Housing

Direct council housing has many barriers in the system for people with learning disabilities, especially if they need 24 hour support. Supporting People funding allowed many people to get their housing choices and tenancies. Owning your own home seems like a dream! It happens very rarely. Many people still live in small groups but they have individual tenancies. This isn't really as it is for people who don't have a disability. Housing Associations seem more flexible than District Councils in their approach.

Welfare benefits

Generally people want to work and be paid for doing so. There are many more people in voluntary work and college courses "preparing for a real job". This can go on endlessly. The benefit trap is one of the reasons and family carers anxieties.

Education

Children's education opportunities are good, but adult education is poor. LSC have cut funding and this has affected adult education opportunities. Education locations have changed to mainstream colleges, which is positive, but people are still "separate" socially. More support is needed in colleges. Hate crime and bullying prevent some people taking up education opportunities.

Relationships

Support lacks for people to have and maintain relationships. There is still a climate of "permission" and anxiety around sexual issues. Many people have boyfriends/girlfriends but in a platonic sense. It is the single most important issue. Local community involvement has increased dramatically; pubs, clubs, voluntary work and general presence in the community. Voting is still largely not taken up. Involvement in Disability Equality Schemes has gone some way to possibly changing this.

Making complaints

The number of complaints made by people with a learning disability is very low indeed. If support is given to make the complaint from an independent source, this can increase. I enclose a form our organisation uses to encourage understanding and the right to an equal and fair service.¹

Having a say in decisions which affect them

This has increased largely due to advocacy organisations and self advocacy groups. Government legislation on Valuing People has helped. Mental Capacity Act has made provision for more vulnerable people lacking capacity. The JCHR should observe how this works over the coming months.

What would help people get their human rights

- Reducing anxiety about challenging decisions for access to services or to challenge poor service quality.
- Hearing "good news stories" in the press about successes.
- Increased advocacy.
- An increase in easy read information about human rights disseminated through *Speak Up* groups or Partnership Boards.

¹ Evidence not printed.

The Convention on the Rights of Persons with Disabilities could most definitely help and support the Learning Disability agenda. It may be able to take an influential and strategic view recommending the linking of disjointed services and campaigning for the issues to be higher on the agenda. This is especially true of health, housing opportunities and relationship issues.

Memorandum by Choice for All Doncaster

We are a User Forum called ChAD (choice for all in Doncaster).

Our committee consists of 20 adults with learning disabilities, who meet monthly to find out what is happening around them which may have an impact on their lives, and to voice any concerns of theirs or the 700 people they represent.

At our recent meeting we discussed your questions on Human rights and collectively as a group the following feelings and opinions were obtained. (The other enclosed sheets are what various groups and individuals have forwarded to us).²

1. Experiences of using services like health services, education, and housing and welfare benefits.

BAD EXPERIENCES WITH DOCTORS WERE:

1. That many did not speak to the individual but to their carer/support.
2. That they felt patronised by the way they spoke to them i.e., like children.
3. Big words were used that they did not understand.
4. They had not arrived when they had been told they would visit on a home appointment (resulting in one elderly lady having to ring an ambulance for her husband).
5. Waiting long time for hospital appointment, having sleepless nights worrying about their condition as they knew something serious was happening but no one explained things.
6. Dentists were also a problem for some people with them not being able to access a service. One lady was alarmed when the tools were unclean.

GOOD EXPERIENCES WERE:

1. Support has been given to people to fill in forms or they did not have to complete them.
2. Reassurance given by nurses when having injections.
3. Health day services offered a good interesting variety of activities.
4. For the individuals who had "health action plans", they felt it helped them.

The group stated that they would like the following:

- (a) treated as adults
- (b) given information
- (c) explain and speak clearly

HOUSING

1. Many people felt that they had to wait far too long to be re-housed (whether it be through ill health or incompatibility of the fellow residents).
2. What was particularly frustrating for most was the lack of Support workers; many had turned to Advocacy to help them after the situation had become critical.
3. Not able to live where they want and don't have a choice who with.

BENEFITS

1. Hardly anyone had any knowledge what benefits they received as it was controlled by their family or staff.

² Evidence not printed.

RELATIONSHIPS

1. Approximately a third of the group stated that they had a partner, however only one of these (who lived independently) saw her partner outside of the day centre environment.
2. Some people were not allowed a partner (parental/carer control).
3. Several of the group stated that they would love to live in the community with a partner with support.
4. One person stated that they did have a partner who they saw occasionally when staffing levels permitted.

The general feeling was that there was a lot more support required to enable anyone to have a “proper” relationship.

TAKING PART IN THE COMMUNITY

Some people did have support workers, however could not go out spontaneously, as support had to be booked for week in advance.

2. A **big** issue is for people who live in a residential setting who go out for the evening to pub, etc and have to be returning back at about 9 pm so the staff member can finish their shift at 10 pm.
3. Again very much controlled by availability of carers/staff.
4. Some people in independent living (with minimal support) are told what time they have to return from the pub and that they can only drink alcohol at weekends.
5. One male member stated that he thought it was particularly difficult for black and ethnic minorities (people with learning disabilities) when out in the community as they don’t just get stared at but also get racist abuse.

HOW EASY IS IT TO HAVE A SAY IN MAKING DECISIONS WHAT AFFECT YOU

1. People stated that they felt they were able to make decisions at ChAD. Advocacy, and the Social education centres.

HOW EASY IS IT FOR PEOPLE TO COMPLAIN ABOUT A SERVICE

1. Some people did not have any knowledge of how to complain but they knew who to. (We are holding a forum shortly with someone from C.S.C.I in attendance to explain).
2. Some were afraid to complain.
3. Others complained to staff but felt that they were thought badly of particularly if it was regarding a member of staff.
4. Some people said they complained but it took ages for anyone to listen.
5. Several suggestions of who to complain to were, Advocacy, Key workers and the Citizens Advice Bureau.

EXAMPLES OF HUMAN RIGHTS WORKING WELL

1. Many people said that Advocacy had helped them to achieve what they wanted and ChAD had given them choices and information.
2. Person Centred Plans were good and helped to have their voices heard.
3. The general feeling was that an interpreter and/or Maketon would be helpful for some people.
4. Everyone agreed that declaration and convention on the rights of people with learning disabilities would be very helpful.

Memorandum by Supporting Asperger Families in Essex (SAFE)

I am writing to you in response for your call for evidence regarding the human rights of adults with learning disabilities.

I am the Chair of SAFE (Supporting Asperger Families in Essex), and also have responsibility for running the adult section of our family support group—ASAP (Asperger Syndrome—Adults and Parents). Our community of adults with Asperger Syndrome (AS) are being disenfranchised from virtually every statutory service available, and their human rights violated, because they are not considered eligible for either learning disability or mental health services by Essex local authorities, despite overwhelming evidence of need.

However, the Implementation Guidance (2001) to the Valuing People White Paper clearly states (and I paraphrase) that people with AS (despite having an IQ above 70) CAN be eligible for learning disability services, subject to an “Assessment of their social functioning.” Thus they are explicitly INCLUDED within the remit of . . . Valuing People, but being EXCLUDED by Essex social care services because our members continue to be told that a learning disability’ is defined as being below 70 and therefore our intellectually-able adult children (most with average to well-above average IQ’s) are not eligible, despite their often severe SOCIAL learning difficulties which adversely affect every area of their daily lives. When I contacted the Department of Health about this, I was told that social care departments should NOT be using IQ as a marker for eligibility to services. But it still goes on, and our adult children are still being turned away, despite clear guidance from the Government.

Next I turn to the Implementation Guidance’s reference to an “Assessment of social functioning.” In order to assess such functioning, the Assessor needs to be trained to understand autism at the high-functioning end of the spectrum so that they can ask the right questions. This Assessor should also have sufficient knowledge of the condition to take into account the Asperger adult’s impairment in communication, and therefore his/her ability to fully understand what is being asked, and thus give an appropriate, reasoned response. In other words, a “standard” Social Care or Community Care assessment would be totally inappropriate: what is needed is a SPECIALIST autism/Asperger assessment. This is not, and never has been, available to our adult members, despite many lengthy communications between myself and social care professionals over the last few years, pointing out this arguably discriminatory system. In fact, only two out of the 145 adults with AS in our group have ever had a Community Care Assessment. Others who have tried have, again, been turned away because they do not fulfil eligibility criteria. Thus, our adult children’s needs are not being assessed, let alone met. They remain invisible, unsupported and excluded.

Even if such an Assessment existed, the specialist autistic services our adult sons and daughters need are not available in Essex. You will be aware that in order to access various statutory and other services, you need to be known to either social care, physical disabilities or mental health teams. But (as detailed above), people with AS do NOT have an intellectual learning disability, being mostly of average to well-above average intellectual ability, so they don’t fit in social care. AS is NOT a mental health condition, so they don’t fit there, (although sadly many end up needing critical psychiatric services BECAUSE of years of lack of support). AS is NOT a physical disability, so they don’t fit there either. So where DO they fit? Apparently nowhere. Our AS community is disenfranchised and marginalised on virtually every level and certainly do not live “full and independent lives as part of their local communities.”

Even the “Fair Access to Care Services” legislation (which also mentions that services for people with AS should be available) has been quietly forgotten—the argument being that Essex does not have a STATUTORY obligation to provide such services. And so they don’t.

As a person with AS, if you are unknown to social care or mental health agencies, (and only 2% of our adult members ARE known to them) despite having a recognised medical disability (accepted by government as eligible for Disability Living Allowance, Incapacity Benefit etc), you are NOT ELIGIBLE to receive (amongst others):

- *Direct Payments*—which could be used to buy in appropriate independent social care.
- *Advocacy Services*. Within Essex, these are only available to those with intellectual learning disabilities or mental health problems.
- *Supported Employment*. Because of their social interaction and communication problems, people with AS find it extremely hard to find and keep appropriate work. The National Autistic Society Report *Ignored or Ineligible?* states that only just over 12% of people with AS are in full-time employment. That means that 88% are on some form of welfare benefit, although most want to be in meaningful appropriate work and not dependent on the State. They are unable to access the many Government-sponsored Supported Employment Schemes they need because they are considered too high functioning, and thus ineligible. Their often high IQ’s do NOT make them any more employable, because most have considerable social interaction problems with others in the workplace and are frequently sacked because of “inappropriate behaviour” or placement in inappropriate employment. This severe social deficit is still not being recognised by Essex as one which requires support in the workplace. People with AS need specialist guidance in workplace skills, office culture, decision-making, organisation, prioritisation and social skills. Such ‘guidance’ is not available to our able-autistics in Essex, only to those with an academic learning disability. Again, our AS children do not fit, but with specialist training they could enter the employment market, come off welfare benefits and start contributing to the State, thus saving millions in Incapacity Benefit etc payments.
- *Supported Independent Living*. In our support group, 77% of adults with AS are still living at home well into their 30s and 40s, being financially and emotionally supported by often elderly and ailing parents. Despite average to well-above-average IQ levels, they lack the basic “life skills” and simple common-sense necessary for them to live independently in safety—such skills as money management, health and safety issues, house maintenance, cooking, cleaning, shopping, personal hygiene etc. In many respects, their life-skills performance ability is well below the 70 IQ marker used by social care services to define learning disability. Most (but not all) will need help with daily

living, but again this essential support is not available because our autistic adult children do not fit eligibility criteria. So, feeling lonely and frightened about being left to fend for themselves, and probably failing, they choose to continue living at home in a structured and known environment, where they are safe and cared for. However, the impact on parents is profound—there is no “retirement” for them. Their children are likely to be dependent on them until the parents die. There are no courses for their adult children to attend which could help them learn basic living skills, eventually leading to the possibility of independent living. These courses ARE available to people with an academic learning disability, but NOT to our intellectually-able adult children, because again they are not eligible for this educational support. You should note that there is’ absolutely NO link between high intellectual ability and performance of daily life skills.

- *Inclusion into the Community.* People with AS are a socially excluded group because of their difficulties with social relationships, social interaction and communication. No attempt at all has been made to include or integrate our high-functioning autistic sons and daughters into the community. There are no social schemes, no appropriate day-centres, no specialist learning opportunities provided by Essex for adults with AS, although there are several schemes for autistic people with an intellectual learning disability. As a local charity, we do what we can, but as unpaid parent volunteers, we are hampered by lack of funds and the total lack of statutory and other support.
- Adults (and children) with AS long to be part of the neurotypical (“normal”) world, but they don’t know how to do it. Unfortunately, inclusion is a two-way process: much as the person with AS wants inclusion, others have to want to INCLUDE them, which simply does not happen. Particularly in school, college and the workplace, bullying is a virtual given where others frequently set out to blatantly EXCLUDE people with AS, because they are perceived as “weird” or “strange” and “not one of the gang.” The notion of “genuine inclusion” is an idealised dream for the vast majority of our adult children, who lead very restricted or non-existent social lives. Outside in the world, they can become victims and the natural prey of unscrupulous people who perceive them as vulnerable adults and take advantage of their naivety and desperation for friends. This desperation to be accepted by others can also lead people with AS into criminal activities, all for the sake of “friendship.”

I would also like to mention three other issues which are of great concern to our adult members and their families, and affect their human rights for equal treatment in society:

1. LACK OF ASPERGER-SPECIFIC DIAGNOSTIC SERVICES IN ESSEX

Despite extensive researches on my part (and confirmed by the National Autistic Society), there are NO qualified NHS Asperger diagnosticians in Essex. If an adult wants a diagnosis, the route is tortuous at best. Firstly, s/he will have to get a referral from their GP to a Consultant Psychiatrist, most of whom are unlikely to have had any experience of autism and will probably misdiagnose individuals with schizophrenia, bipolar disorder, social phobia, personality disorder and so on. (This is borne out by the many letters and anecdotes I have had from parents). If the Consultant is sufficiently unsure and feels a diagnosis of AS is possible, he will then have to put the case before the PCT, who will decide if they have sufficient funds to refer the person to a specialist hospital for diagnosis (like the Maudsley, Guys, Eliot House, the Autism Research Centre in Cambridge etc). Unfortunately, six of our adult members have currently been turned down for funding and thus referral to a specialist diagnostician, so they have no opportunity to get a diagnosis. Where do they go now? It is surely discriminatory that an individual can obtain a diagnosis of, say, bi-polar disorder free on the NHS without having to put their case before the PCT, while people with AS have to go through the trauma of obtaining funding for a diagnosis of Asperger Syndrome. Diagnosis of AS vindicates the individual and their family and helps them make sense of their lives—something which every person has a right to, surely?

2. LACK OF PSYCHOLOGICAL SERVICES IN ESSEX

Despite the NICE recommendations for “talk therapy”—cognitive behavioural therapy etc as opposed to medication—there are no such services available on the NHS anywhere in Essex, unless the person with AS has either an academic learning disability or a “severe” or “critical” mental health problem. (Again, we don’t “fit” Even then, the psychological services offered are inappropriate for able-autistic people, who need a very specialist form of treatment, as confirmed by the National Autistic Society. The percentage of people with AS who suffer from depression, anxiety, suicide ideation etc. is far higher than in the general population, mainly through lack of recognition of their condition as a genuine disability, and therefore total lack of appropriate support. This obviously has a devastating effect on the family, who have to cope, unaided, with the psychological deterioration of their adult child. In all too many cases, parents end up as depressed as their sons and daughters, leading to frequent marriage breakdowns and mental health problems in parents too. (Over 40% of our parent members are on some form of anti-depressant medication). You should also note that the more intellectually able the person with AS is, the more aware s/he is of his/her condition and the knowledge that there is no cure and it will never go away. This knowledge can also lead to mental breakdown and despair. We need therapists who have had specific Asperger training

and know what they are dealing with. The financial burden on the State having to pick up the pieces of these broken lives (hospitalisation, medication etc) must be enormous. Preventing this psychological damage would save the Government millions.

3. LACK OF ASPERGER-SPECIFIC TRAINING IN ESSEX

Despite the good intentions of many professionals within social care and mental health, I have been told on innumerable occasions that, even if people with Asperger Syndrome WERE eligible for services, these teams have no training in how to deal with high-functioning autistic people. All they could possibly be offered was the same service they provide to people with learning disabilities, which would be totally inappropriate for our intellectually able members. It is a dreadful admission of the system's failure that I, as a mere parent and Chair of SAFE, receive many calls from professionals (including Consultants), asking ME for advice about where to place people with AS, because they have no services and no specialist expertise!

I will now turn to your heading *Call for Evidence* and answer each question, insofar as it relates to adults with AS:

- “the provision of public services . . . the ability of individuals to access such services . . . etc” This has been covered above. There are no appropriate services for adults with AS and thus no access.
- “the possibility for adults . . . to form and maintain personal relationships . . .” Due to difficulties with social interaction and communication, many people with AS find it very hard to make and maintain relationships, and to understand the nature of friendships, reciprocity, sexually appropriate behaviour etc. What is needed is a comprehensive course of training in social and other personal skills—something not available in Essex to our intellectually-able adult children, but which IS available to those adults with an academic learning disability. Again, people with AS are discriminated against because they do not fit Essex eligibility criteria.
- “the opportunities . . . to participate in the life of their local community” As above, there is no move to include our adult children into society or facilitate participation because their disability is not recognised as one which needs this essential social support. They remain mostly isolated and marginalised, and this inevitably increases the possibility of mental breakdown. However, many social opportunities exist in Essex for those with an academic learning disability, but again, our adult children are denied access because we do not fit Essex eligibility criteria.

Unfortunately, despite the good intentions of Valuing People, and its explicit recognition of the needs of people with AS, Essex still refuses to acknowledge the condition as an eligible disability which requires trained resources. It is my belief that all autistic spectrum conditions (especially those at the higher functioning end of the spectrum where they receive little or no support) should be placed in a separate category of need—neither learning disability nor mental health. Autism is unique and it's about time the Government took this on board and made it mandatory for all statutory agencies to develop appropriate support services for our adult sons and daughters (and their families/carers) who are suffering a great injustice by being discriminated against. I believe the human rights of people with AS are being violated through lack of eligibility or recognition of their disability; lack of access to, or the provision of, appropriate services; lack of appropriate professional training; and lack of understanding of their autistic condition, leading to rejection by peers and others and consequent isolation and disfranchisement from the mainstream.

Although this is a long letter, it is only a “snapshot” of some of the difficulties our adult children have to cope with through lack of recognition of their severe social problems.

Carolann Jackson
Chair, Safe

17 May 2007

Memorandum by Ann Abraham, Parliamentary and Health Service Ombudsman

You will be aware that as Parliamentary and Health Service Ombudsman I undertake independent investigation into complaints that government departments, a range of other public bodies in the UK, and the NHS in England have not acted properly or fairly or have provided a poor service. It is my task to decide whether maladministration, service failure or both have occurred.

In that capacity I very much welcome the Committee's initiative in inquiring into the human rights of adults with learning disabilities. You rightly cite the Mencap report, *Death by indifference*, published in March, and the Government's *Adults with Learning Disabilities in England 2003–04* a survey published in September 2005. I am mindful too of the Healthcare Commission's report into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust published in January of this year.

Although I am not currently in possession of any evidence that I can put before you in the way of identifiable case studies, my remit regularly entails the investigation of complaints about health and social care services that almost certainly replicate difficulties encountered by people learning disabilities but which for one reason or another have not been translated into formal complaints to my Office. My Annual Report for 2005–06 identified “continuing care”, for example, as one of the key areas requiring sustained attention on the part of the Department of Health and the Strategic Health Authorities.

The desire to make human rights part of everything we do informs the work my Office has been undertaking to incorporate human rights considerations into our investigation of complaints. Our focus has been on raising awareness that human rights frequently affect the daily lives of many people seeking access to public services. I have also taken the opportunity to promote this approach in my discussions with Ombudsman colleagues in Europe. I spoke in Vienna at a General Assembly of the European Region of the International Ombudsman Institute last year; and I have just returned from a Round Table of European Ombudsmen and the Council of Europe’s Commissioner for Human Rights in Athens where we explored, amongst other things, the scope for co-operation between Ombudsmen and National Human Rights Institutions. I enclose a copy of my Vienna speech to give you a flavour of the sort of approach that I am seeking to take and that will shape my future approach to complaints touching upon the human rights of people with learning disabilities.³

Relevant too are the *Principles of Good Administration* recently published by my Office. The purpose of the Principles is to be clear both with complainants and public bodies about the sorts of behaviour we expect when public bodies deliver public service, and the tests we apply in deciding whether maladministration and service failure have occurred. You will see from the enclosed copy of the Principles that the very first principle makes reference to the need for public bodies to act with due regard to the rights of those concerned.¹ That requirement will of course apply acutely in the context of meeting the needs of people with learning disabilities.

If I can assist you further either in connection with this particular inquiry or more generally in connection with the work of the Committee, please do let me know.

Ann Abraham
Parliamentary and Health Service Ombudsman

14 May 2007

Memorandum by Denise Redman, Scheme Manager, Royal Mencap Society

THE HUMAN RIGHTS OF ADULTS WITH A LEARNING DISABILITY

As a Registered homes Manager working with adults who have profound and complex learning disabilities I am responding to your request for information regarding the Human Rights of adults with a learning disability.

HEALTH SERVICES

In my experience Health care provision for adults with profound and complex learning disabilities is somewhat lacking. There would appear to be a lack of understanding from health care professionals to the needs and rights of these people. Lack of knowledge of communication issues and consent for treatment arises regularly.

Admissions to hospital for either emergency or routine appointments require the provision of staffing from the home, as the knowledge of the nursing staff within hospitals with regard to learning disability seems poor.

In our recent experience a service user with no verbal communication who required hospital admission would have been left without food or drink if the supporting staff had not been there to advocate on their behalf.

General practitioners we have found by and large very good, able to communicate with the service Users directly and using the supporting staff as advocates for communication where appropriate. Access to General practitioners however is made difficult by their opening hours and the difficulty of getting appointments on an ad-hoc basis. With service users who may express challenges it is not appropriate to make appointments well in advance, as their behaviour on the day may result in short notice cancellation of appointments. In our experience it is sometime necessary to request home visits from the GP in these circumstances, this could negate from a more important visit for the GP elsewhere.

³ Not printed.

EDUCATION

Most of the service users who live within our home access a day service provision from the local county council. This is meant to provide living skills support and empowerment. It is our experience that these services are provided on a 0900-1500 weekly basis and therefore are not person centred. A better use would be to meet the individual needs on a flexible basis from 0700-2100 where skills such as accessing the community could be better served.

WELFARE BENEFITS

The service users at this particular scheme all receive Income support and Disability Living allowance. As there are issues of consent and capacity for understanding all service users here have the Registered Manager as an appointee in respect of welfare benefits. This could be better served by independent financial advocates.

BANKING AND FINANCES

Human rights in respect of finances and banking could be better served by independent financial advocates. Where there are matters of consent or capacity of an individual there are still no accessible accounts for individuals. No accounts to my knowledge require photographic identification which would ensure that an individual with no verbal communication could access their own finances.

In the case of the service users that we support we have to have two signatories (Management team) on the individuals accounts and the individual cannot access these accounts themselves.

PERSONAL RELATIONSHIPS

Relationships with family and friends are encouraged and private facilities are available within our service for this. Regular contact is made between staff team and families, Families are encouraged to attend regular reviews of the care provision and their opinion is always valued.

Peer relationships are encouraged and developed, this is however usually within the learning disability "world".

LOCAL COMMUNITY

The Registered service that I manage has only recently been built and it is very prominent in a small town, with access to most things within a few minutes walk. We have been welcomed into the local area by most people and the service users invited to participate in events held at the local church.

Local borough facilities such as leisure centres appear to have very restricted use for people with a disability, "disabled sessions" where access to the pool via hoist or chairs can be restricting. This also can lessen the inclusion into community.

No accessible toilets for adults are available in our local area. This makes personal care support very difficult. Support staff usually has to access standard disabled toilet facilities to support service users who have incontinence issues. A changing bench which is designed for an adult would better meet these needs. See the following website, www.changing-places.org

Shopping is difficult for adults who cannot read and have little concept of money. All our service users require support to go shopping, this would be made easier by pictorial aisle guides. The use of more pictures would involve service users much more in their everyday lives and decision making.

VOTING

A basic right that the majority of adults with a learning disability cannot take part in is voting because the formats are non- inclusive. There would be benefit from audio visual voting and parliamentary information. Where there are issues of capacity, this could possibly benefit from advocacy.

HAVING A SAY IN DECISION MAKING

Service users with complex and profound learning disabilities do not generally have a voice. The use of advocates would be a powerful tool in this area, however it is our experience that advocates are only available where an individual has an urgent case of needs. Advocates for service users do not have any verbal communication would benefit greatly from this provision being more accessible.

MAKING COMPLAINTS

Service users who have a profound or complex learning disability rely wholly on the opinions of the staff that support them and their relatives. Advocacy professionals would be more appropriate and better able to represent the individual.

Denise Redman
Scheme Manager
Royal Mencap Society

11 May 2007

Memorandum by Somerset Advocacy

This letter is in three parts. The first consists of quotes collected from Speaking Up groups around Somerset. The second is from the monthly meeting of the Management Committee of Somerset Advocacy for People with Learning Disabilities (consisting of representatives of adults with learning disabilities from around the County) at which they discussed the three questions asked by the Joint Committee on Human Rights. The third section is from the Trustees of Somerset Advocacy and describes what we consider to be a “test case” for the efficacy of advocacy.

1. ISSUES/COMMENTS FROM SPEAKING UP GROUPS

It’s important: for us

- to be able to say what we want to say;
- to be listened to by staff, family, doctors, nurses, dentists;
- to be spoken to as an adult;
- be able to complain if something is wrong—food, someone calling me names;
- to have relationships—boyfriend or girlfriend—it’s up to us to be able to share things;
- to kiss, hold hands, have sex, have babies;
- to have privacy—our own bedroom—people must knock and be asked in;
- to have a lock on the bathroom door; and
- to have choices and to make choices to have a home.

“We’re adults and grown-ups”

“Our carer says we can’t kiss (me and my girlfriend). She says ‘we’ve got to draw the line somewhere’”

“I don’t have much control of my money. My parents take control”

“My parents would say no to me having a boyfriend, I feel let down”

“I’ve been told boys mustn’t kiss”

“People make fun of me in pubs”

“I would like to take my boyfriend on holiday”

“It’s up to us if we want a boyfriend or girlfriend”

“It’s good to have a choice about where to live”

“My brother and sister in law don’t like me going out on my own”

“Travelling on the bus is scary”

“Meeting friends can be difficult”

“Staff and parents do my money”

“There are lots of strangers on the bus”

“We should have privacy. People should knock and ask to come in (to bedroom)”

“We want to earn more money”

2. MANAGEMENT COMMITTEE

How easy is it for people with a learning disability to have a say in the decisions which affect them?

It depends on the circumstances

Difficult decisions are:

- medical;
- where someone puts him or her-self in danger;
- where two decisions “clash”;
- where people have to give and take (compromise); and
- where you live—because there may not be a lot of choice

People need:

- good information which they can understand;
- good quality advocacy;
- chances to try things out;
- staff who are properly trained to support them; and
- staff should be trained about human rights.

How easy is it for people with a learning disability to make a complaint about a service?

- complaints information needs to be easily available and easy to understand;
- it’s hard to make a complaint about someone you know—they might take it out on you;
- some people want to make a complaint to a man, some to a woman;
- groups of people, like advocacy groups help give support;
- sometimes people need support, but know who to complain to in the day centre or the outside world;
- “I’d tell my dad first”; and
- people in residential care find it harder to complain about people they know. They need more support.

What would help people with learning disabilities get their human right and any examples you have of when this has been done well.

People with learning disabilities could be helped by:

Good advocacy support

- taking a friend for support;
- having a telephone number to ring;
- CAB;
- well trained social workers/teachers/doctors;
- Local Council.

To support them in where they live, who they live with, meeting/ making friends, going to hospital/ doctor, work placements, college, day services and transport.

3. TRUSTEES OF SOMERSET ADVOCACY

“The committee would particularly welcome views on the ability of people with learning disabilities to make their voices heard in decisions affecting them (including through advocacy services) and the efficacy of the relevant complaints mechanisms”

A is a woman of 28 years. For the last year she has been living in a respite facility run by the Social Services adult learning disabilities service while suitable accommodation has been sought. She was referred to the Advocacy service when her father did not approve of a place suggested by her social worker and tried to persuade her to go to live in one of a group of residential homes which he owns 250 miles away. An experienced independent advocacy worker met with A, who was adamant that she did not want to live in a home owned by her father—a view she has expressed consistently throughout. When she became very distressed by the situation, she stated that her father always got rid of people who were on her side and she would not give her permission for the advocate to discuss anything with him. As a result, her father became very aggressive towards the Advocacy service manager and subsequently towards the Trustees of the service. He clearly does not understand and will not accept his daughter’s capacity and right to make her own decisions

(consistently tested by the advocate against the criteria for capacity in the MCA). He also misunderstands, in spite of being informed, the role of advocacy in supporting his daughter and is threatening to take legal action. The trustees, who between them have decades of experience working with people who have learning disabilities, have stood firm, in the face of his vitriolic and abusive complaints. Social Services staff have found it very difficult to withstand his bullying behaviour—he is a wealthy man who believes he has the right to, control his daughter’s life. He has tried, unsuccessfully, to take out an injunction to prevent the advocate from meeting with his daughter. The Consultant Psychiatrist has now decided that although A. has capacity to make this decision, she is being emotionally destabilised by the involvement of too many professionals and has asked all to withdraw, including her advocate, leaving her with the social worker, whom she does not want, and who has openly said that he can persuade her to go to the out of county provision which belongs to her father. A. has said that she wants her advocate to continue supporting her. The case continues—

This case clearly demonstrates the difficulties which may be encountered by adults with learning disabilities who hold different views about what they want in their lives from their parents. It also demonstrates the difficulties which advocacy services trying to give such people a voice may meet when challenged by parents who hold a different view about the capacity of their son or daughter to make their own decisions.

In this case, advocacy itself has been rendered as powerless as the person it has tried to support.

We consider that such difficulties are compounded by:

- the lack of a recognised advocacy qualification- advocates not being respected as professionals (currently being remedied);
- a general misunderstanding about the nature of advocacy- often thought to be a sort of arbitration, adjudication or mediation rather than a means of giving a person an independent voice; and
- the fact that many advocacy services are funded wholly or in part by statutory service providers which may lead to a conflict of interests.

Funding of Advocacy Services

The method for funding advocacy is an area that merits careful consideration by the Joint Committee. At present this Advocacy service is at the whim of the Local Authority which-funds it and, further, the funding is not ring-fenced. Uncertainty about the amount and continuity of funding is detrimental to the service’s expansion as well as its existence and detracts from the overall purpose of the service; furthermore, it can result in less access to the service by people with learning disabilities who need to have their human rights supported and protected to the fullest extent.

Advocacy services have a vital role in the lives of those who have learning disabilities. They need to be financially viable and sustainable with scope for expansion, but also, the user needs to have confidence that the service will survive and not be at risk because its future funding may be jeopardised by financial cutbacks in either Central or Local Government funding (but especially the latter).

Jane E Jones
Chair of Trustees

21 May 2007

Memorandum by Speakeasy Now

We are a self advocacy organisation, in Worcestershire, for people with learning disabilities.

We took your questionnaire “Joint Committee on Human Rights Press Notice No 29” to our monthly members’ meeting.

We split into groups to answer the following questions:

1. How easy it is for people with learning disabilities to have a say in decision which affect them?
2. How easy is it for people with learning disabilities to make a complaint about a service?
3. What would help people with learning disabilities get their human rights? Can you give some examples of when this has been done well?
4. What chances you have had to have personal relationships with people like boyfriends, girlfriends, husbands or wives?

We have summarised and enclosed our answers for you.

RESPONSES TO QUESTIONS

1. *How easy is it for people with learning disabilities to have a say in decisions which affect them?*

It is hard to make decisions.

Sometimes help is needed.

Nobody listens.

People in the street do not understand.

We should be treated as individuals, this would help us take control.

It is hard to communicate, sometimes a carer has to do this for you.

Supporters can be a good help.

Some decisions are very difficult to make.

Sometimes it is hard to know who to ask for help.

Most people with learning disabilities are still being told where to live.

Most people with learning disabilities are told what to do during the day.

Sometimes family relationships make it difficult.

Some decisions are difficult to understand.

Sometimes we cannot do what we want because of staff and money.

2. *How easy is it for people with learning disabilities to make a complaint about a service?*

If I have a complaint I would talk to my key worker/supporter.

It can be hard to complain because there are lots of procedures are things to do to complain.

It can be difficult to know where to go to complain.

I know where the forms are but not what to do with them.

It can be embarrassing to complain.

It is hard to complain about people because it might get them into trouble.

It is important to know who to talk to, if you don't it is very difficult to complain. You need to be able to trust someone.

Some people are too nervous to make a complaint.

Staff can get angry and get people into trouble.

Some people worry so much it can make them ill.

Sometimes there is no point in complaining because nothing gets done about it.

A complaint was made about the kerb and they lowered it. It was done very quickly.

There are staff who help us. We could use an advocate.

The government could help by giving more money and making stronger laws.

We need complaint policies with pictures on them.

We could talk to our MP or councillor.

3. *What would help people with learning disabilities get their human rights? Can you give some examples of when this has been done?*

When people go to speaking up groups and are supported. People can speak up on the partnership board.

Information should be easy to understand, bills, fun things and food.

Going to college to learn life skills. This helps increase choices about food and what to do in the future.

More publicity and speakers.

It would be really good not to be treated like children. Some people do treat us like adults and this is good.

Self advocacy groups help people to speak up for themselves.

Consultations help get our voices heard.

4. *What chances you have had to have personal relationships with people like boyfriends, girlfriends, husbands or wives?*

We are stuck in at home with not many friends. I would like to go out to the pub or to bingo. We could go out in a group with just one supported.

Some supporters will not work in the evening.

Lifelinks are doing evening groups, this will help us meet new people.

Transport can be a problem if you want to go out with your partner or friends. Taxis are expensive.

Hard to meet anybody other than the people you see at the day centres. Some of us need help to make arrangements. We need money to go out and about and a bus pass.

There are internet dating agencies for people with disabilities.

30 May 2007

Memorandum by The Wednesday Comet Group

How easy is it for people with a learning disability to have a say in decisions which affect them?

Most of our group feel that they have a say in decisions that affect their lives. But people who have more complex needs often do not because people don't know how to communicate with them. If we receive services sometimes decisions are made because of money not because of what we need.

How easy is it for people with a learning disability to make a complaint about a service?

It is not easy to make a complaint about staff where you live or go during the day because they might take it out on you. For other services complaint forms aren't usually written in an accessible way. People don't always listen to the views of people who have a learning disability.

What would help people with a learning disability get their human rights and any examples you have of when this has been done well?

Good paid staff help us and so do the police when we have had a crime committed against us. The best way for people with learning disabilities to get their human rights is to have enough independent speaking up groups where people can get support to speak up for themselves.

Franco Laidlaw

Chair

Wednesday Comet Group

23 May 2007

Memorandum by The Cambridgeshire Parliament

We are writing to you as representatives of the Cambridgeshire Parliament project. The Cambridgeshire Parliament is an advocacy project and is part of Speaking Up charity.

We are "MPs" elected by other people with learning difficulties in Cambridgeshire and we speak up for them at big meetings. We decide what the agenda is and we invite along people who can make changes in the area we are talking about. Then we campaign to make change happen.

We have discussed lots of different things at Parliament and some of them are relevant to your Committee. So, we are responding to your call for evidence.

BUDGET CUTS

One of the things we have been campaigning about recently is the cuts that the council has made to learning disability services in Cambridgeshire. We have enclosed with this letter a speech that we made supported by our project manager to the Cabinet of our County Council.

Cambridgeshire County Council are having to make a £3 million saving on their social care budgets this year. We are really worried that the cuts that are being made to make this happen will have a bad affect on peoples' human rights.

One of the things that we are worried about is that in order for the council to save money they will be very strict about how they apply criteria for services. We think people who get a service at the moment might lose out and no longer be given a service.

We're told that respite services might also be shut down leaving people with learning difficulties and their carers under even more pressure.

We are really scared about what the cuts will mean. No one will tell us for sure. We think we get a bit of a rough deal already, when money is cut things are going to get even worse. We've told the council that they should have put the council tax up more. They can't put it up any more this year, they've put it up to the maximum. When we spoke to the council about it they said one of the main reasons Cambridgeshire is so poor is because we don't get as much money as others from central government. This seems really unfair. We haven't got the money to pay for things that other counties can pay for.

HEALTH SERVICE

People (in health services) think that because we have a disability they don't need to talk to us and they talk to our carers instead. This isn't fair, we're people too. The nurses and doctors should talk to us, explain things and make them accessible.

We suggest that there should be more training for nurses, doctors and all staff in hospitals around this. There should also be people checking how well people are doing. The people who sit in offices and say nice things about how stuff should be done should come out of their offices and make sure it's really happening.

DISCRIMINATION

We have experienced, seen and heard about lots of bullying happening in the community. People with learning difficulties are often scared to go out. We're often called names or people take the mickey in a really nasty way. This happens out on the street and especially on public transport, like buses.

We think a lot of this happens because of the way schools are organised. Our group can't agree on whether people should all be taught in the same school or whether we need special needs schools. What we do agree about is that there must be integration in schools. There has to be opportunities for mainstream kids to meet people with learning difficulties in a really good, fun way. Perhaps going out on buddy schemes, finding out the things that they have in common, not the things that make them different.

WORK

We don't feel like we have the same chances of getting a job as other people.

We know of someone who went through an interview and got a job, but when the boss found out that she had autism, they changed their minds and gave the job to someone else.

We do get encouraged to work in charity shops. But then we don't get support to move on.

When we have managed to get a job it's been really difficult. When one of us worked at Asda no-one spoke to me, I felt really lonely.

RELATIONSHIPS

We hear lots of people say that their chances to have relationships are limited. Lots of homes, day centres and parents do not allow people to have relationships. We know lots of people who really want a boyfriend or girlfriend, and they may even like someone they know, but people won't let them develop a relationship because they don't think they're grown up enough. That doesn't seem fair to us.

We are also worried about how many people there are who still live at home with their parents when they are in their 40's and 50's. That's fine if it's what everyone wants and they've planned for the future. However, much of the time it seems that parents are clinging onto their children against their will. It seems that people with learning difficulties themselves aren't asked what they want to do, whether they want to live on their own. It seems that if parents want to keep their children with then it goes unquestioned, perhaps that is because it's cheaper for the government?

The problem is that this often means that people don't have the chance to develop their independence skills. This means they can often live with their parents until their parents die. Then they have an awful time because not only are they really, really upset because their mum or dad has died. On top of this they haven't learnt the skills to live on their own and they will have a horrible shock when they move on to somewhere else.

INFORMATION

It's really important that there is better information for people with learning difficulties in all areas of our lives. We need to know the same information as everyone else, but we need to have it broken down and with pictures. For some people they need to have information explained and have lots of support to understand it.

HOUSING

People don't get priority for housing, it feels like sometimes people with learning difficulties are left out because we don't understand the system as well as other people.

One of our group has a young son. She is stuck in a tiny one bedroom bungalow with her partner and young son. He is now nearly one year old and starting to walk. Despite having been on the housing list for a long time she has not been offered any houses at all.

We've been talking about the new Choice Based Lettings system at our Parliament meeting. The idea sounds good because it gives people more choice, but it's really important that people with learning difficulties are given the same chance to bid as everyone else. It feels like we might be at a disadvantage just because some of us can't read and we might not know where to go to get information and help.

INDIVIDUALISED BUDGETS

If we hadn't been at Speaking Up we wouldn't have heard about Individualised Budgets. They sound like a great idea and one of us is going to get one. The important thing is that we must get support to do this. It sounds like individualised budgets will help people get their human rights respected, but that will only happen if they're done properly. They're supposed to be person-centred and lots of people won't know what that means yet. And for people who have high support needs it's really important that plans are done from the person's point of view and that there is a circle of support, not just a parent or member of staff dictating the plan.

These are some of the things we wanted to tell you about. There are lots of things that we think are important for the Joint Committee on Human Rights to consider.

Please find included with this letter documents which we think will be good for you to read.⁴ They all come from the Cambridgeshire Parliament. The minutes tell you about the things that we have discussed. We have chosen to send you ones that are most closely related to Human Rights.

Please think about all the things we have said. We think it is really important for people with learning difficulties to be heard.

Typed by Wendy Lansdown, Project Manager, Parliament project The Cambridgeshire Parliament.

On behalf of the authors of this letter:

- Peter Auckland MP—expert in housing;
- Tracey Auckland MP;
- Ian Culverhouse MP—expert in transport;
- Stephen Hill MP; and
- Michelle Mansfield MP—expert in support.

The authors represented 35 MPs who make up the Cambridgeshire Parliament who in turn represent 1,500 people with learning difficulties in Cambridgeshire.

⁴ Ev not printed.

Memorandum from the Cheshire and Wirral Partnership Trust, Learning Disabilities Division

INTRODUCTION

Cheshire and Wirral partnership trust (CWPNT) learning disabilities division wish to submit the following evidence to the JCHR for consideration in their investigation.

In order to ensure as many people as possible were aware of the call for evidence and could contribute to it we circulated both the easy read version and full document of the call for evidence via joint partnership boards; all CWPNT teams and in patient facilities and to advocacy groups, learning disability commissioning managers and the learning disabilities multi agency provider forums. This was in the hope that as many people as possible residing in Cheshire and Wirral would respond. Hopefully there will be other responses submitted from individuals and / or organisations across Cheshire and Wirral to the committee in due course.

What follows is *evidence collated from within Cheshire and Wirral partnership trust drawn from a number of sources, namely:*

- Information from service user consultations completed over the past 18 months and the more recent Cornwall action plan consultation (ongoing)
- Staff views on what they see in day to day practice
- Direct anonymised case evidence

Layout of document

This document will draw your attention firstly to areas of best practice we feel would be useful to share with others with regards to how we are aiming to safeguard the human rights of people with learning disabilities in relation to their health needs when in contact with CWPNT. This evidence has been drawn from the service user consultation sessions / documentation and current practice within the learning disabilities division.

Next the document will move on to outline some of the wider primary / secondary and social care issues we feel are still major problems for people with disabilities and impact on their human rights. This section will be illustrated with evidence from the direct experiences of people with learning disabilities and clinicians in Cheshire & Wirral. We will also indicate where there are pockets of good practice which are going some way to resolving these issues in some instances.

Finally the paper will make some recommendations as to what people with learning disabilities, their carers and local clinicians felt would make the biggest impact on the human rights issue in learning disabilities within a health context.

Best practice initiatives within CWPNT which demonstrate a commitment to promoting the human rights of people with learning disabilities

- Employment of a consultant nurse and health facilitators to lead on reducing health inequalities and improving health access for people with learning disabilities across Cheshire and Wirral. This virtual team work closely with people with disabilities, their families, primary / secondary care and provider agencies to improve local health care provision by:
 - ensuring learning disability representation on key strategy groups within PCT's / hospitals
 - provide direct support to people with disabilities who need help with accessing healthcare
 - provide education / training to health colleagues on disabilities and to people with disabilities / carers on health issues
- Development of a managed clinical network on health access and inequalities. Includes the people above plus other therapists and people from primary / secondary care. Network is responsible for project development around problematic issues and more proactive work. Eg dementia pathway development group; know your numbers national blood pressure campaign group
- Employment of a consultation and information worker within the learning disabilities service in Cheshire and Wirral partnership trust. Their role is to lead consultations with clients on a range of issues and lead on ensuring our information is in accessible formats. The last 18 months has seen large scale consultations on the following topics: reconfiguration of in patient services; views on respite services; Cornwall action plan; views on health via use of patient stories model; experiences in mainstream mental health services (just started). In addition the post holder helps with the design of evaluation & feedback processes so that people with disabilities can express their views on any training they have received.

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- Development of best practice consultation guidelines
 - Investment in ensuring full involvement of service users in staff recruitment at all levels. Also developed best practice guidance on how to do this
 - Patient & public involvement service (PPI): There has been substantial investment across the trust in PPI. The learning disabilities consultation & information worker has worked closely with this department to ensure creative ways of involving people with learning disabilities in the trusts business other than merely sitting on committees. This has included learning disabilities involvement in foundation trust status and membership; ensuring ways people with learning disabilities can be paid for their contributions to consultations outside of the committees and working parties arena (eg by taking consultations out to the person if they are unable to cope with a meetings setting etc) and redesigning all paperwork / claims forms to be accessible to people with disabilities. Currently working with the trust IT department and social services on possibility of a learning disability website as the trust & borough councils corporate web page style is not accessible to people with learning disabilities
 - There has been major progress around people with learning disabilities being able to access trust wide services based on clinical need (ie adult and older peoples mental health services; drugs & alcohol services and CAMH's) by the development of closer working relationships / joint working and ensuring learning disability diagnosis does not result in exclusion from services
 - Foundation trust contracts are currently being finalised and work has been undertaken to focus on inclusion and ensure there is no exclusion on the grounds of disability
 - All learning disability inpatient facilities have an accessible service user induction pack which is gone through with people on admission and revisited at intervals throughout their stay. (includes things such as where to find things on the unit; how money is looked after; named nurse; what to expect while you are here; your rights etc)
 - Introduction in all areas of picture boards of who's who staff wise and adaptation of all out patient appointment letters to include photos of who they will be seeing and the building they will be going to. Plus all clients offered choice of 3 dates for their out patient appointments
 - CWPNT community team care planning changed to focus on empowering the person to take ownership of their lives / meetings. Use of the "my care planning meeting" process whereby the person sets the agenda for their meeting and pre work is done on looking at what they would like to say, who they want there etc
 - In patient areas and supported living schemes have consultation sessions running regularly for in patients and tenants to comment on the services they receive and any changes they would like to see made. Regular progress is then fed back via meetings and through the talk back scheme within the trust
 - Wirral Health Action Group (HAG): formal working group PCT led and includes representation from advocates; CWPNT; secondary care; social services; primary care & provider agencies. Focus is to lead on health developments for people with learning disabilities in Wirral and ensure PCT public health & health promotion departments look at the access and discrimination issues for people with learning disabilities. Has an action plan which is signed up to by senior officials within the PCT and partnership agencies.

Primary / secondary & social care issues impinging on the human rights of people with learning disabilities

Despite all of the above and the fact that much has been done nationally and regionally to ensure the rights of people with learning disabilities are upheld, there are still a number of cases where one could say a persons human rights have not been upheld, especially in the areas of unjustified discrimination and poor medical care due to diagnostic overshadowing and disability blindness.

The areas we would like to specifically highlight in this section are:

- 1) continuing care processes
- 2) diagnostic overshadowing / disability blindness and the lack of skills and knowledge within NHS staff and care agencies to be able to meet the health needs of people with learning disabilities
- 3) transition from children's to adult services

4) people fit for discharge within in patient learning disability services but have no where to go which continues to impinge on their day to day freedoms / lifestyles and denies them the benefits they would have been afforded had they been discharged (benefits trap)

5) national lack of accessible information and investment in developing such information

(1) *continuing health care process*: people with learning disabilities are not fully enjoying their rights in this area due to unjust discrimination on the grounds of their disability

There is evidence to suggest that people with learning disabilities are not able to access continuing care as swiftly or indeed to the same degree as other citizens. This is due in the main to there being confusion as to the relationship between continuing health care and the learning disability joint commissioning arrangements where they exist. A number of cases dealt with recently have been unduly delayed due to the need for deliberations on whether learning disability clients should go through the continuing care process as other clients do or whether the joint commissioning arrangements pooled budgets is the appropriate route. This could at times negate the rights of people with learning disabilities to apply for continuing care as any other citizen would.

Examples:

- Client with advanced cancer of the bowel deemed palliative: application made to continuing care, PCT unclear as to route the application should take and needed negotiations between a number of commissioners and leads. Issues compounded by the fact that when the case did go to panel they felt ill equipped to make a decision due to the person having a learning disability and not being an older person. Case therefore deferred whilst they sought further expertise / clarification
- Across PCT's generally continuing care panels have built up expertise around older people in the main and are more used to dealing with nursing home care requests as opposed to care within the persons own home and flexible packages for younger disabled people.
- The numbers of people with learning disabilities who have been granted continuing health care status are generally low which could reflect both peoples / carers lack of understanding of their rights to apply and PCT's struggle to understand the needs of people with learning disabilities in relation to continuing care.

Much of the confusion could be due to people seeing continuing care as sitting within pooled budget arrangements and lack of clarity around where pooled / joint funding ends and continuing care begins. Pooled budgets are linked to capped funding for pre commissioned services / teams in the main, which means there is little flexibility to fund additional resources as required via continuing health care. PCT's obligations under continuing care cannot be capped. Hence it would make more sense for Continuing care applications for people with learning disabilities to go directly to PCT's and be heard alongside all other continuing care applications and judged in the same way.

Its essential we concentrate on helping PCT continuing care teams / leads to develop their skills / competencies around learning disabilities and ensure they have access to specialists in learning disabilities when required as this would ensure a timely response to applications and avoid unnecessary delays in the process. There are 3 broad areas where continuing care tends to be applied for in learning disabilities which include:—

- Physical ill health / medical problems.
- Challenging behaviour / mental health.
- Forensic problems.

The former requires PCT specialists to lead on and for learning disability teams to help them build up their confidence in working with people with learning disabilities, as in many instances their learning disability is no longer the primary issue in such applications. The latter two would benefit from bolting learning disability experts onto actual continuing care teams to lead on these cases and for PCT colleagues to skill up the learning disability practitioners in continuing care, as is the case in some PCT's in relation to mental health. (here you see mental health nurses being employed on continuing care teams to give advice and assess the more complex cases)

Good practice examples re continuing health care & possible solutions

- in mental health the above has been gotten around by employing mental health nurse as an advisor to the continuing care teams in order to do joint assessments and monitor / review such cases (Wirral PCT / Halton PCT)

- in some areas panels are set up to have the skills to review any case that comes to it irrespective of client group as they have representatives from older people / mental health / Ld and generic health on the panel (Wirral / Halton PCT's)

(2) Diagnostic overshadowing / disability blindness and the lack of skills and knowledge within NHS staff and care agencies to be able to meet the health needs of people with learning disabilities

Despite much investment in this area locally and nationally we still have regular cases whereby the persons health needs are not addressed due to diagnostic overshadowing and the lack of understanding re consent to treatment and best interest. Although the new mental capacity act is set to try and rectify the latter, without significant investment in building the skills and competencies in primary and secondary care the issues will continue.

Examples:

- GP referred man with Ld and poor verbal communication skills for an ECG as concerned about his health,. Results showed abnormalities. GP deliberated around whether to do further investigations and refer for an echocardiogram feeling this would be difficult as the patient couldn't verbally express any signs and symptoms.
- Care agency requested GP see a man with severe learning disabilities as they were concerned about his health generally and the client would become agitated / anxious and disturbed if he had to be seen at the practice. GP visited and was willing to look at any specific ailment / symptoms but indicated to staff GP's weren't funded to carry out a generalised well mans check which would have been more beneficial to the person concerned
- Woman diagnosed with cancer of the bowel. Was eventually referred to the learning disability team nearly 12 months post diagnosis when primary care staff were having difficulties with pain relief. Family members had told the GP they were not going to allow anything other than a paediatric dose of pain relief to be administered to the woman concerned despite obvious signs of excessive pain as they didn't want her to be drowsy. The GP found themselves at an in pass and was unable to prescribe anything other than paracetamol until the learning disability team and the district nursing team took this up with all concerned and clarified with the family consent to treatment from them wasn't required and that the woman actually needed pain relief. Even after establishing an appropriate pain relief regime care staff struggled with balancing the views of the family with the rights and needs of the woman they were supporting
- Woman with severe learning disabilities and mental health problems whom became a revolving door patient via A&E, numerous admissions to hospital resulted in an extensive stay in hospital following collapse, cardiac arrest and excessive bleeding. Prior to collapse there had been Numerous issues with GP out of hours not attending but instructing care staff to increase sedation instead; A&E consultants struggled to examine her and as she was unable to describe her symptoms were unable to come to a diagnosis even though they were sympathetic to care staff telling them the pacing and moaning behaviours were out of character for her; one consultant when coming in to finding her on the ward yet again insisted on her being discharged home immediately resulting in her being discharged home at 6am in the morning
- Care scheme where carer decided not to take a woman eligible for mammography screening to routine screening appointments based on their belief that it would be "too traumatic for her". The woman was later diagnosed with breast cancer. Carer also initially refused treatment on the client's behalf needing intervention from learning disability team and specialist nurse from the hospital to work through the issues with the carer and ascertain the views of the client independently
- Person with profound learning disabilities at risk of loosing day care placement as has tracheotomy in situ and suffers from chest problems requiring suction via the tracheotomy, at home this is done by parents. Care staff in day centre unable to undertake suction via tracheotomy site and current policy leaves no scope for them to be delegated / taught the task. Primary care services as they are currently configured would struggle to respond to the young mans needs quickly enough as would be reliant on district nursing response as no on site services. Without access to the intervention he is at high risk of collapsing. If unresolved the person will not be able to attend the day centre as it would be putting the person with disabilities at to much risk

Good practice examples:

- Use of a community matron for one young woman with complex health needs in western Cheshire to co ordinate all her care and ensure agencies are able to meet her needs

- Successful Neighbourhood renewal fund (NRF) bid to introduce health checks for people with learning disabilities in the most disadvantaged wards in Wirral via GP practices (Wirral). Involved practice nurse time and LD nurse time undertaking joint health screening. This has led to the identification of numerous unmet health needs including possible prostate cancer; diabetes; high cholesterol etc
- Health passports for hospitals alerting hospital staff of additional support needs of the person with learning disabilities (West Cheshire & Wirral)
- Training sessions for primary & secondary care staff on understanding learning disabilities rolled out across Cheshire & Wirral via CWPNT
- Anticipatory care calendar pilot which seeks to clearly identify symptoms for GP's / doctors to aide diagnosis (Wirral pilot site & due to start in Cheshire)
- Use of consultant nurse & health facilitators to case manage people with complex care needs and ensure pre planning of any interventions where necessary. E.g. woman with severe learning disabilities and challenging behaviour requiring exploration of facial lump and tooth extractions. Facilitated pre planning meetings which included facio maxial surgeon, dentist, woman herself, family, carers, anaesthetist and hospital staff. Much pre work done including pop in visits before the appointment and face masks changed and given to her as part of desensitisation programme leading up to event resulted in successful treatment.
- Countess of Chester hospital learning disability working group meets regularly to flag up issues and address access problems. Includes carer reps as well as hospital department staff and learning disability team representation. Have developed pathway for elective admissions which includes one point of contact for people going in who need additional support; carer identification systems and bleeps for them so that they can have breaks when supporting their relative on the ward etc.

(3) Transition from children's to adult services:

There is evidence to suggest that young people's rights are violated at transition with regards to:

- Colleges, day centres, work placements and respite provision being inaccessible to people with more complex health problems or who are increasingly more technology dependant. I.e. people who need buccal midazolam / rectal valium as rescue medication for prolonged seizures; people who are PEG fed; people requiring things such as oxygen, suction, intermittent catheterisation etc. we have numerous cases of people whose transition into adult services has been hit with them not being able to access services at the last minute as there is no one adequately trained to carry out these tasks for them in these settings and/ or no one will take responsibility for ensuring the tasks are completed. PCT's say they are not their responsibility, social services the same and care agencies and families are left in the middle. The end result is the person often stays at home until a resolution is sought.
- Equipment at transition becomes a huge issue, especially with regards to bespoke pieces of equipment (eg standing frames) and / or communication aides which were funded by children's services as they do not transfer with the young person. This potentially leaves people without much needed equipment and in the case of communication aides without a voice at a vital time in their lives

Much of the above is down to the fact that:

- Transition reviews do not have the right people around the table or indeed the planning is started much to late as adult services tend only to go to the last reviews in the final year.
- A lack of clarity around who would be best placed to meet such health needs in ordinary community settings. District nurses are the main visiting health professionals but tend only to provide services to the housebound. Also a number of the tasks required such as PEG feeding etc are not ones they are familiar with and do not see them as part of their role. Another issue here is sheer volume of work undertaken by district nurses leaving very little time to become involved in training / skilling up care staff to undertake the procedure
- Receiving services (colleges / day centres and respite units) do not have nurses attached to them as was the case in schools
- There's no duty on care agencies to have to undertake these type of care tasks even though they have contracted to meet that persons needs

Examples:

- Teenager needing intermittent catheterisation unable to access respite care as staff are not trained in the procedure and no resolution on who will train the staff. Plus day centre placement in jeopardy as no clarity on who will undertake the task at the day centre. Initially school nursing service did it as a good will gesture whilst in transition phase to ensure continuity of care whilst moving from school to adult day care. Its unclear whether such an invasive task can be taught to care staff in this situation or whether it needs to be health professionals who undertake the task. Infra structures within adult services do not exist to meet such needs

- Young man needing chest percussions several times a day which would include whilst at the day centre and access to suction if required following this. Unable to have chest compressions done at the centre as although centre staff willing and able to undertake chest compressions was unable to be trained in the more invasive procedure of suction. It would be unsafe to do the chest compressions in this case without access to suction
- Numerous people in day centre and some respite settings who require buccal midazolam or rectal valium as first line treatment for prolonged seizures unable to access it in these settings as organisations are unhappy about staff being trained in invasive procedures (despite it being a potentially life threatening situation) hence in these instances the client and care staff have to rely on 999 services if seizures do not subside even though the clients have a prescription drug that if administered would reduce the need for hospital admissions in most cases
- Young woman 20 years old having to accept respite in an old peoples nursing home as the care staff in local respite services unable to meet her care needs and district nursing services unable to meet her high care needs

Good practice examples:

- Complex care tasks policy developed in Cheshire for use across all client groups. It allows care staff to be trained to undertake some of the more invasive care tasks providing primary care staff train them and monitor / review people's conditions on an ongoing basis. (eg PEG feeding; suction; administration of rescue medication; toe nail trimming etc)
- PCT in central Cheshire have gone some way to resolving day centre issues by having nursing services allocated to each day centre. However demand exceeds capacity and the restrictions around their posts means they are only able to train day centre staff and not provide training and support across care settings for individuals
- Piloting of health action planning in transition: joint venture between Cheshire social services, young people with disabilities; parents of youngsters; CWPNT, Cheshire education services and central / eastern Cheshire PCT and Western Cheshire PCT. Pilot with 16 young people in this years transition. Aimed to link adult health facilitators into transition reviews and ensure HAP's contained all the relevant health information to help plan their transition appropriately

(4) people fit for discharge within CWPNT in patient learning disability areas but have no where to go which continues to impinge on their day to day freedoms / lifestyles and denies them the benefits they would have been afforded had they been discharged (benefits trap)

Delayed discharges are apparent in all acute admissions facilities. However, within learning disability in patient facilities the delays can be significant with evidence of people fit for discharge but still on in patient wards several years later as there is no where for them to go or their placement requirements are so high cost that there are disputes around funding. This means that people still have to lead very restrictive lives even though they no longer require it, as in patient units by their very nature are somewhat restrictive as they are often catering for detained patients. Even though the units try to accommodate such people and put in community access wherever possible peoples lives are significantly and unnecessarily restricted through no fault of their own.

This is further compounded by the fact that as they are still technically in hospital they have no rights to claim full benefits, hence their earning capacity is significantly reduced and so their ability to make choices over what they would like to do / how to spend their money etc is denied them, again through no fault of their own

In addition for many people they are also unable to register with a GP of their choice whilst they are in hospital, or indeed miss out on routine health screening and community based health assessment / treatment which would be offered by their GP surgery because their GP is in another area to where they are currently residing

Examples:

- People in CWPNT in patient areas who have been there for a number of years and are in effect "delayed discharges" as there are no agreed packages of care to move them on. These people are unable to access full benefits hence their ability to go out and do things they would like to do is impacted upon
- Young man in inpatient area was initially unable to access tissue viability services as the hospital site contract did not cover learning disability in patient areas and the community services would not see him because he was an in patient.
- young man in inpatient area initially unable to access dietician services as this service is not available on the hospital site and he was not registered with a local GP therefore could not be referred to community dietician services for support re gout

(5) National lack of accessible information and investment in developing such information

As a trust we have invested much time and energy into developing leaflets in more accessible formats around everything from understanding mental health through to how to stay healthy. We have liaised with primary & secondary care teams and service users in the design of them but there remain the ongoing issues of cost for development and role out.

Despite there being a national drive for accessible information there is no central steer or indeed commitment to ensuring information within health care settings is available in formats accessible to people with learning disabilities. You can find leaflets in different languages or in tape format etc but not fully modified for people who are unable to read and rely on more simplified picture based formats.

Without accessible information we are reducing peoples ability to be empowered, take control of their lives and advocate for themselves. Making informed choices about health care becomes difficult and we make people over reliant on carers or others in their lives, when maybe with a bit more effort into accessible information the person could make some decisions for themselves.

CONCLUDING REMARKS

As an organisation we are working hard to ensure that people's human rights are upheld both within our own organisation and when people with disabilities come into contact with primary and secondary care. We have focussed in this paper on giving evidence in relation to health care as opposed to any of the other areas the committee indicated they would be looking at as these issues are upper most in our minds at the moment.

After talking to clients, family members and clinicians throughout this information gathering process there were a number of key themes that came through as needing a lot more than just local intervention. Needing organised national scrutiny, direction and guidance. These areas were:

- In order to ensure peoples right to good health and the identification of health problems there needs to be an incentivised national campaign. Ideally having annual health screening checks as a national enhanced service which would be in line with other UK countries.
- Further guidance for PCT's is required around the rights of people with learning disabilities and continuing care and the fact that all citizens have the right to be assessed for eligibility irrespective of their diagnosis
- Investment in education and support to primary and secondary care colleagues is required regarding learning disabilities, human rights and consent to treatment / best practice. Some of this education needs to be embedded in professional's basic training rather than it be an "optional" subject in many cases. Relying solely on the mental capacity act would be a mistake. There needs to be a clear role out programme and significant investment in building competencies within clinicians and care staff in order to implement the act properly.
- Higher National investment in accessible information and advocacy services with electronic connections for leaflets etc is essential
- Transition from children's to adult services both in terms of more appropriate planning and investment in adult services to be able to meet the needs of young people who are increasingly more technology dependant in ordinary settings (work placements, colleges etc). Without significant investment here young people will be unable to access the ordinary lives we all take for granted.

1 May 2007

Memorandum from Scope

Scope welcomes this opportunity to submit written evidence to the Joint Committee on Human Rights, regarding the rights of adults with learning difficulties. And commends the Committee for investigating such an important issue.

The short timescale for responses has meant that we were unable to consult with people with learning difficulties directly on the issues outlined in the investigation. However, we have drawn on evidence that we have gathered from previous consultation work on a range of subject areas which illustrate some of the key situations in which people with learning difficulties experience abuse of their Human Rights. We have also included evidence gathered by other organisations including independent advocacy schemes and Disability Awareness in Action (DAA) as these organisations felt they were not able to respond individually within the allotted timescale.

We would like to take this opportunity to remind the Committee that consulting with people with learning difficulties, many of whom also have other impairments, takes time and that it is essential for investigations of this type to allow adequate time to engage with people and enable them to contribute their views and experiences in an accessible way.

SCOPE

Scope's mission is to drive the change to make our society the first where disabled people achieve full equality. We will know that this is achieved when:

- disablism is banished;
- all disabled people of all ages and their families enjoy their full and equal human and civil rights; and
- all disabled people are able to exercise full personal choice and control, with the right support, over their own lives.

By the term “disablism” we refer to any discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others. Scope's mission underpins all our work and all the activities included in Scope's Time to Get Equal campaign.

Scope has a particular focus on people with cerebral palsy. Many of the disabled people we support through Scope's information, employment, education and residential and day services have cerebral palsy and a significant number have multiple impairments and high levels of support need.

Cerebral palsy is a physical impairment ostensibly affecting coordination and movement. People with cerebral palsy frequently have multiple impairments often including a learning difficulty. Research suggests that one in every four people who have cerebral palsy also have a learning difficulty [1].

People with multiple impairments including a learning difficulty

Traditional and ongoing approaches to service provision that segregate disabled people according to impairment have led to systems and services which negate the needs of, and are largely inaccessible to, disabled people who have multiple impairments. Specific programmes and strategies aimed at people with learning difficulties tend to assume that people with learning difficulties have no other impairments while services aimed at people with physical impairments often do not take a person's learning difficulties into consideration. Scope would welcome an approach to protecting the Human Rights of people with learning difficulties which recognises that a significant minority of people with learning difficulties also have other, often multiple, impairments and that this changes their support needs and experiences.

Disabled people have also told us that non-disabled people often make assumptions about whether they have learning difficulties based on their appearance, speech or lack of speech. Assumptions by service providers, employers, members of the public and statutory bodies about an individual's mental capacity frequently result in discrimination and exclusion. We therefore feel it is important that the Committee considers the impact of discrimination on disabled people who are perceived to have learning difficulties.

Scope is aware of a significant number of examples where the Human Rights of people with learning difficulties have been infringed. Some of these examples are from our own contacts, some have been provided by independent advocacy schemes that we work closely with. Others have come from Disability Awareness in Action a disabled people's organisation that monitor violations of disabled people's Human Rights.

Human Rights Act, 1998

Schedule 1—Article 2—Rights and Freedoms—Right to life

Case study 1

A student with cerebral palsy and learning difficulties at one of Scope's residential schools was recently admitted to hospital for 3 days during the school holidays. The student returned directly to school from hospital and when staff collected him it was noticeable that he had lost a significant amount of weight. The student stated that he had not been given any food to eat during his three day stay. When challenged the hospital responded by stating that they did not know how to feed him.

Source: Scope

Case study 2

A disabled young man, aged 21 years with learning difficulties who attends one of Scope's educational establishments was admitted to hospital for pneumonia, his parents were contacted and they arrived at the hospital four hours later. When his parents arrived they observed that their son had not been given any oxygen for his pneumonia and "Do not resuscitate" had been written on his notes. A formal letter of complaint was written to the hospital, which was responded to 18 months later, by which time the registrar who treated their son was no longer working at the hospital. No further action was taken.

Source: Scope

These two incidents happened recently and underline the continuing discriminatory attitudes of medical professionals towards disabled people. DAA has many further examples of abuse of disabled people's Human Rights in relation to medical treatment both for routine illnesses as well as life-threatening health issues.

A number of disabled people that we have spoken to have told us that they fear having to go to hospital and some are reluctant to seek medical advice or treatment because they do not believe they will be given equal treatment. Scope would welcome robust Disability Equality Training, with a strong focus on the Social Model of disability aimed at all medical and health professionals as part of their basic training. Compulsory training on the duties of statutory service providers under the Mental Capacity Act should also be introduced and decisions made by medical professionals regularly reviewed in order to prevent discrimination. This is particularly important in relation to life and death decisions as disabled people are often treated as though their lives are less valuable, or in extreme cases, with the view that dying would be in their best interests.

Scope would also like to see specific legal safeguards introduced to protect disabled people from abuse in hospital, including having "do not resuscitate" and "do not intubate" orders added to their medical notes without their express consent and failure to administer treatment or basic care that would automatically be given to a non-disabled person. We believe there should be a duty to investigate any accusation of this kind and significant penalties should be attached to this type of offence.

HUMAN RIGHTS ACT, 1998

Schedule 1—Article 3—Prohibition of torture

Scope has a number of relationships with smaller disability groups who share information, disabled people's experiences and expertise with Scope. One of these relationships is with Disability Awareness in Action (DAA) who, between 1992 and 2006, recorded 179 cases of degrading treatment affecting 507 people with learning difficulties and 536 people with multiple impairments.

Case study 3

A man with physical impairments and learning difficulties was left in a car all afternoon during a summer heat wave by his carer. He had no water and was unable to get out by himself. Police said no crime was committed because, since he was not actually locked in, he was not "falsely imprisoned".

Source: DAA

Case study 4

A 38 year-old, disabled woman living with a family friend was used as an unpaid servant, nanny and hired out to others for £2.00 a day. She sometimes had to sleep on the floor and had her benefits taken away from her.

Source: DAA

Case study 5

Service users at a local authority residential home reported degrading and inhuman treatment, this included tying service users to chairs, administering inappropriate medication and being left in excrement.

Source: DAA

Case study 6

In 2006 Ryan Davies, a boy of 12 years was killed by his mother who enticed him to fly off the Humber Bridge before killing herself. Her family stated that she felt like a prisoner in her own home owing to the demands of caring for her son.

Source: <http://news.bbc.co.uk/1/hi/england/humber/4783517.stm>

The degrading treatment experienced by disabled people with learning difficulties is of grave concern to Scope.

Scope would like to see proportionate penalties for people who abuse or assault disabled people, especially those who are employed to provide support or assistance, and therefore have a duty of care towards them. More accessible complaint and whistle-blowing mechanisms should also be introduced to enable people with learning difficulties to report and stop abuse. Compulsory disability equality training for support worker and care staff would also help to tackle the disablist views and low-expectations that can lead to this kind of treatment.

Ongoing support and training for parents and carers is also essential. According to Mencap 7 out of 10 families provide more than 15 hours of care every day, and 5 out of 10 provide care during the night [2].

More opportunities to live independently and control the support and services, people with learning difficulties receive and less reliance on unpaid family members to provide support is essential to ensure that disabled people receive the same choices and control over their lives that non-disabled people have and reduce the stress on the family unit. It is also estimated that an additional 3.5 million carers will be needed by 2037 if the current trends towards relying on informal care continues. [3]

It is our belief that degrading treatment can be reduced by ensuring that all disabled people have access to the right support to enable them to participate fully in society, and by doing so mix with non-disabled people, and contribute to breaking down the attitudinal barriers prevalent within society. Scope is currently campaigning for an end to the segregation of disabled people whilst promoting the valuable contribution disabled people make to society.

HUMAN RIGHTS ACT, 1998

Schedule 1—Article 5—Right to Liberty and Security and Article 6—Right To A Fair Trial

Disabled people have a right to feel safe in their communities. The Home Office found that 40% of people with a Limiting Long-Term Illness perceive crime to have risen “a lot” more in the past two years. This compares to just 27% of non-disabled people [4]. Evidence produced by other organisations supports the view that people with learning difficulties and those with multiple impairments have a greater fear of crime than non-disabled people. This could be related to feeling more vulnerable than other people or because more disabled people experience verbal and physical abuse or other forms of crime.

Currently statistics are not gathered on the incidences of disablist hate crimes. Scope would welcome the collection of these statistics; particularly as disabled people’s fear of crime is double that of non-disabled people [5] As part of the Duty to Promote Disabled People’s equality under the Disability Discrimination Act 2005 Scope would like to see police forces taking proactive steps to improve contact with the disabled community and work with disabled people to address key areas of concern. Scope would also welcome due punishment for disablist hate crimes that equates it with racist and homophobic crime.

Case study 7

A man with a learning disability was walking home with another physically disabled person when they were set on by a gang of youths and hit to such an extent that they required stitches.

Source: DAA

A young man with multiple impairments who used a wheelchair and a communication aid was attacked by a man who hit him and smashed his communication aid.

Source: Scope

Scope are also concerned about the treatment of disabled people in the prison and criminal justice system, this includes the support mechanisms during trial for criminal offences. Only 21% of disabled people are confident that the criminal justice system is effective at dealing with young people accused of crime and 48% believe that witnesses are not treated well.

Scope would urge the criminal justice system to adopt the Social Model of disability, to ensure that all information about processes are fully accessible, acknowledging the barriers faced by disabled people and making reasonable adjustments where appropriate so disabled people with learning difficulties and multiple impairments can be treated fairly in the criminal justice system. Scope would encourage greater levels of support to reduce the incidence of disabled people’s testimony being disregarded as unreliable by the court. This could be achieved through advocacy and disability equality training for professionals involved to enable disabled people to give evidence and seek redress when they are victims of crime.

Case study 8

A grandmother, who is a primary carer of a child with learning difficulties/disabilities and no speech, put her grandson into respite care. When she collected him he was beaten and bruised. Although the doctor verified the bruising etc the CPS would not allow the case to go through as he could not give evidence himself.

Source: DAA

Case study 9

A 30 year-old man with multiple impairments drowned in a Jacuzzi bath when he was left unattended by the two care staff responsible for him. An inquest decided that neglect contributed to his death but the Crown Prosecution Service is not prosecuting.

Source: DAA

The review by the Prison Reform Trust [6] demonstrated that between 20-30% of offenders have learning difficulties and learning disabilities that interfere with their ability to cope within the criminal justice system. The same report found that prisoners with learning difficulties and learning disabilities this has grave consequences. They are unlikely to receive adequate levels of support which makes it more likely that this group will return to prison again and again.

HUMAN RIGHTS ACT, 1998

Schedule 1—Article 8—Right to respect for private and family life

Many disabled children with learning difficulties and multiple impairments are denied their right to a family life because they are required to live away from home in order to go to school. Disabled adults are often forced to live in segregated residential settings because there is inadequate support to live independently in their local area. Scope believe that the numbers of disabled children and adults who have to live in segregated environments, should be reduced, and inclusive education and independent living options should be increased to enable people to live as part of their community.

Disabled people with learning difficulties have raised concerns regarding their right to privacy. This is particularly an issue for many disabled people in residential environments such as young people in residential special education and adults in residential services. The disabled people we have consulted have expressed that the attitudes of staff, personal assistants, their family and the general public often constrain their ability to form relationships and have time to themselves in private. Particular concerns included not being able to shut or lock their doors, having staff or support workers walk into their private space without asking permission, not being left alone or not being able to talk privately with friends. Being patronised and treated like a child were also common complaints.

Many disabled people with learning difficulties also feel dependent on personal assistants and their family to travel within their local communities, and feel socially excluded because they are often not given the same opportunities to meet new people and establish relationships as non-disabled people would.

Scope's Beaumont College caters for students with complex impairments, nearly all the students at Beaumont have a learning difficulty. When Scope consulted with students the young people told us that general practitioners often assume they cannot attend a medical appointment without either a parent or a personal assistant. This is compounded by the fact that inaccessible transport means disabled people rely on others to provide accessible transportation. The attitudes of support staff and parents often mean that disabled people feel they have no option but to discuss their intimate health issues with their doctor and personal assistant/parent. This can prevent disabled people discussing important health issues whilst enhancing the already prevalent inequalities in the healthcare system.

People with learning difficulties and physical impairments have told us that they would like better access to information and said that things are often not communicated to them in accessible ways. The young people we spoke to said they wanted more accessible information in formats that were aimed at young people. They felt that lots of the information they received perpetuated the negative stereotypes of disabled people's roles in society. Accessible information is vital to enabling people with learning difficulties to get information for themselves, be less dependent on others and have more privacy.

Regulating for privacy is difficult but Scope feels that a requirement on residential schools and residential care providers to have a privacy policy or charter for service users would help emphasise the need to respect disabled people's privacy. It would also help service users to challenge members of staff when they feel their privacy is not being respected. This type of charter or agreement could also be used by people with learning difficulties and multiple impairments when they are with their family or in other environments to help them ensure their privacy and right to express their own opinion is observed.

 HUMAN RIGHTS ACT, 1998
Schedule 1—Article 10—Freedom of Expression

Many of the disabled people Scope is in contact with have difficulty expressing their views and opinions. For people without speech it is often a lack of equipment or support to use the equipment, that restricts their freedom of expression; for many disabled people a lack of respect for their point of view or inadequate support to express that point of view is the major barrier.

Scope is extremely concerned that disabled people with learning difficulties and a communication impairment are not currently able to convey their needs, wishes, thoughts and feelings because they cannot get the equipment they require to communicate. Lack of access to a communication aid severely limits the life chances of disabled people without speech and makes them dependent, frustrated and vulnerable to abuse. Scope believes that the fact that thousands of disabled people do not have access to appropriate equipment to communicate is in breach of Article 10 and a statutory duty to provide appropriate communication aids and support is needed as a matter of urgency.

Scope has a huge number of case studies that demonstrate the valuable role an independent advocate can play in supporting a person to take control of their life and communicate their wishes and opinions.

Case study 10

Mary has learning difficulties and physical impairments. She has no speech and communicates through body movements and emotional displays. Recently she has displayed distressful behaviour when the residents of the residential homes are given their morning and afternoon drinks at set times.

An advocate attempted to find out why Mary is becoming distressed. With no formal communication method available, the advocate uses a series of pictures depicting drinks, other people in the house etc to attempt to ascertain if Mary has any views about what she is being offered and when and how. The advocate also uses the containers used in the house for different drinks. Over a period of time the advocate is reasonably certain that Mary did not like the drink she was being offered. The advocate was able to ask a number of questions regarding the “choice” Mary had in when and what she drank. The service was able to accommodate a system where Mary was offered a choice of drinks on an on-going basis.

Source: Scope

The case study above demonstrates the positive impact of giving Mary choice and control over what happens to her. Access to independent advocacy, communication aids and appropriate support are vital to ensure that all disabled people with multiple impairments have choice and control over the day to day decisions that non-disabled people take for granted. Most aspects of daily life involve simple choices like what to eat and drink or when to go to bed. Having the opportunity and support to make simple choices can make a huge difference to people with learning difficulties’ quality of life. Independent advocates frequently find that a person’s challenging behaviour is the only way someone can express the frustration they feel at being denied choice and control.

Scope would encourage the Government to strengthen their recognition of independent advocacy as a vital vehicle for enabling disabled people, especially those with learning difficulties and multiple impairments, to have choice and control over their lives, and to commit to adequately resourcing and building capacity for this service. Advocacy provision is patchy across the UK and non-existent in some areas. This situation is getting worse as many advocacy schemes are threatened with closure as local authorities withdraw funding.

Scope welcomed the Mental Capacity Act which created an assumption of capacity unless proved otherwise and puts a duty on statutory service providers to support people to make their own decisions. It also gives some people the right to an Independent Mental Capacity Advocate (IMCA).

We remain concerned that individuals only get access to an IMCA for life-changing decisions on health and living arrangements and only then if people have no family or friends to represent their wishes. We believe that widespread access to non-instructed independent advocacy is vital to protecting the rights of people who lack mental capacity in a much wider variety of situations.

Scope are also concerned about the conflict between Care Standards which have a strong focus on safety, prevention of accidents and mitigating risk and the MCA which emphasises the right to make your own decisions, including the right to make unwise decisions and take risks. Scope would welcome clear and comprehensive guidance on how disabled people’s services should balance the duties imposed by the Mental Capacity Act and Care Standards to ensure health and safety and risk do not restrict an individual’s right to make and act on their own decisions.

HUMAN RIGHTS ACT, 1998

Schedule 1—Article 12—Right to marry

When disabled people do form relationships they can face considerable opposition, this is particularly the case for disabled people living in residential settings. Few residential services provide accommodation for couples and it is still not uncommon for older married couples who move into residential care to be separated from each other.

In some care homes relationships are completely banned whilst others assume that all disabled people are asexual. For disabled people who identify as homosexual the opportunity to express their sexuality or have a same-sex relationship can be even more difficult. People with a learning difficulty are often prevented from entering into a relationship because others believe they are unable to make an informed choice. Having the appropriate support to make these kinds of personal decisions is vital to ensure a person's rights and choices are not restricted.

Case study 11

Jane is in her 30s and has learning difficulties. She lives with both her parents in a small community. She attends local authority day services on a number of days in the week. Over a period of time she has become emotionally and sexually attracted to another person at the centre. The feelings are returned and they have formed a close relationship. They have known each other for some considerable period of time. Jane expressed her thoughts to both her social worker and personal assistants. An advocate was called in to support Jane in thinking through the consequences of her wishes, which were to live with her boyfriend in supported accommodation. Jane's parents were adamant that Jane did not understand what she wanted and that she should remain living at home and not get further involved with the boyfriend. After a number of sessions the advocate confirmed the consistency of Jane's views. The advocate represented them to the parents. The parents would not condone Jane leaving home and applied a great deal of pressure on Jane to "change her mind". This case ended with Jane remaining at home.

Source: Scope

As well as being denied the opportunity to meet new people and establish or sustain existing relationships disabled people who do form relationships, particular those who have multiple impairments including a learning difficulty may be likely to have high support needs and may require facilitation to have sexual intercourse. Many disabled people would argue that this should be a right. Though this has implications for the rights of the people supporting them too it is rarely discussed.

Scope would like to see comprehensive sex education included in all special schools that acknowledges that disabled people have a sexuality. This would reduce ignorance around sexual health and reduce the likelihood of sexually transmitted diseases and unwanted pregnancy. Scope would also be keen for further guidance to be issued on this issue for all care homes regarding the development of and sustainability of relationships in addition to a comprehensive sexuality policy.

HUMAN RIGHTS ACT, 1998

Schedule 1—Article 14—Prohibition of discrimination

People with learning difficulties and multiple impairments encounter discrimination in many aspects of their lives. Much of it is based on the belief that they are inferior to others and that they deserve to have fewer rights and opportunities than non-disabled people. The Disability Discrimination Acts 1995 and 2005 prohibit discrimination against disabled people in a wide range of situations and the Disability Equality Duty has recently introduced a duty to actively promote equality for disabled people. Although this is positive it is very difficult to get redress for discrimination prohibited by the DDA and the few cases and low levels of compensation or damages do not serve as a deterrent. Scope would recommend that the DDA enforcement mechanisms are strengthened to make it easier and much less expensive for disabled people to get redress through the courts and tribunals systems for the discrimination they experience.

Where disabled people live

The DRC published a discussion paper on Independent Living in 2006 [7] which states that there is no statutory right to live in your own home rather than institutional care. This is a gap in the existing Human Rights legislation that Scope would like to see filled through adequate and enforceable legislation to ensure that disabled people have choice and control over where they live and with whom.

Disabled people should not be forced into institutional care due to a lack of accessible housing or inflexible Local Authority funding streams. As the recent ODI research [8] indicates, independent living options are not only better for the individual but could also be cheaper than institutional care.

People with learning difficulties are often denied the opportunity to use direct payments because their social worker does not feel they are capable of managing them. The Individual Budgets pilots are helping to expand opportunities for people with learning difficulties and high support needs to control their own money and support but as yet these are not widely available. It is vital that these pilots consider a variety of options to enable people with learning difficulties to have choice and control over the services they receive with appropriate support to manage their money.

The Disabled People's (Independent Living Bill) [9] is a Private Member's Bill sponsored by Lord Ashley of Stoke and Roger Berry MP which calls for a statutory right to independent living. Scope fully supports this Bill which we believe would make a huge difference to disabled people's opportunities to exercise maximum choice and control over their lives.

Scope is deeply concerned by the implications of the Leonard Cheshire case in which a court ruled that residential services for disabled people which take private fee paying clients do not fall under the remit of the Human Rights Act. This ruling means that disabled people living in residential settings do not have equal human rights. Scope would like to see this judgement challenged and legislation clarified to guarantee the protection of disabled people's Human Rights protected regardless of where they live. [10]

Segregation in education

Scope believe that the numbers of disabled children who are educated in segregated environments, particularly segregated environments that mean children have to live away from home should be reduced, and the number of inclusive mainstream places in all levels of education increased correspondingly so that families retain their right to family life. Not only do out of authority placements cost English Local Education Authorities around £500 million each year [11], but inclusive schooling provides greater opportunity for social integration, the breaking down of social barriers and reduces the likelihood of a child having to live away from their family and wider community. A recent Scope study revealed that 60% of parents of disabled children had no choice of school for their child[12] and some parents have to resort to SENDIST tribunals to get their choice of school.

Scope is concerned that the numbers of Further and Higher Education places for young people with high support needs are currently very limited, both within specialist and inclusive provision. At Scope's Beaumont Further Education college alone there are four applications for every place available. In Wales there are no specialist or mainstream colleges which accept students with complex or high support needs; this means that young disabled people with a combination of physical impairments and learning difficulties are denied opportunities to gain skills and qualifications, limiting young disabled people's opportunities to gain employment or move onto independent living.

Parents and disabled children should have a choice of adequately resourced mainstream schools and not be restricted to special schools because local schools are not accessible or not appropriately resourced to accept disabled children. This includes disabled children with high support needs.

To try and achieve this vision Scope is currently working towards co-locating our FE College on a mainstream University campus to enable our students to access mainstream social opportunities and take advantage of aspects of the University curriculum. We believe that this is the first step towards including students with high levels of support need and learning difficulties into mainstream education and we are currently consulting with our students and the University about how to best achieve this.

Poverty

The poverty faced by many disabled people is frequently overlooked. At 30%, the poverty rate for disabled adults is twice that for non-disabled adults, a difference markedly higher than a decade ago. This disparity is compounded by the fact that disabled people often have increased living costs compared with non-disabled people. Scope would like to see the the same level of effort put into eradicating disabled people's poverty as has been targeted at child poverty which the Labour Government has pledged to halve by 2010.

Employment and Income

In the UK, the employment rate of disabled people has risen from 30% to 50% in ten years. Although this is a significant improvement, the employment rate for the rest of the working age population is nearly 80%, so there remains a gap of 30%.

The income of disabled people is, on average, less than half that of non-disabled people and disabled people tend to be in low-paid, low-skilled jobs. Even after direct taxes and benefit payments are accounted for, disabled people still earn 30% less than non-disabled people. [13]. According to Mencap 90% of people with learning difficulties are not in employment [14].

Scope would welcome an increase in positive action by employers, such as the reserved posts policy adopted by Scope which positively discriminates in favour of disabled applicants, as well as the introduction of further incentives to tackle negative attitudes of employers towards employing, investing in and promoting disabled staff.

Appropriate support to develop skills and qualifications, find suitable work and move off benefits through investment in Pathways to Work and Workstep, especially for those disabled people furthest from work, is vital.

Voting

Many people with learning difficulties are denied their right to vote, often based on unsubstantiated claims that they do not have the capacity. In 2005 Scope's Polls Apart campaign assessed the accessibility of the voting process for people with learning difficulties. The results [15] showed that only 56% of respondents said that the information provided on the voting process was easy to read, with 49% of voters saying that the polling station would be inaccessible to a voter with learning difficulties. The following is a quote from a person with a learning difficulty who completed a Polls Apart campaign survey:

"I can't read the voting paper so I asked the man to point to the name of the person I wanted to vote for but he refused. I really wanted to vote so I put a cross in the top box, I don't know who I voted for." *Bedfordshire South West [16]*.

In 2001 in Oxfordshire a group of Scope service users were turned away from their polling station because the Presiding Officer decided that they were not capable of voting. Such arbitrary judgements of capacity are a common occurrence for people with complex impairments. We also have anecdotal evidence of people with learning difficulties in residential settings having their postal votes thrown away or not being told when their voter registration form arrives because staff thought that the service users were not capable of voting.

Such examples are unfortunately not uncommon and until recently electoral law contained a reference to case law that barred 'lunatics and idiots' from voting. Scope has been working with the Electoral Commission and the Ministry of Justice (formally Department of Constitutional Affairs) to clarify how capacity is measured and who has the right to deny people their right to vote. We have also been involved in evaluating e-voting pilots to advance progress towards a multi-channel voting system that will give disabled people a wider choice of voting methods and information formats.

Ashley X

Scope has serious concerns about a recent case in the United States where a girl with significant learning difficulties and physical impairments was subjected to highly invasive surgical interventions to prevent her growing into an adult.

Nine year old Ashley X was given a hysterectomy to prevent menstruation, had her breast buds removed and was given doses of hormones to stop her growing taller. It appears that doctors and the child's parents acted unlawfully by not seeking approval from a court for this intervention yet to date no legal action has been taken against any of the parties involved.

Scope is highly concerned that without tighter legal safeguards interventions similar to that inflicted on Ashley X case have the potential to occur in Britain. Letter to newspapers and comments from revealed that many members of the public felt this type of intervention was acceptable because Ashley was so disabled. The argument put forward by her parents, that if she stayed small it would be easier for them to care for her, is particularly worrying as this suggests that disabled people should be physically altered to make it more convenient for others. Encouragingly, however 82 signed Early Day Motion 792 condemning the intervention [17].

That people believe this drastic and degrading action is necessary not only exposes the continuing prejudice against disabled people, but also highlights the everyday struggle that their families face. As a result of social barriers, prejudices and inadequate service provision, these families suffer from the financial hardship, stress and anxiety that can lead to such extreme decisions.

Scope believes that there must be a legal requirement to seek a court judgement where any invasive or irreversible procedures or therapies are being considered for a disabled person who cannot consent. This is especially important if, like in the case of Ashley X, the intervention is not to treat a diagnosed medical condition or illness. We also believe every individual in this situation should have an independent advocate who will act in the best interests of the disabled person to prevent a breach of the human rights of disabled children, young people and adults.

UN Convention

Scope strongly supports the UN Convention on the Rights of People with Disabilities and is calling on the Government to ratify this, including the optional protocol, without delay.

The Convention is significant not just because of its scope and the fact that it was negotiated, in record time, with disabled people themselves from all over the world, but because it provides written proof that disabled people are human and have the right to be treated as such.

The Convention will have a major effect on the lives of 11 million disabled people in the UK and we hope it will mark a step change in how we perceive and treat disabled people. This Convention is long overdue and is needed for it is more urgent than ever in light of the widespread abuse of disabled people's human rights, as highlighted in this submission. Scope will be monitoring the UK's compliance with the Convention and working with disabled people in the UK and internationally to ensure the comprehensive rights laid out in the Convention are realised.

CONCLUSION

People with learning difficulties and multiple impairments face considerable discrimination and disadvantage in our society and regularly have their human rights infringed. To address this Scope would recommend taking action on the following:

- Provide access to independent advocacy to enable people with learning difficulties to make their own choices and decisions.
- Establish a right not to live in residential care or long stay institutions, but to receive appropriate support to live independently in the setting of their choice.
- Provide the necessary support and resources provided to ensure that choice and control for independent living for people with learning difficulties are in place, enabling more disabled people to manage direct payments and individual budgets.
- Strictly enforce the Mental Capacity Act, particularly in residential institutions, to ensure disabled people are supported to make their own decision and act on them. Comprehensive guidance is also needed on the compatibility of the MCA with the duties in the Care Standards Act.
- Ratify the UN Convention on the rights of person's with disabilities, including the optional protocol, without delay.
- Ensure thorough and appropriate recording mechanisms and appropriate punishment for disablist hate crimes.
- Establish tighter legal safeguards to prevent discriminatory or neglectful medical interventions and proportionate punishments for medical professionals who deliberately endanger the lives of disabled people in their care.
- Establish an equal rights to a non-segregated education in your own community, including the right not to go to a segregated school.
- Introduction a comprehensive and non-discriminatory sexuality policy in all residential care settings, including schools.
- Establish a statutory right to receive appropriate equipment to enable someone without speech to communicate and ongoing support to use it.
- Include mandatory Disability Equality Training for medical professionals and social care staff and teachers as part of their basic training.
- Develop a voting system that maximises the opportunities for disabled people to vote independently and in secret.
- Strengthen the enforcement mechanisms in the Disability Discrimination Act to make it easier and cheaper for disabled people to get redress for discrimination.

Thank you for taking the time to read Scope's written evidence. Scope would welcome the opportunity to give oral evidence to the Committee to expand further on issues affecting the Human Rights of people with multiple impairments including a learning difficulty. We would also be very pleased to support some of the people with learning difficulties and multiple impairments that we work with to give evidence to the Committee about their personal experiences. If you have any further questions please do not hesitate to contact us.

References

- [1] Parkes, J Donnelly, M &, Hill, N (2001) *Focusing on Cerebral Palsy: Reviewing and Communicating Needs for Services*, London, Scope.
- [2] <http://www.mencap.org.uk/download/campaigns/breakingpoint/national—report.pdf>
- [3] <http://www.eoc.org.uk/Default.aspx?page=15440£xxx—endnotereference12>
- [4] <http://www.homeoffice.gov.uk/rds/pdfs06/hosb1206chap123.pdf>
- [5] <http://www.homeoffice.gov.uk/rds/pdfs06/hosb1206chap123.pdf>
- [6] <http://www.prisonreformtrust.org.uk/temp/NospOnespKknowsspPreliminarysPreport2.pdf>
- [7] <http://www.drc-gb.org/library/publications/health—and—independent—living/independent—living—>

discussion.aspx

[8] <http://www.officefordisability.gov.uk/publications/>

[9] <http://www.publications.parliament.uk/pa/pabills/200607/disabled—persons—-independent—living.htm>

[10] <http://www.nhsla.com/NR/rdoonlyres/5DF96DF6-1544-4486-9D67-395774EDD9F6/0/nhslareviewissue30.pdf>

[11] National Audit Commission (2007), *Out of Authority Placements for Special Educational needs*, London: NAO.

[12] Wooster, E Parnell, R, (2006), *Fighting All The Way: parents' experiences of choosing a school for their disabled child*, London, Scope.

[13] <http://www.cabinetoffice.gov.uk/strategy/downloads/work—areas/disability/disability—report/pdf/disability.pdf>

[14] <http://www.mencap.org.uk/html/campaigns/employment—index.aspx#1>

[15] <http://www.pollsapart.org.uk/>

[16] <http://www.pollsapart.org.uk/2005/docs/Polls%20Apart%20report%20final.pdf>

[17] <http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID = 32489&SESSION = 885>

1 May 2007

Memorandum from The Judith Trust

Our evidence to the Joint Committee on Human Rights concerns Article 8 of the European Convention on Human Rights, the right to respect to private life, with specific reference to the European Court of Human Rights' interpretation of this article as including a right to participate in the life of one's local community. We would also wish to reference the Convention on the Rights of Persons with Disabilities that states that disabled persons have equal access to human rights—their rights are in no sense diminished because of any disability.

The Judith Trust is a small organisation that works to improve the quality of life for people with both a learning disability and mental health needs. The Trust supports multi-disciplinary, preventative and innovative approaches. It pays particular attention to the needs of women and Jewish people.

In October 2003 the Trust commissioned research that looked at the importance of being Jewish to people with learning disabilities and their families. This research found that being Jewish was very important to this group and that they derived a great deal of satisfaction from being able to participate fully in their community. However, the research also found that this was often difficult—barriers were placed in the way and the promotion of inclusion was usually not a high priority.

The Judith Trust heard stories from parents whose children had been refused a bar- (or a bat-) mitzvah within their own congregation: an important life event for Jewish people. This refusal is often borne from ignorance about learning disability, as well as a lack of accessible learning materials that would help individuals reach the appropriate and required levels of understanding. Partly it may be based on interpretation of biblical statements that may be read differently and in more enabling ways and there are examples of good inclusive practice by various synagogues.

The research also found a great deal of stigma attached to having a child with a learning disability within the Jewish community, which led parents to feel isolated and ashamed of and for their children, and adults with learning disabilities to become alienated from the community. People felt there was a general lack of tolerance from within the community.

The main barriers to people accessing this very important right to participate fully in their community range from a 'benign' lack of understand of people with learning disabilities to more worrying abuse of rights such as intolerance and discrimination. It is compounded further by a lack of accessible resources.

The Judith Trust would like to see more effort made the UK government to ensure that people with a learning disability are able to participate in the spiritual life of their chosen community. This would involve a greater effort to stamp out intolerance and discrimination of people with learning disability, with particular attention paid to communities that might be more prone to discrimination for cultural reasons.

The Trust expects the UK government to make greater efforts to ensure that religious organisations are fully informed of the priority it places on equality for all. The Trust also draws attention to the fact that power relations within faith communities are also often unequal with girls and women less valued and not able to participate fully and equally with men in their communities. This, too, should not be left unquestioned in the noble attempt to achieve a society free of such inequality or abuse of human rights.

Such efforts on the part of government should form an ordinary part of the work of the new Commission for Equality and Human Rights which must seek to formulate policies to promote equality across the 6 strands. The Trust is concerned that religious faiths are encouraged to think through the meaning of equality within their communities as well as working to establish their own status vis a vis the other five strands and the wider society at large.

May 2007

Memorandum from Disability Action

1. INTRODUCTION

1.1 Disability Action is a pioneering Northern Ireland charity, working with and for people with disabilities. We work with our members to provide information, training, transport, awareness programmes and representation for people regardless of their disability; whether that is a physical, mental, sensory, hidden or learning disability.

1.2 More than one in five (300,000) people in Northern Ireland has a disability and the incidence is higher here than in the rest of the United Kingdom. Over one quarter of all families here are affected. As a campaigning body, we work to bring about positive change to the social, economic and cultural life of people with disabilities and consequently our entire community.

1.3 Our network of services is provided via our Headquarters in Belfast and three regional offices in Carrickfergus, Derry and Dungannon.

1.4 Disability Action has recently established a Centre on Human Rights for Disabled People. The Centre aims to secure the human rights of people with disabilities in Northern Ireland and to foster a culture of human rights for disabled people through education and capacity building within the sector, and the judicious use of lobbying, influencing and legal challenge.

1.5 The main elements of the Centre's work is to:

- Create and sustain a sectoral coalition of human rights expertise on disability.
- Identify and deliver key campaigns to ensure the abuse of disabled people is recognised and accepted as a mainstream human rights issue.
- Develop and ensure the delivery of an effective system of accessible legal redress.
- Deliver key policy changes which promote the human rights of people with disabilities.
- Develop and mainstream a system of human rights proofing which includes disability issues and to report on the extent to which existing protection systems recognize the human rights abuses faced by disabled people.

1.6 The Centre on Human Rights at Disability Action commends the decision of the Committee to inquire into the human rights of adults with learning disabilities. We welcome the opportunity to submit evidence in the hope that the specific circumstances and human rights abuses experienced by people with learning disabilities in Northern Ireland will be urgently addressed.

1.7 An estimated 2% of the Northern Ireland population has some form of learning disability. This is over 33,000 people. Of these 8,000 have a diagnosed learning disability and almost 4,000 have a severe or profound learning disability.

1.8 The number of adults with an identified learning disability is higher in Northern Ireland (9.71 per 1,000) than the Republic of Ireland. It is also higher than parts of Great Britain such as Scotland where an estimated 5.45 per 1,000 are in regular contact with services.⁵

1.9 People with learning disabilities are, first and foremost, equal citizens who possess the same rights as the rest of the population and whose lives are of equal value and worth to non-disabled people.

1.10 Apart from the recent Review on Mental Health and Learning Disability (Northern Ireland), the human rights of people with learning disabilities in Northern Ireland has received inadequate attention.

1.11 The Centre on Human Rights has identified a number of pertinent issues impacting on the human rights of people with learning disabilities. The evidence contained within this submission is concerned with, and draws upon, the experiences of people with learning disabilities living in Northern Ireland.

1.12 The Centre ultimately believes that much more needs to be done to ensure that the human rights of people with learning disabilities in Northern Ireland are actively protected and promoted.

⁵ McConkey, R, Mulvany, F and Barron, S (2006) *Adult persons with an intellectual disability on the island of Ireland* in the Journal of Intellectual Disability Research.

2. GENERAL COMMENTARY

Human Rights Infrastructure in Northern Ireland

2.1 The context of equality, human rights and policymaking in Northern Ireland has been distinctive and made complicated by the “power relay” that has manifested itself in the ongoing struggle between Direct Rule by Westminster and devolved government via the Northern Ireland Assembly. Northern Ireland’s capacity for policy-making, self-government and addressing of social and economic concerns, has thus been constrained by wider constitutional questions.

2.2 The most significant example of policy divergence between Northern Ireland and Great Britain has been the implementation of *Section 75* of the 1998 *Northern Ireland Act*.

2.3 Section 75 clearly outlined a policy-making process based on a participatory form of democracy and ensured the implementation of the first positive equality duty in the UK. The Section 75 statutory duty requires public authorities throughout Northern Ireland to have due regard to promote equality of opportunity between nine different groups, including people with disabilities, through the mainstreaming of policy processes.

These nine groups include:

- persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- men and women generally (including transgendered people);
- persons with a disability and persons without; and
- persons with dependants and persons without.

2.4 As such, Northern Ireland has a relatively strong record of progress and development in the field of equality. Such progress has however, been less evident in relation to disability specifically, “*encumbered by the government’s focus on socio-economic inequalities between the Catholic and Protestant populations*”.⁶

2.5 Disability has, until fairly recently, been an overlooked or “forgotten” dimension of human rights.⁷ Despite the existence of various human rights instruments at regional, European and international levels, people with learning disabilities continue to experience marginalisation, exclusion, disadvantage, and discriminatory assumptions about their quality of life. That is, people with learning disabilities in Northern Ireland continue to be subject to extensive human right violations.

2.6 The lack of substantive change in Northern Ireland for people with learning disabilities in their daily lives is partly due to:

- The lack of strategic priority on human rights for disabled people in general.
- The lack of awareness of human rights issues for people with learning disabilities, amongst themselves, their organisations, the service delivery sector, politicians and the general public.
- A strong paternalist approach which, whilst often claiming good intent, discourages the perception of people with learning disabilities as human rights holders.
- The lack of accessible legal support, including the lack of independent advocacy services, for people with learning disabilities and their carers to instigate human rights cases.
- The lack of effective mainstreaming of policies for people with learning disabilities and limited evidence of joined-up service delivery.
- Assumptions that people with learning disabilities do not have the capacity for decision-making or involvement in decision-making processes.

2.7 Whilst we are aware of the need to balance individual rights with the rights of others, we remain concerned that the rights of those without disabilities continue to be accorded greater priority. The Centre on Human Rights is alarmed at the often contingent and provisional nature on which the rights of people with learning disabilities appear to be based, thus implying that the rights of people with learning disabilities are secondary to those of everyone else.

3. SPECIFIC COMMENTARY

The Review of Mental Health and Learning Disability (Northern Ireland)

3.1 In October 2002, following similar exercises by government in England and Scotland, the Department of Health, Social Services and Public Safety (DHSSPS) initiated a major, wide-ranging and independent review of the law, policy and provision affecting people with mental health needs or a learning disability in Northern Ireland. (This Review, known as the Bamford Review of Mental Health and Learning Disability consists of a number of interlinked reviews, encompassing policy, services and legislation.

⁶ Hill, M, McAuley, C, McLaughlin, E and Porter, F (2006) *Eighty Years of Talking about Equality in Northern Ireland: A History of Equality Discourses and Practices*, Belfast: Equality and Social Inclusion Project, Working Paper 5.

⁷ R Daw (2005) *Human Rights and Disability: The Impact of the Human Rights Act on Disabled People*, DRC/RNID.

3.2 The Bamford Review, throughout its reports, and in particular, the Equal Lives and Human Rights and Equality of Opportunity reports, highlighted the extent of exclusion and disadvantage experienced by people with learning disabilities.

3.3 The Review provides an ethical foundation and rights based vision on which substantive recommendations and proposals for service reform and modernisation, including legislative reforms, are based.

3.4 The Centre on Human Rights welcomes the Bamford Review and believes that implementation of the recommendations of the Review is vital to future provision of services for people with learning disabilities. We strongly encourage the Committee to utilise these reports.

The “Troubles” and their impact

3.5 The 30 years from 1968 onwards, commonly referred to as “The Troubles”, were a period of prolonged violence and civil unrest in Northern Ireland.

3.6 Systematic research exploring the impact of the Troubles on people with learning disabilities and their families is noticeably absent. Nevertheless, a range of pertinent issues can be identified:

- The persistent threat of violence heightened overprotective attitudes towards people with learning disabilities, and limited opportunities to become more independent.
- The potential risk of using public transport during times of violence reduced opportunities to travel independently.
- The Troubles reduced opportunities for social, economic and cultural activities and compounded the social isolation of young people with learning disabilities.
- The Troubles reduced opportunities for families to establish support networks with others in similar situations.
- The Holy Cross School dispute in Belfast in 2001 necessitated the occasional closure of an adjacent day centre for people with learning disabilities.⁸

Legislative provision

3.7 Delays in introducing legislation such as the Special Educational Needs and Disability Order have compounded the lack of legal protection and redress available to people with learning disabilities in Northern Ireland compared to their counterparts in Great Britain.

3.8 The Centre on Human Rights further argues that the prolonged absence of capacity related legislation in Northern Ireland compared to Great Britain breaches baseline levels of established international standards on health and well-being.

3.9 The Committee’s call for evidence is extremely timely given the current and ongoing implementation of the recommendations emerging from the Review of Public Administration. The Centre on Human Rights at Disability Action firmly believes that the Review of Public Administration provides Government and public bodies with a unique opportunity to both protect and promote the human rights of people with learning disabilities within new and reorganised structures. We strongly recommend that people with learning disabilities, supported by their advocates as appropriate, are represented on structures including the new Education Advisory Forum (EAF), Local Health and Social Care Commissioning Groups, and Community Planning structures.

Health and Social Care

3.10 It is abundantly clear that there are high levels of unmet health needs among people with learning disabilities in Northern Ireland. Examples of undetected health needs include obesity, tooth decay, hypertension/hypotension, eczema, poor circulation, diabetes, hearing difficulties and reduced vision.⁹

3.11 The extensive health inequalities that persist suggests a disregard or ignorance of a number of human rights standards, not least Article 12 of the International Convention on Economic, Social and Cultural Rights (ICESCR) which stipulates a right to enjoy the highest attainable standard of health; and Articles 2, 3 and 14 of the Human Rights Act which specify a right to life; the right to be free from inhuman and degrading treatment; and the right to non-discrimination respectively.

⁸ Review of Mental Health and Learning Disability (Northern Ireland) *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland*, September 2005.

⁹ Leggett, P (2001) *Footsteps to health: multidisciplinary health screening of adults with learning disabilities 1999–2001*, Cullybackey, Maine Medical Centre.
McConkey, R, Barr, O, Fleming, P & Milligan, V (2003) *Evaluation of Challenge 2000: Health Screening and Health Promotion Service provided by North & West Locality Consortium (Belfast) to people with learning disabilities*. (Clifton Street Surgery, Belfast and EHSSB).

3.12 Many people with learning disabilities continue to receive unequal treatment because of presumptions by health professionals of what constitutes an appropriate standard of healthcare and quality of life for people with disabilities. Such presumptions are not always intentional and may be simply due to a lack of awareness and training. Similar issues have been raised by people with learning disabilities in a consultative exercise organised by LEAD-NI¹⁰ on behalf of the DHSSPS. Whilst many participants had good experiences of GPs and hospital staff in general, there were instances of poor communication between health and social care staff and service users.

3.13 The most extreme form of treatment denial can be found in Do Not Resuscitate policies and the failure to make life-saving interventions. The Centre on Human Rights is aware of cases where Do Not Resuscitate policies continue to be used without engagement with, or consent from, patients with disabilities. We are concerned that people with learning disabilities may be subject to such practices.

3.14 Research indicates that approximately 3% of people with learning disabilities have smear tests compared to 86% of the general population; 17% have breast screening compared to 76% of the general population.¹¹

3.15 Research carried out by the DHSSPS reported that some people with learning disabilities have expressed fear in engaging with health and social care provision. This is due, in part, to uncertainty about what happens when making contact with health services and compounded by previous negative experiences during earlier contacts with acute general hospitals or health professionals.¹² The lack of equitable access to healthcare for people with learning disabilities has also been highlighted by the Promoting Access project carried out in the Western Health and Social Services Board.¹³

3.16 The Equal Lives report illustrates the distinct lack of health education for people with learning disabilities, and in particular a lack of accessible information relating to health promotion issues and sexual and reproductive health. Equal Lives also highlights the lack of general sexual and reproductive health care services for people with learning disabilities. Issues such as adolescence, premenstrual syndrome, cervical and breast screening, menopause and sexual health screening receive insufficient attention.

Housing, Residential and Community Care

3.17 Northern Ireland has the highest proportion of people living in long stay hospitals in the UK.¹⁴ Many people with learning disabilities are not given the choice of where to live or who to live with. Research carried out in 2004 by McConkey et al highlighted the need for housing and services providers to afford greater consideration to the views and personal preferences of people with learning disabilities in choosing where to live.¹⁵

3.18 Although the number of people with learning disabilities living in hospitals has been declining since the 1980s, in 2003 it was estimated that 455 men and women with a learning disability had no home outside a hospital. This is in spite of the fact that hospital resettlement has been the cornerstone of Government policy in Northern Ireland since 1995. This has been further highlighted by a recent BBC investigation into the circumstances of people with learning disabilities in Muckamore Abbey Hospital earlier this year.

3.19 The BBC investigation found that 17 people with learning disabilities had been moved to locked wards even though they did not require this type of secure accommodation; a fact which potentially breaches Article 3 of the Human Rights Act, the right to be free from inhuman or degrading treatment and Article 5, the right to liberty.

3.20 Nearly 1900 people with learning disabilities are in some form of residential provision. Approximately 450 people with learning disabilities in Northern Ireland continue to live in a long stay hospital despite having been assessed as ready to move to a new home in the community.

3.21 The average age of people living in hospital in Northern Ireland is 49 years. Many have a severe learning disability and more complex needs. They typically live in ward-style accommodation and few have their own bedroom. In the DHSSPS report, *A Fair Chance*, a number of people spoke of being traumatised by the threat of admission to a “special” hospital “as a response to trivial deviations from acceptable behaviour”.¹⁶ There was also the widely held view that there was no need for “special” hospitals and that these should be closed down.

¹⁰ Northern Ireland Coalition on Learning Disability.

¹¹ Band, R (1998) *The NHS—health for all? People with learning disabilities and health care*, MENCAP.

¹² Department of Health, Social Services and Public Safety (2002) *A Fair Chance: Report on a consultation exercise facilitated by LEAD-Northern Ireland Coalition on Learning disability*, Belfast: DHSSPS.

¹³ Barr, O (2004) *Promoting Access: The Experiences of Children and Adults with Learning Disabilities and their Families/Carers who had contact with Acute General Hospitals in the WHSSB Area*, WHSSB.

¹⁴ Mulvany, F, Barron, S and McConkey, R (2006) Residential provision for adult persons with intellectual disabilities in Ireland *Journal of Applied Research in Intellectual Disability*.

Review of Mental Health and Learning Disability (Northern Ireland) Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland, September 2005.

¹⁵ McConkey, F, Sowney, M, Milligan, V and Barr, O (2004) *Journal of Policy and Practice in Intellectual Disabilities*, Vol 1, Issue 3–4: pp115–125.

¹⁶ Department of Health, Social Services and Public Safety (2002) *A Fair Chance: Report on a consultation exercise facilitated by LEAD-Northern Ireland Coalition on Learning disability*, Belfast: DHSSPS (p 32).

3.22 The Centre on Human Rights is aware of instances where fundamental abuses persist. Abuses of privacy, degrading treatment, humiliation and alarming levels of disrespect continue. Such humiliation is exacerbated by the present exclusion of Private Care Homes from the Human Rights Act 1998.

3.23 The Centre on Human Rights remains concerned that the rights of people with learning disabilities can be interfered with on the basis of “best interests”, particularly in relation to mental health service provision. We strongly believe that emphasis should be on the improvement of health and social care policy and provision and not on the restriction of people’s rights.

Relationships

3.24 The subject of relationships is scarcely given attention despite the articulated rights of all not only to respect for private and family life (Article 8, Human Rights Act), but to marry and found a family (Article 12, Human Rights Act). Current legislation in Northern Ireland, which regulates the sexual activity of persons with “mental impairments”, is outdated and arguably contravenes the Human Rights Act.¹⁷

3.25 People with learning disabilities do not have the same opportunities to form friendships and relationships. It is clear that people with a learning disability do not usually marry and rarely have children. Qualitative evidence suggests that the attitudes of society in Northern Ireland and the limited involvement of people with a learning disability in making their own decisions, have resulted in these circumstances.

3.26 The Centre on Human Rights is aware of instances where people with learning disabilities living in residential accommodation have been discouraged from forming relationships.

3.27 A recent report on the sexual health of people with learning disabilities in Northern Ireland shows that there is a lack of acknowledgement of the sexuality of people with learning disabilities.¹⁸ The main findings from the report indicated that:

- People with learning disabilities want to learn more about sexual health and relationships.
- People with learning disabilities want to have relationships and express fears of being lonely. But they feel over-protected by professionals and family carers. Consequently there are few opportunities to develop relationships and meet new people.
- Some family carers want their child to have the same rights as everyone else. But they feel embarrassed to talk about sex with their children and are concerned for their safety. Feeling unsupported and isolated stops them from raising these issues in the home.
- Professionals and front line staff are aware that the issues around sex and sexuality are often not being addressed. However, they are inhibited by being under-resourced, under-trained and at times restricted by a lack of clear guidelines and policies to support them.

3.28 Thus, whilst staff and family carers are fearful of sexual abuse occurring, they seem reluctant to offer specific guidance in self-protection and prefer instead to rely on prohibition and supervision. The Centre on Human Rights is greatly concerned about the potential for the abuse of people with learning disabilities due to the lack of clear and accessible information and knowledge on this issue.

3.29 The report recommends greater access to information, education and support for people with learning disabilities and their family carers. It also calls for clear policies and guidelines and better training and resources to help front-line staff and professionals to implement them. Prioritisation by education and social services on the protection of vulnerable people needs to be balanced with opportunities for personal growth and development to ensure that people with learning disabilities are treated with dignity and respect.

Bullying

3.30 Approximately 88% of people with learning disabilities report being bullied. This issue has been consistently raised by people with learning disabilities at various consultative exercises in Northern Ireland.¹⁹

3.31 Some participants spoke of how unsafe they felt in their own homes and how they had been subjected to regular verbal abuse because of their learning disability.²⁰

¹⁷ Simpson, A, Lafferty, A and McConkey R (2006) *Out of the Shadows: “Our voices aren’t going to go quietly into the dark anymore”*, The Family Planning Association: Belfast.

¹⁸ *Ibid*, p 96.

¹⁹ Department of Health, Social Services and Public Safety (2002) *A Fair Chance: Report on a consultation exercise facilitated by LEAD-Northern Ireland Coalition on Learning disability*, Belfast: DHSSPS.

Review of Mental Health and Learning Disability (Northern Ireland) Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland, September 2005.

²⁰ *Ibid*, p 11.

Education

3.32 The right to education for children with a learning disability in the UK was not extended to children with a learning disability in Northern Ireland until 1987. This means that young people over the age of 18 have not experienced the same educational opportunities as other children. Most adults with a learning disability have never been to school.

3.33 This disparity suggests an apparent breach of Article 1(1) of the UNESCO Convention against Discrimination in Education whereby the definition of discrimination includes the “*subjection of a person or group to education of an inferior standard*” to the extent that person is not enabled to achieve his or her full potential.

3.34 Young people with a learning disability and their families encounter difficulties throughout the transition process from childhood to adult life. Whilst there are examples of good practice and partnerships between schools and the community and voluntary sector, access to such initiatives are inconsistent.

3.35 Equal Lives highlighted concerns about the lack of progression from Further Education provision. This is partly due to students not being able to gain accredited awards from their study; the lack of links with job training and work experience; and students repeating the same course content in subsequent years.²¹

Advocacy and Participation

3.36 People with disabilities have limited opportunities to participate in the life of their local community. This is in spite of Section 75 obligations for public authorities in Northern Ireland to actively consult with a range of groups, including people with disabilities. Consulting with people with a learning disability requires the development of a process which is sensitive to their specific needs and which listens to, values, and acts on their views.

3.37 The issue of who does and who does not have decision making capacity is complex. For people with learning disabilities, assessment and determination of capacity is particularly contentious. Research carried out by Disability Action in 2005 suggests that the effect of the electoral system’s requirement for people with learning disabilities to make a declaration of capacity is one of discouragement.²²

3.38 The LEAD-NI report (2002) found that people with a learning disability wanted to be consulted in issues that affect them. However, the voice of the individual concerned, and of those closest to them, is all too easily ignored in favour of ‘professional’ and subjective judgement. There is a clear and urgent need to promote empowerment and advocacy for people with learning disabilities to participate in the decision making process.

3.39 The Centre on Human Rights for Disabled People is particularly concerned at the lack of independent advocacy services. People with learning disabilities should not be prevented from making decisions due to a lack of effective communication support, inaccessible information or a lack of advocacy services. It is vital that sufficient resources are in place and that these are effectively monitored. People with learning disabilities should have access to advocacy services that are appropriate, timely and effective, and which take account of the diversity, preferences and specific needs of different cultural groups. This can be achieved through self-advocacy, peer advocacy and group advocacy. Such services are currently unavailable in Northern Ireland.

3.40 The Centre remains concerned that people with learning disabilities who reside in institutional or restrictive settings on a temporary or permanent basis are not given real opportunity to express choice and demonstrate capacity to make a particular decision(s) at a particular time.

3.41 The Centre is particularly concerned at the lack of specific skills and training among service providers in supporting people with learning disabilities.

3.42 The availability of accessible transport is of particular significance in ensuring that people with learning disabilities can participate in policy formulation and consultation processes.

The United Nations Convention of the Rights of Persons with Disabilities

3.43 The Centre on Human Rights for Disabled People at Disability Action welcomes the new Convention on the Rights of Persons with Disabilities.

3.44 The international Convention provides a major boost for disabled people’s human rights throughout the world. The Centre hopes that the Convention will have a significant impact in effectively securing the human rights of people with learning disabilities throughout Northern Ireland and in challenging the human rights violations that persist. It is imperative that UK government ratifies the Convention as soon as possible.

²¹ Ibid, p 45.

²² Disability Action (2005) *Polls Apart: Access to Polling Stations, A Study by Disability Action*. Belfast.

3.45 The Convention will only be as effective as member states allow it to be. The Centre on Human Rights strongly recommends that Government and the voluntary and community sector engage with the Convention.

3.46 The Convention will place a legal obligation on governments to adopt appropriate measures to ensure that the rights of all disabled people are protected and promoted. The Centre strongly encourages government to take active measures to engage with people with learning disabilities in light of the Convention and to adopt a rights based approach at all levels of policy and practice.

3.47 The Centre on Human Rights is working to produce information materials for people with disabilities, including people with learning disabilities. Information will be provided in Plain English and Easyread as well as other accessible formats.

3.48 The Centre on Human Rights is also working to raise awareness among people with a range of disabilities of their rights under the Human Rights Act, the new Convention and other appropriate international standards, to empower people with disabilities to advocate for themselves.

4. CONCLUSION

4.1 The Centre on Human Rights for Disabled People has welcomed the opportunity to respond to the Committee's Call for Evidence. We trust that the Joint Committee on Human Rights will seriously consider the issues that have been raised in this submission, recognising the extensive contribution that people with learning disabilities can make to our society.

4.2 We look forward to continued dialogue on this and other issues of major significance to people with disabilities throughout Northern Ireland.

1 May 2007

Letter from St Anne's Community Services

I am writing to provide some feedback from some of the people supported by St Anne's to the Joint Committee's request for information about whether people with a learning disability are getting their human rights.

As St Anne's is a large regional provider of a range of support services, managers were asked to share the request amongst the services they are responsible for. Where service users gave a response they requested that this was submitted on their behalf and so these were forwarded to me to collate.

The issues and questions raised by the Joint Committee were discussed with people either individually or in service meetings and their responses are re-produced below:

One person started off by saying:

"I have got the right of choice, I wasn't very happy where I was before I came into St Anne's because I wasn't given any opportunity to make choices for myself and to do things I would like to do. Much happier here, I go to work which I am paid for and the ATC. Got things to do that keep me busy."

My experiences of using services:

The same person said "They are all alright and fine. My benefits just gone up and I don't have any problem with the house because staff are always there to help us." The other response is from a group of people who said that they all feel they are treated fairly.

Chances for personal relationships:

"I still keep in touch with them (partners), they come visiting and I do visit and chat with them on the phone. I don't have any contact with my family because they don't bother with me and I don't have any children."

Help with these relationships:

"Staff encourage me to keep in contact with friends. Help in booking taxis and other arrangements if I need to go visiting." People involved in the group discussion all felt that they have good opportunities to make relationships.

Taking part in the local community:

"I work in a nursing home and I get a lot of help from the staff in getting to and from work."

Two of the group felt they could be more involved in their local community.

A convention on the rights of people with disabilities:

Yes

How easy it is for people with a learning disability to have a say in decisions affecting them?

"I'm allowed to speak up. When I do staff listen to me and respect my opinion. Though some people might not be able to speak up because of their problems but we are encouraged to speak up for ourselves."

The group all felt that this is OK for them.

How easy is it for people to complain about a service?

"It's easy because I can always talk to the manager (Jane) when I am not happy about anything and I talk to staff as well."

The group felt comfortable with the complaints procedure, they all said they would tell Mark (Service Manager).

What would help people with a learning disability get their human rights and any examples you have of when this has been done well.

"I was allowed to make a choice when I was looking for accommodation. I chose to live in Wetherby and I was given all the support by members of staff."

"I would ask someone."

In addition, a social work student on placement had a discussion with four people living in a residential care home and her report is included below:

"I explained the Human Rights (Act 1998) in simple terms. I explained how all people, as human beings, have rights to life, liberty and freedom. We discussed how people, regardless of their disabilities, should live in dignity. We explained what it means to violate someone's human rights, that is, to treat that someone as if he/she were not a human being."

We discussed privacy and equal opportunity as other aspects that show respect for people. Using some learning aids, we discussed the meaning of equal opportunity, which is giving people a fair chance in life. On this issue I asked service users how easy it is for them to put issues of their concern forward to management. They overwhelmingly say that it is easy as they tell staff that will do the things on their behalf. They cited the examples on the recently purchased sofas as something that staff did for them on their behalf. Pat and Donald once went to the police to complain about the noise next door. This is one proof to show that the service users are conscious of their rights.

I asked service users how they want to be involved more in the services but no issues were raised. Pat explained how she is likely to be part of the Board of Management for St Annes Community Services. She could be involved in such aspects as interviewing new staff.

No issues were raised for Team Plan.

Recorded and chaired by Munasireyi Loveworthy Chiguvo (Student Social Worker).

Once again, my apologies that this is late but I hope that the information is useful. I have not included people's names as it has not been clearly indicated to me whether people have given their permission but if you require any further information or details please do not hesitate to contact me.

Sharon Allen
Chief Executive

30 May 2007

Memorandum from the Department of Health

I am grateful for the opportunity to submit evidence to assist the Committee with the present inquiry.

The Government's policy is to improve the life chances of people with learning disabilities by promoting their inclusion and participation in community life, and control over their lives. People with learning disabilities should be able to participate in the activities other people take for granted like getting a job, travelling, raising a family and are entitled to equitable access to health and social care.

This commitment is set out in *Valuing People: a new strategy for learning disability for the 21st Century* White Paper (published on 20 March 2001), this cross-government paper was the first White Paper for people with learning disabilities for 30 years and is based on the four key principles of rights, independence, choice and inclusion.

Human rights are at the centre of the values of the health and social care system in this country. The Department is striving to ensure that everyone's human rights are respected and on 27 March 2007 published the document *Human Rights in Healthcare—A Framework for Local Action to assist frontline organisations ensure that rights are made a reality*.

Ivan Lewis
Parliamentary Secretary for Care Services

INTRODUCTION

People with learning disabilities tend to suffer higher levels of ill health than the rest of the population, and they tend to die younger than other people. This is partly due people with learning disabilities being more prone to certain medical conditions and partly because they experience higher levels of poverty and deprivation. The Disability Rights Commission Formal Investigation, that considered health inequalities²³ experienced by people with learning disabilities, attributes the NHS not serving the needs of people with learning disabilities properly as another factor.

Several events (see below) over the past year have highlighted the inequalities of access and provision of health and social care services for people with learning disabilities. We acknowledge that more needs to be done to ensure that people with learning disabilities enjoy their full rights as citizens and we are engaged in a programme of work to improve outcomes for people and their families. The Department has pivotal role in learning disabilities as, in addition to being responsible for learning disability policy in health and social care, it also co-ordinates policy across government.

GOVERNMENT POLICY

The Government's policy is to improve the life chances of people with learning disabilities by promoting their inclusion and participation in community life, and control over their lives. People with learning disabilities should be able to participate in the activities other people take for granted like getting a job, travelling, raising a family or going out with friends.

This commitment is set out in the *Valuing People: a new strategy for learning disability for the 21st century* White Paper²⁴ (published on 20 March 2001), this cross-government paper was the first White Paper for people with learning disabilities for 30 years and is based on the four key principles of rights, independence, choice and inclusion.

RECENT EVENTS

The Department was shocked and saddened to learn of the deaths of the six individuals highlighted in the Mencap report *Death by Indifference*,²⁵ particularly in light of the other cases that have come to the Secretary of State's attention over the past year, such as the disturbing events in Cornwall²⁶ and at Sutton and Merton PCT.²⁷ Every person with a learning disability should be treated with care, dignity and respect. This includes receiving the healthcare to which they are entitled.

In response to the publication of Mencap's report, the Secretary of State (SofS) for health has confirmed that there will be an independent inquiry focusing on the acute NHS sector in order to learn lessons and ensure that change happens. SofS has met with the families of the six people whose cases were highlighted in Mencap's report. Details of the form and objectives of the independent inquiry announced by the Secretary of State will be confirmed as soon as possible.

The Disability Rights Commission's Formal Investigation into health inequalities²⁸ experienced by people with learning disabilities and mental health problems was published on 14 September 2006. The report says that people with learning disabilities and mental health problems are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease.

DH acknowledges the barriers described in the investigation and welcomes the DRC's report, which is a major contribution to the thinking around the issues and highlights the scale of the problem.

GOVERNMENT ACTIONS

In March 2005, Rob Greig's *National Director's Review, Valuing People: The story*²⁹ so far, reported on progress. It shows that: people are being listened to more, person centred planning when done properly, makes a difference in people's lives, the Supporting People programme has helped many people live more independently, direct payments are helping change people's lives and that organisations are working better together at a local level. In addition, the report includes improvements in self-advocacy; more councils are giving money to self advocacy. People are increasingly aware of the importance of producing easy-to-understand information, and many self-advocacy groups are leading the way in this.

Ivan Lewis has recently announced that the issues raised in *the story so far* will be addressed when *Valuing People* is refreshed in the autumn to focus on the priorities and actions for the next 3–5 years.

²³ <http://www.drc-gb.org/library/health—investigation.aspx&Finalreportsandsummaries>

²⁴ www.archive.official-documents.co.uk/document/cm50/5086/5086.htm

²⁵ www.mencap.org.uk/deathbyindifference

²⁶ www.healthcarecommission.org.uk/_db/_documents/cornwall_investigation_report.pdf

²⁷ http://www.healthcarecommission.org.uk/newsandevents/pressreleases.cfm/cit_id/4922/FAArea1/customWidgets.content_view_1/usecache/false

²⁸ http://www.drc-gb.org/library/health_investigation.aspx&Finalreportsandsummaries

²⁹ <http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH—4107054>

All PCTs have received a revenue allocation of £42.6 million for 2006–07 and £43.7 million for 2007–08 for the Learning Disability Development Fund (LDDF)³⁰

The Department of Health and the Disability Rights Commission (DRC) are working together to ensure that NHS and Social Services are aware of their duties under the Disability Discrimination Act (DDA).

In May 2006, Nicola Smith, who has a learning disability, was appointed as the new National Director for people with learning disabilities to help lead government policy on the lives of people with learning disabilities. She works alongside the current National Director for Learning Disabilities, Rob Greig. They co-chair the Learning Disability Task Force.

On 27 March 2007 published the document *Human Rights in Healthcare—A Framework for Local Action*³¹ to assist frontline organisations ensure that rights are made a reality.

1. VALUING PEOPLE

White Paper Valuing People

The White Paper Valuing People³² placed Rights, along with Independence, Choice and Inclusion, at the heart of government policy towards people with learning disabilities in England. Published in 2001, it was a logical progression of past policy that culminated in policy being cross government and concerned with how people could be supported to be full and equal citizens.

Valuing People stated in clear and unequivocal terms that people with learning disabilities are not, and should not be regarded or treated as, second class citizens. It spelled out that they have full legal and civil rights, including rights under the Disability Discrimination and Human Rights Acts. However, it also acknowledged that the realisation of these rights for most people with learning disabilities amounted to a vision of the future, and was not a reality in 2001. The strategy laid out by Valuing People was intended to turn that vision into reality.

Despite the many advances in learning disability policy and practice that had happened in the late twentieth century, however, which led ultimately to Valuing People, general attitudes to people with learning disabilities had failed to keep pace. These attitudes and ingrained ways of working and behaving have seriously impeded the implementation of the policies and visions set out in Valuing People.

As a consequence, many people with learning disabilities still encounter prejudice in all areas of their lives, undermining and denying their rights and freedoms. They and their families and other supporters often have to assert and fight for their rights in situations where, had they not had learning disabilities, their rights would be taken for granted.

Valuing People recommended that it should be a statutory requirement that local authorities set up Learning Disability Partnership Boards in each area to bring together people from social services and health services, people with learning disabilities, family carers, people from housing, education and other organisations. In 2002 and 2003, Partnership Boards set out plans to make Valuing People happen in their local area—they are now working to make those plans happen.

Progress of the Valuing People Support Team

The Valuing People Support Team has been working across England to address these issues since 2001. A lot of progress has been made but the scale of the problem is huge, and progress has necessarily been slow. There have been considerable improvements in a number of areas where the Team has worked closely with people with learning disabilities, support groups, families and services to change attitudes and working practices. In particular, the Team works through:

- engaging with partners to raise issues and work with them to bring about change;
- raising the profile of people with learning disabilities as change agents;
- supporting and promoting the employment of people with learning disabilities as consultants and trainers to help bring about change;
- encouraging and supporting the full involvement of people with learning disabilities as members of Learning Disability Partnership Boards; and
- commissioning and publishing guidance papers and toolkits to help and support change happen

³⁰ <http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Learningdisabilities/index.htm>

³¹ <http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH—073473>

³² www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf

Review of Valuing People

The National Director for Learning Disability published a review of Valuing People in March 2005. In the spirit of *Nothing about us without us*,³³ (the Service Users Advisory Group Report, published in March 2001) the National Director and his Team collected information from approximately 3000 people with learning disabilities, family carers and professionals involved in the implementation of the policy so far. They also looked at the data available about how people's lives are changing.

The report is now available, in differing levels of details for different audiences, and shows that:

- people are being listened to more;
- person centred planning when done properly, makes a difference in people's lives;
- the Supporting People programme has helped many people live more independently;
- direct payments are helping change people's lives; and
- organisations are working better together at a local level.

However, the report does not say that everything is perfect. It recognises that for many people not much has changed, particularly for those who face additional barriers, such as people with high support needs, and people from black and ethnic minority communities. A major issue identified was that "mainstream" policy and delivery areas such as employment, housing and education have still not effectively taken on the Valuing People agenda, which means that people are still being excluded from access to crucial aspects of their lives. It also set out the challenges for the next five years of Valuing People.

LEARNING DISABILITY DEVELOPMENT FUND

The Learning Disability Development Fund (LDDF) was established to support implementation of Valuing People. The fund is distributed to PCTs from a total budget of £42.6 million in 2006–07 and £43.7 million in 2007–08. However, it is up to local discretion to determine how to allocate these funds based on priorities agreed with the Learning Disability Partnership Board (who are responsible for implementing Valuing People at a local level). Recent CSCI reports show that around 20% of this funding is diverted by Primary Care Trusts to general NHS funds.

In addition, there is a £1.75 million Implementation Support Fund budget, which funds advocacy development, the national Forum of people with a learning disability, a family advice helpline and work on equality and discrimination.

2. HUMAN RIGHTS IN HEALTH: A FRAMEWORK FOR LOCAL ACTION

The Human Rights in Health Framework that was launched by Rosie Winterton, Minister of State for Health Services, on 27th March 2007 is the product of a project jointly run between the Department of Health and the British Institute of Human Rights. The project worked with five NHS pilots to develop a framework for NHS organisations to help them use human rights based approach to improve service planning and delivery. It is intended to assist NHS organisations that wish to take human rights forward in their own organisations and not as a source of legal advice and guidance on specific issues. The framework covers three broad areas:

- (1) the business case for human rights:
 - what are Human Rights and why they are relevant in Health,
 - what the Human Rights Act means for NHS organisations,
- (2) the practical actions that organisations can do in order to implement a Human Rights based approach, and
- (3) case studies from the pilot organisations involved in the project who have developed and tested some of the practical actions in the framework.

Here are the specific areas that Trusts have been working on:

- (i) Southwark Health & Social Care—A Human Rights-based approach to the commissioning and delivery of Fertility Services in Southwark;
- (ii) Birmingham Teaching Primary Care Trust—Defining an action plan for an organisation-wide implementation of a Human Rights-based culture and way of working;
- (iii) MerseyCare NHS trust—Developing a Human Rights-based decision-making mechanism at the Learning disabilities directorate;
- (iv) Tees, Esk and Wear NHS trust—Developing a Human Rights-based approach to the design and production of the Trusts' service charter and the Care Planning Approach; and
- (v) Surrey & Borders NHS trust—Embedding Human Rights in the Equalities & diversity strategy.

³³ www.publications.doh.gov.uk/learningdisabilities/access/nothingabout/index.htm

 POLICY DEVELOPMENTS IN SOCIAL CARE
Independent Living

The Government's policy is to improve the life chances of disabled people by promoting their inclusion and participation in community life, and control over their lives. Disabled people should be able to participate in the activities other people take for granted, like getting a job, travelling, raising a family or going out with friends.

The Government is committed to improving the health and well-being of the population through a health and social care system, which is provided equally to those who need it, is truly person-centred and supports independent living.

The Government believes disabled people should, as far as possible, live in their communities near to their families and friends. Agencies should support disabled people to live in their own homes with equipment, adaptations and services as necessary to suit their individual needs and lifestyles.

In January 2005, the Prime Ministers Strategy Unit published *Improving the Life Chances of Disabled People*.³⁴ The report sets out a 20-year strategy with some 60 recommendations. It focuses on independent living including individual budgets; person-centred planning and self-assessment enabling choice and control for disabled people.

Independent living is about people having choice and control over the support they need to live the lives they want as full and equal members of society.

Individual Budgets

The individual budgets pilot project³⁵ is a cross government initiative led by the Department of Health working with the Department for Work and Pensions, the Office for Disability Issues and Communities and Local Government.

The central idea behind the individual budget concept is to provide greater choice and control for people needing support, and to place the person who is supported at the centre of the process. People will be enabled to design their own support with the knowledge of what finance is available, and to manage the funding to provide that support. The concept builds on the successful features of direct payments and on other initiatives to develop self-directed support such as INControl³⁶ which is a unique partnership between families, individuals, services, local authorities, Government and many other organisations. IN Control is a result of the Valuing People delivery programme, which has also provided significant funding for the partnership. All these people are working together to define best practice in Self-Directed Support and change the system.

Individual Budgets are intended to benefit everyone who might receive services from the local authority's social services department, including people with learning disabilities, or indeed through any of the other included streams of income. The implementation of Individual Budgets is potentially a lever for change in the current way that community care services are provided. Aspects of the whole system will need to be addressed, including improved information and access as well as work on streamlining assessments. Local Authorities will also need to develop their commissioning processes and the way that they work with service providers to ensure that the appropriate range of support is available.

Ministers have agreed that pilot projects will include the following income streams:

- Council-provided social care services;
- Independent Living Fund;
- Supporting People;
- Access to Work;
- Disabled Facilities Grant; and
- Integrated Community Equipment Services

Respondents to *Independence, Well-Being and Choice*³⁷ were supportive of the proposal to introduce the Individual Budget approach and recognised that it had the potential to promote greater choice and control over services.

³⁴ www.cabinetoffice.gov.uk/strategy/downloads/work—areas/disability/disability—report/pdf/disability.pdf

³⁵ <http://individualbudgets.csip.org.uk/index.jsp>

³⁶ www.in-control.org.uk

³⁷ <http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/Aboutsocialcare/DH—4106483>

Increasing the uptake and extending the availability of direct payments

In the Department of Health White Paper, *Our health, our care, our say*,³⁸ we committed to launching a national campaign, working with a range of external stakeholders to increase awareness and improve understanding of the benefits of direct payments.

The Department of Health has been working with local authorities and their partners through the regional Care Service Improvement Partnership (CSIP) networks. Regional events have been held to identify specifically what issues limit local uptake and highlighted any solutions developed locally which might benefit other authorities. A self-assessment and action planning guide was published in December 2006 to support local authorities and their partners in undertaking this. The guide focuses on six key areas for action:

- leadership;
- straightforward systems;
- learning and development;
- communication;
- comprehensive support; and
- commissioning

We also set out a commitment to extend the scope of direct payments to those currently excluded from having a direct payment, either because they cannot consent to a direct payment or cannot manage one, even with assistance, where this is in their best interest. Extending direct payments to these groups will help provide person centred care. We want to increase individuals' independence and choice by giving them control over the way the services they receive are delivered.

We are committed to driving the personalisation and control agenda forward with our partners, including the Commission for Social Care Inspection, and this work on promoting and increasing the take-up of direct payments is fundamental. Along with the Individual Budget Pilots and the In Control work, direct payments are the future for social care in the next decade and beyond. We are determined to strengthen this approach, bringing together learning from the three programmes to tackle the obstacles we know exist, share best practice and build momentum and enthusiasm for our vision.

Protection of vulnerable adults and the independent mental capacity scheme

On 8 November 2006 the Safeguarding Vulnerable Groups Act received Royal Assent. The Act lays the foundation for a new vetting and barring scheme which will extend coverage of POVA to provide more a comprehensive and consistent measure of protection for vulnerable groups across social care, the NHS and beyond. The new scheme will be phased in from Autumn 2008.

It is extremely distressing when one learns that a person with learning disabilities has been abused. Often they cannot defend themselves and many are utterly dependent on those who care for them. That is why we must encourage carers, paid staff and others to speak out. It is the responsibility of all of us to ensure that people with learning disabilities are not being abused in anyway.

Where people with learning disabilities are being abused and there is no one to consult, an Independent Mental Capacity Advocate can be appointed who will represent them. IMCAs will be appointed from April in England and from October in Wales.

- The IMCA programme is providing £6.5 million of new money per year to local authorities in England to fund advocacy organisations to support people who lack mental capacity to help them with key life choices. Advocates providing independent mental capacity advocacy services will all undergo a standard national induction training and in time have to be trained through the new national advocacy qualification.
- In addition, a fund of £2.1 million has been made available to local authorities this year to set the programme in place before April 2007.

Commissioning

Following the publication of the report of abuse in Cornwall's learning disability services, the Government made a commitment to strengthen the commissioning of learning disability services, including giving consideration to a stronger role for local authorities.

It is important that appropriate consideration is given to any decisions on roles and responsibilities, and the Department will advise of the process for this in due course.

³⁸ <http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Modernisation/Ourhealthourcareoursay/index.htm>

3. POLICY DEVELOPMENTS IN HEALTH

Campus Closure

Many people with learning disabilities still find themselves being sent a long way away from home when services find their needs particularly complex, difficult or challenging. This kind of specialist provision has long been criticised for being harrowing for people and their families, adding emotional and psychological distress to the original problem and fracturing family and local neighbourhood ties.

As set out in the White Paper, *Our Health, Our Care, Our Say*, the Government has made a commitment to close all NHS campuses by the end of the decade.

Development work is currently underway to ensure that a considered approach is taken to the development of suitable alternatives to campus accommodation. The Valuing People Support Team:

- has recently held a successful workshop day to discuss the practicalities with providers and commissioners.
- running a development, learning and support programme for people managing campus closure programmes
- making available project planning support
- (with SHAs) reviewing and monitoring the quality of closure and replacement plans
- working with self-advocate and family organisations to help ensure the best interests of people living in the campuses are always top of the agenda.

Promoting Equality—Response to the DRC

On 12 March 2007, DH published its response to the recommendations set out in the Disability Rights Commission's (DRC) report, *Equal Treatment: Closing the Gap*,³⁹ into health inequalities experienced by people with learning disabilities and mental health problems. The response details the actions that DH will be taking.

Many of the issues are complex and require work with a wide range of healthcare organisations, some of whom have traditionally not been well engaged in the healthcare of people with learning disabilities. Some of the actions include:

- Working with stakeholders to consider how to address issues with diagnosing physical and mental health problems for people with learning disabilities (“diagnostic overshadowing”).
- Making the Department's disability equality duty guidance relevant for learning disabilities.
- Increasing the capacity of self advocacy groups to run training for NHS staff.
- Publishing new guidance on Health Action Plans for people with learning disabilities.
- Working with the professional bodies to address disability equality in the undergraduate curricula.

In addition, the Government remains committed to introducing regular, comprehensive health checks for people with learning disabilities—a commitment reconfirmed in the recent white paper, *Our health, our care, our say*.

Work is underway to develop a service framework to help PCTs commission health checks for people with learning disabilities—this will be available in 2007–08. Following a stakeholder workshop, the Valuing People Support Team has identified a preferred model for health checks. Over the coming months the team will be running a promotional campaign to encourage PCTs to implement the model as a Locally Enhanced Service (LES). In future contractual negotiations with GPs, one of our priorities will be access to regular health checks for people with learning disabilities.

Work on our response to the formal investigation is being led at the highest level within the Department of Health, working closely with the DRC. We will provide the DRC with a formal update of our progress in the autumn of 2007.

Cornwall and Sutton & Merton

The Department of Health continues to be involved in the significant progress being made by Cornwall Partnership NHS Trust and its local partners in changing the way it delivers services to people with a learning disability

The Healthcare Commission's investigation into Learning Disability services in Sutton & Merton makes clear that the PCT did not follow government policy to provide quality services for people with learning disabilities. There is no reason to believe the serious abuse that took place is common occurrence, however, the Healthcare Commission are carrying out an audit of learning disability services across England to check up on the standard of care in learning disability health services.

³⁹ www.drc.org.uk/library/policy/health—and—independent—living/equal—treatment—closing—the—g.aspx

The PCT continues to make progress its learning disability service. The Healthcare Commission, Department of Health and the London SHA are closely monitoring the situation.

In response to the investigations in Cornwall and Sutton and Merton, the Healthcare Commission launched an audit of learning disability services on 8 Jan 07. The audit will include the inspection of up to 200 NHS and private services and will publish findings by the end of this year.

The Secretary of State, the NHS Chief Executive and the Director General for Social Care wrote to the NHS and social services in November 2006 reminding them of their responsibilities in relation to providing quality services and care for people with learning disabilities. In particular:

- SHAs were asked to ensure that NHS bodies that provide residential services are registered with CSCI and, if they are not, to apply for registration immediately.

Directors of Adult Social Services were reminded of their duty to provide comprehensive assessments and person-centred planning.

In addition the NHS Chief Executive wrote to all SHAs and PCTs stressing importance of them having sufficient commissioning competence in their new organisations.

25 May 2007

Supplementary Memorandum from the Department of Health

INDEPENDENT INQUIRY INTO HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES

Following the publication of Mencap's report *Death by Indifference* in March 2007, the Secretary of State for Health confirmed that an independent inquiry into healthcare for people with learning disabilities would be established. The membership and terms of reference of the inquiry were confirmed on 31 May 2007.

The inquiry has been established under Section 2 of the NHS Act 1977 (revised 2006)⁴⁰ to understand how the NHS can ensure adults and children with learning disabilities receive appropriate treatment in general acute health care.

The Inquiry is independent of the Department of Health. Although the Inquiry team and secretariat are based in the Department and have the benefit of ready access to officials and departmental records, all inquiry records, communications, submissions, working papers and working process is independent.

The inquiry is being chaired by Sir Jonathan Michael, former chief executive of Guy's and St Thomas' NHS Foundation Trust. In carrying out the inquiry, Sir Jonathan will be working with two expert panels— one consisting of providers and service managers, and one consisting of people with a learning disability. In addition two carers' forums have been established to help understand the issues that carers face.

Members of the provider and manager's panel are:

- Mr Chris Davies (Consultant in Social Care/Lead Advisor Social Services Agency, Wales);
- Mr Len Fenwick (Chief Executive, Newcastle upon Tyne Hospitals NHS Foundation Trust);
- Professor Sheila Hollins (President, Royal College of Psychiatrists);
- Professor Jim Mansell (Director, Tizard Centre, University of Kent);
- Professor John Moxham (Medical Director, King's College Hospital NHS Foundation Trust);
- Ms Joan Saddler (Chair, Waltham Forest Primary Care Trust); and
- Ms Ann Norman (Professional Advisor for Learning Disabilities, Royal College of Nursing).

The inquiry is currently reviewing national and international research, and taking account of evidence from reports such as those published by Mencap, the Disability Rights Commission and others.

A call for written evidence was issued on 3 August 2007 with 350 written submissions received by the closing date of 19 October 2007. The call for evidence covered the following three questions:

- What are the issues of concern in relation to access to healthcare for people with learning disabilities?
- What should be done to improve services?
- Where is the good practice?

Consultation meetings with and/or visits are currently being made to clinical professionals and other staff (regional Valuing People Support Teams, the Learning Disabilities Taskforce, Mencap, the National Patient Safety Agency, the Healthcare Commission, Advocacy Partners, ICAS, The Disability Rights

⁴⁰ The NHS 1977 Act gives a general power to SoS to set up an external review of virtually any incident in the NHS. Changes made in the Health Act 2006 mean that such inquiries do not have powers to compel witnesses to attend or produce evidence. However, it is not anticipated that such powers will be necessary as most inquiries function well by consent and agreement.

Commission, and the Health Service Ombudsman, Westminster PCT, Shropshire Acute Liaison Nurse Facilitation team, and Haringey Overview and Scrutiny Committee). In addition, Sir Jonathan and his team have met some of the families whose experiences featured in the Mencap report 'Death by Indifference'

Witnesses will be invited to meet the Inquiry team during November, December and January.

The terms of reference for the independent inquiry are:

1. The inquiry will identify action needed to ensure adults and children with learning disabilities receive appropriate treatment, primarily in general acute health care and with reference to wider health services. The Inquiry will not be conducting a detailed investigation of total provision across the NHS.
2. The inquiry will learn lessons from the six cases highlighted by the Mencap report Death by Indifference. The Health Service Ombudsman for England has agreed to conduct an independent investigation of each individual case. The Health Service Ombudsman is a completely independent body with extensive powers to investigate. The Ombudsman's investigations will run in parallel with the inquiry and, subject to the families' agreement, the Ombudsman's reports will be available to the inquiry panel to inform their conclusions and recommendations. The inquiry will not be considering in detail any other individual cases.
3. The inquiry will review existing national and international research on the issue, but it will not undertake original research.
4. The inquiry will undertake a stakeholder consultation to listen to people with learning disabilities, their families and carers, and take evidence from key stakeholder groups.
5. The inquiry will take account of evidence and findings from the Disability Rights Commission Formal Investigation into Equal Treatment.
6. The inquiry will not investigate mental health services or learning disability services, or investigate individual cases or new complaints.
7. The Inquiry will draw up conclusions from the evidence, make recommendations and report these to the Secretary of State.

As noted in the above terms of reference, in addition to the inquiry being led by Sir Jonathan, the Parliamentary and Health Service Ombudsman is carrying out a separate investigation of the cases identified in the Mencap report. The independent inquiry will be taking careful account of any findings that the Ombudsman shares.

Sir Jonathan's report will make such recommendations to the Secretary of State for Health as he deems appropriate, taking account of his terms of reference and the evidence gathered. The inquiry aims to publish its findings and recommendations in June/July.

6 November 2007

Memorandum from Midstream (West Lancs) Ltd

Midstream (West Lancs) Ltd is a not for profit Registered Charity based in Skelmersdale, West Lancashire.

The charity provides opportunities for young people and adults with a wide range of learning disabilities, physical disabilities and mental health issues to obtain nationally accredited vocational qualifications, and to partake in "real life" work activities at its purpose built facility in the following vocational areas:

- horticulture;
- retail;
- life skills;
- woodwork; and
- Business Administration.

The organisation has also successfully operated supported employment in kerbside recycling, and has an employment placement advisor who works with clients to access job vacancies within the wider business community.

The charity has been in existence since March 1995, and has a proven track record of working with its client group. Currently the charity is financially self-sustaining in the recovery of its revenue costs, having initially benefited from grant funding up to 2003.

The charity was founded by the parent carer of an adult with Downs Syndrome, who had expressed a wish to "go to work like his younger brother." Upon investigating the resources available to help her son access work, the parent carer found that there were few opportunities in existence locally. Due to this, she decided to explore the possibility of instigating a service that would support and address the needs of her own son, and others with special needs, in accessing employment.

In consultations with other parents who were the main carers of young people and adults with special needs, it became apparent that such a service was in dire need by this sector of the community of West Lancashire.

It became the parent carer's main mission to address this service need, and the organisation that she founded focussed on the provision of challenging opportunities for young people and adults with special needs.

These opportunities offered individuals the experience of acquiring the work related skills necessary for employment, increasing personal confidence and enabled the local community to engage with and recognise the skills possessed by individuals with special needs.

Midstream continues and enhances this initial work in a caring and supportive environment, and the organisation currently promotes the participation of people with special needs within their own communities by:

- (i) The acquisition of new vocational skills and knowledge.
- (ii) The recognition of the benefit to the individual's wellbeing offered by the raising of one's own self esteem by partaking in worthwhile activities.
- (iii) The improved life chances that opportunity and engagement within the world of work can facilitate.

Service users access the current opportunities at Midstream via referral, which can be from statutory organisations (Social Services Directorate), carers and individual service users themselves.

All of the service users accessing the activities at Midstream require day care support to enable them to partake fully in the work activities offered. To facilitate this, the charity levies a daily charge of £37.50 (£5.00 per hour) to each service user, which is a part contribution to the recovery of the revenue costs of the organisation in relation to providing this support. This daily charge is usually funded via the service users care package, which can be administered by the statutory organisation or the individual themselves via direct payments or "In control" funding.

The package is calculated on an individual basis and is a reflection of the service users assessed care need.

With the advent of the Government white paper, *Valuing People*, it was anticipated that service users would be given increased choices and control over how their care packages were derived, and the opportunities that they would be able to access via the package. However, in the majority of individuals referred to Midstream over the previous three years this has not proven to be a reality. Members of the West Lancashire commissioning team have informed Midstream that due to budgetary restrictions and "over spend" service user's preferences cannot be taken into account when commissioning services. In-fact, the commissioning team is actively exploring ways to provide services "free of charge" by accessing finite grant funding and short term educational programmes. This obviously does not reflect the needs and aspirations of the individual service user, and impinges on their human rights by restricting their exercising of choice in relation to their daytime activity.

Two recent cases involving service users accessing services at Midstream demonstrate this increasing trend of restricting individual choice.

Case Study 1

P is a male service user with severe learning disabilities, Downs Syndrome and related health issues. P lives at home with his parents and other siblings. P's mother has returned to work, advancing her career, due to P's settled involvement with his current daytime activity.

P attended Midstream for five days per week, and accessed horticultural activities. P requires one to one support to undertake the activities, but can also partake in small group activities. P enjoys the activities he is involved in, having attained three units of an Entry level qualification and has had the opportunity of growing a wide range of plants from seed through to full maturity in glass house and amenity settings. P's health, weight and stamina have positively improved due to his inclusion within physical activity. P's speech and interpersonal skills have also improved due to his inclusion within the small group settings.

P recently had a review of his service, and it was felt by the reviewing officer at this review that P's needs could be met by him moving from his current placement at Midstream to attending the local authority day centre.

This centre is part of the current daytime opportunities for people with special needs in West Lancashire, and is resourced via a "block contract" which operates regardless of the number of individuals accessing the centre. By P attending this centre, the referring organisation would obviously make a saving of the costs paid to Midstream.

P's parents are his main carers and advocates and at the review they expressed their concerns at

this change, as they recognised that it was a “cost saving measure” and not to the benefit of P. They also felt that the centre was inappropriate for P’s needs and future development. P’s parents felt so strongly that the centre was inappropriate for P that P’s mother felt she would be forced to leave her employment to care for P during the daytime.

P’s parent’s concerns were noted by the reviewing officer, but they were told that P’s service requirement would have to be decided by panel.

This panel consists of senior commissioning team managers, and as such P’s parent’s felt that P’s service provision would be changed.

As they were unwilling to allow this to happen, P’s mother wrote to senior members of the Social Services Directorate, and her Member of Parliament expressing her concerns and dismay, and also stating that P’s change in service would have a wide ranging effect on his family. In addition to these letters, a detailed progress report was undertaken by Midstream to demonstrate P’s achievements and submitted to panel.

At the panel meeting P’s funding for his service at Midstream was agreed for a further thirteen weeks to allow Social Services time to gather further information regarding the best placement for P in order to meet his needs now and in the future.

P’s parents were obviously happier at this result, but the situation regarding P’s long term day care was still unclear which left the family with uncertainty regarding the continuation of P’s mother’s employment.

During the 13 week extension of funding, P’s parents were encouraged to visit the day centre to assess its provision. They did so, but still felt that it was inappropriate for P.

The reviewing officer also observed P’s activities at Midstream for a full day to ascertain his level of engagement, and the appropriateness of the service. Midstream was happy for this to occur, but P’s parents did express their concerns, and were surprised that the authority would use staff resources in this way. This observation they felt put undue pressure on P and had an unsettling effect once again upon the family.

Following the thirteen week period, P’s service was again reviewed by panel. P’s service funding was reduced from five days to four for his attendance at Midstream. P was forced to attend the local day centre for the remaining day. This is his current level of service provision, and his placement at Midstream is under review each six months.

P’s family feel that they have been forced to accept a place within the day centre which they feel is inappropriate and de-motivating for P by the panel decision. This decision does allow P’s mother to continue employment, but they feel that the six month review of service at Midstream has created an unnecessary uncertainty for P to contend with and with his attendance at the centre he may be forced to exchange further days in the future.

The above case demonstrates how a family, and an individual already disadvantaged by disability, has been forced to maintain services by questioning decisions made by professionals regarding their future. Due to the proactive nature of P’s family they have been able to advocate on his behalf. However, even with this extreme level of support his service has changed, and it is the belief of the family that the underlying goal of the commissioning team is to remove P from the services offered at Midstream thus enabling cost reductions to take place.

Case Study 2

J is a male service user who attended Midstream from leaving school for two years for three days per week via funding secured by Midstream to offer land-based activities. This funding provided sufficient monies to displace all costs usually associated with service users undertaking land-based activities and the related day-care support costs attributed to the referring organisation. J was also able to access Midstream’s own supported employment programme for the remaining two days per week which meant he was actively engaged for five full days.

At the end of the programme, the professionals working alongside J within the supported employment programme assessed him as not being capable of sustaining paid employment. However, J was keen to continue with his land-based activities and widen his knowledge and skills by accessing amenity horticulture activities at Midstream’s Skelmersdale facility.

As funding had ceased, to allow J to undertake the horticulture activities a representation was made to Social Services by J’s parents for him to access day-care at Midstream. J has a learning disability and Downs Syndrome, and requires constant prompting to remain on task along with emotional support and direction.

As with Case Study 1, the request for funding was referred to panel, and initial short term funding was agreed for J to undertake day-care at Midstream as no suitable alternative was available.

Unlike Case Study 1, J has a greater cognitive ability than P, and it was felt by the referring panel that J should be able to access the Lancashire Supported Employment Team with a view to them identifying a vacancy that would match J’s skills and ability. However, following J’s involvement with Midstream’s

supported employment programme, and the findings of the professionals working alongside J in regards to him maintaining employment, concerns were voiced by J's parents and they expressed their wish for J not to be introduced to the County Employment Service. They also felt that J was in need of a service that would allow him to access meaningful activities for five days per week developing his skills and abilities in a caring and supportive environment. The referring panel was reluctant to commission services on a long-term basis, again due to cost, believing that J could be supported into employment, subsequently the panel extended J's funding several times over the next few months by a few weeks at a time. This caused distress, uncertainty and anguish to J and his family.

Coupled with this anguish, J was supported by an officer from Lancashire Supported Employment who shadowed J to ascertain his skill levels, and also removed J on several occasions from his horticultural activities to "Job Search." This unnerved J, and he expressed his concerns to his parents and professionals at Midstream.

As J has limited literacy skills, he was unable to access and apply for job vacancies independently. J also has a speech impediment that reduces his ability to communicate effectively with other people. These two items are significant barriers to J when accessing employment opportunities. J's cognitive ability also restricts his understanding of the limitations these two barriers have on his acquiring sustainable employment.

As a consequence of this, J's aspirations of securing employment were unrealistically raised by the officer from Lancashire Supported Employment. As no employment opportunity was secured by J, he became increasingly depressed, and disruptive at home.

Following the unsuccessful attempts at introducing J to employment, a review was undertaken at Midstream. At the review Midstream's Operations and Training Manager outlined his concerns regarding the way in which J's aspirations towards securing employment were being unrealistically raised, and the behavioural and emotional problems this was causing. J's family confirmed that J was unhappy and unsettled by the process.

Due to the underlying requirement of J being introduced to employment as a means of reducing the funding requirement of the Social Services Directorate, it was agreed that the employment officer would continue to search for opportunities for J, but would not directly involve him in the process.

The employment officer would only introduce opportunities to J if there were a realistic chance of J securing an opportunity. With regards to J accessing day-care it was suggested by Midstream's Operations and Training Manager that a period of stability was required by the family and J to help him develop his skills further, but also to help him regain the emotional stability that his recent experiences had caused. The reviewing officer stated that she would pass this to panel, but as yet no firm decision has been made, and J's day care funding is under short term review.

In conclusion, the two case studies above outline individuals and family members who have had their right to choice changed and denied by others. The main factor for this is due to lack of County funding to enable these individuals to undertake their chosen paths.

The two case studies are not isolated incidents, with many more disadvantaged individuals requiring meaningful services in West Lancashire to allow them to engage with, and contribute to their local community. It is hoped that this review will highlight these issues and facilitate their empowerment.

23 May 2007

Letter from Speaking Up

This is a response from Speaking Up to the call for evidence regarding the human rights of adults with learning disabilities. This document details a number of our initiatives which exist to further the human rights of people with learning disabilities.

SPEAKING UP

Speaking Up is an award winning charity, based in Cambridgeshire, which exists to give disabled people a voice in the shaping of their lives so that they can move away from a position of disadvantage and exclusion.

The founding insight of Speaking Up was that a voice is the key to unlocking the door to a better life. We observed big differences in life-outcomes between those with and without a voice.

Our distinctive approach is Voice/Action/Change—the idea that if you give people a voice, they are then in a better position to take positive action, after which the likelihood of a change in personal outcomes increases substantially.

We support people with disabilities, learning disabilities or mental health issues to play a leading role in shaping their life through advocacy services and a number of innovative, user led initiatives.

BEST PRACTICE

Speaking Up's initiatives have won some of the most prestigious awards in the charity sector, including the Queens' Award for Voluntary Service (2006), The Charity Awards (2006) and the Third Sector Award for Leadership (2006) recognising the success they have achieved.

We believe that these initiatives are positive examples of practical means of securing the human rights of people with learning disabilities and ensuring that people are able to speak up for themselves, particularly through the user-led approach of our initiatives. All our projects aim to offer people with learning disabilities the same opportunities to play an active role in their community and to be valued citizens as all other members of society.

OUR PROJECTS ARE DETAILED BELOW

Next Steps

Next Steps is an innovative, user-led service which provides personalised training for individuals with learning disabilities who wish to leave Local Authority Day Centres and play a more active role in their community. Next Steps training courses range from one to two years and develop invaluable life skills including: "Travel Skills", "Cookery Skills" and developing self-confidence. Prior to joining Next Steps, many people with learning disabilities lack the life skills or confidence required to participate in their community, forcing them to live lonely and isolated lives. Next Steps acts as a "stepping stone" enabling people with learning difficulties to move into a position where they can play an active role in their community.

Next Steps is a user-led service. People with learning disabilities who enrol in Next Steps decide how it should be run and what topics will be covered in the courses and workshops. This ensures that the service remains relevant and truly reflects the needs and wants of people with learning disabilities.

Next Steps has been a massive success, 95% of graduates from the service moving into either paid or voluntary employment or further education. Many of the people who enrol in Next Steps have spent much of their previous life in Local Authority Day Centres where there is a lack of opportunity around personal development and community involvement available to them.

Next Steps is a positive example of empowering people with learning disabilities to play an active role in their community by developing the skills and self-confidence needed to do so. Without the opportunity to develop these essential life skills, people with learning disabilities can find themselves isolated and excluded from society.

The Cambridgeshire Parliament

The Cambridgeshire Parliament is a unique, user-led initiative which represents the views of over 1500 learning disabled people across Cambridgeshire relating to the provision of services. The parliament meets bi-monthly, bringing together learning disabled people, councillors, senior managers and service providers to discuss issues affecting people with learning disabilities and how services for disabled people can be improved. The parliament gives learning-disabled people "a place at the table".

The Cambridgeshire Parliament consists of 25 "MPs" each with a learning disability who are elected by their peers to represent the views of learning-disabled people in a particular area or at a particular service. This highly innovative, user-led approach empowers people with learning disabilities to speak up and ensures the parliament truly represents the views of people with learning disabilities.

The Cambridgeshire Parliament has been a huge success in highlighting the issues and views of learning-disabled people in Cambridgeshire, ensuring their voices are heard and creating positive changes in services. The parliament has also provided a number of innovative ways of empowering "hard to reach" individuals, such as those with profound learning disabilities, to speak up through the use of story boards or video footage. The parliament has also established a cabinet of people with profound learning disabilities ensuring that their voice is heard and a Minister for Diversity representing the views of learning-disabled people from minority groups.

The parliament has been so successful that Speaking Up are now beginning to disseminate the model across the UK by providing consultancy and resources to other groups who wish to start their own user-led parliament.

Consultancy, Training and Publications

Speaking Up provide a range of user-led consultancy and training courses to companies and organisations addressing issues and shortcomings around disability, increasing understanding of the needs of people with learning disabilities and ensuring that their rights are respected. These training and consultancy services are led by people with learning disabilities who have been trained through Speaking Up's "Training 4 Trainers"

programme. The user-led approach of our training and consultancy services promotes best practice and ensures that information and advice is relevant and that organisations are addressing the needs of people with learning disabilities.

Through consultancy and training, Speaking Up aim to create a “level playing field” ensuring that people with learning disabilities have the same opportunities and receive the same treatment as anyone else.

Speaking Up has provided training and consultancy to a wide range of professionals including Nurses, Police Officers and Council Officers. These training services are designed to increase the understanding of learning disability issues within these organisations ensuring that people with learning disabilities are treated equally and not discriminated against directly or indirectly, an issue highlighted in the Mencap report *Death by Indifference*.

Speaking Up also produces a number of accessible publications designed to inform people with learning disabilities of their rights and options. Speaking Up produced the accessible versions of the Disability Equality Duty. Other publication topics include *When someone dies*, *Moving Home* and *Sex and sexuality*. These publications ensure that people with learning disabilities have the same access to information as other members of society.

Young People Speaking Up (YPSU)

YPSU is a range of services, projects and courses designed to support people aged 11–25 years with learning disabilities, who are making the transition into adult life, to speak up for themselves.

YPSU provide advocates to support young adults to speak up and have a say during crucial points in their lives such as educational review meetings, where decisions will have a lasting impact on their future. These meetings can often be confusing and the opinions of parents, carers and social workers can often drown out the voice of the individual involved. YPSU ensures that individuals with learning disabilities are able to make their views and wishes known and that decisions are not made without consulting them.

YPSU also supports individuals with learning disabilities who are making the transition from youth services to adult services. YPSU provide advocates who ensure that people with learning disabilities making this transition are aware of all the options and can make an informed decision.

ADVOCACY

Speaking Up provides a range of advocacy services in secure units, hospitals and the community to support individuals with learning disabilities or mental ill-health to make their voices heard. Speaking up ensures that their advocacy services solely represent the views and wishes of the individual, and ensure the individual is aware of all the options available to them, enabling them to be the architect of their own destiny, our advocates are not advisors.

In order to ensure best practice Speaking Up only employs professional paid advocates, not volunteers, to ensure they have the time and qualifications to represent individuals effectively.

Our advocates will stay with an individual until the issue is resolved; this includes supporting the individual to approach outside organisations, such as the housing association, to ensure the individual is not discriminated against and their wishes are represented. Our advocates do not sign post other organisations and then leave the individual to resolve the issue alone.

Speaking Up also provides independent advocacy services in over 20 hospitals and secure units across the UK to ensure that residents’ human rights are being met and they have the opportunity to speak up, complain and have access to all options they are entitled to. Although our advocates are independent they work in collaboration with secure units and hospitals in order to promote best practice from both sides.

After a successful pilot, Speaking Up now provides an Independent Mental Capacity Advocacy service (IMCA). This service provides an advocate to support people who are facing a major decision such as a change in accommodation or serious medical treatment and lack the capacity to make major decisions independently. IMCA advocates work independently from other parties such as family members or care workers to ascertain the wishes of the individual and provide this information to the relevant organisations.

Currently, Speaking Up employs 45 advocates providing advocacy services to 1750 disabled people across the UK. In the last year our advocacy services have touched the lives of 2500 learning-disabled individuals.

IN CONCLUSION

As detailed above, Speaking Up is an organisation which exists to further the human rights of adults with learning disabilities. Speaking Up work in a context where human rights, choice, control, opportunity and inclusion are foremost. We believe, and external recognition suggests, that our work is innovative and effective in this regard.

Part of Speaking Up's future strategy is to replicate this work on a much larger scale and increase awareness of these new mechanisms for ensuring that the human rights of adults with learning disabilities are respected.

23 May 2007

Memorandum by Jan Thurlow

CALL FOR EVIDENCE—HOUSING BENEFIT RULES

I am writing as a parent of a young woman the label of severe learning impairment, who is also highly dependent on able people to lead all aspects of her life. She is now 30 years old and has been on the end of many, very poor, segregated services from Health and the Local Authority most of her young life. We as parents have had to fight long and hard to achieve what we have. Nothing was handed 'on a plate'. Thankfully, eight years ago my daughter was finally freed her from the binds of living very unhappily in a variety of congregate group settings where she was not only abused by fellow residents, but unscrupulous care staff as well. The services my daughter received from childhood, even though we did not want or choose them, were institutional and segregated which is all that we offered. We had no choice but to accept them as we were desperate for support. As it was, Social Services, in their game of 'financial ping-pong' with our local Health Authority, disgracefully withdrew from our daughters case due to lack of funds but under the smoke screen of her needing Health care. All we wanted was for our daughter to remain in the family with her two siblings and in our community until she grew up and then for her to have her own home, like her siblings. All we needed at the time was some practical supports coming into our family home to assist. A simple, low cost solution. Unfortunately, the inflexibility and unresponsiveness of our Local Authority through lack of funding did not allow that. In 25 years, despite a variety of legislation and White Papers little at grass roots has changed for many of the families I walk alongside. In reality they are still struggling to get the supports they need for there adults sons and daughters with a learning impairment to live in their own homes and lead an ordinary life in the community.

Thankfully my personal, wretched experiences of the impersonal, inflexible, unresponsive service system is in the past and my daughter is now living very happily in her own home, albeit that she is a tenant in a house we own. She has her individual needs met as she is not living her life in competition with other people with a learning impairment She lives near the family home and participates in her local community as a person in her own right. She is also assisted on a 24/7 basis by her own small team of personal assistants whom we as parents and Independent Living Trustees employ directly with a funding package entrusted to us by a combination of monies from the Local Authority, in the form of Direct Payments, the Independent Living Fund and for historical reason, the Health Authority.

It is through my personal experience I have worked independently both in the UK and abroad alongside professionals in the learning disability field and with family members in campaigning for people with a learning impairment to live in their own home, regardless of the assistance they need. I believe they should live in a locality that suits them and for them to be able to access facilities available to us all but most importantly with their own funds allocated to buy the support needed to lead an ordinary lifestyle.

However, the issues I want to raise are around the rules concerning Housing Benefit particularly that of "2contrivance". As many parents of sons and daughter with a learning impairment I speak with want their adult son or daughter with a learning impairment to live in their own home, not a group home. Some of the reasons given are listed below.

1. Housing Associations or Councils tend to have housing stock in designated built-up areas. These properties are often not in a locality near to the disabled family member and can seem ghetto like by lumping disabled people together.

2. Many people with a learning impairment, particularly a severe learning impairment need to live in a house/bungalow that is in a location that suit's the disabled individuals needs. This may be a quiet cul-de-sac; the countryside or quiet area away from the main road. This situation particularly applies to people with a learning disability who have little or no road sense or sense of danger in general or cannot cope with crowded/busy places or noise. Or indeed, their particular impairment may mean the disabled individual is noisy and could upset other neighbours who may be less tolerant and therefore would need a detached property. This does not mean the person with a learning impairment is hidden away out of sight, but that the position and locality of the house must suit the individuals needs.

3. Many parents do not want their son or daughter living in group homes. Or their son or daughter does not want to live with anyone else. Often people with a learning impairment are "put" to live with other disabled people they do not know, like, or get along with. Many cannot even communicate with one another yet the tendency by some professionals is to put people with a learning disabilities together, partly because it is expedient for the system and partly based on the old fashioned notion that 'they like to be with their own kind', whatever that means. It seems the "bums in beds" syndrome or block funded placements that still dominate out services for people with a learning impairment, despite the White Paper '*Valuing People*'.

Many services and the thinking of those working in those services have not moved forward which clashes with the notion of individual needs assessment, the ordinary lifestyle concept and independent living mantra found on courses for those working in the system.

4. There are also parents who want to take their disabled adult children out of block funded group homes because the individual's needs for their adult son or daughter are not being met despite large amounts of funding going into agencies to provide so called care. Often their adult disabled sons or daughters are very unhappy but this is ignored. Some are being abused by fellow residents and some cases by care staff.

Where disabled people have little, no, or poor verbal communication, so often their unique form of communication is not listened to by care staff, who are often transient, inexperienced or have to care for too many people in a group setting that the disabled person does not get heard. This in turn adds to the frustration of the disabled person and can be manifested in so called "difficult behaviour" whereby the disabled person is then blamed and labelled as having "challenging behaviour" by staff. Our behaviour would surely be challenged too if we were regularly not listened to.

All of the issues mentioned above are real. Some from my own experience with my daughter in the system some from other parents. It is because of these issues that many parents want to be able to purchase a house for their son or daughter with a learning impairment. Choosing the location of the property, often near the family home, and having more choice in the range of property is something the open market provides which better suits the individual disabled person needs. Participating and being accepted as an individual with unique gifts, skills and talents, albeit highly dependent, in community life of that chosen locality, is also crucial. Securing suitable property for the long term for their disabled son or daughter safe in the knowledge that no-one can take it away, move their son or daughter on to live elsewhere to suit the system and not the individual. Not turning their son or daughters home into a Group Home is also of great importance/. The security of parents purchasing a house for the son or daughter with a learning disability offers not only peace of mind to the disabled person but to the parents and family.

Invariably, many parents go to great lengths to find money as a deposit on a property and then try to secure a mortgage. Many parents have formed a Discretionary Family Trust, on the advice of lawyers. Unfortunately, most Building Societies do not usually lend money to Trusts but prefer to lend to the Parents of their disabled family member on the strength that the disabled person will be in receipt of Housing Benefit, thus potentially turning the parents into Landlords on a non-commercial basis. It is this position of parents being Landlords on a non-commercial basis that creates a great problems in securing Housing Benefit for their disabled adult offspring. When the parents/trustees make a claim for their disabled son or daughter, as they cannot do this for themselves, some Housing Benefit Managers accuse parents/Trustees of "contrivance" and refuse Housing Benefit. This is surely indirect discrimination against people with a learning impairment who cannot speak or act for themselves.

In my experience, most parents do not go to the lengths they do and fight the battles they do just to 'contrive' or take advantage of the Housing Benefit scheme. Frankly, most would want their children not to have an impairment or the challenges and discrimination they face in life in the struggle to get the support their sons or daughters need. It seems that many housing authorities are not helpful in these matters and show little understanding and instead have hinted to the parents their disabled son should be living in a group home. These negative attitudes from Housing managers are appalling. After all it is not their money but our money they are making judgements about. It is as if people with a learning impairment are not seen as people first. It should be a given that adults with a learning disability with the have the right to live an ordinary life, alongside us all accessing facilities available to us all.

Therefore, my request is that the present Housing Benefit rules should not be open to interpretation which can be subjective to say the least. Instead, the legislation and rules should clearly be re-written to clearly include people with a learning impairment, even if the individual has to have a parent/parents as Landlord/s and Trustee/s. After all, I know there are commercial Landlords who exploit their learning disabled tenants who are in receipt of Housing Benefit by giving them poor or low quality accommodation. Are they doing this from the kindness of their hearts? I am afraid the cynic in me suspects not, they are doing this purely for profit. Which begs the question are they themselves not 'contriving' to make money from vulnerable people?

The present rules Relating to Housing Benefit

as printed in the *Disability Rights Handbook* under *Who cannot get HB* chapter 7 page 37 32nd Ed April 2007-08 state:

Your landlord is a company or a trust connected with you

You cannot get NB if your landlord is a company or a trust of which any of the directors or employees (of the company), or trustees or beneficiaries (of the trust) is:

- You or your partner, or an ex-partner of either of you; or a person who lives with you and who is a "close relative" of you or your partner.

Under this section the rules also state:

“But this rule does not apply if your letting agreement was created for a genuine reason (rather than to take advantage of the HB scheme). What counts as taking advantage of the HB scheme” can be open to argument’.

Your landlord is a trust connected with your child—You cannot get HB if your landlord is a trust of which your, or your (current) partner’s, child is a beneficiary. For this rule, you cannot get HB even if your letting agreement was created for a genuine reason.

The rules go on to say What counts as “taking advantage of the HB scheme” can be open to argument. The handbook goes on to talk about Contrived lettings:—

Contrived lettings—In addition to all the above rules, you cannot get HB if your or your landlord’s principal of dominant purpose in creating your letting agreement was to take advantage of the HB scheme. The motives and intentions of landlord and tenant may be considered in order to determine this.

It would greatly improve things for people with a learning disability and their families if legislation was changed to make it easier and less dependent on the subjective interpretation of Housing Benefit Managers for people with a learning disability to access Housing Benefit if their parents were Trustees and not living in the same household as their disabled son or daughter.

Mrs J E Thurlow

25 May 2007

Memorandum from Edwin Leach

I am a parent carer and I am speaking on behalf of my daughter. Jessica is 19 years and has Downs. I am also a governor of a special school and a trustee of our local mencap association. I am familiar with most of the issues which occupy the lives of carers and their dependents. Jessica is presently going through transition. She is in the first year of a 2 year course at College following a LSC approved course in life skills.

The questionnaire:

Jessica enjoys good health and has always been well attended by our family doctor at the local surgery. She has also perfect teeth which I suggest is the result of a largely sugar free diet and regular dental inspection carried out by our local dentist (the practice has recently left the NHS and is now *private*. We continue to use the service because Jessica is comfortable with the doctors who examine her. On principle we prefer NHS).

Although Jessica is past school age and so is not part of the school health programme she continues to have health checks at the surgery on an annual basis (which includes thyroid function blood tests). She has access to the nurse at the surgery almost on demand for minor ear problems. She is well know to the surgery and given appropriate attention when we take her for examinations and treatment.

Jessica is inclined to be overweight but we maintain a fairly strict diet. I am not sure that diet is elsewhere always taken as seriously as we do at home. Jessica goes to college but we exercise some control by giving her sandwiches and drinks to take with her. Jessica is aware of our concern about diet and she agrees that high fat and sugar foods are bad for her health. She also understands that exercise is good for health (although she prefers to use her tricycle rather than walk). I have had a by pass graft and she often reminds me to take care of my heart—she understands from her experience therefore the importance of healthy life styles. Opportunities for exercise can be difficult to arrange for her since even short journeys can take a long time without transport and time is often a factor in her life as it is with everyone else.

Jessica is quite an attractive looking girl without any of the usual complications associated with her condition and most people respond very positively to her. Speech is a problem, however, and because of relatively non-specific speech/language training when she was at school communication with strangers can be hard for her with the consequent tendency for people we meet to talk over her head, to me or whomever the carer is with her at the time. It is the one thing I regret not making more fuss about when she was school. Provision at school follows *Total Communication* programmes which we feel do not adequately address the issue of speech outside familiar networks of friends and family—essential for LD people to be accepted in mainstream situations.

Jessica lives at home and will continue to do so because we are able to support her in a family setting which is for the moment the best accommodation setting for her. Other arrangements will have to be made when I or her mother become too old to provide adequate support although that is many years into the future. With proper support from Adult Services it may never be an issue. Jessica enjoys being away from us on short respite breaks which she takes once a month for two nights. She pays for this from her allowances. Jessica has said she would like to live in her own place one day and this may happen if the appropriate support network and living accommodation can be offered. We are not aware of the options in this respect although we have not needed to make serious requests for information. My understanding is that *appropriate* accommodation is hard to find for people with LD.

At present Jessica receives all the benefits she is entitled to. For a short period we had the advice of a Social Worker who took my wife through all the benefits she thought my daughter was entitled to. My wife looks after Jessica's finances and pays for whatever is required on Jessica's behalf.

My role is to provide support for Jessica's outside activities including transport (except for college which the LA provides during term time although we have to negotiate with them every year for some reason—we feel transport should come with the course if the student has been accepted for the duration . . .) I take Jessica to her club (Mencap) and any holiday provision we can find—usually about five to 10 days in the summer non-residential. It is provided by The Charities, Rose Road Association or Mencap and costs about £10 a day which is manageable for Jessica and gives her access to friendship circles she would not otherwise have. Jessica is also a member of the church and attends regularly. She enjoys singing in church and she has a powerful if not very tuneful voice. Jessica also takes part in the annual xmas pantomime although she has not had a speaking part yet. Last year we were given parts individually for the first time which meant Jessica performed on her own. A major step I think although she was still in a crowd. We hope one day she will have a speaking part because she enjoys performing and is an expert free dancer.

Jessica voted in the recent local government elections. And was proud to do so.

In terms of personal relationship Jessica likes her friends but generally does not have the freedom to form close relationships with boys. It is difficult to know how to arrange this.

It is quite hard for Jessica to contribute to decisions which affect her life although she has had a PCP and she got help to attend the college of her choice through the discussion of options with her teachers and Connexions.

My experience is that it is virtually impossible for Jessica to make a complaint without support. She may not yet have had any reasons for being dissatisfied with the services she has received. She may be too young to have had any serious problems that I have not dealt with on her behalf. She is highly independent and always answers questions about difficulties she may be facing (in college with other students or with teachers) with a characteristic "I'm alright . . . don't worry about me." Which may be the case.

In connection with human rights and service provision generally, my feeling developed from personal experience and other carers' anecdotes is that training for staff in major areas such as hospitals, mainstream colleges, shops and workplace settings needs to be embedded so that LD is seen as normal rather than exceptional and always elicits appropriate and empathetic responses from staff—including some highly qualified professionals—or contracted service providers.

One final point I would wish to make concerns the safety of LD people. It seems LD can be viewed by some individuals as an object for derision or even opportunities for entertainment if not outright abuse. Complaints by some self-advocates on our local LDPB paint an unpleasant picture of vulnerable people afraid to go outside their homes or to visit certain places. It would seem some public education about HR is required.

24 May 2007

Memorandum from Alan Leyin, Chartered Clinical Psychologist

Thank you for the opportunity to submit evidence to the Joint Committee on Human Rights. I will restrict my submission to two main areas:

- Parents with learning disability.
- Creeping institutional services for people with learning disability and complex needs.

This submission is a personal one and does not necessarily reflect the views of my professional body (The British Psychological Society), or those of my employing organisation.

PARENTS WITH LEARNING DISABILITY

There are growing concerns raised by professionals and the media that parents with learning disability are severely disadvantaged by prejudicial beliefs and by the Family Court system.⁴¹

Whilst it is accepted that the interests of the child are paramount, we should guard against the rights of parents being compromised by such beliefs and processes.

In my opinion, any infringement of rights is not necessarily a failure of the Court judgement *per se*, but often of the quality of the evidence presented to the Court (ie on which the judgement is made). This is compounded by the lack of transparency in the Family Court system ie because of restrictions, it is often not possible to discuss such matters openly.

To illustrate this matter I present some examples, of which I am aware (see appendix).

⁴¹ 1 Tarleton, B, Ward, L & Howarth, J (2006) *Finding the Right Support? A review of issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation. Bristol: Norah Fry Research Centre, University of Bristol.

There is an increasing number of local initiatives established to overcome such difficulties (also cited in the reference [1] below), but the situation remains one of concern.

CREEPING INSTITUTIONAL SERVICES FOR PEOPLE WITH LEARNING DISABILITY AND COMPLEX NEEDS

There is concern about the growing hospital-based provision for people with learning disabilities within the independent sector. This has been raised with particular regard to the advertising policy of the British Institute of Learning Disabilities within its journal, the *British Journal of Learning Disabilities*.⁴² Following this debate, the British Institute of Learning Disabilities responded that it shared the concern raised “... about the proliferation of independent sector hospital in this [the learning disabilities] field”.⁴³ The British Institute of Learning Disabilities, through its journal, no longer accepts adverts for such services.

Although this prohibition may be cited as positive practice, this action does not, of course, mean that such services are no longer operating. It is of concern that such a style of service provision is re-emerging.

A particular concern is that some local NHS services (particularly under the new Foundation Trust status) are beginning to emulate some aspects of these independent sector hospital-based services, by offering placements to people with learning disabilities from other parts of the country ie outside their own locality. Such developments are, in my opinion, contrary to the direction set by the White Paper, *Our Health Our Care Our Say (DH, 2006)*⁴⁴ which states, “Our strategy is to . . . focus on those with complex needs and to shift care closer to home” [para 31]. This service direction is evidence-based: “We finally want to see an end to this type of institutional provision. Campus settings limit choices and give poorer outcomes, whereas community-based settings enable a greater degree of independence and inclusion” [para 4.90] (DH, 2006).

Although it should be stressed that there are many positive examples of good practice within the independent sector, the NHS must guard itself from emulating the worse of these practices.

Although superficially this issue may be perceived as one linked more to the implementation of Government policy than to human rights, the growth of a more institutional mind-set has a number of implications for human rights, albeit currently often acting in subtle ways:

- Informally, in some services, such out-of-area referrals are referred to as “income-generating referrals” (ie already the de-humanising terminology is creeping in).
- Some services are introducing staff uniforms: whilst such initiatives are introduced to enhance the corporate image, it is potentially at the cost of social inclusion for the client ie such a reinforcement of a corporate image has the effect of inhibiting social inclusion particularly when staff are in the community with clients. (Some services are restricting uniforms to in-patient staff for this reason; this however, implies that no social inclusion, within in-patient services, is practiced).
- Within the larger units offering placements for people with learning disabilities who have complex needs there is a greater likelihood of their being a mixture of people detained under the provision of the Mental Health Act. When such a mixture occurs there is a significant likelihood of the people not so detained being subject to some of the safeguards required for those people that are detained ie locked doors, access to the community.
- People potentially being stigmatised by institutionalised processes (one example might be placement on CPA—a particular systematic approach applied to people who have mental health problems—when this is a requirement under the policy of the unit, rather than it being the application of a process based on individual need).

Good practice is promoted by DH (2006) and DH (2001)⁴⁵ but more work is required to achieve this.

25 May 2007

APPENDIX

PARENTS WITH LEARNING DISABILITY

Examples of quality of submissions to the Courts

- Instances where a diagnosis of learning disability has been made based on only two of the three required criteria.

Comment: For a diagnosis of learning disability to be made, three criteria have to be fulfilled; it cannot be based on only two, yet such part-assessment was presented to the Court as conclusive evidence, with no comment.

⁴² Rose, S (2006) [correspondence] *British Journal of Learning Disabilities* 34, 122.

⁴³ Smith, K (2006) [correspondence] *British Journal of Learning Disabilities* 34, 123.

⁴⁴ Department of Health (2006) *Our Health Our Care Our Say A New Direction for Community Services* Cm 6737.

⁴⁵ Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. Cm 5086.

- Where an assessment had taken place in a non-standardised setting (in one the father was being assessed in his living room while his child was throwing tantrums in the adjoining bedroom with his partner; the testing had to be interrupted for the father to attend to the child).

Comment: Whilst some departure from the standardised testing conditions may be inevitable on some occasions, this should always be recorded and caveats presented. On this occasion, no reference was made to these this gross departure from the standardised testing environment—in this particular case it would have rendered the results extremely suspect.

- On occasions, there is an over-reliance on the assessment and diagnosis of learning disability *per se*.

Comment: The important question is one of parental competence not one of learning disability *per se*.

- The staff assessing a family recorded that the father was speeding in his car in a 30 miles per hour speed-restricted zone. (The exact speed was disputed, the staff reporting that it was under 40 miles per hour, the father reporting 33 miles per hour). The father was not stopped by the police or charged with an offence. In the report submitted to the Court, this alleged speeding got translated, variously, as “reckless driving” and “driving dangerously”.

Comment 1: Dangerous/reckless driving is an offence separate from speeding. It is difficult to see how one alleged offence can be described as another.

Comment 2: In this case, the father was not stopped by the police, cautioned, or fined for speeding. It is difficult to see how such allegations are admissible.

Comment 3: We do not know how speeding relates to parental competence, or what the base-rate is for speeding by competent parents. (The implication in the report was that all parents who speed are incompetent parents.)

- A report submitted to the Court included 10 quotes from various published sources, all of which were used to substantiate the alleged incompetences of parents with learning disabilities. Evidence-based references that would have supported the noted competencies of parents with learning disabilities were not included in the report.

Comment: Used in this way, such references can serve to develop a mind-set that reinforces only the incompetence default, rather than to promote a fair and balanced presentation. Obviously, in child care settings the interest of the child is paramount, but this should not be at the expense of unfairly, albeit unwittingly, shifting the default position.

- Following the failure of the family car’s MOT, the father said to one of the staff that was assessing the family, that the family would have to live on “bread and water”. A report submitted to the Court noted that, “*We informed him that, whilst it was appropriate for he and [partner] to choose to endure this hardship and deprivation, it is not appropriate for the children*”.

Comment 1: Taken literally and concretely I can see how the father’s statement may have been a concern to the Court, but in everyday use of the phrase, this would have ordinarily been taken to be a light-hearted comment, implying that family funds were a little short (because of the family assessment period the father had to take a period of three weeks unpaid leave). Such a concrete interpretation of a light-hearted comment would have led to increased stress, as the father would not have understood why his statement was being taken so literally. (There was no evidence that his daughter was ever fed on bread and water alone, nor so for himself or his partner—they always did a weekly “shop” at the supermarket). Staff should be aware of the idiomatic use of language; certainly such gross misinterpretations should not be presented as an example criticising the father’s parenting. (This, in itself, highlights a great need for staff supervision, not only relating to professional issues but also relating to the idiomatic use of language). The ramifications of such simple misunderstandings, if not corrected, are likely to severely affect future interactions between the parties.

Comment 2: This example also highlights the need for staff assessing the family to be sensitive to issues of poverty; particularly any additional, indirect financial burdens imposed upon the family by any formally imposed assessment process—in this case the loss of three weeks wages.

- On one occasion it was presented that a father would, at times, overrule his partner’s authority with their daughter and that should he continue to do so, this will lead his partner “. . . to experience even greater feelings of disempowerment and reduced ability to be an effective parent”.

On a separate occasion it was noted, in a submitted report, that when the father (in trying to toilet train his daughter) said to his daughter, “Only babies sit on potties, big girls go to the toilet”. The report noted that the daughter looked confused and looked to the staff for reassurance. The report noted that “We told him, while [the daughter] listened, that babies wear nappies and ‘big girls sit on the potty’”.

Comment: Making it clear that this statement was said to the father *while [the daughter] listened* would have clearly undermined the father’s authority. This is precisely the style of interaction that the father was criticised for by the assessors. Furthermore it is not clear that the father’s behaviour was intentional (it may have been simply misguided). It is clear that the assessors comment was intended to undermine the father’s comment.

It would have been more appropriate to take the father to one side and to instruct him, rather than contradict him in front of his child. Criticism was made only of the father's comments, not of the assessor's.

- One reason for requesting that the children be adopted was that, the worry is that both children will become carers and will outgrow their parents.

Comment: Such statements have immense implications for many parents, particularly those with other disabilities (eg motor neurone, degenerative diseases and other forms of physical disabilities). Additionally, we did not know the potential of the children ie the statement is speculative; it is only an assumption that the children may outgrow their parents, which is, at this stage, untestable. (In this particular case the father drove his daughter to playschool every morning before he went to his full-time employment—we are looking quite a time into the future before the children attain these functional skills.)

Overall Comment: I am unable to pass an opinion on the weight given to the above statements in relation to children being removed from the natural family. However, I would argue that all the above (of which those presented are a sample) do provide a mind-set that is likely to skew the judgement against the parents with learning disability.

Memorandum from the Centre for Participation (C4P), Cambridge

The Centre for Participation was established in Cambridge by four organisations all directly involved in either research or the support of people with learning disabilities. These include Speaking Up (an advocacy organisation), the Cambridgeshire Learning Disability Partnership (the lead commissioner of services); the Faculty of Education and the Learning Disabilities Research Group in the Academic Department of Psychiatry both at the University of Cambridge, and the Eastern Region representative of the Valuing People support team. The Centre was established with the prime aim of promoting and undertaking research together with users of learning disability services to inform policy and practice.

We recognise that the policy of successive UK Governments since the 1971 “Better Services for the Mentally Handicapped” has very positively promoted community living and that more recent White Papers, “Valuing People” and “Our Health, Our Care, Our Say” have established basic principles of rights, independence, choice and inclusion that should guide service development. We are strongly supportive of this. We recognise that achieving these goals requires appropriate levels of resources from national and local government to Local Authorities and Primary Care Trusts so that the necessary services and adequate and appropriate health and social care support can be provided. We are aware that there are many areas of actual or potential concern with respect to the human rights of people with learning disabilities (for example, health inequalities, parenting, victimisation as a result of being a person with a learning disability, and access to services for minority ethnic groups). However, in this paper we raise four broad areas of concern that we are aware of as a result of a recent C4P conference, and from the work of those of us who are clinicians in the local learning disability services, and as a result of specific research projects. These are considered in turn.

1. CONCERNS RAISED AT THE C4P CONFERENCE

The C4P Conference held on 2 March 2007 had as one of its aims the involvement of people with LD in the setting of the research agenda. Through small workshops people with LD were asked to state what was important to them, the purpose being to identify themes that research by the C4P might subsequently address. The workshops then consider whether what they wished for was achievable. From the list we have selected the following as in each case concerns were expressed: employment, adult educational opportunities, housing, quality of life and family life, and leisure activities. For this section we have no specific data. However, the concerns expressed at the conference had been raised at other local meetings (eg, Cambridge Parliament for People with Learning Disabilities) or were recognised from other sources. Broadly they included: the increasing fragility and inconsistency in the provision of further, adult and continuing education, the lack of full or supported employment opportunities, limited support for community living (in part possibly due to increasingly strict eligibility criteria with respect to additional entitlements for social care support), and attitudes and support structures that were seen as restrictive resulting in limited choice and opportunities. These issues and the concerns expressed illustrate how the level and nature of support offered can help to compensate for any individual limitations and thereby can enable the person with a LD to contribute to society in line with what is expected from the Convention on the Rights of Persons with Disabilities (eg Articles 4, 19). If opportunities to learn and appropriate empowering environments and opportunities are not available then people with LD will be further disadvantaged and socially excluded. We ask that the Committee considers whether services provided to people with LD are adequately meeting such educational, social care and personal needs such that people with LD can be supported to be full citizens in their community and contribute to society.

2. RESEARCH FINDINGS ON VOTING BY PEOPLE WITH LD FOLLOWING THE RECENT GENERAL ELECTION

With funding from a Health Foundation grant, the C4P undertook a study of voting by adults with LD at the last general election. We compared the names and addresses on the electoral registers for constituencies in Cambridgeshire with the names and addresses of those known to be receiving services from the Cambridgeshire Learning Disabilities Partnership. These findings are reported in full in two papers presently in submission. These are available on request. In essence the key findings were:

- (a) only 66% of people known to LD services were registered to vote compared to 95% for the rest of the population; and
- (b) only 22% of those with a LD registered actually voted compared to 61% of the rest of the population.

In looking at what personal or environmental factors predicted the likelihood of registration and of voting, it was the presence of one other person in the household who voted that was crucial. The statutory duty to register adults with LD to vote is being neglected. Furthermore, it is very likely that insufficient attention is being paid to supporting adults with LD to make political choices and to vote. To date attempts to address the political disadvantages experienced by adults with LD have treated their needs as analogous to those of adults with physical and/or sensory impairments or those with low literacy skills. The need to improve the capacity of people with LD to be involved in the political process would appear to have been systematically neglected. This is contrary to the Convention on the Rights of Person with Disabilities (for example Articles 5 and 29). We ask that the Committee enquire as to what provisions are being made to ensure that people with LD are on the electoral register and how they are being supported to gain the knowledge and understanding necessary for them to form a view, if they are able and wish to do so, and to then vote.

3. CONCERNS RELATING TO RECENT OR PROPOSED GOVERNMENT LEGISLATION

These concerns arise from research undertaken by the Learning Disabilities Research Group before and since the establishment of the C4P that informed the then Mental Incapacity Bill and also proposals for revision of the Mental Health Act 1983. These have been the subject of discussion at subsequent C4P meetings. Our concerns also relate to the issues raised by the case of *Mr L vs Bournemouth NHS Trust* and the Government's subsequent response to the ruling from the European Court. In essence our concerns are broadly as follows:

- (a) whilst the *Mental Capacity Act 2005* is an enlightened piece of legislation, there is the worry that not all is or will be done to optimise the decision-making capacity of people with LD or to involve them as part of "best interests" decisions if they lack the capacity to make the decision in question. Thus, the *MCA* will be used to as a restricting rather than enabling legislation;
- (b) with respect to civil sections under proposals for amendment of the *Mental Health Act 1983* no recognition is given to the right of people with a mental disorder to make those decisions about treatment for their mental disorder that they have the capacity to do so. Such a right exists for those with capacity to make decisions about their physical health and not to grant that to those with capacity who are asked to make decisions about their mental health is discriminatory. We recognise that different conditions should apply if the person concerned is charged or convicted of an offence. Research undertaken comparing the present *MHA* and a capacity-based *MHA*, which was created by us, has shown that such legislation would enable those with severe mental illness and/or other mental disorders to be detained, where it was clearly required, as this group of people invariably lacked the capacity to make admission or treatment decisions for themselves (papers available on request); and
- (c) whilst Government proposals address the very narrow concerns raised by the European Court of Human Rights in the *Bournemouth* case (ie, deprivation of liberty) it does little to address the extreme vulnerability of people like Mr L whose mental disability was such that, in the absence of carers who argued on his behalf, he would not have been able to challenge what was being done to him. Families also may be reluctant to challenge authorities for fear of upsetting those that are providing care or concern that they will then be asked to provide the care. For example, whilst we recognise that restraint can be necessary, such restraint can be used excessively, inappropriately, and without a proper understanding of why the person has had to be restrained and what might be done to prevent the need for it in the future. Whilst the *MCA* requires that such restraint is proportionate those people who lack capacity to understand what is happening will not be in a position to challenge the actions of others. The common thread to all these issues are the fact that staff, whilst in no way acting malevolently, rarely take a human rights perspective. With respect to the *MCA* there is a need to recognise the importance of providing the educational opportunities and care strategies that optimises understanding and therefore a person's capacity to be party to decision making (paper illustrating this with respect to financial decision-making available on request), the need for advocacy (such as Independent Mental Capacity Advocates in the *MCA*—see review undertaken by us of the pilot IMCA sites on the Department of Health web-site), and the education of staff about how to address the tension between individual rights and a duty of care. Our concern is that old practices continue to exist and insufficient attention is paid to the importance of care that is both empowering and protecting and which also respects individual

rights but provides for individual needs. We ask that the Committee specifically considers the impact of proposals for mental health reform on the human rights of people with LD (see also the report of the Parliamentary Human Rights Committee on the proposals for mental health reform) and whether further training, monitoring or advocacy arrangements are advisable particularly with the implementation of the MCA 2005.

4. PEOPLE WITH LD IN TROUBLE WITH THE LAW AND/OR PLACED OUT OF COUNTY

We have concerns about people with LD placed some distance from their homes as a result of the failure of local services to meet the needs that have arisen as a result of problem behaviours or offending, often in childhood. This was identified as an issue over 10 years ago in the report on “Services for people with learning disabilities and challenging behaviour and/or mental health needs” prepared by a committee chaired by Professor J Mansell in 1992–93. Locally, our experience is that children placed out of county by education authorities because of their problem behaviour are not readily returned to county in adult life for reasons that are unclear. Furthermore, a recently completed three centre study (research undertaken in Tayside, Northumberland, and Cambridgeshire and Norfolk) of the care pathways of people with LD who have had contact with the criminal justice system has shown that where they are placed, especially in private secure hospital care, they are invariably a long way from their home. The mean distance away from home for those placed in statutory district in-patient services was nine miles, for those in statutory medium secure services: 117 miles, those in non-statutory medium secure services: 137 miles, and those in statutory high secure services: 100 miles. This leads to several concerns. First, it restricts the opportunity for continuing family contact particularly as many are from families who are socially and financially disadvantaged. Secondly, there may be little monitoring by the funding authorities given the distance thus the possibility of undetected abuse, exploitation, or neglect. Whilst inspection processes are improved it is of note that the majority of those who were subject to severe abuse as highlighted by the *Longcare* inquiry in Buckinghamshire (in this case in social care provision) were placed from other counties. Thirdly, for those who are detained under a Hospital Order (*MHA*) following a conviction and placed in an out of county secure setting may be placed there under circumstances that impedes their rehabilitation. For example, if clinicians and managers from local services are not involved when the court is advised by a forensic psychiatrist that a person requires secure hospital care, no local care pathway may be available for subsequent discharge. Delays to being discharged due to lack of engagement of local services at the time of admission and also heightened concerns about risk, given the Government agenda on public protection, both can result in prolonged restriction or possibly deprivation of liberty and prolonged dislocation from family and other contacts. Thus the right of individuals to freedom of movement and to a family life are unnecessarily curtailed. We ask that the Committee seeks information on out of county and secure hospital placements and the impact of such placements on the individuals with LD.

CONCLUSIONS

In our submission to the Committee we have highlighted four broad areas of concern. It is likely that the Committee will receive related evidence on such matters and may therefore be able to form a comprehensive view as to all areas of concern. We wish to re-emphasise the crucial importance of the Government agenda that has set the ideals that we should aspire to. However, there are serious concerns about the human rights of people with LD. These concerns have their routes in legislation, historical and present day attitudes, and in established policy and practice. We are willing to provide further material and/or to attend to give evidence if requested.

MEMBERS OF THE CENTRE INCLUDE

Craig Deardon-Phillips, Amy Forgacs, Wendy Lansdown, and John Woodhouse from Speaking Up. Richard Byers (Faculty of Education) and Isabel Clare, Tony Holland and Marcus Redley, (Learning Disability Research Group) from the University of Cambridge, Simon Whitehouse from the Eastern Region Valuing People support team, and Mike Hay from the Cambridgeshire Learning Disability Partnership.

25 May 2007

Memorandum from Inclusion North Steering Group

1. *Our experiences of using health services, education, housing and welfare benefits:*

Responses

Standard services are not for individuals, we are expected to fit into how they work, and the services aren't created to work around us.

A big part of your experience with services depends on where you live.

2. *What chances you had to have personal relationships with people like:*

- Partners (boyfriends, girlfriends, husbands or wives).
- Your family.
- Children.

Responses

Little or no sex education, service providers assumed we wouldn't need it.

Lots of people have no chance of having children of their own.

People make assumptions that people shouldn't be together to have relationships, get relationships, get married or have babies as it is thought too risky.

Separate services mean moving away from the people that love you and you love, your parents, brothers and sisters and friends—so it's difficult to create relationships.

There are no special antenatal classes or accessible information on having a baby.

3. *How easy is it for people with a learning disability to have a say in decisions that affect them?*

Responses:

A lot of people are not aware they can make decisions.

Information is not presented in a way people can understand, so they cannot make a decision.

Individual voices and decisions can get lost in a large group, but there is strength in numbers and people can feel more comfortable expressing opinions within a group.

It is very difficult, especially for people with complex needs; they are reliant on family carers or supporters to speak up for them and give them relevant information.

There are barriers to communication and it takes time and understanding to really know an individual well enough to speak on behalf of them.

Telling stories is a good way of getting a point across.

4. *How easy is it for people with a learning disability to make a complaint?*

Responses:

To have a say or make a complaint you need to understand what the complaint is and why you are making it.

There's a fear of getting into trouble, worry about being labelled a nuisance or making things worse.

Sometimes people can say you have challenging behaviour if you disagree or complain because people are not taught how to complain the right way.

Sometimes a complaint is made and nothing is done about it; people aren't being listened to.

5. *What would help people with a learning disability get their human rights and any examples you have of when this has been done well.*

Responses:

An independent supporter that understands the person they are caring for/supporting, that has the person's best interests at heart.

Access to buildings and facilities within the community would help people lead fuller lives like good changing places.

Danny's Dream is a personal support agency, which provides excellent support from well trained staff, is a great example.

A great help would be to make sure people know what is available to them from the start.

There needs to be a shift of power and control.

Engagement and understanding what it means.

Self Direct Support will help people to understand their rights and stop people from getting into institutional care.

To make sure people are aware of what their human rights are—self directed support provides the cash for individual services to allow people to be individuals.

Experiences like Partners in Policy Making and Tomorrow's Leaders gives people the knowledge, control and power to be strong, confident and to understand what human rights are.

30 May 2007

Memorandum from Pembrokeshire Advocacy

Pembrokeshire Advocacy is a charity established in 1998 working with adults who have a learning disability throughout Pembrokeshire. We offer 1:1 crisis advocacy and eight self advocacy groups in Social Activity Centres, Pembrokeshire College and private residential units. We also operate a Family Project for parents who have a learning disability and who, we feel, are particularly marginalised by a lack of services and a lack of joint working in the statutory sector. We have four part-time employees: a project coordinator, one self advocacy development worker and two crisis advocates. We are managed by a Management Committee including service users who have a range of skills.

Our mission statement states that we aim to give information and support to people with a learning disability living in Pembrokeshire through the provision of a free, confidential and independent service.

We are funded mainly through the Welsh Assembly Government Advocacy Scheme with smaller grants from other organisations eg the Local Health Board.

RESPONSE TO THE CALL FOR EVIDENCE REGARDING ADULTS WITH LEARNING DISABILITIES

Before discussing the evidence that we have gathered from our work, I would like to quote from the British Institute of Learning Disabilities *See What I Mean* guidelines:

“Acquiescence:

The term ‘acquiescence’ refers to the tendency of people with learning disabilities to agree with what is proposed to them. On the whole, they are more likely to say *yes* than *no* to a proposed course of action. They may also find it difficult to correct misunderstandings, because they do not really understand what is going on, or they lack the skills needed to contradict, or because they feel inhibited about doing so”.

Pembrokeshire Advocacy would concur with this statement. The many agencies (statutory and voluntary) that we work with frequently rely on the compliance of people with learning disabilities in order to make services run smoothly rather than tailoring services to the needs of individuals. Advocacy needs to be freely available and more clearly understood by all sectors to enable service users to make valid decisions about their lives. It is often an extra safeguard for particularly vulnerable people in specific situations.

“Provision of public services . . . and the ability of individuals to access them and the quality of provision”

1. Pembrokeshire Advocacy was involved last year (March 2006 to April 2007) in a group case with the local authority on the manner in which private tenders for running established residential units was carried out. The organisation supported 12 people who were not consulted with and who had no opportunity to participate in the change of staff members and regime change that occurred. Two people came under adult protection procedures as a result of concerns over quality of care from the new staff. No consideration was given to the loss of long established staff members and the extensive relationships that they had built up, especially around particular service users and their care. People were informed about the substantial changes to their care packages less than two weeks prior to handover and no involvement took place with clients and their families to interview potential organisations and staff and to make suggestions about the future. This organisation feels that the lack of consultation embodied an underlying attitude of exclusion towards vulnerable adults from a public organisation whose remit is to promote the well being of those in their care.

2. Through the Family Project (15 parents in total) many have expressed concerns over the lack of joint working within Social Services between the Community Team for Learning Disabilities and the Child Care team. This results in frustrations for the families who understandably see themselves as a unit but whose support comes from disparate organisations that have widely varying agendas. Eighty per cent of parents with a learning disability in our project have had some or all of their children removed into care. Little or no support has been provided for the parents after this traumatic loss has occurred and the parents live with a judgment of being bad parents primarily because they have a learning disability. If children have been fostered there are possibilities for contact to be continued but if the children are adopted, frequently they are never seen by their parents for years. This has resulted in some parents needing input from mental health services and in long term stays in psychiatric wards of local hospitals for three individuals.

The Family Project has also identified a lack of trust in the public sector of those parents who still have some or all their children living with them. This arises from their fear that if they have any problems the children will be taken from them. This results in less awareness of the real problems of this sector and adds to the isolation of this group.

3. Pembrokeshire has three group homes for eleven people with profound needs run by the National Health Service. These homes have committed staff but the people living there have been referred to our service by staff members as the staffing levels do not allow for individual choice in daily activities. Predominantly the residents have either to go out as a group or not at all. This does not fit with the social model of disability and reinforces the institutionalised medical model of care.

Secondly, there has never been clarity over these people's finances and the Pembrokeshire & Derwen NHS Trust has yet to establish transparency over the management of the benefits to which these people are entitled.

The residents in the three homes are some of the most marginalized in society as many of them cannot communicate verbally and are reliant on others for all their care. Pembrokeshire Advocacy feels that the statutory sector should be taking a lead in the social model of care.

4. The ability of learning disabled adults to access services frequently depends on someone else contacting professionals for them and also on the person involved understanding that Social Services can help them with a problem. It is not always in the interests of those caring for an individual to ask professionals in. This is one of the reasons why self-advocacy groups are vital in enabling people to speak for themselves or to refer themselves to our service for assistance.

5. The quality of provision of care can vary widely. Pembrokeshire Advocacy has noted that training for staff in social role valorisation, equal opportunities and awareness of oppressive practice may not always be prioritised in the same way that, for example, moving and handling training will be. This is particularly prevalent in the private sector and as Social Services are increasingly purchasers of services rather than providers this training should be seen as a statutory requirement for all staff working with learning disabled adults.

“The possibility for adults with learning disabilities to form and maintain personal relationships with others . . . and the positive obligations of the state which arise in this context”

1. The experience of Pembrokeshire Advocacy around parents with learning disabilities and their children has already been noted above.

2. Many of the people that are referred to our service live either with their parents or in residential settings. Private providers of accommodation can vary in attitudes to sexual relationships and the scenario that our organisation witnesses is that of public agreement to people's rights but not fulfilling those rights in practice. One of the barriers put in people's way is, typically, that residents must always get the permission of the person in charge before they can go out together. The person in charge is then “unavailable” thus preventing a relationship developing normally. Other difficulties include not supporting one person to see another as staffing levels do not allow cover. Users of our service have reported staff telling them that sexual relationships are “not allowed”. Pembrokeshire Advocacy believes that appropriate statutory training of staff should address these issues.

3. Pembrokeshire Advocacy had fifteen referrals in the last twelve months from learning disabled adults who wished to move away from their parental home to living in supported accommodation. In the majority of these cases the person feared that this may detrimentally affect their relationship with their parents. Some did not achieve their wish due to parental pressure. Parents who have a child with a learning disability understandably wish to protect that person into adulthood. This organization believes that parent/carers need regular support from the birth of the child to transition to adult services to anticipate that the person has a right to a normal life wherever possible and the expectation that the state will support their human rights.

“The opportunities of people with learning disabilities to participate in the life of their local community and the state's obligation to facilitate participation”

1. Pembrokeshire Advocacy believes in the rights of learning disabled adults to have valid work experience. Being seen as valued members of the community will alter attitudes to disability positively. The obligation of the state is to ensure that properly resourced schemes exist to enable people to participate in social firms and other work.

2. Pembrokeshire Advocacy believes in continuing education opportunities in order that people may practice life skills to promote independence. Areas of importance include self advocacy, travel training, budgeting, assertiveness, learning the local area, cookery and work skills rather than an emphasis on group leisure activities such as horse riding, bowling etc.

“The potential of the Convention of Human Rights with Disabilities to promote the rights adults with learning disabilities”

In advocacy case work we encounter many examples of infringements of human rights to a greater or lesser extent. The following is a list of commonly encountered complaints:

1. The staff/family member opens my post.
2. The staff/family member decides how my money is spent.
3. The staff look after my money in the office.
4. The staff tell me when to phone my family.
5. My (family member) asks me for money.
6. The police don't believe me.
7. The staff decided how to decorate my room.
8. I have to go to bed at 8.30 pm.
9. I'm told when to have a bath.
10. I can't go out when I want to.
11. We are not allowed to go to the pub.
12. Intimate details of my life are discussed openly at reviews.
13. No-one listens to me.

IN CONCLUSION

- Advocacy services need to be properly resourced to meet the growing demand in referrals and to challenge discriminatory practice.
- There needs to be a shared understanding of independent advocacy and advocacy standards.
- Pembrokeshire Advocacy believes that adults with learning disabilities should be involved in the training for police and medical staff to help dispel negative attitudes towards disability.
- Local authorities should establish consultation and participation groups of people with learning disabilities (and supporters if necessary) who are part of the decision making process. Training needs to be put in place for people to gain experience of meetings, decision making and possible outcomes. It is vital that this is not a paper exercise but a true commitment to involve those for whom they provide a service in future provision.
- Private providers of care must commit to thorough training of staff in learning disability issues by statutory obligation.
- Local authority complaints mechanisms should not be carried out in-house but through an independent body.

Pamela Evans
Project Coordinator

23 May 2007

Memorandum from The Kingfisher Resource Centre, Peterborough

We are service users at the Kingfisher Resource Centre in Bretton, Peterborough. We would like to respond to the Joint Committee on Human Rights press notice No 29 The Human Rights of Adults with a Learning Disability.

PARKING

Here in Peterborough we have quite a few disabled parking spaces, but these are not policed properly and we often find people who are not disabled parking in these spaces, so people with disabilities have further to walk. We want stronger penalties for this.

BUSES

In Peterborough we are entitled to free bus passes, but we can't use them until after 9.30 am and a lot of our college courses start at 9.00 am which is a problem. Also, if we have electric wheelchairs we are unable to use the public buses even the new low liner ones. We would like to see more low liner buses, larger buses and bringing back trained conductors to assist disabled users.

MEDICAL

We are on the whole quite happy with our medical services here apart from having to wait a long time for an appointment. We would like the doctor's receptionist to talk to the patient rather than just our carers and relatives. All the NHS Hospitals we have used lack readily available hoisting facilities and specially trained staff.

RELATIONSHIPS

We feel supported to have boyfriends or girlfriends if we want to.

OUR COMMUNITY

We can go to a local disco, people who run this disco will arrange taxis for us if we need one. We are able to use the local libraries and we do so, the staff are very friendly and helpful and our local library has a lift down to the lower floor where the computers are so we can go down there if we want to. We can also use the local church. We visit the local coffee shop, staff are very helpful and friendly but the tables are awkward and we have to ask for help to move them, which can be embarrassing. We use the local swimming pools, bowling alleys, cinemas, theatres etc and are happy with these. We use our local parks where facilities are quite good. Our local shopping centre has a lift to enable us to access both levels of shops, this lift breaks down a lot and is never repaired quickly. It sometimes takes months to repair. It is not working again at the moment and has not been for about seven weeks now, we have written a letter about this to our local access officer at our town hall. Our local Sainsbury's shop sometimes have a signer in the shop to assist with shopping. The local pub is very good and the staff are very helpful.

We do have access to supported employment to support us in various jobs and types of work experience, but the waiting list is very long and we are not always successful. It is easier for people who can express themselves to have a say.

COMPLAINTS

We can complain to our key workers or the managers who will support us to use the complaints forms.

FACILITIES

We need more public toilets and the ones we have need to be kept cleaner. Replacement facilities in Cathedral Square are inadequate. They have put more toilets in the car part at the back of the Town Hall instead, but this is a long way from the main town centre. Not all toilets are user friendly for people with PMLD (Profound Mental Learning Disabilities).

Thank you for the chance to tell you our concerns and we hope you find them of some use.

The Service Users at Kingfisher Resource Centre, Peterborough

21 May 2007

Memorandum from the Royal College of General Practitioners

1. The Royal College of General Practitioners welcomes the opportunity to comment on the Joint Committee on Human Rights' call for evidence.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the "voice" of GPs on issues concerned with education, training, research, and clinical standards. Founded in 1952, the RCGP has over 26,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

3. We welcome the instigation of this Inquiry and hope that it will play a part in improving the safeguarding of the human rights of those with learning disabilities and ensuring that they receive fair and appropriate access to services. The majority of our response relates to access of healthcare services and particularly the primary care system, some of the points raised should offer insight into other areas of this Inquiry's remit. In outlining some of the barriers to appropriate access to primary care below and practical solutions to these, it is important to point out that the situation across health and social care is much improved from that in the recent past and that individual rights and preferences are better factored into decision making.

ACCESSING HEALTHCARE

4. Although many people with mild learning disabilities can take full responsibility for their health needs, some people with learning disabilities have cognitive and communication difficulties and those with severe or profound learning disabilities may have little or no capacity to indicate their healthcare needs. They may experience various symptoms but be unable to accurately describe them or express the severity of their discomfort.

CONTEXT

5. Because the current primary care environment design assumes that all are equally capable of accessing the system, those with severe learning disabilities are at a relative disadvantage. They must have a fair right to health provision, and if they are relatively deprived of this because of their intellectual disability, then it is incumbent upon the State to put in place additional facilitatory systems to compensate. Social services and specialist clinical services do help to address the access imbalance. This issue has been identified in *Valuing People*⁴⁶ and confirmed by the recent Disability Rights Commission Formal Investigation report.⁴⁷ The evidence of additional clinical need and of the effectiveness of health checks in meeting this is in our opinion overwhelming and convincing^{48, 49, 50}. As this requires additional training, effort, time and skills by primary care, the State should ensure that this is appropriately resourced, in addition to duties placed on bodies via disability equality rights legislation.

BARRIERS TO ACCESS AND IMPROVING ACCESS

6. Carers of adults with learning disabilities, either family or paid professionals, may on occasion choose not to seek medical help for them through ignorance or through the collusion of institutional complacency, or by the attribution of atypical symptoms to the learning disability rather than the actual proximate medical cause (diagnostic overshadowing). It is even possible that some significantly disabled patients may be deliberately kept from face to face consultation with a medical professional and in this situation an infringement of their human rights may be occurring.

7. For example, they could be being underfunded. This might never come to light unless they were weighed regularly, this requires structured health monitoring. We believe that those who cannot take responsibility for their health should have facilitated access to healthcare, as a right. A pragmatic way of achieving is to offer regular appropriate health checks to such patients. Avoidance of such appointments without good reason, by the responsible carers, for such very disabled people might suggest an infringement of human rights. Because these patients cannot compete on equal terms with non-learning disabled patients, and because their effective care requires extra time, there must be proactive intervention systems in place to ensure that such patients' clinical needs are addressed. Structured health assessments should be used and facilitated access to the same services as the rest of the public use should be offered. Primary care services should be accessed by all people with learning disabilities, as almost all people with learning disabilities are now registered with a GP. This should be monitored and assessed.

8. Use of designated key workers, acting as advocates for adults with learning disabilities are a good way of monitoring and ensuring that these measures take place. In the case of access to healthcare it is important that medical expertise is also sought in decision making.

9. Advice and support should also be taken by public bodies responsible for care from NGOs such as Turning Point, Scope and Mencap. These organisations have a great deal of knowledge in balancing care with human rights and facilitating access to services for those with learning disabilities.

SPECIFIC ISSUES

10. We are concerned, that in some local areas, "nursing homes" with people with complex and severe disabilities are changing status to "residential homes". Though the stated reasoning for this, ostensibly the social model, is a good one in itself the practical reality is that it can lead to the withdrawal of clinical assistant sessions.

LEGISLATION

11. The right of fair access for people with learning disabilities is acknowledged in National Minimum Standard 19.4 (2001) of the Care Standards Act,⁵¹ which states that young adults in residential care should be offered a minimum annual health check which includes vision, hearing, medication review and attention to illness/disability unrelated to the primary condition. Some residential care homes are ensuring that their young adults do receive the health check, while others are not. Access needs to be consistent.

⁴⁶ *Valuing People*. A new strategy for learning disability for the 21st Century DH 2001 Cmd 5086.

⁴⁷ www.drc-gb.org/PDF/mainreportpdf_healthFIpart1.pdf

⁴⁸ Baxter, H *et al* 2006 BJGP Previously unidentified morbidity in patients with intellectual disability vol 56:93–98.

⁴⁹ Cooper S A *et al* Improving the health of people with intellectual disability: outcomes of a health screening programme after 1 year. *J Intell Disab Res* 2006, vol 50 667–677.

⁵⁰ Health Needs Assessment Report: people with learning disabilities in Scotland, NHS health Scotland, 2004.

⁵¹ National Minimum Standards for Care Homes for Younger Adults, Note, Dec 2001; section 23(1) of Care standards Act 2000.

12. I acknowledge the contribution of Mrs Ailsa Donnelly, Dr Graham Martin and Dr Charles Sears towards the above comments. While contributing to this response, it cannot be assumed that those named all necessarily agree with all of the above comments.

May 2007

Memorandum from the Independent Advocacy Services

With support from the local advocacy service for people with a learning disability the views and voices of people in the local community are gathered by regular meetings of self advocacy groups. These groups operate throughout all areas of Essex but this service supports groups in Tendring, Colchester, Chelmsford, Maldon and Braintree. These groups are made up of Service Users who are supported by the advocacy service and by elected members of Essex Peoples Parliament.

Throughout all of the areas of Essex elections are held and members of Essex Peoples Parliament who are all people with a learning disability are elected for a three year period. The elected members attend regular parliament meetings in Chelmsford ensuring the views and wishes of people with a learning disability in the local areas are listened to at county level. The members of Essex Peoples Parliament also sit on the Local Action Groups which meet regularly in the 12 district areas of Essex. This further enables information to be absorbed and disseminated. They have a large attendance from various groups within the community including Housing, Social Services, Health, Voluntary Sector and private establishments together with parents and carer groups. The chairs of each of these groups meet together regularly to share information and concerns and representatives from the chairs also sit on the Partnership Board which meets four times a year in conjunction with the Parliament meetings.

This is an excellent way of sharing and communicating views across all the areas within Essex especially for people with learning disabilities who regularly use these venues to make presentations if they have worries or concerns regarding important issues usually around their care, their health, transport or their housing. Agenda items which are taken to the Partnership Board have full impact at the highest level as the Partnership Board is attended by County Counsellors, Social Services Officers, Health Commissions and Social Care Commissioners.

We feel that with advocacy support there is a clear opportunity for people with a learning disability of make their voices heard regarding the decisions which may affect their lives.

As an advocacy service we constantly support people with a learning disability to access appropriate health care and we have good relationships with the local Community Health Teams, GP's and have a liaison officer in the local General Hospital for people admitted for treatment. The liaison officer makes the transition to acute services and support while and during admission less stressful for our client group.

We are pleased to say that our advocacy service has established excellent links with people making their transition from schools to adult services and Essex County Council had the foresight to support a full time post within the advocacy service specifically for this need.

We constantly support people with housing related issues including renting, tenancies and more recently in an extremely interesting initiative where people are able to joint own their own home using their welfare benefits.

Within the advocacy contracts Essex County Council have recognised the need for specialist support for parents with a learning disability. This support is often based around the family court arena and we are pleased that we do have considerable success and expertise within this difficult field. We not only support within the court arena but with any legal visits to solicitors and barristers along with offering emotional support in the home environment. We feel this has been a very forward thinking decision by Essex County Council which is proving invaluable to parents with a learning disability at some of the most difficult times in their lives.

We have been involved in a pilot for Individual Budgets and are pleased to say that we are seeing a real difference in the way people are able to enjoy a life which they want.

We have also supported service users in self reviews, which have proved to be very powerful and ensure that the service users own views are at the front of the review process.

We have also been involved in the Brokerage pilot where by people with a learning disability might ask for the support of a broker to ensure they have the life they want.

The advocacy service sits on the local Protection of Vulnerable Adults Group which meets regularly to review and ensure as many people as possible are aware of the processes in Essex. We regular support individuals involved in the POVA process including supporting them making video statements at the local police station and court appearances.

This is by no means a perfect answer in ensuring every body's voices are heard but we genuinely feel that Essex recognises the need for these voices to be heard and has commissioned advocacy services and provided a mechanism through Self Help Groups, Local Action Groups, Essex Peoples Parliament and the Partnership Board for this to happen.

We hope this information is useful and we would be only too pleased to provide any further information that you may require.

Avril O'Sullivan
Advocacy Team Manager

21 May 2007

Memorandum by Colchester Mencap

I welcome the opportunity to give evidence to the Joint Committee on Human rights, with particular reference to the rights of adults with a learning disability.

I am the chairman of Colchester Mencap, which is affiliated to the Royal Mencap Society and which has just over 100 members in the Colchester area. Through our members and our donations we help Colchester Gateway, an adult leisure club which has over 300 learning disabled members and Stepping Stones, a fully integrated nursery and playgroup, which helps some 60 families who have a learning disabled child.

I must emphasise that the comments which follow are solely my own and might not necessarily be subscribed to by the aforementioned organisations.

The detrimental effect of the corporate behaviour mentioned in the following comments may not constitute a breach of either the UK Human Rights legislation or of the discrimination law but a slight change in the actions of others can make a vast improvement in the quality of life of some of those who have a learning disability.

Many People with a Learning Disability ("PWLD") are subject to varying degrees of discrimination in their every day lives. As has been found in the area of race relations, it is not easy to educate the general public to be non-discriminatory. In the areas of race; physical disability; and sexual orientation there are role models for the public to look up to. By the very nature of learning disability there are fewer role models and it may be that positive steps are needed to reduce this discrimination. In our local area some of the bus drivers are most supportive but others can be most off putting, even going so far as to having left a PWLD in a wheelchair at a bus stop.

Several of our members have incoming only BT telephone lines. This is so that they cannot run up huge unexpected phone-bills. This type of line costs only £10.97 (inc VAT) per quarter. Although some PWLD may have a bank account (though it is not easy for them to satisfy the anti money laundering provisions to open a bank account) they choose to operate on a cash only basis, as due to the nature of their learning disability they cannot cope with the concept of providing for either a cheque, a direct debit; or any form of debit which does not immediately appear on the balance provided by an ATM. Such persons are now to be penalised by a huge surcharge as their bills are to be increased by £4.50 if they do not pay by direct debit. (Incidentally, most PWLD pay all their bills the day they arrive, due to the previously mentioned fear of being in debt.)

More and more organisations (including the Joint Committee) are now expecting electronic communication. Yet few PWLD have a computer and, despite the fact that computers are available in local libraries, few are likely, due to their disability, to be able to acquire the ability to use the Internet. Even if they had the ability, courses (even fee paying ones) are being rationed to those who need IT skills for employment reasons.

Like most of the able bodied population, PWLD rate housing; employment; money; health care; and leisure as their major priorities.

Appropriate housing with adequate support is, I believe, the key to a good quality of life. "Valuing People" talked about "independent living" but in Essex this has been interpreted as "Solus Living". (ie when arranging for PWLD to live "in the community" the Local Authority favours single person flats rather than housing three or four PWLD in a single housing unit). Most of my able bodied friends I chose not to live alone but with a partner or friend, yet this is often denied to PWLD despite the fact that it seems to me it might be more economical for 2, 3 or 4 PWLD to live in the same house sharing carers. This requirement to live alone can lead to depression, which might need medical intervention and also inhibits the formation of lasting relationships which are enjoyed by the able bodied community.

Employment, whether paid, subsidised, non paid in an open environment or in a training or day centres is, I believe, vital to the self-esteem of PWLD. We are fortunate in Colchester to have Pathway Employment Service, Red House and other agencies to find, assist, and support PWLD in jobs. Unfortunately, the effect of the minimum wage and the fact that many employers now require multi skilled employees (eg shelf fillers who can man a till at busy times) means that the pool of appropriate employment opportunities for PWLD is shrinking. It is, in my opinion, vital that services such as Pathway (which, I believe, goes under different names in other parts of the country) is maintained and adequately funded.

Although, like all of us, PWLD could use more money, it is lack of or diminished services which most affects their quality of life. With Local Authorities needing to make economies across the board there is a strong feeling among those caring for the Learning Disabled that support services for PWLD are being cut

back, especially services for those living in the community. In our area of Essex services for the Learning Disabled are now grouped with other vulnerable adults and there is a fear that services for the elderly may use up money, which might formerly have been spent on services for PWLD. In addition there is a perception that the outsourcing of carer services to profit making organisations may lead to a diminution in services as the profit margin comes out of previously agreed grants.

We have been fortunate in the past in that Colchester PCT, now subsumed within North Essex PCT, has had an excellent proactive programme for PWLD, run by the Learning Disability Community Nursing Team. This included sex education (much needed if PWLD are to have normal relationships), weight advice (again much needed as many persons with Downs Syndrome also suffer from increased weight) and anti smoking advice. In addition there was a programme of education general practitioners and their receptionists in the needs of PWLD. This included body maps for those who could not express themselves and Health Action Plans, which are especially good if it the duty driving carer who accompanies the PWLD to the doctor's and not a carer who has any knowledge of the patient. We hope that these services will be allowed to continue under the new regime.

The doctors and their receptionists don't always appreciate that a PWLD may well need a longer consultation to enable the doctor to overcome the learning difficulty, which may inhibit the patient's ability of expression.

Should a PWLD need to be an inpatient in hospital there are even greater stresses to be coped with as it may be the first time that a PWLD has been out of familiar surroundings and it is sometimes difficult to explain the need for a stay in hospital. Understandably, the NHS nurses do not have time for one-to-one cover of a PWLD 24/7 but sometimes the hospital is reluctant to allow a carer to be present 24/7 (that is assuming a parent or carer can be found for 24 hour cover as Social Services are often reluctant to fund such cover).

Leisure opportunities for PWLD are often restricted by covert discrimination by the general public and by a lack of money. We are lucky in Colchester to have a number of clubs and groups, including a thriving Gateway Club, which cater for the leisure activities of PWLD. Unfortunately, some of the general public can be difficult with PWLD when they visit pubs and other open venues. It is to be hoped that over the years such prejudices will be eroded. Leisure is expensive. PWLD have only a small amount of disposable income when housing and food have been paid for as their grants are small and if they are working they rarely earn more than the minimum wage. The policy of Solus Living (mentioned above) means that those living in the community often have to stay in and watch the television on their own.

Finally, I would urge all politicians to make voting easy and transparent to ensure that the Learning Disabled community do not feel excluded and marginalised. According to newspaper reports some 12% of those who voted on the recent elections in Scotland had spoiled ballot papers presumably because they did not understand the voting system. As there are estimated to be about 3% of the general population who have a learning disability the system must have been very hard to understand. Unless PWLD are not to be disenfranchised voting systems must be straightforward.

I welcome this opportunity to give evidence to such a prestigious committee and would be happy to expand in writing on any of the above points. I am sending, by separate cover, a 3 inch disc of this letter as I do not have an e-mail connection which could transmit it direct.

COMMENTS FROM THE COLCHESTER LOCAL ACTION GROUP

Your Committee's deliberations were also discussed at a meeting of the Colchester Local Action Group for the Learning Disabled held on 22 May 2007. This group is one of 12 local groups set up by Essex County Council and reports to the Council's Learning Disability Partnership Board.

The 16 people present at the meeting could be categorised as follows:

Persons with a Learning Disability (PWLD)	6
Family Carers of PWLDs	3
Professional and Support Staff	7

Discussion centred around the following headings, which arose from a reading of your press notice No 28 of 29 March 2007. Set out below are the salient points which were raised.

DISCRIMINATION IN EVERYDAY LIFE

Some PWLD had to have a CRB check to work in a café in a county library. This proved most difficult as none had any utility bills (they live in sheltered accommodation) nor a driving licence or passport. In addition due to their learning disability their handwriting was poor and they had no recognisable signature. Allowances need to be more readily made for such persons.

PWLD in Essex are eligible for a free bus pass, however some do not look disabled. One was challenged loudly on a bus. If the Local Authority has issued a free bus pass (which clearly has a photo of the PWLD) then the bus driver ought not have the right to challenge it publicly. It could have been done more discretely.

Getting onto trains with a wheelchair can be a nightmare and the exact train must be specified at least 24 hours in advance of travelling to ensure that a ramp is available.

There is a general acceptance by many of the public that minor bullying is in order. eg tipping off of hats. This can be most frightening to a PWLD.

THE RIGHT TO HOUSING IN A CONVENIENT AREA, WITH ADEQUATE SUPPORT AND WITH FRIENDS IF DESIRED

People who have autism have extremely sensitive hearing. Under Care in the Community they are often housed in flats where there are able-bodied persons nearby. Their normal noise (dogs and children) when magnified greatly affects the quality of life of those autistic persons yet there seems to be no mechanism for them to be housed away from such normal noises.

Each year PWLD have an assessment, yet there is little evidence that services are increased as a result. As PWLD age there is often a need for more services eg those with Downs Syndrome often present with the early onset of dementia.

There are few places where the parent/carers can go to obtain advice on how their child can retain the family home, with suitable support when they die.

PWLD feel that they have little choice of house share and too little thought is given to the compatibility of the house mates. They feel that friends are often split up to satisfy the authorities housing stock requirements.

There is much good practice around and more could be done to spread the word. In particular, in our area, many private landlords are happy to have PWLD as tenants so long as an appropriate care package is put in place.

ACCESS TO APPROPRIATE SERVICES

Not just those supplied by Social Services but others eg library; council services and voluntary sector.

Many forms are too hard to understand and complete. Examples quoted were benefit annual forms; job applications; and the Colchester Borough Council Housing Survey.

It is still hard to prove a need for a benefit.

Although there are at present, in the Colchester area at least, sufficient advocates, the funding runs out in 2008 and it is not known whether lasting assistance can be given.

SUPPORT NETWORK WHEN THINGS GO WRONG IN LIFE

Even when a PWLD is coping well with every day life there are times when assistance is needed and there are few places to turn to. Many do not have, and do not need on a day-to-day basis, a Social Worker yet; they often need help with "brown envelopes". The wording can be legalistic and confusing and worrying. Often the explanatory booklets are just as incomprehensible to PWLD as the forms. It was suggested that there may be a place for volunteers to help in this area but it was acknowledged that a considerable amount of training would be needed if they were to be any good.

EMPLOYMENT

Many job application forms are very confusing to PWLD.

Many businesses don't bother to write and say if the application has been unsuccessful. There is a need to build up skill sets before applying for a job.

Large employers and public bodies ought to be made to have, with good grace, a percentage of their workforce who are PWLD.

Pathway Employment Service, which does a super job in the Colchester area is dependent on funding from the European Social Fund. This restricts its area of operations. It was felt that such a vital service to PWLD ought to have a more secure source of funding.

MEDICAL CARE BOTH PREVENTATIVE AND PALLIATIVE

Some doctors and their staff need training in the specific needs of PWLD.

The buzzers installed in some surgeries to call the next patient could be easier to understand.

Some PWLD need support when going to the doctors. This is not always available as the community nurses are very busy.

It is hard to get an appointment under the 24-hour rule. Some surgeries will only make appointments for the same day, which make arranging for a carer very hard.

Opticians need extra training. Where a PWLD cannot read different symbols are needed for the eye test. In the Colchester area there seem to be no problems with dental care.

ADULT EDUCATION

Although the emphasis in adult education is now on learning for living and for work, those present felt that this was an improvement on the old system where PWLD learned to cook the same meals year in year out.

VOTING AND HAVING VOICE HEARD

The political parties in the recent elections ignored PWLD and the flyers were hard to translate to be understandable by those with a learning disability.

Most PWLD understand the English system of putting a cross in a box for the preferred candidate but proportional representation would be much harder to explain.

MONEY

Managing money is a major problem for many PWLD. It is not always easy to get someone to help who is completely trustworthy.

More simple money education would help.

Some banks and their staff are not always helpful. There have been questions regarding capacity to handle an individual's money, especially where reading and writing skills are poor.

LEISURE

Transport to leisure venues can be a problem, especially when they are out of town and not on a regular bus route eg Colchester bowling lanes; leisure centre and swimming pool.

There is still a lack of full integration in leisure but this is more due to the general public than the leisure operators.

Carers' shifts often change at 9.00 pm. This means that PWLD are forced to leave a leisure venue at 8.30 pm to be back at their home for the changeover. There was also one example given of a 2.30 pm changeover on a Saturday, which precluded any afternoon outing.

ABILITY TO FORM RELATIONSHIPS

PWLD need to understand the meaning of relationships. Not primarily sexual relationships but many, due to the nature of their disability, need education in making and keeping friends.

There is a scarcity of courses in this area.

Local Authorities often need to move PWLD from one day centre or home to another but there was a strong feeling that not enough effort was put into ensuring that friendships could be maintained. Many PWLD are not good communicators and need help in this area, yet like the able-bodied feel the loss of friendships.

There was too little bereavement counselling. This could take place as part of education before the death of a parent/carer occurred.

W B Eborn
Chairman

23 May 2007

Memorandum from Citizenship Opportunities and Safety Training (COAST)

We write with regard to the recent call for evidence on the subject of the Human Rights of Adults with Learning Disabilities, and the invitation to send examples of good practice relating to ways in which adults with learning disabilities might be better included in both their communities and in society in general.

We would like to draw the Committee's attention to the work of COAST (Citizenship Opportunities And Safety Training) and its successor COAST 2 COAST.

Funded by HACT and The Calouste Gulbenkian Foundation, COAST was a three year inter-agency partnership project between Advance Housing and Support, The Streetwise Safety Centre (Bournemouth) and Bournemouth University. Focusing on the needs and rights of Adults with Learning Disabilities, it

sought to promote greater social inclusion, active citizenship and to tackle risk, safety and harassment. Based in the Streetwise Centre (see www.streetwise.org.uk) COAST delivered units of learning that allowed participants to explore a range of issues that promoted active citizenship and addressed questions of risk, bullying and harassment. Learning focused on subjects such as safe and effective use of energy, fire safety, money management and keeping money safe, personal safety and reporting crimes, care for the environment and advice on DIY.

COAST adopted some firm fundamental principles in undertaking its work. As our focus was social inclusion we rejected a traditional learning model of teacher and student, and instead invited everyday community-based services and organisations to deliver pieces of work. As such we worked with a host of public services, businesses and voluntary agencies who came face to face with adults with learning disabilities and heard from them about the challenges that affect their lives. This led to changes in practice within organisations and began to encourage these agencies to regard adults with learning disabilities as both customers, and as citizens with the same rights as all members of society. At the same time the participants saw these organisations as approachable and interested in their needs and wants.

Throughout the three-year project we were able to witness change in the lives of many people with learning disabilities for the better. Specifically, we saw:

- the greater use of leisure services such as cinemas, sports and music events;
- more engagement with statutory agencies such as asking for information or;
- complaining about poor service;
- paid and unpaid employment and training opportunities;
- greater confidence to articulate needs and participate in society; and
- the desire to lead more independent lives, with some participants securing independent living opportunities.

COAST's work, and a detailed report on our activities, can be accessed through the webpage www.coast-uk.org.

Whilst we were able to improve the lives of many adults with learning disabilities, COAST was regionally specific to Dorset and parts of Hampshire. As COAST came to an end we were aware of the gap in services that sought to address citizenship rights for adults with learning disabilities, and the need to work with adults with learning disabilities to develop strategies to respond to safety, bullying and harassment.

Having secured funding for a three year project from the Big Lottery Fund COAST 2 COAST was developed to meet this gap on the national stage. Our remit is to provide support, training and information to at least 500 adults with learning disabilities and at least 80 members of staff working with this service user group. COAST 2 COAST covers the greater part of the Midlands and South of England. Whilst we are still in our first year of operation we are currently working across Dorset, Worcestershire, Birmingham, Oxfordshire and Kent to develop a range of opportunities that will enhance the safety of adults with learning disabilities and their rights to participate in society as full citizens.

COAST 2 COAST has a multi-agency advisory panel directing the work, including representatives from PAVA, Values into Action, Voice UK, Advance Housing and Support, Streetwise, Valuing People Support Team, Sunny ARTS. We are currently working with the Hate Crime lead from ACPO to ensure police participation. Although we know that our work will change the lives of those individuals who received education and training through us, and those with whom we work, and will equip participants with the confidence to respond to intimidation and harassment in a safe manner, as a panel we remain extremely concerned about the nature and level of hate crimes directed towards people with learning disabilities.

The nature of these crimes is such that they present a daily hazard to many people and restrict their access to public transport, leisure services, employment opportunities and consumer rights.

Whilst there is significant government attention towards this particular crime (we are currently working with the Valuing People Support Team on a project which explores hate crime and the activities being undertaken to combat such offences), we are concerned about the inconsistent manner in which such crimes are reported. At its most simplest we, as a society, do not have reliable statistics on recordable offences directed towards adults with learning difficulties. We are unable to identify the nature of hate crimes and therefore monitor the changes on an annual basis. If society wishes to address and enhance the human rights of adults with learning disabilities, then we believe that we must first understand the nature and range of incidences which impinge on human rights, and which demean people with learning disabilities as both individuals and as a community.

Memorandum from the British Institute of Human Rights

The British Institute of Human Rights (BIHR) warmly welcomes the JCHR's inquiry into the human rights of adults with learning disabilities. We see this as another positive example of the Committee's increasing focus on human rights as they relate to the everyday lives of people in the UK and in particular where they are facing discrimination or disadvantage.

BIHR knows from its direct experience of working with organisations in the public sector and the voluntary and community sectors that people with learning disabilities, both adults and children, are often denied their human rights. It is essential that learning disabled people, their family members, friends or carers know their rights and can claim them. We also see the wider potential of human rights ideas and human rights approaches for learning disabled people to claim more power and control over their own lives. In addition to individuals acting to claim their rights, we also see the potential for organisations to behave differently—not only taking steps to avoid the worst human rights breaches but also to fully promote and fulfil the human rights of learning disabled people in way that enables them to flourish as human beings.

The following are typical examples of poor practice that have become known to us via our capacity building work:

- failure to provide appropriate support for learning disabled parents expecting a child. In one case we learned about, two learning disabled parents were told their child would be removed because they could not relate to or successfully care for a robotic baby provided by the local authority to “test” their parenting skills;
- failure to support families with learning disabled parents to remain together. In one case we learned about, a child was put up for adoption on condition that there would be no contact between the parents and the child until the child reached 18 years of age. Both parents were highly distressed. Advocates involved in the case said that to the best of their knowledge, Article 8 was never considered at any stage of the decision making process;
- a privately run secure unit for people with learning disabilities punishing service users who declined to participate in occupational therapy sessions, including sessions on health and beauty, by disallowing phonecalls to solicitors and social workers;
- failure to protect learning disabled people from targeting by telemarketing sales teams resulting in their economic exploitation;
- failure to protect learning disabled residents in care homes from the violent behaviour of other residents; and
- learning disabled people being tied down for long periods ostensibly to “protect them” from self-harm.

The Committee has expressed a particular interest in practical means of securing the human rights of people with learning disabilities and positive examples of good practice.

BIHR has direct experience of the positive use of human rights law and wider human rights based approaches (the process of putting human rights principles into practice) to improve the lives of learning disabled people.

In particular, we would like to draw the Committee's attention to our “Human Rights in Healthcare” framework, developed in collaboration with the Department of Health and five NHS Trusts. Please find enclosed a copy of this framework, published in March 2007 (available at http://www.bihr.org/downloads/Health_framework.pdf).⁵² The framework is a groundbreaking attempt to explore how human rights based approaches can be used in the healthcare context.

The Committee has shown an interest in the ability of learning disabled people to make their voices heard. Human rights based approaches are the process of taking human rights principles and standards (like our own Human Rights Act) and making them meaningful in practice. These approaches have been pioneered in the international development context as a way for people in poverty to empower themselves and tackle its root causes but only now are they beginning to be explored in more developed countries. Empowerment and participation are integral to human rights based approaches. them (see in particular pages 20, 23 24 of the framework) and given the experiences of exclusion from decision-making that many learning disabled people report, we believe that human rights based approaches could have much to offer. BIHR, in partnership with other organisations, is developing this work and recently launched Principles to Practice, a programme of work aimed at building the capacity of voluntary and community sector organisations to use human rights based approaches in their work. We will be keen to work with organisations of and for learning disabled people as we develop this programme.

⁵² Ev not printed.

One of the pilot sites for the “Human Rights in Healthcare” framework was Mersey Care NHS Trust (“Mersey Care”). Mersey Care is somewhat unique amongst NHS organisations in that it has placed “rights” at the heart of all its operations. As part of the “Human Rights in Healthcare” project, Mersey Care chose to pilot a “human rights based approach” to its learning disability inpatient services. It has produced an “easy read” tool designed to elicit the views of service users about their experience of human rights as inpatients. The learning generated from this tool will be used in the organisation’s strategy, policy and decision making (for a discussion of the project see Appendix A in the framework).

We understand that other submissions to the Committee refer to the excellent work of Mersey Care in this area. For our part, we would like to stress to the Committee that the staff who attended our “human rights based approaches” induction day were extremely enthusiastic about the potential of human rights to improve their services in a wide range of areas including service user involvement, religious and spiritual care, delayed discharges, equality and diversity, impact assessment processes, and policy making. This reflects our experience of human rights capacity building generally which demonstrates that once equipped with knowledge about human rights ideas and laws and how these might work in practice, service providers quickly see their value as a tool for improving the quality of services and for engaging and involving people who use services more closely in decision-making.

Please also find enclosed⁵³ a copy of our recent report “The Human Rights Act—Changing Lives” (available at http://www.bihhr.org/downloads/Health_framework.pdf). This report, launched in April 2007, tackles the fallacy that the Human Rights Act is only useful for lawyers, or for “chancers” seeking to frustrate our justice system. It reveals instead a range of ways in which the Act has been used by groups and individuals to make a difference to everyday life in the UK. Three of the 15 case studies involve people with learning disabilities and they show how BIHR’s capacity building activities with service providers and voluntary and community organisations has led to real change. Case studies 2, 13 and 14 are reproduced below:

- Case study 2—A learning disabled man in a care home became very anxious about bathing after slipping in the bath and injuring himself. Afterwards, in order to reassure him and to build his confidence once again, a carer, usually female, would sit in the room with him as he bathed. His female carers felt uncomfortable with the arrangement. One carer commented during a BIHR training session: “I knew in my heart he was being treated without dignity, and now I recognise that his human rights are perhaps being violated”. A discussion of the human rights principle of dignity had served as a “trigger” for her and together with co-workers she was able to develop solutions that would both protect the man’s dignity, whilst also providing him with the support he needed. She indicated that she would use the language of human rights, specifically the right not to be treated in an inhuman and degrading way and the right to respect for private life, to seek a new care assessment for the man who, in her view, required manual lifting. In the meantime she resolved to erect a screen in the bathroom for herself and other carers to sit behind while the man bathed.
- Case study 13—A local authority had a policy of providing school transport for children with special educational needs living more than three miles from their school. A young learning disabled girl lived 2.8 miles from the special school she attended. Despite being unable to travel independently, she was advised by the authority that she should instead take two buses to and from school each day. An independent parental supporter who had attended a BIHR training session supported the girl’s mother to challenge the decision using human rights language. The mother approached the head teacher of the school and explained that the decision was a disproportionate interference with her daughter’s right to respect for private life, given the failure to consider her specific circumstances. The head teacher took the issue to the local authority, and the decision was reversed. Thereafter the young girl was provided with transport to and from school.
- Case study 14—A learning disabled man in a privately run residential care home had a history of starting fires. Although this had not occurred for over two years, care home staff were instructed by his psychiatrist to routinely search him each time he returned from being out unsupervised to ensure he did not have matches or a lighter. This practice was challenged by a health commissioner for the NHS Primary Care Trust (PCT) which had contracted the care home to provide the man with residential care. The health commissioner invoked the man’s right to respect for private life to argue successfully that the blanket policy should be replaced with a proper decision-making process. The new decision-making process was based on ongoing risk assessment and was communicated to the man to ensure he understood why, when, how and by who he would be searched and when the practice would be reviewed. It was agreed that routine searching would cease after six months if no matches or lighter were found on the man and if he was not involved in any fire related incidents.

⁵³ Ev not printed.

Finally, we have also enclosed⁵⁴ a copy of “Your Human Rights—A guide for disabled people” (available at http://www.bihhr.org/downloads/guide/bihr_disabled_guide.pdf). This plain English guide touches on the relevance of Articles 3, 8, 2 and 14 to disabled people and we hope it will be useful for the Committee as it considers the range of human rights that apply to people with learning disabilities in particular.

Katie Ghose
Director

22 May 2007

Memorandum by NHS Lothian, Scotland

I am writing in relation to the House of Lords and House of Commons Joint Human Right Committee enquiry into experiences of people with learning disabilities receiving care in general hospital services and the experience of service development in NHS Lothian, Scotland.

The Committee will be aware of the evidence of the increasing and ageing learning disability population, which in turn impacts on all aspects of health services, including general hospital care. This phenomenon is going to continue and as a consequence general hospitals will be required to provide more treatment for people with learning disabilities in the future; many who will have multiple, complex health needs. A useful article that was published in the *British Medical Journal* is enclosed. NHS Lothian is a large health service board that covers the City of Edinburgh, East Lothian, Midlothian and West Lothian, with the total population being some three quarters of a million. There are the full range of Primary Care, General Hospital Care and Specialist Services available for children and adults with learning disabilities. NHS Lothian has had a specific focus on addressing the health needs of people with learning disability in general hospital settings for over a decade.

The focus on patients with learning disabilities in general hospitals in Lothian resulted from a complaint regarding the care of a person with learning disabilities while undergoing medical and surgical care at the Western General Hospital, Edinburgh. At that time the Director of Nursing recognised there were particular care issues and needs experienced by people with learning disabilities. She requested that lead nurses from the general hospital and learning disability services collaborate to develop and review policies and procedures that were in place to ensure needs were met more effectively in the future.

Since then there has been a continued and sustained focus on ensuring that the health needs of people with learning disabilities are fully responded to within general hospital settings.

To the best of our knowledge NHS Lothian was the first health service to establish a dedicated liaison nursing service, based within general hospitals and staffed by experienced learning disability nurses. The service that has evolved and continues to be developed is commonly referred to as “*The Lothian Model*”. Fundamentally the model reflects a person-centred approach to care and provided additional support to patients and their carers and families. The service also seeks to ensure there is additional support and access to specialists in learning disabilities with advanced knowledge and skills of the health and care needs of people with learning disabilities.

The focus of the model is wherever possible on pre-admission planning and assessment followed by communication and collaboration with colleagues in general hospital services to ensure that the care journey is appropriate to the needs of the individual patient. This aspect of the model is important as due to the cognitive and communication impairments experienced by many people with learning disabilities, ensuring effective communication and liaison across and between health services is vital if the care journey is to be effective. The liaison nursing role includes a focus on education and development of colleagues in all wards and departments within the general hospital to ensure that they have an understanding of the broad care issues affecting people with learning disabilities.

For example education seminars have been developed on issues such as capacity and consent. These have been delivered to a wide variety of professional groups including doctors, allied health professions, nurses and many others. Often education sessions are provided to small groups of staff within their clinical areas thereby ensuring individual needs are addressed locally. The liaison nursing service acts as a bridge between primary care, specialist learning disability services, social care services, family carers and independent sector care providers. The care needs can be challenging where there are unplanned and unscheduled admissions

⁵⁴ Ev not printed.

to general hospitals which can occur at any time of the day or night. The liaison nurses as a consequence develop close relationships with colleagues in areas such as Accident and Emergency, Acute Receiving Wards, Outpatient Departments and Day Surgery Services. By developing close working relationships and collaborating with colleagues in these clinical areas it is often possible to reduce the possibility of poor experiences for people with learning disabilities and their carers. The system however relies upon general hospital colleagues recognising the need for additional assessment and support and triggering the referral to the liaison nursing service. Following this it is also possible for the liaison nurse to ensure that there is access to specialists such as speech and language therapists, psychiatrists who specialise in the mental health needs of people with learning disabilities and clinical psychologists. The model is also effective when there is a planned admission and it is possible to undertake domiciliary home based visits to undertake assessment of need that can then be built upon and shared with colleagues within specific clinical areas within the general hospital.

As part of the establishment of the liaison service within Lothian, work was undertaken to try and identify people with learning disabilities receiving general hospital care.

This proved challenging as no dedicated system is in place that enables people with learning disabilities to be identified, unless the person referring them for care specifically highlights this as an issue. In some clinical areas, such as neurosciences and gastroenterology, colleagues within general hospitals get to know some people with learning disabilities and their families who are frequent and regular attendees. This can be particularly helpful in ensuring that the liaison nurse is able to work with colleagues in these clinical areas to ensure that changes in care needs are addressed wherever possible.

The Mencap Report, *Death by Indifference*, highlights the experiences of six people with learning disabilities in England receiving general hospital care. Scotland has experienced challenges when people with learning disabilities access hospital care. The Fatal Accident Inquiry into the case of Mr James Mauchland highlights this. Mr Mauchland was a man with mild learning disabilities and associated mental health problems that died following an unobserved fall in a psychiatric hospital. Following this he had numerous transfers between mental health and general hospital services. The trauma to his cervical spine that resulted from his unobserved fall was not diagnosed and contributed to his premature death. Mr Mauchland's sister reported the death to the Procurator Fiscal which subsequently resulted in the Fatal Accident Inquiry. There were a range of findings made by the Sheriff Principal, Sheriff Dunbar, and a copy of the findings is appended. Within Scotland there have been other Fatal Accident Inquiries into the circumstances of the death of people with learning disabilities within general hospital services. Regrettably the cases detailed within the Mencap Report and those of Mr Mauchland are, in the experience of the writer, not isolated.

In response to the findings of the James Mauchland Fatal Accident Inquiry the Scottish Executive have been pro-active in issuing national guidance to all NHS Boards regarding the care and support of people with learning disabilities in general hospitals. A copy is appended. Additionally the Scottish Executive held an event for NHS Board Chief Executives and Nurse Directors in late 2006 regarding the need to develop and improve services for people with learning disabilities within general hospitals. Specific guidance has been issued in 2007 by the Scottish Executive to all NHS Board Chief Executives and a copy is attached for reference. As a result of the developments within Scotland many NHS Boards have been pro-active in developing dedicated liaison nursing services, drawing on the knowledge and skills of learning disability nurses. At the time of writing half of the NHS Boards have established a dedicated service and many of the others are in the process of developing proposals to establish one locally. A Scotland wide event was held earlier this year for liaison nurses currently in post and this had led to the creation of a learning disability liaison nursing national network.

This network is now seeking to collaborate across Scotland in relation to the development of issues such as admission and discharge protocols and disseminate and share best practice to ensure consistency and continuity of care throughout the journey in general hospitals.

NHS Quality Improvement Scotland and NHS Education for Scotland, two of Scotland's special health boards with a country wide remit for promoting and developing quality within health care and in education have been pro-active in focusing on the needs of people with learning disabilities. NHS Quality Improvement Scotland developed a Best Practice Statement, *Promoting access to health care for people with learning disabilities—a guide for frontline NHS staff* which includes an audit that can be undertaken by local clinical teams to self assess on how accessible their local service is for people with learning disabilities and support changes and developments in their service. A copy is enclosed. Further NHS Quality Improvement Scotland has developed a set of Quality Indicators for learning disabilities that include a focus on the care of people with learning disabilities in general hospitals. A multi-agency pilot inspection of services for people

with learning disabilities was undertaken within NHS Ayrshire and Arran that drew on the learning disability quality indicators to inspect general hospital services. This pilot is now the subject of an evaluation that will inform the development of future multi-agency inspection of services for people with learning disabilities in Scotland. The writer anticipates that there will be a continued focus on general hospital services as a result.

NHS Education for Scotland funded the development of continuing professional development modules with a specific focus on the needs of people with learning disabilities. A new module, *Promoting access to health care for people with learning disabilities*, is being developed.

I hope this information is helpful to the Committee and look forward to the outcome of the inquiry. Please let me know if you require any further information or if I can be of assistance.

Michael Brown
Nurse Consultant

Appended⁵⁵:

1. British Medical Journal Health Needs Article.
2. NHS Quality Improvement Scotland Best Practice Statement.
3. Findings of James Mauchland Fatal Accident Inquiry.
4. Scottish Executive communication to NHS Boards.

Memorandum from Mencap

Mencap is the UK's leading learning disability charity, supporting people with a learning disability and their families and carers in England, Wales and Northern Ireland.

We welcome the decision of the Joint Committee on Human Rights to conduct this inquiry into the human rights of adults with learning disabilities, and the opportunity to submit evidence. We would be pleased to provide further evidence, in writing or orally, if this would be useful to the Committee.

1. BACKGROUND AND CONTEXT

Human rights and people with a learning disability—the framework

Mencap's vision is of a world in which everyone with a learning disability has an equal right to choice, opportunity and respect, with the support they need. We believe that barriers to participation should be removed to enable all people to make meaningful choices and enjoy real opportunities to live their lives as they want to. People with a learning disability will often need greater support in order to exercise their human rights.

Mencap believes that the human rights of people with a learning disability in the UK are frequently not respected. While significant progress has been made in recent years, both in terms of the level of public understanding and acceptance of people with a learning disability and in terms of the laws and policies which govern the way they are treated and the services they receive, we believe that people with a learning disability continue to experience serious discrimination. In brief, they are more likely to need support in order to fulfil their potential, and less likely to get it.

The UK now has a largely very positive framework of human rights law, anti-discrimination law and learning disability policy. However, there is still a very long way to go in delivering practical human rights to people with a learning disability in real life. Indeed, learning disability policy operates in effect in two parallel universes: one in policy documents, in which people with a learning disability are equal citizens with equal rights, opportunities and choices; and the other in reality, in which people with a learning disability are denied meaningful day activities, have unequal access to healthcare and education, and are given no choice about where they live and who they live with.

⁵⁵ Ev not printed.

The Government's policy towards people with a learning disability in England is set out in the 2001 document *Valuing People: A New Strategy for Learning Disability for the 21st Century*, which correctly identifies many of the key barriers facing people with a learning disability and makes a series of proposals based on the four key principles of rights, independence, choice and inclusion.⁵⁶ The Prime Minister's Strategy Unit's 2005 report *Improving the Life Chances of Disabled People* proposes that "By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society".⁵⁷ In Northern Ireland, policy towards people with a learning disability is set out in the 2005 document *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland*,⁵⁸ which makes recommendations based on the five core values of Citizenship, Social Inclusion, Empowerment, Working Together and Individual Support.⁵⁹ In Wales, the Learning Disability Advisory Group's 2001 document *Fulfilling the Promises* sets out proposals for a framework for services for people with learning disabilities.⁶⁰

The following pieces of legislation are particularly important in guaranteeing and promoting the human rights of adults with learning disabilities:

- *The Human Rights Act 1998* guarantees to all people with a learning disability, and indeed to all human beings, key rights including the right to life, the right not to be subjected to torture or inhuman or degrading treatment, the right to liberty and security and the right to respect for private and family life.
- *The Disability Discrimination Act 1995* prohibits discrimination on disability grounds.
- *The Disability Equality Duty*, part of the *Disability Discrimination Act 2005*, places a duty on public authorities to pay "due regard" to the promotion of equality for disabled people in every aspect of their work.
- *The Mental Capacity Act 2005*, which applies to England and Wales, protects people who lack capacity to make certain decisions, ensures that people are supported to make their own decisions wherever possible, and stipulates that any acts done or decisions made on behalf of a person who lacks capacity must be made in his or her best interests.

The UK signed the *UN Convention on the Rights of Persons with Disabilities* on 30 March 2007. The Convention's purpose, as set out in Article 1, "is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity".

Human rights law and disability discrimination law present opportunities to challenge discrimination and inequality, but this has mostly taken place on a piecemeal, case-by-case basis. The lack of respect for the human rights of people with a learning disability is rooted, in large part, in a lack of funding for the services and support which are needed to ensure that they have the same opportunities and choices as other citizens, and a lack of political will to deliver the improvements which the policy framework appears to promise.

In February 2007 the Equalities Review, commissioned by the Prime Minister, published its report. It suggested an Equality Scorecard, to be used in assessing equality for all people. The scorecard contains ten dimensions of equality, as follows:

- *Longevity*, including avoiding premature mortality.
- *Physical security*, including freedom from violence and physical and sexual abuse.
- *Health*, including both well-being and access to high quality healthcare.
- *Education*, including both being able to be creative, to acquire skills and qualifications and having access to training and life-long learning.
- *Standard of living*, including being able to live with independence and security; and covering nutrition, clothing, housing, warmth, utilities, social services and transport.
- *Productive and valued activities*, such as access to employment, a positive experience in the workplace, work/life balance, and being able to care for others.
- *Individual, family and social life*, including self-development, having independence and equality in relationships and marriage.
- *Participation, influence and voice*, including participation in decision-making and democratic life.
- *Identity, expression and self-respect*, including freedom of belief and religion.
- *Legal security*, including equality and non-discrimination before the law and equal treatment within the criminal justice system.⁶¹

⁵⁶ *Valuing People: A New Strategy for Learning Disability for the 21st Century*, (Department of Health, 2001), p 5.

⁵⁷ *Improving the Life Chances of Disabled People*, (Cabinet Office, 2005), p 7.

⁵⁸ *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland* (Review of Mental Health and Learning Disability (Northern Ireland), 2005).

⁵⁹ *Equal Lives*, para 1.13, pp 6–7.

⁶⁰ *Fulfilling the Promises: Proposals for a framework for services for people with learning disabilities* (Learning Disability Advisory Group, Report to the National Assembly for Wales, 2001).

⁶¹ *Fairness and Freedom: The Final Report of the Equalities Review* (2007), p 18.

Adults with learning disabilities fall short of equality with the rest of the UK population on every single one of these dimensions.

There are a number of significant barriers which prevent people with a learning disability from exercising their rights. These include:

- *Lack of understanding of learning disability and assumptions about capacity*—people with a learning disability have often been excluded from decisions which concern them. The first two statutory principles in the Mental Capacity Act 2005, that a person must be assumed to have capacity unless it is established that they lack capacity, and that a person is not to be treated as unable to make a decision unless all practical steps to help him do so have been taken without success, are welcome and apply to all people with a learning disability at all times
- *Lack of knowledge about rights and support to exercise them*—people with a learning disability have historically often been placed in institutions away from the rest of society and “looked after” rather than treated as autonomous individuals and given meaningful choices. They are still frequently not given information about their rights in accessible ways, or support to understand them and exercise them. The education system, both in special and mainstream schools, often fails adequately to prepare children and young people to become adults. Others, including their families and carers, often also lack knowledge, confidence and support to exercise their rights.
- *Unequal access to services and opportunities*—people with a learning disability have worse access to healthcare, worse access to education, training and employment, fewer opportunities to choose where they live and who they live with, and fewer opportunities to participate in the life of their community and form meaningful relationships.
- *Stigma and discrimination*—despite welcome changes both to the law and to social attitudes, people with a learning disability are still subject to prejudice and misunderstanding, and to assumptions that they have little to contribute to society. The experience of prejudice may also discourage people with a learning disability from attempting to play a full role in their community, and contribute to their isolation and exclusion.

People with a learning disability—the population

Throughout this document we will use the term “learning disability” in the same way as *Valuing People*:

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.⁶²

There is no universally accepted figure for the number of people with a learning disability in the UK. *Valuing People* estimated that in England in 2001 there were around 1.2 million with mild/moderate learning disabilities, and around 210,000 with severe and profound learning disabilities—65,000 children and young people, 120,000 adults of working age and 25,000 older people.⁶³ Equal Lives estimated that in Northern Ireland in 2005 there were about 16,300 people with a learning disability, of whom about 8,200 were adults.⁶⁴

There have been a number of estimates about the increase in the population, but a figure of 1% pa is generally accepted. This is because:

- Medical advances and preventative care mean that more children with complex and multiple needs are surviving to become adults;
- More adults are living longer as mortality rates decline—the Local Government Association (LGA) calculates that there will be a 41% increase in people with learning disability aged between 60–79 by 2011 and a 56% increase in those over 80;⁶⁵

Within the overall population of people with a learning disability, those with profound and multiple learning disabilities (PMLD) are particularly disadvantaged—a marginalised group within a marginalised group. All of them will have great difficulty in communication, and will need high levels of support with most aspects of daily life. They are the least likely to be understood, the least likely to be given choices about their lives and the least likely to be valued for who they are as people rather than “cared for”. They face more barriers to participation in social and community life than almost any other group of people. Mencap fully supports, and draws to the particular attention of the committee, the evidence submitted to it by the PMLD Network, which focuses specifically on the human rights of this group. Throughout this document,

⁶² *Valuing People*, para 1.5, p 14.

⁶³ *Valuing People*, para 1.8, p 15.

⁶⁴ *Equal Lives*, para 3.29, p 20.

⁶⁵ Service Working Group—Adults and older people services: Submission to Comprehensive Spending Review 2007 (Local Government Association, 2007), p 40.

wherever we make reference to people with a learning disability facing discrimination and failing to have their human rights respected, you should assume that the point applies with particular force to people with profound and multiple learning disabilities.

2. THE RIGHT TO LIFE AND FREEDOM FROM INHUMAN OR DEGRADING TREATMENT

Summary

The Human Rights Act says that everyone has the right to life (Article 2) and the right to be free from inhuman and degrading treatment (Article 3). It also says that everyone should enjoy these rights without discrimination (Article 14). The UN Convention on the Rights of Persons with Disabilities says that disabled people should enjoy the right to life (Article 10), that they should be free from torture or cruel, inhuman or degrading treatment (Article 15), that they should be free from exploitation, violence and abuse (Article 16), and that they have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (Article 25).

But people with a learning disability are more likely than most other people to have decisions made for them rather than to be involved in making decisions themselves. False assumptions about their quality of life can have far-reaching effects on the way they are treated. There is a considerable body of evidence that people with a learning disability receive a poorer standard of healthcare than the general population, and that they are frequently given inappropriate treatment or denied the treatment they need. In many cases, we believe that people with a learning disability have died because of a failure on the part of health professionals to take their health problems seriously or to make reasonable adjustments to enable them to be given the treatment they needed. Our 2004 report *Treat me right!* looked into the reasons why people with a learning disability are poorly served by the NHS. Our 2007 report *Death by indifference* discussed the cases of six adults with a learning disability who died unnecessarily in the care of the NHS, and explained why we believe that there is institutional discrimination within the NHS against people with a learning disability.

People with a learning disability, particularly those with severe or profound and multiple learning disabilities, are more vulnerable to physical, sexual and financial abuse than the general population—especially where they are in institutional care. Robust safeguards and procedures need to be in place to prevent abuse if people with a learning disability are not to be subjected to cruel, inhuman or degrading treatment. But recent investigations in Cornwall and in Sutton and Merton have uncovered widespread abuse, and a systematic failure to take adequate measures to prevent it.

Health

People with a learning disability receive poorer healthcare than the rest of the population. There is a systemic failure in the NHS to meet the basic human rights of people with a learning disability who need medical care. This is leading to unnecessary suffering and death:

- Between 1988 and 1990 the chance of dying under the age of 50 for people with a learning disability was 58 times higher than in the general population.⁶⁶
- The Disability Rights Commission’s 2006 report on health inequalities showed “people with learning disabilities die younger than other citizens. They also have high rates of unmet health needs, which may contribute to early death”.⁶⁷ They highlighted a “fatal complacency” in the NHS that people with a learning disability “just do die younger”.
- People with a learning disability are more likely to have respiratory disease than the rest of the population and are more likely to be obese.⁶⁸
- Mencap’s research in 2004 showed that 75% of GPs had received no training to help them treat people with a learning disability, and that 90% felt that a patient’s learning disability made it more difficult to make a diagnosis.⁶⁹
- Between 20% and 60% of people with a learning disability are given psychotropic medication—but this is often used as a medical restraint, not as a treatment for mental health problems. The complications associated with these drugs can have serious implications for the overall health of the individual taking them.⁷⁰

Evidence of the failures of the health service in relation to people with a learning disability have been known by government since at least 2001, when Valuing People said that “the substantial health care needs of people with learning disabilities too often go unmet”.⁷¹

⁶⁶ Background evidence for the DRC’s formal investigation into health inequalities experienced by people with learning disabilities or mental health problems (Disability Rights Commission, 2004), p 5.

⁶⁷ *Equal Treatment: Closing the Gap* (Disability Rights Commission, 2006), p 29.

⁶⁸ *Equal Treatment: Closing the Gap*, p 29.

⁶⁹ *Treat me right! Better healthcare for people with a learning disability* (Mencap, 2004), p 13.

⁷⁰ DRC, Background evidence for the DRC’s formal investigation into health inequalities, 2006.

⁷¹ *Valuing People*, para 1.18, p 19.

Since then, the body of evidence has grown. In 2004, Mencap published *Treat me right!* and the National Patient Safety Agency (NPSA) published a report highlighting the fact that people with learning disabilities are more at risk in hospitals than other people.⁷² In 2006 the Department of Health's White Paper *Our health, our care, our say* acknowledged that "people with learning disabilities face particular health inequalities. The National Health Service has historically not served such people well".⁷³ And in March 2007 Mencap published its report *Death by indifference*, which described the deaths of six people with a learning disability while in the care of the NHS.⁷⁴

We believe that Emma, Mark, Martin, Ted, Tom and Warren need not have died. Martin was admitted to hospital after a stroke, and died after being left without nutrition for 26 days. Emma was refused cancer treatment, despite being assessed as having a 50:50 chance of survival with treatment, because doctors believed that she would not cooperate. Her mother had to go to the High Court just to get pain relief for her. We believe that people with a learning disability face institutional discrimination in the NHS. After the publication of *Death by indifference* Ivan Lewis MP, the Parliamentary Under Secretary of State for Care Services, said that there was "systemic indifference" in the NHS towards people with a learning disability.⁷⁵

Despite this acknowledgement, little action has been taken to address these inequalities:

- Annual health checks for people with a learning disability, introduced in Wales in 2006 [check], are still not available in England.
- The confidential inquiry into mortality among people with learning disabilities, suggested in *Valuing People* in 2001,⁷⁶ has still not been established.
- The NPSA's recommendation to produce a Safer Practice Notice on people with a learning disability has been rejected by the Department of Health.
- No targets have been set to address the acknowledged health inequalities experienced by people with a learning disability, showing that they are still not considered a priority.

Since publishing *Death by indifference* in March 2007, Mencap has been contacted by many people who wanted to share their stories about the experiences of people with a learning disability in accessing mainstream health services. The case studies below have all been given to us since March, and all the events described took place within the last two years. Some names have been changed, but the people and their stories are all real. We believe that the new cases illustrate the following serious problems.

The NHS often fails to meet its duty of care towards patients with a learning disability. The most basic of needs of people with a learning disability are not met whilst they are in the care of the NHS. Family carers often have to stay with their loved ones at all times in hospitals to provide personal care and feeding that would otherwise not be done. The NPSA has highlighted that family carers often assume the role of full time carers when people are in hospital, leading to changes in health status being overlooked. There is no guidance from the Department of Health on meeting the duty of care for people with a learning disability.

Case study

Liam, who was 20 years old and had profound and multiple learning disabilities, was found on his back, lying across the bed with his head through the bars of his hospital bed. He had died of asphyxiation. The night he died was the first time Liam's family had left his bedside as they were advised to go home and get some sleep. Liam had marks and indentations on his head where it had been pressed on the bedside bars. He was found dead in this position by the tea lady. There was no record that he had been observed in the night, and no record that the two hourly drainage of his PEG tube had been carried out, or of any changes of his continence pad during the night. The position Liam was in when he died was one that he could not have achieved easily or quickly due to his physical disability.

Medical professionals often dismiss symptoms of illness as being part of the person's disability—this is called "diagnostic overshadowing". Expressions of pain can be ignored and treated as behavioural problems, especially when people communicate non-verbally. This can lead to a sometimes fatal delay in diagnosis, and to ongoing, unnecessary pain for the individual.

Case study

Helen, a 52 year old woman, was taken into A&E complaining of chest pains. She had a learning disability, and was able to live in her own flat with support. Helen was suspected of having gallstones and was told she would need an operation. She became distressed and agitated at this, so the hospital sent her home.

Helen continued to be distressed and her confusion increased. She was sent to a psychiatric ward,

⁷² *Understanding the patient safety issues for people with learning disabilities* (National Patient Safety Agency, 2004).

⁷³ *Our health, our care, our say: A new direction for community services* (Department of Health, 2006), p 100.

⁷⁴ *Death by indifference: Following up the Treat me right!* report (Mencap, 2007).

⁷⁵ *Government launches inquiry after Lewis speaks of NHS "indifference"*, Community Care (15 March 2007), <http://www.communitycare.co.uk/Articles/2007/03/15/103800/government-launches-inquiry-after-lewis-speaks-of-nhs.html>

⁷⁶ *Valuing People*, para 6.8, p 62.

where her she behaved in ways very unusual for her, pacing and groaning in pain. As Helen's behaviour worsened, she was sectioned under the Mental Health Act. Helen's family tried to explain about the gallstones, as they believed that the pain they were causing her was the most likely explanation for her change in behaviour. Doctors informed her family that Helen was "just doing this for attention".

Eventually Helen's family got her an appointment to have the gallstones removed. She missed two outpatient appointments due to being in the psychiatric unit. She was found to have multiple gallstones, and her gall bladder had to be removed as it had become seriously infected, inflamed and full of pus. If the operation had been carried out after her first admission, it would have been a much simpler procedure.

Following the operation Helen developed complications and had to be readmitted. She died in September 2006 of multiple organ failure.

Pain management for people with a learning disability in acute care settings is poor. It tends to rely on patients ability to communicate their level of pain. For those unable to communicate verbally, or to understand "scales" of pain, it is vital that adjustments are made to ensure they are not left suffering unnecessarily. There is also, according to the Joseph Rowntree Foundation, a "generalised but concerning belief that people with a learning difficulty have a high pain threshold" amongst medical staff.⁷⁷

Case study

Sara's parents noticed she was showing signs of distress, crying and falling over more frequently. They took her to hospital to investigate what was wrong, but no investigations took place. Sara kept holding her head and was clearly in serious distress, but was only given paracetamol to manage her pain. Ten days later Sara was screaming in pain and suffered a major seizure. A brain scan revealed an 8 cm brain tumour. It was too late to operate, and Sara died. Sara must have been in intense pain, without appropriate treatment or pain relief, for over 10 days.

The NHS fails to make reasonable adjustments to ensure that people with a learning disability are not discriminated against. People with a learning disability have more unmet health needs than the rest of the population, but have more difficulties accessing health services. Healthcare information leaflets are not produced in easy read format, and do not reach people with learning disabilities.⁷⁸ When people require acute healthcare, too often no adjustments are made to enable them to access these services. No side rooms are made available for people for whom the confusion of an open waiting room and ward would prompt challenging behaviour. As a result, individuals become distressed, are obliged to leave and are unable to access the care they need.

Adjustments are sometimes needed to allow treatment to take place. Mencap is aware of cases where medical staff are unwilling to carry out investigations because individuals with challenging behaviour are fearful in hospital settings and so do not cooperate with staff. If an individual is not able to understand the implications of treatment, it should be assumed, as it is with non-disabled people, that it is in their best interests for treatment that would keep them alive and well to be carried out, unless exceptional circumstances apply.

Case study

John is an older man with a learning disability. He lives in a care home. He started falling over and his mobility decreased, leaving him confined to a wheelchair. His behaviour is changing, and carers believe he is in pain and want the medical causes of this investigated. But because John has challenging behaviours he cannot undergo a scan unless he is anaesthetised. As it is not normal procedure to anaesthetise for a scan, Doctors are currently refusing to carry one out. John's condition is deteriorating and no-one is able to say why.

On 12 March 2007, the day that *Death by indifference* was published, the Secretary of State for Health, Patricia Hewitt MP, announced that there would be an independent inquiry into healthcare for people with learning disabilities, looking at the six deaths highlighted in the report and their wider implications. At the time of writing this submission to the JCHR inquiry, 10 weeks later, the terms of reference for the inquiry have yet to be announced.

Abuse

Many adults with a learning disability are particularly vulnerable to abuse. Abuse—whether physical, mental, sexual, financial or by neglect—is always a violation of a person's human rights. Individual acts of deliberate abuse engage both human rights issues and the criminal law, but we want to focus on the human rights issues raised by structures which are inadequate to prevent the abuse of people with a learning disability in particular.

⁷⁷ Diana Kerr, Colm Cunningham and Heather Wilkinson, *Responding to the pain experiences of people with learning difficulty and dementia*, (Joseph Rowntree Foundation, 2006), p 20.

⁷⁸ *Equal Treatment: Closing the Gap*, p 40.

Cornwall

In July 2006, the Healthcare Commission and the Commission for Social Care Inspection (CSCI) published their joint report into abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust.⁷⁹ Their investigation was prompted by concerns raised by East Cornwall Mencap Society, who wrote to the Healthcare Commission and the Commission for Social Care Inspection (CSCI) in October 2004, raising serious concerns about the care and treatment of people living in assessment and treatment centres and supported living services provided by Cornwall Partnership NHS Trust. The Healthcare Commission decided to conduct a formal investigation in May 2005. In September 2005 the investigation was extended to be carried out jointly with CSCI.

In Budock Hospital, near Falmouth, inspectors found evidence of 64 incidents of abuse in the five years to October 2005.

These included staff hitting, pushing, shoving, dragging, kicking, secluding, belittling, mocking, and goading people who used the trust's services, withholding food, giving cold showers, over-zealous or premature use of restraint, poor attitude to people who used services, poor atmosphere, roughness, care not being provided, a lack of dignity and respect and no privacy.⁸⁰

In most of Cornwall's 45 supported living houses, staff rather than residents held the keys. Many residents were detained against their will. In one house, all of the taps had been removed because of concerns that one of the tenants might flood the house. In another house, all of the light switches had been removed and only staff could turn lights on and off. One resident had his arms tied to a wheelchair for up to eight hours a day. "Staff seemed unaware that it was unlawful to detain people against their will".⁸¹

People with a learning disability and their families and carers were not involved in the delivery of services. Advocacy and therapy services to help people communicate were limited and not seen as a priority. Staff routinely made decisions about almost all aspects of people's lives—whether they could open doors or go outside, which cup they used, how they spent their money, who they lived with. Cornwall's learning disability partnership board was ineffective. Its minutes recorded discussions, but decisions were unclear and actions were not highlighted. It was not clear who had responsibility for implementing key elements of the *Valuing People* strategy, or taking forward priorities agreed by the board. Responses to complaints were very poor. The complaints process was not promoted effectively, and there was only one area in the learning disability directorate which had information on how to complain in easy read form. The trust's board said that "the number of complaints and compliments was lower than expected".⁸²

The Healthcare Commission and CSCI found that the executive team at Cornwall Partnership NHS Trust did not understand *Valuing People* or the extent to which their services deviated from best practice. The trust had no strategic plan for services for adults with learning disabilities and these services were not included in the local delivery plan. According to the report, "none of the trust managers responsible understood what a good model of care for people with learning disabilities should look like or recognised how far short their service actually fell".⁸³ In a damning assessment of the failure of the whole system adequately to protect the people in its care, it concluded:

*Our investigation of the trust's residential learning disability services has identified a whole system failure. The mechanisms that should have protected people living in the trust's services failed; the trust's managers and the board, who are directly responsible for the quality and safety of care, failed; the PCTs, who are responsible for commissioning safe and good quality services, failed to do so; the strategic health authority failed to discharge its responsibility to manage effectively the performance of the trust's learning disability services and the PCTs' commissioning function; and the local system for adult protection failed to protect vulnerable adults as it should.*⁸⁴

Sutton and Merton

In January 2007, the Healthcare Commission published the report on its investigation into learning disability services provided by Sutton and Merton Primary Care Trust.⁸⁵ The investigation was carried out at the request of the chief executive of the PCT, following a number of serious incidents including allegations of physical and sexual abuse.

The report found that institutional abuse was prevalent in most parts of the learning disability service. It said that "the model of care was largely based on the convenience of the service providers, rather than the needs of individuals".⁸⁶ It found that people were living in unsatisfactory and undignified environments, and that restrictive physical interventions and restraint were widely used. Only a minority of the 184 people

⁷⁹ Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust (Healthcare Commission/Commission for Social Care Inspection, 2006).

⁸⁰ Joint investigation into Cornwall Partnership NHS Trust, p 31.

⁸¹ Joint investigation into Cornwall Partnership NHS Trust, p 42.

⁸² Joint investigation into Cornwall Partnership NHS Trust, p 57.

⁸³ Joint investigation into Cornwall Partnership NHS Trust, p 60.

⁸⁴ Joint investigation into Cornwall Partnership NHS Trust, p 62.

⁸⁵ Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust (Healthcare Commission, 2007).

⁸⁶ Investigation into Sutton and Merton PCT, p 3.

with learning disabilities cared for by the PCT had a person-centred plan, as described in *Valuing People*. Communication between staff and people with learning disabilities was poor—one person’s records said, “staff do not require communication training because the client does not speak”.⁸⁷

Both in Cornwall and in Sutton and Merton, people were abused and ill-treated not primarily because of deliberate decisions to commit abuse on the part of staff—although this does seem to have happened—but because of a thoroughgoing failure to understand, respect and deliver the human rights of people with a learning disability. As the Sutton and Merton report says, “Institutional abuse occurs when the rituals and routines of a service result in the lifestyles and needs of individuals being sacrificed in favour of the needs of the institution”.⁸⁸

3. EQUALITY BEFORE THE LAW

Summary

The Human Rights Act says that everyone has the right to liberty and security (Article 5) and the right to a fair trial (Article 6). It also says that everyone should enjoy these rights without discrimination. The UN Convention on the Rights of Persons with Disabilities says that persons with disabilities should have equal recognition before the law (Article 12), that they should have effective access to justice on an equal basis with others (Article 13), and that they should enjoy the right to liberty and security of person.

But people with a learning disability are systematically disadvantaged within the criminal justice system. As victims of crime, their evidence is downgraded and crimes committed against them in care settings are more likely to be dealt with by internal disciplinary measures than by the courts. As perpetrators of crime or when accused of criminal or anti-social behaviour, they are at risk of being dealt with by procedures they do not understand, of being given sentences which are not appropriate for them, and being denied equal access to educational and rehabilitative programmes within the criminal justice system.

Crime and access to justice

The last few years have seen welcome positive changes in the way the criminal justice system serves people with a learning disability:

- The Youth Justice and Criminal Evidence Act 1999 meant that from January 2002 people with a learning disability qualify for “special measures” when they appear as witnesses in court.
- The Criminal Justice Act 2003, section 146, made committing a crime against a disabled person because of hostility based on their disability a “hate crime”.
- The Sexual Offences Act 2003 redefined rape and sexual assault as sexual activity with someone who does not consent. Where someone’s disability means they cannot communicate whether they wanted to have sex, the courts will assume they didn’t consent. It introduced a new offence of engaging in sexual activity with a person with a learning disability who cannot consent to sexual relations.

Legislation is in place for people with a learning disability to access justice, but not the training and reasonable adjustments that would properly enable people with a learning disability to interact positively with the CJS. Practice on the ground still leaves people with a learning disability largely sidelined from the criminal justice system. Until this changes, people with a learning disability will not have equal access to justice, and will not have meaningful access to the right not to be subjected to inhuman or degrading treatment.

Victims without a voice

People with a learning disability, particularly people with communication difficulties, are not seen as credible witnesses. Therefore people committing crimes those with learning disabilities are less likely to face prosecution, and in those cases that do get to court, securing a prosecution is very difficult.

Case study

24 families raised concerns about “accidents” experienced by their sons and daughters at a respite care centre, resulting in bruises, cuts and behaviour changes. However, once the police and CPS were involved the case was dismissed as the witnesses were seen as too unreliable to make the case for the prosecution.

Evidence from the Home Office suggests that despite the availability of special measures for people with a learning disability, they are not being widely used. This is largely due to police and Crown Prosecution Service (CPS) staff not having the skills to identify people with a learning disability who might benefit from

⁸⁷ Investigation into Sutton and Merton PCT, p 5.

⁸⁸ Investigation into Sutton and Merton PCT, p 6.

special measures. The Home Office's evaluation of the use of special measures for vulnerable and intimidated witnesses (VIWs) says, "The police continue to experience difficulties identifying vulnerable and intimidated witnesses and the Crown Prosecution Service (CPS) rarely identify VIWs unless the police have already done so. This makes it extremely difficult to arrange for special measure if they are needed", and "There is little evidence that the distance learning training officers have received has been effective".⁸⁹

Too often Protection of Vulnerable Adult (POVA) procedures, or internal disciplinary measures in care services, are used instead of criminal proceedings, giving the impression that crimes against people with a learning disability are worthy of less serious action than those committed against other individuals.

Nine out of 10 people with a learning disability experience bullying and harassment.⁹⁰ But many are not confident talking to police when they have been victims of crime. Information for victims and witnesses is not provided in a format that is accessible to people with a learning disability, and frontline police officers—often the first or only contact point people with a learning disability will have with the CJS—do not receive sufficient training even to identify someone with a learning disability, let alone to be able to meet their needs and ensure they receive equal access to justice.

The lack of trust in, and willingness to interact with, the CJS amongst people with a learning disability is hardly surprising when at every level it displays ignorance and indifference to their needs.

Case study

A man with a learning disability was taunted by two men at a shopping centre in Essex—they pushed him into a lake where he drowned. At sentencing, the judge commented that others at the scene had managed to "restrain themselves" by only taking part in the taunting and not the drowning—they had not intervened to prevent the man's death.

Good practice

People with learning disabilities can make effective witnesses at trial if all those members of the CJS who come into contact with them understand and make adjustments to meet their needs. A scheme developed in Liverpool, Witness Support, Preparation and Profiling (WSP&P), is enabling people with a learning disability to give evidence in court when otherwise they would not have been able to be used in a prosecution.⁹¹

During the investigation, an assessment is made of the potential witness. They are prepared to give their evidence, and the court is served with a witness profile that includes agreed protocols that must be used when communicating with this witness. The profile includes details of functional skills, powers of concentration, and strategies to enable counsel to formulate questions the witness would understand. The success rate in terms of trials resulting in a conviction is 94%.⁹²

People with a learning disability as offenders

There is no routine data collection to find out how many people with a learning disability come into contact with the criminal justice system as offenders or alleged offenders. According to the Prison Reform Trust, 7% of prisoners have an IQ of less than 70, and a further 20% have an IQ of less than 80. 20% of the prison population has a "hidden disability" which may "affect and undermine their performance in both educational and work settings".⁹³ People with a learning disability are likely to need specialist support at all stages of their contact with the criminal justice system, but this is rarely available to them.

The Youth Justice and Criminal Evidence Act 1999, which provides for "special measures" to support vulnerable or intimidated witnesses, does not provide for these measures for vulnerable defendants. This may lead to unsafe convictions or unjust sentences. For example, in one case a defendant, asked by a judge whether he was "remorseful", did not understand the word. When he said that he was not remorseful, he was given a longer sentence than he would otherwise have received.

Where offenders do not understand the nature or purpose of the punishment they are given, it is less likely to be effective. People with learning disabilities in custody may find it difficult to understand and adjust to rules and regimes, and may behave in ways which are deemed disruptive and lead to further punishment or exclusion from offending behaviour programmes.⁹⁴ Such programmes may in any case be inaccessible to

⁸⁹ Mandy Burton, Roger Evans and Andrew Sanders, *An evaluation of the use of special measures for vulnerable and intimidated witnesses* (Home Office Research, Development and Statistics Directorate, 2006), p 1, p 3.

⁹⁰ *Living in Fear: The need to combat bullying of people with a learning disability* (Mencap, 1999), p 6.

⁹¹ Geraldine Monaghan and Mark Pathak, *Silenced Witnesses*, Community Care (17 May 2000), <http://www.communitycare.co.uk/Articles/2000/04/27/24053/silenced-witnesses.html>

⁹² Kirsten Foster, *Preparation, Support and Profiling for Vulnerable Witnesses in Criminal Court Proceedings*, Disability Rights Commission Legal Bulletin 8 (2005), p 13.

⁹³ Jenny Talbot, *No One Knows—Identifying and supporting prisoners with learning difficulties and learning disabilities: The views of prison staff* (Prison Reform Trust, 2007), p 2.

⁹⁴ Nancy Loucks, *The prevalence and associated needs of offenders with learning difficulties and learning disabilities* (Prison Reform Trust, 2007), p 4.

people with learning disabilities. Where compliance with such programmes is a condition of parole or early release, this may mean that prisoners with a learning disability effectively receive longer sentences than other offenders for the same crimes.

Similar concerns apply to Anti-Social Behaviour Orders (ASBOs). Where a person with a learning disability does not understand the reasons for an ASBO's imposition, or the terms of the Order, then they are less likely to comply, which can lead to the imposition of a custodial sentence without a further trial—and in any case, makes the ASBO largely pointless.

4. INDEPENDENT LIVING

Summary

The Human Rights Act says that everyone has the right to respect for private and family life (Article 8), and this has been interpreted by the ECtHR as including a right to participate in the life of one's local community. It also says that everyone should enjoy these rights without discrimination (Article 14). The UN Convention on the Rights of Persons with Disabilities says that disabled people have the right to access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas (Article 9). It says that disabled people have the right to live in the community, and to choose where and with whom they live (Article 19), and the right to respect for privacy (Article 22) and to respect for home and family (Article 23). It says that they have the right to education (Article 24) and to work and employment (Article 27).

But adults with a learning disability are frequently denied the opportunity to participate in the life of their community. They are often segregated from the wider community and denied meaningful day activities and opportunities to develop their skills and achieve fulfilling employment—indeed, in many parts of the country day services are being closed and not replaced, and further education courses for people with a learning disability are being lost. Many are denied choice about where to live and whom to live with. Most want to work, but most are unemployed. Families and carers of adults with severe and profound and multiple learning disabilities are forced to care around the clock, without a break, in the absence of adequate short break services.

Social and community care services to support independent living

One of the Government objectives outlined in *Valuing People* is “to enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships”.⁹⁵ For many adults with learning disabilities this can only be achieved with access to sufficient good quality support and/or supportive services within their wide local community. For many adults with a learning disability the lack of integrated services and opportunities to get involved in their local community while still getting access to the services they need and wish to use means that they are segregated within specialist services which are under threat and often not providing the right type of support to foster independent living skills. Community care legislation is not rights-based—it does not give anyone a right to the services and support which would enable them to live independently. Consequently, people with a learning disability and their families and carers have to argue on a case-by-case basis against continuing cuts to the services on which they depend.

In England, 122,000 adults with learning disabilities received social care services in 2005–06, of whom 37,600 (about 30%) were living in residential or nursing care. Residential and nursing care accounted for 51% of the money spent on adults with learning disabilities in 2005–06.⁹⁶

Despite increased funding—spending on adults with a learning disability in England went up 23% from £2,469 million in 2001–02 to £3,039 million in 2003–04⁹⁷—services for people with a learning disability are being cut. This is generally attributed to pressures on existing funding and a lack of increase relative to the need for services. Demographic pressures are increasing demand by about 1% per year. Increasing numbers of young people with profound and multiple learning disabilities are coming through transition. There is little planning or funding to meet their needs. This often leads to them being placed a long way from where they live and social services overspending on budgets. In addition, the unit cost of social care services is rising as is the expected quality. All of these factors increase the costs of vital services, and without a matched increase in funding, costs need to be reduced at local level. In many cases this has led to those with low needs for support being denied access to services.

Local authorities use eligibility criteria to determine need for services. Needs are assessed and resources allocated across four bands:

- Critical—people whose life would be at risk without support.
- Substantial—people who are largely unable to care for themselves and their health.

⁹⁵ *Valuing People*, p 7.

⁹⁶ *Referrals, assessments and packages of care 2005–06* (The Information Centre for Health and Social Care, 2006).

⁹⁷ Commission for Social Care Inspection (2007) *State of Social Care in England 2005–06*.

- Moderate—people who need support to do things and stay healthy and safe.
- Low—people who can live quite independently if they have a little support.

Due to increased costs of services and funding pressures, the majority of local authorities are now reviewing their eligibility criteria and restricting access to those with the highest support needs only. The Local Government Association has found that 80% of local authorities are now tightening eligibility criteria and 70% provide support only to those with the very highest levels of need (critical and substantial).⁹⁸ As councils restrict access to support services, many adults with a learning disability with lower needs for support are now finding themselves ineligible for support and unable to use services which they may have relied on as essential in assisting them to live independently and enjoy activities in their community. Without such support, many adults with a learning disability will face a future without access to important social networks and friendships as well as support to carry out daily tasks for themselves.

The current funding crisis therefore threatens the stability and success of current government policy as well as the human rights of adults with a learning disability. It means that a large number of people who are “or will be unable to carry out several personal care or domestic routines” such as going to the toilet, washing themselves or cooking a meal (moderate needs), will be excluded from care, along with many more whose needs may be defined as “low”, but whose ability to live as a full member of the community is restricted. They may fall outside tightened eligibility criteria because they are not considered to be “at risk” if a service is not provided. This will have a major impact on the ability of many people with a learning disability to participate in the life of their local community.

The tightening of eligibility criteria also has an important knock-on effect on families and carers—if a person with a learning disability fails to qualify for services, but in reality needs support, then carers may be forced to give up work to look after them. According to the Commission for Social Care Inspection (CSCI), “Carers, unpaid relatives and friends . . . are bearing the cost of ever-tighter eligibility criteria and shortfalls in current services”.⁹⁹ There is a real need for evidence of the scale of this problem and an analysis by councils on the impact of changes to criteria on the rights of carers under the Carers (Equal Opportunities) Act 2004.

A 2005 report by the Association of Directors of Social Services on funding pressures on learning disability services estimates that a further £800m is needed by 2011 to meet demographic pressures.¹⁰⁰ However, it does not estimate the cost of meeting current unmet demand for services such as respite care, day services, or housing and support. Indeed since the publication of *Valuing People*, there has been no systematic attempt to estimate the cost of properly implementing it.

Despite sound policy statements supporting investment and reform in support services for people with a learning disability to support independent living, the reality is that without any increase in investment to meet the cost of this change, and without sufficient investment to sustain services at their current level, people with a learning disability are actually losing these essential services.

Day services

Day services have enormous potential to be a truly empowering force for people with a learning disability. They should be a critical element in personal development and in enabling people to take control of their own lives and gain independence. They should focus on developing a real life in the real world, on learning new life and social skills and on work opportunities, and not simply on filling up time. At their best, day services can encourage people to look not just at what they are doing, but at what they could be doing in the future, and at how they want their lives to develop.

Historically, day services for people with learning disabilities have been developed and provided without any real strategic examination of their purposes and objectives. Day services have often been based on vague assumptions about “giving people something to do”, without serious consideration of the long-term needs of individuals, carers or the wider community. Many old-fashioned day centres offered little stimulation and were effectively used to “warehouse” people with a learning disability. People with more complex needs, such as those with profound and multiple learning disabilities, were often placed in segregated units which had even less opportunity for inclusion and access to the wider community than other day centres.

Particularly in large “traditional” day centres, person-centred planning has been minimal or non-existent, with a clear lack of creative activities. There are numerous cases of day centres where the same activities are undertaken every day, and even cases where people are expected to watch television or videos for hours at a time. Activities are often dictated by the interests and skills of particular members of staff, rather than the interests and preferences of service users, making it unlikely that service users will be able to focus on their abilities and potential. People with higher support needs are less likely to be fully engaged in activities or to spend their time involved in a constructive activity.

⁹⁸ *Social Services Finance 2005–06—A Survey of Local Authorities*, Local Government Association (2006), 1.06.

⁹⁹ *The State of Social Care in England, 2005–06* (Commission for Social Care Inspection, 2006), p xii.

¹⁰⁰ *Pressures on learning disability services: The case for review by Government of current funding* (ADSS, 2005), p 22.

The modernisation of day services, with a move away from large institutional day centre provision towards community activities, has been accompanied by attempts to rationalise the costs of day services. Day services are inevitably expensive, and few local authorities would claim to have sufficient finances to fund the day services they would like to provide. Funding for day services has never been sufficient to meet the needs of all potential service users, or to develop services. *Valuing People* estimated that in 2001 “some 20,000 people with learning disabilities—often the most severely disabled or those with challenging behaviour—do not attend a day service”.¹⁰¹

In recent years, budget constraints have often led local authorities to reduce day services for people with a learning disability. In some cases, it seems that local authorities are providing the bare minimum to meet their statutory responsibilities. The reduction may be brought about by the closure or removal of services, particularly day centres, often with no replacement service being offered and no reassessment of service users’ needs. A reduction in services can take the form of a complete removal of the service or a reduction in the number of hours or days a service user receives.

Over the last year Mencap has received a huge number of complaints from people about cuts in services at a local level, and the serious impact that these are having on people with learning disabilities and their families and carers. For example, day services have been cut, the number of hours of personal support have been cut, the number of days of daytime activities have been cut, further education courses have been cut, charges have increased.

The premature closure of day centres before viable alternatives are in place is accompanied by concerns that some local authorities are increasingly trying to offer services “on the cheap”—for example, with supposedly community-based activities which are in fact mass group outings.

Charging for day centre attendance and transport has also become much more widespread over the last decade. Local authorities are not required to provide information about the number of people who are effectively excluded from services by such charges, but there is no doubt that charging is a cause of great anxiety and anger among people with a learning disability and their families. Charges cause particular problems when they are imposed or raised with little consultation, to solve or mitigate a social services budget crisis.

Case study

Rebecca is 31 and has profound learning disabilities. Her behaviour is sometimes challenging. For the past five years she has lived with her parents and had regular day care, which has enabled her and her family to have a reasonable quality of life. The day care is provided by a charity which also provides residential care, and the local authority is demanding a progressive reduction in the hourly allowance for residential care. This is affecting the quality of Rebecca’s day care—she has already had her weekly art room session, and her speech and language therapy, cut. These are activities which she and her family value greatly, and which help to address her challenging behaviour, but no alternatives are being put in place.

Short break services

More than half of all adults with a learning disability live with their families, for a range of reasons including a lack of viable alternative options and dependency on others in having their daily needs met. A study of 353 such families by Mencap in 2006 found that 70% of carers provide more than 15 hours care per day to their disabled family member.¹⁰² In addition, 40% always provide care during the night. The caring relationship between adults with a learning disability and their family carers, particularly for those with higher support needs, is a constant and intensive one which impacts on the ability of the family to enjoy ordinary family life and also impacts on the ability of all family members to enjoy their own rights to independence, leisure, employment, education, training and the development of meaningful relationships.

The intensity of the caring relationship can have a negative affect on the health and wellbeing of family carers. Research has shown that carers are more stressed, ill and depressed than other people. Mencap’s study found that 30% of carers considered themselves in poor physical health. Of those, 40% said that this was directly because of their caring role. 20% of carers did not consider themselves to be in good mental health. Of these, 90% say that this is directly because of their caring role. Caring without a break puts undue strain on family relationships and can cause family and relationship breakdown. In addition to instances of family breakdown, Mencap identified an inability to enjoy full relationships with other children and partners due to the constant pressure of the caring role. 70% of carers told Mencap that they have felt close to or reached breaking point because of a lack of support to care.

¹⁰¹ *Valuing People*, para 1.20, p 21.

¹⁰² *Breaking Point—families still need a break* (Mencap, 2006), p 7.

There is very little information available on short breaks for these families. Only one in five adults with a learning disability (21%) who receive services get a short break, according to figures from the Valuing People Support Team.¹⁰³ Mencap's 2006 survey found that 60% of families do not get a short break service at all or do not get one that fully meets their needs. 30% of families also reported that they had experienced a cut in their package of short breaks services in the past year. Local authorities and health trusts are increasingly reviewing the provision of short breaks, especially those options considered to have higher unit costs, including residential provision and provision to people with complex health needs. It is becoming increasingly difficult to access short break services due to cuts to existing provision, the widespread tightening of eligibility criteria, and difficulty in having needs assessed and having those assessed needs met.

Families are finding it difficult to get onto service waiting lists, and even for those on waiting lists there is little confidence that they will ever get a service. Only 10% of the families in Mencap's survey were on a waiting list for short break services, despite 60% of families surveyed reporting that they are currently getting no or inadequate support. Of those families, 30% have been on a waiting list for more than a year.

On 21 May 2007, the Government announced a new £280 million package to provide fortnightly short breaks to 40,000 families with disabled children.¹⁰⁴ This is of course very welcome, but the challenges facing families with severely disabled adults, and their need for short breaks, are no less acute. The crisis in short breaks provision across the UK, for adults as well as children, denies people with a learning disability and their families the opportunity to enjoy family life of a sufficient quality that allows each family member to reach their full potential. This situation is likely to worsen without increased investment.

Case study

"I do worry about the future. As children get older, so do their parents and there are extra needs that go along with this. We are due to have a review of her support soon and I know that cuts have been made in my area already. I had a Carer's Assessment and was told that I needed extra help and would be given direct payments and support from a sitting service. However, because of the cuts in my area, these extra services that I need have been put on hold. I have been told that I have a need, but no one is going to provide anything for me. I have had to fight every step of the way to get support and I know that some families just aren't able to do that".—Mother of a 24 year-old woman, England.

Advocacy services

Many people with a learning disability will need advocacy support to have their voices heard and their human rights respected. According to *Valuing People*, "Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs".¹⁰⁵ While there have been increases in advocacy services over the last few years, provision is still patchy, and often difficult to obtain. In particular, people with profound and multiple learning disabilities (PMLD), the group with the greatest need for advocacy, have the least access to it—only 11% of advocacy schemes can support a person with PMLD, and most advocates are not trained to communicate with people who do not use formal communication such as speech or sign language.

Advocacy and the Mental Capacity Act 2005

The Independent Mental Capacity Advocate (IMCA) service is being established as part of the implementation of the Mental Capacity Act 2005. IMCAs will be provided to people who lack capacity and are "unbefriended"—ie they have nobody else other than paid staff to provide them with support or represent them. Mencap, and other members of the Making Decisions Alliance, argued during the passage of the Bill that everyone who lacked capacity ought to be given the right to an advocate. The Government opposed this position on resource grounds—a legitimate concern, but one which necessarily leaves "befriended" people who lack capacity without advocacy provision.

From 1 April 2007 NHS bodies and local authorities have a duty to consult an IMCA in decisions involving serious medical treatment or changes of residence where the person has no family or friends. Local authorities are responsible for commissioning IMCA services themselves, in partnership with PCTs. They will have flexibility to extend the IMCA service to other groups and situations "within the resources available"—such as involving an IMCA in a care plan review—but they will not have to do this. Local authorities will be required to "take a strategic view in assessing local priorities" and to publish the additional areas where IMCAs will be used—so the level of IMCA provision outside the statutory requirements will vary between local authorities.

¹⁰³ *The story so far . . . Valuing People—A New Strategy for Learning Disability for the 21st Century*, (Valuing People Support Team, 2005), p 17.

¹⁰⁴ *Aiming high for disabled children: better support for families* (HM Treasury/Department for Education and Skills, 2007), p 8.

¹⁰⁵ *Valuing People*, para 4.5, p 46.

Further Education (FE)

Many people with a learning disability have historically not been given training and preparation for employment, and services working with adults with a learning disability have often not made it a priority to help them find work. This has contributed to the fact that people with a learning disability are the most excluded group of disabled people from the UK workforce—according to *Valuing People*, fewer than 10% are in employment.¹⁰⁶ However, expectations and aspirations are changing—around 65% of people with a learning disability want to work. Many unemployed adults with a learning disability will need appropriate FE provision in order to achieve their full potential. The FE system must be inclusive for all learners, recognising the range of abilities and support needs of people with a learning disability and recognising that levels of progression will be different for different individuals.

The policy direction for students with a learning disability is set out in the Learning and Skills Council's 2006 document *Learning for Living and Work*,¹⁰⁷ which contains a focus on improving the quality of provision for learners with a learning disability and/or difficulty (LLDD) with progression routes into employment, volunteering or involvement in mainstream activities within the community. This is welcome, but the grouping together of learners with learning disabilities and learners with learning difficulties in the LLDD category makes it extremely difficult to establish accurate numbers of people with a learning disability, and the exact funding amount attached to this group of learners.

The report's frequent references to higher education also suggests a limited understanding of learning disability, and the range of support needs this group of learners has. Indeed, the all-encompassing nature of the LLDD category means that those learners with severe or profound and multiple learning disabilities are not specifically considered. This is a particularly important issue given that government priorities for FE are focused on young people aged 16–18, and on those learners developing basic skills at Level 2 and above. This may have an unforeseen effect on funding for courses for people with a learning disability, many of whom may never achieve Level 2 but are still capable of learning new skills and moving into work with the right support. 45% of LLDD are participating in a programme at Level 1 or below. Furthermore, around 20% are participating in provision classed as “unknown”. For 2005–06 the Government has increased funding to the FE sector by 4.3%, or £194 million. But this overall figure masks an increase for 16–18 year-olds of 10.3%, or £240 million, and a reduction for learners aged 19 or over of 3%, or £55 million. Around 71% of LLDD are adults aged 19 or over.

Mencap has been receiving reports of cuts in FE courses for LLDD since 2005. 3,000 course places for people with learning disabilities have been lost—this amounts to 15% of the total provision for this group. These cuts are being made at the same time as cuts in day service provision for adults with a learning disability. We understand that the FE cuts have been made as a result of poor and non-progressive provision. While we agree that poor quality provision needs to be addressed, it needs to be addressed by improvements, not by making cuts without putting alternatives in place.

Employment

Paid employment is the most effective route out of poverty. In addition to its financial benefits, it gives people the opportunity to become more independent, as well as enabling them to develop their skills and interests and to build confidence, self-esteem and relationships with others. For most people who do work, it is absolutely central to our ability to exercise our right to participate in the life of the wider community, and to our sense of self-worth. However, because of the many barriers to employment which people with a learning disability face, the opportunities to achieve their full potential are too often denied to them.

Accessing employment is harder for people with a learning disability than for other disabled groups. There are around 800,000 people of working age with a learning disability in the UK, but fewer than 10% of them are in employment compared with 49% of disabled people as a whole. People with a learning disability are the disabled group most excluded from the workplace. Where they do work, it is often for low pay and for part-time hours. This is despite research to suggest that at least 65% of this group would like to work and evidence that people with a learning disability make highly valued employees when given the right support.

The barriers to employment faced by people with a learning disability are varied and often stem from deep-rooted assumptions about what they can and cannot do. Historically, people with a learning disability have been regarded as “unemployable” and such discrimination and stigma is still wide spread. A recent DWP survey found that only 37% of employers said they would take on a worker with a “mental disability”. Further, low expectations about the abilities of people with a learning disability mean that many young people have not been given the appropriate training and preparation for employment, and services working with adults with a learning disability have not made it a priority to help them find work. Where people with a learning disability are in work there still exist many examples of bad practice with people with a learning disability “employed” in bad conditions for low wages in sheltered environments with no opportunities for progression.

¹⁰⁶ *Valuing People*, para 7.51, p 84.

¹⁰⁷ *Learning for Living and Work: Improving Education and Training Opportunities for People with Learning Difficulties and/or Disabilities* (Learning and Skills Council, 2006).

There are further issues around the “traps” of the benefits system, as well as with existing Government welfare and employment services. Despite the exceptionally low employment rates among people with a learning disability, Government employment programmes are not proving effective in reaching this group and increasing the numbers in work. Funding mechanisms for the New Deal for Disabled People mean that very few people with a learning disability benefit. Likewise, only the more able can access Workstep, due to the eligibility requirement that people must work for at least 16 hours a week. Mencap would like to see a Government supported employment programme for people with a learning disability who need a “stepping-stone” towards full-time work. We strongly prefer the supported employment model as a method of moving people with a learning disability into non-segregated work environments, over less inclusive models such as sheltered factory environments or social firms with predominantly disabled employees. We believe that the difficulties that individuals face can be dealt with through appropriate support, and by addressing systematic barriers to inclusion. All disabled people may wish to access work, and no individual or group should be assumed to be unemployable.

The Welfare Reform agenda

The recent Welfare Reform Act 2007 contains powers to replace Incapacity Benefit with a new Employment Support Allowance, and to introduce a new Personal Capability Assessment to evaluate people’s ability to work and to provide them with more targeted support into employment.

It is likely that a significant number of people with a learning disability who would have previously been exempt from the Personal Capability Assessment will now be required to seek work. While such an exemption is no longer appropriate or effective in assisting the large number of people with a learning disability who can and want to work, we are extremely concerned that the appropriate support, with the ongoing funding this requires, will not be available. This could potentially leave large numbers of people worse off than before, through no fault of their own.

In 2006 Mencap drew attention to the fact that the DWP’s claim in the Welfare Reform Green Paper that nearly 40% of Incapacity Benefit claimants have “a mental health condition”¹⁰⁸ was misleading. In fact, this group encompassed people with other conditions, including learning disability, which is not a mental health problem. The number of people with a learning disability counted in this group was unknown. The grouping together of people with learning disabilities and people with a mental health problem, as well as the continuing focus of the agenda on “rehabilitation” and “condition management” implies a preoccupation within Pathways to Work upon people with health conditions at the expense of those with lifelong disabilities. There appears to be a low understanding among Jobcentre Plus teams of the support needs of those whose disability does not need to be ‘cured’ or ‘managed’. Learning disability is an entirely different condition from mental ill-health and requires an entirely different approach to supporting people into work. While mental ill-health is a medical condition which can be treated and can fluctuate, learning disability is a lifelong disability that occurs very early in a person’s life and can not be ‘managed’ or ‘cured’. It is imperative that people with a learning disability are recognised as a distinct group to ensure that they receive the attention and recognition they need.

We are also concerned that the prime providers delivering the welfare reform agenda will be tempted to “cherry pick” those clients who are easiest to place in employment. Outcome based payments will be made to providers when Employment Support Allowance claimants move off benefits and into employment. This makes it difficult to account for the different levels of support different claimants will need, and the progress made by different claimants. While some claimants may be very nearly ready for employment, others may require a lot of preparation. Indeed, getting one claimant a little closer to employment may involve much more work on the part of a provider than getting another claimant into a job. The government must ensure that specialist providers are not “squeezed” out of the process so that particular impairment groups are not disadvantaged.

While Mencap is broadly supportive of the Government’s current welfare reform agenda—in particular, its more positive focus on what people can do, rather than what people are unable to do—we are extremely concerned that people with a learning disability will be left behind by this programme of reform, and that the gap between people with a learning disability and other disabled groups will continue to grow.

Housing

People with a learning disability have little or no choice about where they live, whom they live with and the type of support they receive to enable them to live there.

More than half of adults with a learning disability in England live with parents or other relatives.¹⁰⁹ Even if they do apply to the local authority for housing, living with parents puts people with a learning disability low on the priority list, and especially for people with profound and multiple learning disabilities, their needs are greater and make them harder (and often more expensive) to house. Staying in the family home becomes the only option.

¹⁰⁸ *A new deal for welfare: Empowering people to work* (Department for Work and Pensions, 2006), p 26.

¹⁰⁹ Eric Emerson, Sally Malam, Ian Davies and Karen Spencer, *Adults with Learning Difficulties in England 2003–04* (NHS Health and Social Care Information Centre, 2005), p 28.

Not only does this place a full time, long term caring role on the family, it prevents people with a learning disability gaining independence to grow and develop as an adult away from the family home.

It has also resulted in what Mencap has referred to as a “housing time bomb”. In 2002 it was estimated that 29,000 people with a learning disability were living in the family home supported by a parent over 70. Due to the increasing life expectancy of people with a learning disability, this number will be rising year on year. Older carers are becoming increasingly concerned about the future of their sons or daughters if they become too ill to continue to care, and when they die. Only one in four local authorities had planned alternative housing for those living with parents aged over 70—and only half of local authorities were aware of the numbers of people with a learning disability living with older parents.¹¹⁰

Due to the shortage of council houses, people with a learning disability who want “supported living” options have to access private rented accommodation. As support also has to be arranged, this is a complex and drawn out process. A recent ruling by the Social Security Commissioners, known as the Turnbull judgement, has said that the exemption on local reference rents for housing benefits, that has allowed people with a learning disability with specific needs to access appropriate private rented housing, is not allowed if the support is not provided by the landlord—in other words, that housing benefit can only be paid at market rent levels, which is substantially lower than the total cost of supported accommodation. Best practice says that support services and housing should be kept separate, so that any problems with support services can be addressed without jeopardizing where people live. A lack of a joined up policy leaves people with a learning disability falling through the gaps of housing provision.

In England, 19% of people with a learning disability live in “residential care” and 11% in “supporting people” accommodation.¹¹¹ Whilst person centred planning is accepted best practice, it does not always happen on the ground, so people with a learning disability have very limited choice about where they live and who they live with.

According to the 2003–04 survey of adults with a learning disability in England, 27% of people with a learning disability may be living in unsuitable accommodation, and 39% do not have enough privacy.¹¹²

About 200 people in England with a learning disability are still in long stay hospitals, and about 3,000 are still living in NHS campuses. They are isolated from the rest of the community and kept in institutional settings, despite government promises that these will all be closed, and people given appropriate housing and support packages that enable them to live lives within local communities, with at least some choice and control over their own lives. Orchard Hill Hospital in Sutton and Merton, which is still open, and Budock Hospital in Cornwall, which recently closed, are examples of long-stay hospitals for people with a learning disability. Osbourne House in Sutton and Merton is an example of campus-type accommodation. All of these institutions were the subject of recent investigations which discovered widespread abuse and poor practice.

Family life and parents with a learning disability

There are no official figures for the number of adults with a learning disability who are parents. In a 2003–04 survey of adults with a learning disability, one in 15 said that they had children, of whom 52% looked after their children—almost half of parents with a learning disability have had their children taken away from them by social services.¹¹³ It seems likely that as the population of people with a learning disability increases, and as they expect and gain greater independence, the number who have children will rise.

Valuing People includes the objective of “Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children get maximum life chance benefits”.¹¹⁴ While the best interests of the child must always be paramount, and while there will always be cases in which it is in the best interests of the child to be removed from their parents, most parents with a learning disability will be able to look after their children with the right support.

Many professionals have negative or stereotyped attitudes about people with a learning disability and their ability to be parents. They need better training in child protection issues and in understanding and assessing the support needs of parents with a learning disability. Parents need support, including parenting skills training, help at home, access to parenting groups, and accessible information about parenting. They also need better advocacy support during child protection cases in the courts.

The ability of people with a learning disability to form meaningful relationships with others, and even to have the option of becoming parents in the first place, is of course closely linked to wider questions about the opportunities available for them to develop skills, engage in social activities and meet other people.

¹¹⁰ *The Housing Time Bomb: The housing crisis facing people with a learning disability and their older parents* (Mencap, 2002), p 4.

¹¹¹ Emerson *et al.*, p 28.

¹¹² Emerson *et al.*, pp 45–46.

¹¹³ Emerson *et al.*, p 71.

¹¹⁴ *Valuing People*, p 127.

5. CONCLUSION

Any inquiry into the human rights of adults with learning disabilities must necessarily be very wide-ranging, and our evidence has focused on what we consider to be some of the most important ways in which the human rights of adults with learning disabilities are not respected—it does not claim to be exhaustive. We are also sending copies of our reports *The Housing Timebomb*, *Treat me right!*, *Breaking Point* and *Death by indifference* as evidence for the inquiry.

We would be happy to submit further evidence to the Committee on any other points within the scope of the inquiry.

David Congdon
Head of Campaigns and Policy

May 2007

Letter from the NHS Confederation

I am writing to thank you on behalf of the NHS Confederation for your invitation to submit written evidence for the inquiry you are conducting on the human rights of adults with learning disabilities.

The NHS Confederation welcomes this important inquiry. Learning disability issues have received a great deal of profile over the past year and the Confederation is working to support its members as they implement new policies designed to tackle the problems. We are confident that the health service will adopt the Mental Capacity Act principles and the Disability Equality Duty to improve access and outcomes for people with learning disabilities.

Please find enclosed our recent publications on learning disabilities. I hope they are useful background information for the inquiry. As you are aware, we recently submitted evidence on the human rights of older people and we would apply the principles in that evidence across every part of the service, including learning disability.

Dr Gill Morgan
Chief Executive

23 May 2007

Memorandum by Change

HUMAN RIGHTS OF PEOPLE WITH LEARNING DISABILITIES—OUR VIEWS

We all work for CHANGE. CHANGE is a national organisation that fights for the equal rights of all people with learning disabilities. At CHANGE, people with learning disabilities are employed on proper salaries to co-run different areas of work. We have looked at the call for evidence from the Joint Committee on Human Rights. We discussed the issues as a group, and this letter is to let you know how we feel, please listen to us and contact us if you want us to tell you more.

OUR EXPERIENCES OF USING SERVICES LIKE HEALTH SERVICES, EDUCATION, HOUSING AND WELFARE BENEFITS

Benefits information is not accessible. There is no information or letters that have pictures and easy words.

Shaun was given tax credits incorrectly for a year, even though he had provided all the right information—he was then told that he owed a lot of money. This was very scary and confusing.

John was sent a strongly worded letter accusing him of benefit fraud, which left him very concerned, frightened and upset for a whole weekend until he was able to speak to an advocacy worker. The letter turned out to be due to a mistake within the benefits department, rather than anything he had done wrong. Even people who work in benefits departments were confused by the letter.

If you work with a good support worker they can be very helpful, but even then things can be complicated. We would prefer not to have to rely on having a good support worker as many of us don't. We should be sent information in a more accessible way in the first place using pictures and easy words.

When we visit doctors we can feel like we are on a conveyor belt, and we don't have time to get proper information that we can understand. One person ended up taking a much higher dose than required of their medication, and only found out about this through talking to their chemist. This was because the information was not explained properly and was not in pictures and easy words. We think it is good that people on benefits don't have to pay for prescriptions.

Two of us, who are now in our 30s and 40s had very poor experiences in "special" schools. We felt we were not pushed, or taught enough, and were treated badly by our teachers.

Shaun had to really fight for his dyslexic son to remain in mainstream school. He now works in small groups and gets extra support within a mainstream school and is leaving to go to mainstream college with his friends. He gets really good education now—but it was a struggle to get to this point.

Communicating with the school is often difficult if you are a parent with learning disabilities. A lot of jargon is used, and reports are hardly ever printed on yellow paper which helps if you have dyslexia, even though it's explained every time to the school that they need to be.

OUR CHANCES TO HAVE PERSONAL RELATIONSHIPS

Shaun met the mother of his children while still at school. They are no longer together. Shaun feels that his girlfriend was put under a lot of pressure by her family and friends, who weren't happy about the relationship. Another person was in relationship with someone else with learning disabilities who was abusive. When parents became involved it felt like they were interfering in her life. She is now glad that they were there to support her, but this was very difficult to cope with at the time. One person had money taken from them by a partner, and received no support afterwards from any services. When it was reported to the police they took six weeks to get back in touch. Since then he has been very wary of starting relationships.

John has been happily married for 12 years, and met his wife “in a normal way”. He feels people with learning disabilities just need to be given the chance to have relationships—and if they are they won't always need “extra help”. One of us couldn't let our parents know about having boyfriends—if they found out they would be shocked and angry, so this meant not having anybody to talk to when she wanted to split up with her boyfriend.

We do not want help all the time, but it would be good if we knew there was someone or somewhere to go when we would like support.

There are some dating agencies for people with learning disabilities but some of us feel that this is another example of segregation, and people with learning disabilities shouldn't have to use these agencies.

Most of us have good relationships with our close family, but having a close relationship with our children is made very difficult. John's son was taken into foster care and John is not allowed to see him often enough. He is only allowed to see him for two hours once a month. He feels he is missing out on his son's childhood.

Shaun also finds it difficult only seeing his children at weekends, especially as his youngest daughter is now starting to ask about why this is. There should be more support and information for fathers with learning disabilities in general, they can be overlooked when a baby is born.

At CHANGE we do a lot of campaigning for the rights of parents with learning disabilities who have children taken off them unfairly by social services. We are not given any support at the time to help us look after our children if we need it. Some of us have had our children forcibly removed by social services. There is very little information on parenting that we can understand using pictures and easy words. At CHANGE we produced a book, *You and Your Baby*. It is free to parents with learning disabilities through their health visitors. We have been told that when the department of health runs out of copies they will not print anymore. This means that if you are a parent with learning disabilities you will have to pay for accessible information on how to look after your children and if you are a non disabled parent the information is free. This is against our Human Rights. At CHANGE we have produced a book using pictures and easy words for parents who have children aged 1–5 and are working on an accessible book on being pregnant and giving birth. The government gives us the money to produce these books but we get no support with how to distribute them for free.

When our children are taken off us we get an assessment. In March 2007, John was asked questions in his assessment like: “What is this?”—pointing to a pen . . . “What do you do with this?” This is against our Human Rights it makes us feel like children as if we are thick and don't know anything.

HOW WE TAKE PART IN OUR LOCAL COMMUNITY AND WHAT HELP WE GET TO DO THIS

Frances does a lot in the local community, a lot of this is linked to her church. She volunteers with the Christian Youth Club, and the crèche, and also with the senior citizens dinner club. She is on the tenants committee for a housing trust. She also takes part in a social club for people with learning disabilities. This is a club where there is not much support, apart from for people who would like help with transport. This is how people in the group want it to be.

Somebody else used to volunteer with an old people's comedy club but didn't get any support and was told not to come back after she was poorly, so this was an unpleasant experience. One person who volunteered at a charity shop was told to “stop doing that, as you should be looking after your son”.

How easy is it for people with a learning disability to have a say in decisions which affect us? How easy is it for people with a learning disability to make a complaint about a service?

It can be very hard to get your voice heard and to be taken seriously. One person was told by the head of Social Services “We don’t listen to people with learning disabilities”.

We know how important it is to speak up for ourselves, but it can be very hard and some people with learning disabilities don’t even realise they have that right. Sometimes it feels like people want it to look like we are being listened to, but don’t really listen to us. One of us is working on a project around Partnership Boards. She ticked all the times people who did not have learning disabilities talked, and she ticked the times that professionals talked. People with learning disabilities hardly said a word.

Somebody was in a situation where even though people with learning disabilities are supposed to make decisions about who becomes part of their housing trust, members were not listened to when they were unhappy about the behaviour of another tenant.

People are often surprised that people with learning disabilities are employed at CHANGE and aren’t always volunteers. We have been in meetings where they say professionals one side and people with learning disabilities the other. We are professionals and we are people with learning disabilities.

What would help people with a learning disability get their human rights? Examples you have of when this has been one well

There are some examples of good support. Keyring is a housing trust that has worked well for some of us. It is good because they don’t interfere if you don’t want them too, you can have as much or as little help as you want. This lets you build up your independence and you still know that support is there when you need it. We think that this way of working could be adapted to work with parents with learning disabilities to allow them to care for their own children, in their own home.

There should be more support and education for people with learning disabilities about sex, relationships, and parenting. This would mean people could be more prepared for parenting, and so it would not be as easy for professionals to say their children should be taken away.

We also think that if all kinds of information were made easy to understand using pictures and easy words in the first place it would mean less support was needed. Information from banks, the council, the doctors, and so on should all be presented in an accessible way.

At CHANGE people with learning disabilities work to make information easy to understand. We have a lot of experience as we have done this for over 10 years. We also train staff in different services how to make information easy to understand.

We think that having proper jobs where we have proper responsibility is about our human rights. We think that we should be paid proper salaries. Many of us have worked stacking shelves and pushing trollies before we came to CHANGE. We were bullied, not paid proper salaries, had no way out and were BORED. Some of us went through Pathway and when we told them we were being bullied they did not listen. We think that if organisations like Pathway employed people with learning disabilities to find jobs for people with learning disabilities they would be doing what they are telling other organisations to do. We think that organisations that give services to people with learning disabilities should be employing people with learning disabilities on proper salaries doing jobs that fit our experiences and skills like campaigning, looking at policies, working in residential places.

At CHANGE people with learning disabilities are employed to co-run different areas of work. We are paid good money! We get more working part time than we did on benefits. Some of us are paid more than some of the workers who do not have learning disabilities. We take control. We are the experts. We would like to talk to you more about how we work.

Can the Convention on the Rights of Persons with Disabilities help people with a learning disability to have their human rights?

It will only help if people with learning disabilities are listened to, and given a real say in the decisions that are made. We would really like to talk to you more about this.

We hope this information is helpful to you, we think it would be very useful for you if you came to visit us at CHANGE as this is our lives and we have talked to lots of people with learning disabilities about these issues and how things affect their lives, from around the country.

Please contact us if you have any questions, or would like to arrange this.

Memorandum from Walsall Council

Walsall Integrated Learning Disability Service would like to respond to the Call for Evidence regarding Human Rights of Adults with learning Disability.

We are an integrated service between Walsall PCT and Walsall MBC using Health Act Flexibilities to have a pooled budget. This partnership arrangement has been in operation now for five years. The service is funded 50:50 between health and social care with a £27 million budget supporting 700 people with severe learning disability. People who use the service only have to deal with one organisation.

We would like to submit evidence of good practice on the following issues:

- | | |
|---|------------|
| — Learning Disabilities Partnership Board website | Appendix 1 |
| — Healthcare | Appendix 2 |
| — Welfare Rights | Appendix 3 |
| — Person centred Planning | Appendix 4 |

In addition we regularly meet with our service users and they are invited to attend various meetings. To facilitate this we fund Mencap to support people to make meaningful contributions to meetings. This is done via a group called “Making Our Choice”, they have also submitted evidence (Appendix 5).

We are a pilot site for the Department of Health’s Pacesetters programme and are currently working on three targets relating to health inequalities. Pacesetters programme provides some funding and also support from their regional lead. Evidence of work already undertaken is provided in the health care appendix.

We still have some NHS residential units some of which are long stay campuses. Using person centred planning we have resettled a number of people and hope to close all our long stay beds in the next three years. Even so we continue to try and provide our service users with a good quality of life (Appendix 6 community access).

We have an assessment and treatment unit where we have developed easy read information about the unit and also about sections of the Mental Health Act as some people are detained. These leaflets are attached in PDF format. In addition in response to the Bournwood issue we have updated our admission paperwork in relation to capacity to consent (Appendix 7).

Both within the community and our residential units we continually strive to uphold the human rights of our services users.

18 May 2007

APPENDIX 1

We have a Learning Disability Partnership Board which is co chaired by a person with learning disability. One of the issues raised was that the websites of both the tPCT and Walsall MBC, although full of information about services they were separate websites and not very accessible to people with learning disability.

Supported by an organisation called Web Enable we have developed a website for people with learning disability. This website has all the Partnership Board information including minutes in easy read format. In addition there is information about our services including an interactive section on health issues which we also have as a CD ROM as mentioned in evidence on Health facilitation. We are continuing to develop the website and now have an extensive Links page.

The website will be able to host service users having their own website. We have funded equipment for “Making Our Choice” (see appendix) and they are in the process of looking at leisure services in Walsall and will develop their own website saying what is good and what is not good about what leisure activities are available to them. Eventually people will be able to have their own password protected section to keep personal information such as their person centred plan. This will keep the plan “live” as they will be able to update it online. To facilitate this we are currently prodding training for people with learning disability on how to use computers and how to access the internet. We are also in the process of developing an internet café which should be up and running later in the year.

APPENDIX 2

HEALTH FACILITATION IN WALSALL FOR ADULTS WITH A LEARNING DISABILITY

Health Action Planning

The Government White Paper “Valuing People”: A new strategy for the 21st Century (DOH 2001) has set aims and objectives to ensure that people with a learning disability have the same right of access to mainstream health services as the general population and for all to have a Health Action Plan.

A Health Action Plan is a personal plan about what a person with learning disabilities can do to keep healthy. It will list what help an individual with learning disabilities needs to keep healthy and safe. It will help access the services and support needed to maintain good health.

Walsall Health Facilitation and Community Nursing Team have developed a Health Action Plan filofax. This A5 ring binder folder has easy read, pictorial pages which act as an excellent communication tool. This Health Action Plan fax will be of extreme benefit if a person with a learning disability needs to go into hospital, visit their GP or have their medication reviewed. It contains useful information which allows empowerment for the individual, but does not act as a hand held record, protecting confidentiality issues.

The filofax's are portable and robust. They can be easily updated and reviewed. Information can be completed by the individual, family carers, professional carers, and all health and social care professionals.

The filofax's have been very well received by service users and health and social care professionals.

Health Fair—Hope 4 Health

This marvellous, pioneering event took place at Walsall Town Hall on Tuesday 23 January 2007.

“Valuing People”: A New Strategy for Learning Disability (DOH 2001) outlines a new vision for our learning disability population. The White Paper challenges discrimination, aims to reduce health inequalities and improve the health of this vulnerable client group.

The aim of the Health Fair was to bring health advice and information to this client group in an enjoyable, informal, informative format.

The event attracted contributions from a wide variety of participants, from primary care, secondary care, private and voluntary sectors.

The event was particularly successful for us as we saw evidence from other health professionals working outside learning disability who took time to look at their health advice, information and literature and adapt it into easy read, accessible formats for this client group.

Evaluation of the event was done in several formats including video footage, and a speaking wall. Feedback from service users was very positive.

A DVD presentation has been produced from the event.

We hope to make this an annual event.

“Your Health” CD/ROM

We have designed a CD/ROM “Your Health” as a health education, health promotion tool. The CD has been designed and produced specifically for people who have a learning disability. The format is in easy read format and is very pictorial. There is a full audio voice over, which is performed by people who themselves have a learning disability.

If accessed on line the CD provided options to access further information and links to other health promotion sites.

The CD covers subjects on what is healthy and good for you, what is unhealthy or bad for you and describes several health conditions such as cancer, diabetes and heart disease.

The CD can be used very effectively in group settings or individually by service users.

The CD is available for service users and health and social care professionals. Evaluation of this tool has been very positive.

Down’s Syndrome and Dementia Screening

Due to research highlighting the increasing connection between Down’s syndrome and dementia, Walsall Learning Disability Team felt strongly that we needed to provide a means of assessing individuals with Downs Syndrome. We used the Adaptive Behaviour for Down’s Syndrome Questionnaire (ABDQ) tool devised by Prof V Prasher, Birmingham University.

Initially we identified how many adults had Downs Syndrome in Walsall. We then offered baseline screening to this entire population group. The screening was offered on a consensual basis.

The baseline assessments look at 15 areas of activities of daily living skills. We also incorporated a detailed physical health screen.

The assessments will then be repeated every five years for adults aged between 18–35 years and every three years for adults over the age of 35. This will detail any changes in physical health or cognitive ability. Any identified deterioration can then be efficiently highlighted and acted upon appropriately. Walsall has begun to draft a Dementia Strategy from this work.

Improved uptake to breast screening services by women with a learning

Evidence has shown us that uptake to breast screening by women with a learning disability is poor. Our project was initiated because women with learning disabilities are living longer and fuller lives and should have access to breast screening on the same basis as other women.

Government reports and practice documents have emphasised the need for primary healthcare teams and learning disability teams to work together to provide good quality healthcare for people with a learning disability.

Strategies such as routine screening for preventable conditions including breast and cervical screening occur far less frequently for women with learning disability than for the rest of the population. Studies have shown that women with learning disabilities are screened significantly less than the general population, although there is strong evidence to show that this population group have a significantly higher number of health needs, notable complexities of health needs and extensive unmet health needs.

Walsall integrated learning disability team have implemented innovative strategies to promote good practice in increasing the uptake to breast screening for women with a learning disability.

The main aims of this project were to:

- provide women with good, accessible information to enable them to make their own decisions about whether to accept an invitation to breast screening;
- ensure that they were invited for screening in an appropriate format;
- for them to know what to expect when they attended for their screening so that it was a positive experience;
- to understand the consequences of screening or not screening; and
- to understand breast awareness and the need to be aware of changes in their own bodies.

This project undertaken by the Community Nursing and Health Facilitation team has been supported by the DH Pacesetters programme.

The project undertook several approaches:

- Awareness training with breast screening staff.
- Identifying service user group.
- Easy read literature and easy read invitation letters.
- Health education/health promotion groups for women with learning disability in Walsall.
- Promoting physical access and environmental issues.
- Preparation and effective communication.
- Evaluation of our service.

This innovative programme has demonstrated excellent collaborative working and evidence good clinical practice. There has been excellent engagement between staff from the primary and secondary care teams and we are able to demonstrate that our healthcare is being provided in partnership.

Together we are able demonstrate that we are achieving excellence in caring and that we are moving towards measuring our patient's experience through the increased take-up to breast screening by ladies with a learning disability living in Walsall.

TESTIMONIES

“ . . . The Walsall and Sandwell Breast Screening department have recently been involved with increasing the uptake rates for ladies with learning disabilities from the Walsall area. This work has involved close liaison between the staff from the breast screening unit, office and a community nurse from the learning disability team, Lesley Richards.

The breast screening clerical officers have been working with Lesley to allocate dedicated sessions and time slots for each of the clients. Pre familiarisation visits and demonstration visits have been facilitated by our lead health promotion radiographer Kerry Crabtree who has provided positioning demonstrations of the mammogram examination to the ladies. This proved to be a very successful idea and most clients returned for their mammograms without any problems. The unit will continue to provide these dedicated sessions with these ladies and encourage a close working relationship between the health health promotion radiographer and the PCT learning disability team . . .”.

Julianne Baker
Acting Superintendent Programme Manager
Walsall & Sandwell Breast Screening Unit

“Walsall's initiative under the DH Pacesetters programme has led to the development of my role in collating data on the current and historic uptake to breast screening as well as importantly

supporting ladies with a learning disability with appropriate education and support on breast screening. My remit includes working closely with the breast screening unit at Walsall Manor Hospital by booking adequate appointments and providing 1:1 support with breast screening. Introducing pre familiarisation visits prior to breast screening appointments has proven to be invaluable in facilitating the screening process. Currently there is a 100% success rate in the attendance of this client group to breast screening.

Lesley Richards. RNLD
Community Nurse in Health Facilitation
Walsall Teaching Primary Care Trust

“My role as Health Facilitator is to identify and reduce health inequalities for adults with a learning disability living in Walsall. My aim is to challenge discrimination, enable access to mainstream health services and improve overall health for this vulnerable population group. The initiatives and protocols we have implemented through the Health Facilitation process to breast screening have proven to be a great success. Clear, comprehensible information has been made available to patients, and we have forged excellent collaborative working. The patient experience has been promoted and together we have demonstrated excellence of care.

Julia Kelly, RNMH
Health Facilitator
Walsall Teaching Primary Care Trust

APPENDIX 3

WELFARE RIGHTS AND HOUSING ADVICE

The Integrated Learning Disabilities team has a specialist Welfare Rights and Housing Advice officer, this officer supports service users, and the integrated team with all aspects of welfare rights work. Although there is the traditional benefits take-up work, where the role of this officer is to work with Social Care staff, service users and carer's, from application and in some cases up to representing at tribunal level.

This officer also assists those with a learning disability to access monies from a variety of sources. These could be via the Local Authority in relation to entitlement to housing benefit and council tax benefit or the Department of Works and Pensions, in particular accessing Community Care Grants. This officer also raises awareness that external organisations such as Severn Trent and British Gas have trust funds in place to offer assistance to those who may be experiencing hardship.

The Integrated team has a growing number of service users accessing ILF (Independent Living Fund), The Welfare Rights and Housing Advice Officer works closely with families and team members to promote ILF, showing how by accessing this fund they can control who provides their care and when it is provided, rather than being constrained by the services available via traditional routes. This fund also impacts on the local authority, as those who access the fund are not so reliant on the LA should care needs increase.

The availability of Direct Payments is promoted to those with a Learning Disability and a number of those who access services from the team are benefiting from accessing both ILF and a Direct Payment simultaneously. The Integrated team has an increasing number of active direct payments in place. The Welfare Rights & Housing Advice officer, actively promotes this type of care payment as a more flexible way of accessing care separate from the LA.

This officer supports the team with housing advice and offers guidance where supported living is being considered. She liaises with housing provider's and works with private landlord's to draw up appropriate tenancy agreements for those with a learning disability, particularly those who maybe moving from long term residential accommodation.

This officer also advises on housing issues such as; Neighbour Disputes, repairs and the right to repairs, termination of tenancies and any other housing related queries.

APPENDIX 4

PERSON CENTRED PLANNING

Within Walsall Integrated Learning Disability Service is a Reprovision and Development Team which embodies a unique service namely the Person Centred Planning Team. This comprises of a Coordinator and two Facilitators who are specially trained and highly skilled in working with and supporting individuals in producing plans which reflect Person Centred thinking.

Coming from a background of Health, Education, Day Care and Residential Services their uniqueness is in the form of working closely with their colleagues in Social work and Health Facilitation from which they are able to successfully empower adults with a Learning Disability to achieve their Human Rights. One area being supported living accommodation.

A sample of how successful person centred thinking has contributed to successful tenancies are;

(1) PD, resettled from a secure unit at St Margaret's Hospital. PD displayed extreme behavioural difficulties and was previously assessed at not being suitable to live in the Community.

He was unable to access the kitchen and therefore couldn't make himself a drink or prepare any food. His mother visited but always at the hospital. P was always hiding in places to get some peace ie behind doors etc, he had to live with people he didn't particularly like and his behaviours often increased by new admissions.

Now P lives in his own flat, mom visits or rings him most days, P visits his mother at home, they go out shopping and visit the pub together and have spent Christmas at his home. P can make a drink and cook when he wants (with support). He doesn't hide anymore, he is happy living on his own, has made new friends, happy to have a conversation and goes out most days. He has also been on several holidays. P has choice in what he wants to do, with whom, when and where.

(2) MB After spending years in large hospital settings, had very little opportunity to make choices and express her opinions.

M now lives in her own flat and enjoys a supported living package. She is able to invite her friends and neighbours around whenever she wants, and attends local community activities throughout the week.

Her support package was for 24 hours but she has now indicated "I don't need a night carer I can manage on my own sometimes, and want to". Her support package is being reduced in a phased process.

(3) LH, a young woman who had displayed various forms of aggressive behaviour, lived in a large Residential Home in a rural setting, previous assessments had indicated this setting was appropriate for her.

Indicated through her Essential Lifestyle Plan she stated she wanted to move back closer to Walsall and her parents, but that she did not want to live alone, she also expressed a wish to go abroad on holiday.

Supported living has really promoted Lisa's human rights in terms of being part of the community and having her views "listened" to. Lisa has moved back to Walsall, to a smaller accommodation she is a confident and assertive woman who has explored and experienced everything she wanted to do. The new support provider actively promotes the principles of Valuing People. Lisa's behaviour is a lot more stable and she indicates she is settled and happy in her new home

APPENDIX 5

- Making Our Choice is a self advocacy group for people with learning disabilities. It is for people who live in Walsall. There are 25 regular group members who attend meetings once a month. Group members work closely with Walsall Learning Disability Services.
- Group members play a vital role in the provision of services for people with learning disabilities. Members of Making Our Choice attend Partnership Board advisory group meetings, three members of the group are on the Learning Disability Partnership Board. Their input is both welcomed and respected by colleagues at Walsall Council.
- In 2007 alone, group members played an active role in the organisation and provision of four events, specifically designed for people with learning disabilities. The events were funded by Walsall Learning Disability Services. From planning/steering groups, through to event implementation, members' voices have been heard at all stages.
- The 4 events chosen by Making Our Choice members were:
 - A Health Fair (23 January 2007);
 - A Supported Living Event (14 February 2007);
 - An Employment Fair (14 March 2007); and
 - A Keeping Safe Event (10 May 2007).
- Group members also attended the Learning Disability Partnership Board Open Day in March. (08 March 2007)
- The following statements are from two members of the Making Our Choice self advocacy group. Both group members attended a meeting chaired by Pauline Martin (11 May 2007). The meeting was about service provision for people with learning disabilities within Walsall. It was all about the human rights of people with learning disabilities.

Statement from Michelle Law

(Information has been transcribed by Donna Clifford from Mencap / Making Our Choice supporter).

“My name is Michelle Law, I am a member of Making Our Choice.”

Pauline Martin asked Michelle about her experiences of healthcare services within Walsall. Michelle said “. . . my doctor is really friendly, he listens to me, he always has time for me. I don’t feel rushed when I go to see him—he is really nice. I think that services in Walsall are good and they are getting better.”

Michelle lives independently within Walsall; she is supported by Keyring staff. She said the “staff are very friendly, if I have any problems I know that I can always talk to them, they listen and try to help me.”

Although group members have experienced problems with public transport, Michelle said that she found it “ok”. Michelle is an independent traveller, and regularly uses buses, taxis and trains to travel around Walsall and neighbouring boroughs.

In the local community, Michelle said that people were “friendly and very helpful.” She had no experience of bullying and felt that “people don’t treat me differently because I have a learning disability.” Michelle said that “services in Walsall have got a lot better in the last 5 years.” Michelle knew that she could access the Learning Disability website if she wanted to get in touch with Managers like Pauline Martin. She would also contact “Alison at Making Our Choice.”

Michelle manages her own money; she receives benefits directly into the NatWest Bank in Walsall. She said that “. . . “my benefits always arrive on time, the staff at the bank are really helpful, I haven’t had any problems with my money.”

Michelle works part-time for Mencap in Wolverhampton. “I am a group supporter, I work with other people who have learning disabilities, I support a group called ‘Our Shout’, it is really interesting.”

Michelle has experienced education services for adults with learning disabilities. “I have done courses at Hawbush in Painting and Decorating, Cooking, Babycare, Leather, and a course in Computing. After a few years at college I knew my way round. The staff at the college were really nice and the courses were interesting. My favourite was the leather course, it was the best.”

Michelle is very interested in human rights and issues that affect people with learning disabilities. Michelle expressed an interest in finding out more about human rights and would be happy to be involved in further work within the field.

(This transcription was read out to Michelle and she agreed the contents.)

Statement from Paul Glover

(Information has been transcribed by Donna Clifford from Mencap/ Making Our Choice supporter.)

My name is Paul Glover, I am a member of the Making Our Choice group, I am the new Chair of the group. I like being Chair of Making Our Choice, I like going to meetings. I will do the best for other people with learning disabilities.”

Paul has played an important role in 4 recent service user events (see list on page 1). His role has been as an Executive Consultant for the Health Fair and the Keeping Safe events. “I have enjoyed working on the Health Fair and the Keeping Safe event, it was good.” Paul attended planning meetings for both events, liaising with other service users and Learning Disability Service staff. He said “. . . it was amazing, I was very nervous at first, but once I got involved I really got into it! Donna supported me and I felt that people really listened to what I said.”

Paul had experience of healthcare services within Walsall PCT and local hospitals plus health services in Nottingham and Selly Oak. He said that staff at Walsall were, “very friendly and chatty, if I didn’t understand things they would tell me what was going to happen to me. Some of the staff were very good, some others were a bit strict. When I asked for burger and chips they told me that I could only have the food that was on the menu.”

Paul attends Healthy Lives Advisory Group meetings, they are chaired by Pauline Martin. They feedback to the Learning Disability Partnership Board. “I think Healthy Lives is very interesting, I feel that I am doing an important job going to the meetings. I learn a lot about healthcare and I talk to other people with learning disabilities about health problems.

Paul attends Hawbush College once a week; he is learning all about animal care. “ I would like to work with animals and I enjoy learning all about different animals. I think the staff at the college are very friendly and I can talk to them.”

Paul attends Northgate Centre in Walsall 4 days a week. He said that the services at the centre are “pretty good. There are going to be lots of changes happening in the centre, I will have to go to another centre, but I hope that it will be good. Staff at Northgate are fine, and I talk to them if I have any problems.”

(Transcription was read out to Paul Glover and he agreed the contents.)

- Making Our Choice (and Walsall Mencap staff) work closely with Senior Managers and staff within Walsall Learning Disability Services. Members of the group are regularly consulted and give feedback on diverse issues, eg Pacesetters, Supporting People and many others. They are involved with Quality Checkers and monitoring of service standards within the borough.
- Making Our Choice easy-read minutes have been used as a guideline for LD Partnership Board Advisory Groups. They are currently produced by an Accessible Information Officer employed by Walsall Learning Disability Services. This makes information easy to understand for everyone involved in the meetings, it ensures accessibility for people with learning disabilities.
- If further information is required please contact Making Our Choice / Mencap via Pauline Martin, Head of Learning Disability Nursing/Clinical Service Manager.

Donna Clifford

Memorandum from The British Psychological Society

The British Psychological Society welcomes the opportunity to contribute to the Joint Committee's inquiry into *The Human Rights of adults with learning disabilities*. The Society is the learned and professional body, incorporated by Royal Charter, for psychologists in the United Kingdom, has a total membership of over 45,000 and is a registered charity. The key Charter object of the Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge".

The Society is authorised under its Royal Charter to maintain the Register of Chartered Psychologists. It has a code of conduct and investigatory and disciplinary systems in place to consider complaints of professional misconduct relating to its members. The Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology. It also has in place quality assurance programmes for accrediting both undergraduate and postgraduate university degree courses.

The Mencap Report, *Death by Indifference* (Mencap, 2007) highlights six tragic examples of institutional discrimination against people with a learning disability, and draws attention to a number of factors that may contribute to this situation. It is not our intention in this submission to reiterate or question these findings. Indeed, members of the Learning Disability Faculty of the British Psychological Society would be able to draw on examples from their own clinical experience that would support the themes and recommendations contained in the report.

THIS SUBMISSION SETS OUT TO CONSIDER

1. The need to pay particular attention to the human rights of people with the most complex needs, and the negative consequences of having additional/complex disabilities.
2. Practical steps to enhance the ability of this group of people to secure their human rights.
3. Examples of good practice.

PRIORITISING PEOPLE WHO HAVE THE MOST COMPLEX NEEDS

- A common factor in the six case studies was that all the people had severe or profound learning disabilities, with little or no verbal communication. This level of disability provides an additional barrier that frequently prevents people enjoying their basic rights. The recent Healthcare Commission investigations into Cornwall, and Sutton and Merton NHS Trusts highlighted a correlation between increased levels of impairment and abusive practices (sexual abuse, physical abuse, deprivation of liberty and institutional practices). Research findings consistently draw the same conclusion that adults who have the most severe learning disabilities and complex disabilities, will also be the most at risk of having their human rights denied.
- Despite the efforts to improve the quality of local services for people with additional behavioural challenges (DoH, 1993), there are over 11,000 people living in "out of area" placements. Challenging behaviour and additional diagnoses of autism, mental illness or other complex needs, are common reasons for such placements (Beadle-Brown *et al*, 2006). Consistent anecdotal reports indicate that individuals generally do not give informed consent to be moved to such placements. Most of them are likely to fall within the "compliant incapacitated" group. They are also at the greatest risk of being prescribed anti-psychotic medication to control their behaviour. The Joint Report by the British Psychological Society, Royal College of Psychiatrists and Royal College of Speech and Language Therapists (BPS/RCP/RCS<, 2007) highlights some of the restrictive practices experienced by this group and the steps that might be taken to address this.

- If we can effectively ensure processes that protect the human rights of this most disadvantaged group, it follows that the same processes will protect people with less complex needs. A measure of our success in achieving the aim of supporting the human rights of all people with learning disabilities, should be how well we protect the human rights of people with the most complex needs.

PRACTICAL STEPS WE CAN TAKE

There are a number of practical steps that commissioners, service providers and others could take that would address some of these issues:

1. *Focus for Partnership Boards*

- The experience of many Partnership Boards is that the needs of the people with the most complex disabilities are not specifically highlighted. The service user representatives on many Partnership Boards are self advocates who have little direct experience of the restrictive lives that are led by people who have complex needs. It is suggested that Partnership Boards are asked to review their membership and business, to ensure that the needs of this group are fully considered and prioritised.

2. *Role of regulatory bodies (Healthcare Commission and Commission for Social Care Improvement)*

- In the absence of a specific National Service Framework for adults with learning disabilities, or dedicated NICE guidance, it is important that regulatory bodies pay particular attention to how services for the general population also take account of the specific needs of people with learning disabilities. It is encouraging to see the HCC audit of Assessment and Treatment Units and Respite services in the wake of the recent investigations, but it would be beneficial if the monitoring of Standards for Better Health asked explicit questions about how the standards are met in relation to people with learning disabilities.
- There has long been a concern that the CSCI inspection process does not take adequate account of the outcomes for service users who have complex needs. There are no formally adopted care standards relating to best practice for the operation of registered care homes for adults with learning disabilities who have additional disabilities such as challenging behaviour. Adopting such approaches would help to give clearer guidance to providers about how they can ensure the achievement of the human rights of this group.

3. *Role of specialist community learning disabilities teams (CLDTs) for adults*

- The role of specialist CLDTs has not yet been clearly defined. The consequence is that teams in different areas may have quite different functions. Such teams are generally multi-disciplinary, but there is little consistency about how they operate. It is noticeable that both of the recent HCC investigations highlighted the inability of services to access adequate clinical support from CLDTs. It is recommended that the role of these specialist teams is clarified and they are sufficiently well resourced to provide assessment, interventions and support to individuals, families and services that care for people with complex needs (BPS, 2004).
- One of the roles that these teams take on effectively in many parts of the country is working alongside primary and secondary health care providers to ensure that these services have the necessary skills to support people with learning disabilities in general health settings.

4. *Processes to avoid “out of area” placements*

- It is recognised that once people are placed out of area it is difficult to return them to their original communities (RCP/ BPS/ RCS<, 2007). Steps need to be taken to ensure that people are not unnecessarily placed out of area in the first place. Young people are increasingly being placed out of area, and adult services are then faced with the task of ‘bringing them home’. Local processes need to be established to review all requests to place people out of area. Guidelines and ‘good practice standards’ for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices have been developed recently. These take the form of a self assessment audit for local services (RCP/ BPS/ RCS<, 2007).

5. *Total communication environments*

- Given that one of the most significant factors that contributes to adults with severe learning disabilities being denied their human rights is the difficulty they encounter when communicating with others in their environment, the development of “total communication environments” is a practical approach that can overcome some of the barriers. This approach enables people with

limited verbal communication to express themselves emotionally, socially and functionally, and to be communicated with by others in ways that are meaningful to them. This includes supporting staff to make appropriate use of many non-verbal communications such as body language, facial expression, vocalisation, intonation, movement, gesture etc. In this way, people who support adults who have profound and multiple learning disabilities, can be “tuned into” subtle communications that can indicate distress, pain, discomfort etc.

6. *Guidance for people who support adults who have profound and multiple disabilities*

- The Profound and Multiple Learning Disabilities Network (PMLD, 2007) has recently written guidance about how to provide services for, and to support this group of adults. Their advice covers a number of practical recommendations, including ensuring that their needs are appropriately addressed at Partnership Boards; assigning key workers/case managers to individuals and their families; giving greater priority to carrying out health checks, person-centred plans, day services and staff training.

EXAMPLES OF GOOD PRACTICE

We would like to highlight a number of examples of good practice that have been shown to enhance the ability of services to meet the human rights of adults with learning disabilities. These include:

— *Prevention and management of the use of restraints*

Many authorities have policies and procedures to reduce the risk of inappropriate use of restraints on adults with learning disabilities. One such is the Joint Learning Disability Service in Sheffield which has developed a city-wide policy to support people in ways that prevent the inappropriate use of all types of restraints. This includes a policy that has been adopted by all agencies, a central register of “restraints” that are deemed necessary, with a process for regular reviews, and a structure to respond to requests for advice and support.

— *E-learning for staff in acute hospitals*

Increasingly, staff in general hospital settings are being trained to care for people with learning disabilities who are admitted to hospital and who have additional needs that result from their learning disability (eg communication difficulties, increased anxiety, lack of awareness of procedures that are being used etc). Sheffield Teaching Hospitals NHS Trust is developing an extensive staff training curriculum that will be accessible on their intranet from July 2007. This will provide a wide range of easily accessed training packages for staff, addressing the social and health care needs of people with learning disabilities. It will be targeted at healthcare professionals within the general hospitals, and will build on the direct training that is already being provided to staff about how they can meet the needs of adults with learning disabilities within the acute setting.

— *Care pathways for people with learning disabilities within general hospital settings*

Sheffield Teaching Hospitals NHS Trust has agreed protocols on information and care pathways into many of their services, so that there are easily accessible routes for people with learning disabilities. These processes include:

- Pre-assessment processes, such as longer appointment times or appointments at the beginning of clinics.
- Funding agreements to provide extra staff who have experience of working with people with learning disabilities.
- Inter-Trust guidelines on how services should be working in partnership to support individuals in general hospital settings.

— *Patient records in general hospitals*

Sheffield Teaching Hospitals NHS Trust and the Sheffield Joint Learning Disabilities Service Case Register are developing a system that will ensure that all people who have a learning disability, and are known to the Case Register, will be “flagged” on the general hospital’s patient administration system. This will ensure that people with learning disabilities are identified at any entry point into the general hospital. Partnership protocols are being developed to ensure that care is effectively coordinated, and there is appropriate discharge and support back into the community.

— *Audit of processes within the general hospital setting*

Sheffield Teaching Hospitals NHS Trust has agreed 10 standards of practice and care for people with learning disabilities within the general hospital setting. Two audits have taken place, and a quality consultation is being carried out with regard to patient and carer satisfaction.

References

Beadle-Brown, J, Mansell, J, Whelton, B, Hutchinson, A and Skidmore, C (2006). *People with learning disabilities in "out of area" residential placements 2: Reasons for and effects of placements*. Journal of Intellectual Disability Research, 50, 845–846.

BPS (2004). *Challenging Behaviours: Psychological interventions for severely challenging behaviours shown by people with learning disabilities*. Leicester: British Psychological Society.

Department of Health (1993). *Services for people with learning disabilities and challenging behaviour or mental health needs (The Mansell Report)*. TSO.

Mencap (2007). *Death by indifference*, London: Mencap.

PMLD (2007). *Valuing People with profound and multiple learning disabilities*. PMLD Network.

RCP/ BPS/RCS< (2007, in press), *Challenging Behaviour: a unified approach (Report CR144)*, London: Royal College of Psychiatrists.

22 May 2007

Memorandum from the Swansea Participation Service

1. USING HEALTH SERVICES, EDUCATION AND WELFARE BENEFITS

Health

There is a mixed bag of experiences re access to and experience of primary and secondary healthcare. Good practice tends to lie with the individual healthcare professional and is largely down to whether they have received training and/or have had experience of learning disabilities. Some healthcare professionals find it difficult to communicate with people with a learning disability and do not use plain language, or other helpful aids (books without words, pictures, models, symbols/signs, etc) to help ensure information is as clearly presented as it could be.

A large number of people with a learning disability are reliant on others (carers, staff, parents) to provide them with information about healthy eating/living. Inevitably, as a result people with a learning disability don't always get information they need, or are given choices about what they want to eat and how they wish to look after their bodies. In Swansea we have a Health Framework which sets out what organisations including statutory services have to do to promote health and well-being to people with a learning disability. Many providers of services have signed up to this, but it is more difficult to engage with smaller organisations and carers who care for just one or two individuals.

Generally, there is more awareness of health in Swansea due to a successful and engaging Peer Health Advocacy Project which aims to increase people's understanding of health through role play, learning and discussions. This is a group lead by people with a learning disability and as well as learning about health they have also made excellent links with a broad section of healthcare professionals and provided much needed training to them on learning disabilities.

Education

It is only during this past year that people with a learning disability are being asked about college provision and what they want provided. There is only limited funding. When people move and change services they might not have the same opportunity to carry on with their courses and have to stop going.

Sometimes there is some segregation from other students, though this is getting better. Learning in an environment where there is diversity is best.

Bullying exists.

More could be done to make students more aware of learning disabilities.

Welfare Benefits

People are very angry about benefit information and how it is presented in a confusing and difficult to understand manner with its jargon and difficult to understand words. People have to ask for help to understand benefit communications from their Care Managers (social workers and nurses), and it is this current system of providing complicated and confusing information which is very disabling and disempowering. People want more easy read information, less jargon, more/better access to Benefit Departments to help sort matters out, as well as for their staff to receive training about learning disabilities.

People also told us it is also very difficult for them to have their own money. Their benefits often go into the family pot of money and they can't save for their future and for the things they want in life as their benefits are helping to keep the family out of poverty.

People with a learning disability who are more able and want to work for a certain number of hours each week are also unhappy as their benefits do not allow them to earn more than "therapeutic earnings". It is also very difficult having to complete new forms when a new job doesn't work out and they have to start again. This makes people feel anxious about whether they will get the same benefits they were entitled to before. Some people give up trying to change things as they think it might not work out and they'll be worse off.

2. PERSONAL RELATIONSHIPS

Some people get better support than others to make new relationships and to continue with their current ones. Very often whether the person is supported well will rest with their individual Care Manager. Some will go the extra mile and do their best to support the person with a learning disability live the sort of life they want to live, but others, many of whom have massive case loads are not able to give those they care manage the sort of support they need.

Very often parents are involved in care management discussions about the person with a learning disabilities future and very often they will have a different view to their son or daughter. Some of these parents are very protective, some for good reason, but not all. Parents also need some support to enable them to start letting go and to help them empower and support their loved one to go on and develop the sorts of relationships they want and need. As one person put it: "I want to move on—but my family are coming in the middle".

It is very difficult for people with a learning disability to see others whom they know very well and who have similar needs to their own being better encouraged and supported by staff in day services to maintain or start new relationships.

Only a minority of people have access to personal relationships courses. There are a few more staff being trained to deliver this now, but there is a shortage of trainers (Care Managers) as they also have their own case loads and time is very precious. Up until only a few days ago there was no information available to people with a learning disability telling them this course was available. They were wholly reliant on a care manager or day service staff mentioning it: and if they didn't know it was there they couldn't ask for it.

Forming gay relationships are even more difficult for some people with a learning disability. Additional health risks are also being taken because people do not have access to/or necessarily know they can take control of their own protection.

Several people in our group also talked about their own plans for the future and how they want to form a deeper relationship with their loved one, marry them, move into their own home and maybe have children together. The difficulty is having enough independent money to save up for an engagement ring and a marriage when you only have a few pounds a week as your benefits are supporting an entire family. Some people have a very bleak outlook on their future as there are not that many people with a learning disability married and acting as role models for them.

3. TAKING PART IN THE COMMUNITY

Links with the local community are often made through day service staff, for example, a local gardening project that helps elderly people. There is also a good link with the "Discovery" project which builds links between learning disabled people and students in Swansea University. Families, carers and staff support service users with learning difficulties to access local shops, cafés and pubs; there are specific clubs for people with learning disabilities but there is not much integrated socialising. People are saying they would like to mix with a wider range of people and have volunteers to support them access the local community.

Memorandum from Capability Scotland

Capability Scotland is one of the country's leading disability organisations working for a just Scotland. We work with children, adults and families living with disability to support them in their everyday lives. We also work with disabled people, family members and carers to influence legislation, policy, practice and attitudes.

Many of the people who use our services have some level of learning disability, so the question of how their human rights are protected is of great interest to our organisation, and we welcome the Committee's call for evidence on this issue.

We became aware of this consultation quite recently, and so have been unable to involve our service users in developing the comprehensive response that we would have liked to submit. It is Capability Scotland's view that the voices of the adults themselves must be heard, and we would welcome the opportunity to carry out such an internal consultation in the future.

We anticipate that you will receive a great deal of information from other organisations highlighting areas where there is still much work to be done in ensuring the human rights of adults with learning disabilities, for example in employment, health and independent living.

We hope that you will receive sufficient evidence from individuals and organisations based in Scotland to explain the very different landscape in which we operate. If this is not the case we would urge you to re-issue the call for evidence, and ensure that notification reaches the relevant organisations.

One Scottish development that is particularly relevant to this call for evidence is the passing of the Adult Support and Protection (Scotland) Act 2007. It was the result of a great deal of discussion on how best to protect adults at risk of serious harm, particularly around the Scottish Law Commission's position paper and draft vulnerable adults bill, published in 1997. The much publicised case in the Scottish Borders provided further impetus.

The Act places duties on Local Authorities to carry out investigations into a person's well-being, property or financial affairs if it knows or believes that the person is an "adult at risk", and that it might need to intervene in order to protect them from that risk.

Section 3 of the Act defines an "adult at risk" as any adult who—

- (a) is unable to safeguard their own well-being, property, rights or other interests;
- (b) is at risk of harm; and
- (c) because they are affected by disability, mental disorder, illness or physical or mental infirmity, is more vulnerable to being harmed than adults who are not so affected.

While Capability Scotland welcomed the intention of protecting people from abuse, such a wide definition encompasses any adult affected by disability, and we have serious concerns about the implications of this legislation on their human rights. Our concerns were shared by many other disability organisations, as seen at the evidence session held by the Health Committee at the Scottish Parliament on 19th September 2006.

We felt that there were a number of potential incompatibilities with the Human Rights legislation, and sought a legal opinion from Fisher Meredith solicitors on the compatibility of Part 1 of the proposed Bill with the Human Rights Act 1998. They identified concerns around the following areas:

- *Article 5: Right to Liberty*—the Act contains the power to remove adults from situations where they are at risk of abuse, but no power to detain them. There is potential for such adults to be removed against their wishes, and it is not clear if such adults would be detained.
- *Article 6: Right to a fair trial in civil proceedings*—particularly the power set out in Section 38 for the sheriff to dispense with the safeguards that are in place to ensure fair proceedings, provided they are satisfied that doing so will protect the adult at risk from serious abuse. The sheriff can effectively deny the adult at risk any involvement in the protective order application process.
- *Article 8: Right to private and family life*—The Act places greater emphasis on the removal of the adult at risk from the potentially abusive situation, rather than the banning of the alleged "abuser". It is for the Sheriff to interpret the provision in line with human rights legislation, and grant whichever protective order that provides the best safeguard and which, as per the general principle of the Act, causes the least interference. If the Sheriff interprets the provision to give preference to the removal order, might be incompatible with ECHR.
- *Article 14: Discrimination*—Generally, adults must consent to being medically examined and treated, unless they lack capacity to do so. Under this Act, a Sheriff can order such action, even when the adult has previously withheld consent without having to demonstrate that they lack capacity, which is clearly differential treatment.

In general terms the Act represents a significant step backwards in terms of disability equality. It is based on inaccurate assumptions about the capabilities of disabled people, and an entirely inappropriate view that disabled people are not able to make their own decisions. In a direct example of discrimination, this Act allows for disabled people to be treated differently to non-disabled people. A woman experiencing domestic abuse can make the decision to remain in the situation. If that woman is disabled, the right to make that decision is taken away from her.

This underlying assumption that “we know best” is at the heart of challenges we face in ensuring that the human rights of all disabled people are respected. We need greater focus on supporting people to make such decisions, and to live their lives independently.

We would urge you to keep Capability Scotland informed on all further work on this and other investigations involving disabled people and their families. Our networks could provide an invaluable insight into the real experiences of people affected by disability in Scotland.

24 May 2007

Memorandum from Prison Reform Trust

1. BACKGROUND

The number of people with learning difficulties and learning disabilities caught up in the criminal justice system is a matter which has long troubled those who manage criminal justice services. In 1999, a prison governor writing in the Prison Service Journal noted:

We . . . have a young offender who is due for release shortly . . . Everyone working with this woman accepts that she should not be in prison. She is severely learning disabled as a result of a physical abnormality of the brain . . . We know that regardless of court diversion schemes, many like her slip through the net . . . Perhaps the courts think such people are insolent when they don't reply. In fact, when we had one of these women assessed we discovered that she had a mental age of between seven and eight. Governor, HMP Styal

More recently when talking about some of the challenges to providing support for prisoners with learning difficulties and learning disabilities a head of learning and skills at a Category C prison said:

It is time consuming and is not resourced adequately. It is often the case that it conflicts with performance targets, for example adapted programmes [for people with learning disabilities or difficulties] take longer and are more complex to run and therefore it is harder to achieve targets . . . The key issue is getting everyone assessed adequately . . . so that we can manage them appropriately all the way through their sentence. Many are good at being able to function without anyone suspecting they have difficulties, for example they have learned vocabulary to use but don't understand it. I think autistic spectrum prisoners experience a particularly hard time. It would be much more helpful to know about such difficulties when they entered prison. (Talbot, 2007)

Responding to such concerns the Prison Reform Trust (PRT) has launched a new programme called *No One Knows: offenders with learning difficulties and learning disabilities*.

No One Knows aims to effect change by exploring and publicising the experiences of people with learning difficulties and learning disabilities who come into contact with the criminal justice system. The programme is UK-wide and runs until October 2008. It is supported by The Diana, Princess of Wales Memorial Fund and is chaired by the Rt Hon the Baroness Joyce Quin, former Prisons Minister for England and Wales. The work of *No One Knows* is guided by an advisory group¹¹⁵ and a group of people with learning disabilities, called the Working for Justice Group.¹¹⁶ Mencap is a partner organisation of *No One Knows*.

Studies have been conducted on the prevalence of offenders with learning difficulties and learning disabilities with varying results. The variation is due to a number of factors, including differences in the impairments being screened for or assessed, in how the impairments are defined and in the screening and assessment tools used. What is clear, however, is that significant numbers of men, women and children with learning disabilities and difficulties are caught up in the criminal justice system.

Recent research tells us that:

- 20–30% of offenders have learning difficulties or learning disabilities that interfere with their ability to cope within the criminal Justice system (*Loucks, 2007*).
- 7% of prisoners have an IQ of less than 70 and a further 25% have an IQ of less than 80 (*Mottram, 2007*).
- 23% of young prisoners under the age of 18 have an IQ of less than 70 (*Harrington and Bailey et al, 2005*)
- 20% of the prison population has some form of “hidden disability” that “will affect and undermine their performance in both education and work’ settings.” (*Rack, 2005*).
- Between 20 and 50% of men in prison have a specific learning disability (*Disability Rights Commission 2005 memorandum to the Commons Select Committee on prison education*).

¹¹⁵ See Appendix 1.

¹¹⁶ Members of the Working for Justice Group are volunteers recruited through KeyRing Living Support Network and the Avon Forensic Community Learning Disability Team. Meetings are held every other month and are supported by KeyRing. All members have direct experience of the criminal justice system.

While an IQ of less than 70 doesn't equate to a person having a learning disability it does indicate strongly that some additional support, for example in daily living and communication skills, will be required. Similarly, prisoners with IQs of less than 80 are likely to experience difficulties in accessing key elements of the prison regime including conventional offending behaviour programmes.

Assuming a prison population of 80,000 the above research suggests that on any given day there will be over 5,500 men, women and children with very low IQs in prison and a further 16–20,000 who will require some additional support.

2. HOW THE EVIDENCE BEING PRESENTED HAS BEEN GATHERED

The evidence in this paper comes from three sources:

- From members of the Working for Justice Group.
- From research data published by PRT in a report entitled: Identifying and supporting prisoners with learning difficulties and learning disabilities: the views of prison staff (*Talbot, 2007*).
- From a briefing paper written to support the work of No One Knows, as yet unpublished, by Rebecca Seden (*Voice UK, Respond* and the *Ann Craft Trust*).

The evidence focuses exclusively on the human rights of adults with learning disabilities in the context of the criminal justice system, including the police, courts, prison and probation and some specific human rights issues have been highlighted in the conclusion.

There are two particular human rights issues to which this paper draws the attention of the Joint Committee on Human Rights. The first relates to the positive obligations arising from the Human Rights Act to uphold an individual's article 8 rights (to respect for private and family life) and should events take a negative turn, not to breach article 2 (the right to life). Article 14, the right to enjoy all Convention rights free from discrimination, might also apply in these circumstances. Sadly we have gathered ample evidence to suggest that in many cases those who should—and in many cases wish to—act as human rights guarantors for people with learning difficulties who find themselves within the criminal justice system, either do not understand their responsibilities, or are prevented from carrying them out because of a lack of resources.

The second relates to the need under the Convention, to prohibit discrimination. This is perhaps particularly relevant here in relation to Article 6. Case law has long recognised the fact that sometimes, in order to prevent discrimination, it is necessary to treat people differently to ensure equality, rather than simply treating every individual in the same way. Indeed indirect discrimination occurs when members of a group are treated in the same way as other people and in a way which does not take into account the difference of their situation. This is particularly relevant to defendants in criminal justice proceedings who, because of a learning disability or difficulty do not understand the process to which they are subject, cannot participate effectively in their own trial and once in prison are excluded from elements of the regime.

3. HUMAN RIGHTS AND THE POLICE

3.1 Evidence from members of the Working for Justice Group:

Group members highlighted a number of concerns based on their experiences of being a suspect at a police station. Members were particularly concerned that police officers did not routinely ask if they had learning difficulties and did not always believe them when they said they had. It seemed to group members that police officers didn't know how to recognize or to support people with learning difficulties.

The question of "respect" was raised by group members on a number of occasions. Members wanted to be treated the same as anybody else and expressed feelings of anger, frustration and wonder that they were treated differently because of their difficulties. Members generally felt that they were less well respected because of their learning disability:

How the police behave to you is sometimes not helpful. They should treat you the same as other people. They are rough with you. They think you're thick.

One group member talked about being "roughed up" in a police van, treatment not meted out on his friend who didn't have a learning disability:

It's frightening in the back of a van with 10 coppers looking at you. I was there with my mate and they were worse with me. They were poking fun at me.

One group member simply said:

They shouldn't hurt you, should they?

Not being able to read or write was seen as a particular difficulty at the police station. Although group members were aware of the role of an appropriate adult, in their experience such support was not always readily available. Group members described situations where they felt they were being manipulated into signing a statement which, in the absence of an appropriate adult or a solicitor, they could not read:

Police sort of con you, turn around and say "Do you want a solicitor? It will take three to four hours to get here." They say "Do you want your mother, we will send a car to pick her up but it will take five hours." If they say it's going to take five hours then you say you don't want anyone because you just want to get out and you'll sign it.

I was arrested on a Sunday and they told me it would take eight hours for my solicitor to come. I went in [to be interviewed by a police officer] on my own, I didn't want to wait that long.

However, having an appropriate adult wasn't always as helpful as it might have been. One group member described how the appropriate adult who was present during his interview with the police didn't explain what would happen next and after the interview:

He just wanted to leave as soon as possible. He didn't say how I could get home or if I had any money.

One group member didn't feel that he was believed as readily as people without a learning disability and that this would "go against him":

They will always take what they say more than you.

Group members found the physical environment of the police station intimidating especially when they were locked in a cell:

Cells are very claustrophobic, it's frightening. People shout a lot, it's noisy, you don't know what's happening. They do things to you. They take over.

After 10 minutes you are climbing the wall. You ring the bell and say, "I need to see a doctor" and they say "yeah, when we have time." Five hours later you are still there, maybe with a few bruises on your head from banging it against the wall.

One group member described how he became anxious when he was locked in a cell on his own:

When I don't know what's going on that's when I'm anxious and then I do things I shouldn't.

Another told of a time when he was locked in a cell with a camera so they could "watch" him but which didn't have a toilet. When he needed to use the toilet he pressed the bell but nobody came:

I pressed the bell and kept pressing it and no one came and I didn't get to go to the toilet until after they had interviewed me.

Being able to see a doctor and having access to their own medication was raised by group members. Members understand that medication is generally taken off people before they are locked in a cell for reasons of safety, but that it should be made available as prescribed or as necessary. One member, who has asthma, had his inhaler taken off him before he was locked up despite asking to keep it with him because he felt he might need it. The same member also has epilepsy:

I didn't bring any medication with me but say "I want to see a doctor." They ask what is wrong and I say that I have epileptic fits and I don't have my medication. They say a doctor will be here in three or four hours, and I can choose: I can't see a doctor until after the interview and I will be out of the interview in 30 minutes or I can wait three to four hours for a doctor.

Group members discussed how things could be improved:

- Building relationships between local community learning disability services and local criminal justice agencies.
- Support workers for people with learning disabilities having a better understanding of the criminal justice system, including visits to courts and police stations, and vice versa.
- Training police officers so that they understand more about the support needs of people with learning disabilities including how to identify somebody who might have a learning disability.
- There should be a scheme similar to Victim Support but for suspects and defendants with learning difficulties. The scheme should be accessible at the police station.
- ID cards for people with a learning disability.
- Accessible information on what to expect when people enter the criminal justice system.

4. HUMAN RIGHTS AND THE COURTS

4.1 Evidence from members of the Working for Justice Group:

Nobody explained what court was going to be like. I didn't know what disqualification was or what a licence was. I was asked loads of questions about tax, MOT, licence and I didn't have a clue what he was talking about. I never understood why I got disqualified or why I was banned from driving when I didn't even have a licence. I didn't understand what they were talking about or anything.

I didn't have a clue what the judges were talking about.

I didn't understand what punishment they were giving me or anything.

If they'd explained things to me, I'd be able to do what they said. I was on bail and I wasn't allowed to go to certain houses, and I went there. I didn't understand it because no-one told me what it was about. So I went there, got arrested, ended up in the magistrates because I'd breached my bail conditions.

The above quotes are from members of the Working for Justice Group.

Group members highlighted a number of concerns based on their experiences at court, including:

- Not knowing in advance what was likely to happen to them in court.
- Not being able to understand what was happening to them while they were in court.
- Not fully understanding how to plead and nobody to explain.
- Not fully understanding their sentence or the conditions attached to it.
- Nobody available in court to explain things they didn't understand.
- Magistrates, judges and solicitors generally ill equipped to understand or to support people with learning difficulties.
- The use of words that they had not heard before, or didn't understand, or were unfamiliar with.
- People they didn't know looking at them and spreading rumours about them outside of court.

Several members described their experiences at court as “frightening”:

Court is a very very frightening thing. If you get a duty solicitor they look at your notes and tell you that you could get six months in prison, they don't tell you any of the other things, and that's it. They just say that you could get six months so people are running away and it's because they told you that you could get six months in jail.

One member described how he had missed a court date because he couldn't read the letter sent to him. The fact that he had learning difficulties and couldn't read was not taken into account. The member concerned believed his failure to attend court “went against” him.

Group members discussed how things could be improved:

- Sharing information between the different criminal justice agencies so that if one person is aware that somebody has a learning difficulty then adequate support/provision can be made at all stages.
- Simplify court room terminology.
- Training on how to identify and support people with learning difficulties. This should be undertaken by magistrates, judges and solicitors.
- Having somebody in court to read things out for people who can't read.
- Having somebody in court to support people with learning difficulties or learning disabilities.

4.2 Evidence from research data published by PRT in a report entitled: Identifying and supporting prisoners with learning difficulties and learning disabilities: the views of prison staff (Talbot, 2007):

Prison staff who participated in the study were asked to describe what they thought were some of the most difficult issues facing prisoners with learning disabilities or difficulties.¹¹⁷ A number of respondents commented on the difficulties such prisoners had in understanding not only aspects of the prison environment but also the court processes and sentence requirements that brought them into prison:

On speaking with a young person who had just come into the establishment, he told me that he couldn't understand why he had come to prison. “When the judge asked me, Miss, if I was remorseful, I said ‘no’, and then he told me I was coming here.” This young man had not heard that word before. He also said that he didn't have much idea what was going on in court and didn't understand what people were saying although he knew they were talking about him. These sorts of conversations are not uncommon to us at this prison. Young offender institution,¹¹⁸ head of healthcare.

¹¹⁷ Offenders with learning difficulties and learning disabilities are currently being interviewed as part of the *No One Knows* research programme. Data will be available late 2007/early 2008.

¹¹⁸ Young offender institutions accommodate young men aged 18–21 years.

Understanding complicated court reports and sentencing rules. Young offender institution, diversity manager.

*Understanding their sentence including any requirements to complete offending behaviour programmes in order to identify a reduction in risk.*¹¹⁹ Category C prison, disability liaison officer.

One of the main findings from this study was that: “Some prisoners with learning difficulties or learning disabilities do not know why they are in prison.”

4.3 *Evidence from a briefing paper written to support the work of No One Knows, as yet unpublished, by Rebecca Seden (Voice UK, Respond and the Ann Craft Trust):*

“Research shows us that the experience in court for defendants with learning disabilities is confusing, and often traumatic. Flynn and Bernard (*Flynn and Bernard, 1999*), interviewed 20 adults with learning disabilities who had been through the criminal justice system. The narratives of them are enlightening and demonstrate the problems that exist:

Nobody told me what to expect. When you do something wrong you get fined or go to prison for a long time. Nobody told me anything like that.

Its murder in there with about 20 people watching you, judges, solicitors and that”.

The briefing paper goes on to say:

“The accessibility of the courts for defendants with learning disabilities is not supported by current legislation. The Youth Justice and Criminal Evidence Act 1999 contains ‘special measures’, in Part II, Chapter I of the Act. These measures are available for vulnerable or intimidated witnesses to support them to give their best evidence in police interviews and in court. Special measures are available for use if they help vulnerable and intimidated witnesses improve their evidence. However, the part of the Act that introduces special measures, s 16, states “For the purposes of this Chapter a witness in criminal proceedings (*other than the accused*) is eligible for assistance by virtue of this section” (emphasis added).

Victims and witnesses with learning disabilities are included within the definition “vulnerable”. This entitles them to be considered for the range of special measures within the criminal justice system.’

A number of recommendations are made at the end of the briefing paper. The following have been included here because of their relevance to this paper:

- Appropriate adults scheme should be extended to support defendants with learning disabilities in court. Properly funded appropriate adult schemes should cover all areas of the country. Appropriate adults should be required to undertake training.
- Provision of special measures in Youth Justice and Criminal Evidence Act should be extended from vulnerable victims and witnesses to include defendants with learning disabilities,¹²⁰
- Court services should have a system in place to routinely identify defendants with learning disabilities so that they can cater to their specific needs.
- Court services should make information and procedures accessible to defendants with learning disabilities.
- Where defendants with learning disabilities are known to local community teams they should be immediately alerted and required to provide appropriate support as a matter of routine.
- Court procedures should be flexible according to the individual needs of victims, witnesses and defendants.
- Profiles should be prepared for defendants with learning disabilities so that the court can prepare and make provision for them.

5. HUMAN RIGHTS AND PRISON

5.1 *Evidence from Working for Justice Group members:*

Prison is dark and lonely. Member, Working for Justice Group

Group members highlighted a number of concerns based on their experiences of prison. A particular concern related to not being able to read or write, which posed a number of difficulties:

Getting people to write out visiting orders [so that friends and family can visit] was hard. Sometimes

¹¹⁹ This has implications for a prisoner’s parole and release date.

¹²⁰ The Government has been considering allowing vulnerable defendants to use “the sort of special measures that apply to vulnerable witnesses, including using an appropriate adult to work with the defendant and defence counsel to ensure that the defendant can effectively participate throughout the trial”, Baroness Scotland, House of Lords *Hansard* 11 July 2006, col 679.

I never got mine done because it's hard to find someone to do it. Prison staff were too busy. I missed out on quite a few visits.

I had my visiting form sent back because I didn't know their last name. Had to wait six weeks for the officer to phone and find out their last name. Nobody knows everyone's last name, especially if they can't read.

I wouldn't ask prison staff or other prisoners to read out my letters because I had an experience and I don't trust them. There was something in the letter that got round the whole prison and that caused me difficulties. The person I got to help me was the chaplain.

I missed my canteen [prison form to complete in order to buy small personal items, for example tobacco]; there was nobody to help me tick off what I wanted in time. You turn round and tell them you didn't have time and they say, "tough".

When asked how group members' accessed information in prison, the response was simply, "you don't":

I couldn't read any of the documents. They had to read them for me but they didn't always have time.

And from one group member who can read but is partially sighted:

There's no help in prison. It's difficult to read what's happening, [poor] sight wasn't considered a problem. You don't know what's going on.

Group members also raised concerns about getting their medication:

I had to wait two weeks to get my medication. Medication should be brought first before anything.

Did group members receive any support in prison?

People get no support. Nobody ever comes to see if you're OK. The officers don't care about the conditions.

Prisons and police stations don't have facilities for people with learning difficulties. They just move you through the system rather than take care of you.

Two group members talked about being moved to the vulnerable prisoner unit (VPU) "for their own protection". However, they did not necessarily view this as a positive move:

You're put on with all the fags (sex offenders) and that's not good and then everyone else thinks you're a fag too. So I asked to go back.

The prison no doubt felt they were acting in the best interests of the group members concerned. However the implications whereby already vulnerable people are placed into an even greater situation of vulnerability, potentially from other prisoners on the VPU and prisoners from the main prison, give cause for significant concern.

The following exchange highlights what life in prison was like for two group members:

Group member 1: *People with learning difficulties are targeted, like in the showers. Best keep your head down. Don't get involved in stuff like education. Just bide your time in your cell.*

Group member 2: *They don't treat you with respect.*

Group member 1: *You've got to give respect.*

Group member 2: *How do you do that? Because if you give respect to an officer you are targeted by other prisoners.*

Group member 1: *You've got to stand up for yourself.*

Group member 2: *How can I do that because then they'll get you for it.*

Group member 1: *I always stand up for myself. But then I flip, go mad a bit.*

It wasn't all bad news:

My personal officer was good. He looked after me.

There was one officer who helped me to make phone calls.

Group members discussed how things could be improved:

- Training for prison staff so that they know how to support prisoners with learning difficulties or learning disabilities.
- Asking people when they go into prison if they have a learning difficulty (Note: group members also appreciated that some people wouldn't want to say if they had a learning difficulty).
- Giving every prisoner accessible information explaining what the prison rules are, for example, in a written, pictorial, audio or visual format.

5.2 Evidence from research data published by PRT in a report entitled: *Identifying and supporting prisoners with learning difficulties and learning disabilities: the views of prison staff* (Talbot, 2007):

Prison staff were asked to describe some of the most difficult issues facing prisoners with learning difficulties and learning disabilities. The following are just three replies of many:

“Understanding and processing information, difficulty integrating with peers, understanding and integrating into the daily regime, expectations of them while in custody, accessing written information, lack of one to one support, lack of training for prison staff, lack of allocated professional time to work with or support individuals. Young offender institution, head of healthcare

Not being identified. . . Due to a lack of training/knowledge some prisoners are seen as disruptive and dealt with this way rather than getting appropriate agencies involved. Category C prison, head of psychology

Stigmatisation, bullying, increased adjudications. Women’s prison, head of healthcare”

A number of the main findings from this research relate to the “Call for Evidence” and these are listed below together with appropriate extracts from the report.

- “There is no routine or systematic procedure for identifying prisoners with learning difficulties or learning disabilities.
- Procedures for referring prisoners to appropriate support services are unclear.

Only a fifth of prison staff said that information accompanying people into prison is likely to show that the presence of learning disabilities or difficulties had been identified prior to their imprisonment. As a result, prison staff had no way of knowing about the particular support needs of people with learning disabilities on their arrival into prison.

Although some prisons may have developed effective local arrangements for identifying such prisoners, a note of caution should be sounded. As seen by this research and documented elsewhere, screening and assessment is not systematic or indeed routine (Murphy *et al* 2000). Screening and assessment tools generally used are not specific enough to identify learning difficulties or learning disabilities definitively, (Williams and Atthill, 2005), while the Adult Learning Inspectorate report, *Greater Expectations* (2006), describes the process of initial assessment as being “fundamentally flawed”.

The largely ad hoc way that such a vulnerable population is identified gives rise for concern, not least for those prisoners whose “social camouflage” means they are less likely to be identified. Effective identification of people with learning difficulties and learning disabilities should be made at the earliest point after they have entered the criminal justice system—at the police station.¹²¹

Although referrals to support services are made by prison staff, and by prison officers in particular, procedures are unclear. Furthermore, this same group of staff have very limited access to specific disability awareness training for learning difficulties and learning disabilities that could assist in the identification and referral of prisoners they are concerned about.

To ensure that this group of prisoners receives the appropriate support, consideration must be given to ways in which they might be identified, referred and assessed. A number of prison-based screening tools have been developed but none to date universally accepted as a “gold standard” (Loucks, 2006). One such tool that screens for learning disability, the HASI (Hayes, 2000), is currently being reviewed and another, commissioned by the Learning and Skills Council, will be piloted from April 2007. By their very nature screening tools will identify most people with impairments, but there is no guarantee that they will identify everyone. Other routes for identifying prisoners with learning difficulties and learning disabilities therefore need to be established.

- Most prison staff believe there are gaps in provision for prisoners with learning disabilities and difficulties (77% of respondents believed that services should be provided that were not currently available).
- Most prison staff believe that the overall quality of support for this group of prisoners is low. (On a rating of 1–4, 1 being high and 4 low, 64% of respondents rated the quality of support for this group of prisoners in the lowest two quartiles).
- Most prison staff are not confident that their prison has the skills and expertise to support this group of prisoners. (On a rating of 1–4, 1 being high and 4 low, 3% of respondents rated levels of confidence in the highest quartile compared to 21% in the lowest).

Prison staff were clearly concerned about the level and quality of support available. Respondents identified a wide range of additional services and support that they feel are necessary. It was, however, unclear how such services might be accessed or indeed whether they were available at all. Issues to be addressed include the criteria by which prisoners would “qualify” for support. Prisoners with a learning disability as defined by the *Valuing People* White Paper (Department of Health 2001) may well be able to access support in prison, either through a dedicated learning disability nurse or specific learning disability in-reach, and would generally do so via prison healthcare. Prisoners should be able to access “the same

¹²¹ Once identified, the information should be routinely shared and/or made accessible to appropriate others within the criminal justice system.

quality and range of health care services as the general public”, (Department of Health), however criteria for accessing learning disability services in the wider community vary, and tend to reflect a “post code lottery”, and it might be expected that levels and quality of provision will likewise vary across the prison estate.

Commenting on mental health services for young offenders, Sue Bailey, Royal College of Psychiatrists noted:

The needs of those with learning disabilities are not being met. And it's difficult to get continuity of care as they move between custody and the community. Asha Goveas, Children Now, February 2007

Pre-release care planning is particularly important for this group of offenders who are more likely than other prisoners to need some additional support on release. Support for prisoners with learning difficulties and learning disabilities will also come from education and additional learning support is funded by the Learning and Skills Council.¹²²

Education and training targets are often included in sentence plans for prisoners however work towards these targets may be limited by the absence of specified learning support for prisoners with learning disabilities or difficulties:

The sentence planning system is inadequate . . . This plan will often identify education or training as targets but set no further objectives that would help to define the level of support needed. Adult Learning Inspectorate, Greater Expectations (2006)

Commenting on the quality of education provision the same report goes on to say:

The quality of education provision for offenders with learning difficulties and/or disabilities still largely depends, however, on individuals within institutions and has no structural framework.

In identifying “gaps in provision” for prisoners in their care, respondents pointed to various different support services that are located in the wider community. Some prison staff had found ways of accessing such provision while others had not. Where provision was made available, access seemed to depend on individuals rather than any formal procedures or structural framework, for example some staff members had been successful in building relationships with local service providers and others had achieved results simply by picking up the telephone and asking for help.

- Prisoners with learning disabilities or difficulties are excluded from elements of the prison regime including opportunities to address their offending behaviour.
- Prisoners with learning disabilities or difficulties are unable to access prison information routinely.

There are a significant number of prisoners who, because of their impairments, are excluded from aspects of the prison regime including offending behaviour programmes. As a result they are unable to progress through their sentence plan, which in turn may have a negative impact on parole dates and resettlement opportunities.”

The exclusion of people with learning disabilities and difficulties from programmes that enable them to progress through their sentence in effect condemns them to a prolonged period of imprisonment due to their disability. This is a fundamental human rights concern.

“Reducing re-offending is a central aim of the Government’s national strategy against crime, however, conventional offending behaviour programmes are not generally accessible for offenders with an IQ below 80. There is a mismatch between the literacy demands of programmes and the skill level of offenders, which is particularly significant in speaking and listening skills. (Home Office Findings 233, 2004). Around 40% of young offenders might have difficulty in benefiting from verbally mediated interventions such as anger management and drug rehabilitation courses. (Bryan 2004). Although there is an adapted sex offender treatment programme it is not readily available across the prison estate.

Other activities that prisoners with learning difficulties and learning disabilities are excluded from include prison jobs and certain education classes. Education, training and employment are, collectively, one of the seven pathways out of re-offending identified by the National Offender Management Service (NOMS). Finding and retaining work has a significant impact on the chances of a person not re-offending on release from prison. In preparing for their release prisoners with learning difficulties and learning disabilities, if anything, require more support in this area rather than less.

Many prisoners with learning difficulties and learning disabilities also experience difficulties accessing prison information. Making information accessible is not impossible but it is a challenge. Respondents to this study reported an impressive range of ways in which prison information has been made more accessible and various other aspects of the prison regime changed or adapted. With support, these efforts could be built upon and disseminated across the prison estate.

These prisoners’ lack of access to key elements of the prison regime flies in the face of the central aim of the Government’s national strategy to reduce crime. It also contravenes Prison Service Order 2855, “Prisoners with Disabilities” and potentially the Disability Discrimination Act. Prison regimes should be developed to meet the needs of the whole prison population.

¹²² Arrangements for prisoners who require such support are not as generous as for those people requiring similar levels of support in the wider community.

- Over half of prison staff believe that prisoners with learning difficulties and learning disabilities are more likely to be victimised than other prisoners.

They are vulnerable in this environment, prone to bullying. Category C prison, head of healthcare

They don't fit in with other inmates and are frightened to keep asking questions. Local prison, disability liaison officer'

And it wasn't always just other prisoners:

"A lack of understanding by officers on the landings means they usually get treated as being difficult or stupid. Local prison, registered nurse"

The following quotes from prison staff further highlight some of the challenges faced in ensuring that the prisoners with learning difficulties or learning disabilities in their care are afforded the same rights as other prisoners:

"I hate to say this but know it is common in custodial settings. We are reluctant to identify learning difficulties and learning disabilities because we are then legally obliged, by the Disability Discrimination Act, to diagnose and provide support and there is no funding that prisons can draw on to do this. I hope this piece of research is a powerful tool in redressing this unequal situation. Dispersal prison, head of learning and skills

I am aware that the general heading "disability" comes under diversity but I am not sure that this covers learning disabilities or whether any staff reading the diversity policy of the prison service would even think to associate learning difficulties as being a recognised disability. Local prison, residential governor.

I have been in post for four months and have identified this client group as a key area of weakness for the prison. My previous employment was with the Learning and Skills Council and it is my personal and professional opinion that there is a lack of resources nationally to deal effectively with this client group, however even more so in prisons. This factor is likely to be one of the main reasons why they end up in prison; however it is critical that we do not fail this client group again upon release. Local prison, head of learning and skills

What is clear from this research is that people with learning difficulties and learning disabilities are not routinely identified prior to arriving into prison and once in prison face a number of difficulties. They are more likely to be victimised than other prisoners and will be unable to access prison information routinely. They are likely to receive inadequate levels of support of varying quality and, because of their impairments, will be excluded from certain activities and opportunities. Their exclusion from offending behaviour programmes in particular will make it less likely that their offending behaviour will be addressed and more likely that they will return to prison again and again.

Despite the restrictions placed on prison staff, resulting for example from inadequate resources and time, and the lack of training and expertise, there are many examples of good work being undertaken to support prisoners with learning difficulties and learning disabilities.

Although there is much that prisons can do locally to improve things, for example by ensuring that staff are aware of what support is available at their prison and how to access it, commitment across government departments and leadership are essential in order to move beyond the current state of affairs."

The report, a copy of which is enclosed, goes on to make a number of early recommendations. Further copies of the report may be downloaded from www.prisonreformtrust.org.uk/nok

6. HUMAN RIGHTS AND PROBATION

6.1 Evidence from Working for Justice Group members:

Last week we [group member and his support worker] went to see my probation officer and the first thing he said was, "Can't ask the magistrate for a community service order because you are registered as partially blind and the insurance won't cover it if anything happened."

I was arrested for reckless driving. The court said I was supposed to do community service at the Wheels project. The project wouldn't take me on as I am epileptic and they didn't have insurance. I went to prison for eight months instead.

The above quotes are from Working for Justice Group members.

One group member expressed concern that reports written by probation officers to inform the court were based on very little knowledge of the person concerned:

For a person with learning difficulties, the first time in front of a probation officer, how can they write a six page report when they have only known them for 45 minutes? It's beyond me.

Another group member noted that court reports were not read back to you and so you didn't know what was being said:

Learning difficulties or not you should know what's being written about you.

One group member attributed his staying out of prison to the level of support he was getting as part of his community order. Another said:

I see my probation officer every week and he helps me write things down and think about what I've done.

6.2 Evidence from data gathered from probation staff as part of the No One Knows programme will soon be available

7. CONCLUSION

The evidence presented above suggests a number of ways in which the human rights of adults with learning disabilities are not being respected. This section attempts to highlight some of these and uses the headings contained in the press notice:

The Committee will consider the practical application of human rights principles to:

- the provision of public services . . . to people with learning disabilities, the ability of individuals to access such services and the quality of provision.

The evidence given above demonstrates clearly that adults with learning disabilities often have difficulty accessing services provided by the criminal justice system and where services are accessed the quality of provision is often poor. Of particular concern are the possibilities of “unsafe” convictions as a result of inadequate or limited support from the point of arrest (Article 5 (2) the right to “be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him”) through to “disposal” from the court and consequent infringement of the right to a fair trial under Article 6, in particular those guarantees set out in Article 6 (3). The evidence provided suggests that suspects with learning difficulties face undue pressure to comply with police procedure without adequate advocacy support; that the court system still fails to understand the needs of defendants with learning difficulties, and that people convicted of a crime may go to prison not understanding why they are there, or having been able to participate in their own trial.

Once in prison people with learning disabilities face a number of difficulties. Their exclusion from elements of the regime because of their impairments, including from offending behaviour programmes is a particular concern. Not only are they denied help to address their offending behaviour, they may also experience delays in parole dates due to their inability to complete their sentence plan.

Lack of provision of appropriate services and support was cited by prison staff as one of the most difficult issues facing this group of prisoners. Over half of prison staff (64%) rated the quality of support available at their prison in the lowest two quartiles (Talbot, 2007). This lack of resources to comply with the Disability Discrimination Act surely also means that the human rights of prisoners with learning difficulties are also unlikely to be guaranteed.

- the possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise in this context. Evidence given above demonstrates clearly some of the difficulties that adults with learning disabilities have in keeping in touch with family and friends while in prison. One member of the Working for Justice Group described missing out on visits from family and friends because he was unable to complete a visiting form in time. Another described difficulties relating to the reading and writing of letters compounded by a bad experience which left him unwilling to trust anyone other than the chaplain to help him. What support is available is ad hoc leaving prisoners with learning disabilities having to rely on the good will of other prisoners or staff in order to maintain contact with their loved ones. Public bodies have a positive obligation to safeguard rights under Article 8, the right to respect for private and family life, which was sadly lacking in the evidence given above.
- the opportunities for people with learning disabilities to participate in the life of their local community and the state’s obligations to facilitate participation

Arguably, while a person is held in custody, prison becomes their local community. The evidence given above demonstrates a number of situations where people with learning disabilities are denied access to activities within their local “prison” community or, because of a lack of support or fear of victimization do not to participate. This includes participation in education, work and daily association with others.

A community order rather than a custodial sentence enables a person to remain in their local “home” community. Being denied a community order because of an impairment removes all opportunities to participate.

Public authorities (of which prisons are one) have a positive obligation under the Human Rights Act to take active steps to safeguard Convention rights: it is not only not violating people’s human rights, it’s also “going the extra mile” to ensure that breaches of human rights are prevented—even if these are not their direct responsibility. So, for example, one prisoner behaving towards another in a way which breaches their human rights remains the responsibility of the prison service. This context means that in relation to victimisation it is essential that people with learning disabilities can be identified and supported otherwise

article 8 and potentially rights under articles 3 and 2 are at risk of being violated. For example where a prisoner with learning disabilities is victimised (Article 8), or subjected to treatment that degrades them (Article 3), or pushes them to commit suicide (Article 2). Prison staff are the only way to guarantee a prisoner's human rights in this situation and it is difficult for them to do so unless they have accurate information, training and support.

Running throughout the discussions with members of the Working for Justice Group lies a fundamental desire to be treated with respect, to be accorded the same rights and opportunities as everyone else. Members are creative in their thoughts for solutions and keen to draw on their own experiences to help others who come after them. Their experiences are persuasive in enabling a better understanding that human rights are—or should be—about preventing abuses of power, and that sometimes, that abuse comes from other individuals, particularly in prison, rather than the state. In such situations, the state has a positive obligation to do what it can to intervene to protect vulnerable individuals from others who seek to bully, abuse and intimidate them. At present, offenders with learning difficulties do not enjoy this protection.

Together with members of the Working for Justice Group, I would be pleased to amplify on the evidence contained in this paper either in written form or in person.

Special thanks for their contribution to this paper go to members of The Working for Justice Group, in particular Danny McDowell and Andrew Radford, and to Jenny Watson, Global Partners and Associates.

6 June 2007

APPENDIX 1

Membership of the advisory group for *No One Knows*:

Chair: The Rt Hon. the Baroness Joyce Quin.

Alan Bicknell, Regional Co-ordinator, The National Autistic Society.

Professor Karen Bryan, University of Surrey, European Institute of Health and Medical Sciences.

Judy Clements, Regional Director, London and South East, Independent Police Complaints Commission.

Shirley Cramer, Chief Executive, Dyslexia Action.

Kimmitt Edgar, Head of Research, Prison Reform Trust.

Dr Andrew Fraser, Director of Health and Care, Scottish Prison Service.

Dr Ann Hagell, Freelance Research Associate, Policy Research Bureau and PRT trustee.

Brian Ingram, Head of Resettlement, Northern Ireland Prison Service.

Dr Glyn Jones, Consultant Psychiatrist, Learning Disability Directorate, Bro Morgannwg NHS Trust.

Glynis Murphy, Professor of Clinical Psychology of Learning Disability, Tizard Centre, University of Kent.

Robert Newman, Director: education, training and employment, Youth Justice Board.

Sue O'Hara, Head of Offender Learning, Learning and Skills Council.

Sarah Payne, Regional Offender Manager (South East), National Offender Management Service.

Tom Robson, National Executive, Prison Officer Association.

James Shanley, Governor, HMPYOI Norwich.

Keith Smith, Chief Executive, British Institute of Learning Disabilities.

Kathryn Stone, Chief Executive, Voice UK.

Jo Williams, Chief Executive, Mencap (and partner organisation).

REFERENCES:

Adult Learning Inspectorate (2006) *Greater expectations: provision for learners with disabilities*. Coventry: ALL.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. White Paper, Cm 5086. London: Department of Health.

Flynn and Bernard (1999) *Deep Trouble! Adult with learning disabilities who offend*, NDT.

Harrington, R and Bailey, S, with Chitsabesan, P, Kroll, L, Macdonald, W, Sneider, S, Kenning, C, Taylor, G, Byford, S, and Barrett, B. (2005) *Mental Health Needs and Effectiveness of Provision for Young Offenders in Custody and in the Community*. London, Youth Justice Board for England and Wales.

Hayes, S (2000) Hayes Ability Screening Index (HASI) manual. Sydney: Behavioural Sciences in Medicine, University of Sydney.

Loucks, N (2006) *No One Knows: offenders with learning difficulties and learning disabilities—review of prevalence and associated needs*, London, Prison Reform Trust.

Loucks, N (2007) *The prevalence and associated needs of offenders with learning difficulties and learning disabilities*. London: Prison Reform Trust.

- Mottram, P G (2007) *HMP Liverpool, Styal and Hindley Study Report*. Liverpool: University of Liverpool.
- Murphy, M, Harrold, M, Carey, S, and Mulrooney, M (2000) "A Survey of the Level of Learning Disability among the Prison Population in Ireland." Dublin: Department of Justice, Equality and Law Reform.
- Rack, J (2005) "The Incidence of Hidden Disabilities in the Prison Population." { Egham, Surrey: Dyslexia Institute.
- Talbot, J (2007) *Identifying and supporting prisoners with learning difficulties and learning disabilities: the views of prison staff*. London: Prison Reform Trust.
- Williams, J and Atthill, C (2005) *Learning difficulties and disabilities in prison: Setting the scene*. Briefing paper for *No One Knows*. London: Prison Reform Trust.

**Memorandum from Anne McGuire MP, Minister for Disabled People,
Department for Work and Pensions**

I wanted to write to you in order to welcome the Joint Committee on Human Rights current investigation into people with learning disabilities.

I have heard some very positive comments about its proposed focus from the disability lobby and also parliamentary colleagues. However, I recently met with Andrew Lee from People First, which represents the interests of people with learning disabilities. He was concerned about the two month consultation period the committee had set aside to gather evidence. In particular he noted that organisations that represented people with learning disabilities tend to only meet monthly. He suggested that the current timescales would not be enough time to properly collate and put forward their member's views.

In my experience effective consultation with the disability lobby is critical in order to understand the realities that disabled people face. I would urge that your committee contact Andrew Lee at People First (his contact details are below) in order consider how to ensure that his, and other learning disability organisations, are effectively engaged in the committee's work.

Memorandum from Mersey Care NHS Trust

1. BACKGROUND

1.1 Mersey Care NHS Trust provides specialist mental health and learning disability services for the people of Liverpool, Sefton and Kirkby. The Trust serves a local population of 763,000 including areas of high deprivation.

1.2 The Trust has over 4,500 full time staff and provides services from over 30 sites.

1.3 The Trust provides the following services for people with learning disability in Liverpool and Sefton:

- 3 Community Teams (Liverpool, South Sefton, Southport and Formby).
- 2 Inpatient units with nine beds (Liverpool four beds, South Sefton two beds—Wavertree Lodge; Southport and Formby three beds—Morley Unit).
- 1 Respite facility for people with additional complex health needs (Wavertree Bungalow 6 beds).
- Community Residential Service—16 people supported in Liverpool and South Sefton and 16 in Southport and Formby.

2. A HUMAN RIGHTS BASED APPROACH

2.1 When the Trust was established in April 2001, the Trust Board adopted a rights based approach—that service users and carers had the right to be involved in decisions which affect their lives—everything that we do!

2.2 Service users and carers who get involved (currently 330 people) are valued and offered payment for their time (£10 an hour rising to £12 an hour on 1 June 2007 plus travel expenses).

2.3 Service users and carers are involved in hundreds of different ways including on the Board, in the recruitment of all staff, the induction of staff, awarding contracts, the review of serious incidents, inspections, research, setting the objectives and reviewing the performance of the Chief Executive and the Executive Team. (see "Involving Service Users and Carers—the Mersey Care Way", attached)

2.4 The involvement of service users and carers in decision making is taken forward across the whole Trust by a network of lead officers. The lead officer in the Learning Disabilities Directorate provides specialist support to enable people with learning disabilities to be involved in:

- recruitment of staff—a tailor made approach;
- induction of staff;

- health action plans;
- the development of “easy read” appointment letters, Mental Health Act information, complaints information and feedback forms;
- “easy read” web based information (see www.merseyscare.nhs.uk);
- training of staff eg a service user who is deaf trains staff in British Sign Language;
- governance—through an inclusive annual away day; and
- tackling stigma through telling their stories (“Getting on with it striving for ordinariness”, a photo book by Terry Speake 2007).

2.5 In 2007, the Trust Board set a strategic objective “To promote the human rights of service users, carers and staff”.

2.6 The Trust is currently developing a comprehensive Human Rights Strategy.

3. THE HUMAN RIGHTS PILOT PROJECT IN LEARNING DISABILITIES

3.1 Against this backdrop of good practice, the Trust was delighted to be invited by the Department of Health and the British Institute of Human Rights to be one of the five pilot sites exploring ways to take a human rights based approach in healthcare.

3.2 The Trust was concerned that the most vulnerable, including people with learning disabilities, are those most at risk of having their human rights abused. The Trust decided to:

- develop a specific human rights based tool with people with learning disabilities which could be used in in patient settings in learning disability services both in the Trust and elsewhere; and
- take the learning from the project and apply it to Trust strategy, policy and decision making.

3.3 More detail about the project can be found in Case Study A, “Human Rights in Healthcare-A Framework for Local Action”, Department of Health 2007 pages 50–52.

3.4 A copy of the Questionnaire and the Report of the Pilot Project is attached.¹²³

4. PRACTICAL BENEFITS

4.1 Mersey Care has found that there are a range of benefits to taking a human rights approach to involving service users and carers in decisions which affect their lives.

4.2 An evaluation (2005) showed benefits for:

- Service users and carers—who say they “feel valued”, “have meaningful things to do”, “more confidence”, “learned new skills” and “employment”.
- They see real improvements in information, staff attitudes and clinical practice, family provision and in patient environments.
- Staff—who are positively choosing to come and work for Mersey Care because of the level of service user and carer involvement.
- Managers—who have a pool of well trained and supported service users to draw on who have a wide range of knowledge and experience.
- The Trust which is building a national reputation for its innovative approach to partnership with service users and carers.

4.3 Mersey Care also sees the practical benefits of being a pilot site in the Human Rights in Healthcare project:

- The opportunity for some staff in both the Learning Disability Directorate and the Trust as a whole to have a high standard of training on human rights from the British Institute of Human Rights.
- The access staff involved in the project have had to a high standard of advice on human rights issues in Learning Disabilities from the British Institute of Human Rights.
- The very real opportunity for a small number of people with severe learning disabilities to contribute to some pioneering work on human rights.
- The learning from the project that will be taken into the Learning Disabilities Directorate and inform the Trust’s strategic approach to human rights which is currently being developed.

¹²³ Evidence not printed.

4.4 Whilst the human rights tool the Trust has developed is still a “work in progress” and needs more refinement it has the potential to be developed into a viable human rights assessment tool for some people with learning disabilities in in patient settings.

Lindsey Dyer

Director Service Users and Carers

Anne Lofthouse

Lead Officer for Service User and Carer Involvement in Learning Disabilities

11 June 2007

Memorandum by the Healthcare Commission

INTRODUCTION

1. The Healthcare Commission exists to promote improvements in the quality of healthcare and public health in England and Wales.

1.2 In England, the Healthcare Commission is responsible for assessing and reporting on the performance of NHS and independent healthcare organisations to ensure they are providing a high standard of care. We also encourage providers continually to improve their services and the way in which they work.

1.3 The Healthcare Commission’s remit does not extend to nursing and residential homes and domiciliary care services, which are regulated by the Commission for Social Care Inspection. The expectation currently is that the two organisations will merge in 2009 and the Department of Health is currently consulting on the roles and responsibilities of the new health and social care regulator. The Healthcare Commission already works jointly with the Commission for Social Care inspection on some aspects of assessing local services.

1.4 The Healthcare Commission welcomes the Joint Committee’s decision to conduct an enquiry into this topic. The Healthcare Commission is committed to improving the health and healthcare of people with learning disabilities. We are working to ensure that people with learning disabilities are listened to, that they have equal access and rights to health services and that healthcare is provided in a timely and responsive way. In recent publications of our findings, we have highlighted concerns about basic failings in care and expressed concerns about potential infringements of human rights in the care of people with learning disabilities. The Healthcare Commission is pleased to have this opportunity to present a summary of relevant findings to the Committee.

CURRENT PICTURE

2. This section of evidence responds to the Committee’s concerns over the provision of healthcare services and the ability of individuals to access these services and the quality of provision. Much of this evidence is taken from recent publications, surveys¹²⁴ and also from information submitted to the Healthcare Commission as part of a consultative event to ascertain people’s views about healthcare for people with learning disabilities and a consultation on the Healthcare Commission’s draft three year strategic plan. Recent publications of relevance include:

- Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust (published 17 January 2007)¹²⁵.
- Investigation into the provision of service for people with learning disabilities at Cornwall Partnership NHS Trust (published 5 July 2006)¹²⁶.
- Draft Three Year Strategic Plan for Adults with learning disabilities 2006–09¹²⁷.

¹²⁴ In 2004 the Healthcare Commission, alongside the Valuing People Support Team, looked at people with a learning disability placed in independent mental health hospitals registered to take people with a learning disability. The findings of this were presented at a national conference in York in 2004

¹²⁵ This can be found at

http://www.healthcarecommission.org.uk/_db/_documents/Sutton_and_Merton_inv_Main_Tag.pdf

¹²⁶ This can be found at

http://www.healthcarecommission.org.uk/_db/_documents/cornwall_investigation_report.pdf

¹²⁷ This can be found at

http://www.healthcarecommission.org.uk/_db/_documents/04021628.pdf

Evidence of the provision, accessibility and quality of health services

2.1 There are approximately 210,000 people in England described as having severe and profound learning disabilities, and approximately 1.2 million people with mild or moderate learning disabilities. People with learning disabilities are more likely to suffer from a range of health issues, and they have high levels of need for physical and mental healthcare that is often unmet.

2.2 In February 2005 the Healthcare Commission consulted over 200 people with learning disabilities in a national event to ascertain people's views about healthcare for people with learning disabilities. The main issues that arose from this event were that people were:

- Not getting access to health screening.
- Not getting enough time with their GP, which resulted in people feeling rushed and that carers were asked questions rather than the person with learning disabilities.
- Being kept away from GPs surgeries by reception staff who did not understand the needs of people with learning disabilities and were unwilling to be flexible.
- Not being given information about how to complain or being too scared to do so.
- Not provided with enough easy read or accessible information to make informed choices.

One person told the Healthcare Commission that “being black and having a mental health problem means the services are very very poor”.¹²⁸ There was also concern raised that training for some health professionals does not cover people with learning disabilities, and a strong sense that people with learning disabilities wanted to be part of the training of nurses, doctors and allied health professionals.

2.3 In 2005 the Healthcare Commission and the Commission For Social Care Inspectorate (CSCI) investigated services for people with learning disabilities provided by Cornwall Partnership NHS Trust. The investigation was sparked by serious concerns raised by East Cornwall Mencap Society in October 2004. In the course of the investigation it became clear that there was widespread institutional abuse of people with learning disabilities at the trust. The abuse included some staff hitting, pushing, and dragging people. Some staff were also reported to have withheld food and given people cold showers. The investigation team also found an over-reliance on medication to control behaviour, as well as illegal and prolonged use of restraint. One person spent 16 hours a day tied to their bed or wheelchair for what staff wrongly believed was for that person's own protection. More than two thirds of the 46 supported living houses visited by the investigation team placed unacceptable restrictions to the people living there. For example, investigators found that some internal doors were kept locked by staff to restrict the movement of people who live there as a method of dealing with challenging behaviour.

2.4 The Cornwall investigation revealed serious and wide-reaching concerns in the local NHS Trust's procedures for protecting adults. Senior managers failed to identify and correct situations involving physical, emotional and environmental abuse. As a result of the investigation 40 people were referred to Cornwall County Council under the procedure for the protection of vulnerable adults (POVA). Despite the seriousness of the evidence presented, Cornwall Partnership NHS Trust and Cornwall County Council failed to adequately coordinate inter-agency arrangements in accordance with the Government's guidance “No Secrets”.¹²⁹

2.5 The Sutton and Merton investigation examined the care and treatment of nearly 200 people with learning disabilities during 2006. The team found that some people were restrained unnecessarily, for example one person was strapped into a chair while staff put up the Christmas decorations. Also where physical restraints were used, their use was not regularly reviewed. For example one woman had a splint on her arm to prevent her biting her fingers, this was worn at all times and was not reviewed for many years until the Healthcare Commission challenged this practice. Staff said they did not restrain people, but later went on to say that they held peoples wrists. There was not a policy about restraint, neither had sufficient staff received training about how to restrain properly if they had to, and how to use other skills such as de-escalation and conflict management so that restraint was a last resort.

2.6 The Sutton and Merton investigation found that people with learning disabilities and their needs were not at the heart of the service. They did not have person centred plans of care and they had an extremely low level of activities, with some people receiving only four hours of activity a week. Staff shortages contributed to this lack of meaningful occupation of time. They had little opportunity to participate in community life and only a few accessed services in the community. Many people living in the community came back to the hospital for day care and for health care. Their living environments were sparse, with some bedrooms and bathrooms that were not wide enough to accommodate a hoist or a wheelchair. Some people

¹²⁸ The results of the Healthcare Commission, the Mental Health Act Commission and the National Institute for Mental Health in England carried out the 2006 “Count me in” census have since shown that rates of admission for people with learning disabilities in some of the black, and minority ethnic groups were much higher than the average for all patients and that people from some black and minority ethnic groups were three times more likely than average to be admitted to mental health hospitals. The census can be found at http://www.healthcarecommission.org.uk/_db/_documents/Count_Me_In_2006.pdf

¹²⁹ In March 2000, the Department of Health published *No Secrets: Guidance on Developing Multi-agencies Policies and Procedures to Protect Vulnerable Adults from Abuse*. The guidance sets out an inter-agency policy on how allegations of abuse should be investigated, how actions plans should be developed and how to monitor outcomes.

still had to share bedrooms, resulting in a lack of privacy for personal care and one woman had to take medication to make her sleep at night so that she did not disturb the person with whom she was sharing a room.

2.7 As part of providing a quality service to set standards, employers should ensure that systems of working provide a safe place for people to live in as well as opportunities for staff to promote the rights of people with learning disabilities. A lack of training meant that this was not happening. Staff had not had training in safeguarding adult procedures and many had not heard of the “No Secrets” guidance. Accidents were reported, and also if a member of staff hit a person with learning disabilities those incidents were reported. However when a service user hit another service user this was rarely reported as a serious incident and there was a high level of tolerance of this sort of violence in the service. This particular issue was brought to the attention of the investigation team and hospital managers by the advocacy service. Very few staff were attending mandatory training about what to do in the event of a fire, or how to move someone safely and staff lacked the skills to be able to communicate effectively with people with learning disabilities.

2.8 Whilst progress has been made to close the remaining long stay NHS hospitals for people with learning disabilities it is clear that the number of people in the independent sector hospitals has increased with the number of registered independent hospital beds approaching 1,000. From a commissioning perspective, placing someone in an out of area independent hospital presents several challenges. Visiting that person creates logistical difficulties in relation to monitoring the quality and cost effectiveness of the service the person is receiving. The individual’s relationship with their family and friends is vulnerable if they are many miles away. This is also true of their relationship with their care manager, which may be tenuous.

2.9 In 2004 the Department of Health Valuing People Support Team and the Healthcare Commission undertook a survey of people with a learning disability being cared for in independent hospitals to gain a more accurate understanding of the patient characteristics. The findings of this survey included:

- On average patients were placed 74 miles away from their local community.
- The furthest distance a patient who had been placed away from their local community was 385 miles.
- In one establishment the average distance was 194 miles.
- A breakdown of patients’ legal status revealed that 34% were informal, 41% were detained under section 3 of the Mental Health Act 1983, 15% were detained under section 37 and 10% were detained under section 37/41.

MOVING FORWARD

3. Following on from the investigations at Cornwall Partnership NHS Trust and Sutton and Merton PCT, the Healthcare Commission is in the process of carrying out a national audit of services for people with learning disabilities. The audit was formally launched on 10 January 2007, following a successful pilot programme in two NHS trusts and one independent healthcare organisation. The audit will include the inspection of up to 160 NHS and private services. A national report will be published by the end of the year. This will look at trends, suggest a set of data collections to monitor performance in this field and will map where all the services are and what they look like. The audit has involved both people with learning disabilities and family carers as peer reviewers as well as staff in the field to help encourage an increase in standards across the sector.

3.1 Communication and information are at the very heart of the Healthcare Commission. Accessible information and clear access to formal complaints procedures are part of the core standards against which the Healthcare Commission assess NHS healthcare providers in accordance with the NHS (Complaints) Regulations 2004. Failure to reach these standards directly affects the overall rating of a trust and is something that we take very seriously indeed. We are looking at the way our complaints are dealt with in relation to people with learning disabilities, making sure we have accessible information, not just about our complaints procedure but how the whole, NHS system works to support people to complain in a way that they can. We are revising the role and breadth of expert advisors to ensure we have access to the right knowledge and relevant experience we need in taking forward the complaints with sensitivity to the particular issues raised. We have asked MENCAP to train our complaints staff, ensuring all staff that deal with complaints have appropriate level of understanding.

3.2 Over 600 people responded to the Healthcare Commission’s consultation on a draft three year plan for adults with learning disabilities. From these responses we were able to conclude that:

- The public want the Healthcare Commission to monitor health services including learning disabilities.
- The public want performance indicators specific to learning disabilities.
- The public want all National Service Frameworks to be applicable to people with learning disabilities. The public want the Healthcare commission to work with CSCI and to have joint performance indicators.

- The public want health services to employ people with learning disabilities and family carers for training of professionals.
- People want to be listened to more and for the complaints process to be easier to understand.
- Advocacy needs to be better resourced in health.
- Standards for independent health care need to be specific around people with learning disabilities.

Where appropriate the Healthcare Commission is taking forward these expectation in our programme of work to measure what matters to people with learning disabilities.

THE HEALTHCARE COMMISSION AND THE HUMAN RIGHTS ACT

4. The Healthcare Commission is able to take account of the Human Rights Act by identifying possible breaches when carrying out reviews or investigations of trusts. The Healthcare Commission cannot, however determine that human rights have been breached, only that they may have been, or that there is a risk that they will be. The Commission also cannot take enforcement action against anyone under them Human Rights Act. This would be for individuals, if they feel that a public authority (eg a trust) has breached their human rights.

4.1 The Human Rights Act is referenced to in standard C7e of the Healthcare Commission's core standards against which NHS Healthcare providers are assessed, therefore, we have ensured that the legislation is featured in the corresponding criteria. In addition, we included references to the Human rights Act under C13a and C13c in part because of the research and engagement work we undertook prior to and during the 2004–05 consultation of the criteria. We had a number of meetings with the (then) equalities and diversity team at the Department of Health who challenged us to review whether we had appropriately incorporated issues of diversity and equality, including the Human Rights Act, across our criteria.

4.2 Inspection teams are provided with some background information on the Human Rights Act and are given specified lines of inquiry to focus inspections against the criteria.¹³⁰

4.3 The Healthcare Commission is currently undertaking a piece of work on some of the ways in which we are able to promote the Human Rights Act, incorporate it more fully into the core standards, which would allow the Healthcare Commission to enforce the principles of the act if not the act itself. We will be looking more systematically at issues that coincide under our standards and the Human Rights Act to ensure that our work is appropriately referenced to the Human Rights Act.

CONCLUDING REMARKS

5. The Healthcare Commission believes that the Act has the potential to become a cohesive framework for improving the care of people with learning disabilities—and other vulnerable groups receive in hospitals and other settings and that the adoption of a human rights based approach would drive significant improvements in care and in the relationship people with learning disabilities have with service providers. One way of doing this might be to make more explicit links between the standards contained in *Standards for Better Health*¹³¹ and those standards applying to independent healthcare organisations contained within the Care Standards Act 2000, which form a key part of the performance assessment by the Healthcare Commission of all health care organisations¹³² and the articles that form part of the Act. This linkage could also be used as a vehicle for increasing public awareness of both the standards and the Act.

¹³⁰ For Example C7e—Element 1

It is unlawful for a healthcare organisation to act in a way which is incompatible with the human rights conferred under the Human Rights Act 1998. Healthcare organisations should have arrangements in place to ensure that they comply with the Act. Such arrangements may include, for example:

- a human rights policy or framework that puts an individual at the heart of the service; policies or guidelines to protect a patient from unlawful detention (for example through regular reviews of circumstances requiring the detention of individuals with mental health problems or regular reviews of those detained as a means to prevent the spread of infectious disease);
- provision of training and development for staff in relation to challenging discrimination, promoting equality and respect for human rights;

or screening of training programmes to ensure stereotypes are not reinforced and that equality and human rights are respected as an integral part of any training course provided by or on behalf of the healthcare organisation, etc.

C13a—Element 2

1. The healthcare organisation should ensure staff are aware of the requirements of the Human Rights Act 1998, the Race Relations Act 1976 (as amended) and the Disability Discrimination Act 1995, and how this relates to issues of dignity and respect for different patient groups. The organisation may undertake this through a number of ways, for example, awareness training, briefings, discussion with patient groups, etc.

2. The healthcare organisation should ensure that, staff respect the human rights of patients under the provisions of the Human Rights Act 1998.

¹³¹ This can be found at

http://www.dh.gov.uk/prod_consum_dh/idcplg?ldcService=GET_FILE&dID=19479&Rendition=Web

¹³² The Healthcare Commission is required to develop criteria for use in its assessments of NHS trusts. For the core standards assessment the Healthcare Commission developed a set of criteria, which we call elements, for use by trusts when making their declarations of compliance with the standards and by the Commission's teams when undertaking selected inspections. We explicitly reference the Human rights Act in our Core Standards Assessment process and make clear our expectation that NHS Trusts will be acting in accordance with the Act.

5.1 The department of Health is proposing to undertake a review of healthcare standards applicable across the NHS and the independent healthcare sector in parallel to the establishment of the new regulatory body charged with registering and ensuring the ongoing compliance of healthcare organisations in the accordance with such standards. This will provide an opportunity to underline this commitment to the Human Rights Act.

5.2 In order for the Act to become an effective tool for regulatory bodies such as the Healthcare Commission to use, we believe that the following will also need to be in place:

- Firm commitment from government to embed the principles contained in the Act in all aspects of public policy.
- Better public understanding of the intention behind the Act and its application to public services.

Anna Walker CB
Chief Executive

5 June 2007

Memorandum from Alan F Snow

As a working carer and the chairman of an action group for adults with a learning disability I have had limited time to produce a response and will need to be more brief than the subject deserves.

It first needs to be clearly understood that a person with a learning disability has capabilities that are much below the norm. The diagnosis axiomatically signifies that their ability to understand and act upon information is lacking. Individuals differ greatly, so do their abilities and so does the degree of expertise required in assisting them. There may be physical impairments and mental health problems that compound the problems faced by individuals. In no sense is there a cure for learning disability but repetitious, individualised, educative processes are effective in improving competence. That applies to all of us—to a greater or lesser extent we are all the same!

In response to the four points:

1. *Social exclusion.*

We all work and socialise within a circle of compatible people. Adults with a learning disability should be allowed to do the same. They should have the opportunity to meet like minded people. There is no reason why this cannot be within the wider community but if they are happier in more sheltered locations then who is to deny them this? Enforced socialisation with incompatible persons is not possible for any of us.

2. *Control over their lives.*

One can only control ones own life by having knowledge and understanding and the resources to create a plan and put it into effect. Having a learning disability severely limits the ability to do this. Lacking money to pay for competent assistance compounds the problem. Suitable accommodation is mostly unavailable and is not part of any choice.

3. *Opportunities to be independent.*

No one has independence if they cannot rely upon their own capabilities. The degree of independence available to people depends upon the resources they can bring to bear on their situation. Those with a learning disability have less personal resources than most. With appropriate help, involving appropriate training, their level of independence can be improved. Their ultimate achievement depends upon their starting point. Financial support is important.

4. *Bad things happening in their lives.*

If this is true then it is as a result of their lack of understanding of the situations they find themselves in and their inability to reason a way out. It is dangerous to assume that just because a person has acquired a particular skill they can extend this beyond the environment in which it was learnt. The weak are always vulnerable to exploitation, whether disabled or not.

Various simplistic courses of action are proposed to integrate the learning disabled into society, to improve their lives and at the same time reduce their financial burden on the state. However, successful examples are often based upon special cases and when formulating policy must not be presumed to be generally applicable. Half truths are the norm in this field.

Our immediate family has experience in educating young children with special educational needs and is convinced that one-to-one learning produces the best results—whole class teaching the worst.

Our son went to special schools where his needs were recognised. He has a mild/moderate learning disability, is employed and is very sociable and outgoing. He has a number of interests and activities and is largely independent in deciding what he wants to do. Nevertheless, there are many ways in which he requires

assistance in dealing with the complexities of modern life. There is much that baffles him. He is unlikely to earn much more than the minimum wage and his potential for true independence seems very limited. We are concerned that his needs will not be catered for in the future that is thrusting independence on the unwitting!

25 May 2007

Memorandum from the Shields Parliament

We the people in Southend on Sea have mainly had good experience of adult education, although more choice of courses would be welcome.

It was felt by most that awareness around jobs and benefits was an issue which reflected on housing and other areas of their lives. Employers need to be made more aware that people with disabilities can contribute to a stable working environment with the proper support.

We found that health was a difficult area in that some people seemed to have support and understanding by the professional that they dealt with, while others had extreme difficulties. People with Profound and Multiple Disabilities had a very difficult time. Parents and carers were not really being listened to and most did not have the knowledge to deal with the person they were treating. People with Disabilities need support and understanding so that communication can be built on.

We believe that people with disabilities are still not listened to enough. In some cases, if they have made a decision which they feel is best for them it is then sometimes challenged by professional, especially when people wish to live together who both have disabilities. We heard about this when we were at a conference and it appeared that every obstacle was being put in the way. We wait to hear the outcome.

Although we know there are good areas of practice this needs to be shared. Our conclusion is that although improvements in some services have occurred, and understanding and awareness have increased, there is still a lot to do and we cannot sit back and do nothing. We must challenge for change.

June 2007

Memorandum from Our Choice Project

We are a self-advocacy organisation. A group of members organise a quarterly event called the Have a Say Day. We used this forum to discuss the issues about human rights.

We had a big Have a Say Day in Westminster, 43 people came to it. The group chose four topics from your survey that they thought were important and we supported people to discuss these issues at the day.

Please find enclosed a copy of the things people said about these issues. People were very interested in talking about the issues and we think it would be good to talk more about our human rights. We are doing some work about bullying and we think that this is when people don't recognise our human rights.

We look forward to seeing what you do with everyone's information.

HUMAN RIGHTS LETTER

The Advocacy Project—Our Choice

Health

See a dentist every six months.

Dentist gives me advice.

Some people have an annual health check; some people don't.

One person's doctor talks too fast.

Other people are making choices for me.

Information from health services are not clear.

Sometimes it is hard to get support to go to hospital when you live independently.

Going Out

Using public transport can be difficult.

On your own can be scary or together can be hard to get support.

You need to know how to get there and get back; some people need support to do this.

You need money to go out and about.

It would be good to have transport maps and dvds.
 Some people need support to go out and about.
 It is good to have local information.
 Being safe on the street- it is sometimes worrying to go out after dark.
 It would be good to get free personal attack alarms and to know where to get them.

Relationships

Support on getting a divorce: you would go to a lawyer but may need support to do this.
 It is hard to find the right person.
 People want to get married.
 It is good partners and friends sometimes give presents.
 It can make us feel special to have a partner.
 If you have a partner you can have children. Some people would like to have children and a family.
 It is important that your partner listens to you.
 Talking about sex is hard for some people but it is important.
 Making love with the one you love or taking it slowly. It is good to talk about this.
 Having a good friend and knowing the difference between that and having a partner.
 It is about trust.

June 2007

Memorandum by Inclusion International

Inclusion International (www.inclusion-international.org) is a global federation of family based organizations that advocates for the rights of people living with intellectual disabilities and their families worldwide that promotes shared values of respect, diversity, human rights, solidarity and inclusion. With 200 member organizations in 115 countries Inclusion International, works to link local voices to global change.

Our vision is of “A world where people with intellectual disabilities and their families can equally participate and be valued in all aspects of community life.”

People with intellectual disabilities are among the world’s poorest and most marginalized groups. Among the 600 million people with disabilities world wide people with intellectual disabilities in every country of the world are consistently among the most vulnerable. Even where measures are taken to support the human rights and participation of people with physical and sensory disabilities, little is done to support those with intellectual disabilities. In part this is due to the fact that societies devalue people with intellectual disabilities and because traditional measures to accommodate people with disabilities are not sufficient to meet the needs of people with intellectual disabilities.

Inclusion International’s member organization in the UK, MENCAP, has identified through various campaigns the issues affecting people with “Learning Disabilities” and their families in the UK. This submission from Inclusion International will provide an international context for the issues of exclusion and marginalization faced by people with “learning Disabilities” and their families around the world.

POVERTY AND DISABILITY

Three years ago Inclusion International launched a global initiative on poverty and disability using the Millennium Development Goals as a framework because we understood that despite human rights commitments and calls for inclusion, world leaders and mainstream initiatives targeted at reducing world poverty did not see disability as part of their mandate. We can no longer be satisfied that disability programmes will address our needs we need to be on the large agendas. We must be part of the big plan. Our Global Report helps make the case that our issues are particularly important to the mainstream agenda and that we can no longer be ignored.

Poverty is about exclusion; exclusion from the community; from the labour market; from school; from access to health care from participation in all aspects of life. The results contained in our global report *Hear Our Voices* (available on the Inclusion International website) are a validation of the individuals and families whose knowledge about exclusion and poverty have largely been ignored in places where decisions get made about investments and policy. This work is an affirmation of the voices of families and self-advocates who have always understood these linkages and whose knowledge can lead to real strategies for eliminating poverty.

People with disabilities are disproportionately represented among the poor in all countries, and are disproportionately represented in poor countries. Research by the World Bank and others suggests people with disabilities face a “vicious cycle” of poverty and disability: being poor causes disability; and having a disability makes it more likely that you will be poor. Our research affirms the relationship between poverty and disability but suggests the real “vicious circle” is of disability, poverty and exclusion. People with disabilities and their families are more likely to find themselves in this vicious circle than do most other groups in society.

In fact, at the global level, economic and social development is advancing for some groups, countries, and regions. The proportion of the global population living in extreme poverty is declining. The socio-economic status of certain marginalized groups is improving in general terms (eg women, children). There are certain regions which were previously underdeveloped, such as China and India which are seeing huge economic growth. But there are some groups, like people with disabilities, who are not making it onto this path of development; they remain confined to a cycle of poverty and exclusion.

People experience poverty in many ways—as inadequate income to meet needs, lack of needed supports, and as the experience of not belonging, being excluded. The cost of disability, which must be born by individuals and families, contributes to this experience of poverty. Disability-related supports (personal assistance, aids/devices, medication, etc) are borne not by the public sector, but largely by individuals and families, and only then when they have the resources which most don’t. In Mexico our research found that families provided 80% of supports to individuals with intellectual disabilities.

People with disabilities and families are drawn into the cycle of poverty and exclusion at key moments throughout their lives:

- At birth and infancy when disability is devalued, often resulting in inadequate health care, early intervention, and supports to families.
- When they are excluded from school and labour markets—children don’t develop the networks, or “human capital” needed for community participation and economic contribution in adult life.
- When one or more parents leave the formal or informal labour market/economy to meet needs of child with a disability—because of inadequate family supports.

Poverty entraps not only individuals with disabilities, but their families too. They are drawn into the cycle when attempts to participate in community and public life fail. This can be because of physical and attitudinal barriers exist in communities or because people can’t access needed supports, or because public institutions and law don’t support the equality of people with disabilities.

Our most significant finding is that the link between poverty and disability is Social Exclusion. Poverty is not only about money; it is about being excluded—from school, from work from community. Around the globe we have examples of people with an intellectual disability having limited access to education, health care and vocational training coupled. This is coupled with an undervaluing of the abilities of people with disabilities, which result in fewer opportunities to work, go to school be a part of the community.

Region by region families involved in this study told us about the experience of isolation and the difficulties they experienced in accessing, building or sustaining the formal and informal systems in their communities (education, health social networks, cultural and religious groups).

Taken together, these reports tell us that:

- Poverty is not only about income. It is about exclusion.
- Poverty impacts not only on the individual but also their family and community.
- Poverty of a person with a disability is not about the individual’s disability or their capabilities to contribute but rather about the societies inability to address inequality.
- Policies aimed at addressing poverty of the individual will fail.
- Structural reform is needed to address exclusion.

Hear Our Voices: People with an Intellectual Disability and their Families Speak Out on Poverty and Exclusion, is the story told to us by individuals in more than 80 countries about their plights with poverty and exclusion. The findings of this Global Report *Hear our Voices (2006)*, demonstrate how the rights of adults with learning disabilities need to be promoted and how the United Nations Convention on the Rights of Persons with Disabilities offers a tool to address the sources of exclusion identified by people who have an intellectual disability and their families.

To tackle this Global Report, Inclusion International has looked at how the status of people with intellectual disabilities and their families compares to the targets that were set in 2000 by countries around the world when they signed the Millennium Development Goals. Our research and consultations with participants in 80 countries and five regional studies has provided us with a global picture of the daily lives and disadvantages endured by people living with an intellectual disability across the globe. Collectively,

people from all over the world possess shared ideas of change and are calling for the realization of these ideas. Ultimately, our goal is to close the gap that is keeping this disadvantaged group from achieving a vision of inclusion.

MDG # 1 EXTREME POVERTY

“P.R. is a girl with intellectual disability. She is 10 years old. Since she was diagnosed, she underwent several treatments in different towns. These are very expensive for her family. When she was 4 years old, her father abandoned her. Now she lives with her mother, but the latter does not always have enough money to buy all the medicines her daughter needs. The little girl has no friends. She usually accompanies her mother to various places (parks, artistic performances, etc).”

Source: *Hear our Voices (2006)*

Our research confirms that people with intellectual disabilities and their family's are disproportionately represented among the poor, regardless of the country they live in. Specifically, while it is estimated that 10% of the global population, or 650 million people, have disabilities, people with disabilities make up 20% of the world's poorest populations. Consequently, people with disabilities are over-represented among the poorest of the poor by 100%. Moreover, even people with intellectual disabilities living in northern industrialized countries are hugely over-represented among the poorest in their countries. Our research has demonstrated that a cycle of poverty and exclusion tends to develop in which family's find themselves driven out of the labor market in order to care for family members with disabilities, which in turn only worsens this family's economic and social situation. Furthermore, the un-reimbursed costs of disability such as the costs of health care and medical and technical aid also contribute to this poverty, debt, and exclusion trap.

MDG # 2 INCLUSIVE EDUCATION

“Education is the key to the new global economy, from primary school on up to life-long learning. It is central to development, social progress and human freedom.”—Kofi Annan, The Millennium Report.

Source: *Hear our Voices (2006)*

Research has shown that less than five percent of children with disabilities complete primary education. These children are forced to bear the cost of this exclusion throughout their lives as they struggle to find methods of contributing to society with the promise of remuneration. Furthermore, as the cycle of poverty ensues, it becomes even more difficult for children and youth with intellectual disabilities to access an education. In cases of poverty, it becomes evident that the physical costs of schooling may prove to be unbearable, as well as the opportunity cost of sending a child to school. Moreover, this opportunity cost is especially high when the child in question has an intellectual disability. Furthermore, although research has shown that children with disabilities who are included in regular education are much more likely to finish school, participate in post-secondary education and training, and become active members in their communities, it is evident that laws and policy's intended for inclusive education in a number of countries are either lacking or equipped with poor implementation strategies.

MDG # 3 GENDER EQUALITY FOR WOMEN WITH DISABILITIES

When a child with a disability is born into a family, the mother is often blamed. Many men leave their wives and children and marry other women. There are therefore a lot of single mothers with disabled children.

Source: *Hear our Voices (2006)*

Because of gender and disability discrimination, girls and women who have a disability are doubly disadvantaged in accessing education, health care, and employment. Furthermore, this societal group is more likely to become victims of violence. Similarly, mothers with children who have disabilities are doubly disadvantaged as well. In particular, they bear the majority of care giving responsibilities which limits their opportunity's for paid employment and often isolates them in their communities. Our research has shown that in order to combat the poverty and exclusion of people with intellectual disabilities and their families, it is important to better understand the ways that gendered discrimination operates within society.

MDG # 4 REDUCE MORTALITY OF CHILDREN WITH DISABILITIES

“When Families have little food and access to health care, children with disabilities are often the last in line. As we witness increasing rates of malnutrition in the developing world, the report suggests children with disabilities are usually the worst off systemically the ‘last in line’.”

Taken from the Africa Study; *Hear our Voices (2006)*

Our research has shown that there is a 400% gap in the mortality rates of children with disabilities that cannot be explained by factors such as genetics or bio-medics. Once again, the poverty trap only worsens the challenges associated with childhood disability and as families struggle to feed and care for family members, children with disabilities are often neglected or find themselves to be last in line. Sadly, in some communities, the rate of infanticide of newborns with a disability is rising as a growing cultural devaluation of this societal

group develops. Without active intervention, there is no question that these already grave statistics will continue to worsen and the disadvantages of children living with disabilities will only become more serious as time progresses.

MDG # 5 ACHIEVE THE RIGHTS OF CHILDREN AND FAMILIES

“The principle of ‘all children, all rights’ is still much too far from being a reality.”—Kofi Annan in “The Progress of Nations 2000”

Source: *Hear our Voices (2006)*

Countries are supposed to respect the rights of children with disabilities as outlined in the UN Convention on the Rights of the Child. Furthermore, Inclusion International has recommended that families get the help they need for the care and support of their family member with a disability. Throughout our research, Inclusion International has noted how tempting it is to believe that disability only affects the children, youth, and adults living with the disability. Sadly however, the reality is that disability affects non-disabled family members as well. Moreover, when a child is exposed to severe poverty and suffers from exclusion, the rights of a child to survival and development, protection and participation as outlined in the UN Convention on the Rights of the Child are all violated. Furthermore, the capabilities of the family to care for this child are undermined as well. Thus, in the end, there is no denying that basic development and survival, protection and participation rights granted under the UN Convention on the Rights of the Child are denied to children and youth with intellectual disabilities.

MDG # 6 COMBAT HIV/AIDS

One of the biggest challenges in combating HIV/AIDS among children, youth and adults with intellectual disabilities is the stigma and isolation that make them so vulnerable to sexual abuse.

Source: *Hear our Voices (2006)*

The sixth MDG aims to combat HIV/AIDS, Malaria, and other diseases. Inclusion International is particularly interested in reversing the spread of HIV/AIDS in the community of people who have a disability and ensuring that children who have a disability and have been orphaned will be supported and cared for in the community. To begin with, one of the biggest challenges in combating HIV/AIDS among children, youth, and adults with intellectual disability’s is the stigma, and isolation that makes this group so vulnerable to sexual abuse. As well, a lack of access to information on reproductive health means that people with intellectual disabilities are just as affected, if not more affected, than other members of their communities by these ailments. Furthermore, individuals with a disability who become HIV positive are doubly stigmatized- by both their disability and their illness. Lastly, a person with an intellectual disability who loses a parent or caregiver as a result of HIV/AIDS also loses the support system he or she once depended upon and is more likely than others to be abandoned altogether. As a result, it is necessary to educate communities about HIV/AIDS as well as increase the accessibility of resources and support systems in societies that are most at risk.

MDG # 7 ENVIRONMENTAL SUSTAINABILITY

Environmental degradation is taking its health and economic toll on people with intellectual disabilities and their families, driving them even more into precarious living conditions and deepening their poverty and deprivation.

Source: African and American Studies; *Hear our Voices (2006)*

The seventh MDG is to ensure environmental sustainability by reversing the loss of environmental resources, increasing access to clean drinking water, and improving the lives of 100 million slum dwellers by 2020. As aforementioned, people living with a disability are disproportionately over-represented in the total population of people living in poverty. Through our research, Inclusion International has found that at least 26 million people with intellectual disabilities live on less than one dollar a day. Consequently, these conditions of deprivation leave little chance for individuals with intellectual disabilities and their families to develop the human, socio-cultural, economic, political, and other capabilities that mark the path out of poverty. By failing to provide these populations with their basic needs, governments are only perpetuating and deepening the situation of poverty.

MDG # 8 DEVELOP a GLOBAL PARTNERSHIP FOR DEVELOPMENT AND INCLUSION

Good governance partnerships to address the poverty and exclusion of people with intellectual disabilities and their families would require a clarity about what is to be done in government policies and plans to make a difference. Yet all of our regional studies report that people with intellectual disabilities and their families are by and large invisible in public policy and poverty reduction initiatives of governments, donor agencies and international institutions.

Source: *Hear our Voices (2006)*

The last MDG aims to develop a global partnership for development. Inclusion International has researched and studied how global efforts to promote good governance and global partnerships will contribute to the human rights of people with intellectual disabilities, including citizenship and economic rights by the year 2015. Study’s from all five regions show that people with intellectual disabilities and their families are not benefiting from current governance structures, public policies or partnerships for

development. There appears to be a lack of presence in public policy dialogue and the capacity of civil society to advocate change is either weak or absent altogether. Furthermore, family's that are already marginalized lack the political means to impact policy decision making and those who do become self-advocating find their plans blocked by a lack of communication between their governments and their organizations. Perhaps the most shocking finding of all is that participants in our study conveyed that even if special programs for people with disabilities are funded, they are usually too small scale to make a difference. Moreover, these programs usually do not tackle the larger social and economic issues driving people into poverty and keeping them excluded. As a result, without combating the root of the problem, it is impossible to believe that current strategy's can actually resolve these matters.

The Millennium Development Goals have proven to be an extremely powerful means of promoting awareness of the situation and daily struggles of those living with intellectual disabilities and their family members. After carrying out extensive research and analyzing the findings, it is undeniable that there is a growing divide between the world the MDGs aspire to create and the reality that is for the millions of people living with intellectual disabilities and their families worldwide. Using the Global Report, five main building blocks can be identified with which we can begin to build the foundation of a global agenda for change:

- All people must have equal opportunities to exercise rights to self-determination and full citizenship.
- All people must have the right to live in a community where they can experience belonging, active participation and full membership.
- The foundations to a good and fulfilling life must be laid by having access to inclusive education and lifelong learning, health care and social supports for all children, youth, and adults.
- Individuals, families, communities, and countries must be able to fully develop by exploiting active strategies that assure all people have access to adequate income and employment.
- Families must be fully supported to provide each of their family members with opportunities, support, and high expectations for a good and complete life.

While the findings of the Global Report *Hear our Voices (2006)* demonstrate the complexity and multi-dimensional nature of the poverty and exclusion faced by people with intellectual disabilities, The UN Convention on the Rights of Persons with Disabilities offers a development tool to secure and promote the rights of this disadvantaged group globally. Although the Convention does not provide people with disability's any new rights, it makes clear what these rights are, what they mean, and how it is that they can be upheld.

THE UN CONVENTION: A TOOL FOR BUILDING INCLUSION

For people with intellectual disabilities and their families, the challenge of this Convention will be to have state parties and other groups recognize that this Convention includes and must protect the rights of people who cannot always speak for themselves. People with intellectual disabilities are among the most excluded groups in every society. Even among other disability groups there is little understanding of the issues and perspectives of people with intellectual disabilities nor any recognition of the role families play in supporting individuals to claim their human rights.

Inclusion International and a number of its national member organizations have been actively involved in the Convention process in order to ensure that the voices of people with intellectual disabilities and their families are recognized and taken into account in the Convention.

The Convention's overall impact as a new international instrument will provide a basis to link human rights to public policy at the domestic and international levels. Specific provisions in the Convention are particularly important to the lives of people who have an intellectual disability and their family's and are issues that were identified by self-advocates and families as priorities for addressing exclusion: for example; the right to live in the community (Living in the Community), the right to be included in education (Education), the right to make one's own decisions (Legal Capacity) and the recognition of the role of families in the achievement of human rights. This Convention will be a tool for governments and civil society groups to work together toward the progressive realization of these human rights. Inclusion International has received financial support from the United Nations (Department of Economic and Social Affairs) to promote the inclusion of people with intellectual disability's in the Convention.

Inclusion International is developing a global campaign to promote the Convention as a tool for Building Inclusive Futures and the Eradication of Poverty and Exclusion. This campaign will include strategies and tools for members to use to raise awareness of state parties in the ratification process about the issues of people with intellectual disabilities; it will provide resources and knowledge to governments in their efforts to develop implementation strategies (For example, expertise in inclusive education: teacher training; curriculum adaptation etc); it will develop, track and validate existing practices that promote inclusion (for example in the area of deinstitutionalization; what works and what doesn't) and it will pilot good practices in key priority areas for people with intellectual disabilities and their families.

 LINKING HUMAN RIGHTS TO DEVELOPMENT POLICY AND INVESTMENTS

The new UN Convention contains articles which cover a range of issues including General Obligations, Equality and Non-Discrimination, Raising Awareness Regarding Disability, Accessibility, Right to Life, Situations of Risk, Equal Recognition as a Person before the Law, Access to Justice, Liberty and Security of the Person, Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment and from Exploitation, Violence and Abuse, Living Independently and being included in the Community, Respect for the Home and the Family, Education, Health, Habilitation and Rehabilitation, and Work and Employment.

It is important to understand the significance of this Convention and the context for its initiation in our efforts to address the poverty and exclusion faced in particular by people who have an intellectual disability and their families.

While the disability movement has evolved over time to reflect a human rights approach to disability issues, and while around the world there has been an increase in the human rights protections for persons with a disability entrenched in national and international law, Inclusion International's regional Poverty Studies show that families are becoming increasingly frustrated by the limited implementation of these laws and by their impotence in promoting social change. Many human rights monitoring mechanisms, while useful in raising awareness about human rights abuses, have done little to put in place the institutional and cultural building blocks for societies that are inclusive of all groups.

In response to the call for recognition of the human rights of people with disabilities development agencies, governments and international institutions have developed models and approaches to redressing exclusion of persons with disabilities focused on the provision of direct support. The disability human rights agenda has largely been interpreted by policy makers and development agencies as a service provision agenda; developed as a segregated system of disability specific measures that inadvertently contribute to segregation and exclusion. At the same time, the development agenda itself has failed to address the marginalization, exclusion of the poorest people in the world and has done little to reduce the inequalities faced by these groups in society. The challenge therefore for people with disabilities in the development context is not inclusion in development but rather how to contribute to models for "inclusive development".

Moreover, in poor countries as in richer ones, much of the investment in services and rehabilitation has not proven effective in improving the well being of people who have a disability. Over and over investments in disability initiatives have focused on the provision of therapies or services which are intended to ameliorate the impact of a disability either by preventing the disability; providing rehabilitation, aids or services. There has been less investment in the supports needed for people to participate in the social, economic, political and cultural life of their societies. Even where such supports have been provided, there has been inadequate investment in schools, health care, and child development schemes to ensure they are designed to be inclusive.

This Convention provides an opportunity to step beyond the limitations of other human rights instruments and to link policy and investments in poverty reduction to a human rights framework.

The international normative framework on disability consists of instruments that specifically deal with persons with disabilities, as well as general human rights instruments. While all international human rights instruments are applicable to persons with disabilities, only one of the core human rights treaties—the Convention on the Rights of the Child (articles 2 and 23)—expressly mentions persons with disabilities. Experience has shown that the implementation of existing human rights treaties has not provided sufficient protection of the rights of persons with disabilities.

Contrary to human rights treaties, existing international instruments specifically related to disability are legally non-binding to States. These include the Declaration on the Rights of Disabled People (1975), the World Programme of Action Concerning Disabled Persons (1982) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). These instruments mark the shift from a medical and welfare perspective on disability to a social and human rights model. However, many of these instruments include outdated terminology and concepts.

The UN Convention on the Rights of Persons with Disabilities differs from the above instruments, as it reflects new thinking in the area of disability, and links disability to both human rights and development. It is built on the principle of participation of persons with disabilities and their organizations. In substance, it incorporates most of the areas covered in the previous instruments and offers significant new developments in legal protection and promotion of the human rights of persons with disabilities.

A CONVENTION FOR ALL: PEOPLE WITH INTELLECTUAL DISABILITIES AND THEIR FAMILIES

For people with intellectual disabilities and their families, the challenge of this Convention will be to have state parties and other groups recognize that this Convention includes and must protect the rights of people who cannot always speak for themselves. People with intellectual disabilities and their families are among the most marginalized groups in society. Achieving inclusion for this group of people depends not on the provision of accommodations and services but on the transformation of communities.

Even where measures are taken to support the human rights and participation of people with physical and sensory disabilities, little is done to support those with intellectual disabilities. In part this is due to the fact that societies devalue people with intellectual disability's (to the point that some jurisdictions have seen wrongful life cases won in the courts) but also traditional measures to accommodate people with disabilities are not sufficient to meet the needs of people with intellectual disabilities.

For people with intellectual disabilities and their families the Convention provides an opportunity to develop an aspirational instrument with a vision for the future and can transform the way in which our societies are structured and organized in order to be inclusive. The unique contribution of people with intellectual disabilities and their families is the perspective of "Inclusion". For people with intellectual disabilities participation in society and in their communities requires more than accommodations that provide access; the measures needed to ensure that their rights are respected require systemic changes in the way that public process and systems are organized. For example, many children with disabilities require specific supports to enable their participation in a classroom but for a child with an intellectual disability to participate in a classroom, they require that the curriculum be adapted, that teachers have appropriate training, that the entire school system be organized in a way that takes into account the range of learners whom it is responsible to serve. By approaching inclusion in this way rather than by beginning with a list of individual groups and needs, governments are better able to develop inclusive approaches to the needs of all of its citizens.

Many have pointed to the ineffectiveness of the UN Millennium Development Goals because they are not connected to processes of investment and poverty reduction and from the disability community's perspective, they fail to include people with disabilities. The MDGs provide a set of target but they do not provide a map for the achievement of those targets. The new UN Convention could provide a vehicle for achieving the MDG's for people who have a disability by promoting good practices inclusion at the domestic and international levels.

Despite the pervasive exclusion faced by people with intellectual disabilities throughout the world, there are some examples of inclusion that can teach us about how to structure communities to support the participation of all its members. Examples of children with intellectual disabilities being included in the regular classroom, examples of people who have an intellectual disability living and being included in their communities etc. These examples provide technical knowledge, policy and practical information about what works in inclusion. However this knowledge remains localized, sporadic and disconnected from policy and processes for development. The challenge is to identify sources of knowledge and good practice; use this knowledge to develop models for inclusive practices and to scale up these practices to embed them in development policy and investments.

The Convention will be a tool to help achieve inclusive communities but building these inclusive communities will require collaboration between all stakeholders: civil society, governments, families, experts and policy makers.

24 May 2007

Memorandum from The Royal College of Psychiatrists

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and the Republic of Ireland and is the professional and educational organisation for doctors specialising in psychiatry.

1. INTRODUCTION

1.1 The government has recognised that adults with learning disabilities may have additional healthcare needs. In March 2001, it published the White Paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* in an attempt to secure equity in the four key principles at the heart of its proposals: civil rights; independence; choice; and inclusion.

1.2 The Royal College of Psychiatrists has long recognised that people with learning disabilities can have additional specialist mental health needs. The College established a Faculty of Learning Disability Psychiatry to address the specialist psychiatric and care needs of people with learning disabilities. The Faculty makes this submission on behalf of the College.

1.3 When the UK government joined the European Union by signing the Treaty of Rome in 1951 it committed itself to be bound by the European Convention on Human Rights (ECHR), which made provision that all public bodies were obliged to uphold certain principles for their citizens. By incorporating the ECHR into the Human Rights Act (HRA) 1998, the UK government made the enforcement of rights easier and raised public awareness of these rights. However, it is notable, especially in view of the less able learning disabled population that the UK government failed to incorporate the right of interested parties to enforce individuals' rights in the HRA, one of the few differences between the HRA and ECHR.

1.4 Both the ECHR and the HRA are limited in their application by being binding only on “public bodies”. This is unfortunate because private organisations provide a substantial amount of the care to those with learning disabilities.

2. BACKGROUND

2.1 Children and adults with learning disabilities are more likely to have complex medical and social needs, and, as a result, are more likely to be reliant on carers or advocates in many aspects of their lives, making them more vulnerable to breaches of their human rights. Maintaining and safeguarding human rights underpins good clinical practice within health care organisations, but is an ever-challenging task that requires flexible individuals and organisations to respond to more demanding circumstances.

2.2 The prevalence of learning disability is estimated to be around 3% of the population, making it the largest cause of disability. The majority of people with a learning disability can function independently in society with minimal assistance. There are, however, others who may be dependant upon the assistance of others as they have a higher incidence of physical and mental health needs, making them more likely to need additional help from healthcare services.

2.3 Up to 50% of people with a learning disability will experience mental health issues in their lifetime. Most mental health care for adults with learning disabilities is now delivered in the community, either by generic mental health services or specialist learning disability mental health care teams. Even though only a small proportion of mental health care is delivered on an inpatient basis, over 4,600 individuals with a learning disability were inpatients on a census date in 2006.

2.4 The *Valuing People* White Paper recommended that Learning Disability Partnership Boards should be set up and be responsible for those elements of the Government’s proposals which relate to services for adults with learning disabilities. The Boards were specifically charged with implementing Health Action Plans for adults with learning disabilities in the DOH guidelines *Action for Health*.

2.5 *Valuing People* also recommended that the non-specialist psychiatric mental health needs of those with learning disabilities should be met by generic NHS mental health services. The paper also recognised that a minority of those with learning disabilities needed specialist learning disability psychiatric services. Subsequently, *The Green light for mental Health: a service improvement toolkit* provided a “traffic light” self-assessment tool for local organisations and services to monitor the integration of learning disabled individuals into generic services.

3. CURRENT SITUATION ON MAINTAINING QUALITY PSYCHIATRIC SERVICES AND RESPECTING HUMAN RIGHTS OF ADULTS WITH LEARNING DISABILITIES

3.1 The Royal College of Psychiatrists is aware of the variations in the quality of mental health care for adults with leaning disabilities and actively works to reduce inequalities when it becomes aware of them and to improve the quality of mental health care. The College has members who work in both the NHS and independent healthcare sector. Through structured and peer reviewed reaccreditation and training in the psychiatry of learning disability, doctors are expected to recognise, seek and be aware of any abuses or potential abuses of human rights, and the methods of addressing these. The College’s Human Rights Committee is currently developing training guidance for psychiatrists in this area.

3.2 To ensure that the human rights of adults with learning disabilities are protected, it is important to be aware of the different forms of abuse, including active and passive abuse. Abuse, as described in the *No Secrets* guidance, “is a violation of an individual’s human and civil rights by any other person or persons”. It can be a single act or repeated acts, take the form of discrimination, physical abuse, psychological abuse the taking advantage of an individual and may be a positive act or act of omission. The guidance also refers to “institutional abuse” and provides the following example: “Neglect and poor professional practice also need to be taken into account. This may take the form of isolated incidents of poor or unsatisfactory professional practice, at one end of the spectrum, through to pervasive ill treatment or gross misconduct at the other. Repeated instances of poor care may be an indication of more serious problems and this is sometimes referred to as institutional abuse”.

3.3 The potential of human rights abuses occurring was demonstrated by the Cornwall and the Sutton and Merton reports. Both reports highlighted serious weaknesses in the care provided to adults with learning disabilities. For example, the Cornwall report noted that “The Trust’s services did not reflect the principles of rights, independence, choice and inclusion, set out in the *Valuing People* strategy”. “The institute found that people using the Trust’s services were generally ‘looked after’, instead of being supported to develop their skills.”

3.4 The Royal College of Psychiatrists has publicly expressed concerns over the findings of these reports stating of the latter report “this investigation highlights the need for vigilance in maintaining appropriate standards of care for this vulnerable group of individuals. The failings in relation to provision of care, and the restrictive practices conducted by staff in some of the units, have been present for a considerable length of time. These problems have been compounded by lack of appropriate training, lack of clear policy guidelines and inadequate staffing ratio, amongst other factors. The College would welcome recognition of

the fact that provision of good quality care for people with a learning disability should be backed up by adequate resources. There has been ample evidence of reduction in resources, yet with greater expectations of a higher standard of care for this group of individuals, especially in institutional care”.

3.5 Since the government published its White Paper *Valuing People* in 2001, there has been a focus on responding to the potential risk of the marginalisation and exclusion of adults with learning disabilities. The College and its members have proactively encouraged the implementation of these principles within the functioning of healthcare organisations, publishing guidelines on “Meeting the Mental Health Needs of Adults with a Mild Learning Disability” (2003) and “Psychiatric Services for Children and Adolescents with Learning Disabilities” (2004).

3.6 Nationally, the adoption of person centred planning for people with learning disabilities, where a person’s individual care and social needs are assessed, means that psychiatric services are providing tailored care packages that respect individuals’ human rights. Priority for provision of specialist local care services is also a national priority so that people placed outside of the vicinity of their home due to specialist needs can return to their home area. This helps meet social needs such as easy family contact, and facilitates access to familiar social, cultural and spiritual environments.

3.7 The maintenance of good quality services and promotion and sharing of good practice inevitably leads to a reduction in the risk of human rights abuses. All inpatient learning disability services are now audited yearly by the Healthcare Commission on basic quality indicators and, because of the concerns raised by the reports mentioned above, all NHS inpatient services were inspected by the Healthcare Commission this year. The Commission has also published a three-year strategic plan on assessing and encouraging improvement in the health and healthcare of adults with learning disabilities. Furthermore, every NHS inpatient healthcare facility in England with more than 10 beds is assessed annually on patient environment under the auspices of the Patient Environment Action Team.

3.8 In respect of good clinical care, in some learning disability services all paid carers are expected to complete the LDAF (learning disability awards framework www.ldaf.org.uk), the training having at its centre the “need to promote the following values at all times: individuality, rights, choice, privacy, independence, dignity, respect, and partnership”.

3.9 Despite this work, College members continue to express concerns about the quality of psychiatric care for adults with learning disabilities. Issues of particular concern are: national variations in the quality of care; lack of specialist psychiatric provision or appropriate supported accommodation locally (leading to individuals being placed in accommodation distant to their home area family and social network); and lack of resources to deliver quality of care. These key issues need to be tackled by Government.

4. CONCLUSION

As a professional, educational and training organisation, the College strives to maintain minimum standards in its members and for healthcare services. The College supports the need for minimum national standards for the care of adults with learning disabilities and the need to develop and monitor these standards. It actively supports the development and sharing of good healthcare practice and believes that this can help protect the human rights of adults with learning disabilities.

References

1. Department of Health (2001) *Valuing people a new strategy for learning disability for the 21st century a white paper*.
2. Department of Health (2002) *Action for Health—Health Action Plans and Health Facilitation. Detailed good practice guidance on implementation for Learning Disability Partnership Boards*.
3. Healthcare commission (2006) *Cornwall enquiry—Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*.
4. Healthcare Commission (2007) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust Sutton and Merton (Ref. to be added)*.
5. Foundation for People with Learning Disabilities. (2004). *Green Light for mental health: A service improvement toolkit*.
6. Department of Health (2000) *No secrets No secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*.
7. Council Report 115 “*Meeting the Mental Health Needs of Adults with a Learning Disability*”, Royal College of Psychiatrists, April 2003
8. Council Report 123 “*Psychiatric Services for Children and Adolescents with Learning Disabilities*” Royal College of Psychiatrists, September 2004

Memorandum from the Princes Royal Trust

EXECUTIVE SUMMARY

Recently as the final part of my degree I undertook a piece of empirical research to explore the extent to which the provision of dental care services for people with a learning disability in West Lancashire achieve the recommendations set out by the Department of Health 2001.

In order to achieve the aim of this study the objectives were:

- To identify any unmet dental needs for people with a learning disability in West Lancashire.
- Explore the provision of general anaesthetic dental care for people with learning disabilities within West Lancashire.
- Provide a framework to develop individual dental health action plans following dental check ups.
- Investigate the experiences of people with a learning disability, their families and carers in seeking and attending dental services to highlight any unmet needs and gaps in the service provided.

FINDINGS/CONCLUSIONS AND RECOMMENDATIONS

GENERAL ANAESTHETIC

This research study highlighted that at present the general anaesthetic services are inadequate in West Lancashire. The general response was that treatment that was able to take place in the general dentist chair was excellent, with appointments generally available when needed. However, when treatment under general anaesthetic was discussed participants expressed distress and anger around the long waiting lists for treatment. These waiting lists had been as long as eighteen months in some cases. Although the vast majority of respondents said they usually had to wait between nine and 12 months.

One Learning Disability Community Nurse expressed great concern around a patient who had been referred for treatment under general anaesthetic but had to wait for twelve months for the treatment of eight extractions. 'Whilst waiting for the treatment the patient's behaviour became more challenging due to pain and discomfort. Antibiotics were needed for abscesses that formed and when treatment was eventually received the person with the learning disability needed all their teeth removing. This person is now left with no natural teeth; unable to tolerate dentures they are forced to live the rest of their life without teeth. This research highlighted the concern of family carers around multiple extractions. Many people with a learning disability would not be able to wear dentures and this led to very emotive discussions around nutrition and diet, freedom of choice, quality of life and self esteem. The question was asked by a family carer how many people without a learning disability would have to wait the same length of time for their dental care? Was this morally right and acceptable?

Recommendations

1. Reduce waiting times around treatment under general anaesthetic.
2. Direct patients that could cope with treatment under slight sedation to more General dental practices to free up Specialist Dentist for more complex patients.

ACCESS TO DENTAL SERVICES

Accessing dental care for a person with a learning disability is often reliant upon the availability and willingness of a family carer and support worker. It is quite often a traumatic and frightening experience often with a limited understanding of the treatment people are likely to receive and a limited level of communication can increase worries and anxieties. This research study highlighted the need to increase desensitising programmes which would allow patients to visit dental surgeries without receiving treatment to meet dental staff, see dental instruments and acclimatise to the surgery environment.

In this research the majority of respondents agreed that dental professionals should take the lead from the carer or support worker accompanying the patient in how to communicate and relate appropriately.

Concern was expressed by family carers around the inequity of "out of hours" dental care for people with learning disabilities. Reasons for the inequity given included the lack of information about the patient's medical history and lack of experience in special care dentistry of the dentist on call.

Recommendations

1. Development of more desensitisation programmes.
2. Dental Surgeries can clinical schedule to be adapted to need the people with learning disabilities.
3. Use of visual aids and resources to improve communication about procedures.
4. Improvement of "out of hours" services. Improvement in a system to share Medical histories.

PREVENTION OF ORAL DISEASE

In this research few family carers or people with a learning disability felt that they had received adequate formal training in oral health care. Family carers felt that the planning of oral health initiative are led mainly by dentists but should be altered to a multi-disciplinary approach with more input from carers, other and social care providers and the people with a learning disability themselves.

Recommendations

1. Information and training for family carers and people with a learning disability around oral hygiene.
 2. As part of a Health Action Plan early prevention advice. Development of a Multi-disciplinary approach to include Learning Disability Community Nurses, Specialist Dental Services, Health Visitors, Support Workers and Family Carers.
 3. Improved access to dental hygienists for education and regular appointments.
 4. Transport issues to be raised with local authorities.
-

Memorandum by the Disability Rights Commission



What some people with a learning disability said about their human rights

Who is this document by?



We are called the **Disability Rights Commission**. We work to make things better for disabled people.

What is this document about?



A group of people called the **Joint Committee on Human Rights** wanted to know if people with a learning disability are getting their human rights.

What is the Joint Committee on Human Rights?



It is a group of people who work for the government. The group looks to see if people are getting their human rights.

What are human rights?

Human rights are rights that everyone should have.



For example, everyone should have the right to

- be alive
- have good healthcare
- get an education. This is where you learn things at places like school and college



People with a learning disability are people too. This means they should have the same human rights as everyone else.

How did the Joint Committee on Human Rights find out what people with a learning disability thought?



The Joint Committee on Human Rights asked people to answer some questions about their human rights.



A group called the **Learning Disability Action Group** answered the questions.

The Learning Disability Action Group is a group of people with a learning disability.



Now you can look at what the Learning Disability Action Group said when they answered the questions about their human rights.



Question 1. How easy is it for people with a learning disability to say what they think about decisions that are made about them?

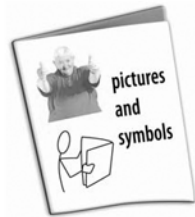
What the Learning Disability Action Group said



- it is difficult for people who need a lot of support to say what they think. These people might need some training to help them say what they think



- people often make decisions for people with a learning disability without asking them what they think first



- not enough groups make their information easy to read and understand. Groups like the government and local councils should always do this



- people with a learning disability do not always get the care they need because groups who run care services do not always think about their needs



- consultations need to be much better. They do not work well. Consultations are when groups who run services ask people what they think about new plans or decisions.

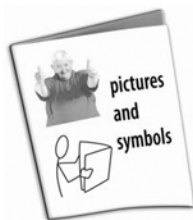


Question 2. How easy is it for people with a learning disability to say when they are not happy about a service? (This is called making a complaint)

What the Learning Disability Action Group said



- groups who run services do not always make it easy for people to make a complaint



- information about how to make a complaint needs to be easy to understand



- some people find it difficult to make a complaint or do not even know they can make a complaint. This is wrong. It should be easy for everyone to make a complaint if they want to



- people called advocates could help people with a learning disability to make a complaint.



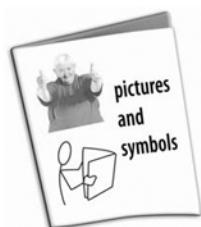
- local councils do not understand what people with a learning disability need. The information they give people is often difficult to understand



Question 3. What would help people with a learning disability get their human rights?

And can you think of any examples of good work that has been done to make this happen?

What the Learning Disability Action Group thinks would help people with a learning disability get their human rights



- easy to understand information. For example, some people cannot read or write. They need information that is right for them



- people called advocates to help people with a learning disability say what they think. There needs to be enough money from the government to make this happen



- people with a learning disability should give people who run services training to help them understand what people with a learning disability need



- people with a learning disability need more information about their rights. For example, their rights to do with health and work



- people with a learning disability should go to the same school as people who do not have a disability. This will help everyone understand more about each other



- there should be enough money from the government to make sure people with a learning disability can live in a place that is right for them



- people with a learning disability who care for someone else need much more help to do this work.

MENCAP
Understanding learning disability

Easy read words by Mencap. Pictures by Photosymbols

Memorandum on behalf of the PMLD Network by Beverley Dawkins (Mencap)

INTRODUCTION

The PMLD Network is a group of organisations who are working together to fight for the rights of children and adults with profound and multiple learning disabilities (PMLD).¹³³ The Network believes that focusing on the needs of these individuals, who face double discrimination, should be a priority¹³⁴. The needs and rights of people with profound and multiple learning disabilities are frequently neglected. They remain some of the most disadvantaged people within our society.

¹³³ Membership of the PMLD Network is listed in Appendix 1

¹³⁴ "Valuing people with profound and multiple learning disabilities" Mencap 2001

The vision set out in *Valuing People*¹³⁵ and *Improving the Life Chances of Disabled People*¹³⁶ have set out some relevant and exciting new initiatives, such as the modernisation of day services and individualised budgets. However, they have largely failed to understand the particular needs of people with profound and multiple learning disabilities. It is vital that we understand the distinctive needs of people who are often excluded from society and respect their right to be included.

Who are people with profound and multiple learning disabilities?

The PMLD Network has developed the following definition:

Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour. Some other people, such as those with autism and Down's syndrome, may also have profound and multiple learning disabilities.

All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of daily life.

Appendix 2 provides more information on what it means to have a profound and multiple learning disabilities and the accompanying CD "Meet the people" contains video clips which focus on the lives of six people with profound and multiple learning disabilities.

This submission sets out the main issues that need to be tackled so that people with profound and multiple learning disabilities can take up their rightful place in society.

The need for better planning

People with profound and multiple learning disabilities have been described as the invisible minority. There is no formal agreement on the words that we use to describe them, and consequently information on their needs is poor. Nobody knows how many people have profound and multiple learning disabilities in the UK. Local authorities, even if they do have an up-to-date learning disability register, do not collect specific data on people with profound and multiple learning disabilities. However, it is clear that the number of people with profound and multiple learning disabilities is rising. For example we know that due to better neonatal care, and advances in medical technology such as tube feeding, an increased number of profoundly disabled children are surviving. Adult services are now coming into contact with higher numbers of people need who need much more intensive support, but there is a lack of planning for their needs.

Services are by no means seamless as young people move from child to adult services. LEAs actually withdraw their funding. Children's social workers sever ties and adult services do not always provide a named social worker to take over. There is often little or no communication between these people. Parents often feel they are falling into a black hole.

Tom's transition story

Tom was a very sociable young man with profound and multiple learning disabilities, including complex health needs. Although he had no speech he had a great sense of humour and a whole range of ways that he communicated his keen interest in food, films, beer and blondes! He attended a residential special school. His parents were both teachers, his mother a teacher of pupils with profound and multiple learning disabilities. They knew the system and they did everything they could to get transition planning underway for Tom so there would be a good plan for when he left school. They were told not to worry, it was too early to start planning. But despite their best efforts, by the time Tom was approaching 19 no provision had been identified for him. The school kept him on for a bit longer, but eventually set a deadline for him to move on. His parents, and eventually a social worker, searched frantically for a residential placement for him but to no avail.

In the end, Tom spent 96 days in an NHS psychiatric assessment unit. His parents think that this was because there was nowhere else for him to go. Eventually a suitable placement did come up in the area and he was transferred to a suitable residential service. But during this time, when he

¹³⁵ "Valuing People: A New Strategy for the 21st Century" DOH 2001

¹³⁶ "Improving the Life Chances of Disabled People". Cabinet office 2005

was not in an environment where he was supported by people with the right skills, his health was deteriorating. Tom was eventually diagnosed with a number of serious conditions but it was too late for Tom and he died a short while after his 20th birthday.

Tom's parents complained to social services about the lack of transition planning and the failure to plan for or commission new provision for him. Both complaints were upheld:

"I agree with the conclusion that both Tom and yourselves were entitled to expect accommodation would be available within a reasonable time to meet Tom's needs and we have failed to deliver this"—Head of adult care services.

However far Tom's death may also be attributed to the care he received in the NHS (on which, see Tom's story in Mencap's 2007 report *Death by indifference*¹³⁷), the question Tom's parents continue to ask is, "If good planning had been in place, and Tom had reached 'safe hands' sooner, would he still be alive today?"

"The totality of the experience of the family was akin to that of experiencing a storm. When it was all over, it was not only the winds that had died"—Tom's father.

The need to challenge attitudes and values

One of the greatest barriers that people who have profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives. This can stop people being offered some of the more innovative forms of support, such as individual funding, because some people do not think that they will benefit, or they think that the costs involved are too high. But these negative attitudes can also be life-threatening—for example, if they result in the denial of medical treatment. These judgements are only ever subjective. Most people do not know what it is like to have profound and multiple learning disabilities and perhaps experience the world by touch and smell. Such judgements also show a failure to understand the contribution that each individual will make to the lives of the people around them.

It is important that everyone understands that people with profound and multiple learning disabilities have the same rights as every other citizen. We must enable each individual to engage with their world and to achieve their potential so that their lives go beyond being "cared for" to being valued for who they are as people.

The need for better family carers support

Mencap's 2001 report *No ordinary life* found that 60% of parents of children and adults with profound and multiple learning disabilities spent more than ten hours per day on basic physical care. One third of these had a continuous caring role of 24 hours per day. 78% of families received either no support at all or less than two hours per week. Unsurprisingly, few families were satisfied with the care support services they were receiving.¹³⁸

The caring task associated with someone with profound and multiple learning disabilities is both highly intensive and long lasting. It has major consequences for the entire family. A parent needs to constantly attend to basic needs such as eating, drinking, washing and changing. In addition, many parents have to provide high levels of physical care, such as lifting and positioning, and cope with a wide range of other essential needs. Typically, a parent will need to support their son or daughter's complete health needs. This may include the use of special equipment, such as suction equipment and oxygen cylinders, or being able to administer various kinds of medication. These are arduous and time consuming tasks, taking up many hours of the day and extending into the night . . . people with profound and multiple learning disabilities currently have no "voice" with which to demand better services. Their parents are so busy fighting their way through the day, fighting to get even very basic needs met, that it is hard for them to fight for their son or daughter's rights. The presence of children and adults with profound and multiple learning disabilities is therefore barely visible within our community. Consequently, both they and their families are disadvantaged across the whole spectrum of service provision.¹³⁹

In particular, parents felt dissatisfied with assessment processes. They felt assessments were not thorough enough, not reviewed frequently enough and failed to deliver what they needed.

Mencap's 2006 report *Breaking Point* found that seven out of 10 families have reached or come close to breaking point because of a lack of short break services. Five out of 10 families who have had a carer's assessment got no services as a result. One in three families has experienced a cut in their short break services in the last year.¹⁴⁰

¹³⁷ *Death by indifference: Following up the Treat me right! report* (Mencap, 2007), p. 14–15.

¹³⁸ *No ordinary life: The support needs of families caring for children and adults with profound and multiple learning disabilities* (Mencap, 2001), p. 10.

¹³⁹ *No ordinary life*, p. 5–7.

¹⁴⁰ *Breaking Point—families still need a break* (Mencap, 2006).

The need for better healthcare

People with profound and multiple learning disabilities may have a wide range of health needs, such as complex epilepsy. An increasing number of people are technology dependent, which can mean they need oxygen, tube feeding or suctioning equipment. However, access to mainstream health care is poor as many health professionals are ill equipped to meet the needs of people with profound and multiple learning disabilities. Many families and care staff report that health professionals hold negative assumptions and beliefs about the quality of life of individuals with profound and multiple learning disabilities. This is illustrated by the worrying trend in “Do not resuscitate” orders attached to people with profound and multiple learning disabilities.

Some people may be described as having “life limiting conditions”. Others have fragile health and can be susceptible to conditions like chest infections and gastro-intestinal problems. Good nutrition is vital for achieving good health, and skilled support is needed for feeding and swallowing in many cases. Many people experience a combination of medical needs and need access to specialised health support to ensure they are holistically managed.

Many people with profound and multiple learning disabilities have multiple physical disabilities and need access to physiotherapy, hydrotherapy and postural care. There is growing concern that adults in particular who may have had regular access to this during childhood have limited support once leaving school. This can result in deteriorating body posture and in some cases, their premature death.

A further example is that Optometrists are not given enough extra money to test people with profound and multiple learning disabilities and so their needs are often not picked up. This affects people’s quality of life. Annual health assessments must include checks of vision and also hearing.

In addition, of course, people with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is in how these can be identified in people who may not be able to communicate their symptoms easily. For example, it is very important to develop effective ways to recognise and manage pain. It is crucial that a proactive approach such as by introducing annual health checks and health action plans to ensure that each person is able to achieve the best possible health they can.

The need for greater representation

The advocacy movement has done much to ensure that the voices of people with learning disability are heard but the Learning Disability Task Force, Partnership Boards, the national forum, regional forums and the majority of advocacy groups are not representative of people with profound and multiple learning disabilities.

This means that their needs remain low on the government agenda. It also directly affects the quality of their lives. People with profound and multiple learning disabilities have the greatest need for advocacy, but they have limited access to it. One survey showed that only 11% of advocacy schemes could support someone with profound and multiple learning disabilities. Most people with profound and multiple learning disabilities will not use formal communication such as speech or sign language and yet they are largely surrounded by a workforce that is not trained to understand their communication method. Nor do they have good access to advocacy services with the skills to support them.

John’s story

John is a young man with profound and multiple learning disabilities. When his family, who lacked support, felt they could no longer care for him, he was moved into a group home.

The staff at John’s new home struggled to understand his communication and what he wanted. Frustrated and confused, John’s behaviour deteriorated. Soon John was admitted to a psychiatric unit as staff were unable to cope. Eventually John got an advocate who spent time with him, got to know him and worked with those who knew him on his individual communication. The advocate supported relationships to be slowly built between John and the staff at his residential home.

John needed an advocate to speak up for him, if he had had one sooner he might never have had to experience inappropriate, and traumatic, time in a psychiatric unit.

An example of a project aiming to support people with profound and multiple learning disabilities to speak up is “Getting to Know You” (photo below). This is a Mencap pilot project which offers an introductory training to self advocates with learning disabilities in including and speaking up for the needs of people who do not use any formal communication system. Self advocacy projects around the country are requesting this training for their members as people with profound and multiple learning disabilities are so excluded from this type of work. Peer advocacy relationships are being built up and the issue of exclusion from decision making is being approached. This work is also very empowering for people with learning disabilities who do use words and speak up for themselves as their skills and experience are so valued.

The need to remove barriers

In addition to the significant barrier of lack of communication, there are some physical barriers facing people with profound and multiple learning disabilities. Two very important examples of these are manual handling practice and the lack of fully accessible toilets:

Manual handling

Local policy and practice in manual handling has become a major barrier to community inclusion for many disabled people. A combination of a risk-averse culture, fear of litigation and over-zealous interpretation of health and safety legislation has resulted in many local authorities imposing blanket bans on manual handling and insisting that all lifting takes place with the use of mechanical aids such as hoists. For many people, this restricts their access to the community. For others, for whom not all lifting can be done mechanically, it can actually mean that they cannot access services or support because no one is able to meet their manual handling needs.

The law on moving and handling is quite complex. The Health and Safety at Work Act 1974 says that “it is the duty of every employer to ensure, so far as it is reasonably practicable, the health, safety and welfare at work of all his employees”. The translation of this law into local authority policies has caused difficulties. Many people have followed the Royal College of Nursing’s Code of Practice for Patient Handling, which aims “to eliminate hazardous manual handling in all but exceptional or life-threatening situations”.¹⁴¹ In recognition of the growing concerns around this issue, the Health and Safety Executive issued guidelines that stated that “implementation of policy and practice on lifting and handling should not place any unreasonable restrictions on client’s right to autonomy, privacy or dignity”.¹⁴² This document made it clear that manual handling practice also has to comply with other requirements under community care legislation such as the Disability Discrimination Act and Human Rights Act.

A legal challenge was mounted by a family in East Sussex caring for two adult daughters with profound and multiple learning disabilities who were receiving no services due to a blanket ban on manual handling. They won their case and the High Court ruling was heralded as a landmark ruling.¹⁴³ The DRC summarised the implications for local authorities as:

1. Blanket no lifting policies are most certainly unlawful.
2. Manual handling regulations do not prescribe a “no risk” regime.
3. Some manual handling is an inherent and inescapable feature of the task an employee is employed to do.
4. Employees have to accept a greater degree of risk if their job is to lift people and not objects.
5. All risk assessments must be based on consideration of individual needs and circumstances.

In July 2005 the organisation National Back Exchange introduced new policy guidance which includes advice on how to make decisions balancing the need for safe working practices with the human rights of the individual.¹⁴⁴

There appears to be a gradual shift in manual handling policy and practice towards a more balanced approach. However, this issue remains highly problematic for many individuals with manual handling needs.

Fully accessible toilets

Another major barrier is the serious lack of adult-sized changing facilities. Standard accessible toilets meet the needs of many disabled people but not all. Most people with profound and multiple learning disabilities, and thousands of other disabled people who need personal assistance to change incontinence pads, face the choice of either staying at home or having to take the risk and indignity of being changed toilet floors. In July 2006 the Changing Places Consortium launched the Changing places, changing lives campaign for changing places toilets which include an adult sized changing bench, a hoist and enough space for two carers as well as the disabled person. The campaign’s website is at www.changing-places.org. There are now 30 such facilities in the UK, but this is a very long way short of the number needed. Evidence is currently being submitted to the relevant British Standard committee, and if successful will help to ensure that a growing number of these facilities will appear. Removing this physical barrier to community inclusion will dramatically improve the quality of life of thousands of people—not just those with profound and multiple learning disabilities. This is also an example of how getting support right for those with the very highest levels of need can benefit many others in the community.

¹⁴¹ *RCN Code of Practice for Patient handling* (RCN, 1996, reprinted 2002), p. 3.

¹⁴² *Handling Home Care: Achieving safe, efficient and positive outcomes for care workers and clients* (HSE, 2002).

¹⁴³ *A&B, X&Y v East Sussex County Council* (2003), EWHC 167 (Admin), High Court.

¹⁴⁴ *The Guide to the Handling of People* (5th Edition) (Back Care, 2005).

The need for better support

While many barriers can be challenged and even removed, we have to acknowledge that ultimately we cannot change the nature of people's disabilities. This means that we need to understand the specific needs of people with profound and multiple learning disabilities in order to ensure that the right support is in place. Since the launch of *Valuing People* there has been far too little focus on these needs, with the result that sometimes well-intentioned initiatives actually further disadvantage some people. One example of this is the modernisation of day services.

Traditional forms of day services for people with profound and multiple learning disabilities were often segregated, and provided even less opportunity for access to the community or inclusion than other day centres. However, they were equipped for complex physical and health needs and thus were appropriate in protecting people's dignity, as well as offering opportunities that met people's specific needs. Often community involvement provision does not have the equipment or the staff training to do this.

Valuing People was the catalyst of this move towards modernisation. It includes the objective "To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships".¹⁴⁵ Day services, it says, should now be structured flexibly around each individual, their interests and their needs. But modernisation has not achieved this for many people with profound and multiple learning disabilities.

The PMLD Network believes that in order for the principles in *Valuing People* to be realised for all, attention must be paid to the specific needs of people with profound and multiple learning disabilities. People with profound and multiple learning disabilities have the right to access their community like everyone else. This means staff training (in issues such as complex communication, complex health needs and understanding the needs of family carers), specialist facilities such as Changing places toilets in the community, more accessible transport, imaginative and meaningful use of the community (including the use of specialist facilities where these are the only kind that meet people's needs), and respect and experience with the different forms of communication that are used to express choice.

The need for equality of opportunity

For most young people, a vital element of growing up involves loosening parental ties and leaving home. For young people with profound and multiple learning disabilities this stage in their development may never take place. Most stay at home well into adulthood, as parents feel the alternative forms of provision are not acceptable. Some parents are offered no alternative and struggle on for as long as they can, but when parents become ill or die, most local authorities make hasty and ad hoc decisions about where family members with profound and multiple learning disabilities will be placed. The placements are often inappropriate, far from the home community, and will most likely be in traditional forms of residential care.

This lack of real choice over where and with whom people may live is just another example of the high level of discrimination faced by people with profound and multiple disabilities in many aspects of their lives. The right to have a home of one's own, to be able to live independently, is one that most adults take for granted—but it is not available to most adults with profound and multiple learning disabilities.

Victoria's story

Victoria lives in her own tenancy in the London borough of Islington. She has 24 hour support, a circle of friends and a person centred plan and very much lives the life of her choice. Her mother Jean has had to consistently fight to keep this in place. Islington have now, made the decision that they will never again fund individuals with complex needs to live independently because the costs are too high.

Individual budgets are another example of an innovative model of support with the potential to have a hugely beneficial effect on the quality of life of people with profound and multiple learning disabilities. However there remain very few examples where someone who needs very high levels of support has been offered this alternative. Is this an example of how some people can be seen as too disabled, too difficult and too expensive to have equal access to support?

Conclusion

The needs of people with profound and multiple learning disabilities are distinctive and mean that this group are currently being excluded from society. This can be turned around through:

- Better planning—The number of people with profound and multiple learning disabilities is rising and services and communities are not equipped.
- Challenging attitudes and values—Judgements about the meaning and quality of people's lives should not stop innovative forms of support being offered to those with the most profound disabilities.

¹⁴⁵ *Valuing People: A New Strategy for the 21st Century* DOH 2001, p. 76.

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- Better support for family carers—Family carers are doing a huge amount of stressful, unpaid work. They are happy to do it but cannot carry on unless they get more support.
 - Better support with healthcare—People with profound and multiple learning disabilities have very complex health needs. It is also important to remember that people with profound and multiple learning disabilities will have the same health needs as the rest of the population but may have difficulty communicating pain or discomfort.
 - Better representation—People with profound and multiple learning disabilities clearly have the greatest need for advocacy, yet research shows they have the most limited access to it.
 - Removing barriers to participation in the community—such as:
 - 1) Poor manual handling practices, (a major barrier to community inclusion, insistence on mechanical aids to lift people restricts their access to the community).
 - 2) Inaccessible toilets, (a serious lack of adult sized changing facilities means most people face the choice of either staying at home or having to take the risk and indignity of being changed on toilet floors).
 - The right support—Modernisation of services, although well intentioned, still needs to take into account some people’s more complex needs or it will further segregate them. For example, the move towards community involvement provision, replacing traditional day services, is currently excluding many people with profound and multiple learning disabilities, as provision does not have the equipment or staff training to meet needs.
 - Equal opportunities—Most young people experience the process of growing up and loosening ties to their parents. The lack of real choice over where and with whom people may live then is just another example of the high level of discrimination faced by people with profound and multiple learning disabilities. It is a basic human right to have a home of one’s own.

Action points

- Undertake research into the numbers of people with profound and multiple learning disabilities.
- Provide education around the meaning and quality of people’s lives.
- Set a minimum short breaks entitlement.
- Train healthcare staff in the rights and communication needs of people with profound and multiple learning disabilities.
- Provide an advocate for all people with profound and multiple learning disabilities.
- Re-think manual handling policies.
- Introduce mandatory planning of fully accessible toilets into all new planned public buildings.
- Introduce the needs of all into staff training and innovative service provision.
- Provide fully supported housing for all adults with profound and multiple learning disabilities.

APPENDIX 1

The PMLD Network consists of the following organisations:

BILD

Circles Network

Deafblind UK

Foundation for People with Learning Disabilities

Learning Disability Taskforce

Mencap

North West Training and Development Team

Rett Syndrome Association UK

Scope

See Ability

Sense

The Challenging Behaviour Foundation

The Children's Trust
 The Ridgeway Partnership NHS Trust
 Westminster Learning Disability Partnership

APPENDIX 2

UNDERSTANDING PROFOUND AND MULTIPLE LEARNING DISABILITIES

Learning needs. Like all of us, people with profound learning disability will continue to learn throughout their lives if offered appropriate opportunities. Such opportunities must take account of the fact that most people are likely to be learning skills that generally appear at a very early stage of development. For example, cause and effect, such as pressing a switch to make something happen, or turn-taking, such as rolling a ball between two people. Learning is also likely to take place very slowly. For example, some people may have a very small short-term memory and so will need the opportunity to encounter events many times before they become familiar. Constant repetition and a great deal of support will be needed to generalise learning into new situations. Supporting the learning needs of a child or adult with profound and multiple learning disabilities also needs to take account of any additional needs, such as sensory needs (see sensory needs section), so that the best approach to learning can be established.

Communication needs. Many people with profound and multiple learning disabilities rely on facial expressions, vocal sounds, body language and behaviour to communicate. Some people may use a small range of formal communication, such as speech, symbols or signs. However, some people with profound and multiple learning disabilities may not have reached the stage of using intentional communication, and they may rely on others to interpret their reactions to events and people. Most people are also likely to find it difficult to understand the verbal communication of others. Some people will rely heavily on the context in which the communication takes place, such as the clues given by a routine event. It is important that those who support people with profound and multiple learning disabilities spend time getting to know their means of communication and finding effective ways to interact with them.

Physical needs. Some people described as having profound and multiple learning disabilities are fully mobile. Many may use a wheelchair. Others have difficulty with movement and are unable to control or vary their posture efficiently. These individuals will need specialised equipment to aid their mobility, to support their posture and to protect and restore their body shape, muscle tone and quality of life. It is vital that people with physical needs have access to physiotherapy, occupational therapy and hydrotherapy, and that their carers receive training to enable them to manage their physical needs confidently on a day-to-day basis.

Complex health needs. There is a wide range of conditions that children and adults with profound and multiple learning disabilities may have, such as complex epilepsy. An increasing number of people are described as being "technology dependent", which may mean they need oxygen, tube feeding or suctioning equipment. Some people have conditions that are described as "life-limiting". Others have fragile health and may be susceptible to conditions like chest infections and gastro-intestinal conditions. Skilled support may be needed for feeding and swallowing, as good nutrition is a vital part of achieving good health. Many people may experience a combination of medical needs and need access to specialised health support to ensure the holistic management of these conditions.

People with profound and multiple learning disabilities experience the same health conditions as the rest of the population. The challenge is about how these conditions are identified in people who may not be able to communicate their symptoms easily. For example, it is very important to develop effective ways to recognise and manage pain. It is crucial that a proactive approach is taken to ensure that each person is able to achieve the best possible health they can, for example, by arranging annual health checks and support to access general health care.

Sensory needs. Special attention needs to be given to the sensory needs of people with profound and multiple learning disabilities. Many people have some degree of visual and or hearing disability or a combination of both. Some people's sense of taste or smell may be affected by the drugs they are prescribed. Other people may be hypersensitive to touch. It is essential to know as much as possible about a person's vision, hearing and other senses in order to develop the most effective way to approach their learning and communication needs.

Understanding behaviour. Some behaviour that is seen as challenging may arise because little attention has been given to other needs. It should never be assumed that certain behaviours are just part and parcel of having profound and multiple learning disabilities. For example, a behaviour that services may see as challenging, such as pushing people, may be an attempt to communicate a need. Other changes in behaviour may be due to undetected health needs, such as scratching the face because of a toothache. However, some behaviour will be because people are simply doing things that they enjoy, for example putting a hand under the tap to enjoy the feeling of running water. The important thing is to understand what the behaviour may mean and to respond accordingly, such as checking out any possible health causes or making changes in the environment.

Mental health needs. The mental health needs of individuals with profound and multiple learning disabilities are often not considered. For example, someone who becomes very quiet and passive may be seen as having improved their behaviour when in fact they are depressed. Research suggests that people with profound and multiple learning disabilities may be more susceptible to mental health conditions than the rest of the population. It is important that careful attention is given to these needs and that the right treatment and support is found to meet them.

Profound and multiple learning disabilities and other syndromes or conditions. There are many other conditions and syndromes used to describe people, some of whom could also be described as having profound and multiple learning disabilities. Conditions and syndromes that are more usually associated with profound and multiple learning disabilities include Rett syndrome, Tuberous Sclerosis, Batten's Disease and some other rare disorders. However, some people who are described as having autism and Down's syndrome may also have the combination of profound learning disability and one or more of the needs we have discussed—therefore, they could equally be described as having profound and multiple learning disabilities.

Support needs. All children and adults with profound and multiple learning disabilities will need high levels of support from families, carers and paid supporters. This will include help with all aspects of personal care, such as washing, dressing and eating, as well as ensuring that each individual has access to high quality and meaningful activity throughout their lives. Those who offer this support will need access to good quality and appropriate training, especially around particular skills. For example, on particular feeding needs and communication approaches. Good support is person-centred, flexible and creative to enable the person with profound and multiple learning disabilities to learn and to achieve their full potential.

26 June 2007

Letter from National Group of Speech and Language Therapists

I am emailing you from the Steering Group of the National Group of Speech and Language Therapists who work with adults with learning disabilities, as a direct response from that group to your recent call for evidence of abuse of human rights. In the course of our work many of the group have come across instances of such abuse and there would be evidence and examples from across the country. In line with what was published in Death By Indifference, the recent MENCAP Report, there are instances where people with LD are discriminated against in healthcare settings, such as poor or inappropriate treatment on hospital wards; One example within the last three weeks is the case of a man admitted to a mental health ward who was persistently given a normal diet despite not being able to eat what was given to him. His parents sat with him daily trying to encourage him to drink as that was all he could swallow. At no stage was he referred for assessment of his eating and drinking, despite there being a team of Speech and Language Therapists in the hospital who would have assessed him and given advice. The main reason for no referral was that he has a learning disability.

Our other concern is also that in many instances the right to be communicated with in a language that they use and understand is ignored by many service providers and this should be enforced or at least advocated more strongly. In my own work I have had direct experience of people who need to use Makaton signing in order for them to understand others and to communicate themselves, be ignored and signing not promoted because it is not convenient for some members of staff to learn to use signs. In addition, quite often any staff member who challenges this attitude by using signs that they have learned becomes demoralised because the other staff refuse to sign. This in turn leads to further isolation of the person with communication difficulties often leading to either behaviours that challenge the service, or to withdrawal and depression.

I am sure that there are also some examples of areas of the country where good practice is demonstrated.

This group is keen to support the work of the committee in any way that we can and would welcome some further guidance from yourselves as to the detail that you require for the evidence that you seek. If you were interested in further input from the National Group, then I would be pleased to circulate any comments and questions that you have for individual responses on specific topics.

24 May 2007

Memorandum from the Foundation for People with Learning Disabilities

EXECUTIVE SUMMARY

“Any fair society should be judged not only on the way it cares for vulnerable people, but on the steps it takes to ensure that they can lead integrated and fulfilling lives”

“Progression through Partnership”, HM Government 2007

1. The evidence in this submission shows that progress has been made in human rights for people with learning disabilities, particularly since publication of the White Paper “Valuing People” in 2001. However, there have also been recent shocking reports of abuses of human rights and the lives of many people with learning disabilities—and their families—are seriously impoverished.

2. Our evidence focuses on progress and problems that we see in our work with organisations and individuals across the country. Too many services that are particularly for people with learning disabilities are “getting by” with the basics of care rather than enabling people to have a fulfilling life. Too many services that we all use are still not inclusive or welcoming to people with learning disabilities. There are some groups of people with learning disabilities who are particularly likely to have a poor deal, including people from black and minority ethnic communities and people with high support needs. There seems to be an expectation in some authorities that family carers will provide increasing levels of support as public sector eligibility criteria are tightened. Greater independence for disabled people should not be achieved at the expense of unreasonable demands on their families. Yet there are some great examples of people being supported to make the most of their talents and live full and rich lives. Why can’t this happen everywhere?

3. We are encouraged that more people with learning disabilities are speaking up for themselves and some are becoming leaders in their communities. We think more needs to be done to invest in these developments so that people and their families can take more control over their lives and the support they need. Alongside this, communities need support to become more inclusive and the “place-shaping” role of local authorities (Lyons, 2007) will be important to this.

4. Key elements of legislation, such as disability discrimination and mental capacity law, are in place and the Government has committed to improving support for disabled children; we now need greater commitment to full inclusion for adults with learning disabilities. The UN Convention on the Rights of Persons with Disabilities could help with that.

ABOUT THE FOUNDATION FOR PEOPLE WITH LEARNING DISABILITIES

5. We promote the rights, quality of life and opportunities of people with learning disabilities and their families.

6. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship;
- support local communities and services to include people with learning disabilities;
- make practical improvements in services for people with learning disabilities; and
- spread knowledge and information.

7. Our objectives are:

- To promote the rights of people with learning disabilities to play a full part in society.
- To help ordinary services and communities to include people with learning disabilities more.
- To empower people with learning disabilities and their families to take control of the planning and delivery of their support.
- To promote person-centred practice, services and systems.
- To help get improvements in people’s physical and mental health, so they can lead fuller lives.

8. Over the last three years we have worked with over 100 public and independent sector organisations across the UK, helping them to improve opportunities and services for people with learning disabilities. We are part of the Mental Health Foundation, a registered charity.

EVIDENCE ABOUT THE HUMAN RIGHTS OF ADULTS WITH LEARNING DISABILITIES

9. It is tempting to set out for the Committee all the information we can compile about the human rights of adults with learning disabilities. However, we note that the Committee is already aware of some key sources, such as the national survey of adults with learning disabilities (Emerson et al, 2005). We are confident that the Committee will also be aware of the survey and data analysis published by the Valuing People Support Team (“Valuing People—the Story So Far”, Greig, 2005). Many of the issues raised in reports about the experience of disabled people generally are also relevant to people with learning disabilities (for example, “Independence Day”, Disability Rights Commission, 2006a; “Disability 2020”, IPPR, 2007).

In general we will therefore not repeat these sources, but will focus mainly on evidence from our own work, together with collated evidence from other sources. We will refer to reports produced by others on specific topics where we particularly wish to endorse their findings.

10. An underpinning issue that does not seem to fit neatly under any of the suggested headings is society's attitude to the birth of disabled people. Guidance on antenatal screening designed to detect fetal abnormalities is clear that advice to pregnant women and their partners should be non-directive. Yet research published by the Foundation (Barr and Skirton, 2006) shows that many women report feeling pressured, both by health professionals and by family and friends, into having screening and into terminating their pregnancy if screening shows that their baby may be disabled. Health professionals who offer screening often have little or no up-to-date information on what life is like for disabled adults. This is important because these early choices and experiences can reinforce stigma about disabled people (including amongst disabled people themselves). The Foundation does not take a position on the choices that parents should make, but is concerned that they should have the best possible, balanced information on which to make their own decisions. The Foundation has commissioned research from the Universities of Plymouth and Ulster on the information that parents and health professionals want and need.

Access to and quality of public services

11. One way of describing independent living for disabled people is as access to the same life opportunities and the same choices that non-disabled people take for granted. That includes growing up in their families, being educated in the local school, using the same public transport, getting employment that is in line with their education and skills and having equal access to the same public goods and services. Some public service issues are particularly relevant to the Joint Committee's interest in relationships and family life, participation in the life of the community and a voice in decision making—these will be addressed under those headings below.

Health and social care services for people with learning disabilities

12. The last 12 months have seen the publication of five key reports detailing abusive, neglectful or discriminatory practice affecting people with learning disabilities:

- report of the Healthcare Commission/Commission for Social Care Inspection (CSCI) investigation into services provided in Cornwall (Healthcare Commission/Commission for Social Care Inspection, 2006);
- report of the Healthcare Commission investigation into services provided by Sutton & Merton Primary Care Trust (Healthcare Commission, 2007a);
- report of the CSCI inspection of services provided by Bedfordshire & Luton Partnership NHS Trust (Commission for Social Care Inspection, 2007);
- report of the Disability Rights Commission Formal Investigation into health inequalities (“Equal Treatment”, Disability Rights Commission, 2006b); and
- report by Mencap on six deaths that should have been avoidable (“Death by Indifference”, Mencap, 2007).

13. The Joint Committee will be aware that the Healthcare Commission is midway through an audit of bed-based health services for people with learning disabilities, set up in response to concerns that the Cornwall findings might be indicative of wider neglect. This will give, for the first time, much more complete and reliable information about the numbers of people in different types of services as well as the quality of those services.

14. Examples of abusive and degrading treatment such as the stories from Cornwall about forced cold showers and the man tied in his chair for 16 hours a day are shocking and made the front page of some daily papers. The six deaths reported by Mencap also received wide coverage. The later reports described institutional practices that also represent blatant abuse of human rights:

- poor management of challenging behaviour and aggression, including inappropriate methods of control and restraint;
- examples of restrictions placed on all the residents of a service because of the behaviour of one person—for example, the kitchen kept locked and the room lights controlled centrally by staff;
- casual disregard for dignity and respect, for example in the way a person was supported to eat and drink;
- poor condition of accommodation;
- great poverty of lifestyle, with lack of opportunities for social and recreational activities, friendship or active citizenship; and
- lack of “reasonable adjustments” in the provision of mainstream health services and failure to promote equality.

15. These examples received far less media coverage. The Sutton and Merton investigation was not even reported in the Health Service Journal. As some commentators pointed out, the same reports from children's services would have provoked a public outcry. This suggests that the human rights of adults with learning disabilities take a lower priority in society.

16. Messages posted by family carers and support workers on our electronic Choice Forum suggest that abuse of human rights is more widespread than the high profile investigations have uncovered. We are not in a position to ascertain the reliability of the allegations made, but they include:

- food being withheld as punishment;
- lack of attention to personal hygiene, so that faeces become hardened into pubic hair;
- lack of attention to health, such as untreated fungal infections and lack of support to attend for regular dental checks;
- failure to offer food in a form that can be managed by a person who is not supported to wear dentures, leading to a person becoming very underweight;
- lack of support for healthy eating and exercise, leading to a person becoming very overweight; and
- staff who support a person in their own home preferring to sit and watch TV rather than support the person to go out.

People making such observations are always encouraged to follow local complaints procedures.

17. In our own work with services across the UK we observe staff in many areas struggling to support people to obtain a reasonable quality of life. Some organisations have worked hard to develop more person centred practice, but find that the funding from council and NHS commissioners is inadequate to deliver this.

Example

Four people have shared a house since they moved out of one of the long stay hospitals about 10 years ago. They have each had a programme of day activities that has taken them out and about most weekdays. This has been cut by the council, which is experiencing significant financial difficulties. The staff team that supports people at home was designed (in numbers and timing) on the basis that people were out of the house most of the day, Monday to Friday. The organisation that provides the support has not been funded to increase the hours. The four people are now spending a great deal of time in the house together, with inadequate staff support to go out and do anything. They have found they do not get on so well together. There have been problems of aggressive behaviour between two of the people. Tranquillisers have been suggested to control this. One person's mental health has started to deteriorate. The support provider says they cannot go on supporting people in this way.

18. Thus too often services focus on meeting basic needs for shelter, warmth, cleanliness and nutrition than around promoting freedom of expression and association. More disabled young people are surviving into adulthood. We have to ask whether society is prepared to support them to get a life, rather than just an existence that may itself be cut short due to unhealthy lifestyles and poor access to health care.

19. We are working with services in Cornwall to help them undertake person centred planning and develop day opportunities, short breaks and employment options. This will give people the chance to participate in a wider range of community-based activities and to exercise their choices and rights as citizens. As in many other authorities, we have found that staff have had little training or support to develop practice that supports people's human rights. In many areas organisations report that one consequence of tighter and tighter funding is reduced training—what capacity is left tends to be focused on mandatory training such as health and safety, at the expense of values-based skills development.

20. Too many people from authorities across the country are still sent away from their home area because local services are inadequate to support them. Sometimes this is because they have complex health needs; more commonly it is because services find their behaviour too challenging. Behaviour that challenges is often the product of frustration, poor communication, pain or boredom. It might result from a poor quality of life or from failure to offer choice and control. It might occur when staff or family carers fail to engage the individual in decision making about his or her life. Changes in behaviour can be a symptom of abuse or of physical or mental health problems that require investigation. Yet a common response is to send people to more restrictive settings, breaking links with their family and community, rather than to investigate and address the underlying issues. In 2006 31% of people with learning disabilities aged 18–64 known to councils (over 11,000 people) were in residential accommodation outside their home area (The Information Centre, 2006). Studies in the West Midlands, Wales and Kent have shown that people placed out of area often receive poor quality care and (out of sight, out of mind) do not benefit from proactive, person centred planning that might change their situation for the better. The substantial costs incurred in such placements reduce the funding available to develop better local services; this vicious circle needs to be broken by better collaboration across authorities to develop local competent, individualised services.

21. Research we have undertaken on person centred planning (Robertson et al, 2005) shows that the "family" of person centred approaches can help to make significant improvements in the quality of people's lives—more choice and control, more social relationships, more activities of the person's choice. Coupled

with the options of self directed support such as direct payments and individual budgets, there are real opportunities for people with learning disabilities to gain more control over their lives. It is disappointing that our research shows that access to direct payments is still limited by restrictive care management practices and inadequate support. The Independent Living Funds have also supported some people to achieve greater control over their support, although the eligibility criteria still exclude people living in NHS campuses who may wish to move to more independent living. This appears discriminatory. Paradoxically our research shows that people who most need person centred approaches, such as people whose behaviour challenges or people on the autistic spectrum, are least likely to be involved in person centred planning.

Mental health services

22. People with mental health problems in addition to their learning disability are also less likely to be offered person centred planning. In addition they are less likely than non-disabled people to be offered the full range of appropriate mental health services. For example, people with learning disabilities are typically not offered cognitive behavioural therapy, even when their cognitive abilities would allow them to benefit from this, because of false assumptions about their mental capacity. Mental health problems often go unaddressed because support services miss early warning signs or misinterpret them. For example, the person may be labelled as having challenging behaviour and contained rather than treated. Primary care services are not always skilled at recognising mental health problems and differentiating the signs from the person's learning disability (diagnostic overshadowing).

Examples

Members of our UK Health and Learning Disability Network cite many examples of people who have developed stress-related mental health problems, yet the health service response is commonly to prescribe tranquilisers or sedatives rather than to address the underlying issues.

23. People and their families still report being passed backwards and forwards between learning disability services and mental health services (Cole, 2003). Data on admissions to bed-based services shows that people are still at risk of becoming "stuck" in in-patient services far beyond any therapeutic purpose for lack of competent and confident community services. The recent "Count Me In" census showed that this is a particular risk for people from minority ethnic communities (Healthcare Commission, 2007b).

24. We are concerned that provisions of the Mental Health Bill currently in passage through Parliament may result in an increased number of people with learning disabilities being compulsorily treated with medication or forced to comply with other conditions, possibly for prolonged periods of time. In most cases, person centred support, provided early, removes the need for this form of coercion. However, this legislation will also address the "Bournewood gap" where people without capacity have in the past been detained without any form of legal safeguard. Although we remain deeply concerned about many aspects of the Mental Health Bill, the developments in regard to "Bournewood" constitute a step forward in ensuring the rights of people with learning disabilities are upheld.

General health services

25. Like the DRC's Formal Investigation (Disability Rights Commission, 2006), we are aware of both good and bad practice in access for people with learning disabilities to mainstream health services. We have conducted a series of projects aimed at improving access to and quality of primary and secondary health care (Giraud-Saunders et al, 2003; Smith et al, 2004; Smith et al, 2007). These and intelligence from our electronic UK Health and Learning Disability Network show consistently that:

- The introduction of annual health checks within mainstream primary care is an essential first step to addressing the substantial health inequalities experienced by people with learning disabilities.
- PCTs have inadequate data about the health status of people with learning disabilities and about their use of services. This means that stark inequalities such as omission of women with learning disabilities from breast and cervical screening programmes remain unaddressed. Improved clinical coding is required to capture better data about people with learning disabilities, but this will not suffice in itself. Stronger leadership is required within PCT and practice based commissioning of mainstream health services to ensure that the inequalities experienced by small marginalised groups, such as people with learning disabilities, are addressed alongside the major public health initiatives.
- Practitioners in primary and secondary care have not generally been well equipped to respond to disabled patients. They commonly report lack of confidence in dealing with issues such as communication, consent and managing risk. In turn, people with learning disabilities complain to us about poor communication, discriminatory attitudes, lack of "reasonable adjustments" in processes, and inaccessible information. Families continue to report that health professionals ignore their expertise and that unreasonable expectations are placed on them to provide personal care for disabled relatives who are admitted to hospital. Concerns raised by the Healthcare Commission and the National Patient Safety Agency about lack of care for vulnerable people in hospital (eg food placed out of reach, failure to prevent falls, lack of attention to dignity) apply equally to people with learning disabilities.

- There are some serious gaps in existing health care services for the growing population of people who have very complex health needs (including the cohorts of young people surviving dependent on a variety of medical technologies). There are particular problems in timely access to equipment and in management of swallowing problems (dysphagia), body shape protection (postural care), epilepsy, and recognition of pain and distress. A new generation of children is at risk of growing up in hospital.

26. Our work with services across the country shows that people with learning disabilities still do not get adequate health checks and that this affects their opportunities.

Examples

A man who lived in accommodation supported by NHS staff used a wheelchair. We were told he could not walk. We found that his toenails had not been cut for a very long time; they had curled round and were cutting into the soles of his feet.

A woman using day services proved hard to engage in person centred planning designed to find out what she would like to do in her life. She spent a lot of time slumped in a chair. We found that her thyroid function had not been checked and that her eyesight and hearing had not been tested. Once these things were done and corrective action taken, she was a different person and we could begin to explore with her the changes she wanted in her life.

Another woman, using supported accommodation, was sleepy all the time and overweight. She no longer went out and about to do the things she used to enjoy. Through health action planning she was supported to talk to her GP about her prescribed medication. It was changed to reduce the side-effects and this had a dramatic effect on her wellbeing. She lost weight, got some new clothes, and started going on the bus again.

Housing and independent living

27. The demand for improved housing choices is very substantial. Over half of people with learning disabilities known to services live with their families and there are increasing numbers who are known to be living with very elderly parents. The national survey of people with learning disabilities, “Valuing People—the Story So Far” (Greig, 2005) and our own work on person centred planning, transition planning and support for older families all tell the same story: the common options of staying with your family or moving into residential care are no longer enough. Mirroring trends in the rest of the population, more people with learning disabilities want the chance to live on their own, or perhaps with one other chosen person, with appropriate support. There are some excellent examples of people with learning disabilities using shared ownership and assured tenancies to achieve this aim and the “Supporting People” initiative resulted in more people getting a chance of more independent living. However, these options are not universally available and “Supporting People” funding is reducing. Much new housing development is geared to meeting the general demand for single person accommodation, but:

- it often does not meet the space requirements for disabled people, including people who need sleep-in support; and
- it is often unaffordable for people reliant on state benefits—particularly where housing benefit levels do not reflect the space requirements of a disabled person.

28. Care is needed to avoid assumptions in exploring housing and support options and choices. People from minority ethnic communities sometimes report that workers promote a version of “independence” that entails separation from the family home and life, rather than interdependence that allows a young person to establish greater choice and control within the family context.

29. People with learning disabilities still experience discriminatory attitudes from some neighbours, who object to someone moving in. This is most common in response to groups of people with learning disabilities, but is also experienced by individuals.

Criminal justice system

30. Some people with learning disabilities still report that the police are not helpful if they wish to report a crime. There are still reports of crimes against people with learning disabilities going unpunished because of assumptions about people’s capacity as witnesses. However, we are also aware of excellent work that some police forces are doing, often in collaboration with self advocacy groups and organisations such as Victim Support, to promote disability equality, address hate crime against disabled people and respond appropriately to disabled people who are either victims of crime or alleged perpetrators.

31. We were shocked by the recent report on people with learning disability in prisons (Talbot, 2007). It is clear that there is institutional discrimination in the criminal justice system, and furthermore that any efforts to address key weaknesses (such as failure to identify people with communication problems) are likely to be seriously compromised by the rapid movement of prisoners around the system. People with learning disabilities may be denied parole if rehabilitation programmes are inaccessible to them. We endorse the determination expressed by the All Party Parliamentary Groups on Learning Disability and Penal Reform,

meeting together on 15 May 2007, to raise the key issues with the Ministry of Justice. We are also concerned that the tighter eligibility criteria for social care, resulting in reduced support, could mean more vulnerable adults getting into difficulty and coming into contact with the criminal justice system. (Young people with learning disabilities entering the criminal justice system are likely to have been excluded from school up to ten times).

Groups at particular risk of poor public services

32. There are four groups of people with learning disabilities who experience particular problems with access to good quality public services:

- young people in transition to adulthood: our evaluation of the Connexions service (Rowland-Crosby et al, 2004) and work with a number of authorities show that poor planning and coordination persists, despite ample guidance on good practice. Many authorities are working on improving their processes, which is of course welcome. However, in many areas this is not yet translating into improved opportunities for young people to become active adult citizens, with the chance to take on new responsibilities, develop personally and contribute to their communities;
- people from black and minority ethnic communities continue to report that services are not culturally sensitive and that as a consequence they do not get the support they need and want. This often starts with lack of information and understanding about what is or could be available, lack of assertiveness about redesigning support and (on the part of support services) continued false assumptions about family and community roles. As described above, the model of independence promoted by services can also appear unattractive to families from some cultures;
- people with high individual support needs (for example, people with profound learning disabilities and complex health needs) continue to have very limited options. Families report enormous problems in access to appropriate equipment and adaptations, and lack of access to opportunities such as further education, leisure and social activities. Problems with access to good quality primary and secondary health care were noted above. People who are dependent on medical technologies such as tube feeding and ventilation are at particular risk of having their lives dominated by rigid NHS practices, rather than being supported to get a full life; and
- people with lower support needs, on the other hand, are increasingly excluded from social care by tighter eligibility criteria. The Commission for Social Care Inspection report on the state of social care 2005–06 (CSCI, 2006) picks up on this issue and raises the question of how councils will meet their duty to direct people to other sources of support—the question for us is: what other sources of support? People with learning disabilities who try to take up opportunities other people take for granted (such as rented housing, college courses and local leisure services) too often find themselves caught in the middle of a disagreement between those service providers and social services about who should meet the costs of “reasonable adjustments” and support to enable the person to exercise their choices.

Relationships and family life

Friendships and relationships

33. Evidence from the national survey of people with learning disabilities shows that many people have few friends and little contact with the people they do regard as friends. This is backed up by our work on person centred planning, consultation with young people and families about what is important to them, and priorities chosen by our advisory group of people with learning disabilities. These all confirm the limited nature of people’s social networks, set against the importance that people with learning disabilities—like everyone else—attach to friendship. Many families and services are particularly nervous about supporting people to develop and sustain intimate relationships.

34. 92% of participants in the national survey were single and always had been. Just 7% had children and of these only half looked after their children. The Norah Fry Research Centre undertook a recent study on the experiences of parents with learning disabilities (Tarleton, et al, 2006), which confirmed the poor support experienced by many. The findings are echoed in our own work with community learning disability teams: members often report on the challenges of working with children and families teams that focus strongly on risk to the child and can be reluctant to invest in support to enable the parent(s) to be “good enough”. Tight eligibility criteria can also limit the support community learning disability teams can offer. We are pleased that the Department of Health and Department for Education and Skills have recently issued guidance about positive practice to support parents with learning disabilities (DH/DfES, 2007).

Family carers

35. The Joint Committee is focusing on the human rights of adults with learning disabilities rather than on family carers. There are instances (for example, in responses to Community Care magazine's recent survey of people with learning disabilities) of families holding back people with learning disabilities and not supporting adult sons and daughters to truly grow up. However, our experience is that for most people, most of the time, their families are their greatest and most reliable allies. Families stick with you. Too often services focus on the disabled person in isolation and fail to take account of the family situation as a whole. Supporting the family can sometimes be the best way of supporting the disabled person to get a better life.

36. This approach is particularly needed in respect of older families. A Mencap survey in 2002 suggested there were around 30,000 people living with older family carers—parents aged over 65. Many such families (“Valuing People” (Department of Health, 2001) estimated 25%) are not in touch with services until there is a crisis. Data published with “Valuing People—the Story So Far” (Greig, 2005) showed that in 2003–04 only one-third of family carers aged over 65 known to councils had had an assessment or review of their needs in the last year. Our Older Family Carers Initiative showed the importance of identifying older families and planning with them for future support (Magrill, 2005).

Examples

One family carer in her late 80s dissolved into tears while discussing possible future housing options for her son. Over 50 years ago the doctor who told her that her son had learning disabilities had said that she would no longer be allowed any contact if her son moved out.

Support for Edith (87) and her daughter Carol (56) has enabled them to change their housing to a bungalow in Carol's name, held in trust for her. Carol is building up her independent living skills. Edith still worries about the future, but she knows there are plenty of people now who care about Carol and will speak up for her when Edith is no longer able to do this.

37. Our older families work also highlighted the increasing number of people with learning disabilities who were becoming carers for their ageing parents. This type of “mutual caring” has not always been recognised and supported by services; we are now working with a few authorities to help them develop better support systems.

38. The issue of tightened eligibility criteria for social care was noted in para. 32 above. This trend raises important questions about the expectations society has of family carers. Many families fear that the reality will be:

- fewer chances for their sons and daughters to move out of the family home if they wish to;
- more people staying at home during the day with nothing to do; and
- increased requirements for family carers to provide round the clock care, despite the legislative support for equal opportunities for family carers to get a full life.

39. Many families are excited about the opportunities of greater choice and control offered to disabled people by direct payments and self directed support. However, some families are finding that this means higher expectations on them to help the disabled person manage their money and support. Not all families wish to do this. We suggest that the movement towards self directed support needs to be sensitive to families' wishes and circumstances and offer alternatives, such as paid brokers. Greater independence for disabled people should not be achieved at the expense of unreasonable demands on their families.

Participation in the life of the community

40. Ask yourself: how many people with learning disabilities have you noticed on your way to work, or in your workplace? How many did you see when you were doing your shopping or last time you went out for a drink or a meal?

Transition to adult life

Example

A parent interviewed for our “What Kind of Future?” project said: “I have a 21-year-old daughter who has Down's syndrome. Since leaving school we have found it extremely difficult to find ways to occupy her in any worthwhile way. At the moment she is doing a college course in computing which keeps her busy but which seems in every other respect pretty pointless. She works in a café at weekends but this is voluntary so there isn't much motivation for her there either. The disability officer at the job centre and social work have been of little or no help. She goes to a youth club once a week which she enjoys but the facilities there are very poor—a TV and a pool table. She needs worthwhile supported employment and more opportunities to socialize with other young adults.”

41. Much of our work has focused on supporting young people and their families to achieve a better transition to adult life, using person centred planning to find out what is important to the young person and attending to mental health and wellbeing in addition to other aspects of life (Foundation for People with

Learning Disabilities, 2002 and 2005). Many authorities, working with Connexions, have improved the transition planning process in response to the concerns that have frequently been expressed (for example in “Improving the Life Chances of Disabled People”, Strategy Unit, 2005). We are beginning to hear that person centred transition reviews at Year 9 are having a positive impact in terms of raising expectations for the future. However, this has not necessarily resulted in increased opportunities for young disabled people in terms of housing, meaningful occupation, or leisure, culture and sports.

42. Our “Developing Connexions” report (Rowland-Crosby et al, 2004) showed that too many young people were transferring from school to college courses that did not appear to have any link with their interests or vocational opportunities and were not being supported to consider employment. These findings have been echoed recently by reports from the Learning and Skills Council, which is aiming to improve the quality of post-16 education by refocusing on courses that can demonstrate educational and vocational benefit (Learning and Skills Council, 2006). The short term effect of this is that many young people are losing college courses and are not being offered alternative day time opportunities (Learning and Skills Council, 2007).

Work

43. For most people work is an important aspect of participation in the life of the community. It is not just a way of earning money, but a way of meeting people, a source of self esteem, and a way of making a visible, valued contribution.

44. It is difficult to obtain reliable data on numbers of people with learning disabilities in paid work (employed or self employed). Published figures range from 11% (“Valuing People—the Story So Far”, Greig, 2005) to 17% (the national survey of people with learning disabilities, Emerson et al, 2005). Whatever the exact figure, the fact is that very few people with learning disabilities have a job compared to those who want to work. Our person centred planning research showed that two-thirds of the people who did not have a job wanted one.

45. As noted above, work options are not yet routinely explored with young people in transition to adult life; young people with learning disabilities often miss out on work placements and tasters from school or college. Supported employment (the job coach model) is a proven method of getting people with learning disabilities into work and sustaining them, but supported employment schemes often have fragile funding and may be disconnected from general economic development work led by councils. Many people with learning disabilities report discrimination by employers and are also put off from employment by the complex relationship between different kinds of social security benefits.

46. Projects and person centred planning work from the Foundation have shown that work is possible for many people with the right support, including people with high support needs (Foundation for People with Learning Disabilities, 2000) and the Foundation is just embarking on a new project (“In Business”) to support people with learning disabilities to start their own small businesses.

Getting around

47. Underpinning participation in the life of the community is the need to be able to get around. A consistent complaint from people with learning disabilities in most areas is the difficulty of doing this. We have been impressed by work that Transport for London and some other transport authorities have done to improve accessibility of information as well as physical access; some have paid attention to the attitudes of public transport staff too. In some areas there are successful travel training schemes and travel buddy schemes. Another big concern for people with learning disabilities is bullying and hate crime on public transport, which of course deters people from going out. Staff training and good links with the police are helping with this in some areas. Some authorities have been proactive in supporting people who are entitled to higher rate Mobility Allowance to get their own car. In many areas, however, people with learning disabilities continue to depend on segregated group transport, such as minibuses. Much more attention is needed to transport and support to get around.

48. People who find travel difficult are of course particularly disadvantaged by the trend to closure of local facilities such as neighbourhood post offices and shops.

49. A further barrier to participation for many people is the closure of many local public toilets. People with learning disabilities may lack confidence to use pub or restaurant toilets instead. Mechanised public toilets are hard to use for anyone with a cognitive impairment. People with high support needs are particularly constrained by the lack of truly accessible toilets. We back the campaign run by the Changing Places Consortium (www.changing-places.org) for toilets in public places that are accessible to people with high support needs, with the room and facilities required to allow an adult with one or two supporters to change their continence pad.

Other day opportunities

50. There are some excellent examples of inclusive services, such as the Waterfront leisure centre in Greenwich and the library service in Leicestershire. However, too many people with learning disabilities are still reliant on segregated day services for their daily routine. We do not advocate wholesale rapid closure of existing day centres, which can leave people and their families without support of any kind, but we do wish to see greater commitment to individually planned vocational, leisure, social and cultural activities that give both the person with learning disabilities and their family carers a life worth living. Examples of good practice are given in the report we produced recently for the Social Care Institute for Excellence (Cole et al, 2007).

Spirituality

51. Whether in private or in company with others, spirituality is an important aspect of life for many people. The Foundation's research (Foundation for People with Learning Disabilities, 2004) shows that people with learning disabilities want to explore what gives their lives meaning, but rarely get support to do so. Some people value belonging to a particular faith, but again do not always get support to participate—and faith communities are themselves not always welcoming or inclusive. The Foundation's publications on this topic have been welcomed by staff in services, who often say that this aspect of people's lives is neglected. We are also offering more support to faith communities to help them become more inclusive (for example, with our DVD "Faith in Practice").

Voice in decision making

Advocacy

52. We welcome the additional funding that has gone into supporting advocacy and self advocacy following "Valuing People". However, we remain concerned that much of this funding is fragile; advocacy groups and organisations are often very small and spend a great deal of their limited capacity applying for short term funding. Many people still do not get the opportunity of information and training to help them become more aware of their individual rights and more self confident and assertive.

53. The Mental Capacity Act has brought with it entitlement to the services of an Independent Mental Capacity Advocate (IMCA) for people who lack capacity and have no family or friends to support them with important decisions. We are concerned at the limitations on this service—first, that a person with learning disabilities may need advocacy that is independent of family interests; second, that it may take a long time to get to know a person if they have limited means of communication and if the decision to be made is a complex one, yet we are concerned about whether responsible bodies will fund sufficient time for an IMCA to understand the person's wishes.

Person centred planning

54. We have referred in earlier sections to the benefits of using person centred planning to find out about a person—their talents and preferences, hopes and dreams—and to plan with them the support they may need to live their life in the way they wish. The opportunity to explore choices in an open way—without prejudging what may be possible or constraining thinking to what statutory services normally do—is vital for people with learning disabilities to gain a stronger voice in decision making about their own lives. Much of our work with statutory services and third sector organisations is focused on helping them to understand the roles they could and should play both in helping people to plan and in responding to their preferences. We have good stories to tell about what can happen when services really listen and respond creatively. However, it is clear from inspection reports and from what we hear directly from people and their families that such examples are still too rare. Much more needs to be done for everyone to benefit from the same chances.

Leadership

55. The "Valuing People" emphasis on people with learning disabilities being involved in decision making has led to increased attention to leadership skills. We are piloting leadership courses for people with learning disabilities and are excited about the impact these are having on individuals' skills and confidence.

PRACTICAL MEANS OF SECURING HUMAN RIGHTS

Person centred planning and self directed support

56. The combination of person centred planning with the means for people to control their own support offers powerful means of securing human rights. We therefore wish to see these options offered as a matter of course to all people with learning disabilities, along with assistance as needed to make them function effectively. A mature attitude to managing risk with vulnerable adults is needed for these to work well—society needs a greater understanding that over-protection and denial of the chance to take risks in a managed way can result in a very impoverished lifestyle.

57. We are very concerned that the new guidance on NHS Continuing Health Care (Department of Health, 2007) makes no provision for people with learning disabilities who become eligible for this source of funding to have the same opportunities for control of their own support as people whose funding comes from other sources. The guidance explicitly acknowledges that people who have been in receipt of Direct Payments or Individual Budgets “may experience a loss of control over their care”. How can this be right?

Building capacity in communities

58. The corollary of person centred planning and self directed support is capacity in communities to be welcoming and inclusive. The history of segregated services and low expectations for people with learning disabilities means that this does not necessarily happen naturally. Members of the public and staff in services we all use—shops, leisure centres, cinemas—are sometimes fearful of disabled people and uncertain how to communicate and interact. Some community capacity building needs to be done at an individual level—introducing one person to others who share an interest, for example, and gradually building confidence. Some can be done at an organisational level, such as working with a leisure centre to develop accessible information, improve physical access and enhance the skills and confidence of staff. The “place-shaping” role for local authorities described by the recent Lyons Inquiry (Lyons, 2007) should support this type of work.

Law

59. Law is important in setting expectations, not just as a recourse when things go wrong. It is therefore important that people with learning disabilities and their families, friends and advocates understand what the law says about their human rights. Important recent legislation includes the Human Rights Act itself, the Disability Discrimination Act 2005 (incorporating the disability equality duty on public sector organisations) and the Mental Capacity Act. The former Department of Constitutional Affairs is to be commended for the efforts it made to consult people with learning disabilities and to produce accessible materials as the mental capacity legislation progressed. Other Government departments would do well to emulate this. It is disappointing that some organisations (such as banks) do not yet seem to have embraced fully the implications of disability discrimination law and the Mental Capacity Act in terms of improving access for people with learning disabilities to services the rest of us take for granted. Our work with individuals bears out the findings of the Employers’ Forum on Disability research on problems with access to banking (presentation 26.6.07 to British Bankers’ Association seminar on the Mental Capacity Act) and we support the “Banking Matters to Me” campaign by the Association for Real Change.

60. With regard to the Human Rights Act, it is disappointing to hear the recent ruling from the Law Lords that the Act does not apply to a publicly funded person residing in an independent care home. It cannot be right that people should be held to have more rights in one setting than another. We hope that this anomaly will be addressed.

61. We are concerned that the Government’s review of discrimination legislation should not remove specific duties to promote equality, such as the disability equality duty. Rather, we would wish to see such duties extended beyond the statutory bodies to which they currently apply.

THE POTENTIAL OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

62. We are of course delighted that the UK is supporting the Convention. Clearly this has the potential to strengthen anti-discrimination law. The most important advance from our perspective appears to be the obligation on State parties to ensure the equal rights of disabled people to live independently in the community and to “take effective measures” to facilitate full inclusion and participation in the community.

REFERENCES

- Barr, O and Skirton, H (2006) *Genetics: screening, choice and rights*. London: Mental Health Foundation
- Cole, A (2004) *Green light for mental health*. London: Mental Health Foundation
- Cole, A, Williams, V, Lloyd, A, Major, V, Mattingly, M, McIntosh, B, Swift, P and Townsley, R (2007) *Having a good day? A study of community-based day activities for people with learning disabilities*. London: Social Care Institute for Excellence
- Commission for Social Care Inspection (2006) *The state of social care in England 2005–06*. London: Commission for Social Care Inspection
- Commission for Social Care Inspection (2007) *Press release on the results of inspections of services provided by the Bedfordshire and Luton Mental Health and Social Care Partnership NHS Trust*
http://www.csci.org.uk/about_csci/press_releases/inspectors_warn_nhs_trust_over.aspx
- Department of Health (2001) *Valuing People: a new strategy for learning disability for the 21st Century*. London: Department of Health
- Department of Health (2007) *The national framework for NHS Continuing Healthcare and NHS funded*

Nursing Care. London: Department of Health

Department of Health/Department for Education and Skills (2007) *Good practice guidance on working with parents with a learning disability*. London: Department of Health

Disability Rights Commission (2006a) *Independence day: social care and disability rights*. London: Disability Rights Commission

Disability Rights Commission (2006b) *Equal treatment: closing the gap*. London: Disability Rights Commission

Emerson, E, Malam, S, Davies, I and Spencer, K (2005) *Adults with learning difficulties in England 2003–04*. Health and Social Care Information Centre

Foundation for People with Learning Disabilities (2000) *Everyday lives, everyday choices for people with learning disabilities and high support needs*. London: Mental Health Foundation

Foundation for People with Learning Disabilities (2002) *Count us in*. London: Mental Health Foundation

Foundation for People with Learning Disabilities (2004) *Why are we here?* London: Mental Health Foundation

Foundation for People with Learning Disabilities (2005) *Making us count*. London: Mental Health Foundation

Giraud-Saunders, A, Gregory, M, Poxton, R, Smith, C and Towell, D (2003) *Valuing health for all*. London: Institute for Applied Health and Social Policy, King's College London

Greig, R (2005) *“Valuing People”—the story so far*. Bristol: Valuing People Support Team

Healthcare Commission (2007a) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*. London: Commission for Healthcare Audit and Inspection

Healthcare Commission (2007b) *Count me in 2006*. London: Commission for Healthcare Audit and Inspection

Healthcare Commission/Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*. London: Commission for Healthcare Audit and Inspection

HM Government (2007) *Progression through Partnership*. Department for Education and Skills/Department of Health/Department of Work and Pensions

Information Centre (2006) *Community care statistics 2006 supported residents (adults) England* <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2006:-supported-residents-adults-england>

IPPR (2007) *Disability 2020: opportunities for the full and equal citizenship of disabled people in Britain in 2020*. London: Disability Rights Commission

Learning and Skills Council (2006) *Learning for living and work: improving education and training opportunities for people with learning difficulties and/or disabilities*. Coventry: Learning and Skills Council

Learning and Skills Council (2007) *Impact on adults with learning difficulties and/or disabilities: issues from the 2006–07 planning round*. Coventry: Learning and Skills Council

Lyons, M (2007) *The Lyons Inquiry into local government*. London: The Stationery Office

Magrill, D. (2005) *Supporting older families: making a real difference*. London: Mental Health Foundation

Mencap (2007) *Death by indifference*. London: Mencap

Robertson, J, Emerson, E, Hatton, C, Elliott, J, McIntosh, B, Swift, P, Krijnen-Kemp, E, Towers, C, Romeo, R, Knapp, M, Sanderson, H, Routledge, M, Oakes, P and Joyce, T (2005) *The impact of person centred planning*. Lancaster: Institute for Health Research, Lancaster University

Rowland-Crosby, N, Giraud-Saunders, A and Swift, P (2004) *Developing Connexions—young people with disabilities, mental health needs or autism*. London: Foundation for People with Learning Disabilities

Smith, C, Giraud-Saunders, A and McIntosh, B (2004) *Healthy lives*. London: Foundation for People with Learning Disabilities

Smith, C, Poxton, R, Giraud-Saunders, A and Swift, P (2007) *A note on commissioning primary health services that are inclusive of people with learning disabilities*. London: Foundation for People with Learning Disabilities

Strategy Unit (2005) *Improving the life chances of disabled people*. London: Cabinet Office

Tarleton, B, Ward, L and Howarth, J (2006) *Finding the Right Support?* London: The Baring Foundation

Talbot, J (2007) *No One Knows*. London: Prison Reform Trust

29 June 2007

Memorandum from the Norah Fry Research Centre, University of Bristol

INTRODUCTION

The Norah Fry Research Centre, University of Bristol, has carried out applied research projects on issues affecting people with learning disabilities for more than 20 years. The Centre's mission is to undertake research to make a positive difference to people's lives, and to carry out research with people with learning disabilities themselves. Through our research findings we aim to influence policy, improve services and support, and inform and empower people who use services, family carers and professionals. The Centre is committed to the inclusion of people with learning disabilities in society at large, and to increased respect for their human rights. The Centre has a national, and international, reputation for its work, including that on accessible information, parents with learning disabilities, transition to adulthood, direct payments and self directed support and user involvement in research. All the Centre's work is funded through external project grants. More details about the Centre and its work can be found on our website, www.bristol.ac.uk/depts/norahfry, from which summaries of the findings from recent projects can be downloaded. We would be happy to supply further information or copies of reports cited in the evidence below to the Committee, if this would be helpful.

OUR EVIDENCE

1. *The provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities; the ability of individuals to access such services and the quality of provision*

The problem of getting "trapped in special service land"

Research undertaken by staff at the Norah Fry Research Centre often has a focus on the support needed by people with learning disabilities, in order to access ordinary community services. In particular, several studies have examined experiences of inclusion or exclusion—within education, and within other services generally available to members of the community. People with learning disabilities are frequently assumed to need specialist services, and their needs are assumed to lie beyond the scope of those services which the majority of the population would use. This in itself constitutes a violation of the right to access generally available services. They become trapped in what has been described as "service land". Examples of this have been evident in many research studies:

EMPLOYMENT

A European funded study about employment issues ("Sequal" project: 2002–06) included a disability strand that was led by the University of Bristol. People with learning disabilities were found to have very little access to substantial paid work, and this was often because the benefits system made it impossible for them to gain financially from paid work. Thus Beyer *et al* (2004) found that only about 10% of people with learning disabilities were in paid work, and that they very often they chose to work in part-time occupations, sometimes for as little as 5 hours or less per week. In part, this seems because of fear of affecting benefits entitlement, and in part, it is because some people with learning disabilities feel that they can only manage part-time work. People with learning disabilities in another consultation study (North Somerset, 2007) said they needed better, clear information about jobs and benefits. The absence of substantial paid work results in adults with learning disabilities remaining in "day services".

"Don't forget, you've got barriers still . . . the benefits problem . . . it took me a long time to understand it." (Person with learning disabilities)

In several research studies (eg *Having a Good Day?* SCIE, 2005), we have found that support for employment is absolutely vital. In many cases, people are restricted to low-level jobs, and do not have a chance to progress.

"Everyone breathes a sigh of relief when they get a person with a learning disability a job. Job done! But it's not job done. There's the continuation of the support, the extension of the work placement so they don't become bored. So the concept of career can be important, and they do get extended." (Deputy Social Services director)

FURTHER EDUCATION

Access to further education is another problem for some young people and adults with learning disabilities. Although Further Education colleges do make provision for this group, ongoing research (Everett and Williams) is finding that the majority of young people with learning disabilities are experiencing specialised, 'discrete' courses in one area in the South West. This has the effect that their social and educational experience whilst in Further Education is limited. One of the students said:

"It is good coming to college, but like, when you see other people around college, because they think

you've got learning disabilities and that, they don't wanna come over and talk to you." (Student in Further Education college)

Furthermore, there are some groups of young people with learning disabilities whose rights to FE are severely limited. These include people who are labelled as having 'challenging behaviour' and sometimes those with autistic spectrum disorders.

MENTAL HEALTH SUPPORT SERVICES

Access to mental health provision was examined in a recent study (*Mind the Gap: 2002–04*) which was one of four action research studies funded by the Foundation for People with Learning Disabilities (Foundation for People with Learning Disabilities, 2005). Young people with a learning disability were found to be four times more likely than other young people to suffer from emotional distress. However, their access to mental health provision was severely limited, and our study found that this was at least partly because professionals tend to attribute any symptoms of distress to "the learning disability":

One young person had been involved in an accident in the swimming pool, and afterwards found it hard to accept having a bath: he reacted in ways that those around him interpreted as "challenging". As one member of staff explained, it was hard to work out what was due to his emotional distress, and what was due to his "behaviour". (Evidence from the Norah Fry report in *Making Us Count*, Foundation, 2005)

FINANCIAL SERVICES

A scoping review on financial exclusion (*Money, Rights and Risks*) carried out by the Norah Fry Research Centre between 2003–06 for Friends Provident (Williams *et al*, 2007) revealed that financial support services often have some very positive strategies for tackling financial capability, for supporting individual clients who are at risk of debt, and for giving practical guidance on dealing with the intricacies of money management—often by direct practical action. All these features of money management would be very helpful for most people with learning disabilities. However, this study found that 74% of the people with learning disabilities relied on parents and carers to control their finances; 86% were confused over their benefits; and only half the sample had a bank account in their own name.

"I'm too scared to go up to the counter—I'm scared. Initially, to set up the account with all the paperwork, I needed help to go through it." (Person with learning disabilities in this study)

Yet the financial support services (eg Citizens Advice Bureaux; Debt Advice Services) considered that they were unable to meet the needs of people with learning disabilities. There is an assumption that their needs are "specialised" and will be provided by special services.

If I'm honest about it, if someone had a severe learning disability, they would struggle to access even our service, which is designed to be there for vulnerable people—without a support worker.

BARRIERS TO INCLUSION

From the evidence of all these studies, it would seem that there are several barriers facing people with learning disabilities, when they seek to be "included" in general community provision. These are:

- attitudes of those around them that their needs can only be met by specialist services;
- the lack of any accessible information in public services; and
- their own lack of confidence in pursuing their rights.

2. *The possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise in this context*

Recent work at the Norah Fry Research Centre has focused particularly on the rights of people with learning disabilities:

- to enjoy the full range of personal, emotional and sexual relationships as other people (including same sex relationships); and
- to be parents and bring up their children.

Both of these areas of research have revealed overwhelming evidence of the widespread infringement of the rights of people with learning difficulties to form the relationships they choose and to bring up their own children, thus depriving them of the right to respect for private and family life.

Evidence from these studies has been submitted to the committee separately (see evidence from the Secret Loves, Hidden Lives project and the Working Together with Parents Network). In addition, a survey amongst people with learning disabilities carried out as part of a European (Grundtvig) project (2002–04) has indicated the need for access to ongoing education about sex and relationships, and in particular the access to one-one, private learning about sensitive areas such as parenting, feelings and relationships.

3. *The opportunities for people with learning disabilities to participate in the life of their local community and the state's obligation to facilitate participation*

A current research study (2007) carried out by the Norah Fry Research Centre for the Service and Delivery Organisation of the NHS is about research priorities for Learning Disability over the next 10 years. In the context of this work, we have carried out four major regional workshops with people with learning disabilities, their carers and families, and with professionals who work in the area. These have revealed a number of priorities and issues in the lives of people with learning disabilities, which include:

- *Bullying and hate crime.* People said that they were restricted in their ability to go out and enjoy their local community, because of name-calling and hate crime. They urgently wanted something to be done about this problem. They also felt it was important to use the words “hate crime” rather than “bullying”, since the latter plays down the importance of what people experience.
- *Getting good support.* People in the research priorities workshops returned time and time again to the importance of having the right support. They wanted to have support staff they could trust, people they had chosen themselves, and staff who could support them on an individual basis to use their own local community and enjoy a full range of experiences. This is not always the case at present.
- *Skills for Support (2005–07),* another study carried out by Norah Fry Research Centre, investigated the skills of supporters and personal assistants who work for people with learning disabilities on a 1-1 basis. 47% of PA's who responded to our survey had no professional background in either residential care or in social services. The majority were paid between £5–7 an hour, and half of them had not done any training since starting work as a personal assistant. Co-researchers in Skills for Support, who had learning disabilities themselves, and self-advocates who took part in the study felt that:
 - (a) more training and support for PAs is urgently needed; and
 - (b) people with learning disabilities should be in control of the kind of training their staff have, and wherever possible should be involved in that training.

One of the models developed in *Skills for Support* was that of joint training and support, where people with learning disabilities and their support staff come together for training days. The project produced some training materials based on videos made during the research, which are accessible for people with learning disabilities to use, in helping to train their own staff. These will be published by BILD in the autumn 2007 (Skills for Support Team, 2007) and some of the material has already been incorporated into training resources for the new LDQ (Learning Disability Qualification).

This study found many people with learning disabilities who were being well supported by personal assistants, often through the means of a direct payment. For instance, one young man who had been labelled as having “challenging behaviour” was filmed going to an ordinary youth club with his personal assistant. However, this project also revealed how easy it is for supporters to slip into treating people with learning disabilities as “incompetent” and to be disrespectful and bossy in their everyday interaction with them. This is an ongoing violation of human rights, in the everyday experience of people with learning disabilities.

- Getting easy to understand information.

Under the provisions of the Disability Discrimination Act, disabled people should be entitled to receive information in ways and formats that are accessible to them. But the experiences of those who have attended our workshops (Research Priorities project mentioned above) or participated in our research projects show that easy to understand information is still not widely available to them.

In 2001 NFRC was awarded a grant by the Department of Health (under the Learning Disability Research Initiative which coincided with the launch of the Valuing People White Paper) for the Information for All project. The project was designed to provide evidence-based guidance on how best to provide information for people with learning disabilities across all formats (print, tape, multi media etc). The Information for All project was advised by people with learning disabilities and included a learning disabled staff member. The resulting guidance can be found at www.easyinfo.org.uk (click on ‘Guides’). A hard copy of the guidance can be provided to the Committee if that would be helpful.

The NFRC has itself been producing accessible versions of its own and other people's research findings for the last ten years, until recently with funding from the Joseph Rowntree Foundation. The Plain Facts series (<http://www.bristol.ac.uk/Depts/NorahFry/PlainFacts/>) won a Plain English campaign award for its work in 1999. Copies of Plain Facts are distributed free to 1500 self advocacy groups and day centres across the UK. There have been 50 editions so far on a huge range of topics, including being a parent, employment, housing, college, making a complaint, becoming an adult, independent living, self advocacy, crime and abuse, direct payments, making friends, person centred planning, being involved in choosing staff, services for older people, having a say in housing and your future and many more. A list of previous Plain Facts is available on the website address above. Copies of individual issues of Plain Facts can be provided to the Committee if they are interested.

- Local facilities which are open and inclusive. Having a Good Day (2005) was a research review of day opportunities for people with learning disabilities, carried out in conjunction with the Foundation for People with Learning Disabilities, for SCIE (Social Care Institute for Excellence).

One significant barrier to accessing local facilities was simply that these facilities were often not accessible, in terms of physical access (eg accessible changing facilities for adults in leisure centres); attitudes (eg clubs and groups which welcome people with learning disabilities); information (eg posters, publicity, forms). However, it was also true that people were often held back by the attitudes of those around them, who assumed that they needed specialist services during the day. Those who had good, one-one support, did not have such difficulties, and were able to enjoy their local communities with relative ease.

— Support and facilities which are culturally sensitive

Finally, the SCIE work mentioned above also highlighted a few places where support groups for people with learning disabilities from BME groups were working well.

The Apna Group in Dudley is based at the Muslim Association in the High Street. Asian staff support Asian people with learning disabilities to meet every week to talk and to do fun things together. “All the activities and classes are chosen by group members”.

These initiatives and similar projects were hard to find, and we need to know how to make such work more widespread and sustainable, so that people with learning disabilities from minority ethnic groups enjoy their rights to full participation. It was disappointing to find so little progress in this area since the pioneering research at NFRC in the late 1980s on services to people with learning disabilities from black and minority ethnic communities, *Double Discrimination?* (Baxter *et al*, 1990). We are aware of the current activities of the National Learning Disability and Ethnicity Network coordinated by the Association for Real Change (contact bridget.fisher@arcuk.org.uk for further details) and hope that this may focus more attention on this still neglected area.

We would be very happy to supply further information to the Inquiry on any of the above, or indeed on any other research carried out at the Norah Fry Research Centre.

20 July 2007

Baxter, C *et al*, 1990, *Double Discrimination: issues and services for people with learning difficulties from black and ethnic minority communities*. London, King’s Fund/CRE.

Beyer, S., Grove, B., Schneider, J., Simons, K., Williams, V., Heyman, A., Swift, P. and Krijnen-Kemp, E. (2004) *Working lives—the role of day centres in supporting people with learning disabilities into employment* (Department for Work and Pensions: report 203) <http://www.dwp.gov.uk/mediacentre/pressreleases/2004/feb/iad-0902-wl.asp>

Foundation for People with Learning Disabilities (2005) *Making Us Count*

<http://www.learningdisabilities.org.uk/our-work/children-and-young-people/making-us-count/£gap>

North Somerset Social Services Department (2007) *Fulfilling Lives*. (Unpublished report on consultation exercise in North Somerset).

SCIE (2005) *Knowledge review 14: Having a good day? A study of community-based day activities for people with learning disabilities* <http://www.scie.org.uk/publications/knowledgereviews/kr14.asp>

Skills for Support Team (2007) *Skills for Support: a new kind of support*. To be published by Kidderminster, BILD.

Williams, V., Abbott, D., Rodgers, J., Ward, L. and Watson, D. (2007) *Money, Rights and Risks: a scoping study* (To be published: Friends Provident).

Memorandum from the Down’s Syndrome Association (ALD 78)

The Down’s Syndrome Association (DSA) is the lead voluntary sector organisation supporting the estimated 60,000 individuals with Down’s syndrome and their families and providing an information and advice service to the professionals who work with them. We are a Registered Charity established in 1971 and have a membership of over 16,000.

Prior to 2006, the DSA believes that the majority of cases which breached an individual’s Human Rights came about as a result of intentional or unintentional discrimination linked to assumptions based on stereotypes about people with Down’s syndrome. The experiences of many people with Down’s syndrome can be likened to those of people who have experienced racism. But with racism there is clear legal redress and public intolerance.

Since mid 2006 we have spoken to, or are informed about, a huge number of adults with Down’s syndrome who we believe, as a direct result of their being denied the right to participate in society on an equal footing, are being subjected to degrading and inhuman treatment. Their situations have arisen as a direct result of the funding crisis in adult social care and the subsequent narrowing of eligibility criteria for access to services across local authorities in the UK.

The Association is concerned about what we see as a crisis in adult social care that, along with a consortium of other leading learning disability organisations such as Mencap, The Foundation for People with a Learning Disability and United Response, we established the Learning Disability Coalition in May of this Year. For more information please see www.learningdisabilitycoalition.org.uk.

The DSA's submission to the Joint Committee is a collection of case studies that have come through the DSA's National Information Helpline. We believe that these cases contravene various articles of the European Convention on Human Rights. The Case Studies that are marked with an asterisk are those where parents/carers would be happy to provide further written and/or oral evidence if required.

ARTICLE 2—THE RIGHT TO LIFE

Case Study 1

S*, a 46-year-old man with Down's syndrome, is denied heart treatment by a cardiologist on the grounds that he has a learning disability and because the treatment would cause him distress. S's sister argues that his being left to die without treatment would cause far greater distress.

Background

There is a substantial body of literature in the public domain about health conditions that are more common in people with Down's syndrome. Despite this, the DSA deals with numerous cases where common medical conditions are missed or misdiagnosed often as a result of lack of communication or lack of information about a person's medical history. Evidence suggests that an unacceptable number of people with Down's syndrome are becoming ill and dying from manageable and treatable conditions.

Diagnostic Overshadowing is prevalent in the approach of the health professionals to people with Down's syndrome. Anything that is apparently wrong with an individual is ascribed to the syndrome. Health professionals often regard symptoms of mental and physical health as 'behavioural' problems. The administration of medication to individuals exhibiting behaviour that is out of character is common rather than health professionals taking a holistic look at the life of the individual.

See attachments.¹⁴⁶

He'll Never Join The Army—A Report On A Down's Syndrome Association Survey Into Attitudes To People With Down's Syndrome Amongst Medical Professionals (Sarah Rutter & Susannah Seyman, 1999)

Mortality And Cancer Incidence In Persons With Down's Syndrome, Their Parents And Siblings (C. Hermon, E. Alberman et al, 2001)

ARTICLE 3—THE RIGHT NOT TO BE TORTURED OR TREATED IN AN INHUMAN OR DEGRADING WAY

Case Study 1

D, a young man with Down's syndrome, was placed by Social Services in a supported living unit where he was subjected to consistent physical assaults by his flat mate who also had a learning disability. To date, despite repeated pleas to Social Services by D's elderly parents, D has now been exposed to physical violence on a regular basis for at least six months. During a recent meeting with Social Services D's parents were asked to sign confidentiality agreements prohibiting them from discussing their son's case with outside parties.

Case Study 2

F, a woman of 48 who has Down's syndrome, has suffered from a series of failures by her care staff. The home in which she was very happy was converted three years ago into supported living flats. Around that time she started feeling unsteady and complaining of back pain, which was not taken seriously by staff. She now uses a wheelchair due to spinal damage. Her mother had to fight for her to get a room suitable for a wheelchair user even though the Fire Service stated that her existing room was unsafe. When she was eventually re-housed, it was because she was unable to use the commode and because she had developed sores. However, now she is in a house with three men, none of who use speech. She does nothing all day except watch TV. She has started screaming and banging her head when stressed. It is unclear whether or not her screaming is as a result of pain and/or sheer boredom. Staff are treating this as a "behavioural issue" and on one occasion when her mother visited she was having "time out" in her room for 45 minutes, and she was screaming the whole time.

¹⁴⁶ Ev not printed.

Case Study 3

B*, a young man with Down's syndrome and Autistic Spectrum Disorder, was locked in a day centre minibus in a garage overnight. There is a real possibility that his incarceration was part of a sexual assault. One week later, four male member of staff at his day centre broke his foot whilst trying to physically force him onto the minibus.

Case Study 4

A dentist who carried out a blanket policy of removing all the teeth of his patients with Down's syndrome regardless of whether or not there was a medical need. The patients were not provided with dentures after the removal of their teeth on the grounds that people with Down's syndrome could not cope with dentures.

Case Study 5

A physician who suggested that the best course of treatment for a patient with Down's syndrome and in-growing toenails was amputation.

Case Study 6

T, a man with Down's syndrome, was pinned down by eight hospital staff in an effort to take a blood sample. In the end, a sample was obtained from the patient's head.

Case Study 7

K, a middle-aged woman with Down's syndrome, threw a cup at a wall in her care home on the first anniversary of her mother's death. This behaviour was totally out of character. Instead of staff trying to find out why she had thrown a cup, the woman was prescribed anti-psychotic medication. The medication subdued the woman to such an extent that she just sat in a chair all day without communicating.

ARTICLE 5—THE RIGHT TO LIBERTY AND SECURITY

Case Study 1

J*, a young man with Down's syndrome and Autistic Spectrum Disorder, was excluded from school at the age of 17. J had a breakdown. Lack of stimulation and meaningful activity after leaving school led him become obsessed with, and to act out, TV-based fantasies. J assaulted a policewoman in imitation of a plotline from a TV soap opera. Instead of J being dealt with by Criminal Justice system, J was Sectioned and placed in a mental health unit for adults. five years later, J's family are still trying to obtain his release. If J had been subject to the Criminal Justice system, there is a strong likelihood that he would have been released some time ago. A fellow resident physically assaulted J at the mental health unit on a daily basis.

Case Study 2

Z, a young man with Down's syndrome, who daily attended a mosque, one of his main social outlets, was detained by the police on leaving the mosque under the Prevention of Terrorism Act. The young man was detained in public and questioned for a period of time. The police did not provide an appropriate adult to support the young man and they made no attempt to contact the young man's family. The man was released in a state of shock and left to make his own way home. The young man was so traumatised by this incident that he would no longer leave the family home.

Case Study 3

R*, a middle-aged man with Down's syndrome, was misdiagnosed with dementia on the grounds that he was unable to find his glasses. R was prescribed various dementia-related medication and he was subsequently sectioned because of his "challenging behaviour". After a lengthy battle by his mother, R was released and medication was withdrawn. Independent experts employed by R's mother have since confirmed that R does not have dementia and the experts have confirmed that R's "challenging behaviour" was caused by the cocktail of psychotropic medication that R was prescribed. R has now been labelled as "challenging" by Social Services. R's mother is finding it very difficult to obtain support services for R despite the fact that he is now off the medication and he is back to his usual self.

Case Study 4

S is 16 years old, she has severe learning disabilities, no speech and she is doubly incontinent. Due to her mother's poor mental health she has been placed by social services into the care of her bachelor male relative, who is in his late 50's and who has a history of strokes and who lives in a remote cottage in a rural county.

As S is unable to see to her own personal care she is dependent on her relative to do this, including her menstrual cycle. The doors of the cottage are kept locked so that S cannot wander off. There are real concerns that if her relative had a stroke on a Friday that no one would know until the Monday when her school bus came to collect her. She is unable to use the telephone or unlock the doors and there are no neighbours to alert.

ARTICLE 8—RESPECT FOR PRIVATE AND FAMILY LIFE

Case Study 1

P* comes to the end of his three-year FE course in June. Due to cuts in FE funding he is not able to access another course and due to a change in LA eligibility criteria to only fund people who have been assessed as to being critical—he does not qualify for a day service/activity. From June, P who is 22 years old, will only have his one-day a week voluntary work at a local charity to fill his days. P's parents live abroad and P lives in the family home with two other men with learning disabilities and has a supported living package.

This support consists of carers being on hand mornings to prepare his breakfast and help get ready for college and evenings to help with his supper. At weekends he receives limited support to assist him with his shopping, washing and housework. At present this fits around his daytime activities and will only increase by four more hours when his course finishes.

His family, friends and carers are extremely worried for him as he cannot manage with the support he is receiving now. He does not know how to fill his spare time. On several occasions he has spent large amounts of money on dvd's by using shopping as a means to fill his time. On one occasion he spent nearly £2,000 (his savings) and was left without any money to buy food. On a recent holiday with his parents they found it extremely difficult to motivate him to do anything but watch dvd's, which worried them immensely as he has always been an extremely active man with many interests. They fear this reluctance stems from the fact that now he spends the majority of his spare time watching dvd's in his bedroom.

His mother is now going to return to the UK, at the cost of her marriage and career, as her fears for him are so great. His friends worry too as he sinks further and further into depression. He has talked several times of ending his life and joining his hero Elvis in heaven. At 22 his life as an adult should be beginning rather opportunities shutting down or being taken from him.

Case Study 2

K*, a young woman with Down's syndrome, invites friends for dinner at her flat. The friends do not come because they cannot travel without support. The care staff looking after K's friends do not have the time to spend providing support to their clients so that they may travel. Care staff looking after K's friends do not contact K to tell her that her friends cannot come for dinner.

Case Study 3

M* is soon to be 18 years old. Both she and her family feel that she is ready to leave home. Her mother found a residential care provider who could offer M a place in a house with three other women of the same age, all of whom were leaving home for the first time. The house has 24 hour support and satellite supported living flats so that clients could move to different settings with less support if they wanted to when they had adjusted to living away from home and living more independently.

M loved the place and was looking forward to moving there. The Local Authority would not fund M's placement, as she did not qualify for this level of support. M is on the Autistic Spectrum; she has Eisenmenger's syndrome and profound hearing loss. This Local Authority will only fund this kind of placement for people who are doubly incontinent. M's mother also cares for her mother who has dementia.

Case Study 4

G, an older woman with Down's syndrome, whose legs were withering away was unable to access physiotherapy services from mainstream elderly services because she did not meet the age requirement and because she has learning disabilities. Elderly services had a surfeit of available physiotherapists. Learning disability services were not able provide the woman with a physiotherapist.

Background

Participation in public life is a human right. The Human Rights Act recognises that the ability to develop one's personality by participating in the life of the community is an important aspect of the right to respect for private life.

*Welfare Benefits**Case Study*

A 42-year-old woman with Down's syndrome, living with her 84-year-old mother, was initially given Lower Rate DLA (Care Component) even though her mother had to do everything for her. Because of this, the mother did not receive a Carer's Premium. It took a Commissioner's Hearing to finally allow Middle Rate DLA to be awarded. The Commissioner agreed that the initial decision was ridiculous.

Many people with Down's syndrome are wrongly assessed when claiming Disability Living Allowance (DLA). They rely on elderly parents, who have little support themselves, to fill in the forms. Many people with Down's syndrome are reliant on the competence of others to help them claim the benefits that they are entitled to. We believe that adults with Down's syndrome should be awarded Middle Rate DLA (Care Component) as a matter of course due to their vulnerability.

It is not always easy for young adults to claim Incapacity Benefit. Many are told that they cannot claim Incapacity Benefit as they are in Further Education. The Department of Work and Pensions (DWP) frequently fail to ask applicants what type of educational course they are attending. Consequently, many applicants are denied an application form because DWP wrongly believe that the young adult is following a mainstream education course rather than a lifeskills or adapted/supported course; neither of which count toward the 21 hour rule that debars an individual from making a claim for Incapacity Benefit.

As a result many people with Down's syndrome miss out on benefits, some for as many as five years. In addition, many are never told about the Income Support Top Up when they initially claim Incapacity Benefit. Young adults claiming Incapacity Benefit and wishing to work under 16 hours per week on supported permitted work schemes have been told that they have to wait or that there are no placements available. As a result the family has to find the young person a placement which can mean that they only have limited time to work before Incapacity Benefit stops.

The Down's Syndrome Association is aware that some Local Authorities have been assessing DLA (care component) received by adults with Down's syndrome as income for the purposes of setting Community Care Charges. This is contrary to guidance issued by Government.

See attachment:

Benefits Lottery—A Survey Of The Down's Syndrome Association's Membership And Their Experience Of The Welfare Benefits System (Christina Katic, 2001)

ARTICLE 9—THE RIGHT TO FREEDOM OF THOUGHT, CONSCIENCE AND RELIGION

Case Study

A young Muslim woman with Down's syndrome, of Ethiopian descent, was given a bacon sandwich by carers at her residential home despite the fact her mother had made Social Services fully aware of her daughter's religious needs. No attempt was made by carers to support the young woman in the practicing of her religious beliefs.

ARTICLE 10—THE RIGHT TO FREEDOM OF EXPRESSION

Background

People with Down's syndrome face particular challenges when communicating, which affect just about every aspect of life—relationships, learning, participation and independence. Speech and language therapy intervention for people with Down's syndrome barely persists beyond primary school level. We believe that the lack of availability of speech and language services to adults with Down's syndrome may significantly impair the ability of many adults to communicate their wishes and beliefs.

The lack of good advocacy services also impairs the ability of many people with Down's syndrome to express their wishes and to make their opinions known.

ARTICLE 14—THE RIGHT NOT TO BE DISCRIMINATED AGAINST IN RELATION TO ANY OF THE RIGHTS CONTAINED IN THE EUROPEAN CONVENTION

The Down's Syndrome Association believes that the current lack of services or paucity of services for people with Down's syndrome infringes their human rights. Young people with Down's syndrome are increasingly being denied services on leaving school or college that would enable them to lead independent and fulfilling lives. Young people, who have often been through mainstream education and who have the same expectations at the outset of their adult lives as their peers, are being written off and consigned to lives without aim and without meaningful activity. Those who are lucky enough to leave home often find themselves in supported living situations where only their most basic needs are met. Social, emotional and spiritual needs of individuals are not considered which all too frequently leads to poor mental and physical health.

There is an argument that people with Down's syndrome are discriminated against from the moment that they are identified through pre-natal testing. Pre-natal testing for Down's syndrome may send the message to society that the lives of people with Down's syndrome are not valued and this may lead to wider discrimination.

Issue Relating to Education

There are various practices which are common place in education settings and within the authorities responsible for assessing adults entitlements to an FE placement these include :

A widespread avoidance of the Statutory Duty to Assess individuals with regard to their education needs.

The Devolvement of SEN funding to schools to manage individually. The spending of these funds are not adequately monitored or ring-fenced to ensure the intended beneficiaries do actually receive benefit from these monies.

A decline in numbers of children included at key stage 2/3/4 (as young people progress through their school careers) due to schools unwillingness to make the necessary adjustments for their inclusion.

A lack of transition planning for Primary to secondary school/ secondary to FE provision and FE to Adult services.

A wholesale reduction in the existing (limited) FE provision in many areas (for example courses being cut from 4 or 5 days a week to 2 or 3 days per week).

Failure of FE providers to offer a range of options for students with Down's syndrome. Often only one course is offered and this is invariably inappropriate.

A 'Postcode Lottery' relating to applications for specialist colleges. The Learning and Skills Council refusing funding in one area whereas the same application would be successful across a County border.

Examples where the Learning and Skills Council funding is withheld for an out of County placement on the basis that local colleges are supposed to be able to meet needs, even when no evidence for this exists.

A Lack of support to take part in vocational training opportunities. Lack of support to access a wider college community, leisure and interest groups.

Lack of support and advocacy for transition to adult services, opportunities for vocational training and employment.

FE—Example—S—Bright young women with GCSEs attending an FE course where she was expected to build Eiffel Towers out of sequins and she was given certificates for identifying the position of the door and the position of her own feet and nose! Meaningless! She developed mental health problems and she tried to commit suicide.

People leaving college/FE with no support or prospects at the outset. All that has been learnt at college is therefore wasted. Social Services are refusing direct payments. People are not being allowed to leave home because they don't meet the eligibility criteria.

See attachment:¹⁴⁷

Access To Education—Experiences Of Transition From School To Further Education—Diversity And Practice For Young People With Down’s Syndrome In The UK (Jane Beadman—Down’s Syndrome Association Education Consortium, 2004).

CONCLUDING COMMENTS

We are grateful for the opportunity of raising our concerns as outlined in this submission and would welcome the opportunity of presenting further oral evidence, should this be deemed appropriate.

28 June 2007

Appendices

He’ll Never Join The Army—A Report On A Down’s Syndrome Association Survey into Attitudes To People with Down’s Syndrome amongst Medical Professionals (Sarah Rutter and Susannah Seyman, 1999).

Mortality and Cancer Incidence in Persons with Down’s Syndrome, their Parents and siblings (C Hermon, E Alberman *et al*, 2001).

Benefits Lottery—A Survey Of The Down’s Syndrome Association’s Membership and Their Experience of The Welfare Benefits System (Christina Katic, 2001).

Access to Education—Experiences of Transition from School to Further Education—Diversity and Practice for Young People with Down’s Syndrome in the UK (Jane Beadman—Down’s Syndrome Association Education Consortium, 2004).

Memorandum from the South East Regional Family Carer Network

This response is from the South East Regional Family Carer Network. This is a network of family carers who are members of local Learning Disability Partnership Boards in the South East region. They all have personal experience as well as knowledge of the experiences of other family carers of people with learning disabilities within their local authority areas.

The network has the following points to raise within your consultation process:

1. PROVISION OF PUBLIC SERVICES (EG HEALTHCARE, HOUSING, BENEFITS ETC) ABILITY TO ACCESS THEM AND THEIR QUALITY

The experience of the family carers network is that people with learning disabilities struggle to access public services and there are many bureaucratic obstacles to overcome. There are however opportunities to make use of current legislation to put in place protocols to ensure that digital information systems work.

There is much evidence of poor access to and quality of services and support. For example, many family carers have to remain with their son/daughter if they go into hospital for treatment to ensure they receive an acceptable standard of care. Appropriate care/supporting acute hospitals is of utmost importance especially for those with communication problems and or those with profound/multiple disabilities.

There are examples of people with learning disabilities being subjected to degrading treatment: for example, the network is aware that some people with learning disabilities who are incontinent have the number of incontinence pads they are provided with restricted, and we regard this as unacceptable.

In addition, there are a number of people with learning disabilities who remain in campus provision- this is indefensible in terms of their human rights. It is essential that this is addressed urgently and very important that skilled advocacy and an individualised person centred process is followed. It is also difficult to understand how the NHS is apparently unable to provide accurate figures of the numbers of people this affects.

Similarly, access to housing opportunities is difficult. For many people with a learning disability the options are to remain living with their family or move to residential care. In residential care, they have little or no control over who they live with or who supports them and can only access £18.50 per week to spend as they wish (if they are supported to do so).

There is a real need to ensure that people with learning disabilities have access to independent advocacy and that this is adequately funded. Independent, skilled and well-supported and resourced advocates for people with complex needs are not widely available.

There are some people with profound/multiple disabilities who need nursing/residential care or 24 hour support. Due to cut backs they are still living with families and it is difficult to identify sources of funding to develop something local and appropriate.

¹⁴⁷ Ev not printed.

The benefits system often hinders people with a learning disability and has a detrimental effect on issues such as employment opportunities (many people with a learning disability are unable to cope with full time employment but could manage part time work and the benefits system does not make this a viable option).

2. FORMING AND MAINTAINING RELATIONSHIPS WITH OTHERS

There are still many people with learning disabilities, particularly those with complex needs or challenging behaviour, who are placed in existing out of area 'specialist' services rather than in person-centred appropriate local services. This is often because it is easier to purchase such services than develop new local ones. (See also response for community participation).

3. COMMUNITY PARTICIPATION

People with learning disabilities often need support to participate in ordinary community life. This support is often not provided due to lack of resources. The Government has a positive duty to support community participation and is failing to do this for people with learning disabilities. (The comments under section 2 also apply here).

There is a development of an "underclass" of people with learning disabilities who do not meet the local authority eligibility criteria for receipt of services. This is a very vulnerable group. It is widely accepted that early intervention approaches can avoid later crises- the tightening of eligibility criteria goes against this principle.

People with learning disabilities are not able to access further education opportunities for recreational and lifelong skills courses. Access to continuing education opportunities for this population is of real value but there is poor partnership working between the Learning and Skills Council and Social Services Departments. Person-centred planning should be the key to further educational opportunities and development but this does not happen in practice.

The network can provide many examples if required. However, the key issues can summarised as:

1. Lack of resources to provide appropriate support to people with learning disabilities to ensure their human rights are met. Services for people with learning disabilities should be a core funded provision.
2. Lack of resources to provide high quality advocacy for ALL people with a learning disability who want it, including those with complex needs.
3. Many families of people with learning disabilities act as powerful, long-term advocates for their sons/daughters but receive little support themselves. If there family carers are not adequately supported, it will impact on the lives of their disabled sons and daughters.
4. There are some very powerful examples of people with learning disabilities who have a good quality life via direct payments. However, for people with learning disabilities who are less able, these "packages" are often developed, arranged and maintained by family carers. This is a significant commitment and not all family carers are able to take on this role: those individuals who do not have such support are therefore significantly disadvantaged.

This is a broad overview of the issues from the network. Specific examples and more detail can be provided on request.

28 June 2007

Memorandum from Values into Action

INTRODUCTION

With this written evidence I wish to submit the following two publications by VIA:

- *One Law for All—The impact of the Human Rights Act on people with learning difficulties* by Patricia Finnegan and Stephen Clarke, 2005; and
- *Rights for All—People with Learning Difficulties Using the Human Rights Act* by Catherine Bewley with Dave McCann and Denes Birta, 2005.

The stories in these two publications are relevant even today. People with learning difficulties face the same issues as they did when the above two publications were written

In this evidence, I will first of all provide a general overview of why the human rights of people with learning difficulties are not enforced. Then I have given examples of real case stories where people's human rights are denied which provides the joint committee an idea about how difficult it is in reality for these rights to be enforced. These examples are different from the ones in the two publications and are more recent.

 AN OVERVIEW

People with learning difficulties have the same human rights as defined in law as anybody else. However, there are factors that stop people with learning difficulties enforcing these laws. Some of these factors are as follows:

- *People with learning difficulties are not aware that they have these rights:* This could be due to them not being able to access the information because it has not been made accessible in a way that they can understand it. If people do not have the information about the Human Rights Act, they don't know what their rights are and how they can get support to enforce their rights. There are people with learning difficulties who can understand these rights if it is explained to them in simple words (easy read), some would understand it if the easy read version is explained with pictures. There are a large number of people with high support needs who will never be able to access this information as we have not as yet found a way to do so. For this group of people having an advocate to speak up for them is the only way we can come remotely close to their human rights being enforced in law. The advocate would be in a position to represent the person with a learning difficulty and has no other vested interest but to ensure that the rights of the person they are advocating for are met. I have said later on in this evidence that funding advocacy on a long term basis is important.

Another really good way of informing people about their rights is spending time with them and explaining their rights in a way they understand. If this is done by people who they trust and who understand them, and there is a rapport between them, then the message does get across.

I must stress that most people with learning difficulties would be able to understand these rights if they are explained in a way they can understand.

- *Public bodies' responsibilities to protect and support people's rights:* Although public bodies have duty of care and responsibilities to ensure that the human rights of people with learning difficulties are protected, in reality this does not happen. Public bodies may have policies that state they protect people's human rights but due to the reasons given below, these policies are not implemented. It is also important to remember that at times there might be a conflict between the human rights of the person with a learning difficulty and the responsibilities of the public bodies. Making that challenge legally takes a lot of courage and very difficult to enforce when there is this powerful large public body that you have to fight.
- *People with learning difficulties are in segregated services:* By this I mean people living in residential care homes, attending day centres and attending special needs classes at college. This results in people being dependent on support staff informing them of their rights. In most cases support staff may not be aware of the Human Rights Act. Although the target through "Valuing People" was to train 50% of staff by 2004, this target has not been met. Another important point to remember is that support staff may not always know about different legislation that govern their role and may also not feel confident about sharing this information. Those that live at home with parents, their parents/carers may not be aware of the Human Rights Act and so would not be able to support their son/daughter stand up for their rights.
- *People with learning difficulties do not even get to experience the community in most cases.* They are "bussed" from home to a segregated day centre and then "bussed" back home. There are no opportunities for them to learn about their rights in these circumstances. People in these segregated services are so "controlled" by the system that they do not even realise that their rights are being denied.
- *People with learning difficulties and the systems around them are institutionalised:* It is very difficult for individuals to fight institutional systems and for people with learning difficulties this is even more so. People with learning difficulties become institutionalised themselves and then fear the unknown. Living independently or going to work instead of going to a day centre are not experiences that most people with learning difficulty have had. They are not aware that these could improve the quality of their lives.
- *People with learning difficulties are dependent on their paid/unpaid carers.* This dependency makes it difficult for them to challenge people they are so dependent on. They know that they need this support to survive now and cannot visualise that their lives could be different. Even people with learning difficulties who are able to speak up for themselves may find it difficult to challenge the person they are dependent on. They need support to do this.
- *People with learning difficulties are poor:* Only a small number of people with learning difficulties are in paid employment. Majority of them are unemployed and so live in poverty. This makes them powerless at many different levels.

EXAMPLES WHERE PEOPLE'S HUMAN RIGHTS ARE NOT BEING MET

Healthcare Services

Dysphagia Service

Article 2: The right to life

Two middle managers in a PCT have been trying for over eight years to get a “dysphagia” service (eating and drinking) for people with high support needs. They have written reports to different senior managers to highlight a lack of service for this group of people. This group of people have problems with swallowing and so the position they sit in and their nutrition intake as well as thickness of food/fluids have to be taught to medical professionals providing care for them. In this PCT (as I am sure is the case in other PCTs as well) this service is only provided if the person is an inpatient in acute services. What is not taken on board that preventative service can avoid an inpatient service and prolong lives. These two middle managers have been asking for a multi-disciplinary approach involving GPs, Community Nurses, Dietetics, Physiotherapists and Speech & Language Therapists. All of these professionals would need specialist training to prevent chest infections. The result for this group of people is early death due to food continually getting stuck in their chests causing constant chest infections. In fact in this PCT a number of young people with high support needs have died due to chest infections in the last 8 years ever since these two managers have been highlighting a need for this service.

Psychology Service

Article 2: The right to life

Article 14: The right not to be discriminated against

Sean, a man in his fifties has had to wait over two years for a service from a Psychologist. He needs support to manage his anxiety and his anger. He gets an appointment for the Psychologist to assess him. A couple of hours are spent by the Psychologist in taking his history. A long phone call is then made by the Psychologist to a family member to verify the history given by Sean. A few weeks later, the assessment arrives through the post. The only recommendation made by the Psychologist is that this man should have a Person Centred Plan (PCP). For most people who have a PCP, it has not changed their life very much because the resources needed to implement it has not been provided by Social Services. To get a service you have to have a fair Access to Care Services Assessment carried out by a Social Worker. So having a PCP is not going to give Sean any support in managing his anxiety or his anger. When challenged about his recommendation, the Psychologist stated that he did not have the resources to provide a service. This man had to wait over two years to be told that he would not be getting a service after all. Enabling him to manage his anxiety and his anger would improve the quality of his life.

Long-stay hospitals and campus provision

Article 2: the right to life

Article 3: The right not to be treated or punished in a cruel way

Article 5: The right to freedom and to be safe

There are still a large number of people living in long-stay hospitals and NHS campus provision. Their human rights are being denied everyday and the abuse that took place at Budock hospital and Orchard Hill hospital will take a long time to change.

Education

Learning English

Article 8: Respect for private and family life

Article 14: The right not to be discriminated against

Protocol 1, Article 2: The right to education

Most Adult Education colleges have a segregated service for people with “special needs” and the provision mainly includes literacy, numeracy, travel training etc. People with learning difficulties attend these sorts of courses for years on end. There is no qualification at the end of it. Most of the people have probably come from a day centre for the session and will go back to the day centre at the end either for lunch or to be taken home (bussed) from the day centre. This situation is changing slowly and courses are geared towards a qualification.

Mina (English is her second language) had been attending literacy classes for years and learnt the same or very similar curriculum every year. She is very keen to learn English and gained a lot from the class. The college due to changes in requirements set up an English language class but the difference this time was that she would have to sit for an exam at the end of every term. The tutor made a judgement after meeting her at the open day that she would not be able to sit for exams so she was not allowed to take this class. The reason given for this refusal was that one of their performance indicators was the per cent of people who passed exams. So to keep up with this indicator, they would select people who they were sure would pass the exams.

Short notice of next year's courses

Article 8: Respect for private and family life

Article 14: The right not to be discriminated against

Patrick received a letter two days prior to the Open day from his college informing him about the courses available in the next academic year. Patrick cannot read and so was dependent on his support staff to read it when they next came in to support him. By this time the Open day had gone. Patrick could not join the course he wanted to attend as that course was full. His college should have provided this information to him a month earlier so Patrick would have been able to spend some time with his support staff working out what he wanted to do.

Housing

A large number of people with learning difficulties live in residential care homes where they have no housing rights. Most of the landlords, Social Services legal departments as well as CSCI and the providers agree that as people with learning difficulties may not understand what a tenancy agreement entails they should not be given one. Also if the care home wanted to get rid of the person for whatever reason it would be easier if they did not have a tenancy agreement. These people have a right to live more independently and not in these institutionalised care homes. However, unless there is a huge investment in housing to enable people to move from residential care homes these rights will be denied them.

Housing with Support (Supported Housing)

Article 8: Respect for private and family life

John is in his 30s and at present lives with his parents. He gets Direct Payments and his parents support him in employing, managing and supervising staff. John has made plans to live more and has been working towards it. His parents also feel that it would be better for them as well as John to leave parental home so he gets settled in his own home while they can still provide some support. They don't want to continue with this responsibility.

John is offered a flat that he will share with another man, Sean. He knows Sean and they both feel this will work out. Sean will get his support from landlord's outreach team. John has been told he needs to be assessed under the Fair Access to Care Services assessment and for that they need a Psychologist to assess whether he has a learning disability or not. The family fear that this is a ploy to cut the services that John receives now. John has also been told that he will continue to get Direct Payments for his support so that he maintains his independence. His parents are not willing to supervise/manage staff who they will never see. Also within the same house there would be staff being paid different levels of money. The hourly rate for a Direct Payment is much lower than the salary that the landlord pays their Outreach Workers. John and his parents are really worried and his joy of moving to his own place has turned into a nightmare. He has been supported by his parents to get a solicitor involved.

Welfare Benefits

Article 4: The right not to be treated like a slave at work

Article 14: The right not to be discriminated against

Julia has been in a job at a hospital records room for 15 years. The job is in the basement and is quite dusty. This is affecting Julia's health. She would really like a change and wants to resign. Everybody advises her that she should not do that as it will be very difficult for her to manage financially as she will not be able to access benefits for some time. Her salary is not very good and so she has not been able to make any savings. She needs time to look for another job and prepare for it. Working full time does not give her this time. So for now she is stuck with this job that she no longer enjoys.

Article 14: The right not to be discriminated against

Phil is receiving training at his day centre to be a telephonist. He would like a paid job but is worried about the impact of his getting a job to his benefits as well as what it would mean to the cost of the residential care home. He won't get paid much even if he does get a job and the worry about the impact on his benefits means that he is being prevented in applying for jobs.

Personal Relationships

Developing a personal relationship

Article 8: The right to private and family life

Article 11: Freedom of assembly and association

Article 12: The right to marry

Richard and Sharon are seen as an "item" at the day service they attend. They can only meet each other at the day centre. Richard lives with an elderly mother and so does not get to go out once he is back from the day centre. He also has epilepsy which is not controlled very well and so needs someone to support him when he is out in the community. He has not been able to access this extra support from social services. The day service is being modernised and as a result Richard and Sharon will not be able to meet. The numbers of days they will have activities has been cut down and they will be going to different venues for their day activities. With the modernising of day services, everyone has had a person centred plan. Neither Richard nor Sharon's PCP mentions the fact that they would like to see each other to continue to develop their relationship.

Mother does not approve of Sarah's boyfriend

Article 8: The right to private and family life

Article 11: The right to meet other people

Article 12: The right to marry

Sarah moved to a Supported Housing scheme and was beginning to get more confident and wanted to live in her own flat. She met Alan at the local disco and started a relationship with him. Her mother met Alan and was very supportive until she found out that Sarah is having a sexual relationship with Alan. She was not happy with this as she did not feel that Alan was a suitable sexual partner. She asked for an assessment for Sarah to assess whether she was able to consent to having a sexual relationship. The assessment stated that she does have the capacity to consent. Sarah's mother took her back home where she still lives with mother and she is not allowed to see Alan.

Child taken away from Sue

Article 8: The right to private and family life

Article 14: The right not to be discriminated against

Sue phoned our office a few months ago informing us that her child had been taken away from her and she was not being given any rights to visit. The reason given for taking the child away was that she was not able to look after her child. When asked what support and training she had had to look after her child she said she did not have any support. She was told that it would be very expensive to provide her this support. This story has not been verified but despite a number of research projects and guidance for Children and Adult services working together to support parents with learning difficulties, in reality this does not happen.

Opportunities to participate in their local community

Segregated Services

You can see from the examples given above that people with learning difficulties still use segregated services and this on the whole means that they will not be participating in their local communities.

Hate crime on public transport

Article 3: The right not to be treated or punished in a cruel way

Article 8: The right to private and family life

George loves visiting art galleries and going to the cinema. However he has to do this when school children are not around. He gets shouted at and taunted on buses and he gets really anxious when this happens. This makes the school children behave even worse. His bag has been snatched and the contents emptied on the road, his shirt has been pulled and a bottle of coke has been thrown at him. This fear prevents George from participating in his local community.

Employment

Article 8: The right to private and family life

Having a job brings in new friends, new experiences and chance of socialising with your colleagues. There is only a small % of people with earning difficulties in jobs. So majority of people with learning difficulties do not have the opportunity to participate and have this experience. Having a job gives you self esteem and gives you spending power.

Poverty

Article 8: The right to private and family life

Article 14: The right not to be discriminated against

Joan is a great fan of a football team. She is not employed and so cannot afford to attend any of the matches as the tickets are beyond her means. It would take her ages to save up the money to buy a ticket and she struggles to have her basic needs met with the benefits she receives.

What needs to happen for the human rights of people with learning difficulties to be met?

The following recommendations were made in VIA's publication, *One Law for All* mentioned at the beginning of this evidence. These recommendations still apply and I hope that the Joint Committee on Human Rights will recommend its implementation.

1. More needs to be done to implement the HRA. In particular, the HRA implications for people with learning difficulties need to be addressed as a governance issue in the same way that sex, race and disability discrimination are. The ways that this could be achieved could include:

- Auditing of policies for compliance with the HRA.
- Development of a corporate human rights policy.
- Appointment of a designated human rights official (who should be obtaining and applying up-to-date information on human rights issues and cases).

2. An extensive programme of staff training is necessary in the areas of:

- Human Rights and its applicability to working with people with learning difficulties, in order for staff to incorporate good practice guidelines and develop a human rights ethos.
- Communication and communication strategies when interacting with people who may need support to express and understand procedures.

3. Public authorities should be developing a 'communication policy' in conjunction with other agencies, covering areas such as:

- Developing alternative and augmentative communication approaches.
- Communicating important information in an accessible form.
- The use of advocates.
- The doctrine of "proportionality" and the principle of "fairness" in order to support the development of a human rights ethos.

4. Public authorities should be developing an advocacy policy which needs to include:

- The scrutiny of the gateway to advocacy services in order to ensure that advocacy is accessible to people at all levels.
- The amount of advocacy needed and how this is being met including the extension of advocacy services to other areas outside the direct complaints area.
- The development of more cross-agency agreements.

5. There are serious concerns about the lack of redress people with learning difficulties receive regarding complaints procedures nationally. Training in this area is crucially needed to protect people's right to a fair trial. Training should take place in the areas of:

- Use of advocates.
- Staff acting as “whistle-blowers”.
- Principles of “fairness”.
- Management support and transparency.
- Communication strategies.
- Staff acting as advocates.
- Cross-agency working (especially with the Commission for Social Care Inspection).
- Developing circles of support.

6. Public authorities should be auditing their policies around people with learning difficulties' rights and opportunities to develop sexual relationships, marry and have children. The policies should proactively highlight the rights that people with learning difficulties have in these areas.

7. Public authorities involved in residential care and education should be developing a privacy policy in relation to letter opening, money management and sexual expression for people with learning difficulties, which incorporates the above principles of “fairness” and “proportionality” in the decision-making process.

8. Public authorities involved in social care and education should be looking for new ways to work in partnership across sectors to ensure people with learning difficulties can “develop social relations with other” and “establish and develop relationships with other human beings” in line with Article 8 rights. The courts' view is that Article 8 imposes an obligation on a public authority to take positive measures to ensure these outcomes. We consider that the Commission for Social Care Inspection needs to apply the implications of this decision when considering monitoring criteria for the protection of that right in care home inspections.

9. Public authorities involved in educational input (which includes health, social care, residential care, day care and education) and should be ensuring that education and training sessions are taught in a language which is meaningful to people with learning difficulties. All staff need to present learning in an accessible way, and allow people to express their learning. These strategies may include signing, symbols, the use of gesture, plain English etc. Our research shows that this is not happening in a systematic way, which means that people with learning difficulties are often unable to express their needs. Where a staff member is unsure how best to communicate with a person, a referral for an assessment is crucial. Speech and language therapists take a key role in this area.

10. The community of people with learning difficulties and their supporters need to become aware of the development of the proposed Commission for Equality and Human Rights so that their agenda is included within the Commission's remit.

The starting point for this task could be to establish a forum within which to debate the key issues arising from the HRA and to map out a strategy for ongoing action and implementation. We expect that the issues will be of particular interest to:

- Advocacy groups.
- Health authorities and NHS Trusts.
- Social services departments.
- The legal community.
- Joint service commissioning agencies (including education departments).
- Purchasers and providers of services.
- Research and development agencies.
- Relevant central government departments.

11. The community of people with learning difficulties and their supporters need to campaign to highlight the obligation of the state to take positive measures to protect the right to a fair trial (under Article 6) and ensure that people with learning difficulties do not continue to have disproportionate difficulty in accessing the legal process. To this end, the Crown Prosecution Service needs to continue to generate standards and guidance in criminal proceedings, and specifically to monitor their application to people with learning difficulties in line with their Article 6 rights. Furthermore, legal networks of interested parties need to be developed to support people with learning difficulties to take court action when human rights principles are involved, and to feed back to the Commission for Equality and Human Rights and the legal community when access to civil remedies is denied.

12. Discriminatory practices in mainstream health care services continue to be reported. There is a need:

- For specialist health care professionals to support mainstream health care colleagues in assessing and managing the needs of people with learning difficulties.

- To provide all professional groups, at all levels, with the necessary training and experience in working with people with learning difficulties.

13. Residential services should be looking for ways to ensure that discriminatory health care practices are avoided when visiting health services. Health Facilitation and Health Action Plans should be an integral part of their approach to people's health. Agency staff, or people new to the service, should not attend GP and other health visits without the necessary knowledge and information.

14. Treatment which involves the use of long term medication is reviewed by medical professionals. Unfortunately, these review often lack the presence of the person with learning difficulties, or of an advocate.

- The person with learning difficulties needs to be involved in a meaningful way in the decision-making process whenever medication is being considered, including during reviews.
- Advocates should automatically be available to support the person with learning difficulties to be involved in decision-making about their medication. Paid staff are unlikely to be appropriate because of conflicts of interest. They may also lack authority to influence outcomes.
- Information needs to be accessible and to be presented in an appropriate way.

15. Public authorities have a duty to protect people with learning difficulties from being bullied as well as from low level harassment. They need to develop strategies which include how to prevent this type of behaviour occurring, through a process of training and education.

16. The community of people with learning difficulties and their supporters need to campaign to highlight the need for the adoption of protocol 12 of the European Convention (concerning a free-standing prohibition against discrimination) into the HRA. This would allow for significantly greater protection for the rights of people with learning difficulties.

17. The community of people with learning difficulties and their supporters need to campaign for people's right to independent advocacy. It seems inevitable that with the advent of the HRA a wider availability of advocacy services will be needed. At present, the state's positive obligation to provide a statutory advocacy service at the point of needs, which we consider to be necessary to protect the rights granted by the HRA to people with learning difficulties, has not been complied with. The Government needs to put additional resources into this area and ensure that advocacy is much more widely available for people with learning difficulties.

Public authorities urgently need to raise awareness of the HRA amongst their staff. If they are in doubt as to whether they are a "public authority" under the HRA they need to presume that they are. In all decisions involving people with learning difficulties they need to apply "proportionality", and to reach balanced decisions based on a human rights ethos. They need to be flexible in their decision-making and ensure (using all possible communication strategies, especially the use of advocacy) that the voices of the people to whom they provide their services are heard, and their rights protected.

Besides these recommendations the one thing that can really make a difference in the lives of people with learning difficulties is for:

Government Departments to work in partnership:

The responsibility for improving the lives of people with learning difficulties needs to be taken by all Government Departments. If this joint work is reflected at the top it can be mirrored in local government.

The example given above where George is in fear of school children, the responsibility of educating the children should be shared by Social Services, Education and the Police/ Crime Prosecution Service. At present because departments work in silos, people with learning difficulties fall through the net and locally these different departments only come together when it is too late.

Other things that are important to remember are:

- the availability of independent advocacy and its skill and capacity to deal with HRA issues;
- how informed and skilled frontline staff are in enforcing people's rights or reacting when they see those rights denied;
- how organisations inform and support their staff and their 'clients' about HR issues; and
- links with other laws, such as the Mental Capacity Act 2005 and other things that support people's rights to choice and control.

Memorandum by the British Humanist Association

1 ABOUT THE BRITISH HUMANIST ASSOCIATION

1.1 The British Humanist Association (BHA) is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society.

1.2 The BHA's chief executive was a member of the steering group for the Commission for Equality and Human Rights and of the reference group for the Equalities and Discrimination Law Reviews and the BHA itself regularly participates in campaigns, working parties, committees and consultations (Government and other) on these issues as they affect the interests of those we seek to represent.

1.3 The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns. The BHA itself is deeply committed to human rights and advocates an open and inclusive society in which individual freedom of belief and speech are supported by a policy of disinterested impartiality on the part of the government and official bodies towards the many groups within society so long as they conform to the minimum conventions of the society.

2 INTRODUCTION

2.1 The BHA welcomes the opportunity to submit our views to the Joint Committee on Human Rights' (JCHR) call for evidence into the human rights of adults with learning disabilities.

2.2 In this submission, we focus specifically on two areas of interest, as listed by the JCHR, which lie within our areas of expertise:

- The provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities, the ability of individuals to access such services and the quality of provision.
- The possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise in this context.

2.3 Our particular focus on these areas is on the type of public service, namely who provides it and how it is provided. We are especially concerned about the ways in which public services provided by religious organisations might infringe the human rights of people with learning disabilities, not least in terms of their article 8 and article 9 rights under the Human Rights Act 1998. These articles provide for the right to respect for private and family life and the freedom of thought, conscience and religion, where religion is understood to be "religion or belief" and includes non-religious beliefs.

2.4 People with learning disabilities constitute one of the most vulnerable groups in society and, as such, individuals with learning disabilities may be more at risk than others of having their rights abused or in other ways infringed upon, when they access public services and particularly in the context of residential settings.

2.5 It is our position that if any religious (or, equally, humanist) organisation be involved in providing public services in partnership with or on behalf of the Government or any public authority, it should not be allowed to discriminate on the grounds of religion or belief in its service delivery.

2.6 We agree with the JCHR that engaging the range of human rights contained in the European Convention on Human Rights, the Human Rights Act 1998 and other international human rights instruments greatly enhances the opportunity for adults with learning disabilities "to access a range of public service and to participate in the life of the community without encountering direct or indirect discrimination (including multiple discrimination)."¹⁴⁸ This submission, therefore, sets out where and why we would like to see the application of human rights principles and legislation, in the context of public services in particular.

3 OUR CONCERNS AND OUR POSITION

3.1 The Government is proposing a radical reform of public services,¹⁴⁹ wishing to marketise and contract out most public services to private and third sector suppliers. We are aware that the Government sees, and is actively promoting, an increased role for religious organisations in the provision of public services, from welfare to education to social services to health care.

¹⁴⁸ Joint Committee' on Human Rights, "The human rights of adults with learning disabilities. Call for evidence". 29 March 2007. <http://tinyurl.com/23tm8s>

¹⁴⁹ For example, as set out in its policy review, *Building on Progress*.

3.2 No religious organisation operating on behalf of the Government should ever be allowed to deliver public services in ways that implied or promoted religious belief, for example, through requirements of adherence to a religious doctrine or practice, or even by delivering services in settings with religious symbolism or in buildings used for worship etc. No service user should feel any pressure or be induced to comply in any way with any religious practice when she accesses and is in receipt of a public service. To do so would constitute a clear abuse of her human right to freedom of religion or belief.

3.3 We have heard of some service providers who create a very religious environment, especially in residential care settings. Even if there is no overt proselytising by staff, in such environments people with learning disabilities may be particularly vulnerable to pressure from the surroundings and those who might wish to impose religion on them.

3.4 We are aware of anecdotal evidence that some service providers (organisations or individuals) who are themselves religious seem to believe that finding god will improve their clients' physical and mental health, and hence that they are fully justified in trying to convert them.

3.5 We have also received some calls from people who are very concerned about the religiosity of the services which people with learning disabilities receive. For example, we have had calls from parents of adults going into residential settings who are concerned about religion being thrust upon them, for a number of reasons. There are real worries that this will confuse or seriously upset them, if, for example, they come to believe that their family/friends will end up in hell, or because they fear it will damage their relationship with their son/daughter. Others do not wish for their relative with learning disabilities to be placed and cared for in a religious environment, because it does not accord with their own convictions. There may even be considerations of inheritance and will-making under the influence of a religious institution.

3.6 It would not be sufficient simply to say that a user may have the choice not to take part in an activity or not to have services delivered from, say, a church hall—those issues should not even occur in the state-funded welfare system of a country which respects its citizens' right to freedom of conscience, however and through whomever services are delivered. This is a concern for all service users but is particularly applicable to the most vulnerable, not least those individuals with learning disabilities, their relatives and carers. In terms of residential care, for example, there is often very little "choice" as to where people are placed, leaving relatives in a weak position to complain about practices of which they disapprove. For those with some cognitive impairment, there are additional and specific concerns regarding the idea that they would have been sufficiently informed to have consented: first, to receive services from a religious provider, especially in a religious setting; and, second, to take part in religious activities once resident. This raises questions about the human rights of those individuals in receipt of such services. Hence, to reiterate, it is our position that all public services must be delivered in an inclusive secular way, in non-religious settings.

3.7 As the Government is set to contract out ever more public services to third sector and private organisations, the issues set out above and in relation to the human rights of people with learning disabilities become even more imminent. We share the concerns of the DRC-coordinated joint response to the *YL* judgment (more discussion below), that contractual stipulations do not and cannot provide adequate protection against potential infringements and violations of a person's human rights. The joint response states that, "any contractual term imposed on the care home to observe residents' Convention rights is not an adequate substitute for potential liability of the care home under the HRA"¹⁵⁰ and that, "despite guidelines on procurement, there is no guarantee that contractual terms relating to HRA compliance will be in place in every case where a breach may occur, nor that any existing contract terms will be enforceable by the care home resident as a matter of contract law"¹⁵¹. This concern, of course, applies to contracting in general, and not only contracts made by "local authorities to private and third sector organisations to provide residential care.

3.8 In our memorandum on public authority and human rights to the JCHR in March 2007, we discuss in detail our position that public authority status should be extended to all organisations providing public services on behalf of the government, in order to ensure service users are protected by the Human Rights Act 1998 (HRA).

3.9 Subsequent to that memorandum, on 20 June 2007, a landmark judgment in the Lords upheld the decision in the case of *YL v Birmingham City Council*, which "held that a private care home providing accommodation to elderly residents under contract with a local authority was not itself exercising "functions of a public nature" for the purposes of the Human Rights Act 1998"¹⁵². In effect, this judgment reinforces the current, narrow interpretation of "public authority" and "public function" adopted by our domestic courts. In practice, this has immediate and serious implications for growing numbers of people, as local authorities are increasingly making use of private care homes to fulfil their statutory duties to provide care and accommodation.¹⁵³

¹⁵⁰ JUSTICE, Liberty, The British Institute of Human Rights, Help the Aged, Age Concern and the Disability Rights Commission, "Joint response to the House of Lords", 27 June 2007. http://www.bih.org/downloads/YL_Response_of_Interveners.pdf, p6

¹⁵¹ *Ibid*, p 7.

¹⁵² *Ibid*, p 2.

¹⁵³ *Ibid*.

3.10 It is worth briefly reiterating some points from our earlier memorandum to the JCHR for this submission, as they relate to the rights of people with learning disabilities. Currently, “public authorities” are bound by sections of the HRA. However, what is deemed to be a public authority is very limited and usually only applies to “pure” public authorities such as local authorities, due to the narrow interpretation of the term adopted by the courts, in plain opposition to the wishes of the Government expressed at the time of legislating. Thus, the Convention rights under the Human Rights Act of many service users are subject to the lottery of whether services are delivered directly by government or indirectly under a contract with a third party. This lack of protection for service users under human rights legislation is likely to become increasingly common when more and more third-party suppliers are involved in the provision of public services.

3.11 We consider that, for individuals who are in receipt of public services from a religious organisation under the proposed reforms, the situation is likely to be even more troubling, unless the definitions of “public authority” and “public function” are much more widely interpreted and applied, as originally intended and explicitly stated by the Government during passage of the HRA. As is made clear in their memoranda to the JCHR on public authority and human rights, some religious organisations have no desire to be public authorities, specifically because they may explicitly wish to discriminate in the provision of services—thus depriving clients of their human rights—in order to maintain their religious ethos and independence. The Salvation Army, for example, remarks that, “Whilst it is appropriate for the state to be religiously neutral, this is impossible for an organisation such as The Salvation Army, which delivers its services as a direct outworking of the Christian faith”¹⁵⁴

3.12 The wider protection afforded to individuals under the HRA should not be underestimated. The HRA protects the rights of individuals to, for example, dignity and respect for family life. Such content may be interpreted very differently by religious organisations, who may have their own definitions and understandings of “family life”, appropriate sexual behaviour and so on. For service users then, it is critical that suppliers of welfare are covered by the HRA, so that their rights above and beyond those covered by equality and non-discrimination regulations are fully protected.

3.13 We think it is the right of every adult individual to form and maintain personal, including sexual, relationships with others. As such, it is the duty of the state to ensure as far as possible that individuals are neither compelled nor actively dissuaded from forming such relationships.

3.14 Article 8 of the HRA protects the individual’s right to respect for private and family life and stipulates that no public authority shall interfere with this right. As detailed above, we have concerns that some religious organisations (their front line staff in particular) providing public services to people with learning disabilities may attempt to “impose their own religious values and ‘morality’ onto their, often very vulnerable, clients.

3.15 Hence, in light of the *YL v Birmingham City Council* judgment, our concerns set out above become even more “imminent. To restate: adults with learning disabilities are some of the most vulnerable individuals in society and those who are in residential care are amongst those most vulnerable to human rights abuses. For the reasons discussed throughout this submission, the Government’s desire and policy to contract out the supply public services to religious organisations may have the effect that increasing numbers of adults with learning disabilities will be put at risk of having their human rights disrespected or violated, with little to no legal recourse.

Memorandum from the Challenging Behaviour Foundation

The Challenging Behaviour Foundation is a UK wide charity. Our vision is to see children and adults with severe learning disabilities, who are described as having challenging behaviour, having the same life opportunities as everyone else, including home life, leisure and education. The Challenging Behaviour Foundation exists to demonstrate that individuals with severe learning disabilities who are described as having challenging behaviour can enjoy normal life opportunities when their behaviour is properly understood and appropriately managed, and to support parents and carers through education and information to enable this to happen.

Adults with severe learning disabilities (SLD) who are described as having challenging behaviour are often excluded from services or considered “too difficult” to include initially. Adults with SLD and challenging behaviour are therefore particularly vulnerable to exploitation of their human rights. Below we have provided evidence of some of the ways in which the human rights of adults with a learning disability described as having challenging behaviour are being breached.

¹⁵⁴ Memorandum from the Salvation Army to the Joint Committee on Human Rights: The Meaning of Public Authority under the Human Rights Act. <http://www.publications.parliament.uk/pa/jt200607/jtselect/jtrights/77/77we09.htm>

THE PROVISION OF HEALTHCARE

— The following example highlights the failure of primary healthcare professionals to understand challenging behaviour in individuals with SLD. Health needs are therefore ignored and risk is inappropriately evaluated.

Challenging Behaviour Foundation Professionals' email network correspondence March 2007

Behaviour Support Advisor "I have received a referral for a man who has recently started to display pica type behaviour. He has in the past placed shoe laces and strip's of material in his mouth and sucked on them, however recently he has started to eat these items. The staff team took away his laces and now he is eating his mattress and quilt cover at night and eating pieces of carpet. We hope to have some health checks done but clearly some of his eating habits are now dangerous, the GP is not supportive nor the community nurse as they feel if he is passing the items then no harm will be done, clearly we feel that we need to address this more urgently."

Consultant Clinical Psychologist: "I think the fact that there's been this apparently "recent" change needs looking into fairly urgently. After all, he may choke himself to death on something if someone doesn't get to grips with this issue"

— This example highlights how inadequate healthcare is being provided by primary healthcare workers which could ultimately lead to an individuals' death.

THE PROVISION OF EDUCATION

— The vast majority of individuals with SLD and challenging behaviour cannot access their local further education college. Often there are only two options available; residential college (if adequate funding can be secured), or no further education.

Parent of a 19 year old man with SLD

"I would like to know how to maintain educational needs, as our LEA are once again robbing our son of this"

— In a small number of instances eg Medway, Kent individuals with SLD and challenging behaviour are able to access further education at the local mainstream further education college. However this is due to a huge amount of work from a large number of partners. The process needs to be much easier.

WELFARE

— Individuals with a learning disability and challenging behaviour are more likely to suffer sexual, physical and emotional abuse

Parent of a 21 year old man with a chromosome disorder

"Reports from independent psychologists times two state that hospital environment is inappropriate and detrimental to our son's well being ie vulnerable, risk of institutionalisation. Our son has been physically and sexually assaulted at the hospital"

THE PROVISION OF HOUSING

— Individuals with SLD described as having challenging behaviour are evicted from residential homes because of behaviour which challenges the service.

— Individuals with SLD and challenging behaviour are also evicted without an acceptable alternative being found, leading to a cycle of eviction.

Parent of a 40 year old man with Cri-Du-Chat Syndrome

"My son is in a residential home. However this is the third placement, having been discharged from two for aggressive behaviour. We are worried that this pattern may reoccur although at present he seems happy and settled where he is".

— Adults with a SLD and challenging behaviour are being evicted from residential homes because of the failure of care providers to appropriately manage behaviours which challenge their service.

— When care providers fail to manage challenging behaviour it is always the individual with SLD and challenging behaviour who is penalised by having to move rather than the care provider who has failed to adequately support the individual.

— The Long-term continuation of housing is very uncertain.

Parent of a 25 yr old man with autism and a severe learning disability

“Although my son and I settled at the moment we are very aware that our futures are not to be taken for granted. We are very much dependent on the whims of national and local government, for example my son’s placement is independent and from attending local strategy meetings this is not the ‘in’ thing at the moment. We are always aware that funding could be withdrawn at any time”

Parent

“My concern is that as I get older, I am now 69 years, I will not be able to fight his corner forever. I fear that the Local Authority Committee will be looking at cheaper options, as they have already threatened to move him to reduce the cost by 20%. He took legal advice, through my advocacy, resulting in his place being maintained.”

BENEFITS

— Individuals who are assessed as lacking the capacity to consent to a direct payment are being refused direct payments. It is currently discretionary for the local authority to provide an indirect payment via a trust for individuals assessed as lacking capacity to consent to a direct payment.

Parent of a 23 year old man with a severe learning disability and autism

“We had direct payments for D for two years then the local authority said they should not have given D a direct payment as he could not consent etc and, even though we had a Trust set up with five Trustees they withdrew the direct payment!”

— This means that some individuals with a SLD and challenging behaviour are unable to access benefits which allow them to have the support they require tailored to their individual needs.

THE ABILITY OF INDIVIDUALS TO ACCESS HEALTHCARE, EDUCATION AND HOUSING

— Individuals with a SLD and challenging behaviour are currently limited in scope to the range of education and housing they can access.

The CBF is currently supporting a family with a 19 year old son who is placed in an out of area residential service. His family want him to live locally and be supported to attend college. When his transition social worker was asked about making this happen, she said she could not help—all she could do was to look for a residential place, and this was likely to be out of area as there were no existing local services to meet his needs. This is despite the family living in an area which is piloting individualised budgets.

— Developing an individual service from scratch is significantly more time consuming and complex than buying an existing service. It is this difference that influences commissioning rather than the difference between quality, appropriateness and locality of the service provision, and this needs to change.

— Parents feel they have a constant battle to support their son/daughter to access appropriate services.

Parent

“Other people need more advice than we got! Through being professionals ourselves and being fairly articulate we have been able to get the right provision for our daughter but it has been a very hard struggle at times!”

Parent

“My concern is that he gets forgotten when I am no longer alive to fight his corner. I always have to follow up the professionals and keep them focused on his needs. Too many mistakes in the past have left me with little or no confidence in the professionals. (I have had to make formal complaints which have been upheld by the investigators)”

Parent of a 24 year old man with a moderate learning disability and an autism spectrum disorder

“The hardest thing is battling with the politics of the NHS and social services and legal matters.”

— There is a need for specialist skilled advocacy for individuals with complex needs to ensure that individuals with a SLD and challenging behaviour have access to appropriate healthcare, education and housing.

Parent

“My son is 21 and has SLD and challenging behaviour. He is a complex individual, (as we all are!) with likes and dislikes, memories and experiences. He does not communicate verbally and has a range of behaviours which are difficult to understand without background knowledge and expertise. I would like him to have an independent advocate but this will require a special individual who has the commitment to take the time required to get to know him and understand his history and behaviours. Such individuals are not widely available! The role of an independent advocate is crucial—but it is a highly skilled and time consuming role that should not be left to ‘goodwill’ or volunteers, and the potential damage that could be caused by a well-meaning but inexperienced advocate is huge.

I hear a lot about advocacy—but at present it is not an available option for my son.”

— Some parents feel that rather than being treated as a valued partner in steering services to achieve a good quality of life for their son/daughter they are treated as an interfering nuisance

Parent of a 20 year old man with autism

“People with learning disabilities{are often not supported in the most appropriate manner in my opinion, and parents can be seen as interfering!!, rather than as a partnership”

THE QUALITY OF PROVISION

— “People of all ages with challenging behaviour do not have their needs adequately met” (CSCI. The state of social care in England 2005–06)

Staff in some residential care homes do not receive appropriate training to enable them to manage behaviours which challenge services effectively.

Parent of a 23 year old man with a severe learning disability and autism

“X’s staff team are caring, but not very well trained in behavioural issues or in teaching him new skills. I worry that his behaviour will worsen, and he will lose skills.”

— If challenging behaviour is inappropriately managed then the individual is more likely to be excluded from their placement, more likely to be restrained inappropriately and less likely to be supported to access community facilities.

THE POSSIBILITY FOR ADULTS WITH LEARNING DISABILITIES TO FORM AND MAINTAIN PERSONAL RELATIONSHIPS WITH OTHERS

— “there are still too many people who are being sent away from their local communities in order to get a service” (Department of Health 2005)

— Being placed out of area leads to greater isolation from family and friends. It is obvious that if a parent lives 300 miles from their adult son/daughter they are going to be able to visit them less than if they live 3 miles away. Too many individuals with a learning disability and challenging behaviour are still being placed out of area.

Parent of a 19 year old man with severe learning disabilities

“(My son is currently in an) out of area emergency placement and I am worried he will end up in an out of area adult service, out of our reach/input and very likely not suitable for him, as has been the case to date”

Parent of a 21 year old man with a rare chromosome disorder

“MHRT recommended that services be provided in his home area 2.12.05 as yet nothing has been found during to lack of specific psychology input. Psychologist at hospital agreed that the environment is detrimental to his well being. There appears to be little evidence of our local agencies taking on board Government recommendations ie

— Close to home

— Our health, Our way

The risk our son presents can be managed in the community with the right support systems—professionals, however, appear not to want to look at positive risk taking. We have been trying for a year to develop a Person Centred Plan for our son, but the hospital (NHS) are reluctant to help us.”

THE OPPORTUNITY FOR PEOPLE WITH LEARNING DISABILITIES TO PARTICIPATE IN THE LIFE OF THEIR LOCAL COMMUNITY AND THE STATE'S OBLIGATION TO FACILITATE PARTICIPATION

- Positive planning for adults with SLD and challenging behaviour is essential or these individuals will remain shut out of society and denied the opportunity to become citizens.
- We believe the state has an obligation to ensure that every individual with SLD and challenging behaviour should receive appropriate support to participate in the life of their local community.

GOOD PRACTICE

- Provision needs to be person centred as recommended in Valuing People.

Parent of a man with autism

“When in adult care, we had five years without respite, then eight years without a holiday. He is now the happiest and most settled he has ever been. His behaviour is improving all the time. Mainly, due to the ‘package’ of care, finally, being built around him and his individual needs, rather than him having to “fit in”, which is not an autistic persons way at all!”

AN EXAMPLE OF GOOD PRACTICE

In Medway, a new service has been developed and brought four young people with a severe learning disabilities and challenging behaviour back to their home area. They live in the local community in a house that looks “ordinary”, are supported by a staff team and attend the local mainstream FE college. At college, a classroom has been adapted to meet their needs, and an appropriate curriculum has been designed. They are also supported to take part in community life.

The whole process took a considerable amount of time, effort and sheer hard work. Many partners have been involved including: Challenging Behaviour Foundation, Connexions, Kelsey Housing, Learning & Skills Council: Kent & Medway, Medway Council, Mid Kent College, Scope, Tizard Centre: University of Kent, West Kent NHS & Social Care Trust.

Further details of the service are available from the Challenging Behaviour Foundation including:

“A new pathway for young people with severe learning disability and challenging behaviour. A review of the planning model used to develop the Medway Challenging Behaviour Further Education service.”
Steve Easter

The Challenging Behaviour Foundation designed this pilot project to demonstrate the potential for ‘inclusion’ of learning disabled young people who are described as having challenging behaviour. The Challenging Behaviour Foundation aims to support the development of local projects across the UK.

Whilst the Government sets out clear aims for the development of local services for this group, including access to FE, in practice this is hard to achieve. Sustaining existing out of area placements whilst resourcing the development of new local ones is costly. The existing systems, funding mechanisms and bureaucracies not only fail to support such local development but actually inhibit it. Part of the original vision was to demonstrate by example that it could be achieved—and then support others to do the same. For this to happen we have to make the process much easier.

The Challenging Behaviour Foundation believes adults with severe learning disabilities, who are described as having challenging behaviour should have the same life opportunities as everyone else, including healthcare, housing, home life, leisure and education. Significant changes in the commissioning of services, the training of primary healthcare workers and access to local FE colleges are needed to enable this to happen.

10 July 2007

Memorandum from Voice UK, Ann Craft Trust and Respond

CRIME AND ABUSE AGAINST ADULTS WITH LEARNING DISABILITIES

The Ann Craft Trust, VOICE UK and Respond are three separate learning disability charities which campaign on abuse, crime and protection issues.

VOICE UK supports people with learning disabilities and other vulnerable groups who have experienced crime or abuse. We also support their families, carers and professional workers. VOICE UK works with, and trains, criminal justice professionals to improve access to the criminal justice system.

The Ann Craft Trust works with staff in the statutory, independent and voluntary sectors to protect people with learning disabilities who may be at risk from abuse. We also provide advice and information to parents and carers who may have concerns about someone they are supporting.

Respond offers a range of services which provide emotional and psychological support to victims and perpetrators of abuse who have learning disabilities. It also provides training and support to professionals and carers working with them.

We work jointly on issues of public policy and regularly advise the Government and criminal justice agencies on vulnerable victims and witnesses.

EXECUTIVE SUMMARY

A deficit of data on crime and abuse affecting adults with learning disabilities hinders policymakers, criminal justice agencies and public authorities who wish to effectively target such crime and abuse and measure their progress in doing so. This is partly a reflection of the difficulty in collecting data on crimes that are often not reported and partly a reflection of a reluctance in society to confront the human rights infringements adults with learning disabilities suffer. The British Crime Survey could fill this data deficit, but it currently under-represents the experiences of people with disabilities. Understanding of adults with learning disabilities' experiences of crime and abuse often only comes from non-governmental organisations direct contact with victims.

Many adults with learning disabilities suffer crime and abuse because they are targeted by people who hate them because of their learning disabilities. The human rights abuses arising from this bigotry include harassment, assaults and even murder. Criminal justice agencies and the Government have recognised this and codified it in the concept of disability hate crime. While joint working between some police forces, local authorities and local advocacy groups has led to efforts to combat this discrimination and empower adults with learning disabilities, the state's efforts in this area are patchy. Disability hate crime is a problem with no public profile and is rarely mentioned by criminal justice agencies. Despite disability hate crime affects adults with learning disabilities going about their daily lives, and despite the great impact this has on their ability to lead a full life in their communities, there has been no concerted action by Government to address this problem. The Government must designate a particular Minister as having responsibility in this area, work to confront prejudice against adults with learning disabilities and push forward concerted action by criminal justice professionals.

The higher incidence of particular illnesses amongst adults with learning disabilities couples with diagnostic overshadowing and poor understanding of learning disabilities amongst medical professionals has led to death through neglect of some adults with learning disabilities. Through the work of Mencap and the Disability Rights Commission, this issue is beginning to receive the public attention it deserves. While the focus on the broad issues involved in these deaths is welcome, the accountability and potential criminal liability of individual medical professionals and healthcare organisations has been overlooked.

Recent inquiries have highlighted how adults with learning disabilities are being deprived of their right to liberty without the protection of law. We fear that this problem may be widespread and that carers are unaware of good practice and the relevant legal requirements. The emphasis must be on identifying and maximising opportunities for people to go outside care settings, particularly if staff find their behaviour challenging. This approach needs to be integrated into care plans, risk assessments, training and the culture of organisations. It also involves applying those measures which limit the liberty of adults with learning disabilities only to those specific people for whom these measures are required and not by default to everyone living with them.

Adults with learning disabilities are at higher risk of sexual assault, rape and domestic violence than the general population. These, and other crimes, are regularly committed in care settings by the very people who are meant to be caring for them. An effective vetting and barring scheme can do much to prevent such abuse by carers. Refuges for victims of domestic violence with learning disabilities are rare and more provision in this area is urgently needed. Adults with learning disabilities who have experienced crime and abuse can benefit greatly from the provision of therapy, but resource constraints and misconceptions about therapy greatly limit its provision for this group. The *No Secrets* guidance was an important step in increasing the protection of vulnerable adults and good practice has come from its implementation. However, this guidance needs to be updated and a lack of police involvement in many cases of crime and abuse against adults with learning disabilities has led to justice being denied. We therefore welcome the Government's recently announced review of vulnerable adult protection guidance and believe it is important that criminal justice stakeholders participate in this review.

All the parties to arranged marriages involving adults with learning disabilities need appropriate assistance and support if these marriages are to succeed and to avoid deterioration into domestic violence.

Forced marriages of adults with learning disabilities are a serious problem which has received little attention. To ensure that courts can understand the wishes and feelings of adults with learning disabilities when considering forced marriage protection orders (as will be established by the Forced Marriage (Civil Protection Bill)), it must be explicit that courts can utilise the special measures available in criminal cases.

These special measures are an effective means of ensuring adults with learning disabilities can give their best evidence and so receive justice. Unfortunately, these special measures may be denied or delayed because criminal justice professionals, in particular police officers, regularly fail to identify adults with learning disabilities. Some members of the judiciary and legal profession are also resistant to using special measures.

In addition, some cases of crime against adults with learning disabilities are not prosecuted because it is felt that victims can not give evidence or that it is necessary to spare them the experience of appearing in court. Training for criminal justice professionals could do much to correct this situation and ensure justice for more victims.

The lack of special measures provision for suspects and defendants with learning disabilities risks miscarriages of justice and is arguably a failure of the state to uphold human rights. This must be corrected.

1. INTRODUCTION

1.1 Adults with learning disabilities have a higher risk of being the victims of crime and abuse, and face greater hurdles to achieving justice, than the general population. They are often targeted because of their perceived vulnerability and are sometimes targeted specifically because of their learning disabilities. Yet, adults with learning disabilities are less likely to report the crime and abuse they have suffered and are less likely to seek help. For many, the violation of their human rights is seen as a normal part of their everyday lives.

1.2 Occasional inquiries and reports briefly bring these issues into the public consciousness, but crime and abuse against adults with learning disabilities is largely ignored or forgotten by the general population. This is partly because it is too uncomfortable an issue to confront. A lack of official information about crime and abuse against adults with learning disabilities makes this easier and hinders the formulation of public policy to prevent and address these human rights infringements.

1.3 Many dedicated professionals work to tackle crime and abuse against adults with learning disabilities. There is also much good practice and appropriate legislation and guidance. Unfortunately, lack of funding, poor implementation and lack of training on good practice limit the positive effects and allow bad practice to continue. While the situation is undoubtedly better than 10 years ago, it remains a fact that adults with learning disabilities regularly suffer preventable infringements of their human rights.

1.4.1 This submission describes the extent to which the rights of adults with learning disabilities are currently being respected in relation to crime and abuse. As such, it examines how rights to life, freedom from exploitation, violence and abuse, liberty and security of the person, liberty of movement and others are being met. It considers the extent to which the obligations of the state fulfils its obligations to prevent the crime and abuse that prevents adults with learning disabilities accessing services and living full lives in their communities. We focus in particular on a selection of public services provided by the state or on its behalf—healthcare, social care, policing and criminal justice.

1.4.2 We make suggestions for recommendations that the Joint Committee could give in its final report. The human rights issues we address are grouped under general headings and under each heading a reference is made to the articles of human rights instruments that we believe are relevant. These references have been abbreviated to UN Convention for the United Nations Convention on the Rights of Persons with Disabilities and ECHR for the European Convention on Human Rights.

1.4.3 We begin by making general points which apply throughout our submission.

2. GENERAL POINTS

2.1 *Language*

2.1.1 In this submission we use both the terms abuse and crime to refer to particular violations of the human rights of adults with learning disabilities. There is overlap between the two terms, but the distinction between the two is important.

2.1.2 Abuse is the term widely used to refer to behaviour which intentionally or unintentionally harms and is often applied to harm inflicted on vulnerable groups. Much abuse is criminal, for instance, assault, rape and theft. However, some abuse is a violation of good practice and, while still harmful, is either not a criminal offence or would be very difficult to prosecute as a criminal offence.

2.1.3 Our organisations are concerned that the use of the term abuse to refer to crimes devalues the offences and the victims. It is our experience that calling a criminal offence abuse also encourages organisations to believe that these crimes do not need to be reported to the police, but can be dealt with by the organisation. For these reasons, we will be restrictive in our use of the term abuse and refer to crimes as crimes when appropriate—for instance, what is sometimes called financial abuse will be called theft, sexual abuse will be called sexual assault or rape and physical abuse will be referred to as assault. We hope that the Joint Committee will adopt a similar approach.

2.2 *The Scope of Human Rights Infringements*

2.2.1 Infringements of the human rights of adults with learning disabilities are perpetrated by members of the public, the state, private bodies and voluntary organisations. Members of the public, private bodies and voluntary organisations are obviously not bound by human rights instruments; however, we contend that crimes and abuse perpetrated by them constitute human rights infringements (even if only in spirit).

Our intention in highlighting many human rights infringements perpetrated by these groups is to illustrate the full picture relating to the human rights of adults with learning disabilities and to describe the human rights infringements that the state has a duty to address.

2.2.2 A further reason is that we believe that private and voluntary sector organisations providing public services by contractual arrangement with a public body should be covered by the Human Rights Act because of the crimes and abuses which occur to those in their care. We touch on this issue later in this submission.

2.3 *Data Deficit*

2.3.1.1 There is a deficit of data on crime and abuse affecting adults with learning disabilities. The total of the academic studies, official figures, surveys and individual cases highlighted in inspection reports amounts to a very partial picture of how crime and abuse infringe the human rights of adults with learning disabilities. That information on crime and abuse affecting this group is not often collected may be indicative of the priority afforded to adults with learning disabilities by official bodies and the resource limitations faced by the non-governmental organisations (NGOs) working in this field.

2.3.1.2 It is also partly a reflection of the difficulties involved in collecting information about any crime—the embarrassment, shame, fear of reprisal and a feeling that nothing will be done that discourages reporting. 58% of crimes affecting the general population are never reported to the police¹ and we believe that adults with learning disabilities are even less likely to report being the victims of crime than the general population.

2.3.1.3 This data deficit is also a reflection of a great reluctance in society to both acknowledge and confront crime and abuse against adults with learning disabilities. The majority of people in our society feel uncomfortable about learning disability and in the company of people with learning disabilities. These feelings are largely born of a lack of understanding and the result can be a reluctance to accept abuse occurs or the severe forms it can take. These feelings can lead to outright denials of abuse, to a lack of priority being assigned to tackling abuse or to a simple failure to think about adults with learning disabilities. The result has been information collected only locally, partially or not at all.

2.3.2 The limited statistical information on crime and abuse against people with learning disabilities makes it harder to get this issue onto the public and policy agenda as well as making it easier to avoid confronting it. This data deficit also hinders policymakers and public authorities who wish to effectively target such crime and abuse and measure their progress in doing so. It is our and other NGOs contact with adults with learning disabilities who have been victims of crime or abuse that is often the only way that any understanding of the situation is obtained.

2.3.3.1 The under-representation of adults with learning disabilities in the British Crime Survey (BCS) is a case in point. This under-representation comes about because:

- The BCS does not survey those living in group residences (eg care homes, sheltered housing) in which adults with learning disabilities will be disproportionately represented in comparison with the general population. This sampling exclusion also prevents an accurate picture being developed of crimes within care settings.
- BCS interviewers do not receive disability awareness training and the BCS is reliant on interviewers' ability to facilitate the participation of adults with learning disabilities in the absence of an easy-read version of the BCS.
- The BCS only publishes analyses against a demographic category of disability with three variables—“limiting disability/illness”, “non-limiting disability/illness” and “no disability or illness”. Also, although respondents are asked to identify if they have learning disability, it is likely that the number of adults with learning disabilities in the sample is too small to produce statistically meaningful results.

2.3.3.2 This has significant implications for public policy. As you know, the BCS provides the statistical yardstick against which anti-crime policy is judged (particularly in the Home Office's Public Service Agreement (PSA) targets). The BCS also provides the information needed to design new policy initiatives and strategies and to judge their success (eg the Home Office's new Crime Strategy). The under-representation of adults with learning disabilities in the BCS therefore hinders the Home Office in designing, implementing and evaluating measures to tackle crime against this vulnerable group. It also raises questions about how accurately we can judge Home Office performance against its PSA targets and whether the Home Office is fulfilling the Disability Equality Duty to ensure equality of opportunity. In other words, methodological issues with the BCS hinder the Home Office's ability to uphold the human rights of adults with learning disabilities.

2.3.3.3 We believe that this situation has not arisen because of a deliberate intent to exclude, but because the BCS has never been fully evaluated against the Disability Equality Duty. We have been in communication with the Home Office on this issue and our meetings with civil servants have been constructive. It now seems likely that the Home Office will implement the recommendation of the Smith Review to include group accommodation within the BCS and that some form of disability awareness training will take place. However, it is unclear at this stage whether an equality impact assessment under the

Disability Equality Duty will be conducted to allow detailed consideration of this issue and the involvement of relevant stakeholders. We hope that the Joint Committee will call on the Home Office to conduct an equality impact assessment.

2.3.4 The data deficit regarding crime and abuse against adults with learning disabilities makes it harder for public bodies to uphold their human rights. This is an issue which we would like to see addressed across government. It also means it is not possible for us to provide the Joint Committee with the statistical information on the human rights infringements of adults with learning disabilities that we would like. In those areas where data is lacking, we have endeavoured to provide insights from our own experiences as well as cases from our helplines and media reports.

2.4 *The views of the Respond Action Group*

2.4.1 The Respond Action Group (RAG) is a group of adults with learning disabilities who have had experiences of an abusive nature and are employed as a consultative group by Respond. The RAG provide their experience and insights on Respond's services, direction, policy positions and how to protect adults with learning disabilities from abuse.

2.4.2 The RAG believe that the Joint Committee's inquiry will not lead to any change in the lives of people with learning disabilities. They feel that the Joint Committee's inquiry will follow the pattern of earlier inquiries into the experiences of people with learning disabilities by having a gap between talk and action. The RAG ask that policymakers finish the job that they start.

2.4.3 It is an indication of the history of public policy and its implementation that adults with learning disabilities feel such cynicism towards the Joint Committee's attempt to consider how their lives could be improved. Addressing this cynicism is not a matter of persuading adults with learning disabilities that the Joint Committee has good intentions and that you have made worthwhile recommendations. This is what has gone before. It is a matter of changing the day-to-day experiences of adults with learning disabilities through sustained action. This challenge from the RAG is something to which we hope the Joint Committee will rise.

2.4.4 The RAG stated what they believed to be the most important things for the respect of the human rights of adults with learning disabilities.

- The need to raise awareness of the abuse of adults with learning disabilities.
- Respect for adults with learning disabilities.
- Adults with learning disabilities to have a say in their own lives and a voice in those matters which affect them.
- No tolerance of abuse.
- No labels to be applied to adults with learning disabilities.

3. DISABILITY HATE CRIME

3.1 *The nature of disability hate crime*

3.1.1 Disability hate crime represents one of the most direct and discriminatory assaults on the human rights of adults with learning disabilities. It is a crime in which adults with learning disabilities are specifically targeted because of their disability and, as such, it is committed by people who fail to see beyond the disability to the human being. It is a physical manifestation of bigotry and a regular, sometimes daily, occurrence for adults with learning disabilities. Disability hate crimes are committed by members of the public across a wide range of crimes and so infringe (in spirit):

- the right to life;
- the right to liberty and security of the person;
- the right to freedom from exploitation, violence and abuse;
- the right to protection of property; and
- the right to liberty of movement as fear of disability hate crime leads people to curtail their movements.

While members of the public are obviously not bound by human rights instruments to uphold these rights, we believe that the state has a clear obligation to tackle disability hate crime.

3.1.2 The Association of Chief Police Officers (ACPO) defines a disablist incident as:

*Any incident which is perceived to be based upon prejudice towards and hatred of the victim because of their disability or so perceived by the victim or any other person.*²

A disability hate crime is any disablist incident that constitutes a criminal offence.

3.1.3 Section 146 of the Criminal Justice Act 2003 has imposed, since April 2005, a duty upon courts to increase the sentence for any offence aggravated by hostility based on the victim's actual or perceived disability. For s 146 to apply the offender has to have demonstrated hostility towards the victim based on their (actual or perceived) disability. Alternatively, the motivation of the offence has to be wholly or partly hostility towards the victim based on their (actual or perceived) disability.

3.2 Prevalence and effects

3.2.1 While it is hard to identify exactly how much disability hate crime affects adults with learning disabilities, it is clear from the limited information that is available that disability hate crime is a significant problem.

3.2.2 A Disability Rights Commission and Capability Scotland survey found that nearly half of respondents (47%) had experienced being frightened or attacked because of their disability. One in five respondents suffered an attack at least once a week. This survey found that there was a greater predominance of attacks against people with learning disabilities. Of those who were made to feel frightened or were attacked, 35% were physically assaulted, 15% were spat at and 18% had something stolen.³

3.2.3 The Disability Rights Commission's Attitudes and Awareness Survey (2003) found that 22% of disabled respondents had experienced harassment in public because of their disability.

3.2.4 Research by Mencap found that nearly nine out of 10 people with a learning disability (88%) reported being bullied within the last year. Two-thirds (66%) of respondents said that they had been bullied more than once a month and 32% said that the bullying was taking place on a daily or weekly basis. Although the definition of bullying in this study includes disablist incidents that did not involve a criminal offence (for instance, name-calling) many of these incidents were disability hate crimes. For instance, almost a quarter of respondents (23%) reported physical assault.⁴

3.2.5.1 Disability hate crime affects adults with learning disabilities going about their daily lives and being a victim of such crime has a great impact on adults with learning disabilities ability to enjoy their human rights.

3.2.5.2 Mencap's research found that nearly three-quarters of people with a learning disability (73%) had been bullied in a public place.⁵ The Disability Rights Commission and Capability Scotland research found that 55% of respondents with disabilities had been made to feel frightened or had been attacked in the street, a park or when out walking.⁶ The first national survey of people with learning disabilities in England found that 32% of people with learning disabilities did not feel safe in their homes, their local area or using public transport.⁷ Mencap's report stated:

*"Again and again, people reported attempting to go about a daily activity and being attacked verbally, threatened or physically assaulted for no apparent reason. People are left fearful to do simple things such as walk down the street or go to the shops."*⁸

3.2.5.3 Three-quarters of respondents to the Disability Rights Commission and Capability Scotland research had made significant changes to their lives to avoid being frightened or attacked, with 47% avoiding certain places and 25% changing where they lived.⁹ Mencap's survey found that:

*"People often stated that their response to the bullying was either to move house or try and address the problem themselves rather than ask for outside assistance, due to the fear of retaliation."*¹⁰

3.2.5.4 The regular nature of such discrimination and human rights violations leads many adults with learning disabilities to see disability hate crime as just a normal part of their everyday lives. This was a view endorsed by the RAG, while Mencap's survey found that:

*"People reported that they had had to cope with bullying for so long that they saw it as a distressing, but inevitable part of everyday life for a person with a learning disability."*¹¹

3.2.6 We believe that it is an indictment of our society that adults with learning disabilities view the abuse of their human rights in this way as normal and something which they just have to cope with.

3.3 Responses of criminal justice agencies to disability hate crime

3.3.1.1 Criminal justice agencies have made some good attempts to address this serious problem.

3.3.1.2 In 2005, ACPO and the Home Office Police Standards Unit updated its tactical manual on hate crime to include disability hate crime. This comprehensive document includes a recommendation that every force establish a specialist hate crime investigation unit.¹² Hertfordshire Constabulary, for instance, has specialist hate crime officers in Community Safety Units around the county. It has also worked as part of People in Partnership¹³ to produce a pack¹⁴ to help people with learning disabilities to report crimes that affect them and to understand their rights. A similar booklet has been produced by the Open Out scheme in Cambridgeshire. This scheme involves Cambridge City, South Cambridgeshire and East Cambridgeshire councils, in conjunction with Cambridgeshire Police. We welcome these practical initiatives and such dedicated local action involving people with learning disabilities.

3.3.1.3 Earlier this year the Crown Prosecution Service produced a Policy on Prosecuting Cases of Disability Hate Crime which had the input of disability charities, including ourselves.

3.3.2.1 However, despite such good work, we are concerned that the response of many individual police officers and police forces may be far from adequate. In particular, we are concerned that the police's response to a disability hate crime against an adult with learning disabilities varies depending on the police force area where the crime was committed. For instance, the Metropolitan Police are to be commended for Community Safety Units in every London Borough spearheading efforts to tackle hate crime. However, there is no mention on the Metropolitan Police's otherwise excellent web pages on hate crime of disability hate crime.

3.3.2.2 The experiences of some of those adults with learning disabilities who have reported disability hate crime to the police raises questions about the response of frontline officers. The Disability Rights Commission and Capability Scotland survey found that nearly one in five of those who reported the incident to the police said that the police did nothing as a result.¹⁵ Mencap's survey found that:

*"People repeatedly stated that if they did report matters to the police, the police's response was often offhand or dismissive. People felt that this was due to their disabilities."*¹⁶

This was also the experience of the RAG, who stated that the police simply did not come around to see them if they reported a crime.

3.3.2.3 We are also concerned that disability hate crimes may not be being identified as such by police forces and that this may result in s 146 not being used. The following case, reported in the local press, has been one of several that have given rise to our concern.

— *"Police are searching for two thugs who attacked a man with learning difficulties in what officers describe as a 'cowardly and unprovoked' assault.*

The victim's family have offered a reward for information that leads to conviction of the attackers, saying their relative is now fearful of going out.

The incident happened as the man, one half of a couple who both have learning difficulties, got off the 6.1 bus from Wirksworth at Matlock Bus Station at 4:25 pm on Saturday, intending to take a taxi home.

Two men approached the couple from behind before one of them punched the victim in the face, causing a nasty injury.

*Police have so far been unable to establish a motive."*¹⁷

We believe the likely motive for this assault was hatred of people with learning disabilities and question why it appears that the police have seemingly not identified this as a disability hate crime.

Another case reported in local media gives all the indications of being a disability hate crime.

— *"In June last year Rikki Judkins, a vulnerable man with learning difficulties and psychological problems, was stranded at Lancaster bus station.*

Just hours later he was dead—kicked to death and bludgeoned with a stone weighing 11kg.

His killers had no motive and showed no remorse.

They even bragged about the horrific act to friends and casually bought food with the money they had stolen from Rikki's body.

Last Friday Simon Unsworth, 21 this week, was sentenced to life imprisonment and must serve at least 18 years before he is considered for parole.

*Arron Singh, 16, was detained at Her Majesty's Pleasure and must serve at least 15 years in prison."*¹⁸

We congratulate the police and CPS on this successful prosecution. However, there is no indication that this was treated as a disability hate crime. As s 146 places a duty on the court to openly state when it has been applied, we presume disability hate crime would have been mentioned in media reports if s 146 had been used.

3.3.3.1 Despite this requirement in s 146, disability hate crime has virtually no public profile. A search for the exact phrase "disability hate crime" in the news section of Google UK yields only one result—a mention of the launch of the CPS policy in the Mid Devon Star. While you regularly hear police officers use the phrase "we are treating this as a race hate crime" we are not aware of one instance of police officers using a similar phrase about a hate crime against a person with a disability. In the wider public's consciousness, disability hate crime does not exist. We fear that this is a reflection of the priority afforded to it and the level of effort applied to tackling it.

3.3.3.2 This has consequences for the human rights of adults with learning disabilities. S 146 and efforts to tackle disability hate crime can have a declaratory value. They can let society know that disability hate crime is unacceptable and that justice will be served on those who commit such crimes. This discourages these crimes as well as reassuring adults with learning disabilities that their rights will be upheld and that reporting hate crime will be worthwhile. This declaratory value will not be achieved without very public action to raise the profile of, and to tackle, disability hate crime.

3.4 Recommendations on disability hate crime

3.4.1 Disability hate crime occurs because of prejudice in society and tackling such crime requires a change in societal attitudes. Robust action with a high public profile can confront prejudice against adults with learning disabilities and begin to make it widely unacceptable.

3.4.2 We recommend that a minister within the Home Office is given responsibility for preventing and combating disability hate crime. Although the new Commission for Equality and Human Rights will have a duty to eliminate hatred of people with disabilities¹⁹ and may be involved with reducing crime affecting people with disabilities,²⁰ we believe that a ministerial lead is additionally required to coordinate and ensure effective action by criminal justice agencies. The primacy of the police in the identification and initial response to hate crime means that we believe this responsibility would rest most appropriately in the Home Office. Tackling disability hate crime is less about policies, it is about implementation on the ground. To ensure effective implementation, we need a strong lead at the top with the ability to push change forward.

3.4.3 We recommend that a national public information campaign be run by this minister with the direct aim of combating the prejudices that lead to disability hate crime and to increase public awareness of disability hate crime. The Disability Rights Commission's excellent cinema ad *Nice Day* highlights the daily abuse endured by adults with learning disabilities and provides a model of good practice for future public awareness campaigns in this area. Educating criminal justice professionals is as much a part of this as educating the public and we recommend that there be requirements for training on disability hate crime. The Home Office Police Standards Unit and ACPO tactical manual already suggests such training is good practice²¹ and the CPS is committed to working with criminal justice agencies to improve understanding of disability hate crime.²² These are good steps, but action needs to be taken ensure that such training actually happens for very busy professionals.

3.4.4 To ensure that progress in tackling disability hate crime is accurately monitored, we recommend that police forces and the Crown Prosecution Service be required to collect data on the disability hate crime cases which are reported and the prosecutions which are taken and that this information is published both nationally and locally.

3.4.5 Adults with learning disabilities should receive information and education from police forces on the nature of disability hate crime and how to report these crimes.

4. RIGHT TO LIFE

ECHR, Article 2—Right to life

UN Convention, Article 10—Right to life

4.1 The infringement of the right to life of adults with learning disabilities can be classified as either death through neglect or as murder. We have touched on murder in our comments on disability hate crime, but unfortunately we are unaware of information specifically on the number of adults with learning disabilities who are murdered each year. Similarly, we are not aware of statistics on the number adults with learning disabilities dying as a result of neglect, yet such cases have been fairly regularly documented. While the state does not murder adults with learning disabilities, it has a duty to prevent and investigate such murders. Unfortunately, there is every indication that public bodies have been involved in deaths by neglect of adults with learning disabilities and could do more to prevent such deaths and hold to account those responsible.

4.2.1 There are several factors that increase the risk of adults with learning disabilities dying because of neglectful care or treatment. The Disability Rights Commission's formal investigation *Equal Treatment: Closing the Gap* noted that:

*“ . . . people with learning disabilities . . . are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease . . . ”*²³

These health problems give adults with learning disabilities more reason to require health treatment, so increasing their risk of coming to harm via neglect in healthcare settings. In addition, research by the National Patient Safety Agency has found that:

*“ . . . people with learning disabilities are more at risk of being involved in a patient safety incident than the general population. The breadth of information received has suggested that the diverse needs of people with learning disabilities, the range of different agencies involved in care and the long term nature of the relationship with the NHS may make them more vulnerable. ”*²⁴

4.2.2 Contributing to the risk of death through neglect is the tendency of healthcare professionals to miss or misdiagnose health problems due to diagnostic overshadowing and the consequent failure to provide appropriate medical care. The Disability Rights Commission found that many people who took part in a consultation referred to problems in communication with healthcare staff:

“This could be a failure by staff to listen or understand and a tendency to attribute health problems to a person's learning disability . . . This tendency, known as “diagnostic overshadowing” . . . people with learning disabilities and their families also reported that when they told health professionals

*about changes in their physical well-being, they were sometimes explained as behavioural but turned out to be caused by pain or a significant physical illness. Some staff do not speak directly to the person making the consultation, make no attempt to use alternative ways of communicating where communication is difficult, and do not check if their understanding of symptoms is correct.*²⁵

The National Patient Safety Agency has found that, in relation to people with learning disabilities:

*“Access to treatment is often delayed because symptoms are not diagnosed early enough or in some cases, at all . . . Mis-diagnosis cuts across all care settings in the NHS . . .”*²⁶

Diagnostic overshadowing is the result of ignorance and prejudice amongst healthcare staff, compounded by a failure to discover and act upon the needs of people with learning disabilities.

4.2.3 Mencap has argued that this prejudice goes as far as institutional discrimination against adults with learning disabilities in the NHS.

*“ . . . institutional discrimination results when organisations fail to make changes in the way they deliver services to take into account people’s differing needs. Nor does the organisation deal with ignorance and prejudice within the workforce and culture of the organisation. We believe that there is a fundamental lack of understanding and respect towards people with a learning disability and their families and carers. This lack of understanding and respect leads to—and is demonstrated by—the poor design of systems, policies and procedures to meet the particular and differing needs of patients with a learning disability.”*²⁷

It is Mencap’s contention that this institutional discrimination leads to neglect and so to premature death. Mencap’s report *Death by Indifference* highlights six cases in which adults with learning disabilities have died through neglect in this way²⁸. We are aware of similar cases through our helplines, for instance;

— *Valerie was initially sent home from hospital despite a prolapsed bowel and a severe fall which, it was later discovered, had broken her pelvis. Although Valerie complained to the hospital of pain and discomfort, she was not taken seriously.*

Valerie was admitted to hospital, where her sister, Katherine, regularly visited her. After a day away from the hospital the staff said to Katherine that Valerie had been up, talking and eating. However, a neighbouring patient heard this and explained to Katherine that Valerie had been dozing in and out of sleep all day and hadn’t eaten or said anything.

The hospital staff refused to take Katherine seriously when she explained how ill Valerie was. They did not believe that Valerie was usually a gregarious woman who was full of life, but assumed that her current state was due to her learning disability. Katherine’s request for Valerie to see a Doctor was ignored and Katherine began to make complaints. Later that day, Valerie died. The staff stated that they were surprised that Valerie had died because they “didn’t think she was that ill”. Katherine was told by staff that they did not know what to write on the death certificate as they were unaware what was wrong with Valerie.

The National Patient Safety Agency cites another case:

— *“One nurse told us about a man she had cared for; he had been frequently referred to the hospital for investigations into bladder and bowel problems but she felt that he hadn’t been listened to because of his disability. The cause of his symptoms were never diagnosed and as a result the man died of kidney and heart failure. The nurse said: ‘This could have been prevented if a clear diagnosis had been made earlier to allow for prompt treatment. Instead, this man suffered. He shouldn’t have died.’”*²⁹

4.3.1 We would like to state our deep concern about deaths through neglect of adults with learning disabilities and commend to you the recommendations contained within Mencap’s *Death by Indifference* report and the Disability Rights Commission’s *Equal Treatment: Closing the Gap* report. We also very much welcome the Department of Health and Healthcare Commission examination of the cases highlighted in Mencap’s report.

4.3.2 However, the recent debate launched by these reports has focused on the wider implications and lessons from individual deaths. While we support this approach, we would like to draw the Joint Committee’s attention to an equally important aspect of this issue—justice in individual cases.

4.4 Recommendations on the Right to Life

4.4.1 Our organisations believe that those individual healthcare professionals whose negligent behaviour has caused the death of anyone with learning disabilities should be held accountable and liable for their actions. To this end, we ask the Joint Committee to urge the police to investigate such cases with a view to prosecuting healthcare professionals for manslaughter and healthcare organisations for corporate manslaughter. Action must also be taken by regulatory bodies such as the General Medical Council and Nursing and Midwifery Council against individual healthcare professionals where it can be shown they have failed in their professional duties. We ask the Joint Committee to urge these bodies to take such action.

4.4.2 We believe that criminal and regulatory action is essential for ensuring justice and for providing an incentive for healthcare organisations to uphold adults with learning disabilities right to life. We also believe that it will send the important message that the life of adults with learning disabilities has equal worth with the life of anyone else in society.

5. RIGHT TO LIBERTY AND SECURITY OF THE PERSON

ECHR, Article 5—Right to liberty and security of the person

UN Convention, Article 14—Liberty and security of the person

ECHR, Protocol 4, Article 2—Freedom of movement

UN Convention, Article 18—Liberty of movement and nationality

5.1 Our organisations are worried that adults with learning disabilities are being deprived of their liberty without the protection of law required by the ECHR and the UN Convention. Quantifying the scale of this problem is hard, but the cases which have been brought to light, and our own experiences, lead us to fear that it is too widespread. Motivations for depriving adults with learning disabilities of their rights to liberty and movement have included ignorance, outdated attitudes and a focus on the needs of the carer rather than the individual. However, we do not consider that ignorance of the law and good practice excuses or lessens such violations of human rights.

5.2.1 Investigations have uncovered examples of adults with learning disabilities being effectively locked up in a way that is clearly detrimental to their human rights and without recourse to the legal safeguards that exist (eg Mental Health Act 1983).

5.2.2 In 2003, the Commission for Health Improvement (CHI) was disturbed to find in its investigation of Bedfordshire and Luton Community NHS Trust that:

“All bedrooms are kept locked so that clients cannot use them in the day. Staff hold the keys. Patio doors and windows are chained. The purpose is to contain one person with particularly complex needs who was assessed by the JCS two years ago . . .

CHI found examples in other homes where clients have complex needs and where bedrooms are locked . . . There did not appear to be clear criteria for when a client’s bedroom should be locked or when clients should hold their own keys if their room is locked during the day. This needs to be resolved so that the human rights of people with learning disabilities are not infringed.”³⁰

5.2.3 The joint inquiry into Cornwall Partnership NHS Trust conducted by the Healthcare Commission and the Commission for Social Care Inspection found that:

“In the majority of supported living houses, staff, rather than residents, held the keys. Most bedrooms could not be locked. The only doors that could be locked were controlled by staff and used to restrict the movement of those living in the houses. In some of the houses, external doors and some internal doors were kept locked. This prevented people from freely entering and leaving and often restricted their access to communal areas, which they had a right to enter as tenants. Stable-type doors were also widely used to restrict movement . . . Staff seemed unaware that it was unlawful to detain people against their will.”³¹

This ignorance of the law was also reflected at Budock Hospital:

“At the time of our visits, only one person was detained at Budock Hospital under the Mental Health Act 1983. Despite this, all external doors and a number of internal doors in the hospital were locked.”³²

5.2.4 The Healthcare Commission investigation team into Sutton and Merton Primary Care Trust found that:

“. . . some people could not go into their bedrooms when they wanted because the doors were kept locked to keep other people out.

The front door to one of these houses had a handle that was so high up that many people could not reach it and this ensured that people did not leave without a member of staff to accompany them. The front door to another house had a small button type handle that had to be twisted, which was difficult for some people to use. There was also an alarm, alerting staff when a person was trying to leave without a member of staff. There was a view that some people were detained inappropriately as they lacked the capacity to consent to their own treatment. Some staff and advocates believed that people should have been assessed to see whether their rights would be best met if the Mental Health Act 1983 was considered and applied if necessary.

. . . When people are restrained on a regular basis in a hospital setting they should be assessed to see if their rights and treatment needs could best be met through the use of the Mental Health Act 1983. None of the people who lived in these houses had participated in such as assessment and no one was actually detained under the Act.”³³

5.2.5 We are concerned that most staff in these settings were seemingly unaware of the legal safeguards and that assessments under the Mental Health Act 1983 were not sought. There is a serious question over the legality of the way in which adults with learning disabilities were detained.

5.3 What particularly concerns us about these cases is the blanket way that measures to limit movement and restrict liberty were applied to all adults with learning disabilities. If unusual door handles, alarms and stable doors had only been provided for particular individuals, we might believe that these were responses to the particular needs of the individual. Instead, the application of such measures to everyone, and in the design of whole buildings, implies that the purpose was to enable staff to exercise control. It also implies that the carers and managers in these settings did not recognise adults with learning disabilities as having rights to liberty and movement equal to their own.

5.4 The similarities between these cases cause us to fear that cases of the infringement of adults with learning disabilities rights to liberty and movement may be widespread.

5.5 *Recommendations on the Right to Liberty and Security of the Person*

5.5.1 Our organisations believe that the focus must be on the individual and their needs if adults with learning disabilities rights to liberty and movement are to be respected. The emphasis must be on identifying and maximising opportunities for people to go outside care settings, particularly if staff find their behaviour challenging. This may require imagination and is certainly resource intensive. This approach needs to be integrated into care plans, risk assessments, training and the culture of organisations. It also involves applying means which limit the liberty of adults with learning disabilities only to those specific people for which it is required and not by default to everyone living with them. Again, this is resource intensive.

5.5.2 The alternative is to apply the Mental Health Act 1983 in far more cases. There appear to be individuals for whom an assessment under the Act should have occurred and we support applying the legal safeguards in those cases. However, sectioning removes adults with learning disabilities from the community and this will not be in the best interests of many people. It is also difficult to identify during these assessments what behaviour is caused by mental health needs, what by learned behaviour and what by learning disability. We therefore caution against applying an all or little approach to applying the Act, emphasising the importance of conducting assessments when to not do so may unlawfully deprive someone of their liberty.

6. FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE

ECHR, Article 3—Prohibition of torture

ECHR, Protocol 1, Article 1—Protection of property

UN Convention, Article 15—Freedom from torture or cruel, inhuman or degrading treatment or punishment

UN Convention, Article 16—Freedom from exploitation, violence and abuse

UN Convention, Article 17—Protecting the integrity of the person

6.1 *Rape and Sexual Assault*

6.1.1 As the Cross Government Action Plan on Sexual Violence and Abuse, notes—

“People with a limiting illness or disability are more likely than those without one to be sexually assaulted.”³⁴

This Action Plan neatly summarises how this situation impacts on adults with learning disabilities.

“2.25. Research by Brown, Stein and Turk (1995) found that there are 1,250 cases of reported sexual abuse against adults with a learning disability annually in England and Wales. This is a conservative estimate given the likelihood of under-reporting . . . People with a physical or learning disability may be targeted by sex offenders because they are vulnerable. Those with a learning disability may also be targeted because offenders think they won’t be believed or make credible witnesses in court. Where the perpetrator is a care worker or in a position of authority, it may be difficult for a learning disabled victim to understand that what has happened to them constitutes a crime, and they may not wish to report the crime to the police, or be a witness if the case comes to court.

2.26. Research from the early to mid nineties showed that the experience of sexual abuse by people with a learning disability affects future relationships and general well being and is a cause of depression, self-harming, eating disorders, soiling and challenging behaviours.”³⁵

As with the general population, these sexual assaults are often perpetrated by someone known to the victim.

6.2 Crime and Abuse in Care

6.2.1 It is a distressing fact that sexual assaults and rapes occur within care settings. The Healthcare Commission's report on Sutton and Merton Primary Care Trust reported one such case of rape and several allegations of sexual assault.³⁶ In sentencing Peter John Clark to six years imprisonment for this rape, His Honour Judge Binning stated:

*"It is difficult to think of a case that would involve a greater betrayal of trust. There you were employed to look after this woman in her 40s with a mental age of two to three. You were employed to look after her and abused her in a way that betrayed the trust placed in you to an appalling extent, and, what is more, apparently in the knowledge that she had already been the victim of sexual abuse. So, as I say, it is difficult to imagine a greater betrayal."*³⁷

6.2.2 The targeting of someone perceived to be vulnerable and less likely to complain is a theme in this and other cases.

- *Lauren has mild to moderate learning disabilities and, at the time of the abuse, she was 24 years old. She lived independently, with carers supporting her with her daily needs. The carers would only be there one at a time.*

Lauren had a male carer, Adam, who acted as her main carer and would always be there. Adam would even stay the night in the spare room if Lauren felt she needed extra support. He organised all his shifts around Lauren's needs. As Adam hardly ever took time off, Lauren never saw the female carers and her relationship with them deteriorated. Adam told her that she didn't need anyone else as she had him. He began to call himself her boyfriend and, although Lauren knew that this was wrong, she did not know what to do. Consequently, Lauren went along with it—she hated the sex, but liked Adam being nice to her. However, Adam began to become more controlling and started to get jealous when Lauren went to college. Lauren soon became pregnant. She has since had the child and Adam is currently being prosecuted.

6.2.3.1 Pregnancy or some other irrefutable physical evidence of sex (such as the used condom discovered by a colleague of Peter John Clark) is in far too many cases what brings rape to light. This represents an unacceptable failure in prevention and in establishing means to detect sexual violence at an early stage.

6.2.3.2 Our experience leads us to believe that many cases of crime and abuse perpetrated by carers against adults with learning disabilities do not come to light and / or are not reported to the police. This is a major reason why it is so difficult to determine the extent of abuse against adults with learning disabilities within care settings.

6.2.4 The *No Secrets* guidance on adult protection does require social services departments to collect information on the adult protection referrals made to them as lead agency on these matters. However, this information is not collected centrally. Following a study of adult protection referrals by Action on Elder Abuse, the NHS Information Centre for Health and Social Care is currently examining how this data could be collected nationally while the Government has committed itself to improving the collection of this information.

6.2.5 Action on Elder Abuse's study found that 25.4% of adult protection referrals to social services involved crime or abuse against adults with learning disabilities. This crime or abuse occurred in a residential home in 29.4% of referrals. The perpetrator was either an institution or a care worker in 28.4% of cases.³⁸ However, these figures should be seen as conservative because of the likelihood of under-reporting.

6.2.6 A common finding of the reports into Cornwall Partnership NHS Trust and Sutton and Merton Primary Care Trust was the lack of awareness and knowledge amongst staff and how this led to their failure to recognise their and their colleagues' practice as abusive.³⁹

*"Staff were largely unaware of their duties with regard to the protection of adults less able to look after themselves."*⁴⁰

*"Although many staff believed that they were not using restraint, our observations and records demonstrated otherwise. Restraint was used inappropriately at times when it should have been used as a last resort . . . One woman had experienced a form of restraint for many years, where a splint on her arm was used to prevent movement in order to stop her putting her hand into her mouth. The psychology department did not believe that the continued use of this restrictive intervention was justified."*⁴¹

*" . . . in August 2005, G, who is deaf, blind, cannot speak and uses a wheelchair, was found strapped to his wheelchair for up to 16 hours during the day and to his bed at night, to prevent him from hitting his head and face."*⁴²

The Healthcare Commission concluded that the institutional abuse that occurred at Sutton and Merton PCT was unintentional, but still abuse.

6.2.7 We accept that lack of knowledge, training, insight and awareness can account for some abusive, and criminal practice in care settings. However, there comes a point when common sense should limit carers' behaviour. We question how anyone can possibly not realise that tying a vulnerable adult to a chair is wrong. We can only conclude that this abusive behaviour is a reflection of both a lack of awareness and of a view prevalent in society that adults with learning disabilities are worth less than other people.

6.2.8 It is important to note that adults with learning disabilities may infringe the human rights of the other adults with learning disabilities who use the same care services as them, for instance, through assault. We have assisted family, carers and professionals in such cases.

6.3 Domestic Violence

6.3.1 Crime and abuse against adults with learning disabilities is also committed by carers (family and professional) in their own homes. Adults with disabilities are disproportionately more likely to experience domestic violence and this includes adults with learning disabilities. In 31.8% of all of the adult protection referrals examined in this Action on Elder Abuse study, the location of abuse was the vulnerable adult's own home.⁴³ Home Office analysis of the BCS has found that having a "limiting illness or disability" is associated with all types of intimate violence for both men and women. It is strongly associated with non-sexual abuse by family members, with women with a limiting disability or illness three times more likely to experience this sort of abuse than women without a disability. It was also found that a limiting disability or illness greatly increases a man's chance of being stalked.⁴⁴ An earlier Home Office study found that over one in ten young men with a long standing illness or disability had been assaulted by a partner in the previous year.⁴⁵

6.3.2 Domestic violence is notoriously under-reported and the BCS is able to produce figures because it contains a self-completion section, the answers to which the interviewer is not able to see. This makes the BCS potentially the best means of measuring the level of domestic violence against adults with learning disabilities. However, for the reasons we described earlier, BCS figures above are not differentiated for adults with learning disabilities and are likely to be an under-estimate in issues relating to disability.

6.3.3.1 The violence involved in domestic violence against adults with learning disabilities can be appalling and the effects can last a long time.

- *Katie, who has cerebral palsy, was in an abusive relationship with a much older man without learning disabilities for seven years. Her partner raped her, physically assaulted her and frequently stole her benefits. This abuse occurred specifically because of Katie's learning and other disabilities and in a manner which we view as a hate crime. He called Katie a "spac", a "retard" who deserved to be abused, told her that she was useless and did not deserve any respect. Katie has been receiving assistance from the Respond helpline for the last six years, but is still trying to deal with the effects of this violence.*

6.3.3.2 The British Medical Association (BMA) has noted that:

*"Certain forms of abuse which may be specific to disabled people include the abuser withholding care or undertaking it neglectfully or abusively; the abuser may remove mobility or sensory devices that are needed for independence; they may be claiming state benefits on behalf of the disabled individual thus making it easier for them to control the disabled person's finances; and using an impairment to taunt or degrade the individual. Disabled people are likely to experience abuse over a longer period of time and can suffer more severe injuries as a result of the violence."*⁴⁶

6.3.4 If an adult with learning disabilities is dependent on the person subjecting them to domestic violence for care and/or accommodation, then reporting domestic violence to the police or other agencies may leave them stranded. This barrier to reporting is exacerbated if the victim is socially isolated due to the control of the carer. Even if support could be found, the fear of being left without a carer or home will discourage some adults with learning disabilities from coming forward. While domestic violence services may be able to, and do, assist adults with learning disabilities, we are concerned that many will lack the specialist provision that this vulnerable group requires if their needs are to be truly met.

6.3.5 A possible example of good practice in this area is Beverley Lewis House, run by East Living Housing Association and set up by the Powerhouse campaign group. Beverley Lewis House provides safe accommodation for women with learning disabilities for up to two years. Staff work with tenants to develop the skills needed to overcome abuse and move towards an independent life. Each woman is allocated a key worker who provides support with accessing support services, employment opportunities and social contacts as well as counselling and advocacy services. Beverley Lewis House currently receives 20–25 referrals a month and we have been told that this is more than they can deal with. However, Beverley Lewis House have told us that local authorities lack the funding to refer many other individuals. Women with children are also not taken because of the cost involved and because Beverley Lewis House is not physically built to accommodate families—this is an issue Beverley Lewis House plans to address.

6.3.6 We are also aware of cases where an adult with a learning disability has subjected another adult with a learning disability to domestic violence.

6.4 The case of Kevin Davies

6.4.1 We would like to draw the Joint Committee's attention to a particularly severe case of crime perpetrated against an adult with learning disabilities—that of Kevin Davies.

- *"For four desperate months, Kevin Davies was locked in a garden shed where he was beaten, burned and given potato peelings to eat. The vulnerable 29-year-old, who had epilepsy and learning difficulties, was let out only to act as a household slave for his captors. They even recorded a video*

similar to those used by terrorist kidnappers in which an emaciated Mr Davies was forced to praise his three jailers for looking after him. His family were unaware of his suffering because he called his mother to say he was keeping well.

Finally, the starving prisoner collapsed dying on his tormentors' kitchen floor and police discovered a diary kept by one of them which outlined the appalling way he had been treated. But the three escaped a murder charge because it could not be proved that Mr Davies's epilepsy did not contribute to his death. They were sentenced at Bristol Crown Court yesterday for false imprisonment and assault.

David Lehane, 36, and his 26-year-old girlfriend Amanda Baggus were each given ten years while their friend Scott Andrews, 28, was given a nine-year term. Mr Davies's mother said they had got away with murder.

The court heard that before the abuse began, Mr Davies had been a long-time friend of landscape gardener Lehane, and helped him with odd jobs. But Baggus decided that Mr Davies should be punished after she blamed him for crashing her three-wheeled Reliant Robin in May last year. She and Lehane locked Mr Davies in the shed outside their home in Bream, in the Forest of Dean, Gloucestershire, and started cashing his benefit cheques every week to pay for the damage. Soon he was being beaten daily—sometimes with a thick wooden bar—leaving the ceiling, walls and furniture of their home stained with his blood. Their friend Andrews moved into the house and joined in with the horrific abuse.

Police were alerted after Mr Davies died because he was malnourished and had serious wounds which included burns caused by a hot knife.⁴⁷

6.5 Theft

6.5.1 Theft from adults with learning disabilities is not uncommon. It often arises because many adults with learning disabilities need to have their personal assistants or carers assist them in the management of their financial affairs and this trust is violated. The following case studies give a flavour of the forms this theft can take.

- *“Dawn Osbourne, 37, systematically stole cash from the bank account of 67-year-old Michael Blackburn who had learning difficulties and was unable to manage his own financial affairs, Norwich Crown Court heard. Osbourne had the pin number of his bank account so she could draw money to buy his shopping, but instead she siphoned £5,674 from his account over a period of months, the court was told.*

The offences came to light when Mr Blackburn himself realised something was wrong and Osbourne was arrested. . . . Jailing her, Recorder Richard Wood said Mr Blackburn was a vulnerable individual. . . . “You required him to come to court and give evidence through a video link to prove to the jury what you did. His particular learning difficulty was self-evident to everyone and you, through your counsel, sought to use his disadvantage to cast doubt on the wrong you had done. . . . He jailed her for 40 weeks and ordered her to pay back the £5,674, which she had saved up to pay back the stolen cash. She was also ordered to pay £2,000 towards prosecution costs.”⁴⁸

- *“A care home owner is facing a jail term after being convicted of stealing money from residents with learning disabilities.*

Leicester Crown Court heard that Caroline Jane Rice kept part of the money she withdrew from bank accounts on behalf of her residents, and covered up her theft by false accounting. The offences took place at Dove House in Kirby Muxloe, Leicestershire, which she ran. Rice, of Cossington Lane, Rothley Leicestershire, who has two other residential homes in the county, denied the charges, saying she had ‘no need’ to take the money. But she was convicted of three counts of theft totalling £500, and eight offences of false accounting to conceal thefts, totalling £745.⁴⁹

- *A home help was employed from an independent agency to support Mavis, an elderly woman with learning disabilities. The home help discovered that Mavis had received a large inheritance. Over the following months she started to talk to Mavis about how hard things were for her financially and Mavis felt moved to help her. The home help offered to drive Mavis to the bank in order for her to take money out of her account. She removed the maximum allowed each week for many weeks until all of the money had been removed.*

This theft only came to light when Mavis embarrassedly approached a friend and confided in her. The friend contacted Social Services immediately and they then contacted the agency who supplied the home help, who then sacked her. Initially neither Social Services nor the agency admitted any responsibility, but did ask Mavis if she wanted to go to the police. Mavis said no, as she felt ashamed of what she had done. It was only when the friend intervened and demanded the return of the money and an apology that the agency offered to return half of the total that was taken. Mavis accepted this.

It also emerged that the home help had only been sacked and not been referred to the Protection of Vulnerable Adults (POVA) list. After some more complaining by Mavis's friend, a referral to the POVA list was made.

6.6. Provision of Therapy for Victims of Crime and Abuse

6.6.1 Those adults with learning disabilities who have experienced abuse or crime are usually traumatised by the experience and that can lead to serious mental health problems. They are likely to have trouble communicating and expressing what they have been through and this can lead to behaviour which others find challenging. When the abuse or crime that they have experienced has not been witnessed by their carers, this challenging behaviour can be incorrectly identified as a symptom of their learning disabilities or as a general deterioration in their behaviour. Attempts are then sometimes made to control their behaviour with restraint or medication. Therapy is an effective means of helping adults with learning disabilities who have experienced crime or abuse to understand what has happened, to move on and to lead fuller lives.

6.6.2 In the past, it was thought that such therapy was a "talking cure", and that people with impaired cognitive functioning and difficulties with communicating verbally could not benefit from such an approach. The work of Respond and other therapists working with people with learning disabilities has proved that this assumption was fundamentally ill founded.

- *A 20-year-old with mild learning disabilities called Gavin had been sexually assaulted by a neighbour on a number of occasions. Gavin lived in a residential home for people with learning disabilities and was actively involved in the local community, taking part in amateur dramatics and attending his local church. A local man who attended the amateur dramatics group and the church struck up a friendship with Gavin and Gavin started to visit the man's home. He would regularly wash the man's car, in return for sweets, money and games for his Play Station. As their friendship developed the staff at Gavin's home felt more and more confident that this was a healthy relationship and that Gavin was happy.*

After a church meeting one Saturday afternoon Gavin did not return to his home at the expected time. Gavin had gone back to the man's home, been held captive all night and had been forced to perform sexual acts and to watch pornography involving children. He had also been threatened with rape if he ever told anyone about what had happened. Gavin was very scared about what would happen next and needed a lot of reassurance before he agreed to be interviewed by the police. Fortunately a very experienced Sexual Offences Investigation Trained (SOIT) officer was assigned to Gavin and he was able to give a detailed account of the offences.

After the man's arrest Gavin was supported by an advocate to attend the subsequent trial and, unusually in similar cases, the man who assaulted him was convicted.

Gavin was referred to Respond for psychotherapy and, after a professionals meeting and an assessment session, he started in treatment. The early stages of the treatment were difficult for Gavin as he had never had therapy before and he found it scary to be alone in a room with a man again. However, as time went on Gavin was able to trust his therapist. He began to use the time to explore the abuse, as well as other issues from his childhood that he had never had the opportunity to address.

Towards the end of what became a three-year treatment, Gavin was able to concentrate on what it was like for him to have a learning disability in both his family and community. This made him feel sad and the fear of ending the treatment at this crucial time was an important area to discuss. Eventually Gavin felt able to move on and to see that the abuse he experienced was not his fault. He continues to have "bad days" when he thinks about what happened to him but he is able to ask for support and to talk about how he is feeling.

For Gavin the opportunity to attend an appropriate service that understands the often complex needs of people with learning disabilities who are the victims of sexual violence was an essential part of his recovery.

6.6.3 Unfortunately, Respond is a rare example of therapeutic services for adults with learning disabilities who have been abused. Many adults with learning disabilities who have experienced human rights abuses simply receive no help. This is partly a matter of funding, as for therapy to be effective it is necessary to have a commitment of between one to three years. It is also partly a matter of attitudes amongst professionals, who do not see the value of providing a form of assistance which is more readily available to people without learning disabilities.

6.6.4.1 A further issue is the denial of therapy to adults with learning disabilities pending the outcome of a criminal trial for fear that their evidence may be tainted and the prosecution lost. Such a denial of therapy can conflict with the need to ensure that adults with learning disabilities are able to receive, as soon as possible, effective treatment to assist their recovery.

6.6.4.2 This issue is dealt with in the Government's Provision of Therapy for Vulnerable or Intimidated Witnesses Prior to a Criminal Trial; Practice Guidance. We participated in the review of this guidance and commend it for balancing the danger of contaminating evidence or coaching witnesses against the mental health needs of victims. However, we fear excessive caution on the part of Social Services and criminal justice professionals sometimes leads to therapy being denied unnecessarily. We believe that this practice guidance must be followed more closely and professionals should have more confidence in the provision of therapy for victims.

6.6.5 Adults with learning disabilities should receive therapy, according to their need, to help them overcome the human rights abuses they have experienced. It is possible that the provision of such therapy would in itself come under Articles 25 and 26 of the UN Convention.

6.7 Vetting and Barring

6.7.1 An effective scheme for vetting those who wish to work with vulnerable adults and barring those found to be unsuitable for such roles is vital to preventing crime and abuse against adults with learning disabilities. The POVA list and Disqualification from Working with Vulnerable Adults list are the current measures designed for this function. They are to be replaced in due course by a list administered by the Independent Safeguarding Authority and established under the Safeguarding Vulnerable Groups Act 2006. How exactly this Act will be implemented is still being determined and we will be making representations on this to ensure the scheme is effective.

6.7.2.1 During the passage of the Safeguarding Vulnerable Groups Bill we lobbied on two issues of particular concern.

6.7.2.2 The Safeguarding Vulnerable Groups Act will establish two lists—one of people barred from working with children and one of people barred from working with vulnerable adults. The rationale behind having two lists was that a person who acted inappropriately with one group might not act inappropriately with the other. The example given was of a carer who was barred because they stole from a vulnerable adult. It was argued that they should not be barred from working with children as children do not have access to money to the same extent as an adult. In our view, an individual who commits abuse or crime against a child has demonstrated a capacity for abuse or crime that could be applied to an adult, and vice versa. We will work to ensure that regulations and guidance ensure that inclusion on one list will lead to automatic referral to the other list.

6.7.2.3 Direct payments/individual budgets are an empowering measure for adults with learning disabilities. However, we believe that it is important that adults with learning disabilities as well as their families and their carers who hire personal assistants through direct payments check these potential employees against barred lists. Official guidance recommends that this is done, but this guidance is not always followed, particularly if the potential employee is a family friend or neighbour and people are too embarrassed to ask them for a Criminal Records Bureau check. Compelling direct payment recipients to carry out these checks risks lessening the empowering effect of direct payments, yet an adult with learning disabilities runs the risk of hiring someone who may abuse them if they do not. This is a difficult issue and we will attempt to ensure that it is suitably addressed.

6.8 Vulnerable Adult Protection Guidance

6.8.1 No Secrets is the existing official guidance for local agencies with responsibility for investigating and taking action when an adult with learning disabilities is believed to have suffered crime or abuse. It provides a structure and content for the development of local inter-agency policies and procedures. The aim of No Secrets is to ensure that health services, social services and the police are able to work together to prevent and tackle crime and abuse affecting vulnerable adults.

6.8.2 Since the introduction of No Secrets in 2000, the Association of Directors of Social Services led Safeguarding Adults network has produced Safeguarding Adults: A National Framework of Standards for Good Practice and Outcomes in Adult Protection Work. The aim of this document was to build upon No Secrets by incorporating best practice from around the country into a set of good practice standards. The Ann Craft Trust was involved in the steering group for both No Secrets and Safeguarding Adults, while VOICE UK was involved with Safeguarding Adults.

6.8.3 No Secrets was a notable achievement and marked a seminal turning point in the nature of adult protection. Yet, in the last seven years, we have witnessed terrible cases of crime and abuse in care settings, including the recent scandals in Cornwall and Sutton & Merton. While we are aware of multi-agency working operating effectively in some areas, we also regularly witness failures in investigations which deny victims justice, fail to learn lessons and leave perpetrators able to repeat their behaviour.

— *In April 2007, Jane James described to the VOICE UK All Party Parliamentary Group her family's experience of an investigation into the abuse experienced by her brother, John, whilst in a residential care setting managed by a social services department. The following are extracts from her speech.*

“John's carer, John's sisters and an employed carer at his place of residence noticed that personal items had gone from John's room . . . It was further noticed that John's money had dwindled rapidly and could not be accounted for by his own spending . . . John told several members of his family that another resident was coming into his bedroom, without John's permission and that this person was

taking his belongings and his money. He repeated these allegations . . . John's agitation and anxiety grew as he disclosed the abuse. He started to experience physical symptoms and was admitted to hospital. Whilst in hospital, he took a shower with the assistance of myself and my sister. He began re-enacting a violent sexual attack; gesticulating and using highly sexualised language. He appeared extremely distressed and traumatised and used the phrase "He keeps hurting me, he keeps making me cry!"

He named the service user as the perpetrator and was crying and weeping uncontrollably . . . The family formally reported the allegations of sexual and other abuse . . . Social Services said they would inform the police. However the social worker involved made prejudicial judgements about John's mental health which had no basis in medical terms despite the fact that John had been extremely lucid and well when he made them. This delayed any police investigation.

The social worker had no knowledge or understanding of John or of autism. She had met him only once previously for 20 minutes, she did not have the necessary experience or training to cope with John's communicative disorder.

The social worker did not seek out evidence or witness statements from John's carer, his family or day staff from the home, instead she called a professionals meeting with managerial staff from the care organisation. The police did not attend this meeting . . . The minutes from the professionals meeting, which were passed on to the family inspired no faith at all in the process. John's name was incorrectly spelt, the date was wrong and the notes were littered with inaccuracies, misinformation and subjective prejudicial comments the social worker trivialised the abuse by informing the police that one DVD and one football shirt had been taken from John . . .

The social workers spoke to the perpetrator, who then suddenly returned all the missing items saying he had found them. She then concluded that as the items had all been returned no theft had taken place.

No support was given to John from the vulnerable adults team and he was not adequately protected even after the allegations were made. The perpetrator was allowed to visit John in hospital. John was never offered counselling or therapy.

The perpetrator was formally interviewed by the police but only after persistent requests from the family. In his interview he admitted showering John . . . The police officer for vulnerable adults had no training in dealing with people with autistic spectrum disorder. She deemed John to be mentally unfit without having any sound basis for this . . . The senior police officer when discussing the issues around the case merely said "we don't do disability very well!" the police have not attended any of the subsequent multi-agency meetings.

John was only interviewed himself 10 months after the event. The meetings to conduct the interview were planned and then cancelled several times and there was a failure to provide autism specific trained staff to facilitate the interview.

The Strategic Director of Social Services informed the family that the CPS had received John's file and had concluded that there was not enough evidence on which to base a prosecution. Therefore the family was appalled to discover that the CPS never received any information about John's case."

- *A senior carer called the VOICE UK helpline with concerns related to the rape of a client, who has complex learning disabilities, by a person with mild learning disabilities. They both lived in the same residential home and it was here that the rape took place.*

The carer was confused and unsure about what she should do to support both the perpetrator and the victim. She had built up a close relationship with the perpetrator as she had been caring for him for the past few years and didn't want him to get into any serious trouble.

The carer explained that she did report the incident to her manager, who then reported the matter to social services. However, some time had passed and she was unaware of any clear action being taken to deal with this rape. She did not believe that the police had been made aware of the attack and being a main witness she was not interviewed by either the police or social services. She was also concerned as she was aware of other occasions when the same perpetrator had been found inappropriately touching the victim, but there were no noticeable measures put in place to prevent this occurring.

6.8.4.1 We are particularly concerned about the lack of police involvement in some cases where it appears a crime has occurred. In these cases assaults, sexual assaults and rapes are investigated internally by organisations. Only once these investigations are completed, weeks later, are decisions made on whether to involve the police. This approach seriously compromises criminal investigations and prosecutions.

6.8.4.2 *No Secrets* is reasonably clear in stating that it is "imperative that reference should be made to the police as a matter of urgency"⁵⁰ when a criminal offence may have been committed. However, this is undermined when it is stated that "some instances of abuse will constitute a criminal offence"⁵¹—the "some" implying that most abuse is not criminal. This is not our experience and we believe that it is imperative that it is presumed that abuse is a criminal offence until demonstrated otherwise by a police investigation. Statements such as this also allow to go unchallenged the unfortunately widespread perception that "abuse" and "crime" are distinct, with adults with learning disabilities only experiencing "abuse" in care and not crime. It is this mindset that is partly to blame for police not being informed immediately, or at all, of crimes

in care. In our General Points above we set out how we use the terms abuse and crime and we believe that the widespread adoption of this approach will assist in fostering a human rights culture amongst those working with adults with learning disabilities.

6.8.5 With *No Secrets* over seven years old, with new good practice and too much bad practice to learn from, our organisations feel that the time has come to review vulnerable adult protection guidance and to consider the need for legislation in this area. VOICE UK and Victim Support made this case when we recently met with Ivan Lewis MP, Parliamentary Under-Secretary of State for Care Services. All of our organisations are delighted that shortly after this the Minister announced a review of safeguarding vulnerable adults guidance. In order to ensure that cases of crime in care are properly investigated, we believe this review needs to involve criminal justice agencies and be co-chaired by ministers from the Department of Health, Home Office and Ministry of Justice. Although we have spoken to Mr Lewis on this point, we hope that the Joint Committee will make a similar recommendation to the Government.

6.8.6 As a point to note; the investigation of crime and abuse against adults with learning disabilities requires appropriate assistance to be provided to adults with learning disabilities to allow them to give their best evidence during investigations, interviews and in court. This assistance is not always provided and adults with learning disabilities are denied justice as a result. This is an issue which we examine later in this submission.

6.9 *Healthcare Commission Audit of Services for People with Learning Disabilities*

6.9.1 We are aware that the Healthcare Commission has submitted evidence to the Joint Committee on its national audit of services for people with learning disabilities. Our organisations would like to state our support for the objectives of this audit. It is important that the Government and care providers give serious consideration to the findings and recommendations of the audit when they are published in November.

6.10 *The Meaning of Public Authority in the Human Rights Act*

6.10.1 We are deeply concerned by the interpretation of “public authority” in the Human Rights Act with the effect that it excludes private and voluntary sector providers of care services. This denies those adults with learning disabilities who have experienced crime and abuse in care a means of receiving redress and of holding to account those private and voluntary sector providers who have contributed to the violation of their human rights. Crucially, it also removes an incentive to follow good practice and to effectively tackle abuse and crime. As is obvious from this submission, much of the crime and abuse experienced by adults with learning disabilities occurs in settings where the immediate responsibility for care rests with a private or voluntary sector organisation.

6.10.2 We support the intent of the Human Rights 1998 (Meaning of Public Authority) Bill and the Protection of Adults in Care (Prevention of Harm and Exploitation) Bill to correct this situation.

6.11 *Recommendations on Freedom from Exploitation, Violence and Abuse*

- Crime and abuse against adults with learning disabilities are often unreported as the victims are unaware that what has happened to them is wrong. Information and education for adults with learning disabilities can correct this and add to the fostering of a human rights culture.
- Adults with learning disabilities should receive information and education on their rights, on how to protect themselves and on self-advocacy. Sex education is a vital part of this as it enables adults with learning disabilities to identify abusive/criminal sexual activity, to say “no” to sexual activity they do not wish to engage in and to enjoy consensual sex lives. This should be provided or commissioned by Social Services departments.
- Care providers should supply information and education to adults with learning disabilities on what is abusive practice and on how to complain about it.
- Police forces should provide information and education for adults with learning disabilities on what is a crime and how to report crime to the police.
- In order to encourage care staff to raise concerns about abuse, the Government should use a public information campaign to counter negative attitudes towards whistleblowers and to inform the public of the protection of the Public Interest Disclosure Act 1998.
- That the review of vulnerable adult protection guidance be co-chaired by ministers from the Department of Health, Ministry of Justice and Home Office. In addition, that this review actively involves criminal justice agencies as well as stakeholders from local government and the voluntary sector.

- That the Government’s review of safeguarding vulnerable adult protection recommend that crimes suffered by vulnerable adults are referred to as crimes in official guidance, future legislation and local adult protection policies. That the term abuse is only used narrowly to refer to those incidents which cause harm but which are clearly not criminal offences.
- That guidance and any legislation coming from this review state that social care and health care providers must presume incidents in which a vulnerable adult is harmed are crimes, and act accordingly, until it has been established by a police investigation that a crime has not occurred. In particular, that the police must be called immediately after such an incident comes to light.
- For Crime Reduction Partnerships (CRP) to establish and fund domestic violence services with the resources, skills and refuge facilities necessary to support adults with learning disabilities and their children. Existing services could be adapted or new facilities created.
- For CRPs to either provide or fund suitable therapeutic provision for adults with learning disabilities who have experienced domestic violence.
- The Independent Safeguarding Authority must ensure that vetting and barring are tightened up so that adults with learning disabilities are better protected from those that might sexually abuse or rape them.
- Care providers should make better recruitment, support and training of care staff a priority.
- For appropriate funding for therapy for adults with learning disabilities who subject other adults with learning disabilities to domestic violence.
- Training for police domestic violence teams on how to assist adults with learning disabilities.
- For appropriate funding, determined according to need, for therapy for adults with learning disabilities who have experienced abuse and crime.
- Social Services professionals and criminal justice professionals should be informed during induction and refresher training of the Provision of Therapy for Vulnerable or Intimidated Witnesses Prior to a Criminal Trial; Practice Guidance. They must also be encouraged to have more confidence in commissioning therapy for victims in line with this guidance.

7. RESPECT FOR PRIVACY

UN Convention, Article 22—Respect for privacy

7.1 The privacy of adults with learning disabilities is often not respected by their family and the services they use. Confidential, personal information is often shared and distributed with little regard for the feelings and right to privacy of the person concerned. Even when confidential information is legitimately shared between professionals, the need for and purpose of such information sharing is sometimes not explained. This can leave adults with learning disabilities feeling that their privacy has not been respected. We know adults with learning disabilities who are reluctant to share personal information because of their experiences of their right to privacy being violated.

7.2 These two case studies may give the Joint Committee some flavour of what can occur.

- *The father of a young woman with complex physical and learning disabilities has total control over her life. This woman is sufficiently capable of providing consent and determining what she wants. However, her father has his own set of keys to her house and lets himself in whenever he likes. He also controls who she is able to speak to and will not allow her to socialise. In addition, her father manages who cares for her. This has led this young woman to bribe her carer not to tell her father what friends she has had at her own house.*

Her father acts as her advocate and she is too scared to tell him that she wants someone independent to be her advocate instead. He also has access to her bank and phone bills and checks them regularly.

- *Kathy moved to a privately run refuge following life-long, immense sexual assault, emotional abuse and neglect from her mother and other members of the family.*

Kathy was sexually assaulted by another resident at the refuge, resulting in terrible internal injuries. Following police involvement, Kathy chose to bring charges. This led to her being ostracised within the refuge. There were examples of other residents barging in on Kathy when she was in the shower. Despite being on the ground floor, Kathy was not provided with curtains for her windows and information relating to the sexual assault became public knowledge within the refuge.

7.3 Some parents of adults with learning disabilities perceive their son or daughter as a perpetual child and so do not afford them the level of privacy and freedom to manage their own affairs afforded to an adult. Professionals, carers and parents perception of adults with learning disabilities’ capacity to manage their lives, and an attitude that privacy hinders the provision of appropriate care, may lie behind breaches of confidentiality and privacy. These attitudes need to be checked.

7.4 As a general rule (and in compliance with data protection requirements), the information held and/or shared on an adult with learning disabilities should be no more than is strictly necessary. Furthermore, as best as it is possible, adults with learning disabilities should be aware of what information is held on them, know why it is held and have means to challenge the holding of certain information.

7.5 *Recommendations on the Right to Privacy:*

- All organisations providing services to adults with learning disabilities should regularly train their staff on their duties of confidentiality and privacy.
- All organisations providing services to adults with learning disabilities should have clear policies on confidentiality and privacy.
- People working with adults with learning disabilities should explain the limits of confidentiality in general and in specific instances where information needs to be shared.

8. FORCED MARRIAGE

UN Convention, Article 16—Freedom from exploitation, violence and abuse

UN Convention, Article 23—Respect for Home and Family

8.1 When an adult with learning disabilities is forced into a marriage it may be done with the best of intentions. However, forcing someone to marry is a violation of human rights relating to family life and the means used to pressure someone into such a life changing move often involves exploitation, abuse and violence. Assaults, rapes and other human rights violations also often continue after the forced marriage itself. This domestic violence may be fuelled by poor understanding of learning disabilities and a relationship which is founded on a lack of consideration for the wishes and needs of one party.

8.2 It is important to make a distinction between forced marriages and arranged marriages. An adult with learning disabilities is forced into marriage if they are not given a choice about the marriage and do not consent to it. A forced marriage is not a religious or cultural practice. An arranged marriage involves an adult with learning disabilities being given a choice and freely consenting to the marriage. This is a cultural practice and, like all consensual marriage, can help adults with learning disabilities lead full and positive lives. An arranged marriage can provide an adult with learning disabilities with such things as a full-time carer, sexual relations, children, contact with an extended family network, contact with friends, financial security, improved immigration status and love. We believe adults with learning disabilities have a right to enter into an arranged marriage.

8.3 The central issues in both forced and arranged marriages involving adults with learning disabilities are consent and choice. Understanding and knowledge is crucial for consent, to make choices and to empower adults with learning disabilities. Adults with learning disabilities need support to understand the nature of marriage and all it entails so that they are able to make informed decisions and engage in mutually supportive relationships. This means an understanding of the legal consequences of marriage, that marriage involves sex, that this sex must be consensual and that both parties have duties and responsibilities towards each other. There is usually an expectation (particularly in some cultures) that spouses will have children together. Adults with learning disabilities need to be aware of this prior to marriage and are likely to need ongoing support if they choose to have children.

8.4 For arranged marriages involving adults with learning disabilities to work, all parties to the marriage must understand what this entails. We have heard of adults with learning disabilities entering into arranged marriages without understanding that marriage involves sex. In these situations, the wedding night can be traumatic and can involve rape. This rape may then be regularly repeated. Issues of this sort are compounded when a potential spouse is not told that the person they are marrying has learning disabilities or has only a limited understanding of learning disabilities. In both forced and arranged marriages, a person's learning disability is sometimes kept secret for fear of jeopardising the marriage and of damaging family honour. For arranged marriages to work, appropriate support for both potential spouses and their families may be needed. CONSENT (Consultancy, Sexuality Education and Training) based at Hertfordshire Partnership NHS Trust assists families for at least a year before an arranged marriage so that all the parties understand what marrying an adult with a learning disability may involve.

8.5 Families that decide not to involve full consent and choice—to force a marriage—do so for a variety of reasons. Izzat (“respect” in Urdu) is a South Asian concept of family and personal honour that puts the collective (eg the extended family) before the rights and feelings of the individual. Adults with learning disabilities have been forced into marriage in an effort by their family members to avoid shame being brought upon the family and community. Not marrying or having a relationship with someone of whom their family disapproves are other examples of actions that a family may perceive as endangering their izzat. Another reason is that a family may want an adult with learning disabilities to marry someone of the same class and religion. Marriages have been used as a means to obtain carers for adults with learning disabilities, often because immediate families feel unable to continue to provide care. Similarly, adults with learning disabilities have been forced into marriage as a means of obtaining financial security for their families. A family may also view arranging their daughter's marriage to a man with learning disabilities as a good option if they are unable to pay a dowry. Forcing an adult with learning disabilities into marriage is also used to

obtain a visa or passport. Adults with learning disabilities may then be left or divorced by their spouses once their spouses' immigration status is secure. The susceptibility of many adults with learning disabilities makes them vulnerable to this form of exploitation. A further reason is the perception in some South Asian and African cultures that learning disability can be "cured" by becoming married.

8.6 The following case studies give an indication of what can occur:

— *Iqbal is a young man with learning disabilities and ADHD. He lives at home and his father was finding it difficult to look after Iqbal following the death of Iqbal's mother. Iqbal's father wanted him to marry his first cousin, Sabrina, in Pakistan. However, Iqbal did not want to marry Sabrina but his girlfriend. His father bullied Iqbal into going on a trip to Pakistan and into marrying Sabrina. This was felt to be the best solution for all involved by the extended family—Iqbal and his father have someone to look after them while Sabrina has a better life in the UK.*

— *Raj lives with his mother, two brothers and his brother's wives. His mother was his main carer, but she was finding it difficult to look after him. Raj's mother took him to India to get married. His wife is from a poor background and her family feels that marrying Raj is a good match because they are unable to give dowry.*

Once back in the UK, Raj's wife became his full time carer. She has no support networks of any kind, is often depressed, does not speak English and does not know her rights (eg in relation to benefits). There is also an expectation on her to have a child to continue the family name.

— *Rani is a young woman with mental health needs and mild learning disabilities. She lives at home with her mother and sister. Rani's mother was put under pressure by the local community for Rani to marry a young man from India who needs to marry a British citizen to remain in this country. Her mother felt that this would be a good match as no one else would marry Rani due to her disability.*

After Rani had been married a year, it became clear that her husband had been taking all of her social security benefits and sending the money to his family in India. Rani has been assaulted on a regular basis and suffered a miscarriage, which has made her husband even more aggressive towards her. Although Rani has asked for help, her mother has told her to stay with her husband for the sake of the family's honour.

8.7 The exploitation and abuse that occurs in a forced marriage involving an adult with learning disabilities is sometimes extended to the spouse without learning disabilities. That a person has learning disabilities may be kept from a potential spouse or be played down. Someone may also have limited knowledge of learning disability and what a relationship with an adult with learning disabilities involves. While someone may gain the benefits of migration to the UK, they may not be aware that their marriage involves them becoming a full-time carer. A person in such a situation may be isolated and lack support networks (as the case of Raj above illustrates). The lack of informed consent in these situations means that these people are as much forced into marriage as the adult with learning disabilities who they marry. The resentment and confusion that arises in these situations can cause domestic violence.

8.8 *Forced Marriage (Civil Protection) Bill*

8.8.1 Our organisations support Lord Lester of Herne Hill's Forced Marriage (Civil Protection) Bill and thank him for introducing this Private Members Bill. We believe it to be a proportionate and useful measure with declaratory value.

8.8.2 The requirement in this Bill that courts ascertain a victim's wishes and feelings when considering whether to issue a forced marriage protection order is especially important when the victim is an adult with learning disabilities. As Lord Lester explained in Grand Committee on 10 May 2007 (column GC262), this requirement aims to ensure that third party requests are victim-led and not inconsistent with the wishes of the victim. Paternalism is an ever-present problem for adults with learning disabilities. This requirement is an appropriate means of ensuring that a well-meaning third party does not succeed in obtaining a forced marriage protection order against the wishes of an adult with learning disabilities. Success in preventing such a paternalistic application depends on courts being able to accurately ascertain the wishes and feelings of adults with learning disabilities. As Lord Lester noted, judges have an inherent power to make orders and give directions for the provision of assistance to witnesses in giving evidence. However, we fear that this inherent power will not be sufficient to ensure special measures are used to enable courts to ascertain the wishes and feelings of adults with learning disabilities.

8.8.3 The special measures available in criminal cases through the Youth Justice and Criminal Evidence Act 1999 enable people with learning disabilities to give their best evidence and can make the difference between success and failure in a case. The intermediaries scheme in particular allows courts and vulnerable victims to communicate with, and understand, each other. We describe these special measures, and the clear benefits they bring for the administration of justice, below.

8.8.4 We also describe the reluctance of some members of the judiciary to the use of special measures, including suspicion and hostility towards the use of intermediaries (based upon misconceptions of their role). This is despite the clear entitlement to special measures (subject to the judge's approval) in the Youth Justice and Criminal Evidence Act and the expectation that they will be used to assist vulnerable and intimidated witnesses.

8.8.5 As cases brought under a Forced Marriage (Civil Protection) Act will be heard in civil courts, there will be no similar entitlement to special measures. Instead, the provision of measures to aid in understanding the wishes and feelings of adults with learning disabilities will be totally dependent upon the judge. Our fear is that some judges will choose not to direct the use of special measures for adults with learning disabilities in forced marriage protection order cases. Applications are also likely to be discouraged from requesting intermediaries in forced marriage protection order cases by the fact that they will have to pay for their use⁵² as Government funding is only available for intermediaries in criminal cases.

8.8.6 An explicit entitlement to the special measures equivalent to those in the Youth Justice and Criminal Evidence Act, or an explicit statement that such assistance should be provided as the court considers appropriate, will assist courts in knowing the wishes and feelings of adults with learning disabilities. We do not recommend this in an attempt to establish a precedent for the provision of special measures in civil cases—this is a matter of parity. If a person is prosecuted for kidnapping and assault in an effort to force an adult with learning disabilities into marriage, their victim will have ready access to special measures. If that same victim pursues an application for a forced marriage protection order to prevent further harm to them, these special measures are likely to be much harder to obtain.

8.8.7 We have written to Lord Lester on this point and he has kindly passed our concerns on to the Government lawyer's considering his Bill. Jo Swinson MP has also helpfully tabled an amendment to the Bill to provide the effect we describe above and this is likely to be debated shortly.

8.8.8 If there is any question over whether an adult with learning disabilities has the capacity to consent to marriage, then we believe that this should be determined through the Mental Capacity Act. We also believe that for preventing forced marriages involving adults with learning disabilities that Independent Mental Capacity Advocates, non-governmental organisations working in this area and social services departments be specified as relevant third parties by the Lord Chancellor.

8.8.9 As the people forcing an adult with learning disabilities into marriage are likely to be their primary carers and/primary means of financial support, an application for a forced marriage protection order may seriously jeopardise the care and support an adult with learning disabilities needs to survive. Any action taken to prevent a forced marriage involving an adult with learning disabilities may lead to their carers withholding care, income and housing. An adult with learning disabilities is therefore in a Catch-22 from which only carefully considered support may extricate them.

8.8.10 This is one of the reasons why we believe that the Forced Marriage (Civil Protection) Bill is only part of the arsenal that individuals, agencies and government need to tackle forced marriage involving adults with learning disabilities. There are a range of criminal offences that a person can be prosecuted for if they force someone into marriage. These include kidnapping, false imprisonment, assault, rape and blackmail. We believe that the police and CPS need to be aware that adults with learning disabilities are forced into marriage and that they should intervene in cases. However, arrest and prosecution carry the danger of jeopardising care and support. To address these issues and tackle forced marriage we make the following recommendations.

8.9 Recommendations on Forced Marriage:

- Increased awareness amongst those working with adults with learning disabilities and criminal justice professionals of forced marriage of adults with learning disabilities. As part of this, they must be prepared to overcome cultural relativism and fear of being accused of racism to challenge and report such forced marriages.
- Training and education for frontline staff in social services departments and criminal justice agencies on safeguarding adults with learning disabilities from forced marriage. We note that the Government has stated that it anticipates that the Judicial Studies Board will undertake training on the Forced Marriage (Civil Protection) Bill when it becomes law.⁵³ It is important that this training covers the forced marriage of adults with learning disabilities.
- The agreement and implementation of multi-agency procedures and policies on forced marriage which address the particular issues involved in cases of adults with learning disabilities forced into marriage.
- Guidance on forced marriage must require the provision of care and housing for adults with learning disabilities whose primary carers remove, or threaten to remove, support following action to prevent or revoke a forced marriage. *The Young People and Vulnerable Adults Facing Forced Marriage guidance*⁵⁴ for social workers does not address this in relation to vulnerable adults.
- Targeted public education campaigns on the nature of learning disability, the right of adults with learning disabilities and the implications of forced marriage.
- The national provision of support and education for families, adults with learning disabilities and potential spouses on arranged marriages.

- Advice and information publications from the Forced Marriage Unit should be available in easy-read versions. Information on the Forced Marriage (Civil Protection) Bill should, when it becomes law, also be available in an easy-read format.
- In the Forced Marriage (Civil Protection) Bill, an explicit entitlement to the special measures equivalent to those in the Youth Justice and Criminal Evidence Act, or an explicit statement that such assistance should be provided as the court considers appropriate.

9. EQUAL ACCESS TO JUSTICE—WITNESSES AND VICTIMS

UN Convention, Article 13—Access to Justice

UN Convention, Article 16—Freedom from exploitation, violence and abuse

9.1 Article 13 of the UN Convention places a requirement on State Parties to “ensure effective access to justice for adults with learning disabilities on an equal basis with others”, including through the provision of measures that facilitate their effective role as participants at every stage of the criminal justice process. Article 16 also includes a requirement that State Parties “ensure that instances of exploitation, violence and abuse” against adults with learning disabilities “are identified, investigated and, where appropriate, prosecuted.”

9.2 Why Adults with Learning Disabilities Need Assistance during Police Interview and in Court

9.2.1.1 The experience of being questioned and of giving evidence to the police and court can be very distressing. Adults with learning disabilities, perhaps more than the general population, find this process traumatic. The nature of learning disabilities may also mean that additional assistance is required if someone is to give their best evidence.

9.2.1.2 Adults with learning disabilities can have difficulty recalling information and details, while some may remember events in a form that can seem incoherent to others. Particular language needs can mean that some adults with learning disabilities have difficulty understanding and responding to a question. Some adults with learning disabilities have little or no concept of time and this can be particularly problematic in giving evidence to the police and in court. In addition, adults with learning disabilities have been found to be more susceptible to leading questions⁵⁵ and are more likely to acquiesce⁵⁶ in criminal justice settings. However, every adult with learning disabilities is individual in their abilities and needs.

9.2.2 There is some evidence to suggest that the nature of regular cross-examination in court is ill-suited to eliciting the best possible evidence from adults with learning disabilities. Research by Lancaster University has found that:

“Lawyers are likely to deliberately exploit the characteristics of leading questions . . . cross-examination is particularly likely to lead to inaccurate testimony from witnesses with learning disabilities.”

First, the way witnesses are examined does little to ensure their memories are as accurate as possible. Second, cross-examination is particularly poor for eliciting accurate memory reports, a problem that is likely to compound the general memory problems associated with people with learning disabilities. Third, the accounts of witnesses with learning disabilities are shorter and more likely to agree with a leading question than those from the general population.”⁵⁷

9.2.3 However, it is wrong to draw from this the conclusion that adults with learning disabilities are not able to give evidence or are unreliable in giving evidence. Adults with learning disabilities are capable of giving sound, reliable and detailed evidence if they are provided with appropriate support and those questioning them tailor their questioning. As Lancaster University’s research noted:

“. . . the accuracy and completeness of eyewitness testimony given by people with learning disabilities can be significantly improved if suitable questioning strategies are adopted.”⁵⁸

9.2.4 Assistance and consideration is therefore vital if adults with learning disabilities are to give their best evidence in police interview and in court. If this is not provided, their evidence may be misinterpreted or not understood and so the chance of achieving justice is reduced.

9.3 Special Measures

9.3.1 The Youth Justice and Criminal Evidence Act 1999 provides a range of special measures to support vulnerable and intimidated witnesses (VIWs), including adults with learning disabilities, to give their best evidence in court. Special measures include giving evidence via television link or in a video recording and the removal of wigs and gowns. Intermediaries (described below) are also available during police interview. It is ultimately up to the discretion of the judge what special measures are permitted in a court.

9.3.2 A Home Office evaluation of special measures found them to have a very positive impact on those using them and on the administration of justice.

“Vulnerable and intimidated witnesses who used special measures were less likely than those not using such measures to feel anxious or distressed overall. A third of vulnerable and intimidated witnesses who used special measures said they would not have been willing and able to give evidence without the availability of these measures.”⁵⁹

The study notes that:

“This suggests that an increased proportion of cases involving VIWs are now resulting in offenders being brought to justice which would not have occurred before the special measures.”⁶⁰

9.3.3.1 The intermediary scheme is one of the special measures tools available to assist adults with learning disabilities. An intermediary is someone who can help a VIW understand questions they are asked and who can then communicate the VIW’s responses. Intermediaries can help VIWs at each stage of the criminal justice process, from police investigations and interviews, through pre-trial preparations to court. They can carry out an initial assessment of a VIW’s communication needs as well as provide advice on how to achieve more productive interviews. This can include information on how someone communicates, the types of questions to avoid, how long they will take to answer a question and their levels of understanding. This can then be used by criminal justice professionals in communicating with the VIW. Intermediaries can also directly assist by helping a witness understand questions during interview or testimony and helping them communicate their answers. An intermediary owes their duties to the court and to justice.

9.3.3.2 The intermediary scheme was piloted in six pathfinder areas and it has recently been announced that the scheme will be rolled out nationally. A Ministry of Justice study of the pathfinder areas demonstrates the value of intermediaries in helping adults with learning disabilities give evidence.

“Feedback from witnesses and carers in trial cases was uniformly enthusiastic. Carers felt that intermediaries not only facilitated communication but also helped witnesses cope with the stress of giving evidence. Appreciation of the role was also almost unanimous across the judiciary and other criminal justice personnel . . .”⁶¹

9.3.3.3 This evaluation concluded that intermediary use brought a range of benefits including:

- potential assistance in bringing offenders to justice;
- increasing access to justice—participants estimated that, in their opinion, at least half of the 12 trial cases would not have reached trial without the involvement of the intermediary . . .”
- potential cost savings—eg by keeping witnesses focused, the use of intermediaries reduced the time needed to question witnesses in court;
- investigatory benefits—eg identifying that the witness’s comprehension level was lower than it appeared and assisting witnesses at identification procedures. “. . . in one instance, a victim interview facilitated by an intermediary revealed that the suspect in custody was not the assailant . . .”
- benefits at trial—eg ensuring that witnesses understood everything said to them, including explanations and instructions;
- addressing wider criminal justice objectives—eg witness satisfaction and public confidence.⁶²

9.3.3.4 The following case studies highlight how beneficial the intermediary scheme has been in practice.

- *“When a young woman with learning difficulties reported that she had been raped, it was initially decided that she could not be a witness because of her difficulty communicating. However, after hearing about the scheme, the police engaged an intermediary to assist in investigative interviews, and the young woman was able to give evidence with the intermediary’s help.”*

“In police interviews, the intermediary identified questions that were too complex for the witness and repeated some of her answers. In court, the intermediary informed the judge and lawyers about how to look out for the witness’s communication difficulties. The intermediary also helped the witness use pictures to identify rooms where it was alleged the offences had taken place.”

“This case resulted in a conviction and the defendant was sentenced to 10 years in prison.”⁶³

- *“In a case where a witness was a 64-year-old man with severe learning difficulties, he first gave evidence using a video statement. However, when he was then asked to give evidence before the court in person, an intermediary was used to help him give his account clearly and with the least upset and disruption to him.”*

“The intermediary produced a report on the witness for the Judge and both the prosecuting and defence counsel, explaining the witness’s difficulties and how he needed to be treated.”

“This report gave the Judge the information needed to challenge inappropriate questioning by, in this instance, defence counsel who asked exactly the type of question the intermediary had reported the witness would be unable to answer. Without an intermediary this questioning would have gone unchallenged, giving the appearance to the jury of a witness unsure of his account and therefore unreliable.”⁶⁴

9.4 Failures to Provide Special Measures to Adults with Learning Disabilities

9.4.1 Special measures are therefore vital for ensuring that adults with learning disabilities’ right to equal justice are fulfilled. Unfortunately, far too many adults with learning disabilities are not receiving the special measures assistance which they need. This is due to the failure of some criminal justice professionals to identify someone as having a learning disability and so needing help in giving evidence. Having to give evidence unsupported is likely to cause anxiety and distress for those affected. Crucially, it also hampers police investigations, interviews and court proceedings by affecting the quality of evidence, with consequently detrimental affects on justice. Early identification of adults with learning disabilities is vital.⁶⁵

9.4.2 The police have initial responsibility for identification of VIWs during the investigation of a crime. CPS, Witness Service and courts are largely dependent on the police to provide accurate and timely information regarding the vulnerability and needs of witnesses as they largely only see them at later stages in cases. Therefore, unless the police inform the CPS early on that a witness or victim has learning disabilities, early CPS decisions on the conduct of a case may be made without understanding what a witness or victim needs to give their best evidence.

9.4.3 A Home Office evaluation of special measures found, on a conservative estimate, that 24% of prosecution witnesses are vulnerable or intimidated. This is five times the figure identified by the CPS and twice as many as identified by the police. This study found that the police have trouble identifying VIWs, particularly those with learning disabilities. It also found that the CPS rarely identifies witnesses as vulnerable and intimidated if they have not been identified as such by the police. Instead, many VIWs are identified for the first time by the Witness Service when they arrive at court, by which stage it is often too late for them to benefit from special measures.⁶⁶ In relation to intermediaries, the evaluation of the pathfinder areas noted that:

“Of those witnesses for whom an intermediary was appointed, 24% had already given a witness statement, suggesting that eligibility was missed at the point of interview.”⁶⁷

9.4.4 There are several reasons why the police have difficulty in identifying adults with learning disabilities. The Home Office research found that:

“People with mild learning disabilities were not always identified by the police because a relatively high level of social functioning may hide a learning disability. As a result, the police did not always use appropriate interviewing techniques. The police practice of constructing witness statements which witnesses then sign meant that the nature of the witness’ disability was not always clear to the prosecutor who later reviewed the case.”⁶⁸

“The police themselves said that officers generally concentrated on obvious cases, which are readily identified, and rarely probe beneath the surface to seek less obvious ones.”⁶⁹

Adults with learning disabilities may also hide their learning disabilities and/or conceal the difficulties they are having during questioning due to pride.⁷⁰ The police have stated that their poor performance in identifying vulnerable and intimidated witnesses is due to:

- insufficient training in the complexities of the relevant legislation and official guidance;
- insufficient training in identifying and interviewing VIWs;
- insufficient resources, particularly a lack of time with witnesses;
- lack of experience of court; and
- other competing initiatives.⁷¹

9.4.5 Even where the police are able to identify a victim as having learning disabilities, there are issues over whether they have the skills and training to provide appropriate support.

- *The mother of a man with learning disabilities, Richard, sought advice from the VOICE UK helpline as her son had disclosed that he had been slapped in the face more than once by a support worker at his day centre. This had left his face red and hurt.*

Richard’s mother had not been made aware of this by the day centre or social services. She immediately called the day centre to complain, but there was no manager available to speak to her.

The duty manager of the day centre called the alleged victim's mother's home the next day in order to get more detail about the complaint. He advised her to call the police and report the incident herself. She was not informed about any adult protection procedures or what social services and the day centre would be doing to address the allegation made. Nor was she given any reason why she was not made aware of the incident earlier.

The incident was reported to the police. Two weeks after the reporting of the assault, a police officer, who claimed that she had been trained in Achieving Best Evidence, came to their home to interview Richard. Because she was unable to completely comprehend Richard's speech, the police officer concluded it would be best to find the evidence needed for the case elsewhere. Richard was given no special measures and no chance of giving his account of what had happened to him. As a direct result of this, the CPS could not take the case any further. There were witnesses in the day centre that were interviewed, but they could only give partial accounts of the incident.

Social services did not seek to interview or question either Richard or his mother about the incident. They accepted the alleged perpetrator's account of the incident—that he merely tried to calm the alleged victim down and only touched his face a few times. The carer was then removed from suspension and is now working at the day centre again. Richard feels unable to go back to the day centre.

9.4.6 However, the fault is not entirely with the police. The Home Office research found that judges attributed some of the fault with not identifying VIWs to the CPS and that there was some indication that CPS lawyers did not understand the concept of a VIW.⁷² Some criminal justice professionals have also demonstrated negative attitudes towards special measures, resulting in obstructive behaviour or a complete failure to provide this assistance. The Home Office's survey of police, CPS, Crown Court Witness Service and Crown Courts found that:

"Approximately one-third of respondents also said that either prosecution counsel or the judiciary were resistant to special measures and preferred evidence to be given in the traditional way with the witness receiving no assistance."⁷³

It also found that:

"Many judges believe that video recorded evidence and the live television link are less effective than the giving of evidence 'live and in the flesh'. This is probably due to a belief that these methods of giving evidence reduce its impact on juries, although this is not supported by the research evidence . . ."⁷⁴

This is partly accounted for by misunderstanding and lack of knowledge about the role and value of special measures—from our experience and the results of the Home Office study, this certainly appears to be the case in relation to intermediaries.

". . . while those with direct experience of intermediaries were almost all very positive, some others encountered pre-judged or misunderstood the intermediary role."⁷⁵

Some members of the legal profession misunderstand the role of intermediaries, viewing them as encroaching on the traditional roles of lawyers and judges. Unless these views are addressed through training, then we are concerned that they may hamper the national roll-out of the intermediary scheme.

9.5 Decisions Not to Prosecute

9.5.1 It is changes in attitudes amongst criminal justice professionals, as well as the availability of special measures, that means that fewer cases of crime against adults with learning disabilities are not prosecuted because the victim is seen as unreliable, unable to communicate or otherwise unable to give evidence. However, decisions not to prosecute are still made for these reasons and because criminal justice professionals feel continuing with a prosecution will be too traumatic for a victim with learning disabilities.

- *Julie has learning disabilities and was raped over a period of nine years by her father. She lived in her own flat, but her father was her main carer and had his own set of keys. Julie was scared to speak up about the rapes and told nobody.*

After nine years of these sexual assaults, Julie disclosed what had been happening to a support worker at a day centre with whom she had built up a relationship.

A criminal case did not go ahead as it was seen that the evidence was too weak. It was only Julie's word against her father's. This fact coupled with the assumption that because Julie has learning disabilities she was less reliable as a witness resulted in the CPS refusing to take the case to court.

9.5.2 The Code for Crown Prosecutors sets out the things CPS lawyers must consider in deciding whether to prosecute a case in which the victim has learning disabilities. The Home Office's research looked at how the CPS applied the evidential test in the Code in cases involving VIWs—

". . . respondents said that the existence of such witnesses may mean that the case was too weak to proceed. The CPS needed to know that the witness would attend court, withstand cross-examination and make a credible witness."⁷⁶

This research found that in considering the public interest test in the Code:

“Generally, vulnerability made the prosecutor more determined to proceed but the risk to the victim was recognised as sometimes outweighing the benefit of going to trial.”⁷⁷

9.5.3 The decision whether to prosecute will therefore be influenced by the CPS lawyer’s understanding of learning disabilities and how special measures can be used to assist adults with learning disabilities give evidence. If a CPS lawyer’s knowledge is poor in these regards, then they may incorrectly believe that an adult with learning disabilities could not withstand cross-examination and would not be a credible witness. As we regularly hear of cases where it appears the case could have been prosecuted but was dropped, we believe that the CPS needs to do more work educating its lawyers.

9.6 *Our Efforts to Help Victims and Witnesses with Learning Disabilities*

9.6.1 Our organisations are working on several fronts to address issues relating to victims and witnesses with learning disabilities.

9.6.2 In conjunction with the Association of Chief Police Office ACPO, our organisations produced the Police Vulnerable Witness Pocket Guide. This gives police officers information on how to identify and help VIWs, including adults with learning disabilities. This credit card sized guide is small enough to fit into the pocket book of police officers and 170,000 have been distributed (one for every frontline police officer in England and Wales).

9.6.3 VOICE UK provides training to police forces, including the Metropolitan Police Service, on identifying and interviewing people with learning disabilities. The Ann Craft Trust also trains individual police forces, including Nottinghamshire and Merseyside, on the Achieving Best Evidence guidance. In addition, Respond has provided training to police officers investigating rape cases and to community safety officers.

9.6.4 VOICE UK and the Royal College of Psychiatrists have produced Supporting Victims, a book that describes in pictures what happens to a vulnerable victim from first police interview to giving evidence in court. It introduces special measures and explains how they work. It is the latest title in the Books Beyond Words series which explain traumatic events in pictures for people who have difficulty understanding written words. These books are of particular value to adults with learning disabilities in understanding difficult concepts and coping with unfamiliar situations. Supporting Victims can be used by victims or professionals working with them.

9.6.5 Our helplines also regularly assist adults with learning disabilities, their families and carers with information and advice about police investigations, their legal rights and appearing in court.

9.7 *Recommendations on Equal Access to Justice—Witnesses and Victims:*

- Mandatory training for police officers on identifying and interviewing VIWs as well as legislation and official guidance relating to vulnerable and intimidated witnesses.
- More resources to allow police officers to spend longer with vulnerable and intimidated witnesses in which to gain an understanding of their needs and to draw out their testimony.
- Routine, refresher training for CPS lawyers on special measures and learning disabilities.
- For judges to be trained on the needs of vulnerable and intimidated witnesses, including adults with learning disabilities, and how special measures can be used to assist vulnerable and intimidated witnesses in giving their best evidence.
- For the Ministry of Justice to promote the intermediaries scheme and its benefits amongst criminal justice professionals during the national roll-out of the scheme.

10. EQUAL ACCESS TO JUSTICE—SUSPECTS AND DEFENDANTS

ECHR, Article 6—Right to a Fair Trial

UN Convention, Article 13—Access to Justice

10.1 In our view, the provisions of Article 13 of the UN Convention apply as equally to adults with learning disabilities who are suspected or convicted of a crime as to those who are witnesses and victims. Equality for adults with learning disabilities includes the recognition that adults with learning disabilities are not just victims and are capable of deliberate wrongdoing. Like all people, adults with learning disabilities commit crimes and are suspected of committing crimes. However, as we described above, the nature of learning disabilities means that adults with learning disabilities require additional assistance if they are to receive a fair trial.

10.2 We are obviously aware that the Prison Reform Trust are giving evidence to the Joint Committee on issues relating to the human rights of adults with learning disabilities in police custody, being prosecuted and in prison. We share the Prison Reform Trust’s concerns and support their excellent work in this area.

Our organisation will not repeat in this submission many of the points the Prison Reform Trust will be making, however, we would like to touch on an issue which has caused us concern for some time—the lack of provision of special measures for suspects and defendants with learning disabilities.

10.3 *Current Special Measures Provision for Suspects and Defendants*

10.3.1 The Youth Justice and Criminal Evidence Act 1999 s 16(1) specifically excludes defendants from the provision of special measures.

“For the purposes of this Chapter a witness in criminal proceedings (other than the accused) is eligible for assistance by virtue of this section . . . ”

10.3.2 However, a judge may use their inherent jurisdiction to ensure that a defendant is able to meaningfully take part in a trial to make an order for the use of an intermediary. In such circumstances, the application for an intermediary would need to be made by the defence and the defence would need to find funding from the Legal Services Commission or other source. As it is likely to cost more to fund an intermediary for a defendant than a prosecution witness, funding may be a serious impediment to defendants with learning disabilities gaining the assistance of an intermediary. Prosecution witnesses will usually only be in court for one day, while a defendant will need to have the assistance of an intermediary for the whole length of a trial (which might last weeks). Relying on judges to make orders also limits the provision of intermediaries to trials, denying suspects with learning disabilities the assistance available to VIWs during police investigation and interview. The lack of statutory backing, and the resistance of some members of the legal profession to the use of intermediaries (described above), means that we are also not confident that judges will make the necessary orders for the provision of intermediaries for defendants with learning disabilities.

10.3.3 The Government has been prompted to consider the issue of the provision of special measures for vulnerable defendants by the European Court of Human Rights case of *S.C. v The United Kingdom* (60958/00 [2004] ECHR 263, 15 June 2004). In this case, the Court found that an 11 year old with moderate to severe learning disabilities had not received a fair trial because his low level of understanding of the proceedings and their consequences meant he could not participate effectively in the trial.

10.3.4 In considering how to meet its ECHR obligations following this case, Baroness Scotland of Asthal stated:

“The solution that the Government have been discussing with the senior judiciary is to make available to vulnerable defendants the sort of special measures that apply to vulnerable witnesses, including using an appropriate adult to work with the defendant and defence counsel to ensure that the defendant can effectively participate throughout the trial.”⁷⁸

10.3.5 A measure that the Government adopted as a consequence was to allow vulnerable defendants to give evidence via a live link. This measure was inserted into the Youth Justice and Criminal Evidence Act 1999 by the Police and Justice Act 2006 s 51. A distinction is made in this measure between vulnerable defendants over and below the age of 18. For those over 18, a live link is only provided if:

- it is in the interests of justice for the accused to give evidence through a live link;
- the defendant “suffers from a mental disorder (within the meaning of the Mental Health Act 1983) or otherwise has a significant impairment of intelligence and social function”;
- the defendant is unable to “participate effectively in the proceedings as a witness giving oral evidence in court”; and
- use of a live link would enable the defendant to participate more effectively as a witness.

10.3.6 It is likely that this measure will only relate to defendants with the most severe learning disabilities—during Committee Stage, Baroness Scotland stated that:

“there should be a strong presumption that adult defendants are able to give oral evidence in court.”⁷⁹

We disagree with the premises behind this statement and its intent.

10.3.7 Apart from this reform, we are not aware of any other outcome from the Government’s stated consideration of special measures support for vulnerable defendants. We question why a wider consultation was not conducted. The provision in the Police and Justice Act is welcome, but it can only assist a small number of defendants with learning disabilities and then only as they give evidence—it does not help them participate in proceedings during the rest of the trial and does not assist vulnerable suspects during investigations.

10.4 *The Need for Special Measures for Suspects and Defendants*

10.4.1 The current legal position in relation to special measures for suspects and defendants with learning disabilities places them at a disadvantage in court and creates the danger of miscarriages of justice. When the needs of adults with learning disabilities in giving evidence are recognised in law for witnesses and victims, it is unclear why similar provision is not available for suspects and defendants with learning disabilities. This disparity appears to directly conflict with Article 13 of the UN Convention. Questions could also be raised

as to whether this legal situation conflicts with the ECHR Article 6 (3)a and (3)e, which place obligations on State Parties to ensure everyone charged with a criminal offence understands what is happening. At the very least, the current position goes against the spirit of these Articles.

10.4.2 The disparity between VIWs and vulnerable suspects and defendants also discourages the provision of special measures for VIWs. This is reflected in this recommendation from a Home Office research report:

“Serious thought should be given to extending to vulnerable defendants all the provisions available to vulnerable witnesses. Not only is this discrimination unfair, but the belief among many lawyers and judges that it is unfair impacts adversely on the use of special measures for prosecution witnesses when the defendant is vulnerable and not able to secure similar protection.”⁸⁰

10.5 Recommendations on Equal Access to Justice—Suspects and Offenders

- The special measures contained in the Youth Justice and Criminal Evidence Act 1999 should be made available to vulnerable suspects and defendants, including people with learning disabilities.

CONCLUSIONS

The infringement of the human rights of adults with learning disabilities by crime and abuse is often hidden, but all that we know tells us that it is widespread, regular and devastating in its impact. There are ways in which the state has acted to tackle this crime and abuse, yet the state continues to fail to fulfil its human rights obligations in this area in the ways that it could. Misconceptions, lack of training, lack of funding and a failure to act are behind this failure. The tragedy is that the lives of adults with learning disabilities could be improved with will, effort and commitment.

SUMMARY OF RECOMMENDATIONS

- That the Home Office conduct a disability equality impact assessment of the British Crime Survey.

RECOMMENDATIONS ON DISABILITY HATE CRIME

- That a minister within the Home Office is given responsibility for preventing and combating disability hate crime.
- That a national public information campaign be run by this minister with the direct aim of combating the prejudices that lead to disability hate crime and to increase public awareness of disability hate crime.
- That criminal justice professionals receive training on disability hate crime.
- Police forces and the Crown Prosecution Service be required to collect data on the disability hate crime cases which are reported and the prosecutions which are taken and that this information is published both nationally and locally.
- Adults with learning disabilities should receive information and education from police forces on the nature of disability hate crime and how to report these crimes.

RECOMMENDATIONS ON THE RIGHT TO LIFE

- That the police investigate cases where an adult with learning disabilities may have died due to the negligence of a medical professional with a view to prosecuting healthcare professionals for manslaughter and healthcare organisations for corporate manslaughter.
- The General Medical Council and Nursing and Midwifery Council take disciplinary and fitness to practice action against individual healthcare professionals who it can be shown have failed in their professional duties in relation to the death of adults with learning disabilities.

RECOMMENDATIONS ON THE RIGHT TO LIBERTY AND SECURITY OF THE PERSON

- Social and healthcare organisations must place emphasis on identifying and maximising opportunities for adults with learning disabilities to go outside care settings, particularly if staff find their behaviour challenging. This approach needs to be integrated into care plans, risk assessments, training and the culture of organisations.
- Measures which limit the liberty of adults with learning disabilities must only be applied to those specific people for which such measures are required and not by default to everyone living with them.

- We caution against applying an all or little approach to applying the Mental Health Act, emphasising the importance of conducting assessments when to not do so may unlawfully deprive someone of their liberty.

RECOMMENDATIONS ON FREEDOM FROM EXPLOITATION, VIOLENCE AND ABUSE

- Adults with learning disabilities should receive information and education on their rights, on how to protect themselves and on self-advocacy. This must include sex education. This should be provided or commissioned by Social Services departments.
- Care providers should supply information and education to adults with learning disabilities on what is abusive practice and on how to complain about it.
- Police forces should provide information and education for adults with learning disabilities on what is a crime and how to report crime to the police.
- In order to encourage care staff to raise concerns about abuse, the Government should use a public information campaign to counter negative attitudes towards whistleblowers and to inform the public of the protection of the Public Interest Disclosure Act 1998.
- That the review of vulnerable adult protection guidance be co-chaired by ministers from the Department of Health, Ministry of Justice and Home Office. In addition, that this review actively involves criminal justice agencies as well as stakeholders from local government and the voluntary sector.
- That the Government's review of safeguarding vulnerable adult protection recommend that crimes suffered by vulnerable adults are referred to as crimes in official guidance, future legislation and local adult protection policies. That the term abuse is only used narrowly to refer to those incidents which cause harm but which are clearly not criminal offences.
- That guidance and any legislation coming from this review state that social care and health care providers must presume incidents in which a vulnerable adult is harmed are crimes, and act accordingly, until it has been established by a police investigation that a crime has not occurred. In particular, that the police must be called immediately after such an incident comes to light.
- For Crime Reduction Partnerships (CRP) to establish and fund domestic violence services with the resources, skills and refuge facilities necessary to support adults with learning disabilities and their children. Existing services could be adapted or new facilities created.
- For CRPs to either provide or fund suitable therapeutic provision for adults with learning disabilities who have experienced domestic violence.
- The Independent Safeguarding Authority must ensure that vetting and barring are tightened up so that adults with learning disabilities are better protected from those that might sexually abuse or rape them.
- Care providers should make better recruitment, support and training of care staff a priority.
- For appropriate funding for therapy for adults with learning disabilities who subject other adults with learning disabilities to domestic violence.
- Training for police domestic violence teams on how to assist adults with learning disabilities.
- For appropriate funding, determined according to need, for therapy for adults with learning disabilities who have experienced abuse and crime.
- Social Services professionals and criminal justice professionals should be informed during induction and refresher training of the *Provision of Therapy for Vulnerable or Intimidated Witnesses Prior to a Criminal Trial; Practice Guidance*. They must also be encouraged to have more confidence in commissioning therapy for victims in line with this guidance.

RECOMMENDATIONS ON THE RIGHT TO PRIVACY

- All organisations providing services to adults with learning disabilities should regularly train their staff on their duties of confidentiality and privacy.
- All organisations providing services to adults with learning disabilities should have clear policies on confidentiality and privacy.
- People working with adults with learning disabilities should explain the limits of confidentiality in general and in specific instances where information needs to be shared.

RECOMMENDATIONS ON FORCED MARRIAGE

- Increased awareness amongst those working with adults with learning disabilities and criminal justice professionals of forced marriage of adults with learning disabilities. As part of this, they must be prepared to overcome cultural relativism and fear of being accused of racism to challenge and report such forced marriages.
- Training and education for frontline staff in social services departments and criminal justice agencies on safeguarding adults with learning disabilities from forced marriage. We note that the Government has stated that it anticipates that the Judicial Studies Board will undertake training on the Forced Marriage (Civil Protection) Bill when it becomes law.⁸¹ It is important that this training cover the forced marriage of adults with learning disabilities.
- The agreement and implementation of multi-agency procedures and policies on forced marriage which address the particular issues involved in cases of adults with learning disabilities forced into marriage.
- Guidance on forced marriage must require the provision of care and housing for adults with learning disabilities whose primary carers remove, or threaten to remove, support following action to prevent or revoke a forced marriage. The *Young People and Vulnerable Adults Facing Forced Marriage*⁸² guidance for social workers does not address this in relation to vulnerable adults.
- Targeted public education campaigns on the nature of learning disability, the right of adults with learning disabilities and the implications of forced marriage.
- The national provision of support and education for families, adults with learning disabilities and potential spouses on arranged marriages.
- Advice and information publications from the Forced Marriage Unit should be available in easy-read versions. Information on the Forced Marriage (Civil Protection) Bill should, when it becomes law, also be available in an easy-read format.
- In the Forced Marriage (Civil Protection) Bill, an explicit entitlement to the special measures equivalent to those in the Youth Justice and Criminal Evidence Act, or an explicit statement that such assistance should be provided as the court considers appropriate.

RECOMMENDATIONS ON EQUAL ACCESS TO JUSTICE—WITNESSES AND VICTIMS

- Training for police officers on identifying and interviewing VIWs as well as legislation and official guidance relating to vulnerable and intimidated witnesses.
- More resources to allow police officers to spend longer with vulnerable and intimidated witnesses in which to gain an understanding of their needs and to draw out their testimony.
- Routine, refresher training for CPS lawyers on special measures and learning disabilities.
- For judges to be trained on the needs of vulnerable and intimidated witnesses, including adults with learning disabilities, and how special measures can be used to assist vulnerable and intimidated witnesses in giving their best evidence.
- For the Ministry of Justice to promote the intermediaries scheme and its benefits amongst criminal justice professionals during the national roll-out of the scheme.

RECOMMENDATIONS ON EQUAL ACCESS TO JUSTICE—SUSPECTS AND OFFENDERS

- The special measures contained in the Youth Justice and Criminal Evidence Act 1999 should be made available to vulnerable suspects and defendants, including people with learning disabilities.

13 July 2007

¹ Allen J and Ruparel C in Walker A, Kershaw C and Nicholas S (eds), *Crime in England and Wales 2005/06*, Home Office Statistical Bulletin 12/06, July 2006, pg 53.

² Home Office Police Standards Unit and the Association of Chief Police Officers, *Hate Crime: Delivering a Quality Service*, March 2005, para 2.3.7.

³ Disability Rights Commission and Capability Scotland, *Hate Crime Against Disabled People in Scotland: A Survey Report*, April 2004.

⁴ Mencap, *Living in Fear*, 2000.

⁵ *Ibid.*

- ⁶ Disability Rights Commission and Capability Scotland, *Hate Crime Against Disabled People in Scotland: A Survey Report*, April 2004.
- ⁷ Emerson, Eric, Malam, Sally, Davies, Ian and Spencer, Karen, *Adults with Learning Disabilities in England 2003/4*, National Statistics, NHS Health and Social Care Information Centre, 2005, pg 92.
- ⁸ Mencap, *Living in Fear*, 2000.
- ⁹ Disability Rights Commission and Capability Scotland, *Hate Crime Against Disabled People in Scotland: A Survey Report*, April 2004.
- ¹⁰ Mencap, *Living in Fear*, 2000.
- ¹¹ *Ibid*.
- ¹² Home Office Police Standards Unit and the Association of Chief Police Officers, *Hate Crime: Delivering a Quality Service*, March 2005.
- ¹³ People in Partnership is made up of East Hertfordshire People First, Hertfordshire Constabulary, Adult Care Services, POhWER, Hertford Regional College, Bullying Task Force and Mencap.
- ¹⁴ *People in Partnership: Pathways to the Police and Other Services*.
- ¹⁵ Disability Rights Commission and Capability Scotland, *Hate Crime Against Disabled People in Scotland: A Survey Report*, April 2004.
- ¹⁶ Mencap, *Living in Fear*, 2000.
- ¹⁷ *Police search for thugs after bus station attack*, Matlock Today, 22 March 2007.
- ¹⁸ *The killers who boasted of their senseless crime*, Lancaster Today, 22 February 2007.
- ¹⁹ Equality Act 2006, s 10.
- ²⁰ *Ibid*, s 19.
- ²¹ Home Office Police Standards Unit and the Association of Chief Police Officers, *Hate Crime: Delivering a Quality Service*, March 2005, chapter 17.
- ²² Crown Prosecution Service, *Policy for Prosecuting Cases of Disability Hate Crime*, 2007, para 1.9.
- ²³ Disability Rights Commission, *Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*, September 2006, part 1, pg 4.
- ²⁴ National Patient Safety Agency, *Understanding the Patient Safety Issues for People with Learning Disabilities*, 2004, pg 8.
- ²⁵ Disability Rights Commission, *Equal Treatment: Closing the Gap. A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems*, September 2006, part 1, pg 69.
- ²⁶ National Patient Safety Agency, *Understanding the Patient Safety Issues for People with Learning Disabilities*, 2004, pg 18.
- ²⁷ Mencap, *Death by Indifference*, March 2007, pg 18.
- ²⁸ *Ibid*.
- ²⁹ National Patient Safety Agency, *Understanding the Patient Safety Issues for People with Learning Disabilities*, 2004, pg 18.
- ³⁰ Commission for Health Improvement, *Learning Disability Services—Bedfordshire and Luton Community NHS Trust*, April 2003, para 3.13, 3.15 and 3.16, pg 17–18.
- ³¹ Healthcare Commission, Commission for Social Care Inspection, *Joint Investigation into the Provision of Services for People with Learning Disabilities at Cornwall Partnership NHS Trust*, July 2006, pg 45.
- ³² *Ibid*, pg 40.
- ³³ Healthcare Commission, *Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust*, January 2007, pg 33–34.
- ³⁴ HM Government, *Cross Government Action Plan on Sexual Violence and Abuse*, 2007, pg 4.
- ³⁵ *Ibid*, pg 8.
- ³⁶ Healthcare Commission, *Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust*, January 2007, pg 38–42.
- ³⁷ *Regina v Peter John Clark*, 31 August 2006, Crown Court at Kingston upon Thames, Case number T20057487, pg 16.
- ³⁸ Action on Elder Abuse, *Adult Protection Data Collection and Reporting Requirements*, March 2006, pg 14–15.
- ³⁹ Healthcare Commission, *Investigation into the Service for People with Learning Disabilities Provided by Sutton and Merton Primary Care Trust*, January 2007, pg 83.
- ⁴⁰ *Ibid*, pg 75.
- ⁴¹ *Ibid*, pg 4.
- ⁴² Healthcare Commission, *Commission for Social Care Inspection, Joint Investigation into the Provision of Services for People with Learning Disabilities at Cornwall Partnership NHS Trust*, July 2006, pg 58.

-
- ⁴³ Action on Elder Abuse, Adult Protection Data Collection and Reporting Requirements, March 2006.
- ⁴⁴ Finney, Andrea, *Domestic Violence, Sexual Assault and Stalking: Findings from the 2004–05 British Crime Survey*, Home Office, Online Report 12/06, 2006, pg 10.
- ⁴⁵ Mirrlees-Black, Catriona, *Domestic Violence: Findings from a New British Crime Survey Self-Completion Questionnaire*, Home Office, Research Study 191, 1999, pg 32.
- ⁴⁶ BMA Board of Science, *Domestic Abuse*, British Medical Association, June 2007, pg 31.
- ⁴⁷ Salkeld, Luke, *Couple imprisoned epileptic man in shed for four months until he starved to death*, *Daily Mail*, 9 July 2007.
- ⁴⁸ *Carer who stole £5000 jailed*, EDP24, 26 June 2007.
- ⁴⁹ *Care home owner guilty of stealing from residents*, *Community Care*, 5 July 2007, pg 6.
- ⁵⁰ *No Secrets; Guidance on Developing and Implementing Multi-Agency Policies and Procedures to Protect Vulnerable Adults from Abuse*, Home Office, Department of Health, 2000, 2.8, pg 10.
- ⁵¹ *Ibid.*
- ⁵² Intermediaries are currently paid either £35 an hour or are reimbursed for loss of earnings from their primary job. These rates include expenses.
- ⁵³ Bridget Prentice, Parliamentary Under-Secretary of State for Justice, House of Commons, *Hansard*, column 1384, 10 July 2007.
- ⁵⁴ *Young People and Vulnerable Adults Facing Forced Marriage—Practice Guidance for Social Workers*, Foreign and Commonwealth Office, Association of Directors of Social Services, Home Office, Department for Education and Skills, Department of Health, March 2004.
- ⁵⁵ Clare and Gudjonsson, *Interrogative Suggestibility, Confabulation and Acquiescence in People with Mild Learning Disabilities (Mental Handicap): Implications for Vulnerability During Police Interrogation*, *British Journal of Clinical Psychology*, 32, 295–301, 1993.
- ⁵⁶ Kebbell, Mark, Hatton, Christopher, Johnson, Shane, *Witnesses with Learning Disabilities in Court: Full Report of Research Activities and Results*, The Institute of Health Research, Lancaster University.
- ⁵⁷ *Ibid.*
- ⁵⁸ *Ibid.*
- ⁵⁹ Hamlyn, Becky, Phelps, Andrew, Sattar, Ghazala, *Key Findings from the Surveys of Vulnerable and Intimidated Witnesses 2000–01 and 2003*, Findings 240, Home Office, 2004, pg 1.
- ⁶⁰ *Ibid*, pg 3.
- ⁶¹ Plotnikoff, Joyce, Woolfson, Richard, Marshall, Emma (ed), *The “Go-Between”: Evaluation of Intermediary Pathfinder Projects*, Research Summary 1, Ministry of Justice, 2007, pg 4.
- ⁶² *Ibid*, pg 4–5.
- ⁶³ *What’s my Story? A Guide to Using Intermediaries to help Vulnerable Witnesses*, Criminal Justice System.
- ⁶⁴ *Ibid.*
- ⁶⁵ Burton, Mandy, Evans, Roger, Sanders, Andrew, *Are Special Measures for Vulnerable and Intimidated Witnesses Working? Evidence from the Criminal Justice Agencies*, Home Office Online Report 01/06, 2006, pg 22.
- ⁶⁶ Burton, Mandy, Evans, Roger, Sanders, Andrew, *An Evaluation of the use of Special Measures for Vulnerable and Intimidated Witnesses*, Findings 270, Home Office, 2006, pg 3.
- ⁶⁷ Plotnikoff, Joyce, Woolfson, Richard, Marshall, Emma (ed), *The “Go-Between”: Evaluation of Intermediary Pathfinder Projects*, Research Summary 1, Ministry of Justice, 2007, pg 5.
- ⁶⁸ Sanders, Andrew, Creaton, Jane, Bird, Sophia, Weber, Leanne, *Witnesses with Learning Disabilities*, Research Findings, No 44, Home Office Research and Statistics Directorate, December 1996.
- ⁶⁹ Burton, Mandy, Evans, Roger, Sanders, Andrew, *Are Special Measures for Vulnerable and Intimidated Witnesses Working? Evidence from the Criminal Justice Agencies*, Home Office Online Report 01/06, 2006, pg 25.
- ⁷⁰ *Ibid*, pg 25.
- ⁷¹ *Ibid*, pg 26.
- ⁷² *Ibid*, pg 28–29.
- ⁷³ *Ibid*, pg 51.
- ⁷⁴ *Ibid*, pg 71.
- ⁷⁵ Plotnikoff, Joyce, Woolfson, Richard, Marshall, Emma (ed), *The “Go-Between”: Evaluation of Intermediary Pathfinder Projects*, Research Summary 1, Ministry of Justice, 2007, pg 5.
- ⁷⁶ Burton, Mandy, Evans, Roger, Sanders, Andrew, *Are Special Measures for Vulnerable and Intimidated Witnesses Working? Evidence from the Criminal Justice Agencies*, Home Office Online Report 01/06, 2006, pg 44.

⁷⁷ *Ibid.*

⁷⁸ Committee of the full House, consideration of the Police and Justice Bill, House of Lords *Hansard*, 11 July 2006.

⁷⁹ *Ibid.*

⁸⁰ Burton, Mandy, Evans, Roger, Sanders, Andrew, *Are Special Measures for Vulnerable and Intimidated Witnesses Working? Evidence from the Criminal Justice Agencies*, Home Office Online Report 01/06, 2006, pg 69.

⁸¹ Bridget Prentice, Parliamentary Under-Secretary of State for Justice, House of Commons, *Hansard*, column 1384, 10 July 2007.

⁸² *Young People and Vulnerable Adults Facing Forced Marriage—Practice Guidance for Social Workers*, Foreign and Commonwealth Office, Association of Directors of Social Services, Home Office, Department for Education and Skills, Department of Health, March 2004.

Supplementary Memorandum from Voice UK, Ann Craft Trust and Respond

CRIME AND ABUSE AGAINST ADULTS WITH LEARNING DISABILITIES

1. WHY ADULTS WITH LEARNING DISABILITIES ARE MORE LIKELY TO BE VICTIMS OF CRIME

1.1 Although there are multiple and complex reasons why any crimes occur, there are some broad, overarching reasons for the higher risk of an adult with learning disabilities becoming a victim of crime.

1.2 *Vulnerability*

1.2.1 Adults with learning disabilities are vulnerable to crime. They are generally less likely to resist, easier to manipulate, less likely to report a crime and less likely to be believed if they do report a crime than the general population. People take advantage of this vulnerability as they are aware that a crime against an adult with learning disabilities is likely to be easier to execute and to get away with than if they targeted someone else.

1.2.2 Our original written evidence included several cases where carers had taken advantage of the vulnerability they perceived in their clients. In particular, the case of Peter John Clarke, who raped a woman with severe learning disabilities (paragraph 6.2.1), and the cases of theft by carers who had been entrusted to manage their clients' financial affairs (section 6.5).

1.3 *Bigotry and prejudice*

1.3.1 Adults with learning disabilities are also targeted for crime because of their learning disabilities. This disability hate crime was described in our original written evidence (section 3).

1.3.2 The bigotry manifested in disability hate crimes against adults with learning disabilities is simply the extreme manifestation of a wide spread prejudice in our society against people with learning disabilities. An intrinsic part of this prejudice is a feeling that people with learning disabilities are worth less than those without learning disabilities and so are deserving of less respect for their rights. It is this prejudice which makes it easier for a person to commit a crime against an adult with learning disabilities, even if that person is in their care.

1.4 *Social Marginalisation*

A contributing factor is that adults with learning disabilities tend to have low incomes, rely on benefits and live in marginal areas. We suspect this places adults with learning disabilities in a situation where they are more likely to be targeted for crime.

2. ADULT PROTECTION INVESTIGATIONS

2.1 In our original written evidence we highlighted how crimes committed against adults with learning disabilities living in care were not always investigated by the police, or else police involvement came after an internal investigation by the care provider or commissioner. We stated that this inevitably had consequences for the conduct of investigations and the chance of securing convictions.

2.2 Adult Protection Committee Figures

Local Adult Protection Committees produce statistics on the adult protection referrals they have received from various organisations and individuals. Unfortunately, these statistics are collected in different ways, making comparison difficult. Last year Action on Elder Abuse made recommendations on how information collection could be standardised.¹ Since then, Cornwall Adult Protection Committee has revised its data monitoring and collection processes to meet Action on Elder Abuse's recommendations. These figures support our concerns about police involvement in adult protection investigations and are of particular importance considering last year's CSCI and Healthcare Commission report into Cornwall Partnership NHS Trust. Unfortunately, these figures relate to vulnerable adults as a whole rather than just to adults with learning disabilities.

2.3 Cornwall Adult Protection Committee Figures

2.3.1 Between 1 September 2006 and 30 April 2007, there were 255 new adult protection referrals to Cornwall Adult Protection Committee. After investigations and in the period October 2006 to March 2007, 62% of these allegations were found to have been either substantiated or partly substantiated. Yet, only 1% of these adult protection referrals resulted in a criminal prosecution and 3% in police action. The police were involved in only 9% of investigations in this period. While we accept that some of the allegations that were substantiated or partly substantiated will be about abuse rather than crimes, we believe that this factor can not account for why police were involved in so few investigations.

2.3.2 We are concerned that the low number of non-criminal sanctions for perpetrators raises serious questions over whether people are (i) being held to account (ii) being prevented from working again with vulnerable adults and (iii) being deterred from engaging in crime or abuse against vulnerable adults. The figures from Cornwall show only 1% of perpetrators were referred to a registration body, 6% disciplined and 3% referred to the Protection of Vulnerable Adults (POVA) list.²

2.4 Figures from Other Adult Protection Committees

2.4.1 Similar data on police involvement and outcomes is rarely published by Adult Protection Committees and is unlikely to comply with the Action on Elder Abuse's recommendations. However, we have included other figures to allow the Joint Committee some form of rough comparison. These figures suggest that the extent of police involvement in a case varies between areas, but that the Cornwall experience is not unique.

2.4.2 Between 1 October 2002 and 31 March 2005, Shropshire Adult Protection Committee received 398 adult protection referrals. Of these, 6 (1.5%) resulted in a successful prosecution or the issuing of a formal caution.³

2.4.3 North East Lincolnshire Adult Protection records that in 2003-2004 the police were involved in 73% of adult protection investigations.⁴

2.4.4 The Nottinghamshire Committee for the Protection of Vulnerable Adults received 778 adult protection referrals between April 2005 and March 2006. The Committee received forms on the outcome of 492 cases. Of these known outcomes, there were 100 cases which were proven. Of the 492 cases for which outcomes were known, criminal proceedings were undertaken in 19 cases and nine members of staff were referred to the POVA list.⁵

3. FORCED MARRIAGE (CIVIL PROTECTION) BILL

3.1 Since we submitted our original written evidence the Forced Marriage (Civil Protection) Bill [HL] has passed through its Committee and Third Reading Stages in the House of Commons. In response to Jo Swinson MP raising the issue of special measures assistance, MPs related how their constituents with learning disabilities had been forced into marriage. Dominic Grieve MP stated:

*"There is a school in my constituency for children with learning disabilities. I am afraid that there is a consistent pattern of girls being removed at the age of 16 to be sent to the Indian subcontinent—if that is where they originate from—to be married, even though many of them probably have little understanding of what it is they are going to do."*⁶

Ann Cryer MP:

*"Over the years, I have been involved in some very upsetting interviews with families putting pressure on me to allow their son or daughter to bring in a spouse from the subcontinent. They said that they wanted the spouse to take care of their son or daughter. I can understand their problems, but to meet the young boy or girl who clearly did not know what was going on was upsetting, so I should welcome anything that can help young people in such situations."*⁷

3.2 We welcome that the Government reaffirmed during the Bill's Committee Stage that intermediaries and other special measures may be used in forced marriage protection order cases and that it is important to encourage the courts to use these measures.⁸ However, our organisations are disappointed that the Government did not accept the need for an explicit entitlement to special measures provision on the face of the Bill. Instead, Bridget Prentice MP, Parliamentary Under-Secretary of State for Justice, stated that:

*"An early task for us is to discuss with the president of the family division the possibility of his issuing a practice direction to promote the effective handling of such cases in courts that have jurisdiction over such cases. A key element of such a practice direction is to set out what special measures are available to assist vulnerable witnesses in giving evidence."*⁹

3.3 While this does not go as far as we would like, we hope that the Joint Committee will join us in welcoming this commitment to issue a practice direction. We also hope the Joint Committee will recommend that this practice direction be complimented with training for family division judges on how adults with learning disabilities need assistance to give their best evidence and how special measures can assist them in doing this.

3.4 The debate on this Bill has begun to improve the very low profile of the issue of the forced marriage of adults with learning disabilities. We hope that the Joint Committee will help us ensure that this issue does not disappear from view again by addressing the issue of adults with learning disabilities forced into marriage in its report.

4. SPECIAL MEASURES FOR VULNERABLE DEFENDANTS

4.1 Our attention has recently been drawn to a recommendation from the Government's Review of Child Evidence:

"Recommendation 12

*Child defendants should qualify for assistance via a menu of special procedures ensuring that they understand the function and process of the trial and the potential outcome for them."*¹⁰

4.2 We are obviously aware that the issue of special measures for children with learning disabilities appearing as defendants is outside the remit of the Joint Committee's current inquiry. However, we are bringing this to the Joint Committee's attention as we believe it is another indication of the growing recognition of the need for parity between witnesses/victims and suspects/defendants with learning disabilities in the provision of special measures.

25 July 2007

REFERENCES:

- 1 Action on Elder Abuse, *Adult Protection Data Collection and Reporting Requirements; Conclusions and Recommendations from a Two-Year Study into Adult Protection Recording Systems in England, funded by the Department of Health*, 2006.
- 2 Cornwall Adult Protection Committee, *Annual Report April 2006–March 2007*, pg 30–34.
- 3 Shropshire Adult Protection Committee, *Adult Protection Annual Report, 2004–05*, pg 11.
- 4 North East Lincolnshire Adult Protection, *Annual Report 2003-2004*, pg 15.
- 5 Nottinghamshire Committee for the Protection of Vulnerable Adults, *Annual Report 2005–06*, pg 4–8.
- 6 *Hansard*, column 1393, 10 July 2007.
- 7 Public Bill Committee on the Forced Marriage (Civil Protection) Bill [HL], *Hansard*, 17 July 2007.
- 8 *Ibid.*
- 9 *Hansard*, column 643, 23 July 2007.
- 10 Office for Criminal Justice Reform, *Improving the Criminal Trial Process for Young Witnesses; A Consultation Paper*, Criminal Justice System, June 2007, pg 46.

Further Supplementary Memorandum from Voice UK, Ann Craft Trust and Respond

Disability Hate Crime against Adults with Learning Disabilities

1.1 In the last 18 months there have been at least three disability hate murders of adults with learning disabilities. It is possible that prejudice and hostility towards people with learning disabilities played a part in other murders in this period, but that this fact was not identified by criminal justice agencies or these murders received less public attention. The murder of Rikki Judkins, mentioned in our original evidence to the Joint Committee, is likely to be one such case.

1.2 These three murders share several common, interlinking and reinforcing features;

- the vulnerability of the victim;
- the savagery and cruelty of the murder;
- perpetrators who are likely to have seen their victim as worth less than themselves or other human beings because of their learning disabilities; and
- all appear wholly or partly motivated by prejudice and hostility towards people with learning disabilities.

These murders are disability hate crimes and they have received a public exposure unprecedented for disability hate crime. Yet these murders do not resonate in the public consciousness as disability hate crimes—as examples of appalling prejudice and hate that involve the fundamental violation of the human rights of the victims. This is because the term disability hate crime is alien to the vast majority of the population and has not been tied to these murders in people’s minds. This term has not been used to describe these murders in the mainstream media and so, we presume, has not been publicly used by criminal justice professionals to describe these cases. The commonalities we mention above are not being highlighted and the public attention paid to these murders is proving to be fleeting. We fear that these murders, and the lives of these men, will be forgotten by everyone but their friends, families and a few professionals and campaigners. If society is to confront disability hate crime against people with learning disabilities, and the prejudice that feeds it, then everyone must face these murders for what they are and remember them. The public and all criminal justice professionals must know the term disability hate crime in the same way they know the term race hate crime. They must be able to do what we fear at the moment many of them can not do—recognise a possible disability hate crime. There must then be clear, public declarations that such prejudice-fuelled violence is unacceptable and will be robustly dealt with. Only from knowledge and understanding can we hope to address prejudice and achieve the change that will see the human rights of adults with learning disabilities respected.

1.3) The Joint Committee can make a valuable contribution to tackling disability hate crime by highlighting these murders and what they mean. Details of these three murders have recently become available through court cases and media reports, allowing us to provide the Joint Committee with the following information. We also highlight important issues raised by these murders and connect these to the recommendations in our original evidence. Lastly, we note comments from the Metropolitan Police Service on their efforts to address disability hate crime and the first national figures on disability hate crime cases pursued by criminal justice agencies.

RAYMOND ATHERTON

- *“Despite daily visits from social services, Raymond Atherton suffered the most appalling campaign of physical abuse at the hands of ‘feral’ teenagers. They shaved clumps of hair from his head as he slept and daubed makeup on his face. They beat him, urinated in his drinks, smoked cannabis in his flat, scrawled graffiti on his walls and poured bleach over him. On May 8 last year, the 40-year-old was viciously beaten by two of his tormentors and thrown into the river Mersey in Warrington, Cheshire, where he died.*

At the trial in April of his persecutors, Craig Dodd, 17, and Ryan Palin, 15, were jailed for life for manslaughter . . . Mr Justice Hodge told the teenagers: ‘You both treated Mr Atherton as a punchbag. What you did was not opportunistic. It was premeditated, it was a savage attack: cruel, brutal and vicious, and on a very vulnerable man.’

Yet although Atherton, who had a learning disability and a history of alcohol abuse, was in the care of social services, there is no suggestion that he was failed by the system. Atherton was proud of living independently in the community and did not want to move to supported accommodation. In addition, because of his vulnerability, whenever social workers noticed he had been beaten up, Atherton was unable to provide dates of incidents or the names of his abusers. He was unwilling either to report incidents or to seek medical help for his injuries.

...

Three years ago, he lost touch with his mother and had moved to Warrington, where he was targeted by youngsters including Dodd and Palin. He was befriended by groups of teenagers who abused his kind, gentle nature and exploited his vulnerability. Social services moved him once because of the teenagers, but the trouble followed him to his new address.

...

Reports prepared while Palin and Dodd were on remand showed they had no empathy with their victim nor any understanding of what they had done.”¹

2.1 We are not aware of Mr Atherton’s murder being referred to as a disability hate crime, despite what we know of it bearing all the characteristics of one. As section 146 of the Criminal Justice Act 2003 places a duty upon courts to openly state that an offence is receiving a harsher sentence because it is a disability hate crime, this means that one of three outcomes has occurred in this case. The first possibility is that this case was not recognised as a disability hate crime by criminal justice professionals or, after consideration,

these professionals concluded this was not a disability hate crime. The second possibility is that the judge did increase the sentences of Dodd and Palin because of s.146, but did not publicly state this. The third possibility is that the judge applied s.146 and did state this, but this fact has not been reported by the media. All of these possible outcomes are unsatisfactory in some way. In particular, all involve at least one party failing to provide public recognition of disability hate crime. Criminal justice professionals must identify disability hate crime and publicly emphasise it in cases where it occurs if these crimes are to be effectively addressed.

2.2 Mr Atherton's case also highlights the importance of ensuring that people with learning disabilities (i) know that crimes against them are unacceptable (ii) know how to report disability hate crime (iii) receive appropriate support to enable them to make such reports and (iv) feel confident that any report they make will be responded to appropriately. Accessible information, support from independent advocates and education might reduce unwillingness to report incidents similar to Mr Atherton's. These are likely to be most effectively provided by local schemes which involve social services departments, police and non-governmental organisations (such as we noted in 3.3.1.2 of our original written evidence). Police involvement in such schemes is particularly important because of, an all too often real, perception amongst many adults with learning disabilities that the police will not be interested in pursuing a report of a disability hate crime. If frontline police officers meet with adults with learning disabilities to discuss reporting crime and what incidents they are experiencing it is likely to challenge assumptions held by both parties, leading to more reports of disability hate crime and a more effective response. If criminal justice professionals give disability hate crime a higher public profile by publicly emphasising the role of disablism in particular cases, this will also encourage adults with learning disabilities to report such crimes.

2.3 In cases similar to Mr Atherton's, this support might help adults with learning disabilities to report crimes and harassment against them as an early stage. If disability hate crime and harassment is reported early and robustly responded to by police and social services, then there may be less chance of any escalation in the nature of the disability hate crime (eg assaults turning to murder). We do not second guess the social services department responsible for the care of Mr Atherton—it appears they acted appropriately in helping him move home and in enquiring about his injuries. They may also have faced a difficult conflict in wanting to respect his wishes to not report incidents while wanting to ensure his welfare. Instead, we note how, when harassment and relatively minor crimes against Mr Atherton were not robustly challenged, a pattern of behaviour with the potential for escalation was able to develop. Robust action by police and social services is needed to send a clear signal that such behaviour is unacceptable and must end. This may not only end campaigns of disability hate crime against particular individuals, it may begin to challenge the prejudice that underpins such crimes.

STEVE HOSKIN

— *“A 17 year-old girl and her boyfriend were jailed yesterday for torturing a friend with severe learning difficulties before forcing him to fall to his death from a 100ft (30m) railway viaduct. Sarah Bullock, who was 16 at the time laughed as she stamped on the hands of Steven Hoskin while he clung to the viaduct in St Austall, Cornwall, was sentenced to 10 years for murder. Her boyfriend, Darren Stewart, 30, was jailed for 25 years for murder and Martin Pollarn, present when Mr Hoskin fell, was jailed for eight years for manslaughter.*

...

The court heard after moving into his flat, the couple used Mr Hoskin, 38, as their slave, making him wait on them. They forced him to wear his own dog's collar and dragged him around with a lead. On the day of his death, 5 July last year, they forced him to falsely confess that he was a paedophile then beat him, stubbed cigarettes out on him, forced him to swallow 70 painkillers and marched him to the viaduct. Mr Hoskin was terrified of heights but his tormentors told him there were snipers in the bushes who would kill him if he did not climb the bridge.”²

“They took pictures of him sitting against a wall under graffiti spelling out the words “scum bag” and “should be hung”. Then in July last year—after torturing him for an hour and a half—they force-fed him 70 paracetamol. Along with their friend Martin Pollard, 21, they then made him falsely confess to being a paedophile and frog-marched him to a viaduct in the middle of the night. As they lead him to his death, Mr Hoskin—who was terrified of heights—was convinced he would be shot by snipers if he cried out for help.

*Bullock ordered him to dangle over the edge, where he clung on to a set of railings, before she kicked him in the face and stamped on his hands, shouting “Come on you f***ing pr**k”.*

...

Mr Justice Owen said their victim had been “bullied to death”. He said: “Your victim was a highly vulnerable man with severe learning difficulties.”

“He was subjected to substantial mental and physical cruelty in which he was violently assaulted, degraded and humiliated. A dog lead was put around his neck. He was dragged around and forced to lick split drink from the floor. Cigarettes were stubbed out on his head”.”³

3.1 A notable similarity between the murders of Mr Hoskin and Mr Atherton is that they both involve a vulnerable individual taken advantage of by people whose harassment, exploitation and assaults escalated into murder. For this reason, we believe that our comments above on the importance of supporting adults with learning disabilities to report crime and early action may hold true for Mr Hoskin.

3.2 As with Mr Atherton, media reports of Mr Hoskin's case have not referred to this murder as a disability hate crime.⁴ However, Crown Prosecution Service (CPS) Devon and Cornwall has made the following statement regarding Mr Hoskin's case which indicates that it was considered as such a crime by the trial judge.

"I have been asked to respond to the question of whether or not Sec.146 CJA 2003 played any part in the prosecution of this case, or to be more precise, whether or not the Sentencing Judge paid due regard to the fact that this was a disability hate crime.

Although I only attended the sentence of this case I can unequivocally confirm that due consideration was given to Sec.146. Mr. Mercer, QC, for the defendant Stewart, conceded in his mitigation that the vulnerability of the victim was an aggravating feature (together with the suffering he was made to endure).

Mr Justice Owen, who referred to the offence, in terms, as a hate crime told Stewart that he took as a starting point a term of 15 years (before the possibility of parole) but he had to take account of the aggravating features. First among these aggravating features was the vulnerability of the victim, the Judge saying that a witness had described Mr Hoskin as "a child in a man's body". He added that Stewart had "betrayed the friendship he simply gave you", and that he had subjected him to a prolonged period of physical and mental torment, "you literally bullied him to death". Taking into account these aggravating features Stewart was sentenced to life imprisonment and ordered to serve a minimum of 25 years.

I am in no doubt whatsoever that Mr Hoskin's disability was to the forefront of the Judge's mind when he sentenced these offenders."

3.3 Our organisations are delighted that s.146 was applied in this case. We thank the police, CPS and Mr Justice Owen for ensuring justice for Mr Hoskin. However, from the CPS we understand that Mr Justice Owen did not explicitly refer to disability hate crime when passing sentence and we are concerned by this. As we have stated, it is vitally important for challenging disability hate crime, and the prejudice that fuels it, that it is made very clear when s.146 has been applied.

BRENT MARTIN

— *"Three people were charged last night with the murder of a man with learning difficulties who died at the weekend after he was beaten up in the street near his home. Brent Martin, 23, was dragged along by his belt during the attack before being left bloodied and dying. He was found by neighbours and his uncle with his underpants and trousers around his ankles, his family said. The beating, on a council estate in Sunderland on Thursday night, was so severe that sand was thrown on the pavement to cover the blood. Mr Martin died in the early hours of Saturday with his family by his bedside.*

...

It was unclear why Mr Martin was targeted, but police suggested that he may have been picked on for his learning difficulties.

...

Detective Superintendent Barbara Franklin, who is leading the murder investigation, said: "... There is no motive for the assault but children often bully people with learning difficulties".⁵

4.1 To the best of our knowledge, this is the first time a police officer has been reported in the media connecting an attack to a victim's learning disabilities. As such, it is a milestone which we welcome. However, we are disappointed that the officer does not state that prejudice and hostility towards Mr Martin because of his learning disabilities appears to be the motive. To say that there is no motive and then make the connection to learning disabilities is an odd half-way house that makes little sense. This, together with the failure to explicitly refer to Mr Martin's murder as a disability hate crime, undermines any message that disability hate crime exists and will be robustly dealt with by the police. It also fails to do justice to Mr Martin.

4.2 Stating that "children often bully people with learning difficulties" seems to show a lack of awareness of the seriousness of the crimes that are committed against people because of their learning disabilities. It also grossly underplays the seriousness of a brutal murder.

We hope that this statement by Detective Superintendent Franklin is not indicative of some police officer's understanding of disability hate crime. It reinforces our belief that police officers must be trained on disability hate crime if they are to effectively investigate it and ensure justice for its victims.

COMMENTS BY COMMANDER ROD JARMAN, METROPOLITAN POLICE SERVICE

Commander Rod Jarman, Metropolitan Police Service lead for the Safer Neighbourhoods Programme as well as Association of Chief Police Officers Lead for Mental Health and Disability, recently participated in an online interview in which he answered questions submitted by members of the public. Commander Jarman's response to a question by a journalist from Disability Now provides useful information on the challenge of investigating disability hate crime and how the MPS is attempting to meet it.

KATHARINE QUARMBY

- *“There have been a number of high profile cases in which disabled people have been brutally attacked, tortured or murdered in recent months. Most have been described by the SIO's leading the investigation as “motiveless” or “senseless”.*

Do you think that police officers are sufficiently aware that such cases may indeed be disability hate crimes? Having looked in detail at four cases where disabled people were killed, I have established that police officers did not attempt to establish whether disability hate crime played a part and did not highlight that as an aggravating factor when they forwarded on their files to CPS.”

COMMANDER ROD JARMAN:

- *“I think I'd like to start off with saying this is an extremely important area of how policing is delivered and considered. The whole emphasis of policing must be protecting those who are vulnerable and those who are vulnerable because particular people who are targeting them comes high up the agenda.*

In London, our response to hate crimes against people with disabilities is robust in order to prevent other people believing it's an appropriate way of behaving. In London, we have a number of policies that our officers have to follow in order to ensure the level of service provided to victims who are the subject of hate crime is significantly higher than it is for victims of other crime. The difficulty comes, which I think is where you're trying to get at in your question, between our own ability to identify and provide this enhanced service and the other factor, which is our ability to prove that there was an aggravating factor in the case, which was one of disability hate. That second factor has to meet an evidential standard which is set within the law and which requires us to be able to objectively prove beyond reasonable doubt that it was the motivation behind the attack. That is difficult, and if you look in race hate crime you will see that whilst we identify a large number of crimes as racially motivated and provide an enhanced service to the victims, a very, very much smaller number are eventually charged with racial aggravation on top of the original crime.

I've given quite a complex answer and I'd just like to try and break that down into 2 simple points. The first one is, we have standard operating procedures; we have trained and we have put in place community safety units across London to provide an enhanced level of investigation and support to victims of hate crime, but in the cases that you've raised we have clearly not been able to prove the aggravating factor to a sufficiently high level in order for us to put it before the courts. I think that over time there will be more cases where we do prove that aggravating factor, that this is just an indication of the complexity of investigating and dealing with hate crime.”⁶

NUMBER OF CASES

The difficulties described by Commander Jarman are likely to play a part in the very low number of cases of disability hate crime so far recorded this year—just 20 cases, of which 18 were characterised as successful.⁷ The experiences of our organisations and the studies on disability hate crime which we cited in our original evidence (see 3.2) give us reason to believe that this is just a tiny fraction of the disability hate crimes that have occurred in this period. We believe that lack of reporting by adults with learning disabilities, as well as failure by criminal justice professionals to identify crimes as disability hate crime and / or investigate such crimes, are likely to be reasons for this low figure.

This reinforces the urgent need for measures to ensure adults with learning disabilities report disability hate crime and training for the police on such crimes.

These murders highlight how disability hate crime is an appalling infringement of the human rights of adults with learning disabilities. They also highlight how relatively simple steps to tackle disability hate crime are not being taken. We hope that the Joint Committee will note these murders in its report and recommend the steps we have suggested as a means to address violent prejudice and hostility towards adults with learning disabilities.

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- ¹ Carter, Helen, *“He couldn’t say no”*, Society Guardian, 15 August 2007.
- ² Morris, Steven, *Three jailed for forcing man to fall 100ft to his death*, The Guardian, 31 July 2007.
- ³ Salkeld, Luke, *Evil teenager bullies man with learning difficulties to death*, Daily Mail, 30 July 2007.
- ⁴ The one exception we are aware of is: Quarmby, Katharine, *If these are not hate crimes, what are?*, Disability Now, September 2007.
- ⁵ Condron, Stephanie, *Gang dragged victim by belt to his death*, The Times, 27 August 2007.
- ⁶ Commander Rod Jarman, Metropolitan Police Service, interviewed on the Disability Agenda website, 10 August 2007.
- ⁷ Quarmby, Katharine, *If these are not hate crimes, what are?*, Disability Now, September 2007.
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71. Further supplementary memorandum from Voice UK, Ann Craft Trust and Respond

DISABILITY HATE CRIME AGAINST ADULTS WITH LEARNING DISABILITIES

1. Our supplemental evidence on disability hate crimes against adults with learning disabilities (dated 3 September 2007) included a statement from the Crown Prosecution Service (CPS) Devon and Cornwall on the case of Steven Hoskin. We told the Joint Committee that this statement indicated that Mr Hoskin’s case had been considered as a disability hate crime by the trial judge and that section 146 of the Criminal Justice Act 2003 had been used to increase the sentences of Mr Hoskin’s killers. In addition, we stated that the trial judge had applied section 146 but had not stated this as required to do by this section of law.

2. These assertions were made on the basis of e-mail correspondence and telephone conversations with the CPS. During these communications we noted some ambiguity in the statement from CPS Devon and Cornwall and sought clarification from the CPS as to whether section 146 had been applied. We were informed by the CPS on two occasions that section 146 had been applied in Mr Hoskin’s case, but that the trial judge had not stated this.

3. The CPS has recently informed us that Mr Hoskin’s case was not a disability hate crime and that the trial judge did not apply section 146 during sentencing. The CPS has told us that a misunderstanding arose because of the ambiguity of the initial statement from CPS Devon and Cornwall and that this led to incorrect information being supplied to us. We then, in turn, passed this information on to the Joint Committee.

4. In correcting this misunderstanding, the CPS has informed us that the prosecution fully considered the applicability of section 146 in Mr Hoskin’s case and decided that it did not apply. The rationale for this decision is as follows:

- Those who tormented and then killed Steven Hoskin were not motivated by hostility towards him as a result of his disability. He was set upon initially by them because he was suspected of having informed a store detective that Sarah Bullock had been involved in an offence of shoplifting.
- Thereafter, Mr Hoskin was forced to confess to being a paedophile. This enflamed his captors who treated him with escalating brutality.
- There was no evidence that at any stage Mr Hoskin’s ill-treatment was prompted by hostility arising from his learning disability. On the contrary, right up until his final moments he was berated for having given information.
- Section 146 does not apply to the facts of this case.
- Steven Hoskin’s disability made the offences more shocking, but was not the motive for their commission.
- However, it would be quite wrong for anyone to suppose that Steven Hoskin’s disability was not central to the sentencing exercise. There should be no doubt in anyone’s mind but that Steven Hoskin’s disability was very much a factor in the judge’s sentences in this case.

5. We would like to thank the CPS for clarifying this matter and for their kind apology for this unfortunate misunderstanding. The CPS has been very helpful in clearing this misunderstanding up and we thank them for their assistance.

6. We are pleased that Mr Hoskin’s disability was a factor in determining the sentences of his killers—this is a just response to this tragedy. However, for us, there are still some lingering issues in this case and these issues may never be resolved. In particular, there is the issue of whether Mr Hoskin’s killers felt able to treat him in the manner in which they did because his learning disabilities devalued or dehumanised him in their minds. Also, to what extent Mr Hoskin’s learning disabilities meant he was unable to successfully rebut accusations of having told a store detective that Bullock was shoplifting and of being a paedophile.

7. Our organisations apologise to the Joint Committee for any inconvenience this misunderstanding has caused and for inadvertently supplying information which we now know to be incorrect. We hope that the clarifications provided in this document will assist the Joint Committee in their consideration of disability hate crimes against adults with learning disabilities.

7.1. This consideration may be helped by statistics on disability hate crime prosecutions which the CPS has kindly supplied to us in the last couple of weeks. These supplant the only previously available figures which were contained in an article in *Disability Now* and which we quoted in our supplemental evidence on disability hate crime.

7.2 Between April and September 2007 there were 68 cases of disability hate crime prosecuted in England and Wales. Of these, 57 resulted in a successful outcome.

7.3 The criminal justice system deserves congratulations for this 84% success rate in disability hate crime prosecutions. Unfortunately, 68 prosecutions is still far below the levels of disability hate crime indicated by surveys of people with learning disabilities and which was referred to in our original evidence.

Please feel free to contact us if we can be of any further assistance.

3 December 2007

Memorandum from the National Family Carers Network

1. INTRODUCTION

The National Family Carer Network (NFCN) brings together groups and organisations that support families, which include adults with a learning disability. By linking groups and organisations, the network gives a national focus to a wide range of policy issues concerning family carers of adults with a learning disability. These family carers increasingly include people with a learning disability who are family carers in their own right, caring for or supporting children, partners, parents or friends.

The Network supports family carer representation on the National Learning Disability Task Force and the Commission for Social Care Inspection's Learning Disability Improvement Board. By offering a coordinated response to national consultations, and through information sharing (including the maintenance of a database of groups and organisations), the Network provides a mechanism for sharing ideas and the development of good practice in support for families that include an adult with a learning disability. The Network also circulates a regular newsletter, highlighting national developments and holds regular events in different regions to enable groups, organisations and individual family carers to come together to share ideas in person and to contribute collectively to national policy and review.

Our key objective is to work together to promote better life chances for families that include someone with a learning disability.

2. FAMILY CARERS IN CONTEXT

2(i) It is estimated that there are around six million family carers in the UK—10% of the total population. Of these about a third are estimated to provide support for more than 20 hours a week. Women of working age form the largest group of family carers, providing support typically to parents, partners or older children. However, around 58% are thought to give up paid employment because of pressures of caring and variable local support. Around 175,000 young people under the age of 18 are also carers.

2(ii) Although there is no national data on the breakdown of family carers between different impairment groups, it is estimated that around 60% of adults with a learning disability live with their parents or with another family member. Although a growing number of people with learning disabilities are forming relationships and having families, there is considerable concern at the numbers of children removed for fostering or adoption and the lack of appropriate support for the parents' caring roles.

2(iii) The NFCN is aware of increasing numbers of people with learning disabilities who are becoming family carers. This population is likely to increase, as life expectancy improves for all disabled people and people with learning disabilities are living in family or their own homes in local communities. The numbers of people with learning disabilities living with elderly parents or relatives (ie over the age of 70) is increasing. In many cases there are no reliable arrangements made for their future.

2(iv) Financial hardship characterises many family carers. The Disability Rights Commission estimates that families with a disabled child earn 17% less than other families and are 50% more likely to be in debt. Some estimates put the numbers of families with disabled children living in poverty as high as 50%. One in three children living in poverty also has a disabled parent. Child poverty predicts poorer life chances, which contribute to social exclusion in adulthood.

2(v) People with Learning disabilities should not be regarded as isolated individuals—they are sons, daughters, brothers, sisters, friends, cousins etc. These relationships are important and are often the “gateway” to participation in the community and the “active citizenship” to which we all aspire. Families often act as powerful advocates for their disabled relative, providing practical support, information and the means to challenge authorities regarding access, provision and quality of service. If family members are not adequately supported in this role, it will impact not only on their lives but also on the lives of their learning disabled relative. This support includes the need for practical support as well as information that is timely and appropriate.

2(vi) People with learning disabilities who do not have active family members who are able to advocate for them, as noted above, can be substantially disadvantaged. This situation is magnified if the individuals have profound or complex needs. The lack of appropriately funded advocacy for people with complex needs denies them an effective “voice” that is independent and focussed on their needs. Families (like people with learning disabilities themselves) frequently seek independent advocacy but it is seldom available.

2(vii) Family carers too often provide the “fall back” position for their learning disabled relatives: if services break down or encounter difficulties, it is often the families who step in to provide support for their relatives, usually with insufficient support for themselves. This has implications for the human rights of both the person with a learning disability and the family carer. There are frequently difficulties in translating policy into practice.

2(viii) Many families have insufficient information about their son’s and daughter’s entitlements, or indeed the possibilities and range of support and services available. For example, a family carer contacted a voluntary organisation regarding her 24-year-old son’s respite care. He has learning disabilities and complex healthcare needs and lives with her. She described herself as “absolutely desperate” for a break and was told that he could have a direct payment to buy respite in a residential nursing home for the elderly. She felt this was inappropriate and unacceptable especially as it would mean that he would be unable to attend his regular day service due to “double funding” (of the residential place and the day service). The carer organisation contacted the local authority. The situation was resolved, and the family carer wrote:

“I cannot quite put into words what I will feel if this all works out for us. Thank you so much for your prompt support when I so needed it. The carers’ meeting showed how much of an interest and need there is for information and support. I have now got the real facts on what practical support and respite can and cannot be had without benefits being affected. Thank you again for helping me and being a champion of carers in general.”

This family carer’s story raises important issues about information and support for family carers and people with learning disabilities and the role of carers’ support groups, Partnership Boards and of course organisations of people with learning disabilities in providing information and support in their areas.

2(ix) Family carers have high expectations for their relatives with a learning disability. But some families face particular challenges in achieving these expectations. For example, there is particular concern that family carers of people with learning disabilities who are still living in campus provision are not being adequately supported in ensuring that wherever possible, their relatives move to independent living in the community. New and positive initiatives for disabled people, such as self-directed services, direct payments and individualised budgets are broadly welcomed but there is concern that these should be adequately funded to include support for co-ordination, facilitation and independent brokerage (particularly for people with complex and high individual support needs). Often family carers adopt a significant unpaid role in developing, co-ordinating, managing and maintaining complex packages of support. Whilst some families choose this role, it should not be assumed that they are willing and able to adopt it on a long-term basis, nor should those people with learning disabilities who do not have access to such support be disadvantaged as a result.

2(x) People with learning disabilities and their family carers face particular challenges when there is a diagnosis of “challenging behaviour”. Challenging behaviour is a widely used term, but the agreed definition amongst LD professionals is:

“Behaviour of such an intensity, frequency or duration that the safety of the person, or others, is placed in serious jeopardy, or behaviour that is likely to seriously deny access to and limit use of ordinary community facilities. Challenging behaviour can take a variety of forms including aggression, self-injury, disruption (of others), destruction (of the environment) and stereotyped behaviour.”

There is ample evidence to demonstrate that people with learning disabilities and challenging behaviour are amongst the most disadvantaged in our society—they and their families may be excluded from some of the more exciting developments around independent living and employment and they are at particular risk of being placed in services at a considerable distance from the family home. The Department of Health is currently revising the Mansell Report—but ten years on the conclusions and recommendations in the original report are still relevant. Many of the recommendations have not yet been implemented in order to improve services and support both for people with learning disabilities and their families. Particular challenges include:

- The use of physical restraint.
- Access to family and community life.

- Access to appropriate support & understanding & management of their behaviour Exclusion from services—resulting in out of area placement.
- Exclusion from further education—local FE colleges are not designed to meet the needs of people with complex needs, either in the environment, the curriculum or the skills of teaching staff.
- Excessive or inappropriate use of medication.

2(xi) We make special reference of challenging behaviour because of growing evidence in children's services of official (and unofficial) "exclusions" from school and children's services. These exclusions, which affect people with challenging behaviour and families throughout their life-cycle, can blunt expectations and dramatically affect the life chances of both people with learning disabilities and family carers. We also note that in many areas, there are poor connections between learning disability and mental health services, which can have serious consequences in terms of late and often crisis interventions.

2(xii) Because many children with learning disabilities and challenging behaviour are sent out of area, the transition to adult services is frequently problematic, with the home authority lacking expertise and capacity to make appropriate provision. We recommend that there should be national and regional strategies to plan provision for people with complex needs (in particular challenging behaviour) and that families should be given appropriate information and support before crisis point.

3. THE PROVISION OF PUBLIC SERVICES—ACCESS TO SOCIAL CARE

3(i) Families and people with learning disabilities have welcomed the policy shift away from block contracts to self directed care (eg through Individual Budgets, In Control, Direct Payments etc). But there is widespread concern about tightening eligibility criteria and a "postcode lottery" in the provision of support and services.

3(ii) Spending on adult social care by councils is reported to have increased by 65%, with the Local Government Association (LGA) claiming that spending for people with learning disabilities represents the biggest increase in expenditure (around 100%). The increase in expenditure (with parallel reports of unmet needs) is not only due to increased demand, due to improved life expectancy and higher expectations. The LGA claims that councils are having to increasingly "pick up the tabs" as a result of cuts in NHS budgets and Learning and Skills Council funding for people with learning disabilities. The supporting people grant has been reduced and the Disabled Facilities grant is generally regarded as insufficient.¹⁵⁵

3(iii) Money matters! Tightening eligibility criteria have been accompanied by widespread introduction of charging for services provided through the local authority. In some instances, this may make a service too expensive for a family to continue using. The formation of the Learning Disability Coalition indicates the degree of concern amongst disabled people, family carers and commissioners in local authorities about the current funding arrangements for social care.

3(iv) NFCN has heard widespread concern about variable eligibility criteria (and very varied interpretation of the Carers (Equal Opportunities) Act 2004. Many families point out that practical and affordable support at the time of day they need it (eg to help someone get up in the morning so that he can attend college and his mother get to work!) can keep a whole family out of poverty.

3(v) Services too often focus on crisis intervention rather than improving the life chances of disabled people. One family carer was incensed to be told that "*one bath a week was sufficient for her son (who had a physical impairment and was incontinent following a stroke)*" and being informed that if she wanted more than a "*blanket bath*", she could use a private agency or ask friends or other relatives to help. She noted that:

*"Personal dignity, respect for privacy are cornerstones of the Human Rights Act and surely should be respected by a local authority."*¹⁵⁶

3(vi) Family carers, like people with learning disabilities themselves, want services designed to support independent living. Expectations are changing and family carers and people with learning disabilities are ambitious for services, which improve life chances and move beyond traditional models of service provision. As noted above, the introduction of Individual Budgets, Direct Payments and identification of need based upon person-centred planning has been widely welcomed. However, many families are concerned at the barriers, which they face in enabling their adult sons or daughters to lead "ordinary lives". There has been widespread endorsement of the Independent Living Bill, with the Disability Rights Commission noting that:

"Independent living means ensuring that disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, work and in the community. It does not mean living by yourself or fending for yourself. It means the right to the practical assistance and any necessary support in order to participate fully in society and to live an ordinary life."

¹⁵⁵ Reported in the DRC (2007), The Disability Agenda and also in "Choppy Waters Ahead for Social Care" (report of a joint DRC/Guardian Roundtable on the future of social care, Spring 2007)

¹⁵⁶ Comments from family carers and people with learning disabilities are used with permission, but names have been changed to provide anonymity. These personal views come from NFCN members and from workshops and interviews carried out by Philippa Russell with reference to her guide to the Carers (Equal Opportunities) Act 2004, op cit.

However, many family carers (and people with learning disabilities find their lives anything but “ordinary” at the present time. One mother noted that:

“We wanted our daughter (with a learning disability) to have the same life chances as her sisters. We were able to help her get a house of her own, a little house in the area she wanted to live in. But we could never organise the support at the right time. Worst of all, the evening support workers wanted to ‘put Jenny to bed’ by 8.15pm each night—even though she was a very lively 22 year old! We were told that the block bookings worked that way and we could take it or leave it. Jenny was despondent, no social life, nothing so we started driving her to and from the club, the coffee shop and the places she wanted to go to. But it’s killing us—and it’s killing her, having elderly Mum or Dad huddled on a street corner waiting to pick her up! In theory she could have a Direct Payment and we could pay someone of her own age to go out with her and see her safely home. But our local authority says that leisure activities are not social care! We say getting a life with your friends costs a lot less than traditional day services—but evidently getting a life is a low priority. And it’s VERY tiring for us!”

Another mother¹⁵⁷ noted that:

“Independent living should mean supporting the life chances of both family carers and the person with a learning disability. Our son has a college place—after many battles he got the support he needed, but he needs help getting up in the morning. I have had major surgery and I cannot manage to lift him, even with a manual hoist. The local authority and PCT agreed to joint-fund some limited domiciliary help to support Peter first thing in the morning and see him off in the taxi to college. That meant I could continue to work part-time and we were better off in every way. I got a Carers’ Assessment (many families still don’t know about it!) but the contract with the domiciliary service agency changed. Now the ‘morning shift’ is often late. It’s usually someone we don’t know and if Peter isn’t up, the taxi drives off without him. That means I can’t work either—we are getting poorer each month. Really it would make such sense to give us an Individual Budget, which was sufficient to employ regular support. If only Peter could get the Disabled Students’ Allowance? But he’s at college, not university, so he can’t. And we’re told that we don’t meet the eligibility criteria so we have to struggle on. It’s such a pity because I think Peter could get a job if he finishes his college course. He is so depressed—and so am I!”

Another parent cited a “lack of appreciation of people’s human rights” when her daughter became too heavy for her to help up the stairs to the house’s only bathroom and toilet. She was incensed that the local authority initially refused a Disabled Facilities grant. On appeal and with the support of her MP, the decision was over-turned. This mother pointed out that:

“When ‘Della’ was a child, somehow nobody seemed to think she would grow up. She did grow up—into a tall and heavy young lady. My back simply gave up. We started keeping a commode behind the curtain in the sitting room. What does that do for someone’s self respect and dignity? Some days Della didn’t want to come downstairs, she hated that commode and she knew my back was hurt. The downstairs accessible shower-room made such a difference—and we’ve saved social services a lot of money because really I thought Della might have to move into a group home if I couldn’t cope.”

This mother attributed some of the problems to:

“Multiple and un-joined up assessments for everything—I think all our assessments must have cost as much as the accessible loo in what was our garden shed! It was all so undignified—what criteria could anyone have for saying it was OK for a grown woman to go to the toilet in the family sitting room?”

She also noted that:

“Getting a Carers’ Assessment was a nightmare. I may be entitled to one, but getting it! Really it’s so silly to dodge the carers’ needs. If I’d broken down and walked away, what would they have done?”

“Jenny” (personal communication from a family carer who has a learning disability) told us that:

“Nobody really thought of me as a family carer—but when Mum had a stroke, I did everything round the house. I wanted to, I was good at it, but I got tired. I needed a break, to go to my club and to the church. My friend told me about the Carers’ Assessment and I asked for one. My social worker said to me, you’ve got an assessment and a direct payment—I said yes, but this is about being a carer. She didn’t say anything for a bit, then she said, ‘yes I see’. I got my assessment and I have some extra help for Mum. It’s good for us to get out and about. I go to the local Carers’ Group too. They’re nice, I’ve got new friends. I feel good about myself.”

3(vii) The concerns raised by family carers above are replicated in a wide range of issues raised by families who attended workshops run by HFT’s Family Carer Support Service.

¹⁵⁷ Parent respondent to survey, cited in Philippa Russell, “Care Matters: a Guide to the Carers equal Opportunities Act 2007, Elizabeth Nuffield Educational Fund

4. AN “ORDINARY LIFE” AND HOUSING

4(i) Many families felt that housing and a “place to live” were important omissions from wider discussions and assessments about future services and in particular about transition planning. Most families did not have relevant information on housing options. They felt they had not been encouraged to think ahead and were generally told of funding problems and cost issues in any possible independent housing arrangements for their son or daughter.

4(ii) this lack of information means that people with learning disabilities were often not registered with the local authority’s Housing Department (which in turn had no reliable data on future need). Some families were reluctant to discuss future housing options because of raising expectations, which could not be met. A number of families highlighted the importance of opportunities to acquire independent living skills so that a transition from the family home was a realistic option. They also emphasise that housing needs should be regularly reassessed.

“We know of the sister of a woman with a learning disability who now has to sleep on the sofa in her living room every night. She brought her sister to live with her when her elderly parents could no longer look after her safely. It’s not a good situation for anybody. We also know of a father who has had to give up work to help his wife care for their son. It’s not that the young man needs so much extra care. But the stair-lift is now unsuitable and unsafe for him, it requires a degree of mobility to use it and he can’t manage any more. So his father has given up work to lift him when required. In both these cases help with equipment to make housing safe—or new housing to meet changing needs—would make such a difference.”¹⁵⁸

4(iii) There is little evidence that people with learning disabilities—or family carers—are prioritised within local housing strategies. The Disability Rights Commission has pointed out that many local authorities are not aware of the numbers and location of accessible housing in their area. Additionally, disabled people living in a family home may be deprioritised because they are accommodated, albeit wishing to have greater independence and a “home of their own.” In the past few years a growing number of families have helped their son or daughter with a learning disability to purchase their own home, but families may have received limited information on this and other options. Some families have experienced problems in moving with their relative to other authorities, where housing may be cheaper and where the family may have relatives or other connections. One father reported that:

“Of course we do not want people with learning disabilities shunted off to distant care homes miles from family and friends. But equally citizens of the EU are in theory allowed to move freely and live anywhere within the member states. But not our sons or daughters! We have an adult son with a learning disability, who has a partner, and they want a home of their own. There is no suitable housing in our city but we have strong family connections in another area. We found suitable housing—and support—so that our son and his partner could have their own home and we would live nearby (with two more relatives down the street). Both were enthusiastic about moving to a small town with lots of activities. But we were firmly told that we could not transfer the care package—or even the funding—to the new area. Our son and his partner were apparently ‘ordinarily resident’ in London and that’s where they belonged. We managed to sort it out, but it seems an abuse of human rights in the 21st century that the crucial decision about where you live should rely on a poor-law definition within a 1948 Act! Why shouldn’t our son and his partner move, just like us, to an area they like and where their care is actually cheaper? Other people move all the time—why not people with learning disabilities, if it is their choice?”

5. THE CHALLENGE OF REDUCING SOCIAL ISOLATION

5(i) HFT, in their “Bridging the Divide” research into the transitions of young people with learning disabilities, found major concerns amongst parents as to how their son or daughter would fare in adult life without the friendships and social opportunities enjoyed whilst they were in schools. However, the development of social networks and friendships was hardly ever considered in planning meetings.

5(ii) Many parents (at very different ages and stages in their lives) related how they had taken responsibility for helping their relative to maintain social relationships and “get a life”, often in the way families with younger children might more usually expect to—through setting up and running or seeking out and transporting them to activities, including them in what they themselves are doing, finding holidays that will suit their needs and interests etc. This means that family carers and their relatives both frequently lack spontaneity in what they are able to do. Over time, in very many situations, this isolates those who care for and about someone with learning disability from their wider family, neighbours and society at large—in turn exacerbating the likelihood of restricted potential networks for the person with learning disabilities.

¹⁵⁸ Personal communications from family carers

5(iii) Parents and other family carers were very clear about the importance of social networks and independence and choice for their relatives in what they decided to do. One father noted that:

“We fought long and hard to find friends and interests for ‘Edward’. We got to know a range of people and clubs and leisure services, which we would never have met otherwise! We did have a Direct Payment to help with travel and so on, but it took so much work. Now we are producing a local directory through our Partnership Board. But we are still subsidizing Edwards’ interests. He belongs to a sailing club and we pay the subscription. He goes to the gym regularly—he has a real obesity problem. And he also goes to our allotment. He’s made some friends there over his onions and carrots! But we were horrified to find that although the Government has introduced some special schemes to help disadvantaged people get fit and lose weight, our local authority didn’t really want to know. They said healthy living wasn’t social care—we had to ‘dress it all up’ as short breaks for myself and my wife. I didn’t want to say I needed a break from Edward—I didn’t. I just wanted him to get a life. Silly thing is, if he gets ill and we get old, he’ll cost a lot of money. I hate playing games.”

5(iv) A key message from family carers is that assessment matters—from childhood through to adult life. A number of family carers commented on the variable quality of transition planning—and the fact that transition planning was usually “finished and done with” at much too early a stage. One father commented that:

“If you have a learning disability (or you are a family carer) you seem to be assessed all the time. It’s like being an old car, all those endless MOT tests. And worst of all, the worse you are, the more you get! That’s why person centred planning matters—it’s about a career pathway not a placement. But why won’t children’s and adult services talk to each other? My child achieved so much at school—so many talents—and nobody seemed interested when he moved to adult services. Transition plans should be regularly updated—and how about having a transfer of a statement from school to college? It’s such a waste, if you had a good school and high expectations, to find the slate wiped clean when you moved over to adult services. Everybody should have the right to a properly planned future.”

6. THE ASPIRATIONS OF FAMILY CARERS AND PEOPLE WITH LEARNING DISABILITIES FOR “FULFILLING LIVES”

6(i) Family carers frequently describe the contrast between the emphasis on developing skills, interests and a sense of purpose within school and the subsequent difficulty in maintaining this in adult life, College courses are subject to cuts; day-time opportunities are rarely structured to lead to work or enjoyable, sustainable volunteering; creative activities can get lost in the move to engage people in mainstream settings; school was full time whilst resource limitations lead to part-time “programmes”. The resultant cost in boredom and depression is borne by family carers as well as those with learning disabilities themselves.

6(ii) The core principles in “Valuing People” are:

- Rights
- Choice
- Inclusion
- Independence

Family carers endorsed these core principles but felt they should also be applied to family carers. Several younger family carers suggested that assessment of both carers’ and people with learning disabilities’ needs should be based on the key principles outlines in “Every Child Matters”, namely:

- Being healthy
- Being safe
- Enjoying and achieving
- Making a contribution
- Economic well-being

6(iii) There is general concern that assessment is currently deficit laden in many cases because of tighter eligibility criteria. Person centred planning focuses on personal development and well-being but as one parent of a young adult with a learning disability noted:

“The assessment was fine, nobody disagreed with it. It was person-centred, about getting a life not a placement. But the crunch line was not enough money. To get the vision translated into practice, we had to meet eligibility criteria. They call them ‘Fair access to care’ but they don’t seem very fair to us! We were told that ‘David’ was neither ‘severe’ nor ‘critical’ enough to get what we wanted. Then there was an incident on the bus—some kids really harassing David and a friend. He pushed one and suddenly the police and everyone was round. Our social worker said, you won’t believe this but you should be pleased. If we say David has challenging behaviour, we can get him into the ‘severe’ category and he’ll get a service. I thought great, we get the service but what if a future employer wants to know more about ‘David’. We should be challenging the kids but we’re keeping quiet because ironically they’ve got us a service. It shouldn’t be like this!”

6(iv) In discussing what constitutes “fulfilling lives”, perhaps the greatest challenge lies in how we improve the “life chances” of both family carers and people with learning disabilities. At a time when there are major demographic changes, an ageing population and a significant skills gap as identified by the Leitch Review, it must make sense to enable those family carers who wish it to remain in the workforce and very importantly, for people with learning disabilities to enter it. It is estimated that between 58% and 60% of family carers retire early because of their caring roles. Premature retirement damages pension prospects, it diminishes quality of life for carers and their relatives and as noted above, it damages the nation by diminishing the workforce. It is equally unacceptable that people with learning disabilities experience major challenges in finding and retaining paid employment—and that many of those who could work are unable to do so because of the perverse incentives within the current benefit system.

“My son wanted to work and we supported him in doing so. We found him a job with a local nursery—he enjoys working with plants. They were very pleased with him and he had a job coach to sort out any problems in the early days. He could have stayed. His employers were satisfied. But he needs a lot of extra support and we realised that we couldn’t challenge the benefit system. Basically he couldn’t afford to continue working and he is now at home. He has a day service for a couple of mornings, but he is so depressed. He was making a contribution but the system made us all lose out. Also, because he is now at home four days a week, I can’t work either because ‘Daniel’ does need some support during the day. Two people on the scrap heap—what a waste!”

Another father noted that:

“Our son wanted a job. He was at college and they had some really useful courses—helping with mobility training, communication, independent living etc. But they were ‘axed’ because of the change in LSC funding. ‘Paul’ enjoyed the courses and he was making real progress. We thought he could perhaps get a job, his big ambition. But it didn’t work out for him. Also, why the focus on younger people—Paul was really ready to learn at 25 but he was ‘too old’ then to get on the courses he needed. I would like to see an individual learning budget for people with learning disabilities—to be used when and how the person concerned needed it. I think this would get a lot of people with learning disabilities into training and into work.”

The same father noted the “big debate” about the future of day services but felt that:

“Local authorities too often taking a sticking plaster approach, ‘giving the parents a break’ for a couple of mornings but not thinking clearly enough about real day-time opportunities. What most people with learning disabilities want is a real job, like everyone else—why don’t we get some social entrepreneur (preferably a philanthropist with some money to invest!) to find a new way of doing things! If people with learning disabilities can’t find the right jobs, maybe more could make their own?”

6(v) Family carers, like people with learning disabilities, may have major problems in finding suitable employment or retaining their current posts because of challenges in finding suitable support for their relatives. The Government is to be congratulated on the introduction of child and working tax credits (enhanced for families with disabled children). The Childcare Act 2006 requires local authorities for the first time to plan strategically for local childcare arrangements, which include the disabled children of parents who wish to work. Childcare is defined dynamically as provision, which improves children’s life chances as well as “covering” working parents. Poverty matters and can blight family lives, as clearly demonstrated in the DRC *Disability Agenda*¹⁵⁹ and in Emerson’s and Hatton’s analysis of the General Household Data, is endemic in families with disabled children¹⁶⁰. They are 50% more likely to be in debt, to be poorly housed and unable to afford the “treats” like school trips which enrich the lives of other families. We also know that in almost 70% of households with children where both parents are unemployed, at least one parent is disabled. Therefore the economic well-being of family carers is also of key concern for disabled people, with the growing inter-changeability of roles.

6(vi) However, the current investment in childcare for disabled children is not matched by similar initiatives for family carers of disabled adults. The Carers’ Allowance is paltry, means-tested and a disincentive to any family carer wishing to move into employment. There is no equivalent of the child tax credits for family carers of adults. In a survey, which preceded a guide to the Carers (Equal Opportunities) Act 2004¹⁶¹, 85% of respondents of working age wished to either work (often part-time) or to study (often to gain qualifications for a different form of employment more compatible with caring responsibilities). We know that 58–60% of family carers of working age have to give up work in order to care and would suggest that the Government should:

- Take account of the particular needs of people with learning disabilities and family carers within the current debates about welfare reform and also within the delivery of the strategy for students with learning disabilities within “Progression through Partnership”.¹⁶²

¹⁵⁹ DRC, *Disability Agenda* (2007), available on the DRC website at www.drc-gb.org

¹⁶⁰ Emerson, E, and Hatton, C (2005), *The socio-economic circumstances of families with a disabled child*, Institute of Health Sciences, University of Lancaster

¹⁶¹ Philippa Russell (2007), *Care Matters: A Guide to the Carers (Equal Opportunities) Act 2004*, Elizabeth Nuffield Education Fund, Nuffield Foundation

¹⁶² DfES/DWP/DH, *Progression through Partnership*, (2007) (Strategy for FE/adult education for people with learning difficulties/disabilities).

- Consider introducing a tax credit or other allowance for families with adult family members who wish to work but who may incur extra expenses in so doing. We note the particular problems faced by families of young adults making the transition to adult services, where the loss of tax credits and a range of family support services and childcare options can cause major difficulties.
- Review the level of the current Carers' Allowance.
- Consider introducing individual learning accounts to enable family carers to enter, or re-enter education or training at times and in ways (eg through distance learning) which are appropriate to family responsibilities.
- Proactively implement the Carers (Equal Opportunities) Act 2004—seeing it as a “springboard” to enable family carers (who may also be people with learning disabilities) and their family members to have ordinary lives, access education and employment if they so wish and encouraging real partnerships with Job Centre Plus, health and other relevant services.

7. ACCESS TO HEALTHCARE

7(i) The Disability Rights Commission's Formal Investigation into Health Inequalities in Primary Care as experienced by people with learning disabilities or mental health problems found widespread evidence of health inequalities in its findings and recommendations:¹⁶³ The DRC found widespread evidence of:

- Problems in accessing high quality primary healthcare, in particular accessing the full range of primary care services including health promotion and screening programmes.
- People with learning disabilities were much less likely than the general population to be screened routinely for cancer etc.
- Notwithstanding strong evidence on the effectiveness of evidence-based Annual Health Checks, the majority of people with learning disabilities were still missing out. In a pilot study in Wales, the DRC found high levels of unmet health needs (some serious) in a sample population of people with learning disabilities receiving Annual Health Checks. A repeat Health Check a year later found further new unmet needs, some serious.
- People with learning disabilities and family carers reported some very positive practice. But there were widespread concerns about access arrangements. Notwithstanding the DDA, the appointments systems used, the often crowded accommodation in surgeries and a lack of disability equality training caused problems in some areas.
- There was very limited evidence of evidence based commissioning (ie real consultation with family carers or with people with learning disabilities). There was also much “diagnostic over-shadowing” (ie attributing behaviour or symptoms to the learning disability rather than to a possible health condition).
- The DRC concluded that some people with learning disabilities were dying prematurely because of late diagnosis of preventable conditions and, in some cases, arbitrary decisions about the likely effectiveness of medical interventions, which would generally be made available to a non-disabled person.

7(ii) Family carers also felt concerned at what one father saw as:

“Ambivalence to the role of family carers. Of course our sons and daughters are entitled to privacy and confidentiality. But if parents are to care-givers at home (and they often are, with early discharge from hospital the norm), then they must get reliable information. In our son's case, he came out of hospital with medication which was not explained to us. He took a double dose and was back in A&E within eight hours. His doctor said he thought he had understood and he had not talked to us because of patient confidentiality—but nobody else talked to us, to the GP who knows him well, as to whether he did or not.”

Another father was angry because:

“I knew our son was ill and in pain. He can't speak but he shows his emotions pretty clearly. He was really ill, holding my hand. I knew it was his stomach and I thought 'appendicitis'. I called our GP and he thought so too, he called an ambulance. But the hospital didn't believe us! We waited, and waited, and 'Tom' seemed to get worse. I said, I'm not having any more of this and I picked him up and walked out. We drove to a hospital in the next town. They operated immediately. The A&E doctor listened to me, he looked at Tom and he said 'you know him, I believe you'. I felt so angry, because I thought they had thought it's just his disability, when we were waiting at Hospital Number 1.”

Tom's family's concerns are borne out in MENCAP's report, “Death by Indifference”, which also underlines the importance of listening to parents and friends and valuing their knowledge of the patient and his or her communication skills.

¹⁶³ Disability Rights Commission (2006), Closing the Gap: Formal Investigation into Health Inequalities experienced by People with Learning Disabilities or Mental Health Problems, DRC available at www.drc-gb

7(iii) We were also told about “Susie”, who went into hospital for a routine operation. Her relatives visited after the operation and found Susie lying on her back, eyes open but not saying a word. Usually she was talkative and lively and worried, they went to ask the Sister why she couldn’t talk. The Sister glanced at the notes and commented “well, she can’t talk, can she, if she has a learning disability?” Susie was re-examined and found to have had a minor stroke. She made a complete recovery but her father felt that “the family would never trust a hospital again”.

7(iv) Another sibling commented sadly that the families of people with learning disabilities also experienced health inequalities—her sister had belatedly revealed that she had breast cancer. She had known for seven months but had refused treatment because she did not know who would look after “Stacey”. Stacey had complex health needs and received very limited support at home. Her mother provided the bulk of her care, which included tube feeding and intimate personal care. Stacey’s mother did survive but Stacey had to move into a residential home (after an emergency and unsatisfactory placement in an adult acute ward) so that her mother could have surgery and subsequent treatment. As Stacey’s aunt commented:

“Families matter—if the family carer (who might be a disabled person in their own right!) needs medical care, then it also affects the person who is being cared for. Some doctors are good—my GP notes whether a person is disabled or a family carer on the practice records and they offer some useful services, like prescription collection and delivery and flexibility over appointments. Of course my sister should have known better—but she just did not feel that she could ‘let go’.”

8. IMPROVING SUPPORT FOR FAMILY CARERS—THE CARERS (EQUAL OPPORTUNITIES) ACT 2004

8(i) The implementation of the Carers (Equal Opportunities) Act 2004 was regarded as a triumph in terms of formal recognition of the rights of family carers to an assessment—and the requirement of that assessment to have regard to the family carers’ wishes to study or work, in addition to requiring support such as short breaks or childcare. However, the Act has been variably implemented and there is a widespread “postcode lottery” in terms of accessible services.

8(ii) Key issues raised in a recent report¹⁶⁴ included:

- Continued problems in some areas in getting a Carers’ Assessment.
- Poor quality assessments which focus on crisis intervention rather than on “life chances”.
- Limited partnerships between social services, education and the DWP.
- Variable consultation with local family carers.
- Similarly variable quality of the local Carers’ Strategy.
- Eligibility criteria.

8(iii) The national development of more personalised ways of assessing support needs and enabling less institutionalised lives is obviously of key interest to family carers—both to enable them to ensure that their relative benefits and also to ensure support systems and commissioning arrangements develop in “family-sensitive” ways. Person centred approaches, including direct payments, individualised budgets and self directed support mark a cultural change in the way in which assessment and subsequent provision should be managed. However it is still not commonplace for those with responsibility for developing strategies to include family members in the design, monitoring, evaluation or communicating of systems.

8(iv) The Carers (Equal Opportunities) Act should encourage proactive assessment of family carers’ needs in a way which complements the parallel (but distinct) assessment of their relatives’ individual needs. However, it is important to note that an increasing number of family carers are also people with learning disabilities and several people have told us that:

“Nobody wanted to assess us as carers. They saw us as two disabled people but they didn’t think what we needed to care too. I can look after myself—but I need help to look after ‘Dave’. I did get a carer’s assessment and I’ve got a direct payment now. I get someone in to help with the housework and they help Dave have a bath. It’s good. I’m in control. But we couldn’t go on as we were, it was too difficult.”¹⁶⁵

9. DISABLED PEOPLE AND FAMILY CARERS—CREATING POSITIVE ALLIANCES

9(i) Positive partnerships between disabled people (including those with learning disabilities) and family carers are crucial to ending discrimination, promoting life chances and demonstrating solidarity when resources are scarce.

9(ii) In the USA, family carers and other non-disabled people can be regarded as “disabled by association” under the Americans with Disabilities Act. That is to say, a family carer who experiences discrimination in access to the community or services for a reason relating to a person’s impairment or disability is protected by the USA equivalent of the DDA. The USA has recognized that disabled people and family carers must be allies if the “big goals” of equality and independent living are to be achieved.

¹⁶⁴ Russell, P (2007), Care Matters: A Guide to the Carers (Equal Opportunities) Act 2004, Elizabeth Nuffield Education Fund

¹⁶⁵ Personal communication

9(iii) The long-term goal of policy towards disabled people in the UK (as set out in the launch of Equality 2025) is that they should enjoy the same rights as all other citizens and lead valued lives in their communities. To achieve this goal, UK policy is moving in the direction of the “In Control” approach, ie towards the development of a suitable Resource Allocation System for setting individual budgets. Self autonomy and empowerment are integral to a person-centred planning approach and there is currently a wide debate about how to achieve the optimum balance between self-autonomy’ and “dependency” and thereby to support active citizenship. There is general recognition that it is good that people will get support from family, friends and other community members—advocates and keyworkers are as yet what one parent called a “dream in someone’s eye”. However, there is an ongoing debate about the balance of interest between people with learning disabilities and family carers.

9(iv) The vast majority of families would welcome feeling their disabled relative was less dependent on them. If this were the case they would face the future with less anxiety. However, there remain challenges. The introduction of the “New Deal for Carers” and the present consultations on a new National Strategy for Carers must engage people with learning disabilities and families as key stakeholders in the future. Families matter and as one parent commented:

“The UK is really debating the future of social care in the 21st century. It is a huge topic. Family carers will (and wish to) continue caring—but families need time to be families, as well as unpaid care providers. We know that parents of disabled children are increasingly saying that they want time just to be a family—to give their children a childhood and not to be a continuous provider of therapy, education, personal care etc. The UK is also becoming a very diverse society—what do families from different minority ethnic groups want? The family is probably more important to them than it is to us. I think we need to open up the debate and not set disabled people and family carers against each other. We know that non-disabled adults are now staying at home well into adult life, saving money but still having their own lives and lifestyles. Our European (and African and Asian) colleagues think this perfectly normal. What I’d like would be a New Zealand/Maori style ‘Whanau’ (a traditional family conference) where everybody is heard, their views respected and there can be open and honest discussion about tricky issues. If family carers are over-protective, it’s usually because they’ve been let down in the past. But if they are well informed, then they are allies—long-term, committed and there!”

And as one young man (caring for a partner with a learning and other disabilities) commented:

“I grew up in a home—the people were nice, but it wasn’t a real home. I knew kids who had real homes. They used to fuss about Mum and Dad being old-fashioned, making them come in early, not do this and that, worrying all the time. I just wish I had someone to worry about me! My friend was really cross; her Dad would come driving out looking for her in the evening. There are bad people about, he’d say. She was so cross. But I wished I had a Dad to worry about me, I said just talk to him. You’re lucky. Families matter!”¹⁶⁶

9(v) The Disability Rights Commission and the Equal Opportunities Commission and Carers UK have recognized the importance of protecting family carers from discrimination on grounds of association in a test case to the European Court of Justice later this year. Sharon Coleman, the parent of a disabled son, has won the right to bring a case to Strasbourg, alleging unfair treatment by her employer (a London law firm) due to the primary caring role she has for her disabled son. The case revolves round the interpretation of the EU’s equal treatment directive and its impact on UK disability discrimination legislation. If successful the case could lead to greater rights and protection for family carers on grounds of “association” with a disabled person.

9(vi) As the UK moves towards a new Commission for Equality and Human Rights in October 2007, the reciprocal and complementary human rights of disabled people and family carers will require further exploration. We believe that this in turn will lead to improved mutual understanding, shared aspirations and, hopefully, an ending of the “us and them” attitude which can influence adult social care. This shift in balance also underlines the growing recognition that disabled people are also family carers and hence the “family debate” needs broadening to encapsulate changing communities, family structures and expectations.

10. IN CONCLUSION

10(i) The past decade has seen major changes and developments in services for children and adults with learning disabilities and their families. There has been a welcome focus on inclusion and on person-centred assessment and services. The Disability Discrimination Acts 1995 and 2005 have benefited people with learning disabilities (and thereby family carers). But conversely there have been challenges, in particular:

- A growing debate about the future direction of social care. A shift to individual budgets, whilst welcome in principle, must be properly funded. The current postcode lottery is unacceptable and we need greater clarity and consistency with regard to local interpretations of “fair access to care” and transparent (and equitable) eligibility criteria. The lack of equity is of considerable concern

¹⁶⁶ Personal communication

to disabled people in general as well as family carers. We consider that it would be useful to look at the systems in some of our fellow EU states to see if there are better ways of ensuring greater national consistency alongside local democracy and delegated budgets.

- Although much concern is expressed about social care, funding policies in education (both at the schools and post-16 level) and in health are crucial. The principle of commissioning for “health and well-being” is welcome in principle, as is the new strategy for post-16 education for people with learning disabilities (Progression through Partnership). However equality of access is essential.
- We hope that the new Commission for Equality and Human Rights (which will bring all the equality strands together) will take forward the work of the three existing Commissions. We also hope that the new Equality Bill will not dilute the DDA 2005 Disability Equality Duty, which has the capacity to change and develop the way in which public services respond to people with learning disabilities—and family carers.
- There is growing awareness that family carers (and thereby their relatives) are disproportionately likely to be poor and socially disadvantaged. A growing number of disabled people are also family carers and effective and funded implementation of the Carers (Equal Opportunities) Act 2004 could improve all their life chances by enabling carers to work, study, train and have the practical support which they need. However, as the VPST has pointed out, the Carers’ Assessment is often not offered and frequently inadequate.
- People with learning disabilities and family carers experience multiple health inequalities—as the DRC Formal Investigation clearly demonstrated, poor access to primary care can lead to poor health, limited lifestyles and sometimes preventable early death.
- People with learning disabilities (and family carers) can experience multiple disadvantages in accessing appropriate housing, education, leisure and other activities. Poor housing, lack of suitable equipment, limited opportunities for social inclusion can blight the lives of people with learning disabilities and family carers.
- Family carers worry (sadly often rightly) about the risk of abuse to their relatives. Tackling the consequences of the Cornwall, Merton & Sutton, Health Care Commission National Audit and other inquiries—and engaging family carers in discussions about prevention and protection—is important. Family carers are likely to be in regular contact with services, but report endlessly that they are not believed when they make complaints.
- We still have inadequate data about the numbers and circumstances of family carers. We gather that there is a risk that the next Census may not include a question about family and the groups of vulnerable citizens they support. We are concerned that without such data, planning and resourcing of family carer support services will continue to be inadequate.
- Despite being a priority for the Learning Disability Development Fund in the past, only limited progress has been made for those who come from minority communities and have a learning disability. Our work with family carers from a range of community groups indicates additional isolation, lack of accessible information and support (through dedicated and general carer support services). Again progress is tenuous when targeted funding is precarious.
- We need to build upon and expand some of the recent policy initiatives, which have enabled people with learning disabilities and family carers to work positively together in policy development, implementation and review. Such initiatives include the Family Leadership and Partners in Policymaking courses, Expert Patient courses for family carers and (separately) for people with learning disabilities and the work of some Partnership Boards.

10(ii) We hope that ODI and Equality 2025 will address the family carer debate (taking into account the dual role of many people with learning disabilities). Family carers are almost all entirely committed to promoting the life chances of their relatives. Many commit considerable energy and often financial support to provide an ordinary life. We need an honest, open and positive debate about the role of family carers (not least in the context of an increasingly diverse society where families historically have a much stronger role than in our own culture). Families at their best offer strength, love, commitment and tenacity. But they need information, support and a “place at the table” in discussing future policy directions and the longer-term debate about how we can best promote the human rights of all our citizens.

10(iii) The “refresh” of *Valuing People* offers a real opportunity to review the roles, rights and responsibilities of family carers and people with learning disabilities. With increased life expectancy for people with learning disabilities (and the welcome increase in people with learning disabilities in relationships and enjoying family lives of their own), we have to positively promote (and educate and inform) family carers so that they and their relatives have valued lives and the necessary support to achieve the “ordinary life” and “independent living” which have been the aspirations of so many families for so long.

Memorandum by the Scottish Consortium for Learning Disability

Thank you for asking us to respond to the Joint Committee on Human Rights: Inquiry on human rights of adults with a learning disability.

The Scottish Consortium for Learning Disability's mission is to work in partnership with people with learning disabilities of all ages and family carers to challenge discrimination and to develop and share good practice. Our goal is an inclusive Scotland where everyone is valued and respected for who they are and what they contribute as equal citizens.

We are pleased to enclose two pieces of evidence.

In 2006 we carried out a survey of the views of people with learning disabilities in Scotland, commissioned by ENABLE Scotland. This contains the views of 605 people with learning disabilities and we think the findings are very relevant to your enquiry so please accept the enclosed report as contribution to your evidence. In particular:

- Experience of services.
See "What matters most" which explains that people said a home was the basis of their independence and the need for more appropriate provision. The sections on work and leisure are also relevant.
- Chances for personal relationships.
See the section on Friends and Relationships. This shows that people had far less chance of having closer relationships, like a boy/girlfriend or getting married. They had lots to say about the support that would help.
- Taking part in the local community.
See Leisure section. This is particularly a problem in rural areas.
- The Convention.
We did not ask specifically about this. However people do see these issues as one of rights. See the chapter on Individuals and Citizens.
ENABLE Scotland's Self Advocacy Committee (ACE) also had a meeting in June to discuss your questions. I enclose a summary of their views compiled by Lena Gillies of ENABLE Scotland.

Views of ACE, ENABLE Scotland' Self Advocacy Group—June 2007

During these discussions, members of ACE were very clear that people with learning disabilities have the same rights as others. Whether people with learning disabilities have the same chances to carry out these rights became less evident.

1. Your experiences of using services like health services, education, housing and welfare benefits.

Responses

- some positive experiences using health services in particular where people knew nurse or doctor and they took time to explain things;
 - quite a few negative experiences—too rushed, didn't understand, felt worried about asking for more information;
 - people did not think that people with learning disabilities have the same chances as others with education—lots of college courses still doing "life skills" which don't lead to anything; and
 - Welfare benefits are really difficult to understand, not many knew whether they were getting all the benefits they were entitled to or how they would find this out.
2. What chances you have had to have personal relationships with people like:
 - Partners (boyfriends, girlfriends, husbands or wives).
 - Your family.
 - Children.

Responses

- Not good chances for people with learning disabilities to have relationships.
- Very often stopped by family.
- Also lots of risk assessments done by social workers etc—negative from the start.
- Always are alarm bells ringing.
- "People say I have the same rights but they don't believe it when it comes to sex and having a girlfriend—they don't like to think about it."

- “Don’t think that many people with learning disabilities can have children, it’s too difficult.”
 - Need more groups for people to talk about this and get better information about sex and relationships.
3. How you take part in local community and what help you get to do this.

Responses

- local groups are good like ACE or People First—help you speak up;
 - lots of people don’t get help to take part in the community—“just have to get on with it”;
 - some people get support to do things like shopping and finding out about local opportunities;
 - sometimes support is not very “natural”—means it is difficult to fit into the community;
 - not having much money stops you from doing things before you even get out of the door; and
 - still a lot of bullying, feel like I don’t fit in, don’t like going out sometimes.
4. If you think the Convention on the Rights of Persons with Disabilities can help people with a learning disability to have their human rights.

Responses

Although one or two people had heard of this, none knew what it was about in any detail or how it was relevant to them.

5. We would really like you to tell us what you think about:
- How easy it is for people with a learning disability to have a say in decisions, which affect them.
 - How easy it is for people with a learning disability to make a complaint about a service.
 - What would help people with a learning disability get their human rights and any examples you have of when this has been done well.

Responses

- Some people felt that they had a say in decisions about them—felt it had got better and they had become more confident. Help from an advocacy service was mentioned as being very useful.
- Not easy for people with learning disabilities to make a complaint. Everyone said that you have the right to do this but many said they would be too scared to do it or would not know how to do it.
- Some said that they were unclear about knowing when they had grounds to make a complaint. One person gave example of buying radio from shop and this broke but she “didn’t like to take it back”.

June 2007

Memorandum from the Department for Innovation, Universities and Skills

LEARNERS WITH LEARNING DIFFICULTIES AND/OR DISABILITIES

INTRODUCTION

We are pleased to provide evidence on the human rights of adults with learning disabilities from the perspective of the Department for Innovation, Universities and Skills. Comments will be confined to areas of responsibility in the provision of education and skills training for learners with learning disabilities.

Over the last two years there has been a considerable focus on prioritising learners with learning difficulties and/or disabilities in the further education system, recognising that such learners are among the most vulnerable in the community. We have been concerned to get the messages right and realise we cannot achieve sustainable change for the better without partnership with other government bodies and stakeholders to produce better outcomes for learners. One of these outcomes must be the promotion and protection of human rights for learners with learning difficulties and/or disabilities.

BACKGROUND

In providing this evidence we have used the definition of “adult” beginning at 19 with no upper age limit. There are various definitions in use generally, but in DIUS we categorize funding for adults from 19. Similarly we use a generic term of “learners with learning difficulties and/or disabilities” to describe learners with a variety of learning disabilities or learning difficulties but we note that the Committee is concerned to cover those with learning disabilities and we offer the following observation.

The term “learning disability” can be seen as a medicalised one. Furthermore, there are difficulties in identifying target groups because learning difficulty and disability are not absolutely fixed, but are comparative and dynamic states. The “problem” or “deficit” should not be seen as located within the individual (medical model) but as a result of the attitudinal and physical barriers which people with impairments and health conditions, face in everyday life (social model). It is this interaction which is disabling.

A “learning disability”, defined (within the Department of Health) is the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with lasting effect on development.

(Valuing People White Paper, DH, 2001)

DIUS relies on its delivery partner, the Learning and Skills Council (LSC) to deliver provision for learners.

THE POSITION OF THE DIUS IN RELATION TO THE HUMAN RIGHTS OF LEARNERS WITH LEARNING DISABILITIES

Our belief is that all people with learning difficulties and/or disabilities:

- have a right to expect high quality services which are person-centred and/or personalized to meet need;
- should expect to learn and to continue to learn as appropriate to their needs and aspirations—and be expected to do so by services provided to help them succeed;
- should have the opportunity to fulfil their aspirations for adult life across all areas of their lives, including to work;
- should receive the support they need to enable them to live independently;
- should lead fulfilling lives as equal citizens in our society.

Furthermore we believe that all people with learning difficulties and/or disabilities should have an entitlement of opportunity and access to education provision that is meaningful, relevant and appropriate. Underpinning this is the need for:

- alternative and more flexible assessment methods on both accredited and non-accredited programmes, including certain vocational qualifications on the National Qualifications Framework, to enable wider access to mainstream programmes;
- dissemination of best practice, and guidance for the LSC and post-16 providers, which enables them to plan for and develop a balanced and varied curriculum locally that can be used to build on what the individual has already learnt at school or other education setting;
- person centred planning and Individual Learning Pathways for all learners with learning difficulties and/or disabilities to ensure that individual needs and aspirations are central to any and all learning objectives.

We have arrived at this position after a number of key documents have been published to which the department has been pleased to respond. The most important of recent years was in 2004, when the LSC commissioned Peter Little, OBE, to chair a Steering Group to carry out a thorough review of all Learning and Skills Council provision for the full range of learners with learning difficulties and/or disabilities. “Through Inclusion to Excellence”, published in November 2005, was a unanimous report by the Steering Group and made 40 recommendations, most of which were for the LSC. These included a key recommendation for “the Minister for Lifelong Learning, Further and Higher Education to raise the issue of the LSC’s spend on health/care costs with appropriate Ministers in other government Departments and seek to reach an agreement about appropriate funding responsibilities and partnership working.”

The LSC set out its own response in the strategy document “Learning for Living and Work” published in October 2006, and that presents a number of challenges to the post-16 learning community. This followed a formal public consultation, which produced an overwhelmingly positive response to “Through Inclusion to Excellence”. It also sets out the LSC’s core ambition that by 2015, England will be an international exemplar in providing high quality post-16 learning provision for learners with learning difficulties and/or disabilities.

“Progression through Partnership” is the Government’s joint response to “Through Inclusion to Excellence”. It was launched on 18 June and reviews the planning and funding arrangements for learners with learning difficulties and/or disabilities post-16.¹⁶⁷

This cross government strategy focuses on improving outcomes for learners with learning difficulties and/or disabilities in Further Education and training and raising the level of progression into employment. “Progression through Partnership” sets out what is expected from the DfES (the main responsibility will now be taken over by DIUS), the Department of Health and the Department for Work and Pensions. It also outlines expectations of their delivery partners and sets milestones over the next few years on the way in which improvements will be made.

The strategy is practical and commits to joint planning and action to ensure policy is made between the three Departments which helps these learners to achieve their full potential, including employment where possible. All too often there are low expectations of this group of learners, but by building on good practice and by working together to enact change, the three Departments will challenge these attitudes and change this culture.

This cross government strategy focuses on improving outcomes for learners with learning difficulties and/or disabilities in Further Education and training and raising the level of progression into employment. Progression through Partnership sets out what is expected from the three Departments and their delivery partners and sets milestones over the next few years on the way in which improvements will be made.

A crucial outcome of this strategy will be a “framework” for the three Departments setting out a) how we can make learning for this group more relevant, meaningful and accessible, b) how we can ensure support is provided at the right time and c) how pathways to work can be made more flexible.

It requires that their principal delivery agents and local delivery partners, the Learning and Skills Council, Local Government’s Adults and Children’s Social Services and Job Centre Plus, mirror this approach in delivering sustainable positive change to learners with learning difficulties and /or disabilities. By working more closely together we can maximise the impact we have and ensure we use the resources we have more effectively and efficiently.

We need to concentrate on three areas: what further education is provided; the quality of that provision; and how it is funded. We have developed a joint “programme of change” which over the next five years will:

- 1) Agree a definition of the target group and an exploration of the various interagency issues and barriers through data collection and supporting research and analysis.
- 2) Deliver joint policy development, so that each department is aware of the priorities and how each contributes to the delivery of these, the impact on other departments of policy change and to establish processes to deliver future joint policy.
- 3) Improve workforce capacity and performance around assessment, delivery of support services, and delivery mechanisms.
- 4) Develop joint data collection, evaluation and monitoring systems to measure progress.
- 5) Support our delivery agents and local partners to help them achieve their aims and targets.

A joint delivery group will be responsible for making this happen and will link up with wider delivery action around employment and day services. The Group will include key stakeholders as well as the three Departments, and will oversee the delivery plan accompanying this strategy. The Group will report progress on a regular basis to Ministers.

PROVISION OF EDUCATION AND TRAINING OPPORTUNITIES IN THE FURTHER EDUCATION SYSTEM

There has been education and training provision for many years for adults with learning disabilities and the further education sector has a number of excellent centres providing education and training for the full range of learning disabilities, whether in a general further education college, work based learning, or specialist college. Traditionally places in further education are essential to help learners with a learning disability progress at their own pace and achieve within the constraints of their learning disability.

However there is a perception that often colleges, out of the best of intentions have offered places to adults as a safe environment, but one where they are unlikely to progress, particularly into independent living. This has been manifested in phrases such as “colleges offering ‘alternative day care’” or offering repeat courses characterized as “revolving doors”. This is not in the best interests of the learner and the Learning and Skills Council is concerned to ensure that all its learners are offered provision which leads to positive outcomes in a reasonable timeframe which takes account of their needs.

The LSC has declared it will cease commissioning inadequate provision, including provision for learners with learning difficulties and/or disabilities, by September 2008. This declaration is particularly important because of the need for all provision to lead to clear outcomes including employment, and within the overall reform programme for the further education sector.

¹⁶⁷ This can be downloaded at the following link:
<http://www.dfes.gov.uk/publications/progressionthroughpartnership/index.shtml>

The DfES through its delivery partner the LSC has been concerned to monitor the effect of changes on vulnerable groups in the reform of the further education sector, and commissioned the LSC to carry out a survey on changes in the number of places available for learners with learning difficulties and/or disabilities. The subsequent survey published in January 2007 established that there had been some 2900 places removed from those available to adults with learning disabilities. It is important to put this in context. There has not been this number lost to the system. Some have been converted from full time to part time and some have been re-designated as part of support packages in conjunction with new care arrangements with adult social services.

The LSC Survey of Impact on Adults with Learning Difficulties and/or Disabilities was published in January 2007 and identified where there have been changes in provision for adults (learners aged 19 or over) with learning disabilities.

FINDINGS

In Summer 2006, the LSC began a survey to determine the extent of discrete provision, for adults with LDD, that FE providers decided not to continue to offer in 2006–07. A follow up survey was performed at the beginning the 2007–08 planning round. The survey determined that provision was discontinued for a total of 2,960 learners, 15% of the cohort (1,071 full-time and 1,889 part-time learners). The Survey included a region by region analysis which was more useful. Two regions (London and South East) reported no reductions, and the largest number affected were in the North East (782) and the South West (519). This decline in participation must be understood in the wider context of falling general adult participation rates of 14% from the comparable 2004–05 to 2005–06 academic year. The statistical variation resulting from the relative small numbers of learners and the anticipated numbers of adults with learning disabilities included with ILR categories of Not known/Information not provided/Other indicate that although the decrease for all adults learners is at a lower rate than that for adults with learning disabilities, the rate is comparative and proportionate.

The Survey concluded “that the perceived vision of a widespread ‘crisis’ in provision for adults with learning disabilities is misplaced” caused by considerable coverage of isolated incidents. Some full-time provision has been switched to part-time and access is being provided in different ways to create alternative provision for most cases. In a small number of isolated cases provision was discontinued without sufficient consultation or provision of other options and this generated some bad publicity.

- The LSC Survey shows there has not been any wholesale reduction of provision and that in the majority of cases the reasons identified for reductions have been sound and done in consultation with the local LSC and other partners and learners.
- Better alternatives have been sought and provided in the vast majority of cases. It is not appropriate that learners receive provision of poor quality where they may be learning very little and not progressing and it is right that these courses are withdrawn.
- The LSC has clearly stated in multiple strategies that it will no longer contract with poor quality providers. This is and will be, no different for providers for learners with learning difficulties and/or disabilities and it is equally inappropriate for these learners receive provision of poor quality as for any others.

We recognise the impact this may have on the lives of adults with learning disabilities, and we have agreed with the LSC to have the second survey building upon the work of this one, with more emphasis on determining progress in finding positive alternatives for those adults affected. We are also determined that provision continues to offer meaningful opportunities for progression, and that adults with learning disabilities do not find themselves on poor quality courses. We must drive up the quality of provision to improve the life chances of adults with learning difficulties.

In 2004–05 expenditure on LLDD provision rose by 15% from the previous year, to £1.5 billion. FE funding (on programme costs) accounted for roughly half of this figure, with FE Additional Learning Support adding a further £218 million to this. SEN Allocations come to £167 million and Specialist Colleges £125 million. The remaining £214 million was divided between Work Based Learning, University for Industry and Adult and Community Learning. The Department is currently sourcing comparable 2005–06 figures for this group. Funding per learner is expected to continue to rise and the LSC grant letter commits a record £181 million to Specialist Colleges in 2007–08.

PROGRESS OF ADULTS WITH LEARNING DISABILITIES INTO EMPLOYMENT

There is a cross government group working on a strategy designed to increase the numbers of adults with learning disabilities entering work. This group is tasked to provide the response to the Learning Disability Task Force report entitled “Improving Work Opportunities for people with a Learning Disability” published in the July 2006.

There is little reliable data available on the numbers of adults with learning disabilities in work. Background information for the report *Improving Work Opportunities* highlighted that there were few in the labour market and where such adults were in some sort of employment it was usually low paid and short hours. The types of jobs were usually low skilled and stereotypical eg cleaning, catering, manual labouring. Transition from learning usually results in transition to these outcomes or day centre provision.

Tackling attitudes among employers is a key element. We have assembled some case studies which highlight exciting success stories of adults with learning disabilities, but we need a cross departmental approach to effective practice. Working in particular with the Department for Work and Pensions we will explore how we can raise the profile of adults with a learning disability to demonstrate how they can contribute effectively to the productivity of a commercial enterprise, or improve services in the public sector.

VOICE AND INFLUENCE OF LEARNERS WITH LEARNING DISABILITIES

The ability of the learner to influence provision and provide a customer focus has been a key driver of policy for some time, and recently the DfES (now DIUS) published a consultation document (*Delivering World Class Skills in a Demand led System* January 2007) on proposals towards a demand-led system or how to place the power to choose in the hands of the individual, as a means to driving up quality and delivering more innovative provision. The voice of the learner in shaping provision is essential and the DIUS requires the LSC to ensure it has embedded procedures to involve learners in determining direction.

The LSC has included in its LLDD strategy the intention to launch a National Learners with Disabilities Panel, which will feed into the National Learners Panel and the LSC governance structure. This will be replicated at regional level and the delivery model will be agreed this summer. The LSC has other mechanisms such as on-line, telephone help lines and stakeholder groups to feed in views and comments.

DISABILITY LEGISLATION

The Disability Discrimination Act 2005 makes substantial amendments to the Disability Discrimination Act 1995, building on Special Needs and Disability Act 2001. As originally enacted, the Disability Discrimination Act contained provisions making it unlawful to discriminate against a disabled person in relation to employment, the provision of goods, facilities and services, and the disposal and management of premises. It also contained some provisions relating to education. This new Disability Discrimination Act takes forward the Government's remaining proposals to include the functions of public bodies, including education bodies ("access to goods, facilities and services"), and will place a duty on them to promote equality of opportunity for disabled people.

This Disability Employment Duty brought into force in December 2006 has caused all education providers to re-examine their policies and procedures for learners and for staff. In particular it is worth noting that the requirement to anticipate future service users' needs has had a beneficial effect by focusing on the need to plan better provision. It is too early to be able to report on the impact, but the DfES (now DIUS) in its role of employer and funder will have a major impact on the provision for users of its services through its delivery partner, and arrangements have been put in place to monitor impact and developing effective practice.

APPENDIX A

It could be argued that the barriers* which this group of learners face fall into two broad (but interrelated) categories:

- i) those related to the attitudes of policy makers, education and other sector professionals, and post-16 funders about the purpose of learning for this group, and
- ii) those related to or arising from the political or structural processes which govern or influence post-16 education, including the sometimes conflicting Government priorities and interdepartmental debates about the best way to support young people and adults with learning difficulties and/or disabilities in our 21st century society.

*Some of the most widely accepted and documented "barriers" to ensuring that people with learning difficulties and/or disabilities, access the provision they want and need are listed below.

As part of our commitment to learning for its own intrinsic value we have agreed a safeguarded budget for learning for personal and community development (PCDL) of £210 million pa in 2006-07 and 2007-08. This comprises part of the old Adult Continuing Learning budget but also some funds from mainstream FE. Our objectives are to ensure a range of good quality opportunities in every area and to widen participation in this type of learning. This is why we have commissioned the National Institute of Adult Continuing Education to develop a toolkit of good practice in ensuring such opportunities are attractive to learners with learning difficulties and disabilities. However we must ensure that we do not distort the purposes of PCDL with a move away from properly funding courses for these learners through FE. In PCDL funding rates will generally be lower and without the funds for learner support that these learners need.

 SPECIFIC BARRIERS TO LEARNING

- Cultural expectations: low expectations/aspirations and assumptions about people's (lack of) potential for learning and working; this includes parental views on where and how young people should be educated.
- Inadequate and inappropriate provision—particularly for those with more severe or complex needs: often this provision is discrete, segregated and focuses on stereotypical “life skills” or “work preparation” which does not meet the interests or desires of the individual.
- Lack of appropriate support services for people with high support needs living at home (particularly in non-term time).
- Lack of staff awareness and/or training: staff often do not understand how to measure progress on non-accredited programmes making Individual Learning Plans difficult to review (Ofsted 2007); some staff simply lack awareness of how to support people with specific impairments.
- Poor transition planning: schools often do not think about the whole life needs of the individual young person beyond 16/18; colleges often do not receive the information given on statements of special education need or other documentation about the existing levels of skills and knowledge, and conversely where this may be received is not implemented adequately (Ofsted, 2007).
- Lack of real work experience opportunities or real-life situations of learning (proven to be most effective for people with learning difficulties and/or disabilities).
- Narrow or restrictive assessment methodologies (particularly on accredited programmes) which exclude many people from getting any credit or recognition for the things they can do.
- Lack of person-centred approaches at transition to FE and beyond.
- “Systems of support” (at transition and other times) which are overly bureaucratic and complex: this includes the way that funding support is allocated to individuals wanting to enter the workforce.
- Lack of co-ordination or shared responsibility between different agencies involved in decisions around funding placements.

20 July 2007

Memorandum from the Human Rights Department of Leigh Day & Co Solicitors

We are an 18-partner law firm in private practice, which specialises in claims for personal injury and human rights. We only act for Claimants, who may be individuals, charities or NGOs, or community groups.

We have a particular interest in the rights of the learning disabled. We act for individuals with learning disabilities, their families and carers in claims over access to public services, which raise issues of equality in access to services and access to good quality services corresponding to levels of need. We have been concerned for some time about the barriers to access of state provision that exist for people with cognitive and / or communication difficulties. Furthermore, that professionals involved have made assumptions about people with learning disabilities, and failed to listen to their views and concerns.

We make this response with the benefit of our experience in acting in such cases. We refer to a number of our cases below, but have anonymised the personal details of our clients to preserve client confidentiality.

We will address such of the areas that the Committee will be considering as are within our expertise.

1. The provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities, the ability of individuals to access such services and the quality of provision

We have found significant deficits in terms of the quality of provision of public services to people with learning disabilities and the responsiveness of such services to the needs of people with learning disabilities.

HEALTH SERVICE

Our experience is that general hospital wards with little or no expertise of people with learning disabilities struggle to meet the needs of patients with learning disabilities who are ill.

Staff on the ward may not understand the communication systems used by a learning disabled patient (which could be verbal, a recognised sign language such as Makaton or sounds, signs and gestures idiosyncratic to the patient). They may misinterpret or even ignore what the learning disabled patient is trying to communicate.

Family members may find themselves providing some or even most of the care on ward. It is not unknown for the parent of a disabled adult patient to be obliged to stay in the hospital full-time in order to ensure that their child's needs are being met. This may or may not be permitted or encouraged by the Hospital.

Friction can result between the family member and Hospital staff where the family member is providing nursing care on ward over issues such as, for example, administration of medication and record keeping, which adds to the stress of an already difficult time for the patient and their family.

In turn, Hospital staff may find the constant presence of a parent or carer who is “expert” in the needs of a patient with learning disabilities challenging to deal with. They may view this more as an obstacle to doing their job, rather than a potential partner in the successful care and treatment of the patient.

This situation of conflict can mean that helpful information that the family could provide to aid the treatment of the patient may not be heeded. The relatives and carers may, in this situation, lose trust and confidence in the Hospital staff. In our experience, poor communication often lies at the root of disputes that can arise as to the treatment that is in the “best interests” of an incapacitated patient.

What we believe may be helpful is the appointment of a named person—someone, preferably, with expertise in the needs of people with learning disabilities—to coordinate the admission arrangements, ideally prior to admission (if the admission is a planned one) or from the time of the learning disabled patient’s arrival on ward. The person in question can then prepare a care plan for the learning disabled patient, dealing with issues such as communication systems used by the patient and the respective roles of parents and Hospital staff in their management.

In cases where several different specialisms are involved, it may also be useful to hold a multi-disciplinary meeting to promote coordinated care and to provide an opportunity to discuss in an holistic way any concerns.

In one of our cases, a woman with learning difficulties was admitted to hospital with a fractured left tibia and fibula. A Plaster of Paris (POP) was applied to her left leg from her toes to the groin. Even though she displayed signs of severe discomfort associated with the POP over the next few days, which various members of her family brought to the attention of the nursing staff, no action was taken. Family members later noticed a bad odour emanating from the POP and reported this to nursing staff and again no action was taken.

Two months later she attended a pre-arranged outpatient appointment at a different hospital. It was discovered during the appointment that the fracture had not healed. The POP was removed at the insistence of her family and a pressure ulcer was found at the back of the woman’s left heel. On the front of the lower leg, below the knee, there were black areas consistent with tissue damage, which had caused large tissue cavities. There was also damage to the tendons.

For nine weeks she tolerated extreme pain and discomfort associated with the plaster cast, which had been too tightly applied and was restricting her circulation.

As a result, she has no physical control of her left foot and is currently confined to a wheelchair and still in much pain.

We believe that she was subjected to inhuman and degrading treatment. Her expressions of pain were ignored. She was allowed to endure incredible pain whilst her skin and underlying tissues rotted under the plaster. We doubt very much that our client would have been treated in this way had she not been a person with a learning disability.

In another case, a 20-year old woman with profound learning disabilities and physical disabilities was admitted to Hospital with a severe respiratory infection. She was accompanied by her mother, who had cared for her all her life and was devoted to her daughter. The young woman had many previous admissions to the same Hospital during her childhood and her mother had a good relationship with the paediatric consultant.

The client suffered from diabetes insipidus, a condition in which there is a deficiency in the hormone necessary to regulate urine output, in our client’s case due to severe brain damage. Maintaining a strict fluid balance for our client was therefore necessary.

She received hydration and nutrition enterally via a percutaneous endoscopic gastrostomy (PEG).

The client was initially assessed as needing a scan and it was decided that in the meantime she should be nil by PEG. Her mother wanted to feed her but was told by the hospital staff that she would have to wait until after the scan the following morning. As it turned out, the next morning the decision was made not to do the scan after all. By this point, the client had been off her medications and fluids for 24 hours. She had developed a high temperature, become dehydrated and her condition was critical. She was admitted to the Intensive Care Unit.

At this point, the consultant under whose care the young woman had been admitted decided to discuss with the client’s mother the appropriateness of life-prolonging treatments. The conversation was focused around the treatments that would not be provided, rather than the care that would be. The client’s mother recollected the doctor told her that her daughter was suffering, had been in pain for the last 20 years and it would be better to “let her go”. To the client’s mother—who felt that her daughter’s health had been compromised by the Hospital’s decision-making around the scan—this gave the impression that the Hospital staff felt that her daughter’s life was of lesser value because of her severe disabilities. She felt her daughter, when not ill, had a worthwhile life, which the consultant had failed to recognise. It was not for the doctor to “play God” and decide that her daughter’s life was not of value.

We were subsequently instructed in “best interest” proceedings in relation to the further treatment that the client’s best interests required. This case was compromised following a round-table meeting between the client’s mother and the Hospital clinicians at which meeting a treatment plan for the client was agreed. An important element in this was that the treatment plan described the care and treatment that the Hospital would provide, as well as the treatments that were not in the client’s best interests (which, in the event, were largely agreed).

In a third case, we are instructed by the Official Solicitor on behalf of a 59-year-old man with life long learning disabilities.

He was a passenger in a taxi and was being taken home from day activities.

At a junction, the driver of the taxi failed to see a Land Rover approaching him from the road on his right as he entered the junction and his taxi was hit by the Land Rover on the right hand side. Our client was taken to hospital by ambulance.

On arrival at the hospital, he was taken to the spinal unit where he is said to have had chest, pelvic and back x-rays. Each time he was asked to stand whilst the medical team supported him, he collapsed. He was discharged home the same day. He was taken home by ambulance and the ambulance personnel had to use a stretcher to take him to his bedroom, as he was unable to walk.

The following day, our client was unable to get out of bed and complained to his full time carer that he could not feel his legs. His carer telephoned our client’s GP who advised him to call an ambulance. The carer called an ambulance and he was taken back to hospital. An MRI scan was done, which showed a cervical 7 fracture.

Our client was initially on neck traction and thereafter had surgery to insert steel rods and plates to the front and back of his neck. He was discharged from the Spinal Injuries Unit more than nine months later.

As a result of his injuries, he is now confined to a wheelchair. The family and social services have been informed by the hospital that he will never be able to walk again.

We believe that in this case our client received a lower standard of care because of his learning disabilities. His inability to walk was dismissed by doctors as the tantrums of learning disabled person. He was not taken seriously. If he had not had a learning disability, we believe that it is very unlikely that his inability to walk after the accident would have treated so lightly.

Our client has now been discharged to a nursing home and not to the home where he was brought up, so this case has had a significant and lasting impact on his home and family life.

In a final case example, we were instructed to represent a father at the inquest of his son. This was one of the cases to have been reported by MENCAP in their report, “Death by Indifference”.

Our client’s son was a 30-year old man (“M”) with severe learning disabilities and uncontrolled epilepsy. He had very little speech.

He was admitted to Hospital having sustained a fractured left femur whilst in residential care.

After assessment in A & E, M was moved to the ward. He was very distressed in unfamiliar surroundings and needed a lot of comfort and reassurance.

It became clear to the family that the nursing staff did not understand M’s individual needs as a person with learning difficulties.

For example, he was initially allocated a bed in an inappropriate position at the very end of the ward, out of sight of the nurses’ station. The family protested that this would not be appropriate due to M’s epilepsy and learning difficulties. The nursing staff seemed annoyed but agreed to move him.

Additionally, the nursing staff would leave him drinks and medication and walk away without saying anything to him. This practice continued throughout M’s treatment of our client, even though M was unable to self-medicate.

M had surgery on his leg the following day, losing 40% of his blood during the process. After his operation, routine checks to monitor blood pressure and urine output were completely omitted. On the same day he also suffered several epileptic seizures, which the family noticed but were not noted by the nursing staff.

The day after his operation, M was extremely agitated and in pain. This was explained away as all being a part of the trauma of the surgery he had undergone.

A day later, he continued to look pallid and unwell. His condition continued to deteriorate, and it became apparent that M was in fact in a semiconscious state and was unable to swallow. His family insisted that a doctor be called.

The doctor on call arrived and did a full blood count. The results showed a very low Haemoglobin level and the doctor ordered that T should be given four units of blood.

There was also an increase in the number of severe epileptic seizures M was experiencing. The family now feared that he would enter a state of continuous seizures if he did not receive his usual medication. This, however was initially refused, and only received by M when an on-call pharmacist was called. The fact that M was in status epilepticus (ie continuous fitting) was later also confirmed by a neurologist.

M was discharged, but was soon readmitted to the Accident and Emergency Department as he continued to experience excruciating pain and discomfort whilst at home. The pain team delayed by two days in seeing M.

M was discharged two weeks later with no change in his condition, but had again to be readmitted to hospital due to a high temperature and continuous seizures. He was found to be malnourished and dehydrated and at the beginning of kidney failure. He also vomited an immense amount of bile, which the parents had to help clean up.

Although he was evidently seriously ill, he was again placed in a bed which was out of sight of the nursing station.

A day later a doctor saw his family and explained that M's condition was very serious. He was moved to the Intensive Care Unit. It was later discovered that his lungs had collapsed, as well as having aspirated again and suffered a cardiac arrest. He also continued to suffer petit mal seizures.

In two weeks' time, his condition worsened and it was agreed that if he did not show any sign of improvement in the next 24 hours, it would be in his best interests to withdraw treatment and allow him to die peacefully. His medication was stopped and his sedation brought forward with the family's agreement. He died on the same day.

The needs of our client's son and his way of communicating were not properly understood at the Hospital. Among other things, when he was unable to take his medication, this was not administered. His pain was largely uncontrolled. His family were left to look after his needs both at home and in hospital, and had to demand medical attention for him. He vomited and aspirated bile unobserved by the nursing staff, which led to his lungs collapsing. He did not receive the care he required as a person with learning difficulties.

HOUSING

Whilst we do not specialise in housing law, clients for whom we act in claims relating to health or social services may also have issues with their housing, which we therefore become aware of. In one case, our client was a 47-year-old woman with Asperger's syndrome, living in a rural part of South West England. She has mild learning disabilities and is psychologically mute.

Our client receives some support from the local authority social services department and is known to the local mental health team. She does not meet the eligibility criteria for a service from the community team for people with learning disabilities, as her learning difficulty is assessed as mild.

In 2005, the client was seriously assaulted by another tenant in the block in which she lived. The client gave evidence at her assailant's criminal trial and he was made the subject of a hospital order. We were instructed in connection with a civil claim arising out of the assault.

Until this incident, the client had lived in her own tenancy and received outreach support from a "floating support" scheme run by a not-for-profit organisation. She managed the tenancy well with minimal assistance and was settled and happy.

Following the assault, our client became deeply distressed and was unable to remain in her flat due to the traumatic memories. She was not offered alternative accommodation by the local authority. She was forced to move home to live with her elderly parents. The local authority has placed her on its housing register and has allocated her a level of priority but it is likely that she will have to wait several years before she is offered accommodation, due to the acute shortage of social housing in the area. Our client wishes to live independently and not with her parents. There is concern that she is socially isolated and is not maintaining the life skills that she acquired whilst living in her own flat.

Our client has a care manager and care plan. That care plan identifies a need for independent housing or appropriate supported housing. She has also been assessed as needing an outreach worker to facilitate engagement in social and community activities. The local authority has not identified or recruited an appropriate worker. She has recently now been assessed for counselling after waiting over a year.

We feel that this case shows the failure of services to operate in a holistic way to meet the client's needs. In this case, the social services authority identified the client's needs but the failure of the housing authority promptly to re-house the client undermined the client's care plan and actually caused her to regress. The housing authority's procedures did not allow them properly to assess the impact on the client's social care needs if she were not re-housed.

This was then compounded by the additional failures to identify an outreach worker and offer counselling at a timely stage.

Our experience is that this client's case is not uncommon and public services do not operate as they should in a "joined up" way. This may be because of bad communication between services or different budgets. We are aware that this can be a source of frustration for professionals working on the ground as well as individual disabled people and their families.

EDUCATION

We regularly act for children and young people and their families in disputes concerning special educational provision, including appeals to the Special Educational Needs and Disability Tribunal and claims for judicial review.

We are aware that for individuals and families the transition between school and further education can be a particularly anxious time.

In complex cases, we have become concerned that the Connexions Service does not have the appropriate skills properly to compile the appropriate referral paperwork for the Learning and Skills Council, who fund further education placements.

In one recent case, concerning a 19-year old man with learning disabilities, this caused a lengthy delay. As is set out in their published guidance, the Learning & Skills Council generally expects to receive requests for placements for learners with learning difficulties and / or disabilities at specialist providers by no later than 31 March 2007, for placements commencing in September 2007. In our client's case, time was, in fact, more of the essence as the placement did not follow standard terms and funding was needed from August 2007.

The section 140 assessment completed by the local Connexions Service was inadequate and the client's mother and the specialist placement had to re-write it themselves. They completed this in April 2007, and sent it to Connexions during the third week of April but, for reasons that have not been properly explained, Connexions then did not submit the funding request to the Learning & Skills Council for a further two months.

The proposed provider of the client's further education was not registered with the Learning & Skills Council, and this was too short a timescale for the Learning & Skills Council to make a decision on funding. In the event, the issue has been resolved in the short to medium term as the local authority and health service has agreed to fund our client's placement for 1 year, but the failure of the Connexions Service to understand the client's needs and promptly to submit the funding request for this atypical placement could have resulted in serious disruption to our client's education.

Clients have complained to us that the priorities of the Learning and Skills Council, which form the basis for the funding of further education, disadvantage learners with severe or profound learning disabilities. This leads to funding being refused and clients in this group having to look to health and social services for funding. We think that this is wrong as a matter of principle. Further education funding should be available for all, even if the potential outcome for a client with severe or profound learning disabilities may be very different to that of someone who can achieve in a traditional academic sense.

COMMUNITY CARE

We should also like to add some comments about social care provision for people with learning disabilities.

Good quality community care can be vitally important for people with learning disabilities to enable them to participate in social and community life. As one disabled client told us, "I do not know how to be a disabled person without support".

In one case, we challenged the decision of a local authority to withdraw community care provision to our client, a 14-year old boy with cerebral palsy, learning difficulties, and very high levels of anxiety, associated with previous abuse.

The local authority said that it was impossible for them to continue to provide community care. Their position at that time was that, because of the client's complex needs, child protection issues, and health and safety issues for their own staff, the client was too difficult to provide care for.

Despite this, they were prepared to offer the client's mother a direct payment in lieu of services so that she could arrange care for the client, although she had no experience in setting up and managing a complex care package. The other alternative that was offered was for the client to be admitted to a health provision under the Mental Health Act.

Our client's mother managed to find a support worker who was willing and able to provide the client with care, but who required an hourly rate significantly higher than the Council usually expected to pay. We had to issue judicial review proceedings to compel the Council to finance this provision, which they had refused to do.

We have been involved in a number of other cases where there have been disputes over the amount of direct payment that is required. We believe that this raises issues under Article 8 (right to private and family life). It is imperative that authorities are prepared to be flexible when it comes to making direct payments and pay rates that are commensurate with the client's needs. As in the example given, this can be the difference between enabling someone to continue to live in their local community and being required to move into institutional care, quite possibly long-term.

PRISONERS

We act for a number of prisoners, some with learning difficulties in relation to complaints of inadequate care and treatment in prison. We realise, in all too many cases, that disabilities are not recognised, assessed or addressed.

We are aware that there have been a number of recent reports looking at these problems by the Prison Reform Trust and HM Chief Inspector of Prisons for England and Wales.

The Prison Reform Trust has recently drawn attention to an important new piece of research prepared by the University of Liverpool, which specifically examines the situation of prisoners with learning difficulties (<http://www.prisonreformtrust.org.uk/temp/StudyspReport2.pdf>). This document was highlighted by the Prison Reform trust ahead of the launch in March 2007 of "No One Knows", a new UK-wide programme of work to investigate and improve the treatment of people with learning disabilities and difficulties in the criminal justice system.

Another interesting report commissioned by the Prison Reform Trust is "Time to learn" in which the researchers interviewed a diverse cross-section of prisoners—both in and not in education—exploring their experiences and giving a voice to their ideas on how to develop prison education to reflect their needs.

The thematic reviews, individual prison inspections and annual reports prepared by HM Chief Inspector of Prisons for England and Wales also provide a valuable source of information in this area. We respectfully refer the Joint Committee to these documents.

2. The possibility for adults with learning disabilities to form and maintain personal relationships with others (such as parents, partners and children) and the positive obligations of the state which arise in this context

We have limited comment to make on this issue from within our field of expertise. In general, we believe that it is vital, in order for people with learning disabilities to be able to form and maintain proper relationships, for the state to provide good quality services. Without adequate service provision, parents all too often have to continue as primary carers of their adult learning disabled children, and the relationship between the learning disabled adult and their parents is dominated by their caring obligations. Without adequate community support, individuals with learning disabilities can end up socially isolated, perhaps at home with their parents, and opportunities to meet and form relationships with other people are limited.

3. The opportunities for people with learning disabilities to participate in the life of their local community and the state's obligation to facilitate participation

We repeat our response to the previous point.

4. The potential of the Convention on the Rights of Persons with Disabilities to promote the rights of adults with learning disabilities

The UN Convention on the Rights of Persons with Disabilities could have a far-reaching effect as it includes a multitude of areas, such as civil and political rights, accessibility, participation and inclusion, the right to education, health, work and employment and social protection.

However, as the Convention only comes into force if twenty countries have ratified it, the extent to which the Convention will produce changes in attitude will depend on how many countries will be willing to ratify as well as to sign the Convention.

The United Kingdom is a signatory to the Convention. Although, as an international treaty, the Convention cannot be directly relied upon in UK courts, we believe that it may usefully be used as an aid to interpretation, in particular in relation to the State's obligations to protect and promote human rights.

We also feel that in itself the fact that a Convention has been drafted and signed by 100 countries highlights growing awareness of the rights of disabled persons and their need to be respected. It can also be referred to in this context, when it comes to looking at the State's obligations.

Memorandum from the National Institute of Adult Continuing Education (NIACE)

INTRODUCTION

The National Institute of Adult Continuing Education (NIACE), believes that the right to education is the key which enables people to access other human rights. Individuals can learn about rights that they have and they can develop the skills to get them.

NIACE welcomes the opportunity to submit evidence to the Parliamentary Joint Committee on the subject of Human Rights and Adults with Learning Disabilities. This outlines recent legislative and policy developments that have the potential to make a positive impact on post-16 education and training provision for adults with learning difficulties (NIACE, in common with most in the field of education, uses this term in preference to the Department of Health phrase “adults with learning disabilities”). It then goes on to outline our concerns regarding the quality of and access to provision and presents the views of people with learning difficulties with whom we have worked, reflecting on their experience of post-16 education and training.

NIACE

NIACE is an independent non-governmental organisation and charity. Its corporate and individual members come from a range of places where adults learn: in further education colleges and local community settings; in universities, workplaces and prisons as well as in their homes through the media and information technology. NIACE’s work is supported by a wide range of bodies including the DIUS formerly the DfES (with which it has a formal voluntary sector compact) and other departments of state, by the Local Government Association and by the Learning and Skills Council. The ends to which NIACE activities are directed can be summarised as being to secure more, different and better quality opportunities for adult learners, especially those who benefited least from their initial education.

NIACE’s work on disability is based on the social model of disability; this approach focuses on the barriers in society that disable people and does not see the individual as a “problem” to be solved.

A group of adults with learning difficulties produced their own *Charter for Learning (shown below)*. It highlights 12 key principles that people with learning disabilities want to see applied in post-16 education provision.

Charter for Learning

The right to speak up

— *We are adults with a voice, we want to be heard*

The right to choose to go to classes

— *We should have a say in what we learn*

The right to have support

— *Someone to help who you can rely on*

The right to have the chance to make friends

— *To mix with the crowd a little more and make new friends*

The right to have fun learning

— *The more you enjoy it, the more you learn*

The right to good access

— *Lifts, ramps, more room for wheelchairs*

The right not to be bullied

— *Cut out bullying—everybody equal*

The right to be treated as adults, with respect

— *Talk to us like adults*

The right to have clear information that we can understand

— *The information needs to be easy to understand—it is too complicated*

The right to have good teaching

— *You need a good teacher to help you learn*

The right to be able to do a course to get a job

— *To give us the skills to maybe get a job*

The right to learn in a nice place

— *A place where you feel comfortable*

(NIACE, 2000)

Practical application of human rights principles to the provision of public services, the ability of individuals to access such services and the quality of provision—Post-16 Education and Training.

LEGISLATIVE AND POLICY DEVELOPMENTS

There have been significant legislative and policy developments recently which champion the rights of disabled learners and provide significant and relevant strategies to take forward work to improve the quality of provision in the post-16 education and training system for people with learning difficulties.

In 2002 disabled learners gained new rights under the Disability Discrimination Act (DDA) Part 4 which requires education providers:

- not to treat disabled learners less favourably than other learners for a reason related to their disability; and
- to provide reasonable adjustments for disabled learners.

The Learning and Skills Council has funded a training, research and development programme in the post-16 sector based on the duties of the DDA. The purpose of this has been to support providers to implement their duties under the act and to develop good practice in provision for people with learning difficulties and/or disabilities. Most recently this has focussed on supporting organisations to implement the requirements of the duty to promote Disability Equality.

In 2006 the Learning and Skills Council published its national strategy for disabled learners: *Learning for Living and Work: Improving Education and Training Opportunities for People with Learning difficulties and/or disabilities*. (LSC, 2006). NIACE welcomed this strategy and the LSC commitment to:

“Securing and funding appropriate high-quality learning provision for learners of all ages with learning difficulties and/or disabilities remains a consistent aim and priority” (LSC, 2006)

One of the action points of the *Learning for Living and Work* strategy was the development of a cross-departmental strategy between the three Departments most closely involved in this area: Education and Skills, Health, and Work and Pensions. Our staff contributed to this development which resulted in launch of: *Progression through Partnership: A Joint Strategy between the DIUS (formerly) DfES, DOH and DWP on the role of Further Education and Training in Supporting People with learning Difficulties and/or Disabilities to Achieve Fulfilling Lives* (June 2007)

NIACE welcomed this strategy, believing that it should take forward joint policy development; person-centred planning and the improvement of workforce capacity and performance. NIACE anticipates involvement in supporting the work to develop a delivery plan for the planned “Programme of Change”.

OUR CONCERNS

In the UK a person with a learning difficulty has a slim chance of receiving high-quality post-16 education and training provision taught by an adequately qualified and experienced workforce. Good practice exists but it is rare and patchy. People with learning difficulties are frequently on courses or training which have a vocational focus but rarely are they supported to make a transition to work. The transition from school to college for people with learning difficulties is particularly poorly supported. The curriculum choice on offer to people with learning difficulties is increasingly narrow with a focus on literacy and numeracy at the expense of opportunities to develop skills for self expression, choice making and self-determination. Such skills are essential to individuals leading a fulfilling life. There is evidence that existing provision will shrink due to wider cuts in services. Rather than improving poor quality courses, it appears that providers are cutting courses leaving people with learning difficulties with no choice or no provision.

QUALITY AND ACCESS—THE LEARNER VOICE

NIACE has undertaken two consultations (2004, 2006) with people with learning difficulties about learning and the education they receive. The findings highlighted some key messages from learners:

1. They wanted learning to help them move on in life, particularly into work—mainstream education and job centres were not doing enough.
2. They wanted to be able to choose from the whole curriculum offer and not just provision specifically for people with learning difficulties.
3. There was a sense that very often all that was on offer in discrete provision was “reading, writing and numbers”.
4. Courses were too expensive and they needed support to help pay.
5. Transport should be reliable, accessible and affordable.
6. Some staff appear to have had minimal training in working with people with learning disabilities.

The issues highlighted by learners have been consistent over a period of seven years. They overlap strongly with recent findings of Inspections of post-16 provision and research of post-16 education and training. None of these issues are new yet there is a sense in the field that progress in tackling them is not seen as a priority or a mainstream quality issue but rather as a specialist concern.

CUTS IN PROVISION

There have been substantial cuts in post-16 education provision in 2006–07. Although spending has risen about one million places have been lost since 2005. Information from providers and learners indicated that this was affecting learners with learning disabilities disproportionately. The cuts were due to providers being required to prioritise spending upon basic literacy, language and numeracy and provision leading to qualifications and level 2 targets.¹ In response to concerns voiced the Learning and Skills Council undertook out a survey which found that 3,000 of a total of 20,000 students with learning disabilities had lost their places as a consequence of this policy.² The justification for this was reported as being due largely to provision concerned being of poor quality. NIACE suggests that rather than cutting poor provision, a more appropriate response should have been to support providers to improve the quality of the provision.

QUALITY

The quality of teaching and learning support support for people with learning difficulties is patchy and, on occasion, poor. A recent OFSTED report (January 2007)³ found that the quality of the provision in 22 colleges surveyed was very uneven. NIACE's work consistently supports this finding on a national scale. There are pockets of good practice but also many gaps in provision and examples of poor quality services. Recent research has highlighted that provision for people with learning difficulties who come from minority ethnic communities and who have English as a second language is particularly scarce and under developed.⁴ At present it appears that people with learning disabilities cannot be assured either of comparable levels of quality or levels of quality (choice) in contrast to other learners in the UK.

TRANSPORT

Most people with learning disabilities rely on transport in order to get to their place of learning. Inadequate transport or support to travel and opportunities learn how to be an independent traveller, can often mean no or severely restricted participation in education and training for people with learning disabilities. Barriers that people with learning disabilities face when travelling to their college include: public or contracted transport which is not reliable or easily accessible; travel information that is not accessible to people with learning disabilities; problems with funding and paying for transport. Transport is crucial for the social inclusion of people with learning disabilities.

TRANSITION

The two key transition points for people with learning disabilities in education are the transition from school to college and the progression from college to work and/or fulfilling lives in the community. The planning and support for both of these transition points is recognised to be problematic for people with learning disabilities. Effective transition is supported by person-centred planning and approaches; based on learners' hopes and aspirations. This will support learners to participate in meaningful programmes of learning if there is enough flexibility allowed in the funding of provision. This in turn will lessen the possibility of them becoming part of the "revolving door" syndrome, whereby learners returning to the same provider year after year with very little thought given as to how their learning can support them with progression. Effective transition is essential to meaningful progression. Much work remains to be done here and key to this a multi-agency approach to planning and funding of services as well as increased awareness of person-centred planning and approaches in education.

WORKFORCE DEVELOPMENT

There is currently a lack of appropriate qualifications for staff working with learners with learning difficulties and/or disabilities. Having a poorly trained workforce will of course impact on the quality of provision. Staff working in this area often report that they feel isolated and that their work is not valued by other colleagues and managers. This isolation of staff and learners is exacerbated by a common situation in colleges where people with learning disabilities are being taught in segregated or discrete provision, often to the exclusion of them being able to chose to join mainstream classes. The sector skills council, Life Long Learning UK is currently developing some qualifications for teachers working in this area. NIACE will watch with interest as workforce development was one of the recommendations in LSC *Learning for Living and Work* strategy.

Can the Convention on the Rights of Persons with Disabilities promote the rights of adults with learning disabilities?

NIACE welcomes the UN Convention on the Rights of People with Disabilities. NIACE endorses wholeheartedly Article 24 on Education. Education should be fully inclusive. Disabled people should be able to access education, training and lifelong learning without discrimination and on an equal basis with others.

CONCLUSION

NIACE would welcome the opportunity to provide the Committee with any further information or comment as it requires. In the first instance, please contact Yola Jacobsen.

REFERENCES

1. "The wrong sort of learners". "Guardian article, 25 July 2006.
2. They're calling my son ineducable" Guardian 5 February 2007.
3. Current provision and outcomes for 16–18-year-old learners with learning difficulties and/or disabilities in colleges. OFSTED, 2007.
4. Making It Happen: An inclusive approach to working with people with learning difficulties who have ESOL needs. (DfES, 2006).

24 July 2007

Memorandum from the Working Together with Parents Network

INTRODUCTION

1. *The Working Together with Parents Network*

The Working Together with Parents Network is a consortium of six national organisations and individual experts working to improve support to parents with learning disabilities and their children so that they can stay together as a family. The project partners are:

- The Norah Fry Research Centre, University of Bristol (NFRC)— which coordinates the Network and acts as its administrative base in England and Wales.
- CHANGE—an organisation of disabled people, which supports the activities of parents with learning disabilities within the Network.
- The Scottish Consortium for Learning Disability (SCLD)—which runs a parallel network in Scotland.
- The Family Welfare Association—which links the Network into a wider range of mainstream family support groups and activities.
- Dr Jenny Morris—an independent researcher, currently employed by the Office for Disability Issues' Independent Living Review, who also works on policy related issues on behalf of the Network.
- Dr Sue McGaw—who established one of the first UK services to support parents with learning disabilities in Cornwall and has developed many resources to support professionals and parents in this area.

2. *What the Network does*

The Network is currently funded by the Baring Foundation, with support from the Esmee Fairbairn Foundation. It was set up in June 2006, following the publication of a report undertaken by NFRC (funded by the Baring Foundation) on issues and positive practice in supporting parents with learning disabilities and their children (Tarleton et al, 2006). The Network aims to facilitate policy and practice change designed to enable families where a parent has a learning disability to stay together with their children.

3. *How the Network operates*

The Network operates in a number of ways:

- A national Taskforce of parents, professionals and policymakers from key organisations, including government departments, meets twice a year to progress action on key issues.

- A Parents’ Network, facilitated by CHANGE, enables parents with learning disabilities to meet together to share ideas and experiences and feed these to the Taskforce. Parents from the Network also provide input into meetings for professionals (see below) and are involved in creating easy to understand, illustrated leaflets on important issues, like child protection and court procedures.
- Multi-disciplinary Professionals’ Networks are being set up or supported in different parts of the country through initial one day events organised by the National Network. These events provide an opportunity to gain and exchange ideas and information (eg on the new government guidance on working effectively to support parents) and to collaborate with colleagues in other professions.
- A UK wide database of Network members has been established, through which members receive email updates on relevant issues and regular email newsletters. (Network membership is free of charge).
- A Scottish Network—also operates, coordinated by SCLD, with regular meetings.

OUR EVIDENCE

4. *Numbers*

There are no precise figures on the number of parents with learning disabilities in the population but it is generally accepted that their numbers are rising and that their needs for support have not been adequately addressed by health and social services (Booth, 2000). The recent national survey of adults with learning disabilities in England found that one in 15 of those interviewed had children. 48% of these parents were not looking after their own children (Emerson et al, 2005).

5. *Policies*

National learning disability policies in both England and Scotland state clearly that parents with learning disabilities should be supported appropriately “to ensure their children gain maximum life chance benefits” (Department of Health, 2001; Scottish Executive, 2000). Other (non learning disability specific) policies also provide a context where the presumption is that children should be supported to stay with their families and that parents with additional needs should receive the support they need from statutory services working collaboratively (eg. Every Child Matters; The National Service Framework for Children, Young People and Maternity services). In practice, though, parents with learning disabilities are far more likely than other parents to have their children removed from them. Research suggests this happens in around 50% of cases (Tarleton et al, 2006), as a result of the lack of appropriate support to the family and concerns about the welfare and development of the children.

6. *Barriers to support*

Our research (executive summary of findings attached) identified a range of barriers to parents receiving the support they needed. These included:

- Negative, or stereotyped, attitudes about parents with learning disabilities on the part of some professionals and a lack of knowledge and experience of how to work with them.
- Parents were often given differing, sometimes contradictory, advice from the different professionals involved with them on how they should handle their children, so confusing them and compounding any difficulties they were already experiencing.
- Parents were frequently “disengaged” with services because they felt staff had a negative view of them and “wanted to take their children away”.
- Referrals to support services were too late to be of optimum use to the family, because professionals did not realise parents had learning disabilities and parents were not known to learning disability support services (often because they had managed without formal support until their baby arrived).

7. *Research evidence*

Research indicates that adults with learning disabilities can often be good parents to their children, when provided with the ongoing emotional and practical support they need. (eg Tarleton et al, 2006; SCIE, 2005).

8. *The role of professionals*

Professionals who understand the needs of parents with a learning disability can play a valuable role in raising the awareness of other staff (eg midwives, children’s social workers) about their support needs and the best ways of working, eg the need to offer advice in a consistent fashion, in “bite-sized” chunks, and in easy to understand language.

9. *Strategies for positive practice*

The following are also important:

- Early identification of parents with learning disabilities—Professionals need to be able to identify if parents have a disability so that they can develop care pathways for them. Protocols for joint working between different services are also needed to support parents and their baby.
- Easy to understand information—Parents with learning disabilities need accessible information on every topic to do with pregnancy and child rearing, from the antenatal stage onwards. CHANGE’s publications, like *You and Your Baby*, are good examples of what is needed. *You and Your Baby* was funded by the DfES. But at the moment parents with learning disabilities do not routinely get given a copy. This needs to change.
- Appropriate assessment—of parents’ support needs, should be based on their competencies (ie building on what they can do) rather than focussing simply on their IQ level and what they can’t do. There needs to be enough time for them to be given a proper explanation, in words they can understand, of what is going on.
- Skills training and support—This needs to be available, in appropriately accessible formats, and on an ongoing basis, as children develop and families’ needs change. A useful resource on what works for parents with learning disabilities and their children is the Barnardo’s publication by Sue McGaw and Tony Newman: *What works for parents with learning disabilities?* (2005).
- Access to parenting groups—Here parents can advise and support each other about what works for them. Parenting groups can reduce parents’ isolation and provide them with the chance to make contact with staff and seek guidance on an informal basis as issues—like bullying and harassment—arise.
- Effective multi-agency working—between children’s and adult services is vital, as is partnership working between health, education, social and housing services, so parents are well supported and given consistent messages about what is required of them, in order for them to keep their children.
- Advocacy—This is especially important when parents are involved in child protection and judicial proceedings, to help ensure their case is represented adequately and from their point of view. Mencap’s recent publication, *Providing the right support to parents with a learning disability*, illustrates clearly the difference that advocacy can make to parents’ ability to keep their children at home with them.
- Child protection awareness—This is needed by ALL professionals if they are to engage appropriately with other services. If ongoing support is provided to parents, this can prevent relatively small difficulties escalating into child protection concerns and procedures.
- Child protection and the courts—Parents need easy to understand information and explanations about these processes and the roles of all the different professionals involved. They need extra time with solicitors for this reason, and support to visit the court beforehand. Solicitors need to ensure that reports put to the court are appropriate and proceedings are slowed down enough so parents have a better chance of understanding what is going on.
- The need for training—Only half of the staff in the study by Tarleton et al had received any training for their role in supporting parents. They wanted training on child protection, on the best ways of assessing parents’ support needs and on strategies to support their parenting.

10. *Good practice guidance and the Disability Equality Duty*

In June this year one of the recommendations of our research—that good practice guidance for professionals on how to support parents with learning disabilities should be produced—was realised with the publication of *Guidance from the DH/DfES (2007)*. The guidance acknowledges that “there is little evidence of effective working between adult and children’s services. Children’s services practitioners, and adult learning disability workers, rarely have a good working knowledge of the policy and legislative framework within which each other are working” (p.4) The guidance aims to address this situation and “to assist local authorities to fulfil their disability equality duty to promote equality of opportunity for disabled people. It will do this by helping to ensure that people with learning disabilities have equal opportunities to be parents and bring up their children, and that parents with learning disabilities have equal access to family support services” (p.5)

11. *Implementing the guidance*

Our Network is running three events for professionals in different geographical areas on what this guidance means for them in practice. It is clear, however, that much more needs to be done in this area. All of our workshops have been heavily oversubscribed within days of their announcement. There are currently no plans from the DH/DfES (as was) to run any events to ensure that information on the guidance is well disseminated to the professionals who should be implementing it in practice.

12. Funding support services

We are aware that since the publication of our report, at least one of the examples of good practice we cited—a community service for parents with learning disabilities in Stockport—has closed because of funding problems. Given current pressures on local authority budgets it seems all too likely that this situation will be replicated elsewhere.

CONCLUSION

We remain deeply concerned that the rights of parents with learning disabilities and their children to a family life, as provided by Article 8 of the Human Rights Act¹ will continue to be infringed, despite the fact that the financial costs to the state of placing a child in care exceed the costs of providing appropriate and timely support to the family, so that they are able to stay together as a family.²

REFERENCES

- Booth, T, 2000, Parents with learning difficulties, child protection and the courts, *Representing Children*, 13 (3), 175–188.
- CHANGE, 2004, *You and your baby*, Leeds, CHANGE.
- Department of Health, 2001, *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London, The Stationery Office.
- DfES, 2004, *Every Child Matters*, London, The Stationery Office.
- DfES/DH, 2004, *National Service Framework for Children, Young People and Maternity Services*, London, DH.
- DfES/DH, 2007, *Good practice guidance on working with parents with a learning disability*, London, DH.
- Emerson, E et al, 2005, Adults with learning difficulties in England 2003–04, www.ic.nhs.uk/pubs/learn_diff2004
- McGaw, S and Newman, T, 2005, *What works for parents with learning disabilities?* Ilford, Barnardo's.
- Mencap, 2007, *Providing the right support for parents with a learning disability. Evaluating the work of the north east parents' support service and the Walsall parents' advocacy service*, London, Mencap (for executive summary of findings go to www.right-support.org.uk)
- Scottish Executive, 2000, *The Same as You? A review of services for people with learning disabilities*. Edinburgh, The Stationery Office.
- Social Care Institute for Excellence (SCIE), 2005, Helping parents with learning disabilities in their role as parents, www.scie.org.uk
- Tarleton, B, Ward, L & Howarth, J, 2006, *Finding the right support? A review of the issues and positive practice in supporting parents with learning difficulties and their children*, Bristol, Norah Fry Research Centre/ Baring Foundation (www.right-support.org.uk)

NOTES

¹ See the following extract from The British Institute of Human Rights publication, *Your Human Rights: A guide for disabled people* (BIHR, 2006), p.19:

“Sometimes public authorities must do something active to protect your family life. This might mean providing support to help your family live together. For example, this may include providing educational or financial resources for disabled parents who need this support in order to look after their children.

CASE EXAMPLE

“A couple in Germany, both with learning difficulties, had two children. The children were removed from their parents some years after their birth as a court decided the parents were incapable of bringing them up. However, there was no evidence of neglect or bad treatment. The children were separated and eventually fostered. They had very little contact with their parents after this. The European Court of Human Rights

said the right to respect for family life was breached in this case. The separation of the family was not proportionate. The authorities could have provided educational or financial support to enable the family to stay together.”

² An uncomplicated case where a baby of a parent with learning disabilities is placed for adoption costs around £106,000 in total (figures supplied by a specialist learning disability team). More complicated cases can cost up to £500,000 (ODI, 2007, *The costs and benefits of independent living*, London, Office for Disability Issues.)

Where children remain in local authority care (which is more common), average costs for residential care are about £2,100 per week and for foster care, £438 per week (Curtis, L and Netten, A 2004. *Unit Costs of Health and Social Care*, Canterbury: University of Kent, PSSRU.) Outcomes for young people who grow up in care are very poor.

ENCLOSURES/ATTACHMENTS

1. *Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children* (Executive summary)
2. *Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children* by B Tarleton, L Ward and J Howarth, Baring Foundation, 2006 (Full report)

Both the above can be downloaded at www.right-support.org.uk

25 July 2007

Memorandum from Who cares for us?

You kindly asked us to write to the committee about our work with carers with a learning disability and their human rights.

There are very many carers with a learning disability, yet, despite sometimes high levels of need, this issue is only recently coming to the attention of social care services. These carers fall into three main groups:

1. People who are still living at home with parents who, often because of age, have care/support needs of their own. The relationship often changes over time from the support of a son or daughter to a mutual support and then support of a parent.
2. People with learning disabilities living with partners who also have a learning disability and higher support needs. As more people with learning disabilities are leading independent lives many naturally form relationships and live with a partner or spouse. Frequently, one of the partnership needs more social care support than the other.
3. Parents with a learning disability caring for a child. Whilst this is naturally an area of concern for us, we know that others have addressed the issue and we have not included it in our remit.

The numbers and role of carers with a learning disability are largely hidden. This is due to a number of factors.

- Due to the nature of the relationships, many carers do not regard themselves as carers, having naturally fallen into the role as a part of the relationship. They don't therefore think about contacting anyone for help.
- Contact with services is feared due to concerns they will be viewed as not coping and the person cared for will be “taken into care”.
- Social services themselves do not regard carers with learning disabilities as potential or actual carers due to preconceived ideas about when people with learning disabilities can and do do.
- Services are not geared up to find or support carers with a learning disability.

As a result of these factors many carers are left to struggle on until a crisis point is reached. This has an obvious impact on their lives and their rights to a family life. Examples of this are:

- Carers do not get access to the carers support services available to other carers groups. This includes short term breaks, support, benefits advice, mutual carers support groups etc.
- People are assessed singularly as opposed to being a couple. As a result they get no holistic assessment or a picture of their lives together, the importance of that relationship and the mutual support that comes from it.
- Relationships become damaged after becoming dominated by a caring role as opposed to a partner / son daughter role.

Many carers with a learning disability can undertake a significant caring role, but many need the right help or support to do so. Without that support people can flounder from lack of information about what to do and where to go for help.

As carers responsibilities increase, many people do not manage to get much of a life outside of the home, and certainly are unable to partake in ordinary community life. Without adequate or appropriate support health can often suffer through inadequate diets and a lack of access to ordinary primary care services.

As a consequence of not even recognising or calling themselves a “carer” people are often financially less well off. Carers grants and benefits such as council tax relief go unclaimed.

We would want to see equality achieved by:

- Supporting people with learning disabilities to recognise that they are actually undertaking that role, even if the label is not always readily accepted, such recognition is a first step towards achieving what other carers expect.
- Finding out more about the size of the issue, the numbers of carers with a learning disability.
- Helping social services recognise the issue and provide equal access to services.
- Supporting carers with a learning disability to become expert carers and take part in self help and mutual support groups.

Eve Rank and Richard West

20 July 2007

Memorandum from the Commission for Social Care Inspection

BACKGROUND AND CONTEXT

1. The Commission for Social Care Inspection (CSCI) was launched in April 2004 as the single inspectorate and regulator for social care in England. Since April 2007 CSCI has concentrated on encouraging improvements in adult social care services, responsibility for the inspection and regulation of most children’s social care services having moved to Ofsted.

2. CSCI’s main statutory functions are to:

- carry out an annual performance assessment of councils with adult social services responsibilities and publish the results in the form of “star ratings”;
- register and regulate social care provider organisations—public, private, and voluntary—against national minimum standards and publish our findings;
- publish an annual report to Parliament on the state of social care; and
- carry our enforcement action where poor performance requires it.

3. Whilst many adults with learning disabilities live in the community, often with their parents, as at 31 March 2006 there were 57,587 places in homes registered with the Commission for younger adults with learning disabilities. On average, such homes are smaller than those for other groups, such as older people, with the average size of care homes overall now some 18 places. Around nine out of 10 care homes for adults aged 18–64, many of whom are people with learning disabilities, are in the private and voluntary sectors, with 25% of the total run by the voluntary sector, compared with 13% of homes for older people.

CSCI AND THE HUMAN RIGHTS ACT

4. CSCI has sought to adopt a human rights approach to its work. The inaugural meeting of the Commission in April 2004 formally resolved to adopt human rights principles. The first point in CSCI’s statement of Vision and Values is that we will seek to put people who use social care services first and will speak and act in a way that respects people’s rights and choices. In addition, our overarching Equalities and Diversity Strategy, published in August 2006, says that “In all that we do, we recognise and respect the human rights of those who use social care, provide it and regulate it.”

5. Accordingly, rather than seeing human rights as a separate strand of activity, CSCI has endeavoured to weave the rights of individuals into the fabric of all that we do. In this way we aim to ensure that providers and commissioners consider an individual’s rights a core aspect of social care and that people who use services are able to recognise the importance of their rights.

6. Moreover, whilst the Commission has not issued specific guidance to providers of services on the Human Rights Act, we believe that we deliver our positive duty to implement the Act through:

- the application to regulated services of the HRA-compliant national minimum standards (and associated legally-binding Regulations)¹⁶⁸;
- our performance assessment of councils with adult social services responsibilities;

¹⁶⁸ The legislation governing CSCI’s work—The Health and Social Care (Community Health and Standards) Act 2003 and the Care Standards Act 2000—are both Human Rights compliant, introduced after the enactment of the Human Rights Act 1998.

- disseminating information on the state of individual social care services in England; and
- publishing the overall picture of the state of social care.

7. The Commission also believes that Article 8 of the HRA, which gives everyone the right to respect for their private and family life includes those in residential care, who rightly regard care homes as their own home. When we gave oral evidence to the JCHR in March 2007 as part of its earlier enquiry into the human rights of older people, this point was raised. We argued that, although the national minimum standards used when regulating services were HRA-compliant, there remained a loophole whereby those placed in private care homes by public authorities such as councils and PCTs (as opposed to those placed in homes run by councils) had no enforceable rights of redress under the Human Rights Act if it were held not to apply in such circumstances. We are aware that as a consequence of a recent House of Lords judgement, this problem remains unresolved.

ENFORCEMENT POWERS

8. The Care Standards Act 2000 sets out the enforcement powers available to the Commission in relation to regulated care services. We may take enforcement action if a service persistently fails adequately to meet the needs of people who use it—see sections on Cornwall and Merton below.

9. We can take a range of enforcement actions in order to improve poor or dangerous care practices when we find them. Our powers include urgent cancellation of registration in the most serious cases. We work with others to protect the interests of people who are at risk and cannot protect themselves and indeed recently signed an updated protocol on safeguarding adults with the Association of Directors of Adult Social Services and the Association of Chief Police Officers.

10. We seek to enforce the law in a way that is:

- Fair and non-discriminatory.
- Efficient and effective.
- Transparent.
- Proportionate (to the quality of care and approach to improvement).
- Consistent across our organisation.

11. Guidance to our staff on our enforcement policy makes specific reference to human rights, stating that “We will make sure that the improvements we require promote equality and protect all people’s human rights and choices.”

“INSPECTING FOR BETTER LIVES”—PUTTING PEOPLE WHO USE SERVICES FIRST

12. The Commission recognises that, despite being HRA compliant, the National Minimum Standards do not always capture what matters most to people. They are framed more in terms of inputs and processes than outcomes. The Commission is therefore developing approaches that focus more strongly on outcomes for people.

13. For example, CSCI is modernising the way it regulates services, through its “Inspecting for Better Lives” programme. We have adopted a proportionate and risk-based approach to regulation. This enables us to focus more attention on poorer performers. Our new inspection methodologies are supported by guidance for inspectors on assessment (called Key Lines of Regulatory Assessment) which guide inspectors on how to look at, for instance, aspects of services related to the dignity, respect and human rights of those in receipt of services, whether in care homes or through domiciliary care agencies. People with learning disabilities should particularly benefit from our more accessible inspection reports and methods which focus on person-centred planning.

WORKING WITH COUNCILS

14. The Commission is also developing new methodologies for inspecting and assessing local council social services for adults which reflect the importance of dignity and safeguarding—one of the Department of Health’s key outcome challenges. The proposed methodology will be designed within the overall system which delivers judgments in the Annual Performance Assessment of councils.

REPORTING ON THE STATE OF SOCIAL CARE

15. CSCI also has a statutory duty to report directly to Parliament annually on the performance of social care services in England. CSCI’s most recent report to Parliament, *The State of Social Care in England 2005–06*, was published in December 2006. The report uses the findings from CSCI’s inspections and assessment activity to describe how far trends in social care have changed over the year (2005–06), looks in depth at commissioning by councils and support provided by family carers and provides an overview of the current state of social care across public, voluntary and private sectors.

SAFEGUARDING ADULTS FROM ABUSE

16. Abuse as described in the DH's "No Secrets" guidance "is a violation of an individual's human and civil rights by any person or persons". It may be a single act or repeated acts and can take the form of physical abuse, sexual abuse, psychological abuse, financial or material abuse, neglect and acts of omission and discriminatory abuse. The guidance also refers to institutional abuse and provides the following example:

"Neglect and poor professional practice also need to be taken into account. This may take the form of isolated incidents of poor or unsatisfactory professional practice, at one end of the spectrum, through to pervasive ill treatment or gross misconduct at the other. Repeated incidents of poor care may be an indication of serious problems and is sometimes referred to as institutional abuse."

17. CSCI has a very clear focus on ensuring that people who use services are properly safeguarded from abuse by those who commission and manage those services. As well as our regulation of services, which aims to raise standards of provision for people using services and which assesses how far providers are meeting a range of standards, including those relating to safeguarding issues, CSCI has undertaken larger scale investigations in response to serious complaints or where otherwise deemed necessary for the protection of people using services. One major example of this was the joint inquiry by CSCI and the Healthcare Commission into services at the Cornwall Partnership NHS Trust.

CORNWALL PARTNERSHIP NHS TRUST

18. In 2005 CSCI worked closely with the Healthcare Commission (HCC) on an investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust.¹⁶⁹ The investigation was triggered by serious concerns from the East Cornwall Mencap Society in October 2004.

19. The findings of this investigation relate to the people living in the trust's three assessment and treatment centres and 45 supported living settings in the community in Cornwall. The investigation found that institutional abuse was widespread, preventing people from exercising their rights of independence, choice and inclusion. One person spent 16 hours a day tied to a bed or a wheelchair, for what staff wrongly believed to be their own protection. Another person told investigators that he had never chosen any of the places he had lived as an adult.

20. In more than two thirds of the sites visited, unacceptable restrictions were placed on the people who lived there. Internal and external doors were kept locked by staff to restrict the people who lived in settings in the community. In one home taps were removed from the bathroom and, in another, light fittings were taken out. Arrangements for the financial management of people's individual monies were of concern and referred to the NHS Counter Fraud and security Management service for their investigation.

21. During the investigation HCC & CSCI made referral of 40 individuals under the protection of vulnerable adults procedures to Cornwall Social Services Department (SSD). The Trust's investigation of these matters revealed systematic flaws in the local procedures, with managers investigating their own services. Cornwall SSD, as the lead agency for coordinating the vulnerable adults procedures, failed to coordinate inter-agency arrangements in accordance with the "No Secrets" guidance, in relation to an interagency policy, staff training in the policy and guidance.

Assessment and Care planning

22. The trust's services did not reflect the principles of rights, independence, choice and inclusion as set out in "Valuing People". The Assessment and treatment centres, run by the Trust, did not meet best practice as detailed in the "Mansell report":

- Some services were provided in unacceptable environments, preventing effective care from being provided.
- There were no effective guidelines for handling challenging behaviour or adherence to treatment programmes.
- There was evidence of physical restraint being used illegally.
- There was evidence of excessive use of *pro re nata* (PRN) medication to control unacceptable behaviour.
- In two of the three treatment centres there were no treatment plans for those people residing there.

23. In the 45 community settings there was little evidence of community care assessments for residents by Cornwall SSD and it was therefore not possible to determine if people's needs were being met or receiving appropriate services. CSCI consider that these settings were being run as unregistered care homes. In addition:

¹⁶⁹ The full report can be downloaded from the CSCI website at http://www.csci.gov.uk/about_csci/press_releases/investigation_finds_widespread.aspx

- Staff in these homes received inadequate training or management support to provide appropriate services for the residents.
- There were few policies and procedures to run a supported living service; those policies in existence were not updated, reviewed or monitored.
- Staff were recruited without Criminal Record Bureau checks (CRB).
- People using the supported living services were offered no choice as to where and with whom they lived, or who provided their care.
- The residents and their families had no access to an independent advocacy service, apart from the support of the East Cornwall Mencap Society.

Summary

24. The investigation report details the whole system failure involved in this case. This resulted in the denial of human rights to the people with learning disabilities to whom the authorities locally owed a duty of care. HCC advised the Secretary of State for Health that the Trust be placed on special measures and an independent change team was deployed to devise and implement an improvement plan to meet the recommendations of the investigation. This has resulted in:

- the closure of the two adult treatment centres, assessment of all people in the treatment and community settings to determine their needs;
- service redesign to meet assessed needs;
- the development of an independent advocacy service to support people to make informed choices as to where they wish to live and with whom and what services they require to support them to live independently in the community;
- the trust has registered as a domiciliary care agency to support people living in the community; and
- staff are being recruited, managed and trained to meet the needs of a modern service for people with learning disabilities.

25. HCC & CSCI will be conducting random inspections of a sample of the community settings to determine whether these are sheltered housing or still being run as unregistered care homes. The Trust is negotiating with a number of national care providers for the modernisation of the service. The outcome of these inspections will determine whether the Trust's special measures are lifted this autumn.

SUTTON AND MERTON PCT

26. In addition to Cornwall, another investigation, led by HCC with the support of CSCI, was carried out into the abuse of people with learning disabilities in Sutton and Merton PCT. The investigation was triggered by the PCT itself, which requested an independent investigation of its learning disability services, following their own concerns about a number of serious incidents.

27. The report, released by HCC in January 2007, showed that old fashioned and institutionalised services had led to the neglect and unacceptable care of people with learning disabilities in Sutton and Merton PCT. Evidence in the report highlighted living environments that were "impoverished and completely unsatisfactory". The investigation also found evidence that:

- staff were poorly trained and lacked support;
- residents experienced lack of stimulation and activity;
- there was poor communication from staff members; and
- failures in management and leadership were found at all levels of the Trust.

28. The Commission's report contained 25 recommendations and the Trust was required to prepare an action plan within nine weeks to address these recommendations. The Healthcare Commission will closely monitor the plan's implementation.

29. CSCI has taken other recent action in respect of learning disability services. In one case we obtained an emergency closure order against a small care home for people with learning disabilities run by an NHS Trust in Bedfordshire and we are currently seeking to cancel the registration of three similar services in Devon. We will not hesitate to use our powers to safeguard and promote the human rights of people in these situations.

30. We are also working jointly with the Healthcare Commission in:

- supporting their audit of NHS learning disability services, following the Cornwall inquiry;
- planning of the two Commissions' work on learning disability services, which takes place in a Joint Improvement Board; and
- planning joint action, for 2008–09, in response to the audit findings, expected in the autumn of 2007.

 THE DISABILITY RIGHTS COMMISSION

31. The Disability Rights Commission (DRC) conducted an inquiry into the physical health inequalities experienced by people with learning disabilities and/or mental health problems in 2005.¹⁷⁰ The report of this inquiry highlighted possible solutions to the problems raised, including action points for CSCI.

32. Many of these points have been or are being addressed. For example, CSCI worked with the Healthcare Commission on guidance in relation to the healthcare needs of people with learning disabilities and CSCI issued guidance for inspectors in relation to annual health checks, including what can be expected of providers under the current legislative framework. This guidance is aimed at ensuring that people with learning disabilities have equal access to a GP and access to options for healthy living.

33. However, one important point to note is that CSCI is statutorily obliged to operate within the relevant regulations. As a result we can only require action of providers if they are covered by those regulations. The Department of Health's review of these regulations and associated national minimum standards, which will no longer have an interim stage but which is still designed to equip the forthcoming health and adult social care regulator—Ofcare¹⁷¹—with a new set of health and care standards, needs to ensure that measures are incorporated into any new standards which properly safeguard the rights of people who use social care services.

“EXPERTS BY EXPERIENCE”

34. CSCI's “Experts by Experience” approach was developed to improve social care services by involving people who use them in our inspection process. An “Expert by Experience” is someone who uses services themselves and can use this experience to assist during inspections. We have “Experts by Experience” representing a range of social care needs, including Experts with specific experience of services for people with learning disabilities.

35. “Experts by Experience” take part in inspections, accompanying an inspector, and talk to the people who use the care service. They look at what happens in the service, discuss the service with the inspector and report on their findings. CSCI is using their expertise to influence how we inspect, and how we write our inspection reports and other publications. An Inspector reported: “I feel that the Expert had a clear understanding and awareness of how to obtain the required information to contribute to the inspection process. Service users felt relaxed talking to him. He was able to relate to people very well. He was able to observe non-verbal communication that validated his and my thoughts. The registered manager was very pleased that an Expert by Experience was at the inspection.”

CONCLUSION

36. The Commission for Social Care Inspection seeks to put the people who use services at the very heart of what we do. The legislation that created the Commission is HRA compliant and we have embedded human rights principles into our work, from assessing providers against the National Minimum Standards, incorporating relevant principles into our methodology for assessing councils, to investigating abuse and taking enforcement action.

37. The Commission would welcome the opportunity to discuss these matters further with the Committee in the event of being called to give oral evidence.

July 2007

 Memorandum by Mencap in Northern Ireland

SUMMARY OF MAIN POINTS

1.0 INTRODUCTION

Mencap supports people with a learning disability and their families in Northern Ireland by providing a range of services, supporting a membership network and by campaigning for equal rights and chances.

The evidence submitted by Mencap in Northern Ireland should be read alongside that of our national organisation.

¹⁷⁰ The report of this inquiry can be downloaded from the DRC website at http://www.drc-gb.org/library/health_investigation.aspx

¹⁷¹ Ofcare is the body being planned to replace, subject to legislation, CSCI, the Healthcare Commission and the Mental Health Act Commission from April 2009.

This evidence is submitted because of the different circumstances experienced by people with a learning disability living in Northern Ireland such as the marked differences in service provision and the continued reliance on long stay hospitals; the impact of the conflict, and the historic underfunding of learning disability services.

The Bamford Review of Mental Health and Learning Disability has produced a number of reports which are relevant to the matter being considered by this inquiry. We draw particular attention to the report on learning disability, *Equal Lives*, and to the report on human rights and equality of opportunity.

2.0 SUMMARY OF POINTS

- People with a learning disability do not enjoy equal access to the same services and opportunities as others in their community.
- People with a learning disability do not get the support they need to exercise their rights. Advocacy provision is under developed in Northern Ireland.
- There is a higher proportion of people with a learning disability in Northern Ireland resident in long stay hospitals and nursing homes. There is a greater reliance in Northern Ireland on hospitals for assessment and treatment services.
- There is a higher proportion of people with a learning disability attending day centres and a lower proportion of people with a learning disability attending college. There appear to be fewer opportunities for people with a learning disability in Northern Ireland to access supported employment.
- According to a Mencap survey, eight out of 10 families are at breaking point because of the lack of short break services.

3.0 RECOMMENDATIONS

- The UN Convention on the Rights of Persons with Disabilities provides an important opportunity to raise awareness of the rights and dignity of disabled people, including people with a learning disability. We believe that the Convention should be ratified by Westminster.
- Additional investment is required, as a matter of urgency, in Northern Ireland to ensure the implementation of all the recommendations made by the Bamford Review.
- There should be sufficient funding to support the development of a range of advocacy models to reflect the different needs and circumstances of people with a learning disability in Northern Ireland.

Paschal McKeown

Mencap in Northern Ireland

July 2007

1.0 MENCAP IN NORTHERN IRELAND

Mencap provides support to people with a learning disability and their families in Northern Ireland by campaigning for equal lives and chances; by providing a range of services; and by supporting a membership network of 67 local groups.

2.0 EVIDENCE TO JOINT COMMITTEE ON HUMAN RIGHTS

We welcome the decision of the Joint Committee to inquire into the human rights of adults with a learning disability.

The evidence produced by Mencap in Northern Ireland should be read alongside that provided by our national organisation. Mencap in Northern Ireland decided to submit this evidence because of the distinct circumstances of people with a learning disability living in Northern Ireland.

We also wish to draw attention to the Bamford Review of Mental Health and Learning Disability (Northern Ireland). This independent review was established by the Department of Health, Social Services and Public Safety in 2002 to carry out a review of law, policy and service provision affecting people with a learning disability or mental health needs in Northern Ireland.

People with a learning disability and family carers were involved in a number of the committees and sub-committees which took forward the work of the Bamford Review.

The Bamford Review produced a number of reports, including one specifically looking at learning disability policy and services, entitled *Equal Lives*¹⁷². Mencap in Northern Ireland has already submitted to the inquiry this and other reports which we consider to be most relevant to the work of the Committee.

¹⁷² *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland Bamford Review of Mental Health and Learning Disability, DHSSPS, 2005*

3.0 EQUAL LIVES REPORT

The 75 recommendations made in the Equal Lives report were informed by extensive consultations involving people with a learning disability and family carers. An advisory group, also called “Equal Lives” and made up of 16 men and women with a learning disability from different parts of Northern Ireland, met each month to advise the work of the Review.

The Equal Lives report identified five core values that, it stated, should underpin all policy and service developments:

- Social inclusion: people with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.
- Citizenship: people with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.
- Empowerment: people with a learning disability must be enabled to actively participate in decisions affecting their lives.
- Working together: conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability.
- Individual support: people with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible.

These values, stated the report, are a challenge to practice and policy, which has traditionally focused too much on the need for protection and resulted in unnecessary segregation and dependency.

The Equal Lives report indicated that there would be an increase in the numbers of people with a learning disability in the next 15 years including more parents with a learning disability and more people with a learning disability from different ethnic backgrounds to reflect the diversity of Northern Ireland communities.

The report also drew attention to the challenges of complexity—people with complex health needs; people with severe learning and/or physical disability; people with an Autistic Spectrum Disorder and learning disability; and those with challenging behaviour. Concerns were expressed by family carers that the move towards social inclusion would lead to an even greater marginalisation of their family member due to the inaccessibility of community facilities and opportunities and the negative attitudes of some members of the public.

4.0 UN CONVENTION ON THE RIGHTS OF DISABLED PEOPLE

The UN Convention on the Rights of Disabled People provides an important opportunity to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”¹⁷³.

Mencap welcomes the recognition given in the UN Convention to the importance of economic, social and cultural rights and supports the commitment to equality and non-discrimination outlined in the Convention.

We believe that the Convention can play a key role in fostering respect for the rights and dignity of people with a learning disability and should be ratified as soon as possible by Westminster.

5.0 INEQUALITIES AND PEOPLE WITH A LEARNING DISABILITY IN NORTHERN IRELAND

The Equal Lives report stated, “there was ample evidence to demonstrate that people with a learning disability did not enjoy equal access to the same range of services and opportunities as other people in Northern Ireland”¹⁷⁴. It included within a list of examples:

- People with a learning disability do not have the same opportunities in employment, further education, leisure, social life and personal relationships. Poverty contributes to some of these.
- Fewer people with a learning disability achieve accredited qualifications.
- There are higher levels of unmet health needs among people with a learning disability in Northern Ireland.
- Particular attention was drawn to the difficulties experienced by people who display challenging behaviours. People who challenge services are frequently the last people to move out of institutional care and the ones most likely to be admitted to hospitals for specialist assessment and treatment. Those with the most severe behavioural problems are also more likely to be excluded from day opportunities.
- People with a learning disability who commit offences may not come before the courts but will have to live in more confined and highly supervised settings, often long-stay hospitals.

¹⁷³ UNCRDP Article 1

¹⁷⁴ Equal Lives, op cit

- Many older people with a learning disability are at particular risk of neglect, poor access to health care and marginalisation within society.

6.0 DIFFERENCES IN SERVICE PROVISION IN NORTHERN IRELAND

The Equal Lives report stated that Northern Ireland has the highest population of people resident in long stay hospitals: 264 places per million in Northern Ireland, compared with 15 places per one million in England and Wales and 163 places per one million in Scotland.

The report also drew attention to the higher level of places provided (or to be provided) in Northern Ireland hospitals for assessment and treatment admissions; the higher proportion of people with a learning disability who lived in nursing homes in Northern Ireland compared to England and Wales; the lower proportion of people in supported housing within Northern Ireland than in Great Britain; and the higher proportion of people with a learning disability who attend day centres in Northern Ireland.

The Equal Lives report stated that none of the Health and Social Services Trusts in Northern Ireland achieved the minimum number of funded accommodation places suggested by the Department of Health for England and Wales.

Fewer people with a learning disability attend college in Northern Ireland (4.1%) than in Great Britain (5.7%), and fewer are enrolled on a full-time basis (45% in Great Britain compared with 11% in Northern Ireland).

Although there are no centrally collated statistics in Northern Ireland, the Equal Lives report stated that there appear to be more opportunities for people with a learning disability to be in supported employment in Great Britain.

The Bamford Review, in its report on equality and human rights, drew attention to the fact that people with a learning disability in Northern Ireland did not have a right to education until 1986 and recommended that adults with a learning disability have access to lifelong learning opportunities to help address this disadvantage.

7.0 IMPACT OF THE CONFLICT IN NORTHERN IRELAND

Most people with a learning disability live in and are members of local communities. They are likely, therefore, to have experienced the conflict in the same way as others in their community. They are just as likely, for example, to have had members of their family killed or injured during the conflict, just as likely to have experienced sectarian verbal abuse, just as likely to know victims of punishment attacks.

Unlike other members of their community, however, services for people with a learning disability are usually non-denominational and may be located outside the local area. Usually people with a learning disability travelled outside their community to attend schools and day centres. This may have meant that they were not viewed as being part of their local community and made inclusion in the life of their local community more difficult. In addition, the natural protectiveness of parents coupled with fear and uncertainty associated with the conflict is likely to have limited the opportunities they had to travel independently or to take part in social activities.

8.0 EQUAL ACCESS TO AND ENJOYMENT OF RIGHTS

The Bamford Review, in its report on human rights and equality of opportunity, acknowledged the barriers which prevent people with a learning disability enjoying the same rights as others. These barriers include:

- The attitudes of others about their capacity to make decisions and to contribute to the life of their local community.
- A lack of knowledge by people with a learning disability and their families about their rights as well as an absence of support to exercise their rights.
- Unequal access to the same services, opportunities and experiences as others.
- The stigma and discrimination experienced by people with a learning disability which can lead to greater isolation and exclusion and discourage people with a learning disability from taking part.

The importance of accessible information and accessible processes in supporting people with a learning disability to enjoy the same rights as others was recognised by the Bamford Review.

9.0 ADVOCACY: SUPPORT TO SPEAK OUT

The Bamford Review recognised, too, the vital role that advocacy could play in supporting people with a learning disability to exercise their rights. It acknowledged the recent development of advocacy in Northern Ireland and recommended the development and funding of a range of advocacy models to reflect the different circumstances and needs of people with a learning disability.

10.0 SUPPORT FOR FAMILIES

Mencap's survey of families in Northern Ireland caring for people with severe or profound learning disabilities found that:

- 8 out of 10 families have reached or come close to breaking point because of a lack of a short break service.
- 8 out of 10 families provide more than 15 hours care every day.
- 6 out of 10 families who are in poor physical health say it is because of the amount of care they provide.
- 10 out of 10 families who are in poor mental health say it is because of the amount of care they provide.
- 7 out of 10 families have not had a carer's assessment.

Mencap believes that support for families is vital if people with a learning disability are to experience equal rights and chances. We believe that there should be an automatic entitlement to short breaks for families caring for people with a learning disability who live in the family home and get the care component of the Disability Living Allowance. We believe that each family should have their needs assessed and receive a written support plan. We believe that each Health and Social Services Trust should audit its provision of short breaks and take steps to make sure that every family that needs a short break gets one.

11.0 VISIBILITY IN POLICY DEVELOPMENT, FUNDING PRIORITIES AND MONITORING

The Bamford Review acknowledged the historic underfunding of learning disability and mental health services. It recognised, too, the need to ensure that funding allocated by the government to localities did not disadvantage small, geographically dispersed populations, like people with a learning disability. Mencap believes that the government must identify, as a priority, the funding of the recommendations made by the Bamford Review in Northern Ireland.

We also believe that the distinct needs and circumstances of people with a learning disability are often considered, if at all, as a footnote by those developing mainstream policies and priorities. The absence of research about the circumstances and experiences of people with a learning disability in Northern Ireland adds to their invisibility. The failure to monitor the uptake and use of mainstream services and opportunities by people with a learning disability also reinforces their invisibility and exclusion.

12.0 THE DIGITAL DIVIDE

Mencap draws attention to the increasing reliance by the government and public services on internet technology as a means of providing information about, and engaging with, public services. We believe that additional investment is needed to ensure the accessibility of such developments, to enhance the skills and access of people with a learning disability to such opportunities, and to provide alternative targeted approaches to people with a learning disability who are unable to benefit from such initiatives.

13.0 SECTION 75 OF THE NORTHERN IRELAND ACT

Mencap draws attention to Section 75 of the Northern Ireland Act. We suggest that this positive duty to promote equality of opportunity has helped address some of the barriers and disadvantages experienced by people with a learning disability. We believe, however, that additional resources and support are essential if people with a learning disability are to enjoy equality of opportunity in Northern Ireland in all aspects of their life.

14.0 CONCLUSION

Mencap in Northern Ireland welcomed the opportunity to contribute to this important inquiry.

Paschal McKeown
Policy and Information Manager

20 July 2007

Memorandum from People First Scotland

1. EXPERIENCES OF USING SERVICES

Health

People with learning difficulties are not treated equally by health services. This is mostly because of staff attitudes.

- In general hospitals staff attitudes are awareness of the needs of people with learning difficulties are not good.
- Some staff are patronising and disrespectful and treat people like children.
- Written information is often inaccessible.
- There is a lack of accessible information about routine health checks and screenings. Also not everyone gets the support they need to make sure they take up screening appointments.
- Some doctors over simplify things so that people don't get the right information.
- Generally doctors talk too fast, use jargon and don't give people enough time
- The appointment system can be difficult for people with learning difficulties to understand and to use. Having to phone at 8AM can be difficult. Some people find it difficult to use the phone and some people aren't good at telling the time.
- The appointment system can be inflexible. If you want to go to your doctor with your supporter it can be hard for GPs to understand that your supporter is only there at certain times.
- Sometimes it is hard for people with learning difficulties to register with a GP. Some GPs don't want too many patients with learning difficulties.
- The attitudes of receptionists are not always positive towards people with learning difficulties.

Good things:

- Some GPs have good attitudes.
- There was a project in Edinburgh about producing accessible information about having cervical smear tests for women with learning difficulties.
- People First (Scotland) have been involved in running training sessions for nurses.

Education

- Special schools can lead to segregation, isolation and harassment from other members of the community.
- People with learning difficulties are still having difficulty getting into mainstream schools. There is not enough support.
- You leave special schools with out any qualifications and without the skills you need to get work.
- There are still separate special schools being built in Scotland.
- It is hard for people with learning difficulties to do mainstream college courses; hard to get course materials that are easy to understand, difficult to get supporters who can help you understand and help you do the course work, hard to get the course time extended to allow you the chance to understand and work through all the information. Most people are sick of "life skills" type courses and want to study something that gives them a better chance of getting a job.

Welfare benefits

- The benefits system is hard to understand. There is a lot of jargon and the forms are hard to fill in.
- Job application forms and information are often inaccessible.
- The benefits system is not flexible enough. If you start work it is hard to go back onto benefits. This is stressful and means that people don't want to take risks.
- People with learning difficulties, if they get paid work, often get boring, low paid jobs.
- It is hard to get qualifications or an education that helps you get work.
- Employers' attitudes are often not positive towards people with learning difficulties. This can lead to discrimination.
- Many people fear that if they get work they will lose the support they get.
- There is not enough independent benefits advice.

Housing

- There is not enough low cost housing.
- In areas where housing is limited there is little choice. When people are moving out of long-stay hospitals it is really important that they are near people they know, family or friends, so it is easier for them to be part of their local community. Some people with learning difficulties can be very vulnerable so moving into a very rough area can be especially hard.
- Some people end up sharing when they don't want to because houses or support isn't available.
- The process of applying for housing can be very complicated and inaccessible. The bidding process in Edinburgh, for example, is very hard for people with learning difficulties.
- Supporting People money has been cut so support packages are limited—because of this there is a danger of moving back towards group homes. This often isn't what people want.
- There needs to be easy read information on home ownership.
- Housing support and social support need to link in better with each other.

Police

- People with learning difficulties are often not taken seriously by the police and not listened to.

Personal relationships

- Parents with learning difficulties do not get the support they need to look after their children themselves. Too many parents with learning difficulties get their children removed.
- Information about parenting and about child protection is inaccessible.
- There is not enough independent advocacy.
- Often parents only get support after a crisis. If they got support earlier the crisis may not have happened.
- Some parents got support when their children were babies but not as they got older.
- Many parents have been told they cannot get support for themselves as parents. If they have a social worker it is for the children, not for them.
- Many parents lack the support they need to support their children at school. It is hard to go to parents' evenings at a mainstream school if you went to a special school. It is hard to support children with exams that you didn't do yourself. Parents have been told they can't get support with meetings at school.
- Social workers and other professionals often speak to parents with learning difficulties using jargon and words we don't understand.
- Some parents have been forced into making decisions that they don't understand.
- Some parents feel social workers had made their minds up before even meeting them.
- Some parents are frightened to ask for support in case social workers judge them. Parents are always worried that social workers will take their children away. It is difficult to speak to social workers about problems as this fear is always there.
- We know of parents who have had no emotional support when their children are taken into care.
- Parents with learning difficulties are often assessed in a stricter way because of lack of understanding or discrimination.
- Support with parenting is not an optional extra. It needs to be part of a person's overall support plan.

Taking part in the local community

- Some people don't feel safe in the community so they don't go out much.
- More people with learning difficulties are out in the community now so it is getting better, but we are still not included in community life as much as we would like.
- People with learning difficulties often still go out in groups. There is not enough support to go out and about in the way that you want.
- The attitudes of some people such as café workers is not good if for example you can't read the menu.
- There is a lack of good, flexible, accessible transport. This stops people from getting out and about.

How easy it is for people with learning difficulties to have a say in decisions that affect them

- It is not very easy. There is a lot of jargon, and papers are complicated, in small print and with long sentences.
- It is very difficult if you don't get good support.
- Through People First (Scotland) we get good support to break down the information and prepare what we want to say. This makes it easier, but it can still be difficult because of the attitudes of some professionals.

How easy it is for people with learning difficulties to make a complaint about a service

- It is not very easy. It can be hard to get information about how to complain.
- Often information is not very accessible.
- It can be hard to make a complaint over the phone.
- It is difficult if you have no support to make the complaint.
- If people are institutionalised they can lack the confidence to complain.

What would help people with learning difficulties to get their human rights and examples of when this has been done

- Good support.
- Better attitudes towards people with learning difficulties.
- DDA helps a bit but it doesn't have enough teeth.
- People First (Scotland) is run by people with learning difficulties and so is a positive example.

Monica Hunter
Chairperson

20 July 2007

Memorandum by in Control

in Control is a social enterprise that currently works to change the current system of social care and to replace it with a universal system of Self-Directed Support. It works in collaboration with local communities, organisations and government.

Our Memorandum focuses on a number of critical abuses of Human Rights that are an unavoidable feature of the current system for organising of care services, but which could easily be avoided. The current social care system:

1. Fails to maximise the self-determination of people with learning difficulties
2. Blocks people's ordinary life aspirations
3. Encourages poverty and social isolation for many people with learning difficulties
4. Limits ordinary housing rights and options
5. Makes it difficult for people to control and direct their own support
6. Invests in services that exclude people from community life

in Control currently works across the whole of social care, for adults and children. However between 2003–05 we carried out ground-breaking research with people with learning difficulties, showing that people could benefit significantly from Self-Directed Support. Evidence from this work and our later research and development work is set out in the Memorandum.

EXECUTIVE SUMMARY

The current system of welfare and social care is organised so that it constrains, or even undermines, the basic human rights of people with learning difficulties. In particular the system:

1. Fails to maximise the self-determination of people with learning difficulties
2. Blocks people's ordinary life aspirations
3. Encourages poverty and social isolation for many people with learning difficulties
4. Limits ordinary housing rights and options
5. Makes it difficult for people to control and direct their own support
6. Invests in services that exclude people from community life

If the social care system were reformed it would help people to achieve better lives and enable them to be full citizens

IN CONTROL

in Control is a social enterprise that was set up in 2003 to develop a new model for social care called Self-Directed Support (Poll et al). In Control's model of Individual Budgets, plus Support Planning and Brokerage, has demonstrated that it is more effective to shift power and control over resources to people or their representatives. Today there is a ground-swell of support for these ideas and central government is also exploring whether to back these changes.

KEY FACTS

The diminished life chances of people with learning difficulties are well documented and will not be repeated here. On their own those statistics do not demonstrate that there is an abuse of human rights. However if it can be shown that these diminished life chances are not inevitable but flow from the organisation of the current system then the intentional continuation of such practices is an abuse of human rights.

When local authorities implemented in Control's model of Self-Directed Support they found:

Self-determination—Dissatisfaction with the amount of control the person had over their own life dropped from 58% to 3%.

Direction—People achieved 79% of the life changes they desired in less than a year when they used Self-Directed Support.

Money—Use of Direct Payments increased from 3% to 52% when people were told how much money they were entitled to (ie given an Individual Budget).

Home—Everybody living in registered care at the beginning of the test period had left and moved into a home of their own within one year.

Support—There was 175% increase in people receiving support through personal assistants (people hand-picked to support the individual).

Community Life—Satisfaction with community life increased from 61% to 100% when people used Self-Directed Support.

Most people do not realise that the current social care system is ineffective. It is deeply flawed and results in systemic abuse of human rights because:

People are not told how much social care money they are entitled to.

People are not given the chance to decide how that money is spent.

Instead that money is committed, in advance, to spending on institutional services that do not reflect ordinary life aspirations: care homes, special units, day centres, special buses etc.

FURTHER READING

The arguments, data and analysis which support this Memorandum can all be found in the following papers and publications.

Keys to Citizenship by Duffy

Report on in Control's First Phase by Poll, Duffy, Hatton, Sanderson & Routledge

Economics of Self-Directed Support by Duffy

Much of this and more can be downloaded for free from www.in-control.org.uk

FURTHER ACTION

Our hope is that the Joint Committee will consider the impact of the current welfare system on people with learning difficulties. Increasing the resources that the state already commits to people with learning difficulties will only help if those resources are under the control of people or their appropriate representatives, and only if those resources can be used freely to maximise citizenship. Further investment in the current system will only exacerbate the exclusion and powerlessness of people with learning difficulties.

Simon Duffy
Chief Executive

20 July 2007

Memorandum from Skill: National Bureau for Students with Disabilities

Skill: National Bureau for Students with Disabilities promotes opportunities to empower young people and adults with any kind of disability to realise their potential in further, continuing and higher education, training and employment throughout the United Kingdom. Skill works by providing information and advice to individuals, promoting good practice and influencing policy in partnership with disabled people, service providers and policy makers.

Access to education and learning opportunities is just as important for adults with learning disabilities as for other learners. The benefits to personal well being and mental health from learning, and further benefits from the personal and economic well being of entering employment as a result of learning opportunities are well established. Skill is concerned that the emphasis on skills and Level 2 targets is reducing the opportunities for adults with learning disabilities to continue their education in a variety of settings.

PROVISION AND PROGRESSION OF LEARNING

Skill welcomes the commitment to provide learning opportunities for young people with a learning difficulty, through new legislation strengthening funding entitlement for adults to free training in basic literacy and numeracy skills, and to achieve their first full Level 2 qualification¹⁷⁵. Skill also believes that there needs to be effective transition arrangements to enable young disabled people to move smoothly into adult services, as currently there can be difficulties with this transition.

It is important to acknowledge the problem of the “revolving door”, where people with learning disabilities are continually on a revolving cycle of courses without progression and without consideration of what would be best for their education and development. This should not be the case, as a young person’s transition plan should look at curriculum needs and be person-centred and therefore enable them to progress. Person-centred planning should continue for adults with learning disabilities so that they continue to get the most out of learning.

Progression for disabled people also needs to be a reality in terms of non-accredited provision. Not all learners, especially those with learning difficulties, will gain a Level 2 qualification, for example, but this does not mean that they have not succeeded in their learning goals. Education, at all levels, needs to monitor progression and participation as well as attainment, and must look at how achievement and attainment can be recognised without accreditation. Indeed, non-accredited courses should not be considered as a lesser product, as they can be of equal high quality as accredited courses. There are a number of quality approved (by QCA) non-accredited courses, but post-16 providers, particularly smaller providers such as those in work-based learning, are often unaware of the content or availability.

In order to support the learning of young people with learning difficulties and disabilities, it is essential to have recognition that achievement and attainment can be lateral across a breadth of experiences, and does not have to always be upward progression. Adults with learning disabilities should have an entitlement to Information, Advice and Guidance, and guidance workers need training on progression and working in partnership with providers.

The Foundation Learning Tier (FLT) provides a qualification at a range of levels of learning entitlement of learners with learning disabilities. In Skill’s response to the QCA on the FLT welcomed the principle that prior achievement, the interests, needs and aspirations of learners should be taken in to account and that disabled learners should be involved in the design and structure of their personal curriculum to enrich their learning experiences and facilitate progression. Skill agrees with the Skills for Life¹⁷⁶ publication on person-centred approaches to adults with learning difficulties that for some learners it may be inefficient and ineffective for them to spend time acquiring literacy and numeracy skills when there are more appropriate ways for them to develop their skills in a particular area.

¹⁷⁵ World Class Skills: Implementing the Leitch Review of Skills in England, DIUS 2007

¹⁷⁶ Skills for Life: The national strategy for improving adult literacy and numeracy skills. *Person-centred approaches and adults with learning difficulties* NIACE and DfES 2006

TRANSITION FROM LEARNING TO EMPLOYMENT

Skill remains concerned about the substantial minority of learners who may never achieve a Level 2 qualification yet for whom work is still a reality. It is therefore important that appropriate vocational training should be available for them without always having to have the proviso that it must lead to a Level 2 programme.

Skill is particularly concerned about the high number of disabled people, particularly those with learning disabilities, who attend a sequence of learning programmes, often entitled preparation for work, yet who never actually achieve employment.

Skill recommends that the Government look to the development of clear and effective strategies which support the full range of disabled people into full or part time employment rather than providing them solely with work preparation programmes.

One of the recommendations of Through Inclusion to Excellence¹⁷⁷ was that the Learning and Skills Council “ensure that employment-related provision is accessible, and actively encourages participation of those with learning difficulties and/or disabilities.” The LSC accepted all of the recommendations in their response; Learning for Living and Work¹⁷⁸ and Skill recommends that the Committee also encourages opportunities for supported employment that can really benefit adults with learning disabilities.

The participation by learners with learning disabilities in employment related provision is patchy. To improve access to quality employment related provision, awareness and understanding of learners needs and achievement needs to be raised. The benefits of support employment programmes for this group of learners are currently receiving neither the recognition nor the funding they deserve. Supported Employment has always been a fringe rather than a mainstream activity often existing only in short-term pilot project resources. Yet many practitioners, particularly those working with people with learning disabilities, say it is one of the most effective ways of supporting young people and adults in to work. Skill is aware of the Shaw Trust project “Young People with Learning Disabilities—What Works?” which will culminate in a blueprint Good Practice Guide for parents and education authorities when research is completed later this year.

Skill recommends that there is a real commitment to building up and sustaining this kind of employment where it is appropriate for people with learning difficulties and/or disabilities.

TRANSPORT

Skill has found that funding for transport is particularly problematic in the further education sector, especially post-19. Students of 19 and under often struggle to have their transport needs met as well. Concern about transport was by far the most common response to Skill learner feedback survey last year for those in further education.

The root of the problem seems to lie in statutory wording that describes transport provision by specifying “powers” rather than “duties”. Social services, local education authorities and (under the Disability Discrimination Act part 4) even colleges have the power to arrange appropriate transport, but not a duty to do so. This leads to all three agencies on occasion avoiding making provision, and turning requests for transport down, sometimes without an appropriate exercise of their discretion. Without transport funding, some people with learning disabilities simply cannot take up educational opportunities. Added to this, there is erratic regional variation, which does nothing to increase clarity and confidence for disabled learners trying to plan their education. For all young people with learning disabilities, this climate of uncertainty is destructive to their life chances and planning, and disruptive to their confidence when considering the continuation of their educational career.

Skill suggests that the Committee ask the joint department teams for “Progression through Partnership” to make clear their timetable for sustainable transport arrangements for those that need them.

INTEGRATED SERVICES

People with learning disabilities can have a complex set of needs, and these needs are often best met by contributions from different organisations. A multi-agency approach can be beneficial for the disabled person, as each organisation can bring their own expertise to meet the persons individual requirements. This has been particularly shown through the Valuing People (2001) white paper and the Learning Disability Partnership Boards which were set up following the white paper, bringing together representatives from Social Services and health services, people with learning disabilities, family carers, people from housing, education and other organisations.

Coordinated action can assist disabled people to pass successfully and smoothly between the different stages of their life. Unfortunately, a study for the Department of Work and Pensions (DWP)¹⁷⁹ suggested that there was insufficient joint working and an overall lack of planning for disabled people.

¹⁷⁷ <http://readingroom.lsc.gov.uk/lsc/2005/research/commissioned/through-inclusion-to-excellence.pdf>

¹⁷⁸ http://readingroom.lsc.gov.uk/lsc/National/Learning_for_Living_and_Work_Complete_2.pdf

¹⁷⁹ DWP research report no. 204 (2004)—Making the transition: addressing barriers in services for disabled people

Therefore, one of the major barriers for people with learning disabilities is that service provision is very often disjointed rather than truly joined up. Different people tend to be eligible in different ways for different services and therefore disabled people find themselves having to fulfil different criteria for services that they access. Eligibility for services is often based on specific disability categories and therefore many individuals with complex or multiple disabilities and impairments are not having their needs fully met because of the service structures. In addition, another major contributory factor is the confusion regarding the responsibilities of different organisations, as well as lack of general communication between different agencies. It can also be difficult for people with learning disabilities to understand which organisation provides a particular support or provision.

Morris (2002)¹⁸⁰ states that, “There are still significant differences between the intention of inter-agency working expressed at Government and policy level and the experiences of disabled young people and their families. Strategic commitments to joint working are rarely translated into effective co-operation in practice.” More specifically, this study found that there was poor co-ordination between children and adult social services and between education institutions and social services departments.

Skill welcomes Progression Through Partnership the joint strategy between the Department for Education and Skills, Department of Health and Department for Work and Pensions and recommends the Committee consider asking them how this will be implemented for people with learning disabilities.

CULTURAL BARRIERS

Research carried out by Skill¹⁸¹ (Aasha, a copy of which is with the Clerk) has shown that people with a learning difficulty from a minority ethnic group can face particular difficulty in accessing services, including education. There are many reasons for this, such as segregation of race and disability issues which pervades peoples’ ways of thinking, providers’ lack of understanding of particular cultural attitudes to disability, and the difficulty these groups can often have accessing information.

Skill recommends that the Committee seek assurance from the Commission for Equality and Human Rights that specific attention be paid to those people who cross over boundaries of equalities legislation, eg race, disability, age.

Skill recommends that the Committee respond to the consultation on the Proposals for a Single Equality Bill¹⁸² to ensure that existing law and human rights legislation are seen as the minimum standard for a single public sector duty.

LISTENING TO PEOPLE WITH LEARNING DISABILITIES

The Foundation for People with Learning Disabilities carried out an evaluation of Connexions: “Developing Connexions for young people with disabilities, mental health needs or autistic spectrum disorders”.¹⁸³ The report found that the Personal Adviser is a key role as a supporter and advocate, and that their independence was essential: enabling them the freedom to support the young person and perhaps challenge the status quo.

People with learning disabilities can continue to need a supporter or advocate after the age of 25 and as such an appropriate agency needs to be established for adults with learning disabilities to provide this role and independent and professional Information, Advice and Guidance.

Disabled people are often not adequately consulted about what they want for their future or about what service provision in general suits them best. This was also identified in the Developing Connexions report. Service providers should ensure that any initiatives relating to disabled people should incorporate the views of disabled people to ensure their needs are being met and to ensure that provision is appropriate. All of the learners that Skill interviewed for the Skills for Life Review conducted in 2006 commented on how important they felt it was for planners to hear their views. The Disability Equality Duty on public bodies to actively involve disabled people has brought about much good practice and positive developments in this area. Skill is particularly concerned about the potential erosion of this duty in the current Proposals for a Single Equality Bill Green Paper¹⁸⁴.

Skill recommends that the Committee respond to the consultation on the Proposals for a Single Equality Bill¹⁸⁵ to ensure that existing law and human rights legislation are seen as the minimum standard for a single public sector duty.

20 July 2007

¹⁸⁰ Morris, J (2002), *Moving into Adulthood: Young Disabled People moving into adulthood*, Joseph Rowntree Foundation

¹⁸¹ Skill (2003) *Aasha: working with young people with a learning difficulty from a South Asian background*

¹⁸² <http://www.communities.gov.uk/index.asp?id=1511245>

¹⁸³ <http://www.learningdisabilities.org.uk/connexions/intro.htm>

¹⁸⁴ <http://www.communities.gov.uk/index.asp?id=1511245>

¹⁸⁵ <http://www.communities.gov.uk/index.asp?id=1511245>

Memorandum from Learning Disability Wales

1. INTRODUCTION

We very warmly welcome the decision by the Joint Committee to conduct an inquiry into the human rights of people with learning disabilities. It is our view that children and adults with a learning disability regularly face discrimination in their daily lives and that their human rights are undermined.

Unfortunately our capacity constraints have meant that we have not been able to prepare a well-evidenced and grounded submission, but we trust that the committee will find our perspective useful.

2. LEARNING DISABILITY WALES

Our mission is “Creating a Wales that values and includes every child and adult with a learning disability”. We represent 110 member organisations, a comprehensive alliance of all non-government organisations in Wales who are active in the field of learning disabilities. This includes service providers, parent carer organisations, self advocacy groups and parent carer groups.

We are a campaigning and lobbying organisation, we have a website www.learningdisabilitywales.org.uk, regular publications and a growing training programme.

In addition to making this submission, we have circulated an e-news to all our members giving them details of the committee’s work, and encouraging them to make a submission.

3. SUBMISSION

We limit our comments to three of the four areas that the committee is seeking to focus on.

The provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities, the ability of individuals to access these services and the quality of provision

We wish to identify two specific areas where we believe that people with learning disabilities are discriminated against in the provision of public services. These both relate to employment and training, and have been the subject of detailed presentations by us to the National Assembly of Wales Education, Lifelong Learning & Skills Committee and to Welsh M.P’s.

When young people with learning disabilities move from school to adulthood in Wales they do not receive the same opportunities as their non-disabled peers. During this transition process, while they may often have an interest in vocational training and seeking employment, they are treated unfairly by public services. Typically they do not have the usual opportunities through work experience, or job sampling, they are not encouraged or assisted to undertake vocational training, do not benefit from individual learning coaches and, even where these exist, are not encouraged to pursue supported employment. The potential that many individuals have to develop independence and to hold down a regular job is too often ignored, at great cost to the individual and to society.

We welcomed the introduction of changes to Incapacity Benefit, if it maximises the support to enable people with learning disabilities to try paid work, and if there was no coercion. Disappointingly the anecdotal feedback we have received is that Job Centre Plus continues to overlook people with learning disabilities. Not only has there been no coercion, which we welcome, but that often people with learning disabilities are reconfirmed as being incapable of work with no review taking place. It is alleged that Job Centre Plus is looking for “quick-wins” to reduce the number of claimants, rather than being prepared to invest the time and resources in helping people with learning disabilities into work.

We would also encourage the Committee to look at the criminal justice system and how it treats people with a learning disability. The Prison Reform Trust and Mencap are currently completing an important research project on prisoners with learning disability. Their work is highlighting the abnormal prevalence of people with learning disabilities amongst the prison population, and the extent to which they remain unidentified, let alone supported. We particularly note that there is no forensic psychiatry service for people with learning disabilities in Wales.

The possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise

We are partners to a project led by the Norah Fry Research Centre, Bristol “Finding the Right Support Project”. Our work with parents with a learning disability, and professionals is highlighting the extent to which the human rights of parents with learning disabilities are being undermined.

We fully recognise and promote the fundamental point that in any family situation the best interest of the children are paramount. We are, however, collecting some heart-rendering stories where the parent has been ruthlessly separated from their child and no attempts have been made to assist or support continued access and contact.

The potential of the Convention on the Rights of Persons with Disabilities to promote the rights of adults with learning disabilities

We monitor the development of the United Nations Convention with great interest, and consider it to be a major milestone in promoting human rights. Its provisions, if fully reflected in U.K. government policy and in civil society would do much to promote the rights of people with learning disabilities.

We would ask the committee to make specific recommendations to the U.K. Government, that will demonstrate real commitment to the Convention by this country.

James Crowe

24 July 2007

Memorandum from the Learning Disability Alliance Scotland

The Learning Disability Alliance Scotland is extremely concerned over the current recognition of the human rights of people with learning disabilities. Despite many years of verbal support for these rights many people with learning disabilities have their human rights, at best, recognised as something that can be managed and delivered through a system of patronage and at worst, as an optional extra that can be dismissed when resources are reduced.

To be able to enjoy one’s human rights there is a need to:

1. have accessible information about what these rights are;
2. have enough support to be in a no worse situation than other citizens in enforcing them; and
3. be free from systematic denial of these rights through withdrawal of public or private services.

1. INFORMATION

Article 21 of the Charter of Fundamental Rights covers non-discrimination.

Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.

Accessible information is rarely produced and is normally only for specialist subjects such as discussion on care for people for learning disabilities or even human rights for people with learning disabilities, not usually for access to a football stadium or civil rights such as getting married.

When it is produced Easy Read format is used which is only accessible for a small minority of people with learning disabilities. Even Easy Read suffers from a lack of standardised pictures to help illuminate text and those that are available are sold commercially placing further restrictions on the wide spread adoption of this.

Audio and visual forms of accessible information are rarely produced and when they are not updated or easily available.

2. SUPPORT AND REPRESENTATION

Article 41 of the Charter of Fundamental Rights covers the right to good administration:

Every person has the right to have his or her affairs handled impartially, fairly and within a reasonable time by the institutions and bodies of the Union.

This right includes:

the right of every person to be heard, before any individual measure which would affect him or her adversely is taken.

People with learning disabilities require additional support to manage unusual and challenging events in their lives. Many people are able to cope with the day to day issues that arise but need support to manage the unexpected.

New legislation passed by the Scottish Parliament in 2003 gave everybody with a learning disability a right to support and representation in helping them take as much control or influence they wanted over their own care and welfare. This applies whether or not people were living in their own homes or had once been in hospital. The law insisted that local authorities and health boards work together to make sure everybody had the opportunity to get this support.

The growth of advocacy services has been one response to this. In Scotland there are now in the region of 50 separate agencies providing advocacy to people with learning disabilities. In 2006 2,467 people benefited from this service, about 11% of the population of people with learning disabilities¹⁸⁶.

There has been no new funding for advocacy service since 2004 and access to this support is limited by lack of resources. Waiting times for an advocate can be lengthy and even agencies can find it hard to respond to emergency services. One of LDAS's member organisations was recently involved in a situation where the local authority put the service it was providing out to competitive tender. The local advocacy organisation was brought in to consult with the tenants and users of the service. They had to drop all other activity they were carrying out for a two month period and even then were unable to meet with all the people affected.

However even without the pressure on existing advocacy services, many people find that they cannot get the help they need when they have problems with the Department of Work & Pensions or local housing departments. Similar problems have been identified when:

- people have complaints about the action of social work staff;
- social work staff are considering taking children away from disabled parents;
- people have complaints about health services or health service workers;
- people need support to use public transport;
- people would like to get Direct Payments or apply for ILF money; and
- people need help in getting and using a bank account.

Even when people want a formal advocate in more complicated situations such as having a community care assessment or review they find there is a shortage of these. Proper support at critical times in people's lives can prevent the need for more serious (and expensive) interventions at a later stage.

3. EXCLUSION AND MARGINALISATION

Article 26 of the Charter of Fundamental Rights covers the Integration of persons with disabilities.

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

The growth in participation of people with learning disabilities in civic society has not been led by a change in ideas but rather by the change in support structures that has created space for this participation. From the early 80s the introduction of "residential Care Home Allowances" and flexibility in payments for new services by local authorities opened opportunities for people with learning disabilities to enter public space.

New forms of organisations emerged with user participation groups being quickly followed by self organised groups and advocacy organisations. These groups were able to justify and consolidate the changes that had taken place and encourage other innovations in care and support provision to follow.

For the first time many people with learning disabilities were able to exercise a number of their human rights directly. Within the restrictions of funding mechanisms not specifically designed for the purpose, people began to take the first steps to controlling their own lives, taking part in the planning of their own support and helping to hire, employ and fire their own carers.

However control of most of these funding mechanisms lies directly or indirectly in the hands of local authorities—directly through the administration of grant systems such as Supporting People, or indirectly through a gatekeeper role in external funding such as the Independent Living Fund.

Now concerns over the restriction of funds in certain areas such as Supporting People or Grants to Voluntary Organisations are beginning see signs of this moving into reversal. One of our members report situations where people with learning disabilities are having human support removed and replaced with assistive technology or "tele-care" without discussion or agreement. In one such situation a woman was told in a Care Planning meeting that her "sleep in" support was being withdrawn from the following Monday without notice or agreement.

¹⁸⁶ Adults With Learning Disabilities Implementation Of "The Same As You?" Scotland 2006, The Scottish Executive, April 2007

Our members have seen examples of tenants being told that they are no longer able to “bank” hours not used in a particular week for planned events in the near future. Support not immediately used by its “sell by” date is lost. Opportunities for planned social inclusion are lost and not replaced. One person with a learning disability told us how he was no longer able to go on holiday. Tenants are told that money from Supporting People can only be used for a narrow definition of what is tenancy maintenance.

Voluntary organisations have had to cut hours of support for tenants and make staff redundant. This has affected both direct support staff and administrative support staff.

While these cuts may be limited to particular areas and may not continue beyond the current financial year, this is a major setback for the human rights of people with learning disabilities. It had come to be expected that we were on a path of extending people’s rights and that progress only went in one direction.

Now people with learning disabilities are being moved out of the public sphere and back into the home. The exercise of their human rights becomes conditional on the whim and generosity of the surrounding local authority.

CONCLUDING REMARKS

These points are intended to be illustrative of the challenges that exist in ensuring that people with learning disabilities are able to make a reality of their rights. Many people are able to exercise and use some of their rights but as long as a few are denied their rights then what others enjoy may more properly be described as permissive rather than obligatory.

There is much about the Charter of Fundamental Rights that is supportive and helpful. Rights are clearly explained and those described form a coherent whole. However as we have tried to demonstrate in our comments the failure to adequately ensure that these are enforced or that individuals receive sufficient support to enjoy these rights means that for many they are nothing more than pretty words on a sheet of paper.

BACKGROUND TO THE LEARNING DISABILITY ALLIANCE SCOTLAND

The Learning Disability Alliance Scotland was formed in 1999 when a number of users, carers and professionals working with people with learning disabilities came together to create an organisation that could represent the views of people with learning disabilities. Our membership currently stands at sixteen organisations working throughout all areas of Scotland.

Members include Enable Scotland, Down’s Syndrome Scotland, CrossReach, Quarriers, PAMIS, Enable Glasgow, Association For Real Change, Unity Enterprises, The Action Group, Ark Housing Association, Gowrie Care, Key Housing Association, Leonard Cheshire Scotland, Cornerstone, L’Arche, Quality Action Group.

19 July 2007

Memorandum from Advocacy Partners

1. Advocacy Partners welcomes the Joint Committee on Human Rights inquiry into the human rights of adults with learning disabilities. We are pleased to have the opportunity to submit evidence and are able to provide further evidence, in writing or orally if required.

SUMMARY

2. Advocacy Partners welcomes this inquiry as an opportunity to make a start at turning human rights into a reality for people with a learning disability.

3. Rights without effective remedies are of little value and only accentuate the lower value that many give to people with a learning disability. It is imperative to review more than the theory of human rights and their impact but also the barriers to making it work in practice and how to combat the differential access to redress and the law experienced by people with a learning disability.

4. It is abundantly clear that people with a learning disability continue to experience serious discrimination. This is due to an unequal access to services and opportunities, which is borne by a lack of understanding and respect for difference. People with a learning disability are more likely to need support in order to access their rights and fulfil their potential yet they are less likely to get appropriate support. The provision of advocacy can be an effective tool in the realisation of rights for people with a learning disability.

ADVOCACY PARTNERS INTRODUCTION

5. Advocacy Partners was the first advocacy organisation in the UK. Rights, voices and choices are at the centre of all our work. Since 1981 we have been working to ensure that people who have the greatest needs, including people with a learning disability, can make their own decisions and have control over their lives. We strive to ensure that no one gets left out or treated as second best. We do this by ensuring that people's rights are respected their voices heard and their choices responded to.

6. Our team of highly experienced staff and volunteers do this by listening, helping people to express their views, and by providing independent support and representation. We work on a one to one basis and also with people in groups to support one another.

7. Advocacy Partners was commissioned by the Department of Health to provide one of the Independent Mental Capacity Advocate pilots and we wrote part of the national IMCA training. We have also now been awarded contracts in ten local authorities to provide the Independent Mental Capacity Advocate service.

The provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities, the ability of individuals to access such services and the quality of provision.

QUALITY OF PROVISION AND USE OF RESTRAINT

8. While of course there are good services, we encounter many poor quality services for people with a learning disability where people's rights are not respected. Many people are for all intents and purposes prisoners in care homes due to poor resources, low staffing levels, overly paternalistic ideals and lack of choices. People's access to meaningful leisure and day opportunities are often limited and their quality of life poor, not due to their learning disability but due to the failure to provide quality services that are rights based.

9. We have also worked with many people with a learning disability who are being inappropriately restrained through mechanical and chemical and physical restraints. Despite guidance which sets out procedures and best practice for the decision making and use of restraint we have found a worrying amount of extremely poor practice in this area. We have found a resistance to involving advocates in these decisions and in the review of restraints. We have also found that restraint is often used as a way of managing low staffing levels and as a first response rather than as a carefully assessed last resort. When advocates question this type of restraint it is often met with strong resistance and surprise. Often we believe that without advocacy input, the inappropriate restraint used on some of our clients would go unchallenged.

Case study 1: Diana, who has a visual impairment and scoliosis kept colliding with people and furniture and falling, resulting in injuries. The staffing levels at her home were not sufficient to support her when walking round her home so she was strapped into her wheelchair. The advocate complained about this, a meeting was held and more staff were put in place and the straps were removed so she can now walk around her home freely.

Case Study 2: Abdul, who has a learning disability and a visual impairment lived in a NHS residential service. Abdul spent most of his time in a specialised chair with several straps to stop him getting out of the chair as sometimes he would bang his head on the floor. Staff felt that Abdul liked the restraints. Whenever Abdul's advocate visited Abdul would take the advocate's hand and put it on the restraints. The advocate spent time with Abdul without the restraints and then requested several reviews about the use of this restraint. Eventually after the advocate's persistence the team were supported to use a less restrictive approach and Abdul is no longer restrained in this way.

Case study 3: Shem has profound and multiple learning disabilities and had worn splints on his arms for many years. This was to stop him putting his hands in his mouth and choking. Shem's advocate felt this was restrictive and also noticed that Shem was more likely to put his hands in his mouth when bored. Shem's advocate continued to raise this as a need to be reviewed on a regular basis. It was felt that staffing levels were not adequate to enable Shem to be supported to be distracted and engaged in other activities instead of using the splints. Eventually after persistence from advocacy this was reviewed and the splints were removed.

Case study 4: Giles sometimes gets bored, distressed and agitated, this could be at times due to his complex seizures. Giles is also unable to tell staff why he is upset and may kick out. Staff respond to Giles becoming agitated by ensuring he is strapped in a chair until he calms down. This practice was also seen by the staff as acceptable to pre-empt that Giles might become agitated when they had chores to fulfil. Giles' advocate witnessed this on several occasions, sometimes with no recording. The advocate requested for this to be reviewed, eventually after a lot of letters and a lengthy complaints process it was agreed that this practice was too restrictive and the straps were thrown away and a new behavioural care plan was developed for Giles.

HEALTHCARE

10. Whilst it has been acknowledged that people with a learning disability face particular health inequalities (In 2006 the Department of Health's White Paper *Our health, our care, our say*) and are more at risk than others in hospital (*Understanding the patient safety issues for people with learning disabilities—National Patient Safety Agency, 2004*). There is still no national guidance on meeting the duty of health care for people with a learning disability. Mencap's research in 2004 also showed that 75% of GPs had received no training to help them treat people with a learning disability, and that 90% felt that a patient's learning disability made it more difficult to make a diagnosis.¹⁸⁷ *Treat me right! Better healthcare for people with a learning disability* (Mencap, 2004), p. 13

Case Study 5: Andy, who has severe learning disability, was displaying significant changes in his physical and mental health. Health professionals involved in his care had divided opinions as to whether the cause was likely to be dementia or a space-occupying lesion. The GP refused to refer Andy to a neurologist for further investigations to clarify the diagnosis on the basis that any further investigations might cause Andy distress and that it was unlikely that any treatment would be offered due to his learning disability and associated behavioural issues, which would make it difficult for them to tolerate any surgery. The GP concluded it was better to make Andy comfortable and manage his symptoms. This refusal to refer has prevented Andy from receiving fair and equal access to health services.

Case Study 6: An advocate was called by adult services to a hospital where a man with learning disabilities and autism was in critical care as his organs were failing. Leon was refusing to have any treatment including the blood tests that were required to try and establish the cause of his organ failure. The doctors felt there was little they could do and the advocate was told Leon's heart could give out at any time. It was felt by the medical team that Leon lacked the capacity to consent to his treatment. The advocate requested that a best interest meeting was called and asked the medical team to consider all the options available including methods of enabling the blood tests to happen. Eventually the medical team took a best interest decision that Leon should have a sedative and be held back to have the blood tests. This enabled the medical team to provide further treatment. After several weeks of treatment Leon was well enough to go home.

11. We regularly experience that people with a learning disability do not get the same opportunities for treatment options. Individuals are often not given a chance to see if they can actually tolerate particular treatments as GPs often make decisions very early on not to refer in the belief that people with a learning disability will not comply with the treatment or aftercare. Rather than looking at creative options, extra support or desensitisation a regular outcome is to not try. We have also experienced repeatedly doctors who decide not to offer treatment solely on the basis that an individual is unable to consent to treatment rather than following a best interest decision-making process. We support the introduction of the Mental Capacity Act and the Independent Mental Capacity Advocate service and believe that this will in practice help to address some of these issues.

Case Study 7: A pregnant woman has a mild learning disability, mental health needs and a severe needle phobia. The psychiatrist decided that the client did not have the capacity to make the decisions about her medical treatment deemed to lack capacity to consent to medical treatment during childbirth, including the use of restraint should it be deemed necessary. The obstetrician decided that as the client was that he would decide it would be in the client's best interests to have an elective caesarean and recommended that a contraceptive implant should be inserted at the same time. The woman did not want to have the implant as she would like to have further children and is also not sure whether she would like a caesarean. It is felt that professionals have failed to involve the client early enough to give her the time she needs before the imminent birth, to be able to assimilate, retain and weigh up the information needed to make those decisions and as a result has been assessed as lacking capacity, which might not have otherwise been the case. The decisions that will now be made for her, may well be different from those she would have made for herself, had she been given the time and support she needed to be able to have the capacity to make them.

12. We have experienced that it may go unrecognised that people with a learning disability are in pain as it can be considered to be behavioural problems, particularly with those who communicate non-verbally. This can lead to the person having to suffer unnecessarily and sometimes leads to a fatal delay in diagnosis. People with a learning disability experience a lack of understanding and a lack of facilities to support their needs in relation to some of their behaviours. This can mean that people miss out on the treatment they need because they are unable to wait for long periods of time in an unfamiliar place.

Case Study 8: Manny suffered from arthritis in his hands and was in constant pain. His GP refused to prescribe medication on the grounds of "he wouldn't understand" because he has Downs Syndrome. Staff at the residential home were unable to challenge this effectively. The advocate attended an appointment with Manny, and medication was then prescribed.

Case Study 9: Rob who has a learning disability and behaviours that challenge services, had an accident, which meant he was unable to walk any more. Rob was spending most of his day in bed. Rob indicated through pointing, to his advocate where the pain was. His advocate looked at his

¹⁸⁷ *Treat me right! Better healthcare for people with a learning disability* (Mencap, 2004), p. 13.

notes and spoke to staff and physiotherapist and then wrote to his GP to ask for a referral for a second opinion about the decision not to perform surgery after the fall. The advocate supported Rob to attend the consultants meeting. It was then decided to perform the surgery. Rob is now more comfortable.

HOUSING

13. People with learning disabilities in residential care often lack choices about who they live with, experience a limited income, lack security of tenure (they can be given 28 days notice), and lack control over their living environment. Staff support is almost invariably compromised by the needs of the other people they live with. Supported living offers a way out of these problems, but all too often in practice what is described as supported living shares all too many negative features with residential care. Advocacy can help enable people to exercise greater choice and control over their housing and support.

Case Study 10: As Ray, a 24-year-old man, grew in confidence, he became increasingly frustrated by the way in which the home that he shared with two other people with learning disabilities was run. He wanted to eat at the times that suited him, and to follow his own interests. Ray's advocate enabled him and his family to encourage the local authority to agree that Ray was able to live more independently and to manage a Direct Payment to fund his own support. Ray was able to purchase a share in a house near to his family through a shared ownership scheme. He is now studying and doing voluntary work. He is far less reliant on support services and feels far more in control of his own life.

14. We have supported many people with a learning disability through home closures and moves from inappropriate housing. Despite well-established policies on enabling people to remain living in their local communities, our clients often experience a lack of appropriate services within their borough and people are still being moved out of borough. This is particularly an issue for people with additional needs such as mental health, behaviours that may challenge us and complex health needs.

Case Study 11: Richard had lived a residential home since the death of his mother. At the request of a friend adult services decided to move Richard to a residential home that this friend owned. This was decided without a comprehensive assessment or consultation with Richard. An advocate was instructed who got the move suspended, while an assessment was undertaken. The advocate supported Richard to be involved and ensured his preferences were listed to. Richard was then able to remain in his home.

15. For many years people with a learning disability who lived in residential care provided by the NHS did not have to have regular inspections with regards to their services. When they are checked because they are NHS owned the criteria checked against is that of a hospital rather than a "home". This lack of appropriate national standards for these type of homes makes challenging the levels of care very difficult. Whilst the defence is that these homes are in the process of closing, our experience is that this takes some time and does not address the here and now for those who live in very poor services.

Case Study 12: Several adults with severe learning disabilities clients lived in a home in which they faced constant risk of abuse from others living there. It was only because of persistent advocacy input over two years that this was finally recognised as abuse and action taken to seriously address the risk. It is too often assumed that if a person poses a risk to other people it is acceptable for them to be at risk from others.

Case Study 13: Ebony lives in a residential home she disclosed to her advocate that she was unhappy about sharing a room with another resident. Also all mail addressed to Ebony was opened and read before being passed to Ebony. The advocate supported Ebony to get the issue of her mail was addressed, and with support Ebony moved into supported living with her own bedroom.

Case Study 14: Clare has lived in a residential home for a number of years, it is recognised by adult services that this service is unable to meet her needs and the home is under investigation by CSCI. However, she has still not been re housed six months after being in this situation.

16. The focus on having to understand a tenancy agreement can be limiting for some people with a learning disability and result in them losing their homes. When homes change from residential care to supported living, individuals who do not have the capacity to sign a tenancy agreement may be forced to move out, rather than looking at creative ways to address this to enable people to stay in their homes.

Case Study 15: Daria has a mild disability and lived in council flat in the community. She did not receive any support services. Because of her perceived differences she became the focus of harassment from neighbours, one in particular. Daria complained to housing frequently but was not able to provide proof of the harassment. She was not believed. Eventually Daria became so frustrated that she began to retaliate against her neighbours, action was swiftly taken against her and she was hospitalised. Advocacy was then involved. Daria has now relinquished tenancy of her flat, and adult services are looking at supported living accommodation for her. She is still very angry and fearful about the lack of support to enable her to live in the community, and the discrimination she received from her neighbours and housing services.

WELFARE BENEFITS

17. People in residential care experience an extremely low disposable income. We have supported many people in health funded residential care who receive a very low amount of benefits due to their “in-patient” classification. However, they still often are required by the NHS body to pay for many essential items themselves such as wheelchairs, kirton chairs (chairs that enable people with particular seating needs to be comfortable), specialised furniture and sensory equipment. In effect this militates against the principle of healthcare free at the point of delivery.

Case Study 16: Lizal a 19 year who was living in a children’s home, had not received any benefits, for three years she had lived off things that staff bought her. Her advocate discovered this and ensured she not only started receiving benefits but also that she was backdated the money she had not been receiving.

The possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state, which arise in this context:

Case Study 17: Ben and Maggie do not have the capacity to consent to getting married. However, they have a close relationship that is very important to both of them. Ben and Maggie knew they wanted to celebrate their relationship of 10 years in front of their friends and family and to have this acknowledged and respected. Their advocate supported them to arrange a celebration of their relationship with a blessing from a priest. Ben and Maggie enjoyed this celebration, which helped them to communicate the importance of the commitment they had to one another.

18. People with a learning disability are often denied the right to have friends and relationships. Relationships are not respected and people are moved on with no provision to maintain their friends. This is particularly so for people with a severe or profound learning disability as it may be more difficult to prove that the relationship is important to the individual. We have worked with people who are moved away from all their previous relationships because particular kinds of services are not available locally.

Case Study 18: Tom had lived in an area for 40 years he only had very limited contact with his family but he had a lot of important relationships with other clients and staff. Tom’s needs changed and because there was inadequate mental health services locally all these relationship were severed overnight as he was moved to an out of borough service.

19. Although *Valuing People* includes the objective of “Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children get maximum life chance benefits”.¹⁸⁸ *Valuing People*, p. 127. Our experience has often been that in practice this is far from a reality. People with a learning disability are expected to be “super parents”. Parents with learning disabilities are frequently given little or no support to learn parenting skills. They are assumed to be unable to parent until they have proved otherwise. Their children are often taken away from them before they have been given the chance and appropriate support to parent. Parents are then observed in contact sessions with their child to monitor their parenting skills but are not given any support in this unnatural setting. In many instances, if individuals were given the opportunity to be supported in a foster setting with their child they would have a better chance at achieving appropriate parenting skills.

Case Study 19: Vashti and Ola had their baby removed in the first week. Their advocate supported them to get a solicitor and facilitated the meetings with the solicitor to help ensure their needs were understood. The solicitor and advocate persuaded adult services to give Vashti and Ola the opportunity to go to an assessment and support centre, which is a home where vulnerable families are supported. The couple and baby lived there for a period of three months. Their advocate ensured their benefits were sorted out so they could move there. Whilst there, their parenting skills and the potential vulnerability of their son was assessed as well as the couple being supported to learn parenting skills. Vashti and Ola were able to go back to their original home with their son.

The opportunities for people with learning disabilities to participate in the life of their local community and the state’s obligation to facilitate participation.

20. The right to private life has acquired an interpretation, which includes a right to establish relationships with others and the means to exercise positive choices and access a comparable quality of life, including access to ones local community, to that of their non disabled peers. However, in practice there is a lack of appropriate support and opportunities to enhance an individual’s quality of life and to access the community.

Case Study 20: Irena, a woman with learning disabilities is doubly incontinent. She is lucky to get a bath once a week. This is the only time she would get out of her room if it were not for her advocate. She would also have not had the opportunity to get out of bed had not her advocate insisted she got a wheelchair. Her life is restricted to her room even though she clearly enjoys getting out.

¹⁸⁸ *Valuing People*, p. 127.

21. Whilst the role of the NHS in providing residential services to people with learning disabilities is reducing, there has still been an increase in the acquiring and commissioning of private hospitals. These hospitals are often in isolated areas with all day opportunities being held at the hospital.

Case Study 21: Anya is 19 years old with severe learning disabilities and she lives in a private hospital, which is funded by the NHS who asserts that they are not required to fund her “social and leisure needs”. Adult services have stated that because she is health funded, it is not their responsibility to fund her social needs. So Anya gets out once a month. Drawing attention to recent healthcare commission investigations into institutional abuse, her advocate has called for improvement from Anya’s service provider. They respond that they are too big to support people to get out often. This private hospital has five, six bed units, with an in house activity coordinator. So Anya spends most days watching the coordinator makes cake and goes to go on a rota basis.

22. We have experienced in the areas we work in a cut in day opportunities and further education. There is a lack of meaningful and appropriate provision in place particularly for those with more complex needs. The result being for most people a lack in opportunities to meet people and to have support to meet their potential. We regularly experience extreme difficulties in ensuring provision and funding for day opportunities and further education being included in individual’s community care assessments and care plans. This is due to some local authorities not wanting to be specific about peoples levels of needs with regards to day opportunities, particularly where someone may require extra staff support to achieve this. Without an advocate many of clients would not have someone to insist their right to access the community is given adequate consideration.

The ability of people with a learning disability to make their voices heard in decisions affecting them and the efficacy of the relevant complaints mechanisms.

23. Advocates work to support people to have their voices heard in decisions affecting them and where possible support the individual to gain skills to speak up for themselves.

24. All too often our experience of complaints procedures is one of defence rather than being focused on resolution and learning. Our experience has also been that whilst the initial letter acknowledging the complaint may be on time, often little happens after that without pressure from the advocate. We have also experienced difficulties in a lack of clear process in taking forward complaints on behalf of people with a learning disability who are unable to instruct us to take forward a complaint on their behalf. However, most of the time we are involved in supporting people to make complaints or making complaints on their behalf, there would have been no one else do to this.

Case Study 22: Terry and Celia were homeless the housing department were prepared to provide housing conditional on adult services putting an adequate package of support in place. Adult services took a year to decide their eligibility for services. And then they were eventually housed. The couple complained to adult services and just received a letter back saying that the fault was with the housing departments. Their advocate is now supporting them to take the complaint further.

Case Study 23: Nora had experienced another service user in her home several times coming in to her room and behaving inappropriately. Adult protection proceedings were not engaged. Nora’s advocate insisted that they were, the result of which was that several measures were put in place to minimise the risk but the service user remained in the home. The protective measures were then removed and the advocate was not informed. There was another incident. Nora’s advocate made a formal complaint. There were severe time delays at each stage of the complaint process and a lack of understanding from the investigator about the issues. The service user was eventually after much pressure from the advocacy service supported to move to a more appropriate home.

Case Study 24: Maria who has a learning disability and behaviours that challenge services was living in a home that could not meet her needs and put herself and others at risk. Her advocate kept raising this at meetings but the service was not responding, the advocate then made a complaint but Maria was still not supported to move. The advocate took the complaint to the next stage and the HCC took six months to respond and upheld the complaint. By this time Maria had finally moved due to the advocates persistence.

The potential of the Convention on the Rights of Persons with Disabilities to promote the rights of adults with learning disabilities.

25. Britain’s signing of the Convention on the Rights of Persons with Disabilities to promote the rights of adults with learning disabilities is of course to be applauded. However, it needs to be acknowledged that without the support and encouragement to use it, in practice its potential will be wasted. The Convention on the Rights of Persons with Disabilities should be used to flesh out and support Human Rights arguments for people with learning disabilities under the Human Rights Act.

26. Advocacy Partners experiences through our clients a distinct lack of access to effective remedies for addressing the violations of the human rights of people with a learning disability. Human rights therefore remain often illusory and hypothetical to people with a learning disability. Whilst human rights legislation is directly relevant to the experiences of people with a learning disability the inaccessibility of the legal system for people with a learning disability means it is woefully underused as a method of combating the discrimination faced. This lack of directly relevant human rights cases means that despite the convention of

human rights being a living instrument, it is unable to develop interpretations to reflect the circumstances of those with learning disabilities. A result is for example that the restrictive definition adopted by the court of degrading treatment does not encompass the impact of the very real neglect and abuse that people with a learning disability may endure.

27. Additionally, although the Human Rights Act was enacted to make the convention of human rights more accessible, its intent was also broader than just legislative. The aim was also to support Britain to embrace a human rights culture. However, this has not been given the impetus needed and practitioners and policy makers need to take greater account of human rights and draw working parallels. People who support or work with people with a learning disability need to be trained and encouraged to embrace a rights based model of working.

28. The language that the courts and the public use bring negative assumptions about the quality and value of the lives of people with a learning disability. These assumptions, even if implicit diminish humanity and provoke prejudicial attitudes, which can have an impact on judgments and decisions about the lives of people with a learning disability.

RECOMMENDATIONS FOR ACTION

29. Resources and time needs to be put into promoting a culture of rights. The recent health care commission investigations have shown us that institutional cultures devoid of human rights considerations are apparent in services for people with learning disabilities. Human Rights should be used as a lever to make a change in policy and practice as well as in law. For this to be taken seriously it needs to become higher on the agenda and be used as a measuring tool in standards.

30. The courts need to be fully informed and have a wider understanding about what it means to have a learning disability and complex health needs, to enable them to have a more rounded perspective. Courts need to educate themselves and be encouraged to call expert (individuals and their friends and families who have relevant personal experience) evidence about the experiences of people with learning disabilities. Additionally, there is a role for organisations advocating on behalf of people with a learning disability to put such evidence in the public domain.

31. We welcome the Mental Capacity Act and the Independent Mental Capacity Advocate service. However, there is some resistance, particularly from some doctors to engage with this and to discharge their duties under the Act, particularly with regards to consulting with an IMCA. A stronger push to raise awareness, monitor and respond to doctors who do not consult with IMCAs would strengthen this important safeguard for people with a learning disability when they lack the capacity to consent to their treatment.

32. In our experience and as our case studies show the provision of Advocacy can have a real impact on the realisation of rights for people with a learning disability. However, the provision of advocacy other than IMCA is patchy. We recommend that Advocacy is given a higher priority in policy. Advocacy both generic and IMCA can be a powerful tool in supporting people with a learning disability to access their human rights.

20 July 2007

Memorandum from the British Institute of Learning Disabilities (BILD)

INTRODUCTION

BILD is committed to improving the quality of life of people with a learning disability in the UK. We focus our work on “turning policy into practice” and support commissioners and service providers to deliver support that is flexible and addresses individual need.

We support people with a learning disability to take control of their lives by:

- Giving people real opportunities to train staff, check services and work in BILD.
- Working with people who make and implement policies and decisions.
- Encouraging those who offer support to work in person centred ways and see people as individuals.
- Share research and information, particularly about what works well.

This submission reflects the accumulated wisdom of our networks of people with learning disabilities, family carers, members, specialist advisers, trainers, consultants and BILD staff.

POLICY CONTEXT

We believe that the current policy framework as outlined in *Valuing People* (2001), *Improving the Life Chances of Disabled People* (2005) and *Our Health, Our Care and Our Say* (2006) represents a positive way forward.

However, the momentum that accompanied the launch of *Valuing People* appears to have dissipated, leaving increasing frustration for many people with learning disabilities who were sold the vision but are still waiting for the reality.

The reasons for this are many but include the following challenges for commissioners, Trusts and authorities.

- Demographic changes—there are increasing numbers of people with learning disabilities, including young people moving through transition to adult services with very complex support needs. In addition, there is an increasing population that is becoming older.
- An increased need for specialist services—the lack of appropriate local support for individuals with complex support needs has often meant that people have been placed far away from their home communities.
- Higher expectations of quality and person centred support from people with learning disabilities and their family carers.
- There is often very little information about the quality of services and their outcomes and impact on the quality of life for people with learning disabilities.
- The difficulties of changing traditional service provision.
- Moving money to support better ways of supporting people can be difficult when most is used to buy residential, nursing care or day services. This commitment is often both costly and long term.

We strongly support the four principles of rights, independence, choice and inclusion that underpin *Valuing People*. However, we are sceptical about whether there can be a real impact on peoples' lives unless there is a move from assessing needs and weaknesses to a human rights approach to access to services; from the professionals know best to the person and their family being in control; from people being seen as vulnerable and dependent to them being able to contribute as members of their local community; from working towards integration to having a right to inclusion: and from support being service based to individual person centred support.

There needs to be a stronger emphasis upon values and human rights to ensure that people with learning disabilities receive the support that they require. Currently, the tightening of eligibility criteria under Fair Access to Care means that in 70% of authorities, people will only receive support if their needs are assessed as being “substantial” or “critical”. Many people with learning disabilities who will not meet this criteria still need limited support to enable them to live independently. Unfortunately, the absence of such support leaves many at risk of failing in the community, or not even having the opportunity of living independently. Over 60% of people with learning disabilities live with their parents or extended family, with many parents continuing to care into their 70s and 80s.

In America and Canada, there is a stronger emphasis on rights in relation to accessing community supports. This is especially true in relation to employment, where this is seen as a right for all people with disabilities and the challenge is then for employers to design jobs that are suitable. In this country, it has proved difficult to convince employers that they should employ people with learning disabilities, as this is seen as asking for a favour or a charitable response rather than a basic human right.

“GETTING A LIFE”

We need to move away from a service orientated approach to a rights based option that seeks to deliver individual support. BILD facilitates an approach to reviewing services and supports that involves people with learning disabilities, family carers, staff and key stakeholders. This is known as the Quality Network and focuses on ten key outcomes for people's lives that were determined by wide consultation with people with learning disabilities. We believe that the following outcomes should be available to people as a right:

1. I take part in everyday activities.
2. People treat me with respect.
3. I have friendships and relationships.
4. I am part of the local community.
5. I get the chance to work or do other activities that are valued by others.
6. I am safe from bullying and abuse.
7. I get help to stay healthy.
8. I make everyday choices.
9. I make important decisions about my life.
10. People listen to the views of people who are important to me.

People with learning disabilities often say that they do not want services but that they want a life. Measuring people's lives against these outcomes allows a measure of the flexibility and responsiveness of their support against their individual needs and also identifies what connections people have with their local community.

All people with learning disabilities should have access to rights, independence, choice and independence. However, we believe that the following groups have failed to benefit so far from the Valuing People initiative:

- People with profound and multiple disabilities.
- People with challenging behaviour.
- People with a dual diagnosis of learning disabilities and mental health.
- People from black and minority ethnic communities.

COMMISSIONING FOR VALUES

If people with learning disabilities are to benefit from a rights based approach to the provision of individual support, then commissioning will have to become more creative, responsive and flexible. The difficulties with commissioning at present is:

- It has focused on outputs rather than outcomes.
- Learning disabilities is often a small part of the responsibilities of many generic commissioners.
- Selecting large provider organisations reduces the risk—but evidence suggests that smaller organisations are able to be more creative, person centred and adaptable.
- There has been a reluctance to develop a range and diversity of providers that will provide flexibility for those using services.
- Too much emphasis on competitive tendering for contracts rather than partnership working between people with learning disabilities, family carers, commissioners and service providers.
- There is limited market analysis based primarily on cost and volume and an inability in many areas to “develop the market”.
- An ongoing emphasis on services and segregated support rather than looking at opportunities in the community to provide support flexibly.

INDIVIDUAL BUDGETS AND DIRECT PAYMENTS

We support the In Control initiative to provide access to individual budgets as a means of placing control firmly with the person with learning disabilities and their family. In addition, this provides flexibility and an opportunity to enable current service providers to become more person centred if they wish their support to be purchased.

It is important that a wide range of ways to obtain support are developed from local community links to specialist service providers. We have some concerns about the sustainability of some of the arrangements that are dependent on families, especially as family members grow older. Some families will be reluctant to pursue individual budgets if they believe that it will increase the demands on them.

The shift to individual budgets and direct payments is positive, but does require a major cultural shift. The balance of power transfers to the person with learning disabilities and their family. However, there does need to be ongoing opportunities for all stakeholders to learn, consider and reflect upon the potential changes for them.

SPECIALIST SUPPORT

We believe that people with learning disabilities should have access to mainstream and specialist supports to enable them to fully participate in their local communities.

We support the programme of closures of the long stay hospitals as soon as possible, and the intention to close NHS campuses by 2010. It is significant that the recent Healthcare Commission investigations into specialist health services in Cornwall and Sutton and Merton found a lack of understanding of how to provide good support. However, there is a need to develop flexible specialist support in local communities for people with profound and multiple disabilities, and people with challenging behaviour.

We remain concerned at the number of individuals who are moved away from their home communities to live in “specialist services” that are often very costly and appear to contain rather than develop the skills of the people they support. Not only does this mean that people are distant from their families and communities, but it takes significant investment away from local service.

ACCESSING MAINSTREAM OPPORTUNITIES

The advent of community care means that people with learning disabilities should expect to live a fulfilling life in their local communities. However, all too often, people are living in the community but are not really part of the community, and often do not have opportunities to contribute.

There is a need for mainstream organisations to work together and prioritise the ways in which people with learning disabilities are supported. The new duties of publicly funded bodies to produce and act upon Disability Equality schemes should provide a lever to enable this to happen. However, it takes vision for authorities to work in joined up ways.

In addition, frontline staff offering support need to develop the skills to network, identify opportunities and build links in the local community. However, such community bridge building requires creativity and different skills than traditional care. This is not yet appreciated and there is a danger that the “community” is blamed for not being welcoming when the support that is available is failing to network effectively.

The move away from segregated day services to community based support is one that we would support IF it means that the activities are meaningful; that people choose the activities that are best for them; that they receive individual support; and that people can develop local links, relationships, friendships and a sense of belonging.

It continues to be more difficult for people with high support needs to have a choice of activities in the community. In addition, opportunities to volunteer, contribute or work have often been denied to this group of individuals. This must be challenged because it is the limitations of the ways in which support has been delivered in the past that has prevented people from having a right to a real life.

A practical issue that prevents people from accessing town centres is the lack of adult sized changing facilities that have a changing bench, a hoist and enough space for two carers as well as the person with a disability.

Employment must be seen as a right for all people with learning disabilities. Loss or reduction in benefits continues to be a major disincentive for people to pursue employment initiatives and needs resolving. Local Authorities and health services are often the biggest employers in areas and they must set an example and lead to local employers in developing employment opportunities.

Access to generic and mainstream services must be seen as a right and integral to enabling people to be seen as equal citizens. The challenge then is how the support is provided to enable the inclusion of people with learning disabilities in their own communities. At present, there does not seem to be the urgency or commitment required to make local communities inclusive and welcoming.

PEOPLE WITH HIGH SUPPORT NEEDS

We believe that the rights of people with high support needs are not being met. They require:

- Support in relation to communication. A fundamental right is the ability to communicate because without this, it is impossible to have control over any aspect of your life. In general, front line staff have a lack of awareness about how to assess, assist and support people who cannot communicate with words. There is a lack of priority given to this area in training and a national shortage of speech and language therapists who work with adults. This can mean that the work done with a person during their school years will often not be continued into adulthood and vital skills may be lost. The need for communication aids may not be appreciated or staff may be left unable to understand how to support a person who uses such aids. In summary, most people with profound and multiple disabilities who do not use words or sign language will be supported by front line staff who have received no training in the way that they communicate.
- Good support must be developed in partnership with the individual, in terms of how they wish to be supported. This is particularly true for people who need help with their personal care. For many people with high support needs, they will be dependent on support providers spending time to get to know them, and learning from their families, friends and people who know them best. However, there is often a lack of appreciation from front line staff and their managers of the values of respect and dignity that should underpin this support. The investigations in Cornwall and Sutton and Merton emphasised that staff did not understand the basics of “good support”. Unfortunately, the rights of people with high support needs are easy to dismiss simply because they are often totally reliant on the support providers. This is not just about checking the minimum care standards but reaches a deeper cultural level of how to provide rights based person centred support.
- The transition from school to receiving support as a young adult is described by many carers as “falling off a cliff”. All too often, there is a reduction in support and an expectation that parents and families increase their caring at a time when most young people would be moving away from home and reducing their dependency on their families. Despite the fact that most young people have been in the special school system for many years, there still seems to be an inability for children’s and adult services to work effectively together.

BEHAVIOUR SUPPORT

Over the past 10 years, BILD has worked in partnership with people with learning disabilities, family carers, service providers, a wide range of professionals and academics, and with front line staff to develop positive and respectful approaches to supporting people who present challenging behaviour.

We believe fundamentally that such behaviour is the way in which people choose to communicate and that it is important to respond in ways that acknowledge this. We recommend a holistic approach that is dependent upon knowing the person well and seeks to address all of the contributory factors.

We encourage a range of approaches and interventions so that the need to physically restrain someone is seen as the last resort. It is important that behaviour support strategies are developed and that these are based on good assessments, risk assessments, and that behaviour prevention strategies, support, de-escalation and reactive approaches are developed. We run an accreditation scheme for organisations that train staff in this way and to make sure that if restraint is used, it involves no pain and is respectful to the person. We have 22 organisations accredited at present.

In relation to a rights based approach, we would raise the following concerns:

- Although the DoH and DfEs recommended that BILD accredited training organisations be used in their “Joint Guidance for the use of Restrictive Physical Interventions” (2002), it is a voluntary scheme and there are many organisations that train in this field that do not have a holistic approach.
- Frontline staff can be expected to support people with challenging behaviour without the necessary training or understanding. This places both the individual and staff at the risk of harm and excessive use of force. It also means that individual staff will be expected to decide for themselves what are effective interventions.
- We believe that there is too much use of chemical and mechanical restraints and an increase in the use of seclusion with staff being unaware of the impact on people’s rights.
- We believe that many organisations supporting people who challenge are failing to address the human rights and legal implications of their practice.
- We believe that organisations should be positively seeking to reduce their use of restraint and physical interventions as part of a planned strategy.
- We would like to see more people with learning disabilities actively involved in determining their preferred ways of being supported if they need to be restrained in any way.

WORKFORCE ISSUES

It is estimated that there are 83,000 people in the learning disability workforce. Providing values based respectful support is not easy and recent investigations have shown that front line staff may not always have been provided with the learning opportunities, coaching, mentoring and supervision required. Many service providers are struggling to recruit and retain staff and unfortunately, supporting people with learning disabilities does not have the status and prestige that it should. However, the quality of the support provided makes a real difference to the quality of people’s lives.

If people with learning disabilities are to have their human rights addressed, then the workforce issues to be addressed include:

- Staff having learning opportunities that reinforce values and the human rights/citizenship perspective.
- All workers to understand what “good support” is and how to provide it.
- The impact on the workforce of the anticipated increase in the use of individual budgets and direct payments. This will result in an increase in the number of “personal assistants” and the challenges of their learning, development and supervision needs.
- Staff needing to develop new skills in relation to networking in the local community.
- Staff needing to develop skills in communication, and how to better support people with high support needs to make choices and decisions.
- Reducing the use of agency or casual staff who have no long term commitment to the people being supported and where continuity of support and relationship is difficult to maintain.
- The employment of black and minority ethnic communities at all levels of the workforce to help increase the diversity of service provision.
- Leadership and management development that is focused on the delivery of rights, independence, choice and inclusion is required.
- Training and learning opportunities driven by and delivered by people with leaning disabilities and family carers.

It is our belief that the learning disability sector needs to be provided with the tools to provide radically different types of support in the future that is much more focused on the individual and their dreams and aspirations and their full involvement in their community. The new Learning Disability Qualification at induction provides a good foundation. We would like to see the development of further qualifications for the workforce that build on the values covered at induction and address human rights, choice, communication and inclusion.

HAVING A SAY IN DECISIONS

The strong emphasis on the participation and involvement of people with learning disabilities in the decisions that affect their lives on an individual and wider level is having an impact. However, the power and control over their lives still rests largely with staff, professionals and carers. This is particularly true for those with high support needs. This could be improved by:

- The availability of information in a wide range of formats. Information is power, and currently, most information remains with service commissioners and providers. If people are to have real choice in their lives, then much more independent information needs to be available.
- Access to independent advocacy. Currently, this is dependent on a post code lottery as there is no guarantee of the availability of advocacy for all of those who need it. Funding for advocacy schemes tends to be very fragile and short term in nature.
- A priority for staff learning to focus on how to support people with high support needs to make choices and decisions, and particularly those who do not use words to communicate. We would anticipate that the requirements of the Mental Capacity Act 2005 will reinforce the need for this.

MAKING COMPLAINTS

We believe that it remains very difficult for people with learning disabilities to make complaints about any service or support that they receive.

This is because:

- Most complaint procedures are formal in nature and require written submissions. Unless the individual has the support of an advocate, they may find themselves having to get support from the staff or organisation that they wish to complain against. People with high support needs may have no one to complain on their behalf unless an advocate is involved.
- Many people with learning disabilities have limited opportunities to form friendships or relationships. Therefore, they spend most of their time with their family, staff or peers. Often this means that staff become their “friends” and they choose not to complain because they think that will cause trouble for their friend. In addition, staff can easily persuade people not to make a complaint or can disempower people by not taking an issue seriously.
- Many people with learning disabilities have had negative experiences when they have not been believed. If it is the word of a member of staff or someone with a learning disability, then they can think that it is the member of staff who will be believed. This is particularly true in relation to abusive situations.

We believe that a range of formal and informal ways to complain should be available, but more importantly, all those who are involved in support must be constantly reinforcing that it is safe and ok to complain, and actively encourage this to happen. Judging a good support provider positively could be linked to a high number of complaints that were treated seriously and addressed appropriately.

BUILD FOR THE FUTURE SUBMISSION

Build for the Future is a group of over thirty people with learning disabilities drawn from five advocacy organisations:

- Somerset Advocacy.
- Taking Part, Shropshire.
- Wyre Forest Advocacy.
- Talk back, Buckinghamshire.
- Options for Life, Walsall.

They work with BILD to ensure that our work is rooted in the real life experiences of people with learning disabilities. They discussed the issues raised by the Joint Committee on Human Rights and wanted their comments to be included in this submission.

WHAT ARE HUMAN RIGHTS?

- The rights to run our own life.
- How we want to live.
- What we wear.
- What we want to do.
- What job you want to do.
- How you choose to spend your time.
- Choices and decisions.
- Being part of the community.
- The freedom to go out and about.
- Support.
- Communication.
- The right to say “no”.

OUR EXPERIENCES OF PERSONAL RELATIONSHIPS

- It can be hard when they go wrong.
- It’s hard to meet people of my own age.
- It can be hard to find someone to talk to.
- It’s hard when people try to influence you eg having alcoholic drinks when you don’t want them.
- It’s hard to say “no”.
- You want to have your “no” listened to.
- It’s hard to have equal relationships.
- Not feeling able to be assertive and so being taken advantage of.
- People not listening to you or taking you seriously.
- People abusing power.
- Feeling very vulnerable.
- Being treated differently.
- Stop treating us like children.
- Having self confidence.
- Compassion.
- Compatible.
- Understanding yourself.
- Needing more approval than others.
- My family were vey negative and did not want us to be together when I took my girlfriend home.
- When you are independent and away from your parents, then you can do what you want.
- Parents set curfews.
- I can go out and meet people freely.
- I have good experiences and support.
- I live alone and can live free.
- I am frustrated by my parents’ control—I need trust, freedom and privacy.
- I want to choose who I can and can’t be with.
- My parents are not supportive.
- People don’t want you to be on the dating scene.
- Everyone watches you when you have a partner.
- Friends and other people make you believe that you won’t be happy.
- Others were suspicious of my relationships and were not encouraging and jealous, asking questions, making trouble by spreading rumours.
- We are entitled to relationships.

- Staff in residential homes restrict personal relationships.
- They always put you down—“you could never do . . .”
- They are “keeping an eye on you”.
- They said I can’t go to the social club.
- I have difficult relationships with my staff.
- I have a right to be born and a right to work in the community.
- I don’t see my girlfriends any more.
- I didn’t feel entitled to have a relationship.
- People listened in to my conversations—not private.
- They interfered because of my learning disability.

OUR SOLUTIONS

- More privacy.
- Less gossip and intrusion.
- Take our love partners seriously!
- Less shouting and control.
- Give us the chance to stay with our partners/to live together and go out.
- Being and sticking with each other.
- Away from others interfering.

HOW WE TAKE PART IN OUR LOCAL COMMUNITY

- Dancing.
- Bingo.
- College.
- Gateway club.
- Snooker.
- Swimming competitions.
- Song writers.
- Weight watchers.
- Red Cross.
- Volunteer job.
- Talkback.
- Training.
- BILD.
- Meetings.
- Training social workers.
- Children’s work.
- Independent group.
- Advocacy groups.
- Speaking to other professionals who work in the learning disabilities sector.
- Charity work.
- Shopping.
- Restaurants.
- Cafes.
- Pubs.
- Sports centres, community youth clubs, banks, job centres.
- Cultural visits.
- Churches.
- Day centres.
- Public transport.
- Taxis.

-
- Voting.
 - Doctor.
 - Dentist.
 - Opticians.
 - Hospitals.

SOME OF OUR ISSUES

- Our local buses are good; helpful drivers; accessible timetables; diagrams of bus stops.
- Some people live in their own flats but are too scared to go out.
- Sometimes no help or support is provided.

Wyre Forest Advocacy discussed human rights with a group of people with learning disabilities who live in a health service resource and are sectioned under the Mental Health Act. They have asked for their views to be included as part of this submission.

WHAT ARE HUMAN RIGHTS?

- The freedom to voice your opinion and say how you feel.
- To be treated equally.
- To make your own choices.
- To be told the truth.
- The right to be involved in plans for your future.

HOW DO YOU TAKE PART IN YOUR LOCAL COMMUNITY?

- “I don’t.” I have to get permission from the doctor every time I want to do something. It can be very frustrating even when understandable explanations are given.
- I would like to become more involved with community activities but that would be difficult because I can’t do anything without asking doctors and staff. When you live in the community, you have the chance to get to know more people and do more things.
- I have very few chances to get involved in the community but when I can I like to go for a meal and to church. A few weeks ago I went to college and that was good.
- When it’s planned, we do go out and do things in the community. I like to go shopping and out for a meal. There are several places I would like to go. I have told the staff and they are hopefully going to help me.
- Voting—we don’t vote. I would like to vote. I don’t see why I can’t vote for my country because I know all about the Government, what they do and who they are.

WHAT ARE YOUR EXPERIENCES OF PERSONAL RELATIONSHIPS?

- My best relationships are with my family.
- I had a relationship with a girl but it went wrong and broke up. I was living in a hospital at the time. Staff were very supportive and helped me through a difficult time.
- I try and get on with everybody. My advocate and community nurse are good listeners and help me get things sorted.
- When you live in hospital, you have to talk to and trust people that you don’t know, and that can be difficult.
- I like people to be honest with me. I ask staff what the next step is for me but nobody answers the question. People seem to avoid questions—if they cannot answer them, they should say so. I know my age is a problem (I’m 70) but nothing really gets mentioned in case conferences. There should be a clear moving on plan, and then people would know what was happening.
- I get good reports and told I am doing well but it does not seem to get me anywhere. The doctors ask “can they trust me not to get into trouble?”. I need the chance to try.

HOW EASY IS IT TO COMPLAIN?

- It is difficult to complain because if you keep asking questions, you get told that's enough. If you keep asking, it gets you into trouble.
- I don't complain. I try to keep my head down. When you are on a section, you keep things to yourself.

20 July 2007

Memorandum from The Home Farm Trust

1. I am writing on behalf of HFT (The Home Farm Trust) a national voluntary organisation for people with learning disabilities and their families.

Mindful of the volume of submissions you are likely to receive, I will confine our responses to a few key points.

2. FAMILIES

We very much welcome your reference to families. Most people with learning disabilities live with their families, who are the most continuous carers and have often been the innovators. Families themselves are often denied their own rights to be participating citizens because of the demands placed on them.

Also there are a considerable and growing number of older families who are in a position of mutual interdependence with their learning disabled relatives —so that many people with learning disabilities of middle age are simply denied the opportunity to be participating citizens.

The solution to this must include finance so that support staff can be provided.

3. MAINSTREAMING

HFT was the major and UK partner in an EU funded project entitled "Walking the Talk", which examined the reality of mainstreaming for people with learning disabilities and their families in several different countries. Mainstreaming was defined as equal access and equal contribution. I attach the various reports produced by the project. These include:

- UK National Report.
- Easy to Read UK National Report.
- Comparative Report.
- Easy to Read Comparative Report.
- UK National Recommendations.
- European Recommendations.

The UK has, comparatively, made huge steps to enable people with learning disabilities and their families to be part of the mainstream, but the project showed there is still a considerable way to go.

4. UK ALLIANCES

Government initiatives such as "Inspecting for Better Lives", are welcome and commendable.

However there is a danger that the voice of people with learning disabilities will not be as easily heard as that of the more articulate and established views of people with other disabilities, many of whom also have a different view of families.

We need to ensure that vision and perspective of people with learning disabilities is properly provided for.

5. PUBLIC SECTOR DISABILITY EQUALITY DUTY UNDER THE DDA

This is now an explicit requirement on local authorities, but is still in its infancy. It needs to be properly resourced and made an explicit performance target so that it does not wither or become tokenist.

It is also crucial that local authorities are explicitly required to ensure that learning disability initiatives are included.

6. COMMISSION AND REGULATIONS

Specific and demonstrable targets should be built into commissioning and regulation which require year on year commitment to empowering people with learning disabilities to enjoy “citizenship”. CSCI (Commissioning for Social Care Inspection) has already made an encouraging start in this direction, and this initiative must not be lost.

7. THE EUROPEAN YEAR OF EQUAL OPPORTUNITIES 2007

This is an important opportunity to share inspirational stories from across Europe and within the UK.

HFT will be compiling example of real achievement and participation, and would be happy to share these and indeed to discuss the Walking the Talk report in more detail.

Phil Madden

Director of Care Policy and Quality

16 July 2007

Memorandum from the Family Welfare Association (FWA)

FWA welcomes the opportunity to respond to the Committee’s inquiry on the human rights of adults with learning disabilities. The inquiry covers a significant range of issues, and comments here are restricted to examining “the possibility for adults with learning disabilities to form and maintain personal relationships with others and the positive obligations of the state which arise in this context”.

This response is based on FWA’s experience as a provider of support to families affected by parental learning disability. Recommendations are in bold type.

INTRODUCTION

While the Human Rights Act (1998) provides the “right to respect for private and family life” (Article 8), and “the right to marry and found a family” (Article 12), our experience is that many adults with learning disabilities continue to be denied such rights.

This response highlights particular areas of concern for FWA and focuses on four key issues:

1. “The presumption of incompetence”¹⁸⁹ and perceptions of the abilities of adults with learning disabilities.
2. The availability of support; access issues and eligibility criteria.
3. Child protection.
4. What works in supporting families affected by parental learning disabilities.

CONTEXT

The number of parents with learning disabilities in the UK is unknown but there is wide acceptance that they comprise a sizeable population and that their number is rising.¹⁹⁰ One study estimates that approximately 250,000 are known to health and social care agencies.¹⁹¹ In the Department of Health’s England-wide survey of adults with learning disabilities, 48% of parents interviewed were not looking after their children.¹⁹² This figure is broadly in line with other studies, both in the UK and across the world, which indicate that between 40 and 60% of parents with learning disabilities have their children removed.¹⁹³

Despite the vulnerability of families affected by parental learning disabilities, few support services are available and many professionals lack the skills to respond to their specific requirements.

¹⁸⁹ Booth T, Booth W (1996) Parental competence and parents with learning difficulties. *Child and Family Social Work*, 1 (2), 81–86.

¹⁹⁰ See, for example, Booth T (2000) Parents with learning difficulties, child protection and the courts. *Representing Children* Vol. 13 No. 3 and Ward L and Tarleton B (2007) Sinking or swimming? Supporting parents with learning disabilities and their children. *Learning Disability Review* Vol. 12 Issue. 2

¹⁹¹ McGaw S (1997) Practical support for parents with learning disabilities. In J O’Hara & A Sperlinger (Eds.) *Adults with learning disabilities: A practical approach for health professionals*. Chichester

¹⁹² Emerson E, Malam S, Davies I and Spencer K (2005) *Adults with learning difficulties in England 2003–04*. Department of Health

¹⁹³ McConnell, D & Llewellyn, G (2002) Stereotypes, parents with intellectual disability and child protection. *Journal of Social Welfare and Family Law* Vol 24 Issue (3)

The fact that almost 50% of parents with learning disabilities are not looking after their children demonstrates the huge extent to which they are denied the right to family life. There is a growing body of research literature which demonstrates that the removal of children from parents with a learning disability is due to factors more complex than the an individual possessing inadequate parenting skills.¹⁹⁴ It is symptomatic of a number of issues which are explored in greater depth in this submission.

PRESUMPTION OF INCOMPETENCE

Negative stereotypes mean that there is a widely held presumption that adults with learning disabilities are unable to be effective parents. The families that FWA works with are commonly frustrated by the tendency to presume that they lack the capacity to be good parents.

In reality, adults with learning disabilities can be successful in their parenting role but may require additional support. Despite the fact that the Children Act 1989 and subsequent Government guidance states that, wherever possible, children should be supported in their own family, there is a widely held belief among professionals that the best solution is to remove children and place them with other carers.

A study, carried out by the Norah Fry Research Centre at the University of Bristol, asked professionals supporting parents with learning disabilities about the attitudes of staff, who did not work with this client group. They reported that staff presumed people with learning disabilities:

- Were incompetent and never going to be effective parents.
- Would be unable to understand their children's needs.
- Would be unable to learn skills quickly enough to meet their child's developmental needs.¹⁹⁵

This presumption of incompetence is often compounded by a tendency to focus on individuals' deficits as opposed to their strengths and often leads parents with a learning disability to feel that they have been set up to fail by statutory agencies:

"I didn't know what they meant—they didn't help, they just told me to do better. They were waiting for me to get it wrong."

FWA *Valuing Families* service user

Underlying the negative views held by many staff is a lack of experience of working with those with a learning disability and therefore failing to understand what its impact may be.

There is a need to raise awareness of the support needs of parents with learning disabilities among non learning disability specialist services and to ensure that professionals receive appropriate training which enables them to understand the challenges faced by parents. Social work training must equip students with the skills to separate personal and professional values and professionals working with adults with learning disabilities should receive training on child protection issues.

Research has shown that families affected by parental learning disability are commonly victims of the tension which exists between adults and children's social services.¹⁹⁶ Too often families get caught between two stools—with adults' services wanting to uphold the rights of the parent and children's services concerned with child welfare and likely to believe that a child's well-being is more likely to be safeguarded if they are placed in an alternative setting. This latter view is rooted in a stereotype that perceived parenting deficiencies are irremediable and there is little point in offering parents with learning disabilities support.

Joint working between adults' and children's services needs to improve. Services need to be co-ordinated to ensure that appropriate support is available at an earlier stage to prevent situations from reaching crisis point.

SUPPORT SERVICES—ELIGIBILITY AND ACCESSIBILITY

A key predictor of effective parenting is the existence of formal and informal support structures. The social exclusion and isolation often experienced by those with a learning disability often means that they lack informal support networks—friends, neighbours and family—which can compound the inadequacies of formal support that many experience.

Many adults with learning disabilities are not known to statutory services and it is only when they have children that they require additional support. This raises issues about the accessibility of support services and the extent to which professionals in mainstream services, such as health visitors, are equipped to recognise the potential support needs of parents with learning disabilities.

¹⁹⁴ See, for example, Booth T (2000) Parents with learning difficulties, child protection and the courts. *Representing Children* Vol. 13 No. 3 and Disability and discrimination in Australian care proceedings. In McConnell D, Llewellyn G, & Ferronato L (2002) Disability and Decision-Making in Australian Care Proceedings *International Journal of Law, Policy and the Family*, 16.

¹⁹⁵ Tarleton B, Ward L & Howarth J (2006) Finding the right support? *A review of issues and positive practice in supporting parents with learning difficulties and their children*. The Baring Foundation

¹⁹⁶ McGaw S and Newman T (2005) *What works for parents with learning disabilities?* Barnardo's

Fundamental to providing responsive support services is early identification and timely support which, where necessary, starts during pregnancy, includes an early assessment of support needs and is tailored to the requirements of individual families.

There are a number of barriers to parents with learning disabilities accessing timely and appropriate support which are outlined in more detail below:

- lack of resources;
- eligibility criteria;
- the perceived tension between children’s and adults services; and
- parental reticence to engage with services.

Lack of resources: The relative scarcity of resources means that many parents with learning disabilities fail to meet the eligibility thresholds for support services. Too often families are unable to access services until a situation has deteriorated to the point of crisis. This is a false economy—the respective costs of placing a child in foster or residential care far outstrip those of providing effective support at an earlier stage to families at home.

Local authorities need to ensure that they are complying with the Fair Access to Care Services guidance¹⁹⁷ which requires social services departments to include social roles, such as parenting, in their assessment of an adult with a learning disability.

Eligibility criteria: Many adults with learning disabilities are considered “too able” to qualify for support services; there is little recognition of the additional strain placed on those who have parenting responsibilities. Too often parents are only identified and referred to specialist services when a situation has reached crisis point and care proceedings are imminent.

Professionals need to recognise the additional needs of parents with a learning disability and ensure that eligibility criteria reflect these.

The perceived tension between adults’ and children’s services: As outlined above, when it comes to families affected by parental learning disabilities, many professionals perceive a tension between adults’ and children’s services. In reality, such a tension should not exist providing that, on a strategic level, there is sufficient co-ordination between the two services and frontline staff make links with their counterparts in children’s/adults’ services.

A national training programme should be developed on supporting families affected by parental learning disabilities for staff working in adults’ learning disability services and children’s services.

Parental reticence to engage with services: Many adults with learning disabilities have had negative past experiences of engaging with statutory services. This, coupled with a perception on the part of many parents that statutory agencies are looking for an excuse to take their children away, results in a reticence to engage with professionals and high drop out rates from interventions such as parenting support programmes.

Providers of non-specialist services need to ensure that they are accessible to parents with learning disabilities. Adopting a preventative approach would be more empowering for parents and reduce the need for specialist interventions at a later stage. Long term preventative support is more popular among families and prevents the need for intensive short term interventions at times of crisis.

CHILD PROTECTION

Parents with learning disabilities face a high risk of having their children taken into care and are over-represented in child protection proceedings. An Australian study concluded that parents with “cognitive limitations” were almost twice as likely to be involved with social services on child protection issues than non-disabled parents.¹⁹⁸

Parents with learning disabilities are likely to be disadvantaged in child care proceedings by a lack of independent advice and legal representation. Similarly, legal representatives often lack experience of dealing with people with learning disabilities which means information is often not provided in an easy read format, there is little awareness of the support needs of clients and a shortage of independent advocates.

All parents with learning disabilities who are facing child care proceedings should have access to an independent advocate who can support them through the process and help to secure the best possible settlement.

¹⁹⁷ Department of Health (2002) *Fair access to care services*. <http://www.dh.gov.uk>

¹⁹⁸ McConnell D & Llewellyn G (2000). Parental disability and the threat of child removal. *Family Matters* 51 (4).

 WHAT WORKS IN SUPPORTING FAMILIES AFFECTED BY PARENTAL LEARNING DISABILITIES?

While every family will have different requirements, there are a number of common measures that can be put in place to support families affected by parental learning disabilities:

- *Early identification*—adults with learning disabilities, who may require additional support, should be identified as early as possible, ideally during pregnancy.
- *Holistic assessment*—assessments of support needs should take into account parenting responsibilities and the needs of an individual in the context of their family situation.
- *Informal support*—where informal support is not available through family members, friends or neighbours, parents with learning disabilities should have access to an informal parenting group.
- *Effective interventions*—services need to combine skills training, help at home and support to help users engage with other agencies.
- *Responsive services*—families' requirements change over time as children become older and the dynamics change. Services need to be sufficiently flexible if they are to respond to changing needs.

FWA's *Valuing Families* model provides support to families affected by parental learning disabilities. Families are assigned a Family Support worker who adopts a whole family approach, visiting families in their home to provide practical and therapeutic support. The model aims to improve the quality and stability of family life by:

- improving children's emotional wellbeing;
- improving adults' ability and confidence in parenting;
- enabling families to access the services they need; and
- improving the physical environment in which the families live.

This is achieved by visiting families in their homes, agreeing with them the goals we are working towards and keeping in regular contact with them. We visit families often and we keep in touch with them between visits by telephone and text. We believe this level of contact and involvement is the key to our ability to work successfully with parents with learning disabilities.

Typically, the pattern of support is that a lot of effort is required in the early stages to establish trust and build relationships with families and to then agree and work through a plan of action. As families make progress the role becomes less hands-on as families consolidate the progress they have made.

Coaching sessions are central to achieving our aim of improving parents' ability and confidence in parenting. We spend specific sessions working on specific goals. These are structured interventions where a goal is broken down into its component tasks and parents are helped to work through these until they complete the overall goal.

Our practical, hands-on approach means that we work with families wherever they need us—be that in their home, at the doctors, in meetings, at the school gate, or at court—to assist them in ordering their lives and making positive change. In many respects it is not what we do with families that makes our work a success, but rather the way we go about working with them; our support workers get alongside people, demonstrating that they are reliable and will help the family—providing that they keep to their side of the agreement, and work towards the goals we set together.

Our approach is multi agency; we work closely with schools as well as health and housing professionals and, when necessary, the police. We deliver results with families who have often failed in the past. As a result of our work with a family, we are able to identify the following positive outcomes:

- A family routine is put in place and followed—with set times for breakfast, leaving for school, dinner and bedtime.
- Children get to school on time and with the right items of uniform.
- The family's diet improves—parents are more confident to prepare and cook a wider range of foods.
- The home environment is calmer—there is less human traffic coming through the household, which means that neighbours are less frequently disturbed.
- Children's personal hygiene is improved.
- The family is supported in dealings with other agencies—such as housing, education and social services—resulting in improved relations with statutory agencies.
- Parents understand the role and workings of social services.
- Younger children are taught to have a better understanding of road and home safety.
- Life is less chaotic and the family is more stable, with family members enjoying better relationships with one another.

The *Valuing Families* model demonstrates that, with the right support, adults with learning disabilities can be effective parents and their children can thrive.

CONCLUSIONS

The Committee's decision to examine the human rights of adults with learning disabilities is welcome. In FWA's view it is vital that this encompasses the right to be parents and to family life. Currently, children of parents with learning disabilities remain 200–300 times more likely to be removed from their parents care than other children;¹⁹⁹ this is nothing short of a scandal and needs to be urgently addressed.

ABOUT FWA

The Family Welfare Association was founded in 1869 to help some of England's families in greatest need. We provide home-based and centre-based support for families in a range of circumstances, many of whom have complex needs and are at risk of social exclusion. We have always sought to work holistically with families by working with all family members together and individually. Throughout our history we have worked across the lifecycle and across traditional service boundaries with a particular blend of practical advice, financial help and therapeutic individual and relationship counselling. These principles and this approach underpin our work today.

FWA helps 45,000 children and families each year through 100 local services across England and our national grant-making programme. A further 60,000 benefit from our educational grants advice.

Our local services are based in a variety of settings where people feel comfortable and safe including their own homes, family, day and drop-in centres, playgroups and doctor's surgeries. Many of our services offer home-based support where we can work intensively with families to bring stability back into their lives.

Claire Kober

Head of Policy and Campaigns

19 July 2007

Memorandum from Rotherham Advocacy Partnerships

RAP is an advocacy organisation which works with adults with learning disabilities in Rotherham. Over the past six years we have worked with around 100 parents with learning disabilities. Between them, these parents have had around 150 children; of these 150 approximately 60 are now adopted, in long term foster care, or under a residence order with relatives. We estimate that 80% of the parents have had social services intervention in some form, including being registered on the child protection register, registered as children in need, looked after children or under a residence order.

Our experiences lead us to believe that adults with learning disabilities do not enjoy equal rights to a family life; we are constantly witnessing ways in which existing services and systems do not support people to maintain family relationships. Ultimately, in the many of cases we work with, this leads to the removal of children from the family home.

We would like to raise the following points about the specific difficulties which are encountered by parents with learning disabilities, and the barriers which they face.

1. PROFESSIONALS LACK OF UNDERSTANDING OF LEARNING DISABILITY

This includes social workers from Children and Families, health visitors, school staff etc. Skills and experiences are variable, but often people lack understanding of how to present information, how to communicate and how to offer support to our client group. This means that often they receive an inferior service from professionals.

2. LACK OF ADVOCACY

Where there is an advocate involved, the effects of the above can be mediated to some extent. However, many parents do not have access to advocacy; in our own case we have recently had to cut the service we offer considerably, following the withdrawal of funding from Children and Families Services. This leaves people in a situation where they are not given the opportunity to participate in assessments and processes in a way that is meaningful to them. It denies them the opportunity to do justice to their skills and abilities. It can also leave them confused and bewildered about what is happening around them.

¹⁹⁹ Booth T (2004) University of Sheffield

3. ASSESSMENT PROCEDURES

The assessment procedures put families under the microscope in an unnatural way. It relies heavily on the ability to verbalise and to “say the right thing” which immediately puts people with a learning disability at a disadvantage. There is an assessment tool designed especially for use with parents who have learning disabilities which is used by a few social workers in Rotherham. However, this in itself is problematic since they don’t have the proper training to use it—the author of the tool states that it is essential to be trained.

4. AN ASSUMPTION OF INABILITY

We feel that there is usually an assumption that people with learning disabilities cannot parent adequately. This is often related to the lack of ability to “say the right thing” and places them immediately in the spotlight. Other families are less likely to be scrutinised in the same way.

5. COMPLETE ABSENCE OF JOINT WORKING, NO PROTOCOL

In our experience of services in Rotherham, families are never offered a proper joint assessment by both the Learning Disability Team, and the Children and Families Team. Instead, the contact between the two teams seems to be based almost entirely on an attempt to place responsibility on the other. A protocol on joint working was drawn up a number of years ago and a final draft written; this was due to go to the Policies and Procedures panel, but for some unknown reason has never been presented. There seems to be a lack of political will to deal with this difficult subject.

6. APPLICATION OF FAIR ACCESS TO CARE SERVICES

Because Rotherham has now set eligibility to services at Substantial and Critical, many parents with mild to moderate learning disabilities are either turned away completely, or offered a very minimal service.

7. INABILITY TO ACCESS DIRECT PAYMENTS

Many parents would benefit from support via a direct payment. However, no social services team is prepared to foot the bill for this—Adults’ services say they are not there to support children, and children’s services don’t seem to have a budget for ongoing family support. A family may be getting regular visits from social workers, but there is no ongoing, consistent, hands on support work being done. As well as denying people the chance to have a family, this seems nonsensical as often the considerable costs of legal proceedings, and of placing a child in care are incurred because there is no budget for a few hours support a week.

8. LACK OF SUITABLE PARENTING CLASSES

Most parents are able to access a range of activities and classes to help them in their parenting role. However, there are very few classes designed to meet the needs of people with learning disabilities. This places them at a significant disadvantage, particularly since they are unlikely to be able to access information via books/the internet.

20 July 2007

Memorandum from the Wokingham Learning Disability Partnership Board

The Wokingham Learning Disability Partnership Board was set up in 2001. It is the hub for all things to do with learning disability in Wokingham, and has members from all parts of the learning disability community. Its main aim is to make positive changes in the lives of people with a learning disability with the help of the White Paper, Valuing People.

One of our primary aims is to consult with our membership about issues that are important to people with a learning disability and their supporters. Securing equality is a common theme of our meetings. Please find below our response to your consultation on human rights of adults with a learning disability.

ON ACCESS TO HEALTHCARE

- We still feel that most mainstream health care services do not cater well for the needs of people with a learning disability. Evidence of this is that people with a learning disability tend to be in one of the statistically unhealthier groups in the population. As a Partnership Board we support the recent campaign and report by National Mencap entitled “Death by Indifference”. Although we recognise that the cases in this report are particularly harrowing, people locally echo some of the experiences. A local health care issue currently is that of access to appropriate dentistry services.

People with a learning disability tend not to be able to afford private dental services, they also need more time and specialist support. Locally these specialist services have been cut back without consultation, with no hope of an under developed mainstream service being able to cope. An example of how good practice can be developed is that of the Wokingham OK Health Checks. This is where the PCT have worked with people with a learning disability to get GP surgeries to offer everyone with a learning disability a free annual double appointment health check.

ON LEARNING

- We feel that people with a learning disability have equal access to education on a life long learning basis. Locally it is felt we have an under provision of specialist learning environments, especially for people with more profound disabilities. It is hard for people with a learning disability to access mainstream services, as they are not geared up to meet the needs of this group. This often leads to segregation of learning for this group.

ON HOUSING

- Many people with learning disabilities live in residential care homes. Legally this means they have little security of tenure. Newer models of housing and support provide legal tenancies for people as well as more control over how people are supported and who they live with. There is however only a small amount of this type of accommodation available.

ON BENEFITS

- People with a learning disability rely on benefits to function in society. It is felt that benefits are not structured in such a way as to support those people with a learning disability that could work into work. New types of benefits such as tax credits have sought to remedy this but the sheer range, complexity and intimidating approach of the benefits system often makes this impractical. A more coordinated or one stop approach is needed to support people's rights—such as the right to work.

ON RELATIONSHIPS

- People with a learning disability don't have the same opportunities to extend their networks and form relationships as other members of the community. For instance the "Stay Up Late" Campaign (www.stayuplate.org) highlights the fact that lots of people with learning disabilities lives are governed by services and staff rotas—rather than being able to lead a life that they want and meet the people that they want.

ON COMMUNITY LIFE

- Mainstream organisations do not reach out to people with a learning disability, which means they end up using segregated facilities and thus excluded from community life. The Government could put pressure on these organisations to arrange things differently. A typical example of this is the fact that someone with a learning disability would be picked up in a mini bus and taken to a day centre some miles away and then taken home at the end of the day, at considerable expense to the tax payer. Many people with a learning disability could use some of that money to participate in their communities more effectively. This would serve to promote the positive message that people with a learning disability can be active and productive citizens as apposed to people who are drain on public resources.

CONVENTION ON RIGHTS OF PERSONS WITH DISABILITIES

- We were disappointed when we found the document was not accessible or well publicised. If people are not aware of it's existence and can not understand it then it will not have much of a practical impact. At the very least an easy read summary should be made available.

We hope you can take our comments into consideration. If you would like more information and more detailed feedback, please let us know.

20 July 2007

Memorandum from The National Autistic Society

SUMMARY

- An autistic spectrum disorder (ASD) is not a learning disability in itself but many people with an ASD have a learning disability. The issues raised in this submission also affect those who would not usually be considered to have a learning disability.
- Many people with an ASD may miss out on learning disability and other services because of an arbitrary definition of learning disability or eligibility criteria.
- The main human rights issues faced by people with an ASD in accessing services are discrimination and a possible threat to life by accessing no services at all, or poor or inappropriate services.
- People with an ASD have difficulty in accessing care services at all and a lack of understanding of ASD can lead to inappropriate healthcare and mental health services.
- Specific guidance on ASD and training for professionals would help to resolve many of these issues.
- People with an ASD will have difficulty, by the nature of their condition, forming relationships, participating in the community and having a say in decisions about them.
- There are steps that public bodies can take to improve this, including social skills training; alternative mechanisms for participation; and ensuring that staff understand ASD.

1. INTRODUCTION

1.1 *About The National Autistic Society*

The National Autistic Society is the UK’s leading charity for people affected by autism. We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children. Today we have over 17,000 members, 70 branches and provide a wide range of advice, information, support and specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism.

1.2 *What is an autistic spectrum disorder (ASD)?*

There are over 500,000 people in the UK with an ASD—around 1 in 100. An ASD is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with an ASD share three main areas of difficulty, their condition will affect them in different ways. Some people with an ASD are able to live relatively independent lives but others may need a lifetime of support. The three main areas of difficulty are:

- *Difficulty with social interaction*
This includes recognising and understanding other people’s feelings and managing their own. Not understanding how to interact with other people can make it hard to form friendships.
- *Difficulty with social communication*
This includes using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice.
- *Difficulty with social imagination*
This includes the ability to understand and predict other people’s intentions and behaviour and to imagine situations outside of their own routine. This can be accompanied by a narrow repetitive range of activities.

1.3 *ASD and learning disability*

An ASD in itself is not a learning disability, but a substantial proportion of people with an ASD have an accompanying learning disability—estimates vary and it is not possible to give an accurate figure, but a rough estimate is half of those on the spectrum. Diagnosis varies between individuals and professionals, but people with classic or Kanner autism will often have a learning disability; and people with high-functioning autism or Asperger syndrome would not normally be considered to have a learning disability. But the “autistic spectrum” describes the degree of need as well as ability, and people at the higher end of the spectrum may have a high level of need.

However, the definition of learning disability is inconsistent in policy and legislation. Many people with an ASD will not be assessed as having a learning disability, but will be near the borderline and often miss out due to arbitrary criteria such as a certain level of IQ (as explored later). Furthermore, in one legal case a child with high-functioning autism was judged to have a “severe mental impairment” because of his impaired social intelligence.²⁰⁰

This leads strongly to an important point: that people who do not qualify for learning disability services often do not receive any services at all; this situation has human rights implications, as noted later. Whatever the definition, the issues raised in this submission are equally relevant to those with high-functioning autism or Asperger syndrome, who would rarely be considered to have a learning disability.

1.4 Outcomes for adults with an ASD

Outcomes for adults with an ASD are still frequently poor. ASD specific support is often not available and adults with high functioning autism or Asperger syndrome struggle to access any support or even to have their needs recognised. Despite it being estimated that there are more than 500,000 people with an ASD in the UK, there has been very little action taken to ensure that the needs of adults with an ASD are understood and that support is in place to meet those needs. NAS research²⁰¹ has shown that:

- 49% of adults with an ASD are still living at home with their parents;
- only 38% of adults with an ASD have had a community care assessment;
- 66% of those who had had a community care assessment said that they had no lead agency responsible for their adult son or daughter; and
- only 9% of adults are receiving social skills training.

We are currently analysing results of a new survey about support, services and outcomes for adults with an ASD: an early finding is that only 15% of adults with an ASD are in full-time paid employment.

2. ACCESS TO PUBLIC SERVICES

2.1 Human rights issues and access to public services

Two human rights issues arise in describing the challenges faced by people with an ASD in accessing public services: an absence of services, and poor or harmful services. The failure of public services to take account of this group could potentially breach article 2 and article 14 of the European Convention on Human Rights. Equally relevant are the Disability Discrimination Act and the UN Convention on Disability.

2.2 Care services

One of the greatest challenges to people with an ASD in terms of accessing public services is in accessing appropriate care services. People with an ASD often fall into gaps between established services, most typically between learning disability and mental health services. It has been made clear that Valuing People does not preclude people with an ASD from accessing learning disability services, yet many local authorities still measure eligibility on the basis of an IQ under 70 and many individuals with an ASD are not appropriately supported by local services. This is recognised by the Government: a clarification note, *Better services for adults with an ASD*, was published in November 2006 to outline how existing services apply to people with an ASD. It states that “The current position whereby some people with an ASD ‘fall through’ local services—in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy”. The NAS is currently assessing the extent to which *Better services* is being used by local authorities.

The examples below illustrates the difficulties adults face in getting recognition about their needs:

“We recently received a call to our helpline from a father with a 23-year-old son, Ben, who has Asperger syndrome. The local authority has refused to provide Ben with any support and he is now sleeping rough. He has been through the mental health and learning disabilities teams but was told him he was not eligible for support. Ben’s father complained to the local health authority who said that when his son developed a mental health difficulty they would put support in place”. NAS helpline advisor

“There seems to be a lack of services for adults with Asperger’s . . . it seems that once you’re diagnosed as an adult you’re pretty much on your own. We often get lumped in with learning disabilities . . . We fall between categories. We can give the impression of being quite high-functioning although that’s not necessarily the case. We also get lumped in with mental health although I don’t think I’m a mental health case”. 63 year old male with a diagnosis of Asperger syndrome

²⁰⁰ Megarry v Chief Adjudication Officer, 29 October 1999.

²⁰¹ Barnard et al (2001), *Ignored or ineligible*, The National Autistic Society.

In reality many people receive no services at all, because of an arbitrary definition of “learning disability” or an arbitrary threshold of need. Agencies may say that this is fair and rational discrimination on the basis of degree of disability; but when the degree of disability is measured in a crude or arbitrary way, people are plainly discriminated against on the basis of the nature of their disability. Agencies should consider how to address the hidden needs of people with an ASD so that they do not face discrimination.

An absence of services can also constitute a risk to a person’s life in certain cases. Some people with an ASD who are articulate and appear to live independently may still require a degree of support, an absence of which can lead to serious consequences. For example, being unable to plan a meal therefore going hungry; spending too much money on a special interest and not leaving enough for essential spending; or having no concept of hazard and being afraid to leave the house as a result.

The National Autistic Society has published “*Taking Responsibility: Good practice guidelines for services—adults with Asperger syndrome*”, which includes a range of suggested actions for public bodies. “*Better services for people with an ASD*” contains several good practice examples; this is welcome but it demonstrates the need for statutory guidance on services for people with an ASD.

2.3 Healthcare (including mental health)

“*Closing the gap*”, the DRC formal investigation into health inequalities, covered people with an ASD. It found “diagnostic overshadowing” whereby physical health conditions or symptoms are put down to the mental illness, learning disability or ASD. For example, many people with an ASD have difficulties with gastrointestinal disorders; these should be treated as with anyone with a gastrointestinal disorder and not ascribed to the person’s ASD.

A paper by the Royal College of Psychiatrists described the inappropriateness of many psychiatric settings for people with an ASD:

“This group of people may well find the usual clinical environ distressing and unhelpful. This can be because of an intrusive peer group, a day that is insufficiently structured or predictable, or an overstimulating setting”.²⁰²

The Mental Health Act 2007 includes a new “appropriate treatment” test; it will be helpful for the Government to outline what “appropriate treatment” means for people with an ASD. The draft Code of Practice accompanying the Act contains a chapter on ASD and we will work with the Government to develop this.

A further problem identified by the Royal College of Psychiatrists is that, because of a lack of appropriate services, people with an ASD may remain in hospital:

“For many it is not unusual for their short-term admission to become extended as there is a realisation that, even after a lengthy period of hospital admission, they are going to require a specialist community placement with substantial resources. This gives admission a flypaper quality, trapping the patient in hospital”.²⁰³

Ultimately this could arguably amount to a deprivation of liberty and therefore a breach of article 5. It is clear that training is essential to increase the level of understanding amongst healthcare and mental health professionals. Implementing the recommendations of *Closing the gap* would go some way towards this.

3. RELATIONSHIPS, PARTICIPATION AND HAVING A SAY

3.1 Relationships

By the very nature of the condition, people with an ASD have barriers to forming personal relationships. Not all people with an ASD will have a desire to form relationships, but many will. There are examples of services that can improve relationship-building, such as social skills training, social groups and an emphasis on social education in schools. Some authorities fund social skills groups for adults with an ASD.

“Groups like that are a great way to bring people together who would not otherwise be meeting people with similar issues”—Adult with an ASD

“Helping adults with an ASD form and maintain relationships is clearly at the core . . . there is an obvious lack of general provision of training, both social skills and otherwise”—Sibling of an adult with an ASD

The rights of people with an ASD can be closely linked to those of their families. If someone is “trapped in hospital”, or otherwise remains in a service that is not appropriate for them, the whole family are denied a family life, potentially breaching Article 8. Similarly, access to respite care is an ongoing problem, and this creates a barrier to personal life.

²⁰² Psychiatric Services for Adolescents and Adults with Asperger Syndrome and Other Autistic-Spectrum Disorders, Royal College of Psychiatrists Council Report CR136, April 2006.

²⁰³ *ibid.*

3.2 *Participation in community life*

The disability equality duty incorporates a requirement to encourage the participation of disabled people in public life. This is especially important for people with an ASD, who will have particular support needs that affect their ability to be represented in public life. Support to participate in a school community is much more likely than similar forms of support as an adult; this change in itself can be distressing and can have an isolating effect.

“Over the years I have met a lot of people at the club who I get on with but I am limited as to how far I can socialise because of my coping and cut off points”—Adult with an ASD

“Much more support is needed: peer mentors, not parents taking young adults to activities”—Parent of an adult with an ASD

There are ways that government could fulfil its positive obligation to facilitate participation, and most important is for professionals to recognise and understand the needs of people with an ASD. There will often be limits to the extent to which some people with an ASD want to, or are able to, socialise. Therefore public bodies can introduce alternative mechanisms for participation. The National Autistic Society is developing materials for public bodies on involving people with an ASD.

3.3 *Having a say*

The difficulties all people with an ASD have with communication and social norms clearly have an impact on their ability to have a say on issues that affect them. At one extreme, some people with an ASD are non-verbal; others will simply have a different way of interpreting a situation and communicating their feelings about it.

“I received negative responses to the complaints and I felt that they had been very unprofessional in the way that they had treated me. I then lost all faith and trust in public bodies”—Adult with an ASD

Recipients of advocacy services have a range of experiences and it is clear that there is a gap in the provision of advocacy for people with an ASD. Understanding of ASD is essential in this situation. The National Autistic Society is running a government-funded project to provide training to increase the level of awareness of ASD amongst advocacy organisations and independent advocates.

4. POTENTIAL OF THE CONVENTION OF THE RIGHTS OF PEOPLE WITH DISABILITIES AND THE DISABILITY EQUALITY DUTY

The UN Convention on the Rights of People with Disabilities has great potential as a benchmark of rights and obligations, particularly if the UK signs up to the optional protocol. In Article 8, the Convention touches on a further barrier to forming relationships: the level of understanding that other people have about disability. It gives the Government both an obligation and an opportunity to promote the Convention to those who can broaden its impact, including employers and the media. It would be useful to hear from the Government how it intends to proceed with the Convention and this particular article.

The Disability Equality Duty serves as a strong impetus to securing the human rights of people with learning disabilities and people with an ASD. As the Disability Rights Commission dissolves, the Commission for Equality and Human Rights will take on the vital role of pushing and enforcing the implementation of the DED, but ownership of the DED must become entrenched across government. It is of concern, therefore, that the proposals for a single equality act include a watered-down equality duty. When the Secretary of State for Health and the Department of Health, as well as local agencies, report on their progress towards disability equality, they should consider whether the rights of people with learning disabilities have been breached.

25 July 2007

Memorandum from The Royal College of Speech and Language Therapists

(1) EXECUTIVE SUMMARY

1. People with learning disabilities form the largest group of communication-impaired individuals in the general population.

Many people are unable to communicate verbally and rely on other methods such as gesture, pointing or facial expression to communicate their needs.

People with communication problems have difficulty with:

- Understanding the spoken or written word, or other non-verbal communication.
- Expressing themselves through speech, writing or other non-verbal communication.

- Language functions affecting their ability to express want to get over in a meaningful and appropriate way.
- Interacting with others in socially accepted ways.

Communication problems may include problems with expression, articulation, comprehension, and coping with social situations. People with learning disabilities have difficulties understanding complex sentences and abstract concepts with time being a particularly difficult concept to comprehend.

Communication difficulties have a major impact on the formation of relationships and problems with communication are often linked to difficult or challenging behaviour, which can then present a barrier to accessing appropriate care and services. These preventable difficulties have a major role on an individual's life, with a significant impact on education attainment, employability, access to health care and the ability to lead a full and active life in the community.

2. Levels of literacy are very low amongst people with learning disabilities.
3. The incidence of eating, feeding and swallowing problems (dysphagia) is higher in people with learning disabilities than in other population groups.
4. Provision of speech and language therapy for people with learning disabilities is inequitable. In many parts of the country some/all of the above services are not available for this highly disadvantaged and vulnerable group.

RCSLT key recommendations are:

- That communication disability is recognised as a core disability in the same way as physical disability or visual disability.
- All people with learning disabilities and communication problems have regular access to speech and language therapy input.
- All health staff consult with the person with learning disabilities and their family or carer to check if they have dysphagia and require texturally modified food or liquids.
- Speech and language therapists should be an integral part of all community learning disabilities teams.
- All healthcare professionals, nurses and doctors should receive initial and ongoing training to understand communication problems experienced by people with learning disabilities, from a trained speech and language therapists to ensure that they are able to understand and communicate with the individual.

(2) INCIDENCE

Speech, language and communication problems are the most common disability presenting in people with learning disability.

Communication problems:

- Up to 90% of people with learning disabilities have communication difficultiesⁱ.
- About 80% of those with severe learning disabilities fail to acquire effective speech.
- About 60% of people with learning disabilities have some skills in symbolic communication, such sign languages or picture symbolsⁱ.
- Approximately 20% have no verbal communication but do demonstrate intentional communication and up to 20% have no intentional communication skillsⁱⁱ.

Dysphagia:

- Swallowing difficulties are more common in people with learning disabilitiesⁱⁱⁱ than of the population.
- At least half of adults with learning disabilities suffer from dysphagia^{iv, v}.
- Amongst people with cerebral palsy swallowing problems can be as high as 81%.

(3) OUTCOMES

Communication problems

There is good evidence to highlight that people with communication problems benefit from speech and language therapy. In a study of global aphasia where people were randomised to intensive daily therapy and regular therapy three sessions per week more individuals in the intensive group achieved significant improvement^{vi}.

A meta-analysis concluded that outcomes for people with aphasia who received therapy for their communication problems was superior to those for untreated individuals^{vii}.

Dysphagia

The presence of dysphagia is associated with poor outcomes and increased mortality. Specialist intervention for dysphagia minimises the health risks associated with dysphagia, reduces the risk of aspiration, pneumonia and death and maximises safe and adequate nutrition.

(4) VULNERABILITY: RISK ISSUES

Communication

People with learning disabilities are at risk of being unable to exercise their right to communicate.

A lack of accessible information creates a barrier to accessing healthcare and appropriate intervention. People with learning disabilities may not understand health information. Harm may result if a person with learning disabilities is unable to understand information relating to illness or interventions^{viii}.

People with learning disabilities often have health needs that are unrecognised and unmet. Access to treatment can be delayed because symptoms are not recognised early enough. Individual's may be unable to describe adequately their symptoms, degree and site of discomfort and may inform staff that they feel fine even when clearly unwell^{ix}. This can lead to their illness or disease being misdiagnosed or undiagnosed and therefore mistreated or untreated^x.

An individual's capacity to understand and communicate can be affected by a number of factors, including anxiety, pain and distress, unfamiliar people and environments. People with communication problems report to have increased distress, increased negative emotional responses (such as fear, anxiety and frustration) and reduced involvement in activity, which predict poorer health-related quality of life^{xi, xii}.

People with learning disabilities are unable to exercise real choice in their own life, as they may not have the means or the opportunities. Individuals are at risk of not being asked their opinions due to their communication problems. There are many day-to-day tasks and events that people with learning disabilities are routinely excluded from.

The RCSLT recommends that all people with learning disabilities and communication problems should have access to regular speech and therapy input.

Dysphagia

Dysphagia is a serious under-recognised problem for people with learning disabilities^{xiii, xiv}. If not managed this can lead to serious health consequences including poor nutrition, dehydration, aspirating on food or liquid, choking, respiratory tract infections and reduced quality of life^{xv, xvi}. Many of these problems can be life threatening, indeed asphyxia and respiratory infections^{xvii, xviii} are the leading cause of death amongst people with learning disabilities^{xix} highlighting the need for an ongoing focus on this key issue.

Admittance to hospital with an acute condition and a vulnerability around swallowing may leave adults with learning disability very vulnerable to inappropriate types of food and drink being offered, as well as to these being offered in an appropriate way.

The RCSLT recommends that health staff consult with the person with learning disabilities and their family or carer to check if they have dysphagia and require texturally modified food or liquids.

(5) SUPPORTING EVIDENCE

The impact of language and communication difficulties in addition to a learning disability increases the incidence of challenging behaviour^{xx} and/or mental health issues^{xxi} in people with learning disabilities.

A lack of accessible information creates a barrier for people with learning disabilities to accessing healthcare and appropriate intervention^{xxii}. People with learning disabilities are at risk when required to self medicate because the information provided is often inaccessible. People with learning disabilities lack knowledge about why they are taking medication, what it's for and what the potential adverse effects might be.

Adults with learning disabilities have a higher incidence of additional health problems when compared to the general population^{xxiii, xxiv}.

(6) SPEECH AND LANGUAGE THERAPY VALUE

Speech and language therapy is crucial to enable people with learning disabilities to communicate their own needs, interact with others and to access services.

The need for SLT expertise has been highlighted by the appointment of an SLT by the NPSA to support their work on risk management for adults with learning disabilities.

Speech and language therapy enables persons with a learning disability to express their opinions to the full extent of their ability^{xxv}.

In order for individuals to exercise real choice people with learning disabilities have to have the means and opportunities to do so. Speech and language therapists have a key role in determining an individual's capacity to make choices, since language is fundamental to making choices and communicating them with others. Speech and language therapists are well placed to be involved in determining a person with learning disability's ability to consent.

Without shared communication there is automatic exclusion and isolation. Progress towards real social inclusion is only possible with effective communication. Speech and language therapists have a key role by raising awareness of the fundamental role of communication.

The Department of Health has recognised that people with a learning disability need to be enabled to be more independent and empowered to achieve the greatest potential autonomy. In order to achieve independence in their daily lives, people with learning disabilities need to be given appropriate support. A difficulty with, or lack of, communication significantly impairs the ability to achieve independence.

SLTs support people with learning disabilities when making the often-difficult transition to adult services.

The RCSLT recommends that speech and language therapists are an integral part of all community learning disabilities teams.

(7) WORKING WITH OTHERS

Speech and language therapists' work with others and through others to ensure good practice and that people with learning disabilities receive the best joined-up care.

Speech and language therapists train and support family members and carers to meet the needs of the person with learning disability on a daily basis.

Speech and language therapists provide training and awareness for primary and secondary care health staff, day centres and care homes in communication with people with learning disabilities. This can also include specific skills training for example the use of gestures and signing.

Speech and language therapists work with other professionals to make health information more accessible, through the use of easy read material, easy speech, photographs and symbols to explain what happens when someone is admitted to hospital. For example SLTs work with hearing assessment clinics to produce easy to read information on what happens whilst at the clinic.

Speech and language therapists are core members of the multidisciplinary team and work with the individual to develop health action plans and to ensure that the plans themselves are accessible to the individual^{xxvi}.

Speech and language therapists work with health, education, employers, housing and community services such as banks, libraries, and leisure facilities to raise awareness of the communication needs of people with learning disability within the community^{xxvii}. This enables people with learning disabilities to participate fully within their local community.

The RCSLT that all healthcare professionals, nurses and doctors should receive initial and ongoing training to understand communication problems experienced by people with learning disabilities, from a trained speech and language therapists to ensure that they are able to understand and communicate with the individual.

(8) CONCLUSION

We received extensive feedback from speech and language therapists on this topic. The main comment was that many barriers to healthcare could be overcome by effective communication. All health professionals must communicate effectively with all people with learning disabilities and also with the person's carers, family members and learning disability team staff.

(9) TERMINOLOGY AND ABBREVIATIONS

Communication problems

For the purpose of this document the term "communication problems" has been used to encompass speech, language and communication problems and cognitive aspects and right hemisphere problems. Communication problems may involve any or all aspects of language use, such as speaking, reading, writing, and understanding the spoken word, difficulty initiating and programming movements needed for speech, or difficulty articulating motor speech.

Dysphagia

The term dysphagia describes feeding, eating and drinking and swallowing problems. This includes problems with positioning food in the mouth and in oral movements, including sucking, mastication and the process of swallowing.

Aspiration

Aspiration occurs whenever food or liquids “go down the wrong tube” and enters the airway and lungs. Aspirating material into the lungs can lead to respiratory problems, such as pneumonia.

Percutaneous endoscopic gastrostomy tubes (PEG tube)

Percutaneous endoscopic gastrostomy (PEG) administration of enteral feeds is the most commonly used method of nutritional support for patients in the community. A PEG tube goes into your stomach through an opening made on the outside of your abdomen. To put a PEG tube in you have an endoscopy, where a tube with a camera on the end is put down your food pipe and into your stomach to see where to put the PEG tube.

(10) APPENDIX ONE

How SLTs help people with learning disabilities to communicate

Use of signs and symbols

Signs are an accepted means of communication for people with learning disabilities. The introduction of signs can reduce frustration, enable the person to obtain what he or she wants, and enable them to participate in activities that others take for granted. However, this only works when everyone in the individual’s environment takes the time to learn how to sign and use them with the individual concerned.

SLTs use symbols and signs to support people with learning disabilities understanding and especially use symbols to help people order their ideas and express their views, eg for meetings, on potential operations etc. SLTs use Talking mats to gain the views of individuals. For example they can be used to identify what is wrong with someone, identifying where the pain is or if future treatment or surgery is required.

With speech and language therapy input a lady suffering from severe oral dyspraxia (complete inability to produce coordinated speech sounds) was introduced to Makaton signs and symbols. She became a proficient signer and could communicate fluently through the signs that she used. She became a Makaton peer tutor training to support other people with more severe learning difficulties and to ensure that all staff were signing and engaged with the process.

Personal Placemats (PPM)

Professionals and staff are unaware of the risks faced by people with learning disabilities at meal times and lack knowledge on how to minimise these risks.

Personal Placemats (PPM) help support people with learning disabilities to have safe and successful mealtimes. They have a summary of the important information that is needed during mealtimes and can be used as a quick reference.

Communication passports

Communication passports are useful for a variety of people who have communication impairment, including people with a learning disability. SLTs provide training to anyone working with adults with learning disabilities in the areas of communication passports.

The majority of communication passports are for people who use little or no spoken language to communicate. This includes people with profound and multiple learning difficulties as well as people with a significant communication difficulty caused by a mild learning disability.

Communication passports are used to explain to others the individual communication styles of an individual with communication problems. One of the common features of a severe communication problem can be challenging behaviours, which can be disruptive and distressing for individual and their carer alike.

The communication passport could be a short version, containing no more than two pages with information on the individual’s likes and dislikes, needs and preferences.

Alternatively it could be a detailed longer “about me” passport which details all aspects of communication, including for example how I tell you I . . . am cross/need the toilet/want to be on my own/am in pain. The communication passport allows carers and other professionals interpret some responses that are unique to that person for example where rubbing of someone’s temple could mean that the person is becoming frustrated and needs to be removed from the situation.

The information recorded in the passport enables other people and staff to quickly understand how best to communicate with the individual and ensure that all staff follow the same strategy.

Communication passports made by the speech and language therapy service are effective popular with staff and families alike. Communication passports inform other people, staff and professionals what the individual is able to do and also what they must do to support and develop the individual’s communication.

Creating a communication passport involves many different people and the speech and language therapy service are key in co-ordinating this process and may even receive referrals from other professionals such as social workers or community nurses that specifically state that a communication passport is the type of intervention that is required.

As a result of a communication passport individuals needs and wishes are conveyed which leads to a significant reduction in challenging behaviour. Further the detailing of an individual’s communication passport in their care plan can ensure that they it is used consistently for the other day and respite services that they may receive.

The Hospital Booklet

SLT work with{the community nurses, challenging behaviour teams and others to develop a Hospital Book. This is symbolised and contains important information about the person, including personal details, eating and drinking needs, communication needs, professionals involved and a history of health issues. It also contains a symbol chart at the back that could be used as a communication aid for both the hospital staff and the individual.

This booklet helps to ensure that people with learning disabilities have the correct information with them when they go into hospital and is also a useful tool for hospital staff. The booklet will refer to the communication passport if the individual has one. This enables the person with learning disabilities to make their views known.

Health Action Plans

Some learning disabilities services are setting up health action plans for people with learning disabilities that the individual holds on to and it provides information about health checks and interventions that a person has had and plans to have for example eye tests, weight issues, drug/alcohol dependencies. Some trusts have interpreted this uniquely and may use it to link into GP practices.

Providing accessible information about health appointments

As part of a special visual assessment project for adults who have learning disabilities, an accessible information pack was developed to help prepare people for a visual assessment, gain their consent, and help them understand the result of the assessment.

This pack contains a “going for an eye test book”, which has easy to understand language with photographs, symbols and pictures to describe what will happen at each stage of the eye-test.

A number of resources were collected to practice some of the tasks within the visual test in advance, for example a picture chart, a pen torch and glasses. A number of other accessible resources were also produced for the pack including letters, reminders and an assessment form.

The result is accessible information, which means more people are being assessed and understand the results of their assessment leading to a better quality of life.

Speech and language therapy prompts social inclusion

The Bexley speaking and signing team won an award at Oxleas NHS foundation Trust’s annual recognitions awards. The team won the award for their weekly speaking and signing group for people with moderate learning disability and dysarthria.

The weekly group aims to provide opportunities to practice and develop alternative methods of communication. They use a combination of photos, symbols and signing to help group members develop their communication skills to allow them to share their thoughts and feelings with others. They also encourage family members and carers to the group both to show them how to use alternative methods of communication and to help aid general skill development.

(11) APPENDIX TWO

Case studies

How SLTs work

Jane was 51. She lived in a large residential home. She was diagnosed with dementia three years ago, following signs of neurological and behavioural changes. For the last six months she had exhibited increasing dysphagia. Symptoms included limited chewing, forgetting to chew, coughing on liquids and dry foods, and chest infections. SLT have worked closely with the nursing home to ensure that they gradually adapted her food, drink, utensils and positioning to ensure where possible, safety, nutrition and hydration, comfort and choice. She then developed epilepsy. Often Jane's coughing and/or chest infections triggered epileptic fits, which resulted in Jane going into status epilepticus, which resulted in hospitalisation. Jane had a phobia about hospitals. Through detailed discussion with Jane's brother, the multidisciplinary team, and Jane's carers and medics, the decision was made to request a PEG for Jane, given Jane's personal circumstances, and the level of ill health and distress Jane's dysphagia resulted in, a person centred decision was made to place a PEG for Jane. This allowed her to die peacefully at home 6 months later, without further hospital admissions.

Working with others

Jane is 30, has moderate learning disabilities and lives in a residential home. Her speech is very difficult to understand even to those who know her well and she experiences high levels of frustration and embarrassment. She refers herself for speech therapy. She wants to work on her speech and although she has learned a large amount of Makaton signs in the past she does not use it in everyday situations to help her get her message across. 12 x 1 to 1 sessions result in her making a small change to her speech and she is delighted and more confident. She also uses Makaton signs when talking to her speech therapist, which allows them to understand each other. Jane's mother attends a Makaton training session. Jane now uses signs at home and it helps her and her family to communication together. Although Jane's speech has only changed a small bit, her attitude to it has changed a lot and she is less hard on herself.

Working with others

Jack has been known to the SLT service since childhood. He has complex disabilities including cerebral palsy. Jack lived in a small residential unit for people with learning disabilities for many years until he moved into his own community accommodation in 2005. Jack is entirely non-verbal, but can communicate effectively with supportive communication partners.

There was a period in Jack's life when there was no ongoing SLT cover for the unit he lived in. There was no recognition by staff that Jack might be having some serious difficulties in eating and drinking. Their impression was that Jack was just "restless" or "fidgety" or even just fussy when he was being fed. Jack needs total support to eat and drink he is unable to hold either a cup or a spoon effectively due to involuntary and uncontrolled movements.

When a new SLT was appointed to the unit Jack was referred to her for assessment of a communication aid. As part of the assessment he was observed being fed at a lunchtime session. As an immediate result of her observations his whole lunchtime assistance programme was changed. He was indeed fidgety and restless and had been known to move so uncontrollably during mealtime assistance that he had ripped the footplate straps from the footplates on his wheelchair. He was fed off midline, by his support staff standing well to his left, (because he coughed and spluttered and food came out of his mouth at high speed!). His drinks were offered to him in a large open plastic beaker with his supporter standing behind him.

Initially there was resistance from staff to feed sitting down and feeding in the midline. They were afraid that with the restless feet, knees and elbows there was a significant risk of their being accidentally thumped. Ways round this included the therapist demonstrating sitting in a chair close to Jack, feeding slowly and from the midline, and using a lot of verbal reassurance. The results of a videofluoroscopy examination confirmed that there was significant risk of aspiration and were taken on board immediately by trained staff in the unit.

Utensils were changed, advice was followed and within a short time Jack was most often predictably still whilst being fed and became less of a "risk" to either himself or staff.

Jack is a very sociable character. That side of his character has emerged as has his sense of fun as he became more stable. It has been suggested that given Jack remains at risk of aspiration, that partial gastronomy feeding be introduced Jack's family have indicated that they do not wish this at present. At the moment Jack remains stable and relatively free from chest infections due to the care taken by the provider staff. It is highly likely that Jack will be re-referred to SLT when the situation deteriorates.

Working with other professionals

Mike is 39 years old. He has profound and multiple learning disabilities, as a result of quadriplegic spastic cerebral palsy. He lives at home with his parents who are in their 70s. He attends a social services day centre five days a week, and has regular respite care. He was referred to SLT May 2005 due to increased coughing at mealtimes.

Assessment indicated very limited oral skills, a reduced ability to chew, excessive food loss from mouth, and an apparent delayed swallow trigger, with weak and uncoordinated movements. This resulted in lengthy mealtimes, limited oral intake, excessive coughing on all consistencies. However Mike was reported not to suffer from chest infections. Videofluoroscopy (VF) in July 2005 indicated difficulty in controlling liquid, difficulty chewing solid food, a delayed and a weak swallow, and significant silent aspiration of residue food. Following VF extensive multidisciplinary discussion with his parents were conducted and reached an agreement that we would adapt Mike's diet, position, feeding methods and support. Discussed risk and instigated a regular review process. In 2006, following a "serious" mealtime incident, we held another MDT meeting, with Mike's parents. His parents agreed to referral to a physician for opinion re non-oral mealtime support, in order to inform further discussion. At this time a decision was made by the physician that non-oral support was not indicated at present. He has since been reviewed by the physician on a six monthly basis. He has had one serious chest infection since 2005. This case demonstrates informed risk discussion and management with Mike's parents and carers, that has been well informed by a full multidisciplinary team. This allows us to make decisions that are in Mike's best interests, in a robust fashion, but also ensures good communication and regular review and monitoring. This allows timely response to any changes in Mike's condition.

Working with other professionals

Ann is a 21 year old woman with downs syndrome, severe learning disabilities and fluctuating hearing loss. New carers wished to provide community based opportunities but on a number of occasions she hit members of the public on one occasion causing an injury. The behaviour support team got involved. The SLT became involved in MDT due to: behavioural issues, which highlighted the person's communication difficulties. These are clearly linked with behaviour but to date have not been addressed as part of the behaviour support plan. Ann does not hear or understand the staff when they tell her where she is going. She did not have a verbal or non-verbal means of communicating she is feeling crowded or tired other than hitting people near her.

The following strategies resulted in reduced incidence of pushing and increased her opportunities for joining in with community activities:

- Staff using pictures to show her where they are going and in what order.
- Staff checking with her at regular intervals whether she is feeling okay by showing her thumbs up/down pictures and using matching gesture. When she is asked this she can indicate by pointing to the picture and/or by using the gesture to say how she is feeling.
- At regular intervals staff giving Ann a choice about what they do next. Eg using pictures ask her if she want to carry on shopping, stop for a drink or go home.
- Increasing staff awareness of non-verbal indicators of Ann getting tired/fed up eg facial expression.

Ann's pictures are in a velcro book and she now spontaneously goes to get this when she is going out and she has it attached to her belt.

Social inclusion

M is a man in his mid-20s with downs syndrome, a severe learning disability and a severe hearing impairment. He lives with his mum and goes to a large social services day centre. He was referred to speech and language therapy following his mum's concerns that he was being left out. She was also concerned that his communication had got worse since he left school. At school he used to use some Makaton sign language and say some words. Now he just pointed.

The day centre was often very noisy and very busy. M often sat on his own unless he was walking to the dining hall for tea break or meals. He didn't take part in activities and couldn't pay attention to a group activity for very long. He never approached staff or other services.

A speech and language assessment showed that M was able to understand very little verbal speech alone, however when signs were used he could understand single words and some short phrases. Assessment also showed he knew the words and signs for most of his needs and interests and would use them when looking at pictures in a small group or 1 to 1 situation, even though he hadn't been observed to use them in the centre. It became apparent that the large groups, noisy environment and emphasis on verbal communication alone excluded M and that he had given up trying to communicate.

The speech and language therapist worked with key workers at the centre to develop smaller groups for M to join, where the focus was on visual activities he was interested in such as drawing, sharing comics, computers. The key workers learnt a few signs to use with M, to greet him, praise him and offer him choices. M also was given a pocket book to ask for things he liked and to help make choices. This pocket book could also be used at cafes and shops in the community when M went out with his mum or daycentre staff.

One month later M had become a different person. He was smiling more and taking part in the smaller group activities. He had started signing and saying the words regularly, to make choices, ask for drinks and food and to talk about things in activities. Staff felt that they were getting to know him and that his sense of humour and fun was now apparent.

By working with the daycentre on introducing Makaton signs, more use of pictures and smaller groups based on person centred activities, speech and language therapy enabled M to participate more fully at his daycentre and in the wider community.

Healthcare information

X required dialysis as a result of kidney failure. The speech and language therapists in community learning disability teams worked jointly with community learning disability nurses to support X access services from local primary care trusts. The use of talking mats allowed X to consider the treatment options available to her. By using pictures and diagrams to interpret complex information about kidneys, treatment and dialysis, it has been possible to support X's understanding of what is happening, to keep her informed and to allow her ability to express choice.

Healthcare information

Wilma has been known to the SLT service for many years. She has mild learning disabilities, cerebral palsy, and has lived semi-independently for many years. Wilma is a user of augmentative communication aids including voice output and communication books consisting of photographs and symbols. Wilma is almost entirely non-verbal, but is clearly able to communicate wishes, desires and need efficiently with supportive communication partners. Wilma was discharged from SLT in 2001.

In 2002, aged 42 she was assessed by her GP who referred her onto the local oncology unit for investigations around a lump in her breast. Wilma was very aware of the impending investigations and was quite naturally fearful of their impact on her life. Wilma asked carers to contact the SLTs to request that we add some specific symbols with written short questions for her use whilst being in consultation with the consultants and specialist teams. These questions included the possibility of her staying in hospital, the length of time between the initial appointment and any treatments, the level of pain she might have to tolerate, and if her family could be with her at any or all times.

Wilma took her communication book to her appointments and was treated very well by all the specialist teams in the acute setting. They gave her lots of time to formulate her questions and to think about the answers she was given. They are reported to have been very happy to use the book as a communication tool. It is very unlikely that Wilma could have formulated questions easily, especially at the initial appointment, given the level of anxiety and apprehension any woman in these circumstances would feel. Also, the level of distress she might have shown could have discouraged hospital staff to pursue the more sensitive issues under the mistaken belief that because she is non verbal she is unable to either understand or communicate effectively.

Wilma sadly had to have a mastectomy, and she used her communication book throughout all the hospital visits and subsequent out patient appointments.

Subsequently, Wilma has asked the SLT department for support in symbolising personal issues for follow up and counselling sessions. These were not traditional SLT sessions but were important in allowing Wilma to be as much in control as was possible.

Multidisciplinary team approach

Maggie and Dave have lived at long stay care all of their lives. Neither had had any SLT input for either communication or eating and drinking difficulties until Maggie was 83 and Dave 67. They both lived in units for people with learning disabilities, Maggie in a house for elderly people and Dave in a house containing more challenging service users with moderate learning disabilities.

Both had other major disabilities apart from mild learning disabilities, Maggie had a very rare physical condition which as she grew older made it increasingly difficult to eat. Dave was congenitally blind.

As in Jack's case staff who were very caring and kind, did not clearly see the deterioration in either of these elderly people. Changes happened quite slowly and initially they were resistant.

Dave was assessed at the request of a Staff Nurse who had known him for many years, but having been seconded out of the unit for a period of several months noted changes in eating. Initially after observation and a videofluorocopy, Dave's diet was changed to a "Stage Two/mousse consistency". He refused to eat

this and after some discussion with care staff this was altered to a soft moist stage instead, with severe limitations on some foodstuffs. After a period of a few months, Dave became increasing unwell and the modification was altered back to a “Stage Two”. A second videofluoroscopy was suggested however this was replaced with an endoscopy, which showed that Dave had oesophageal cancer.

Dave allowed us this time to modify his diet and additionally thickened fluids were given. This allowed Dave to live as comfortably as was possible in the unit with caring people around him until his death several months later.

An OT referred Maggie to the speech and language therapy team. Maggie’s meal consistency required alteration, over a much longer period of time through the staged modification to both foods and fluids. As with Dave, staff were sure that Maggie would not accept these changes, however she did and with great grace. The links between nursing staff in the unit, the kitchen staff who accommodated all our requests, the care staff and other professionals was exceptional. Maggie was 86 when she passed away and like Dave she was able to do so in relative comfort with familiar staff and co-residents.

Hospital services were used for both these individuals, but because of the co-ordinated care they were enabled to live their lives out in what they believed to be “home”.

Professionals working together

Rob has also been known to the SLT service for many years. He has mild LD, Cerebral Palsy, and lives at home with family. Rob uses augmentative communication aids including voice output and communication books consisting of photographs and symbols. Rob is entirely non-verbal, but is clearly able to communicate wishes, desires and need efficiently with supportive communication partners. He is known to be humorous, polite and very sociable. Rob currently receives SLT for support with communication.

A new SLT who was also a newly qualified practitioner met Rob in the course of being introduced to a social work centre as the new SLT. The centre was relatively newly formed, and received some other LD health professional supports but not SLT.

The NQP asked for assistance from a more experienced colleague. Rob was very obviously aspirating and advice was given to the social work staff in the resource centre. Staff at the resource centre put changes to mealtime assistance into practice immediately. Contact with the family was established but at this time they did not wish to change Rob’s diet or to accept that there appeared to be some significant issues around eating and drinking.

Patience and diplomacy was required. After a period of several months, the family agreed (reluctantly) to attend a videofluoroscopy clinic with Rob. The examination clearly showed that Rob was aspirating substantial amounts of foodstuffs. The family did not at this point accept that there was a major problem and continued to feed him as before.

Three months after this just around the time of Rob’s 43rd birthday he was admitted to A&E with aspiration pneumonia. Hospital SLTs immediately declared him *nil by mouth*. Within days Rob had a gastrostomy fitted and he remains *nil by mouth* five years later.

The SLTs in the then acute hospital setting had the ability to declare his eating unsafe which is not an option realistically in the community. They did however after this initial contact step back to allow the community SLTs to deal with the family and to answer any of the questions posed by them.

This underlines the need for Hospital therapists and community therapists to be in regular contact and to formalise the links, which at present are dependent on knowledge of each other. Without the vigilance of the NQP and his patience and persistence it is a certainty that Rob would have died as a result of untreated dysphagia.

27 July 2007

(12) REFERENCES

- i Foundation for People with Learning Disabilities, 2000
- ii Emerson, Eric; Hatton, Chris; Felce, David; Murphy, Glynis, *Learning Disabilities—the Fundamental Facts*, the Foundation for People with Learning Disabilities, London, 2001).
- iii NPSA, 2004.
- iv Hardwick, 1993.
- v Chadwick et al, 2003.
- vi Denes G, Perazzolo C, Piani A, Piccione F. Intensive versus regular speech therapy in global aphasia: A controlled study. *Aphasiology* 1996; 10: 385–94.

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- vii Robey R R, A meta-analysis of clinical outcomes in the treatment of aphasia, *Journal of Speech Language Hearing Res* 1998; 41: 172–87.
- viii NPSA, 2004.
- ix Emerson, Eric; Hatton, Chris; Felce, David; Murphy, Glynis, *Learning Disabilities—the Fundamental Facts*, the Foundation for People with Learning Disabilities, London, 2001, p25.
- x NPSA, 2004.
- xi RCSLT Clinical guidelines, 2005.
- xii Hilari K, Wiggins R D, Roy P, Byng S, Smith S C, Predictors of health related quality of life (HRQL) in people with chronic stroke, *Aphasiology*, 2003, 17(4): 365–81.
- xiii NPSA, 2004.
- xiv Dobson, 2003.
- xv Aziz & Cambell-Taylor, 1999.
- xvi Chadwick et al, 2003.
- xvii Hollins et al, 1998.
- xviii NPSA, 2004.
- xix Hollins S, Attard M T, von Fraunhofer N, McGuigan S and Sedgwick P (1998): Mortality in people with learning disability: Risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, 40:127–132.
- xx Chamberlain et al, 1993.
- xxi The care and management of patients with learning disabilities, Docet pack, undated, p 2.
- xxii Equal Treatment: Closing the Gap Interim Report of a Formal Investigation into Health Inequalities, DRC, 2005.
- xxiii Department of Health, 2004.
- xxiv NPSA, 2004.
- xxv Grove, et al, 1999.
- xxvi Department of Health, 2001.
- xxvii Matthews and Dean, 1999.

Memorandum from SeeAbility

1. ABOUT SEEABILITY

SeeAbility is a national charity established in 1799 which works with young people and adults who are visually impaired with additional disabilities. SeeAbility offers a range of residential and supported living services, day services, rehabilitation services and community development projects. In 2005 SeeAbility launched the eye 2 eye Campaign to improve eye care and vision for people with learning disabilities. The Campaign has established a range of community development projects across the UK, a national information service called Look Up and undertakes lobbying and campaigning activities to influence government policy on eye care and vision for people with learning disabilities.

2. WHAT ARE THE FACTS?

Vision is the key to learning, communication and movement. The ability to see creates drive and motivation. The more people can see, the easier they find it to make sense of their world and take control of their lives.

Surveys consistently show that people with learning disabilities are at risk of eye problems—both congenital and acquired. The NHS Executive suggests that “About 30% of people with learning disabilities have a significant impairment of sight . . . There is a high rate of under-detection of sensory impairments, most of which can be treated”. (Department of Health, 1998, *Signposts for Success*).

This means that there are two “groups” of people with learning disabilities that have sight problems:

- People who are blind or partially sighted and need appropriate help.
- People who have difficulty seeing because they need glasses, eye surgery or other treatment to improve their sight.

Regular and effective sight tests are rare amongst people with learning disabilities—therefore visual impairment often goes undetected leading to poor eye health, dependence, and in some instances preventable blindness.

Children and adults with learning disabilities have the same health needs as the “general population”. Children with profound and multiple learning disabilities and/complex health needs are surviving into adulthood. Many of them are born with sight problems. It is now recognised that many people with learning disabilities have unidentified medical problems, such as diabetes (which can cause blindness) and allergies which may cause them to rub their eyes. In addition, some people experience premature ageing (such as people with Down’s syndrome) so they develop the eye problems associated with ageing (particularly cataracts) earlier than the “general population”.

Sight loss may be a terrifying experience for many people with learning disabilities, but especially for people with severe learning disabilities. They may not understand what has happened and why their once familiar world is now frighteningly different.

Changes in their behaviour may be their only way to tell family carers and staff how they are feeling. But the clues they are giving out about their deteriorating sight may be missed and their behaviour may be misinterpreted.

3. THE PROBLEMS BEING EXPERIENCED BY PEOPLE WITH LEARNING DISABILITIES ACROSS THE UK

People with learning disabilities are not receiving effective eye tests:

“John had regular eye tests—but he was not getting a full eye health check. When he was finally seen for his cataracts, he had undetected problems at the back of the eye. The Ophthalmologist agreed to operate, but the chances of success were poor. If these problems had been detected earlier, they could have been solved”.

People with learning disabilities who are born blind or partially sighted are not having these issues identified:

“Janice was totally blind in one eye. She had gone through her life holding her head on one side. She was so devastatingly astigmatic that she had discovered that if she put her head on one side at least vertical lines appeared sharper. The optometrist couldn’t help her, it was too late. If we had found this out at an earlier age she would have had a much happier existence”.

People with learning disabilities are not being prescribed glasses:

“Barry was 40 when he was first prescribed glasses. He soon became less clumsy, doing many things he had never done before. The optician said Barry had needed glasses all his life. I had always believed him to be one of the more dependent people at the day centre, but now he is learning new skills and I am very proud of him”.

People with learning disabilities are unnecessarily losing or damaging their sight:

“Alan damaged one eye badly by eye poking. Then he began damaging the other one. The GP found he had an eye infection, which responded to antibiotics. But he is now totally blind in one eye and his ‘good’ eye still looks pretty nasty, although it is healing”.

The behaviour of people with learning disabilities is being misunderstood:

“We thought Susie had developed dementia as she kept on getting lost and tearful in the home where she had lived for 16 years. Then we found out that her sight had deteriorated considerably”.

People with learning disabilities are being denied sight-saving eye surgery:

“Brenda’s sight loss made her severely depressed. She needed help with things she used to do. We finally persuaded the GP to refer her to an eye hospital. The ophthalmologist announced: ‘we don’t operate on the mentally handicapped; it’s a waste of money’. We found another consultant, who operated willingly. Brenda’s depression lifted”.

Optometrist lack the skills necessary to work effectively with people with learning disabilities:

“It was a tiny little practice and the optician kept shouting at John, who just burst into tears. I sent him a leaflet about hard of hearing people anonymously later”.

Optometrists are not receiving appropriate funding to work with people with learning disabilities:

“Optometrists are not just interested in money. We’re health professionals and provide a service. But because of the ridiculously low fee, and the length of time it takes to test some people with a learning disability we’re often out of pocket with special needs people who obviously have the right to an eye test”.

4. WHAT CAUSES THESE PROBLEMS?

A lack of knowledge amongst those who support people with learning disabilities

Many people with learning disabilities are not aware that they have a visual impairment—they have always seen that way. Others cannot explain that their sight is deteriorating. People with learning disabilities may not know about the importance of eye tests or they have found them frightening.

Supporters may not be aware of the high incidence of sight problems in people with learning disabilities and may assume that it is impossible for people with limited communication skills to have an eye test. They may be unaware of the special tests available and how to support people before and during an eye test. It is important therefore that familiar supporters can prepare people for an eye test—so they know what will happen to them. Many supporters believe that glasses will be rejected—but there are ways of introducing glasses successfully.

The complexity of the benefits system

Most people with learning disabilities are entitled to a free eye test and a voucher towards the cost of glasses. However, others may have difficulty establishing that they should benefit according to the low income scheme.

A discriminatory payment system for optometrists

Whilst optometrists are part of primary care, most are also in business or employed by commercial organisations. Many people with learning disabilities need longer to test, thus costing the practice more. There are few reports of Primary Care Trusts providing additional funding for eye tests or to purchase the special tests for people who cannot cope with standard letter tests.

The need for additional payment to work with people with learning disabilities is constantly stated, with some optometrists feeling that recognition for this specialism is long overdue.

Optometrists not being aware of local planning mechanisms for people with learning disabilities

Local Optical Committees and Low Vision Committees have little contact with Learning Disability Partnership Boards so they may be unaware of local developments and resources for people with learning disabilities.

A lack of expertise among eye care professionals

Professionals may be ill-informed about people with learning disabilities. Hospital staff (including doctors) who work with out-patients and in-patients and receptionists in optometry practices need training to help people with learning disabilities to gain the maximum benefit from eye examinations and treatment available.

Children and adults do not need to be able to talk or read in order to have their sight tested. There are now tests developed for adults with limited communication. Where people cannot co-operate, there are sight tests that record an individual's reflexes and involuntary movements. However, the existence of these tests is not widely known, nor publicised.

Optometrists frequently state that they have received no training to work with people with learning disabilities. In recognition of this, the College of Optometrists produced the Docet distance learning pack, the Care and Management of Patients with Learning Disabilities. This introductory course now needs updating and extensive promotion.

The lack of clear feedback after an eye test

People with learning disabilities and their supporters may not understand what has been found. Important information about how to help someone to see needs to be communicated clearly and included in their Person-Centred Plan and their Health Action Plan in England.

A dearth of training for staff in all settings and at all levels—both in social care and health

Staff working with people who have learning disabilities need eye care included in their basic induction training. They also need on-going training and validated courses. Training on eye care and visual impairment should be included in the basic training of all the professions that are represented in community learning disability teams—social workers, learning disability nurses, psychologists, occupational therapists etc.

People with learning disabilities not being registered as blind/severely sight impaired or partially sighted/sight impaired

Many people with learning disabilities are eligible for registration as blind/severely sight impaired or partially sighted/sight impaired but this often does not happen. People who meet the criteria can be registered—registration is voluntary, but it can help people get practical support, qualifies them for concessions and may help when claiming certain welfare benefits. The register also helps the local council plan their services.

People with learning disabilities not being referred for rehabilitation and low vision support services

People with learning disabilities are seldom referred to low vision clinics/services. Optometrists, ophthalmologists, GPs and staff in low vision services may wrongly believe that people with learning disabilities may not be able to learn to use low vision aids (such as magnifiers) and equipment. Many people with learning disabilities could benefit from low vision training, advice on lighting, contrast and from low vision aids being prescribed.

Blind and partially sighted people with learning disabilities need long term support and training from rehabilitation officers for visually impaired people, if not this may result in their displaying disturbed behaviour and losing skills. There is a national shortage of qualified rehabilitation officers for visually impaired people—and only a minority of them have received training in work with people with learning disabilities and/complex needs.

People with learning disabilities being denied eye surgery

People with learning disabilities are increasingly having successful eye operations. Some ophthalmologists and hospitals have been flexible in the way they carry out procedures for people with learning disabilities. However, supporters report that eye care professionals frequently lack training in work with people with learning disabilities and national guidance is urgently required.

Some family carers and staff have complained about hospital staff holding out-dated attitudes to people with learning disabilities and discriminatory practices.

5. CONCLUSION

SeeAbility maintains that the human rights of adults with learning disabilities—both sighted and visually impaired—are seriously compromised by a lack of appropriate eye care. It is a scandal that so many people have unidentified visual problems, which may cause pain, lower potential and undermine successful participation in a range of activities. We recommend the following actions:

1. Accessible information about eye care should be available to people with learning disabilities in their chosen format.
2. Information and training on eye care should be available to staff working with people with learning disabilities and family carers.
3. Introductory and post qualification training in learning disability should be available to all eye care professionals and staff in clinics and optometry practices including low vision practitioners and rehabilitation officers for visually impaired people.
4. Annual eye tests are required for “high risk groups” of people with learning disabilities—such as people with Down’s syndrome, cerebral palsy, people of Afro-Caribbean origin, people who rub or poke their eyes etc. People who cannot articulate that their sight is changing or deteriorating need an annual eye test.
5. Optometrists should receive an enhanced fee in recognition of the additional work involved with people with learning disabilities and the need to purchase special eye tests.
6. Salaried community optometrists are required to examine people who cannot be supported to use existing services. Whilst the Valuing People white paper stresses that people should have support to use ordinary local facilities, there is a need for a minority of people with learning disabilities with special needs to access this service model.
7. Short pre-examination reports, completed with the person with learning disabilities and their supporter, should be available to optometrists before an eye test. Post examination reports completed by the optometrist should also be provided at no cost to the person who has received the eye test. Some optometrists have asked for payment to complete the post examination report. SeeAbility recommends that optometrists receive an enhanced fee for eye tests for people with learning disabilities, which would include the completion of a post examination form or report.

8. People with learning disabilities who are dependent upon their glasses need a spare pair. At present, the value of the voucher will not cover the cost of two pairs—even if the person cannot cope with their daily life without glasses. Repairs should not be delayed by problems obtaining consent. The value of the voucher for spectacles needs to be increased for people who may damage their glasses to pay for “unbreakable” frames or lenses.
9. Low vision services, registration and help from rehabilitation officers for visually impaired people should be actively promoted for people with learning disabilities. A referral should be made to a low vision service if an operation, or glasses and contact lenses cannot correct a person’s vision.
10. Local Optical Committees and Low Vision Committees should work with Learning Disability Partnership Boards to establish how they can plan to improve services.
11. Ophthalmologists in eye clinics need longer appointment times when they are consulting with people with learning disabilities. Targets set for ophthalmology clinics usually give the specialist only 10 minutes with each patient. This presents difficulties when they have to examine patients with learning disabilities, who often need a longer appointment—because of communication difficulties.

David Scott Ralphs
Chief Executive

27 July 2007

Memorandum from United Response

United Response welcomes the opportunity to submit evidence to the Joint Committee on Human Rights on the human rights of people with learning disabilities. United Response is a national charity which provides skilled care and support to adults with learning disabilities or mental health needs. We work in over 200 locations across England and in Wales and at any one time support around 1,500 people. United Response, the national charity creating opportunities with people with learning disabilities or mental health needs. To find out more visit our website www.unitedresponse.org.uk

1. HEALTHCARE

Many of the people we support with learning disabilities receive excellent care from health professionals, and we have some specific examples of good practice, including for example a consultant being willing to examine a person we support outside hospital (after staff explained his fear of hospitals) and also of people receiving good health services.

A group of our service users with learning disabilities contributed to the compilation of evidence for this submission. Everyone in the group had largely good experiences of using health services, although one woman felt that she was not properly consulted before being given surgery, and one man has been looking for an NHS dentist for several years.

We have also identified a number of barriers to people with learning disabilities accessing health services, including:

Discriminatory attitudes among staff

- In one recent case A, a man with Down’s syndrome, became unconscious during the night and was admitted to the local accident and emergency department. A was diagnosed with pneumonia. The doctor advised his support worker that normally a person with such acute symptoms would be put on a ventilator, but that “people with Down’s syndrome don’t do well on the machine”. The support worker challenged the doctor, asking him to put this advice in writing. The doctor then backed down and A was put on the ventilator and the man subsequently recovered. Our manager’s view is that A would probably have died if he hadn’t been put on the ventilator.
- B, a man with multiple disabilities, died last year following a stroke. Staff believed that B was very unwell and over a period of three or four months he had 37 GP appointments. The GPs were also concerned that B was seriously ill and had suffered a stroke and repeatedly tried to get him admitted to hospital. The hospital refused to admit him until a further deterioration in his health. B died in hospital a couple of weeks after being admitted.

Whilst in hospital both the NHS trust and local authority refused to provide any additional nursing care or personal support for B. Information about B’s dietary preferences was ignored and on one occasion he was administered an injection without warning, causing him considerable distress. United Response provided personal support for him in hospital for two weeks, for which the NHS trust and social services have both refused to reimburse us. (This support was beyond the

terms of our contract and not funded. We provided it for him because we did not want to leave him unsupported when he was critically ill). B's relatives do not wish to make a formal complaint as they want to put the matter to rest.

- A disabled woman, C, has been repeatedly admitted to hospital suffering abdominal pain. Even though nursing staff have identified a bowel blockage she has not been referred to the gastroenterologist for treatment and the treatments prescribed have been ineffective. The problem is painful and unpleasant for her. United Response staff believe C is not being taken seriously because of her learning disability.

Accessing mental health services

We have several instances of people with learning disabilities having difficulties accessing mental health services. There is a tendency for mental health professionals to attribute of all a person's symptoms to their learning disability, rather than accurately diagnosing mental illness.

- A young woman, D, experiencing severe anxiety and auditory hallucinations was repeatedly refused treatment by psychiatric services. On several occasions the police and fire brigade were involved because she climbed onto the roof of the building where she lived. On another occasion D tried to escape from a moving car on the motorway, ran off into the fields and was finally picked up after a search involving a police helicopter. Following this incident D was finally admitted into a psychiatric unit for assessment and treatment for a period of several weeks. D's psychiatric condition has stabilised and she is now able to live in her own flat with support and receives treatment from her GP for her mental health needs.

Lack of support in hospital

Vulnerable adults in hospital may need one-to-one support from a familiar carer or supporter for the duration of their stay. Some health trusts are unwilling to provide for individual's personal support needs, expecting United Response and other care providers to pick up the tab, or leaving people vulnerable and unsupported, causing them distress and jeopardising their health.

- In one recent case a health trust refused to make any financial contribution to the £7,000 which we incurred for providing 24 hour support to E, a man with a learning disability admitted to hospital for life-saving surgery for cancer of the stomach. E became extremely distressed and exhibited very disturbed behaviour, upsetting other patients on the cancer ward through his loud crying and by shaking them and pleading with them to help him go home. Other patients became angry with E and asked for him to be moved. The usual approaches of providing hospital staff with advice and information such as a communication plan and emotional and personal support needs were inadequate to enable nurses to support E. E also repeatedly removed his feeding tube and kept getting up during the night, waking other patients. We agreed to provide 24 hour waking cover for E.

People not being properly consulted about medical treatment

We have instances of people being told by doctors that they need to have treatment, without their consent being sought and without the benefits and potential risks of treatment being adequately explained. Doctors appear to be making assumptions about people's (lack of) capacity to consent, based on stereotyped judgments rather than an individual assent as required under the Mental Capacity Act.

Communication issues

Generally, we find people receive a good service from their local GP, especially where they have had the opportunity to get to know each other over a number of years. Difficulties most commonly arise in relation to emergency treatment, especially for people with limited or no verbal communication.

2. EMPLOYMENT

People with learning disabilities are at much greater risk of being unemployed/economically inactive than non-disabled people. According to a major national surveyⁱ of people with LDs only one in six (17%) say they have a paid job. 65% of those who are economically inactive say they would like to have a job. The White Paper *Valuing People* suggests a much lower estimate of those in work, at less than 10%.

Many people we support would like to be able to work but are unable to access employment for a variety of reasons. These include:

Lack of support to look for work and apply for jobs

Many people have aspirations to work in particular fields, or just to have a job, but need support to attend Job Centres, look for jobs and make applications.

Insufficient places in supported employment appropriate for people with learning disabilities

Generally, whilst some excellent local services do exist, provision of employment support for people with learning disabilities is patchy and very limited in many areas. Our supported employment services could support many more individuals if additional resources were available. We believe that higher priority should be given by government and local authorities to facilitating employment for people with learning disabilities. Employment services need to be person-centred and adapted to the particular needs of people with learning disabilities, rather than attempting to fit people to what is available.

Some people we support have worked in the past but have stopped working for a variety of reasons, such as because they developed health conditions or because the office they were working in closed. They then become detached from the labour market. Others have never worked. We have several examples of people in their forties who had never worked before but who with the right support have been able to successfully enter paid employment.

Employers' attitudes

United Response's experience is that given the right support many people with learning disabilities are able to do paid work, often requiring relatively minor adjustments by employers. We find that positive employer attitudes, as well as the availability of continuing support, are key to successful employment. Relatively minor adjustments are often enough to enable people with learning disabilities to enter work and make a genuine economic contribution. Employers often report that employees with learning disabilities make an equal or greater contribution to their non-disabled colleagues. We also have positive examples of people with learning disabilities offering training to non-disabled people.

3. EDUCATION

Many people we support attend college courses, studying both vocational and non-vocational courses. The increasing requirement that colleges teach to NVQ level poses a severe barrier to people with very limited literacy for whom this may be unattainable.

Some people we support say they would like to be able to attend college, for example to improve their literacy skills. They have identified a number of barriers including lack of support to find out about suitable college placements and to apply to college, and for their support workers to attend with them.

Colleges generally provide their own support for students with special needs and they have specific budgets for this purpose. However this may not meet the needs of students with a learning disability who may need familiar personal support to access educational services. We have instances of people who have had to leave courses because they have not been allowed to attend with their usual support worker.

4. RELATIONSHIPS

Again, insufficient hours of support means that some people with learning disabilities struggle to maintain relationships with family, partner or friends, or see them far less frequently than they would like. For example, one woman says she rarely sees her boyfriend because she needs support to telephone him and he himself has no support (despite his learning disability).

5. COMMUNITY

People with learning disabilities often face barriers to being part of their local community and may not be perceived as individuals with anything to offer others. Attempts at building community participation often rely on individual service providers developing innovative practices which are by and large not funded by local authorities. There is a lack of strategic planning to support community building for people with learning disabilities, despite the fact that building community around vulnerable adults is the most effective way to keep them safe from harm or abuse and to break stigma and isolation. In some instances the drive to independent living can result in an "independent" situation for a person who is then isolated and lonely and may develop mental health needs as a result.

The increasing tendency of local authorities only to provide services for people whose needs are classed as “substantial and critical”, highlighted by the Commission for Social Care Inspection (CSCI), means that that adults with learning disabilities with mild and moderate needs may receive no formal support and may experience neglect and isolation as a result.

6. HOUSING

Shortages in the supply of social housing, especially for individuals, mean that people with learning disabilities often seek housing in the private rented sector. However, many private landlords refuse to accept people on welfare benefits because of concerns to exclude “undesirables” and perceptions about unreliable rent payments. This has the effect of indirectly discriminating against people with learning disabilities who are generally in receipt of benefits, including those moving out of group accommodation, and considerably constrains the housing options open to them.

7. HOLIDAYS AND LEISURE PURSUITS

The relatively limited number of hours of support which many people receive means that they are constrained in their choices, limiting their ability to participate in everyday leisure activities such as going swimming. One man said he would like to be able to go to watch football matches but his local team only provided free tickets to wheelchair users. He was unable to afford the cost of a ticket for himself and for his support worker to attend.

Many people have not been on holiday for years because of the cost involved in paying for a support worker to go with them. One man would like to be able to have a weekend away at a local Butlin’s seaside resort but this would cost him around £1,000 including paying for his support worker to attend, which he is unable to afford.

People with mild to moderate learning disabilities often receive only a few hours support a week under the Supporting People Grant, which provides for housing-related support needs such as help with cleaning, cooking and managing their personal finances. Particularly as increasing numbers of local authorities are imposing high thresholds for accessing care, they may receive no additional support from social services to participate in the kinds of activities that non-disabled people take for granted, such as going to work, attending leisure activities and keeping in touch with family and friends. As social services continue to raise their thresholds of entitlement to care, so that in many areas only those whose needs are “critical and substantial” are supported, this situation is likely to worsen, with people with learning disabilities increasingly facing social isolation and exclusion, in contravention of Valuing People principles.

Can you hear us?

I am also enclosing a copy of a DVD entitled *Can you hear us?* made by a group of people with learning disabilities with professional support which examines people’s experiences of discrimination through a series of real-life dramas. Some of the key messages from the DVD are:

- People have the right to be listened to (but are all too often ignored).
- People should have the right to have a relationship and to get married if they choose.
- People should have the right to choose where they live.
- People should be allowed to make their own decisions about their lives.
- Not being able to speak doesn’t mean that you have nothing to say.
- Everyone should have the opportunity to do things they enjoy.

30 July 2007

REFERENCES

ⁱ E Emerson, S Malam, I Davies and K Spencer (2005) *Adults with Learning Difficulties in England 2003/4*, National Statistics/NHS Health and Social Care Information Centre.

The survey was carried out by a research team BMRB Social Research, Institute for Health Research at Lancaster University and Central England People First, and involved interviews with 2,898 people with learning difficulties aged 16 and over. In three-quarter of interviews a support person was present.

Memorandum by Speaking Up For Yourself In Brent

Speaking Up For Yourself In Brent is a speaking up group of people with learning difficulties in Brent. The group has been going since the 1990s and has spoken up on a lot of issues, from bullying, moving house, education and jobs, Iraq war and the introduction of identity cards. Speaking Up For Yourself in Brent wants the Joint Committee on Human Rights to know that people with learning difficulties are still not getting their human rights respected by services funded by the Government and local authorities. This is a snapshot of some of the appalling treatment which some of use have experienced within one hour session. Now if many of us enjoyed the same freedom of movement as their non-disabled peers, in terms of arranging longer meetings together with the availability of accessible transport and staff support then imagine the amount of human rights abuses evidence we would be able to give to the committee.

“I live in a house with two other people, it is a group home. Someone made a complaint about the manager, I got the blame. They excluded me, said things like ‘go to your room and eat your breakfast’. There are house rules and special meal times. Breakfast is at 8.00 am, lunch is at 12.00 noon, 4.00 pm tea and dinner at 6.00 pm. If I go out they don’t like it, I miss the meals. I have to starve myself till the next morning. I sat in my room feeling hungry. Call this my home? It’s more like a prison”. Says S

“Staff go into my flat to check the bathroom to see if it is clean. I have cleaned it, they said it was dirty, do it again. I am made to clean my cupboards again, it made me late to go to my mums. If I don’t clean the room properly I wouldn’t be able to go to my mums. They said that would ring my mum and tell her. I have an ABC chart, it is a behavioural chart. If I shout at them they write it down. They write down what happens. If I say anything to them they write it down. Things like winding up staff or being aggressive. When I say morning to a staff member she doesn’t answer, she is in a bad mood sometimes. They can be bossy at times, say things like ‘get on with it’”. Says E

“They want me to bath twice a day, the water is often cold I clean my room, when I get home they’ve done it all again. Why should I do it if they want to do it again? I have a street door key but I can’t lock my room door. They go in without knocking like a bull in a china shop”. Says S

“It was my birthday. I went out. I am staying as an informal patient in Pine Ward in the local hospital at the moment. When I got back they had put me in another room, my stuff went missing. I haven’t got my clothes back yet. They lost them and other things. My social worker and support worker put my there. I live in a bedsit. I want a flat with a garden, it’s time to move on. I want a job one day a week, I would like to be a DJ or a car mechanic, my DJ name is DJ Bleach”. Says N

“I have bad nerves. I was put on a ward with people on drugs, naughty people. Mum’s doctor did that. Patients threw milk over me. I was in Kingsbury hospital for over two years. It was not very nice”. Says S

“I live by myself. My older brother wants me to go to a place called Brookdale for Autistic people. It’s miles away. He suggested it would be a nice place for me to go. He didn’t talk to me about it, he emailed my psychologist about it. He didn’t mention it to me. I feel things are being done behind my back. I think it’s a therapeutic place. I am happy where I live, I think I am a cut above living in a residential home. I got angry with mum about it because she didn’t say anything to me in case I flare up. I get paranoid about my mum. I’m used to it around here, I have everything I need. I’ve been in my flat for six years. I am coping well”. Says S

“I had two children. I don’t see them often. I gave them a good home, they are grown up now. They didn’t live with me, they went with a social worker, they were small. I was upset when they went away. They cut me open here so I couldn’t have any more children. I was 15”. Says B (This woman was sterilised)

Other general things came up in these discussions as well. Most of use are expected to stay at home during the weekend because there is not enough staff to help us go out and do the things that are of interest to us, including visiting friends and family. It is hard to do something else on the spur of the moment or indeed with notice because there are not enough staff to support us to follow our own individual interests and lives. We see this as having our liberty deprived by services. Sometimes, some of us are punished and stopped from going out if we answer back, talk too much or our rooms are not tidy enough. Again we see this as restricting our liberty which would not be the case for our non-disabled peers.

Is the Human Rights Act working for disabled people with learning difficulties?

Like with People First, Speaking Up For Yourself In Brent welcomes the Human Rights Act and the associated European Convention Human Rights Articles. However, we do not think the HRA is working as it should be for disabled people with learning difficulties for a number of reasons:

Knowing about human rights

People First said whilst giving their spoken evidence that people with learning difficulties need more accessible information about their human rights. Whilst this is true, but information in itself will not automatically means that disabled people with learning difficulties will have the strength

to stand up for their rights. Many of us have grown up accepting limitations being imposed upon us by parents, schools and service providers and therefore not see them as possible human rights violations.

Enforcement of human rights

The courts only need to take into account ECHR rulings when considering human rights breaches. It is therefore up to each judge to determine to what extent they will consider disabled people's human rights violations. This means that there would be no consistency with ensuring that disabled people with learning difficulties' human rights are consistently upheld. As bringing cases are so problematic and difficult, many human rights violations are not being brought before the courts and holding public bodies to account. As my of our lives are dominated by public sector services either provided by directly or through a voluntary or private sector organisation, we are not going to get the support needed to get the Human Rights Act tested more often. Whilst advocates can support, their knowledge, experience and time is limited to assist appropriate claims to be brought before the courts to hear.

ECHR Article 3—No one shall be subjected to torture or to inhuman or degrading treatment or punishment

There is a clear breach of Article 3 where disabled people are being forced to go without food if they do not come home in time for meal times. No-one should be forced to starve because of any inflexibility within the care regime. Further, the use of punishments which would not be used for non-disabled people should also be highlighted as human rights violations. After all, how many non-disabled people would be punished (not allowed out) if they left a mortgaged or rented home untidy?

ECHR Article 8—the right to respect for private and family life, home and correspondence

This is probably the right which has the greatest impact upon disabled people's lives. This is because many of the complaints we hear about are to do with privacy, right to form relationships and have children and so on. In *A & B v East Sussex County Council*, Munby J described this as including a right to human dignity. It is a right to respect for a person's fundamental humanity; their physical and bodily integrity; personal identity and lifestyle; and importantly—the right to develop a private sphere both alone and in conjunction with others. This can be used to support a disabled person's views about the nature of, and the way in which, community care and other services are provided. However, it does not require the state to take extensive steps to support an individual's right to self-determination (*Pretty v UK*). A balance must be struck between providing disabled people's assistance (equipment) and the needs of the population (*Sentges v Netherlands 2003*). This is unhelpful as it leads to an increasing gap between the personal autonomy experienced between disabled and on-disabled people. We feel it is essential that the law must be changed to incorporate Human Rights with a greater emphasis on the expectation to ensure everyone's human rights are upheld equally which they are currently not.

ECHR Article 5—Right to liberty and security

The State can only detain or deprive an individual of his or her freedom for a particular purpose. Article 5(1)(e) provides for detention of "persons of unsound mind", which includes people with learning difficulties. The deprivation of liberty must also be necessary, proportionate and the appropriate for the purpose for which is permitted. And it is important to note that deprivation of liberty is not limited to "locking" up someone against his/her wishes in an institution. The courts have attempted to go further to explain what would constitute "deprivation of liberty" under Article 5.

“. . . The distinction between a deprivation of, and restriction upon, liberty is merely one of degree or intensity and not one of nature or substance. There must be particular factors which provide the "degree" and "intensity" to render the situation one of deprivation of liberty (rather than merely a restriction on liberty)". (*HL v UK*)

Deprivation of liberty is not simply achieved by outright refusing someone their opportunity to leave the front door of an institution, whether that being a psychiatric hospital (*HL v UK*) or a nursing home (*HM v Switzerland*). Article 5 rights can be violated by more subtle means. In *HM v Switzerland*, judges thought that a deprivation of freedom could exist if "she (resident) was not permitted to leave the institution and go home, and that if she did, she would have been brought back to the nursing home" and similarly if healthcare professionals treating and managing the applicant (*HL - Patient*) exercised complete and effective control over his care and movements.

These two important European cases involve individuals lacking capacity. The Mental Capacity Act's Code of Practice attempted to give further guidance on what would not constitute a deprivation of liberty under Article 5 in response to the Bournemouth Gap. The Code stated:

"a patient needing accompanying to leave a facility does not itself constitute deprivation of liberty. And that restrictions which are unavoidable in a group living situation, in a residential or a group home and which apply to all residents, would be unlikely in themselves to constitute deprivation of liberty".

Besides being unaware of such legal cases which confirm this conclusion, we feel it is unhelpful and indeed detrimental as many individuals are deprived of their liberty because of how community care decisions are made. We would argue that only providing group days out to the seaside, pub

or theatre for the tenants rather than giving assistance for individuals to go where they want must be considered as a deprivation of liberty. And further, we do not accept that a deprivation of liberty does not occur when for example family members and friends can choose when they want to accompany and individual patient as stated in the Mental Capacity Act's Code of Practice. We think setting the threshold too high is treating disabled people with learning difficulties less fairly than the rest of society. The determining factors for deciding if a "deprivation of liberty" has occurred is to compare the degree of liberty when typical non-disabled people experience rather than taking a unfair pragmatic approach, eg the restrictions in group living and shared staff.

For many of us in Brent we feel the degree of control the staff have over us, whether that is just a threat, the tone of voice used, the actual rounding us up or to impose more punishments on us if we do not comply with the restrictions imposed on us amounts to effective control of our movements—deprivation of liberty as defined in *HL v UK*.

These important Human Rights cases are dealing with individuals lacking capacity, that being they are perceived as being unable to make decisions for themselves. In the UK, individuals lacking capacity have insufficient safeguards in place to protect their human rights. In addition there has been little focus on how individuals with capacity and who's mental health condition does not warrant detention) human rights can be better protected as well. There will be no legal protection under the Mental Capacity Act as individuals must lack capacity in order to be subjected to its provisions. The difficulty is that many of us have no choice because we need a degree of support, and if we do not live in these institutions which imposes some severe unnecessary restrictions on our liberty then we may not live anywhere and therefore should be considered as "deprivation of liberty". This is because technically speaking, many of us have no CHOICE regardless of whether we have or have not got "legal capacity" to make our own decisions.

The important HRA cases have focused on wholesale loss of liberty for individuals concerned. Whilst such a loss should not be underestimated, it is equally as important to acknowledge that the constant restrictions imposed on individuals' individual liberty should not be underestimated because of care regimes. We must never underestimate the distress of a restriction imposed if any of us are being prevented from participating in our favourite activities (however "unimportant" we may find them to be), even if that is just on a weekly or less frequent basis. We feel preventing a member from going to a sports centre should be treated as equally as someone else being prevented from leaving the front door for anything. This is because what gives our lives meaning is the value and pleasure we get out of being able to participate in everyday activities however frequent they are. We fear the courts, including the Court of Protection would not possibly hear such a case involving a person whose liberty is being restricted or lost because a service provider would not provide appropriate assistance like to one of us who wanted to attend a sports centre as this could be seen as being "trivial" and a waste of the judge's time.

Who is a Public Body?

Many of us depend on state funded services to support us to live in the community. These services include the funding of "staffed" homes, day, employment and educational services, discounted or free transport. If such services are being funded by the state we feel that they should be expected to comply with the Human Rights Act, contrary to the *Johnson v London Borough of Havering* House of Lords ruling. This is because many of us need support services which the state can only provide in order to have potential access and opportunities which non-disabled people take for granted.

Whilst in theory the HRA can be of major benefit for disabled people, how it is interpreted in practice has undermined its benefits both by Europe and domestic courts. This is because we feel that judiciary does not have an adequate understanding and appreciation on how "state" care can severely affect the independence that disabled people seek to have and therefore has a bearing on how such human rights are interpreted for us in mind.

UN CONVENTION ON PEOPLE WITH DISABILITIES

We welcome the UN Convention as it will for the first time ever provide an international convention on how human rights articles should be interpreted for disabled people. The UN Convention has been developed by disabled people, even though this has not necessarily included people labelled with learning difficulties. Nevertheless, the convention can serve as a very useful reference to how human rights can be interpreted for people with learning difficulties. We hope the Government will move quickly with ratifying the convention and incorporating its principles into domestic law so that disabled people's rights can be properly understood and implemented.

We recognise that promoting disabled people's human rights goes much further than their living arrangements but because of them it has been impossible to cover everything, including education, employment, and right to life and so on. In order for a culture of disabled people with learning difficulties

human rights to be respected, there is a lot of work needed to be done to make society change so that they see all human beings of equal worth and having a degree of autonomy which non-disabled people take for granted.

Simone Aspis

Speaking Up For Yourself In Brent and People First Member

Simone Aspis is a disabled women, labelled by the IQ tests as having learning difficulties. Simone was instrumental with securing civil rights and direct payments for disabled people with learning difficulties whilst being People First's Parliamentary and Campaigns Worker. Through Changing Perspectives Simone is People First's leading consultant.

**Letter from the Chairman to Michael Wills MP, Human Rights Minister,
Ministry of Justice**

The Joint Committee on Human Rights is currently conducting an inquiry on Human Rights and Adults with Learning Disabilities.

When the Human Rights Act was launched, a number of groups, including the British Institute of Learning Disabilities and Values into Action published their own guides to the Act. Earlier in the year, your Department helpfully provided our Committee with a number of copies of its Easy Read Guide to the HRA. Although the Ministry of Justice publishes its guide to the HRA in an Easy Read format.²⁰⁴ This format is not available to download from the Ministry of Justice website. Instead, people with learning disabilities are invited to call and ask for copies.

Some of our Committee members have asked for further information on the Easy Read Guide and I would be grateful if you could provide me with some more information:

- Who was responsible for the preparation of the Easy Read Guide, including checking its accessibility and accuracy?
- Are the Government satisfied that that this format presents an accurate Guide to the operation of the HRA? If so, why?
- Why is the Easy Read Guide to the HRA only available on request from the Ministry of Justice, rather than as a downloadable document?
- What work, if any, have the Ministry of Justice (or its predecessor, the Department of Constitutional Affairs) done to introduce the HRA to people with learning disabilities and their supporters?
- Does the Ministry of Justice have any role in ensuring that the work of the Department of Health, the Officer for Disability Issues (DWP) or any other Government Department on the implementation of *Valuing People* is compatible with the human rights obligations of the United Kingdom, in respect of people with learning disabilities?

We will hear from the Minister for Care Services and the Minister for Disability Issues in the last oral evidence session in this inquiry on 12 November 2007. It would help inform our inquiry if you could ensure that your response is received before that date.

If you have any questions about this inquiry, or would like further information about submitting evidence, please contact our Committee Specialist.

29 October 2007

Letter from the Chairman to the Rt Hon Jacqui Smith MP, Home Secretary

The Joint Committee on Human Rights is currently conducting an inquiry on Human Rights and Adults with Learning Disabilities. Although our initial terms of reference made no specific reference to criminal justice issues, we have received a number of submissions which directly refer to the treatment of people with learning disabilities, whether as victims of crime, accused or defendants or as prisoners, by the criminal justice system. Witnesses have raised particular concerns about:

PEOPLE WITH LEARNING DISABILITIES AS VICTIMS OF CRIME

- Failure to identify people with learning disabilities/offer support.
- Investigation of crimes against people with learning disabilities in residential or other settings (eg care homes or hospitals).
- Crimes against people with learning disabilities as an adult protection issue.

²⁰⁴ Copies have been requested and will be circulated when they are available.

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- The Government review of “No Secrets”: involvement of criminal justice agencies.
 - Theft and people with learning disabilities.
 - Responses of criminal justice agencies to disability hate crime.
 - Prosecution decisions in cases involving victims or witnesses with a learning disability.
 - Accessibility: Supporting people with learning disabilities to report crime.
 - Accessibility: Assistance during interview and trial.
 - Accessibility: Special Measures and the Youth Justice and Criminal Evidence Act 1994.
 - Use of Intermediaries.
 - Training for police, lawyers and judges in vulnerability and learning disability.
 - Relationships between local community learning disability services and local criminal justice agencies.

PEOPLE WITH LEARNING DISABILITIES AS SUSPECTS OR AS DEFENDANTS

- Failure to identify people with learning disabilities and offer specialised support.
- Access to justice and people with learning disabilities (eg ability to understand arrest, questioning or trial and to engage effectively with the process).
- Training for police, lawyers and judges in vulnerability and learning disability.
- Accessible information on the criminal justice system.
- Extension of special measures to suspects and defendants.
- Compliance with PACE1984 and people with Learning Disabilities.
- Access to well-trained “Appropriate Adults”.

PEOPLE WITH LEARNING DISABILITIES AS PRISONERS

- Failure to identify people with learning disabilities in prisons.
- Should people with learning disabilities serve custodial sentences?
- Access to community based sentences for people with learning disabilities.
- Recent research by the Prison Reform Trust, “No one knows” (2007).
- Accessible information in prison.
- Accessing support in prison.
- Relationships between prisoners with learning disabilities and their families (ie distance from support and difficulties securing visits through visiting orders).
- Ability of prisoners with learning disabilities to engage with rehabilitation programmes; and to access early release.
- Access to appropriate probation services for people with learning disabilities.

Although the deadline for evidence in our inquiry passed sometime ago, I would like to invite you to submit written evidence on these issues in order that our consideration of the evidence in this area may take into account your views. I also extend this invitation to the Ministry of Justice, the Crown Prosecution Service, the Association of Chief Police Officers and the Metropolitan Police Service (to whom I have copied this letter).

We will hear from the Minister for Care Services and the Minister for Disability Issues in the last oral evidence session in this inquiry on 12 November 2007. It would help inform our inquiry if you could ensure that any written evidence you intend to submit is received before that date.

If you have any questions about this inquiry, or would like further information about submitting evidence, please contact our Committee Specialist.

29 October 2007

Letter from the Chairman to Anne McGuire MP, Minister for Disabled People, Department for Work and Pensions

I am pleased to note that UK has recently signed the new United Nations Convention on the Rights of Persons with Disabilities. My Committee recognises the potential of the Convention to ensure the greater protection of the rights of people with disabilities living in the UK.

The Committee is encouraged by the Minister's recent statement (29 March 2007) that the UK's legislation, policies and practices are being checked for compatibility with the Convention and that, before ratification, the Convention, along with an Explanatory Memorandum, will be laid before both Houses of Parliament and sent to my Committee for its consideration. I should be grateful for an indication from you of the likely timescale for this process and what, if any, changes you expect will need to be made before the Convention can be ratified.

I also draw your attention to the Optional Protocol to the Convention, which the UK has not signed. As you are aware, this Protocol creates the right for individuals to complain directly to the Committee on the Rights of Persons with Disabilities about alleged breaches of their rights under the Convention. I would be grateful if you could let me know whether the Government intends to sign the Optional Protocol to the Convention and, if it does not propose to do so, explain its reasons for this.

Within central Government, domestic human rights policy is the responsibility of the Department for Constitutional Affairs. Given this, and the breadth of issues covered by the Convention, it was therefore surprising to see that the Department for Work and Pensions has taken the lead in Government on this. It is clearly important that there should be co-ordination across Whitehall. I would be grateful if you could explain why your department, rather than the Department for Constitutional Affairs, has had lead responsibility for the Convention. I would also welcome details of the arrangements for co-ordinating across Government on the many policy areas that the Convention touches.

I should be grateful for your response by Monday, 4 June 2007.

24 April 2007

Letter from Anne McGuire MP, Minister for Disabled People, Department for Work and Pensions

Thank you for your letter of 24 April 2007 welcoming the UK's signing of the UN Convention on the Rights of Disabled People on 30 March.

As you may imagine, I was honoured to have been able to represent the UK at the signature ceremony and like you I recognise the importance of the Convention in the lives of the estimated 650 million disabled people worldwide. Securing human rights for disabled people on the same basis as already enjoyed by non-disabled people is a significant and signal achievement for the international community. I am proud of the role that the UK has been able to play in this.

Your letter raised a number of questions which I will answer in the order given.

On the ratification timetable, it is not possible to be precise at this stage as to how long it will take the UK to ratify the Convention, though we would not have signed if we anticipated undue delay. We are still in the process of checking compatibility between the Convention's obligations and UK law, practice, policy and procedure. We need to do a thorough job. It is therefore still too early to say whether we need to change any legislation.

Imprecision about the timetable also arises because this is the first human rights treaty which organisations like the European Community share "competence" with member states. As a result there is a need to coordinate action with the Community, as represented by the European Commission, and with other member states; particularly around the Commission's eventual proposal for conclusion of the Convention. So the timetable is not within our control.

You asked about the Optional Protocol. The Government's position remains unchanged since the publication of the Interdepartmental Review of International Human Rights Instruments in July 2004. The UN monitoring committees which receive individual petitions from citizens are not courts, and cannot award damages, or produce a legal ruling on the meaning of the law. Because of that, the government believes the practical value to the individual citizen of the UK remains unclear. However, in 2004, we decided to accept the Optional Protocol to the Convention on the Elimination of all forms of Discrimination Against Women (the CEDAW OP), so we could consider on a more empirical basis the merits of the right of individual petition under other UN treaties. We propose to review this experiment in the autumn of this year. Clearly, I will need to consider carefully the findings of that review but, at this moment, I do not rule out the possibility of acceding to the Optional Protocol to the Disability Convention some time in the future.

Finally you ask why my Department took the lead on this Convention and about cross-Whitehall coordination of activity related to it. The Department for Work and Pensions (and its predecessor Departments) has led on cross Government policy on disability for a number of years. It is where "Whitehall" responsibility for cross-Government disability issues, including disability discrimination, lies under the established machinery of Government. The work is located within the Office for Disability Issues (ODI) and in my view the particular nature of disability as an issue means that this is the right place for the work.

The ODI has worked closely with the Foreign and Commonwealth Office, which leads on international human rights matters, and the Ministry of Justice in the whole process of negotiating the Convention. But it has also worked closely with all Government Departments and the administrations in Wales, Scotland and Northern Ireland.

Those arrangements remain in place with contact generally being at official level. You may judge their success by the fact that the UK was in the first group of nations to sign the Convention and on the first day it opened for signature. But these arrangements may need to be strengthened for the ratification process and this is something my officials are considering. We are also trying to engage more with the European Commission with a view to moving matters along at a pace which fits with our progress towards ratification.

I hope this is helpful to the Committee's deliberations.

Anne McGuire MP
Minister for Disabled People

17 May 2007

**Memorandum from Anne McGuire MP, Minister for Disabled People,
Department for Work and Pensions**

Thank you for inviting me to submit a brief memorandum of evidence, on the United Nations Convention on Disability Rights, for your inquiry into the Rights of Disabled people and its potential to promote the human rights of adults with a learning disability.

The attached Memorandum sets out the background to the Convention and our view of how it will influence the development of a human rights culture in the formulation and delivery of disability policy—together with some examples which relate primarily but not exclusively to my own Department's policy interests.

I hope the Memorandum is helpful to the Committee and I look forward to giving oral evidence to the Committee and to answering its questions.

Anne McGuire MP
Minister for Disabled People

SUMMARY

1. This memorandum is provided by the Department for Work and Pensions (Office for Disability Issues) in response to the request from the Committee for evidence of the potential of the United Nations Convention on the Rights of Persons with Disabilities ("the Convention") to promote the rights of adults with learning disabilities.

2. The Department tends to refer to the Convention as the United Nations Convention on the Rights of Disabled People—reflecting the preferred use of language in this country to describe disabled people.

BACKGROUND

3. The Convention (including the Optional Protocol) was adopted by the General Assembly of the United Nations on 13 December 2006. It was opened for signature on 30 March 2007 at the Headquarters of the United Nations in New York. The United Kingdom signed the Convention on that day, but is not a signatory to the Optional Protocol.

WHAT THE CONVENTION IS DESIGNED TO DO

4. The Convention aims to ensure that the estimated 650 million disabled people worldwide enjoy human rights on an equal basis with others. It is not designed to create new human rights. Rather it sets out to express in terms relevant to disabled people the rights already set out in the existing human rights instruments of the United Nations. It forms part of the series of "thematic" UN Conventions such as the Convention on the Rights of the Child and the Convention on the Elimination of All forms of Discrimination against Women.

 COMING INTO FORCE

5. As of 17 October 2007, there have been 117 signatories to the Convention (including signature by the European Commission on behalf of the European Community), 67 signatories to the Optional Protocol, seven ratifications of the Convention and three ratifications of the Optional Protocol. The Convention has not yet entered into force. It will enter into general force 30 days after 20 countries have ratified or acceded to it. Provided it is in general force it enters into force for any particular State 30 days after that State has ratified or acceded to it (Article 45 of the Convention refers).

GENERAL APPLICATION IN THE UNITED KINGDOM

6. The United Kingdom intends to ratify the Convention without undue delay, although at this stage it is not possible to provide a timetable. The Government will lay the Convention before Parliament under the Ponsonby Rule when it is satisfied that the UK's legislation, policies, practices and procedures are compatible with the Convention's obligations. The exercise within the UK's Governments of assuring compatibility is not yet complete but at this stage the Government believes that the UK is already largely compliant with the obligations in the Convention.

7. Once in force the Convention is, expected to have an important persuasive effect on the domestic promotion of the human rights of disabled people. It will also provide the standard by which the international community may judge the UK's commitment to and delivery of human rights for disabled people.

8. As with other similar international human rights instruments, the Convention, following ratification, will not form part of the UK's domestic law and will therefore not be directly justiciable. This contrasts with the European Convention on Human Rights which is justiciable through the UK's own Courts following the Human Rights Act 1998. The Convention may, however, be referred to by the domestic Courts (and the European Court of Human Rights in Strasbourg) as an aid to interpretation. As such, it might provide a means, for the future, for resolving the complex human rights issues where a balance of rights and interests are at stake.

9. Although at an early stage of development, the Government has started the process of setting up the national monitoring and implementation arrangements, with its independent element, required by Article 33 of the Convention which will have to be in place before ratification. The Convention also imposes robust reporting arrangements set out primarily in Articles 35 and 36 of the Convention.

10. Traditionally the Government has not favoured accession to Optional Protocols that provide an individual right of petition to the appropriate UN Committee. The reasons for this are well known to the Committee and are not elaborated further here. However in the light of the evaluation of the UK's accession to the Optional Protocol to the Convention on the Elimination of All Forms of Discrimination against Women the Government will consider whether or not to accede to the Optional Protocol to the Disability Convention as part of the ratification process.

11. The Government's aim of achieving disability equality and full participation in society for disabled people within a generation (by 2025) as described in the Life Chances report, of which the Committee is aware, is fully consistent with the Convention's aim of protecting disabled people's human rights. The Government is firmly committed to the creation and development of a human rights culture in the public sector. The Convention will provide an additional spur to the mainstreaming of disability policy making and delivery in this human rights culture context.

APPLICATION OF THE CONVENTION TO ADULTS WITH A LEARNING DISABILITY

12. All of the rights set out in the Convention apply to adults with learning disabilities. The table below sets out those Articles of the Convention which appear to the Department as being of particular relevance to the Committee's enquiry.

<i>Article</i>	<i>Description</i>
9	Accessibility
19	Living independently and being included in the community
23	Respect for home and the family
24	Education
25	Health
26	Habilitation and rehabilitation
28	Adequate standard of living and social protection
29	Participation in political and public life
30	Participation in cultural life, recreation, leisure and sport
49	Accessible format

13. The Annex to this Memorandum gives examples of how existing UK practice supports the possible application of the Convention to adults with learning disabilities, largely but not exclusively from a Departmental perspective.

31 October 2007

Annex

EXAMPLES

ARTICLES 24 AND 27 (EDUCATION, WORK AND EMPLOYMENT)

Article 27 prohibits discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and healthy working conditions.

The law of the United Kingdom already provides substantial protection against discrimination for a reason related to disability. The Disability Discrimination Act 1995, as amended (DDA) makes it unlawful for an employer not to discriminate against, or harass, a disabled person who works for them, or who applies for a job with them. An employer must not discriminate by treating the disabled person less favourably because he or she is disabled (this is direct discrimination) or for a reason related to their disability (referred to as disability-related discrimination). Less favourable treatment might be, for example, refusing to take on, train or promote a learning disabled person, or not allowing them access to work-related facilities like a canteen or social club. The DDA applies to all aspects of employment from recruitment to termination.

An employer also discriminates against a disabled person by refusing to make a “reasonable adjustment” to certain aspects to a job or to a physical feature of premises they occupy, where the disabled person would otherwise be at a substantial disadvantage compared to a non-disabled person. Reasonable adjustments must also be considered during the recruitment process.

A reasonable adjustment could be any change, minor or major, to any aspect of a job, which will enable a disabled person to take or keep a job.

Examples of reasonable adjustments for learning disabled people in employment could include providing a mentor or assistant to the disabled person or reallocating some non-essential duties of a job. Reasonable adjustments to the recruitment process might include making application forms available in an accessible format like Easy Read, or allowing additional time at interview.

CURRENT GOVERNMENT PROJECT—GETTING A LIFE

Helping people with a learning disability make the transition from education to employment

A major barrier to people from having real choice and control over their lives is the way that different local services plan and fund services. To help address this, the Department of Health, Department for Work and Pensions (DWP), Department for Children Schools and Families (DCSF) and Department for Innovation Universities and Skills (DIUS) have established the “Getting a Life” demonstration project.

A small number of localities will join the project and explore how to bring together the funding and planning processes around:

- Special educational needs transition planning.
- Post-16 education planning and provision.
- Disability employment advice and support.
- Local authority social care assessment and support.

Raising the expectation of young people with learning disabilities, and their carers, that employment is a real option once they leave education is very important. Starting from person centred planning; the aim is to achieve an integrated assessment and decision-making process that will allow people to use public resources flexibly in a way to get the outcomes they want. The initial focus of the work will be on young people going through the transition to adult life. This transition beyond compulsory education can be a particularly difficult time for young people with learning disabilities and the quality of current transition provision varies.

We are currently developing the project and held a conference of key stakeholders in London on 17 October. The project is scheduled to begin in April 2008 and will last for four years. We will share learning from the project across England so that other parts of the country can learn and take on new ideas at an early date.

ARTICLE 28

To ensure access by disabled people and their families living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care.

Work Psychologists are employed by Jobcentre Plus districts to provide one-to-one specialist employment-assessments to help customers with complex disabilities develop strategies to overcome or circumvent their work related difficulties.

Disability Living Allowance (DLA) and Attendance Allowance (AA) provides for a non income related and tax free cash contribution towards the disability related extra costs of severely disabled people. Nearly 266,000 people with a learning disability receive DLA.

DLA/AA are flexible in that recipients can spend the money in the way that best fits their circumstances.

ARTICLE 31

States Parties to undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the Convention.

The Office for Disability Issues is a central resource for Government and disabled people by commissioning, gathering and disseminating strong, research evidence.

For example, in the last year, the ODI commissioned research to identify and review available evidence on the potential costs and benefits of investment in independent living for disabled people. This analysis was required as part of a wider programme to establish a business case for providing disabled people with more choice and control over the support they need.

ARTICLE 49

During the negotiations for the Convention the Government produced an Easy Read version so that people with a learning disability could more easily access and understand the Convention as it developed. A version to reflect the final wording of the Convention has been prepared and will shortly be placed on the ODI web site.

Memorandum from KeyRing

VISIT TO KEYRING NETWORKS IN LEWISHAM

ISSUES AFFECTING KEYRING MEMBERS

1. *Housing*

The majority of KeyRing members access social housing via Housing Associations and Local Authority Housing Departments. A very small group rent privately and an even smaller group own or part own their homes.

- There are very long waits for housing, if you are not homeless (for example living in residential care or with elderly parents) it can be difficult to meet the criteria to access housing.
- In London people are being offered bedsits only as long term permanent accommodation, if you are not working and are spending significant amounts of your day indoors, living in one room can have a major impact on your mental health and general well being.
- The confusion surrounding the rules on ordinary residence can make it very difficult for someone to move to another Local Authority, they may be eligible for housing but there is no guarantee that the new Local Authority will meet their support needs. This has affected members who wish to marry someone living in the neighbouring borough.
- The Green Paper Homes for the Future July 07 identified the significant reduction in available lettings over the past 10 years. This is having an impact on the housing estates with an increasing proportion of the community requiring additional support which is not provided and results in environments in which people do not want to live, but are unable to move from.
- The cap on mortgage interest payments under income support are making access to full or shared home ownership more difficult for people with learning disabilities as house prices increase.

2. Abuse

- Harassment and anti-social behaviour is a fact of life for many KeyRing members, impacting on their quality of life.
- Even where there is support members can find themselves with “friends” who exploit them. The risks of financial and sexual abuse increase significantly where support is minimal or absent.

3. Parenting

- Increasing numbers of people we support have children or wish to have a family; there is little support available for those families. According to the DH and DCSF Good Practice working with parents with a learning disability, 40% of parents with learning disability do not have their children living with them and 60% of mothers with a learning disability do not have their children living with them.
- Assessment of need is carried out separately by the learning disability team for the parent and the childrens team for the child. With eligibility criteria now being at substantial or critical in many Local Authorities parents are not eligible for low level preventative support which could enable them to parent effectively.

4. Access to Support

Social service departments will often only deal with people whose needs are assessed at substantial or critical:

- So people with preventative needs can't access available services.
- Members have been taken out of care management without being consulted/informed.
- Members (and KR staff) are often unable to access care management if there is a crisis (eg if there is a protection issue).

5. Poor access to health care

- Accessible information and support to access healthcare are all limited.

6. Employment

- We have found it difficult to engage with Job Centre Plus to support members into work, there is a tendency to refer members to more specialist agencies which offers more work experience than proper jobs.

Karyn Kirkpatrick
KeyRing

10 October 2007

Supplementary Memorandum from KeyRing

Further to our meeting on 17 October we have considered what action we would like to see to improve the experience of people with learning disabilities living in the community and would like to make the following recommendations:

1. Local authorities to be required to give learning disability a significant profile in their Disability Equality Schemes, for instance through requiring them to monitor learning disability and physical disability separately, specifically seeking feedback through consultation with people with learning disabilities on information and services and engaging people with learning disabilities as mystery shoppers for local authority services.
2. Training on working with people with learning disabilities (particularly in relation to communication) to be core in community-based agencies and organisations, such as housing providers, health settings, police, courts, Job Centre Plus and advice centres.
3. More accessible information in relation to a wide range of issues related to day-to-day living such as health, housing, benefits, employment, crime and safety etc.
4. The growing national agenda around healthy living ie nutrition, weight, fitness, sexual health, aging healthily, alcohol and smoking, etc also needs to be targeted at people with learning disabilities.

5. There should be one first point of contact with an organisation for anyone with communication needs. This doesn't necessarily need to be one individual; it may be one phone number to ring for all enquiries.
6. Review the points systems for prioritising housing need, to take into account the specific circumstances of people with learning disabilities.
7. Wider availability of training to develop skills for work ie basic skills like managing your time, what to wear, what happens at an interview, employers' expectations, your rights at work, etc.
8. Improve information about work and benefits. It is currently very difficult to get this information "up front", ie before someone actually gets a job, so people fear that they might be worse off when this might not actually be true.
9. Continue to develop work on Individual Budgets. This will give people real choice and control of their service provision.
10. Review the rules and cap for DSS making mortgage interest payments, to make home ownership a real possibility for more people with learning disabilities.
11. Resolve issue of "ordinary residence" and cross-authority moves (NB the attached article is a good example of how this leads to people becoming stuck in services that don't meet their needs). This could be done either by setting up a mechanism for local authorities to transfer funds from one to another, or, more radically, by stipulating that local authorities are responsible for the provision of services to people who are ordinarily resident within their boundaries.
12. Improve co-ordination of children's and adult services regarding support to parents with learning disabilities. Increase resources in this area.
13. There is already work going on regarding health inequalities and people with learning disabilities. This should include dentistry.
14. People should only be taken out of care management if this has been discussed with them first.

31 October 2007

Memorandum by the Crown Prosecution Service

THE ROLE OF THE CROWN PROSECUTION SERVICE

1. The Crown Prosecution Service (CPS) was created by the Prosecution of Offences Act 1985. It is the principal public prosecuting authority for England and Wales and is headed by the Director of Public Prosecutions (DPP), Sir Ken Macdonald. The CPS is superintended by the Attorney General.
2. The CPS is a national organisation consisting of 42 Areas. Each Area is headed by a Chief Crown Prosecutor and corresponds to a single police area, with one for London (policed by the Metropolitan and City police).
3. The DPP is responsible for issuing a Code for Crown Prosecutors (the Code) under section 10 of the Prosecution of Offences Act 1985. The Code gives guidance on the general principles to be applied by prosecutors when making decisions about prosecutions.
4. The CPS is independent of the police although prosecutors work closely with police investigators to provide advice and guidance throughout the investigative and prosecuting process. Except in the most routine cases, it is the responsibility of the prosecutor to decide whether to charge a suspect with an offence.
5. It is the duty of prosecutors to review, advise on, and prosecute cases, ensuring that all relevant evidence is put before the court and that obligations of disclosure are complied with in accordance with the Code for Crown Prosecutors.
6. The Code requires prosecutors to be fair, independent and objective. They must not let any personal views about ethnic or national origin, disability, sex, religious beliefs, political views or the sexual orientation of the suspect, victim or witness influence their decisions.
7. In reaching a decision whether to prosecute, prosecutors must follow a two stage test known as the full code test²⁰⁵.
8. The first stage of the full code test is consideration of the evidence. If the case does not pass this stage, it must not go ahead no matter how important or serious it may be. If the case does pass the evidential stage, prosecutors must move on to the second stage and consider whether a prosecution is in the public interest.

²⁰⁵ In cases where it is necessary to keep a suspect in custody but the evidence to apply the full code test is not yet available, prosecutors apply a threshold test—there must be a reasonable suspicion that the suspect has committed an offence. Once the evidence is available the full code test must be applied (Section 6 Code for Crown Prosecutors)

9. When considering the evidence, prosecutors must be satisfied there is enough evidence for a realistic prospect of conviction. This is an objective test. It means that a jury or bench of magistrates or judge hearing a case alone, properly directed in accordance with the law, is more likely than not to convict the defendant of the charge alleged. This is a separate test from the one that the criminal courts themselves must apply. A court should only convict if satisfied so that it is sure of a defendant's guilt.

10. When deciding whether there is enough evidence to prosecute, prosecutors must decide whether the evidence can be used and is reliable. In relation to reliability, the Code requires prosecutors to consider a number of factors including the accuracy or credibility of a witness and the reliability of any confession by a defendant having regard to age, intelligence or level of understanding.

11. If there is sufficient evidence for a realistic prospect of conviction, the prosecutor must go on to consider the public interest stage.

12. The Code provides that, as a general rule, a prosecution will usually take place unless there are public interest factors tending against prosecution which clearly outweigh those in favour, or it appears more appropriate in all the circumstances of a case to divert the person from prosecution. In reaching the decision the prosecutor must balance factors for and against prosecution carefully and fairly.

13. A non-exhaustive list of factors for and against prosecution is set out in the Code. Generally, the more serious the offence, the more likely it is that prosecution will be required in the public interest.

14. Amongst the relevant factors in favour of a prosecution are:

- the defendant was in a position of authority or trust;
- the victim of the offence was vulnerable;
- the offence was motivated by any form of discrimination against the victim's ethnic or national origin, disability, sex, religious beliefs, political views or sexual orientation or the suspect demonstrated hostility towards the victim based on any of those characteristics; and
- there is a marked difference between the actual or mental ages of the defendant and victim, or there is any element of corruption.

15. Amongst the relevant factors against prosecution are:

- a prosecution is likely to have a bad effect on the victim's physical or mental health, always bearing in mind the seriousness of the offence; and
- the defendant is, or was at the time of the offence, suffering from significant mental or physical ill health, unless the offence is serious or there is a real possibility that it may be repeated. The CPS, where necessary, applies the Home Office guidelines about how to deal with mentally disordered offenders. Crown prosecutors must balance the desirability of diverting a defendant who is suffering from significant mental or physical ill health with the need to safeguard the general public.

16. The prosecutor acts for the public at large, not the victim alone. Decisions as to whether prosecution should take place must be made by the prosecutor alone taking into account all the circumstances of the case. In doing this, prosecutors should always take into account the consequences for the victim of whether or not to prosecute and any views expressed by the victim or victim's family.

17. In addition to the Code for Crown Prosecutors, the CPS has responsibilities under the Code of Practice for Victims of Crime (Victim's Code). This was introduced in April 2006 and sets out the service responsibilities for criminal justice agencies. It is overseen by the Parliamentary Ombudsman.

18. Under the Victim's Code, the CPS will:

- tell victims if they decide not to charge someone in relation to the victim's case within one day if victims are receiving the enhanced service or within five days for other victims;
- tell victims if they decide to drop or alter the charges after someone has been charged within one day if victims are receiving the enhanced service or within five days for other victims;
- offer to meet with victims to discuss their decisions, if the victim's case involves a death caused by criminal conduct, child abuse, sexual offences, racially and religiously aggravated offences or offences with a homophobic or transphobic element;
- ensure that someone from the CPS is introduced to victims at court and answers questions from victims;
- pay victims' expenses within ten days of receiving victims' expenses claim forms; and
- answer any detailed questions that victims have about the sentence given.

19. In addition, the CPS complies with the Prosecutor's Pledge (issued in October 2005).

20. Under the Prosecutor's Pledge, the CPS will:

- take into account the impact on the victim or their family when making a charging decision;
- inform the victim where the charge is withdrawn, discontinued or substantially altered; where practical, seek a victim's view or that of the family when considering the acceptability of a plea;

-
- address the specific needs of a victim and where justified seek to protect their identity by making an appropriate application to the court;
 - assist victims at court to refresh their memory from their written or video statement and answer their questions on court procedure and processes;
 - promote and encourage two way communications between victim and prosecutor at court;
 - protect victims from unwarranted or irrelevant attacks on their character and may seek the courts intervention where cross examination is considered to be inappropriate or oppressive;
 - on conviction, robustly challenge defence mitigation which is derogatory to a victims character;
 - on conviction, apply for appropriate order for compensation, restitution or future protection of the victim;
 - keep victims informed of the progress of any appeal, and explain the effect of the courts judgement; and
 - where a case is the subject of an appeal to the Court of Appeal (Criminal) Division, the prosecutor will ensure that the victim or victim’s family are advised of the hearing and that the grounds on which the appeal is made and the effect of the courts judgment are properly explained.

SPECIFIC ISSUES RAISED BY THE JOINT COMMITTEE ON HUMAN RIGHTS

21. Our response sets out each issue separately, with an initial summary of policy and procedure, before moving on to deal with those specific questions that are relevant to the work of the CPS.

People with learning disabilities as victims of crime

Summary of CPS role

22. It is important to recognise from the outset that every victim or witness has individual requirements and the service provided to the victim or witness should be tailored to fit those requirements. Each case should be considered according to individual needs.

23. This requires the police and prosecutors to be aware of all relevant issues when considering how best to support victims and witnesses through the court process so that they can give their best evidence. Notwithstanding the need to consider each witness’s needs on an individual basis, witnesses who are deemed vulnerable because of a learning disability or mental disorder are more likely to require greater support through the process than other witnesses.

24. The first point at which support should be considered is when the prosecutor decides on charge. The prosecutor will need to consider whether there is sufficient evidence for a realistic prospect of conviction, and therefore, charge.

25. When doing this, the prosecutor will have to have regard to all the circumstances of the case and all the evidence available. In addition, in any case, the prosecutor must consider the reliability of the evidence that the victim can provide and, if the evidence is reliable, the best means of ensuring that the victim can give his/her best evidence in court.

26. While every case will differ, victims (and other witnesses) with learning disabilities may require assistance in communicating their evidence in court. They may find the court intimidating or threatening. Depending on the circumstances of the case they may fear seeing the defendant again. Additionally, there may be concerns as to the effect that giving evidence will have on the subsequent well-being of the victim.

27. Processes are in place to assist the prosecutor in making this decision. Information pertaining to a particular witness’s needs should be set out by the police on the reverse of the statement, using a structured process, with a set of specific questions. This process is intended to ensure that the officer taking the statement establishes whether the witness has learning difficulties and /or needs support.

28. The prosecutor should discuss the contents of the form with the officer in the case when deciding what support, if any, is required for the witness. In the case of vulnerable witnesses (witnesses with a learning disability or mental disorder will normally come within the formal legal definition of “vulnerable”) this should include consideration of which special measures might best assist the witness to give their best evidence²⁰⁶.

29. In such cases prosecutors should hold an early special measures meeting with the police officer in the case in order to decide on which special measures, if any, are appropriate. With the advent of face to face contact between the police and the prosecutor in order to decide on charge, this meeting can usually be subsumed into the charging meeting.

30. The Youth Justice and Criminal Evidence Act 1999 (“YJCEA”) introduced a number of special measures designed to assist vulnerable and intimidated witnesses to give their best evidence in court.

²⁰⁶ Section 7.8 of the Code of Practice for Victims of Crime states that the CPS must have systems in place to allow for special measures applications to be considered for potentially vulnerable or intimidated witnesses.

31. The relevant provisions are set out at sections 16–33 of the YJCEA. Eligibility criteria are set out at sections 16–17, special measures are set out at sections 23–30.

32. Section 16 deals with witnesses who are vulnerable because of their age, mental or physical capacity. Section 17 deals with intimidated witnesses.

33. Section 16 provides that special measures may be provided to: a person under the age of 17 at the time of the hearing; a person suffering from a mental disorder within the meaning of the Mental Health Act 1983; a person who has significant impairment of intelligence and social functioning; a person who has a physical disability or is suffering from a physical disorder.

34. The special measures available are set out at sections 23–30: screening the witness from the accused (previously a common law provision); evidence by live TV link; evidence given in private; removal of wigs and gowns; video-recorded evidence in chief; video-recorded cross examination or re-examination; examination of a witness through an intermediary; aids to communication.

35. Not all the special measures are in force for all witnesses. Video recorded evidence in chief is only available for intimidated witnesses in serious sexual offences in the Crown Court and video recorded cross-examination has not been introduced at all, (and may never be) due to considerable practical limitations.

36. It is important to note that, with the general exception of child witnesses, special measures are not automatically available to eligible witnesses. Once it has been established that the witness is, in principle, eligible for a special measure, the court must satisfy itself that the special measure available would be likely to improve the quality of the witness's evidence. In determining this, the judge must consider all the circumstances of the case including the witness's views and whether the measure, or measures, might tend to inhibit such evidence being effectively tested by a party to the proceedings.

37. Prosecutors received comprehensive training and guidance on the use of special measures. In addition, the CPS is bound by the Victim's Code of Practice to have systems in place to ensure that special measures are considered by prosecutors.

38. The introduction of joint police/CPS witness care units under the "No Witness No Justice" programme throughout England and Wales means that we can be much more responsive to witnesses requirements throughout the process. There are 165 such units across England and Wales since their introduction in 2005.

39. The units, staffed by trained specialists from the police and CPS, provide a single point of contact from the point of charge until the conclusion of the case. Witness care officers are required to undertake a needs assessment with every witness once a not guilty plea has been entered. Dedicated Witness Care Officers ensure that the individual needs of victims and witnesses are identified and met so that they have all the support and information they need to enable them to attend court and give their best evidence. The support provided is tailored to the needs of the individual and can include transport, arrangements for childcare or a pre-trial familiarisation visit to the court.

40. Vulnerability and intimidation are both priority areas for witness care officers when conducting a needs assessment. When conducting a needs assessment (usually by telephone) with a victim or witness who has learning disabilities, a Witness Care Officer (WCO) may be able to identify the need for special measures or specialist support that has not previously been apparent or identified during the investigation stage (although proper consideration (informed by the victim/witnesses own views and preference as reported to the investigating police officer) by the prosecutor at the point of charge should render this exercise otiose in most cases).

41. The WCO is then able to pass the relevant information to the CPS lawyer who has conduct of the case, with a view to an application for special measures being made. With their consent, the WCO is also in a position to refer the witness to an appropriate specialist organisation and to the Witness Service, to provide additional support.

42. All Witness Care Units have been required by NWNJ to conduct local consultation, to learn about the needs of all sections of their community. The inclusion of local help groups and support services in the Contact Directory provides a flow of information between WCUs and local community disability services and improves the quality of service available for victims and witnesses.

43. In order to encourage strong local relationships, the national NWNJ programme has run events for Witness Care Unit managers and staff with presentations involving the identification of needs and support for people with learning disabilities. These events have utilised the expertise of the voluntary sector and Voice UK will once again be participating in the 2008 NWNJ conference.

44. Any aspects of victim or witness care that do not relate to giving evidence (such as child care issues, preferred means of communication of case progress, travel expenses, assistance in getting to court, advice as to where to go for emotional support) will be dealt with by the WCO in the ordinary course of events.

45. Under paragraph 6.7 of the Victim's Code of Practice, Witness Care Units are required to inform vulnerable witnesses of the outcome of all pre-trial hearings (including applications for special measures) and the trial and sentence within one working day of the conclusion of the hearing.

46. In the lead up to the trial, the victim or witness may choose to have a special measures meeting with the trial advocate, reviewing prosecutor (if different) and police. A supporter may attend with the witness—both for support and, where necessary, to assist in understanding. The purpose of the meeting is for the court's decision on special measures to be explained. It is also an opportunity for the witness to establish a rapport with the trial advocate and ask any questions he/she may have about the process. In addition a court familiarisation visit in advance of the trial should be offered by the Witness Service—many witnesses take up this offer.

Failure to identify people with learning disabilities/offer support

47. It is the responsibility of the police officer to identify the needs of victims and inform the CPS prosecutor. If the police officer identifies that the victim is vulnerable, the officer should contact the CPS prosecutor to have an early special measures meeting to discuss the needs of the victim and their eligibility to benefit from special measures.

48. Similarly, if the police officer identifies the victim as being learning disabled and thus requiring support, this will ensure that the correct support is provided from the outset. A failure on the part of the police to identify that a victim (or other witness) has a learning disability may be rectified when the witness care officer conducts the needs assessment.

Investigation of crimes against people with learning disabilities in residential or other settings (eg care homes or hospitals)

49. The police are responsible for conducting the investigation with advice and guidance from a prosecutor as and when it is deemed appropriate. Historically the police have engaged with the CPS at an early stage in relation to allegations of institutional child abuse. Where there is an investigation into allegations of institutional abuse, be it sexual or physical, of people with learning disabilities, we would expect the police to engage with the CPS at an early stage of the investigation for advice, assistance and discussion of any strategic issues.

Crimes against people with learning disabilities as an adult protection issue

50. The CPS supports the Department of Health's document "No Secrets", which provides guidance on the development of multi-agency policy and procedures to protect vulnerable adults from abuse. The CPS will contribute to the exercise to revise "No Secrets".

51. The CPS works with its criminal justice, support and voluntary partners to safeguard vulnerable groups. On a local basis, the CPS participates in Crime and Disorder Reduction Partnerships. The Partnerships consider, in particular, how to respond to the needs of adults experiencing domestic abuse, which may include an adult with a learning disability experiencing abuse from a carer.

The Government review of "No Secrets"- involvement of criminal justice agencies

52. The CPS supports the multi-agency approach as set out in "No Secrets". The CPS is a member of a criminal justice group which will contribute to the review.

53. The CPS contributed to the production of the 2007 edition of "Achieving Best Evidence in Criminal Proceedings". The document, like "No Secrets", encourages a multi-agency approach to permit a vulnerable witness to give their best evidence.

Theft and people with learning disabilities

54. The CPS reviews all cases in accordance with the Code for Crown Prosecutors. The fact that the victim has a learning disability would be considered to be an aggravating feature when considering sentence, which the prosecutor would bring to the attention of the court. The CPS recognises that people with learning disabilities may be the targets of crime because of their perceived or actual vulnerability.

Responses of criminal justice agencies to disability hate crime

55. The CPS issued a public policy statement on Prosecuting Cases of Disability Hate Crime in February 2007, following extensive consultation with external agencies and individuals who had experience of and expertise in issues surrounding disability hate crime. The Policy makes clear our commitment to dealing with this serious and sensitive type of offending, which is, motivated by discrimination and hate.

56. Section 146 of the Criminal Justice Act 2003 requires the court to treat evidence of hostility based on disability as an aggravating factor and to sentence accordingly. Disability is defined as any mental or physical impairment.

57. The section requires the prosecutor to prove that at the time of committing the offence or immediately before or after doing so, the offender demonstrated towards the victim of the offence hostility based on a disability or presumed disability of the victim. Alternatively, the prosecutor was motivated (wholly or partly) by hostility towards persons who have a disability or a particular disability.

58. The CPS Policy urges prosecutors to be proactive in seeking evidence of hostility or motivation.

59. Some disabled people may be victims of crime because they perceived as being vulnerable—easy targets. Where there is no evidence of hostility or motivation and s.146 cannot therefore be applied, prosecutors are nevertheless reminded that they should consider the culpability of the defendant and the consequences for the victim so that the case can be put before the court in a way that enables it to sentence appropriately.

60. It is proposed to revise the Director's guidance on charging to require the police to refer hate crimes—defined for this purpose as “any incident, which constitutes a criminal offence, perceived by the victim or any other person, as being motivated by prejudice or hate” to the CPS prosecutor for early discussion, for consideration of section 146 and for a charging decision. This will ensure that, at the earliest stage, relevant information regarding the offence, the offender and the victim is identified and that where such information is missing, steps can be taken to find it.

61. The CPS has appointed disability hate crime co-ordinators in each CPS Area. In cases of domestic violence, racist and religiously aggravated crime and homophobic crime, hate crime co-ordinators have played a key role in helping to reduce unsuccessful outcomes.

62. The role of the disability hate crime co-ordinator includes:

- acting as a specialist advisor to colleagues and management regarding the prosecution of disability hate crime cases;
- undertaking community engagement with local disabled communities to help build confidence to increase reporting of these crimes;
- working with criminal justice colleagues, in particular the police, to improve our response to these crimes and to increase the number of offences brought to justice; and
- supporting CPS Area management in assessing area performance on prosecution outcomes and putting on place strategies to tackle underperformance.

63. The first meeting of the disability hate crime co-ordinators was held on the 12 November 2007 and it was opened by the DPP. Its main aim is to ensure compliance with the disability hate crime policy among CPS frontline staff.

64. The CPS will also soon begin a campaign to raise awareness of disability hate crime through internal News articles, posters and postcards.

65. We are looking at wider training needs in relation to all hate crimes, including mainstreaming specific hate crime modules into prosecutor training.

66. The CPS will be setting national and local targets for disability hate crime and will be developing its first Annual Hate Crimes Report, which will enable us to present improved and enhanced data sets on hate crime prosecutions in a composite format across all hate crime categories.

67. It is also proposed to undertake a themed review on disability hate crime in the 2008–09 business year, as part of the Area Performance Review System. This will enable us to identify better how the policy is being implemented in CPS Areas, assess the performance of each Area and identify appropriate actions for improvement on the handling of disability hate cases. Data will be taken from 2007–08 and the report is expected to be published in summer 2008.

68. All CPS Areas are currently developing hate crime scrutiny panels where external organisations that support victims of hate crime will undertake analysis of unsuccessful cases. Community—Involvement Panels will involve and consult people on the business of the CPS and provide a forum to which the local CPS Areas are accountable.

Prosecution decisions in cases involving victims or witnesses with a learning disability

69. See above in paragraphs 1–46.

Accessibility: supporting people with learning disabilities to report crimes

70. The CPS supports “Achieving Best Evidence”, which provides guidance for the police on how to support vulnerable witnesses to report crime and the options available for the recording of the information, such as the use of video interviews.

Accessibility: assistance during interview and trial

71. The CPS supports the use of video recorded interviews and the use of intermediaries, where required, both at the investigative stage and the trial stage of proceedings.

72. The CPS and ACPO have published revised guidance (2007) on video recording of interviewing with vulnerable and significant witnesses.

73. The CPS supports the Witness Profiling initiative operated by the Investigations Support Unit, Liverpool City Council. The unit provides an in-depth support and preparation programme for witnesses with learning disabilities. The process commences at the investigation stage and involves an assessment of the individual’s potential to be a credible and competent witness in the trial. A detailed witness profile is served on the court, the prosecution and the defence. The profile deals with issues such as the witness’ functional skills and powers of concentration, as well advice to counsel on how to ensure the witness is able to give his/her evidence.

74. Since March 2006, the CPS has been piloting pre-trial interviews with witnesses in four CPS Areas in the north west of England (Merseyside, Manchester, Lancashire and Cumbria). This process allows prosecutors to interview witnesses in order to assess the reliability of the evidence the witness can provide, or to assist in understanding complex evidence. The purpose of the process is to assist prosecutors in making fully informed prosecution decisions.

Accessibility: special measures and the Youth Justice and Criminal Evidence Act 1994

75. See above in paragraphs 30–37.

Use of Intermediaries

76. Certain vulnerable witnesses may give evidence through an intermediary, (section 29 of the YJCEA 1999). The CPS supports the national roll-out of the Intermediaries announced in June 2007.

77. The decision to use an intermediary during the investigative process is the responsibility of the police. However, Duty Prosecutors may become involved in these decisions as part of the witness needs assessment at the pre-charge stage.

78. Anecdotal evidence from prosecutors suggests that the use of intermediaries has been of significant benefit in assisting witnesses to give their best evidence. Vulnerable witnesses who would otherwise have been denied access to justice are able to give their account with the assistance of an intermediary.

Training for police, lawyers and judges in vulnerability and learning disability

79. The CPS delivered a three day training course in 2002 to coincide with the introduction of “special measures” for victims and witnesses. The training was delivered in conjunction with the Ann Craft Trust and included a full day on learning disabilities.

80. Training is delivered in local CPS areas according to need and local priorities. For example, CPS West Midlands are currently updating their training which will include a comprehensive practitioner guide to learning disabilities and mental disorder.

81. Local CPS Areas have organised interagency conferences and training on witnesses and offenders with learning disabilities. For example, in 2006 the CPS West Midlands organised a conference for their Local Criminal Justice Board on Learning Disabilities, and in conjunction with the voluntary sector produced a comprehensive delegate pack and glossary of terminology. This will be used as a basis for a national practitioner guide that will be issued in 2008 to coincide with the implementation of the Mental Health Act 2007 and the updated CPS legal guidance. In October 2007 two prosecutors spoke at conferences on Vulnerable Adults and Special Measures to explain the additional assistance available to vulnerable adults who come into contact with the criminal justice system.

82. In October 2007, a senior CPS lawyer/manager who is also a mental health specialist in Cambridgeshire attended a conference organised by Health and Social Care in Criminal Justice. Operational managers across the criminal justice system, including the police, worked together in a workshop to explore

the changes to law and —practice regarding the responsibilities and obligations towards people with mental incapacity and ill health. The key learning points will be cascaded at an Area training day, and all CPS lawyers and caseworkers have been alerted to the issues raised and can seek specific advice from the lawyer/manager.

Relationships between local community learning disability services and local criminal justice agencies

83. The CPS is a member of the Local Criminal Justice Boards which engage with local groups and service providers. Also, each CPS Area employs an Area Communications Manager who will establish links with support, voluntary and service provider groups in their area to inform them of CPS practice, raise awareness of relevant issues, and build up working relationships with community groups.

84. On a national level, the CPS has a good working relationship with Respond, which supports people with learning difficulties who have been affected by trauma and abuse. Respond is a member of the CPS' External Consultation Group.

People with learning disabilities as suspects or as defendants

85. The prosecutor has an important role to play when considering charge in relation to a suspect or defendant with a learning disability.

86. So far as the evidence is concerned, there may be issues, depending on the nature of the offence alleged, as to whether the suspect could form the appropriate mens rea. Where there is a confession, or an admission in interview, the prosecutor will have to consider whether the interview was conducted in accordance with the provisions of the Codes to the Police and Criminal Evidence Act 1984 (PACE).

87. Where there is sufficient evidence to proceed, the prosecutor must consider whether or not it is in the public interest to proceed with the case having regard to the suspect's disability balanced against other relevant factors.

Failure to identify people with learning disabilities and offer specialised support

88. The CPS has no direct contact with suspects at the police station and initially relies on information supplied by the police when providing charging advice or reviewing a file following the police decision to charge.

89. At present, prosecutors rely on the word of the officer in the case, the custody record and summary of interview, where supplied, to identify defendants with mental disorder or vulnerability. The information provided by the custody record is minimal and does not usually describe the nature or degree of the disability or vulnerability. Nor does it differentiate a person with a learning disability such as cerebral palsy from a person who has a mental illness such as schizophrenia.

90. The custody record should contain information to alert the prosecutor to potential disorder or vulnerability such as the attendance of the Forensic Medical Examiner and his conclusion as to whether the offender is fit to be detained or interviewed. However, the custody record is not routinely supplied to the CPS, either when charging advice is sought or with the case file when the police have already charged the suspect. The presence of an appropriate adult during interview is usually recorded on the typed interview summary, which is routinely supplied with case papers. Again this merely alerts the prosecutor to a potential disorder or vulnerability but provides no further information.

91. Prosecutors may not be aware of any disability or vulnerability until the defendant attends court. CPS legal guidance recognises that prosecutors may receive information about a defendant's disability at court from sources such as relatives and gaolers, who have observed the offender's behaviour or demeanour, and that this information may prompt further investigation to ascertain the nature and extent of the disability and its relevance to and impact on criminal proceedings.

92. Where there is a mental health diversion/information/liaison scheme at court, the CPS may request or receive information about the offender, his disability, availability of treatment etc. to assist in identifying the nature and extent of the disability. This will inform the CPS' decision whether to prosecute and if the case is to proceed, the information will assist the court to manage the case and facilitate specialist support if necessary eg allowing extra time for the trial where frequent breaks are necessary.

93. Where there are no such schemes, prosecutors should be proactive in obtaining further information, whenever it appears that the disability may have an impact on the prosecution. The CPS will usually liaise with the defendant's solicitor or the duty solicitor to obtain recent and reliable information about the nature and extent of the disability. The involvement of a solicitor ensures that the defendant's rights are protected and that the implications and consequences of sharing information about his medical history are understood.

Access to justice and people with learning disabilities (eg ability to understand arrest, questioning or trial and to engage effectively with the process,

94. The custody officer at the police station is responsible for all detained suspects, including those with learning disabilities, and must conduct a risk assessment to ascertain whether the detained person may need medical attention by asking and recording on the custody record the answers to the following questions:

- do you have any illness or injury?
- have you seen a doctor or been to hospital for this injury/illness?
- are you supposed to be taking any tablets/medication? If so
- what are they? What are they for?
- are you suffering from any mental health problems or depression?
- have you ever tried to harm yourself?

95. The custody officer is also responsible for implementing reactions to the risk assessment such as calling in a health carer and to assess whether a person needs medical attention whether or not it is requested.

96. Code C of PACE also requires that if an officer suspects or is told in good faith that a person may be mentally disordered or otherwise mentally vulnerable, unless there is clear evidence to the contrary, that person must be treated as such for the purposes of the Code. Note 1 G of Code C defines a person with:

- “mental disorder” as in section 1(2) Mental Health Act 1983 as “mental illness, arrested or incomplete development of the mind, psychopathic disorder and any other disorder or disability of the mind;” and
- “mentally vulnerable” as “any detainee who because of their mental state or capacity may not understand the significance of what is said, of questions or of their replies.”

97. A person who is or may be mentally disordered or otherwise mentally vulnerable must have an appropriate adult present during interview at the police station. The appropriate adult should facilitate communication with the police and solicitor and explain the procedure at the police station to the detained person.

98. The detained person has the right to speak in private to the appropriate adult, who will ascertain what action the detained person wishes to take in interview and assists the person in doing so eg. by reminding the person who wishes to exercise their right to silence that this means that they need not answer any question posed by the police. In the West Midlands there are dedicated police officers who liaise with the CPS specialist in respect of best practice when interviewing vulnerable adults.

Training for police, lawyers and judges in vulnerability and learning disability

99. We have set out the general training proposals for both victims and suspects above at paragraphs 79–82.

100. The CPS National Youth Offender Specialist Course. includes training on effective trial participation for offenders with low cognitive ability, learning disability and/or learning difficulties. This is summarised in the CPS legal guidance, which advises prosecutors to be proactive in encouraging the court to take appropriate steps to enable an offender with learning difficulties or mental impairment to, participate in his trial, including:

- keeping the offender’s cognitive ability in mind;
- using concise and simple language;
- taking regular breaks;
- taking additional time to explain court proceedings;
- being proactive in ensuring the offender has access to appropriate support;
- explaining and ensuring that the offender understands the ingredients of the charge;
- explaining the possible outcomes and sentences; and
- ensuring that cross examination is carefully controlled so that questions are short and clear and frustration is minimised.

101. The Police and CPS in the West Midlands work closely with “Autism West Midlands” which has delivered training to lawyers and police and improved understanding of the needs of suspects with a range of learning disabilities and difficulties.

Accessible information on the criminal justice-system

102. The CPS does not have direct contact with defendants, unless they are representing themselves, and information on the criminal justice system is provided by other criminal justice agencies such as the police, the Legal Services Commission and HM Courts Service. Information in a format preferred or more easily understood by people with learning disabilities is provided by organisations such as Mencap and Voice UK.

Extension of special measures to suspects and defendants

103. In March 2007, the CPS issued guidance to prosecutors and updated the legal guidance to alert prosecutors to the use of live link for mentally disordered offenders.

104. A live link is defined in section 33B of the Youth Justice and Criminal Evidence Act 1999 as an arrangement by which the accused, while absent from the place where the proceedings are being held, is able to see and hear a person there, and be seen and heard by the judge, justices, jury, co accused, legal representatives and interpreters or any other person appointed by the court to assist the accused.

105. A defendant may use the live link to give evidence in his trial at the Crown Court or Magistrates' Court if he suffers from a mental disorder, within the statutory definition in section 1 of the Mental Health Act 1983 or otherwise has a significant impairment of intelligence or social function. This is used if the defendant is unable to participate effectively in the proceedings, but use of the live link would facilitate better participation, whether by improving the quality of his evidence or otherwise, and the court considers that it is in the interests of justice to allow use of the live link.

106. It is the responsibility of the defence to apply for a live link direction, but as officers of the court, prosecutors would be expected to remind the defence of this facility if it appeared in the interests of justice to do so.

107. There is no provision for the defendant to be interviewed on video or DVD and to have that recording played in lieu of evidence in chief.

Compliance with PACE 1984 and people with Learning Disabilities

108. The CPS and police are alert to the need to comply with PACE 1984 and the Codes of Practice, as evidence obtained in breach of the provisions may be excluded at court because it was obtained by oppression (section 76 of PACE 1984) or admission of the evidence would be unfair in all the circumstances of the case (section 78 of PACE 1984).

109. The exclusion of the evidence may result in there being insufficient evidence on which the court could properly convict and lead to an acquittal. Where the CPS is aware of a breach of PACE and anticipates that the court would rule against any evidence obtained as a result of the breach, it may decide that there is insufficient evidence to provide a realistic prospect of conviction. The CPS would therefore advise the police not to charge the offender or to discontinue a case where the offender has already been charged eg where the sole evidence against the offender is an admission made in an interview where no appropriate adult was present, but should have been because the offender had learning disabilities.

Access to well trained "Appropriate Adults"

110. There are many advantages to having an experienced and well trained appropriate adult, in particular:

- ensure that the correct procedures are followed and that the detainees rights are protected;
- ensure that the detainee understands their rights and what help the appropriate adult can provide;
- ensure that the police act fairly and properly;
- facilitate communication between the police and the detainee; and
- ensure that the detainee has access to legal advice. Even if the detained person refuses legal advice, the appropriate adult may request that a solicitor attends and encourage the detained person to take legal advice.

111. However, the statutory duty on local authorities to provide appropriate adults under the age of 17 does not extend to vulnerable adults. The provision of experienced and well trained appropriate adults is dependent on the priority attached by the local authority and voluntary and charitable agencies in each local area. The wide range of disabilities and vulnerabilities means that appropriate adults require extensive training in order to communicate with and serve the interests of offenders with differing disabilities and needs.

112. The CPS is supportive of initiatives to improve the quality of training of appropriate adults. However, it is important to note that a mentally disordered or vulnerable suspect has a right to have a relative, guardian or other person responsible for their care or custody, rather than a well trained experienced stranger, as their appropriate adult. An appropriate adult may be:

- a relative, guardian or other person responsible for the care or custody of the detailed person;
- someone experienced in dealing with mentally disordered or mentally vulnerable people but who is not a police officer or employee; or
- failing these, some other responsible adult aged 18 or over who is not a police officer or employee.

113. A relative may be best placed to communicate with the defendant, but may lack the experience and knowledge of the role of appropriate adult, and the confidence to challenge police or explain the benefits of legal representation to the defendant. A relative may not understand that as an appropriate adult he is not

bound by a duty of confidentiality. In some cases, it may be in the interests of justice for a defendant to communicate directly with a relative appropriate adult who could be advised by a trained and experienced appropriate adult on specialist aspects of the role.

People with learning disabilities as prisoners

114. We have no observations on this area or the issues raised.

12 November 2007

Memorandum by the Association of Chief Police Officers of England, Wales and Northern Ireland

CRIMINAL JUSTICE AND LEARNING DISABILITIES

I am writing in response to your letter dated 29 October 2007 seeking the views of those involved in the criminal justice process on the treatment of people with learning disabilities across the full spectrum of criminal justice engagement. I have taken the opportunity to seek the opinion of those who lead on these issues within the Association of Chief Police Officers and would like to proffer the following comments.

The issue of people with learning disabilities is an extremely complex one, with no one step or measure taken on its own able to ensure fair and equal access to justice. In taking steps to bring offences against people with learning disabilities to justice, and to provide the necessary support, the police service will rely heavily on health care professionals and the voluntary sector. We have shown in recent years that working together in the best interest of the victim, cases are more likely to be brought to justice, and much progress has been made to achieve the step change required.

DEFENDANTS

The way in which the police service engages with adult suspects or defendants who have learning disabilities or who are otherwise considered to be vulnerable is set out in the Police and Criminal Evidence Act 1984 Code of Practice. Custody Officers must, as soon as is practicable, inform the appropriate adult (as defined) when authorising the detention of mentally disordered or otherwise mentally vulnerable detainee. (Code C 3.15) The extent to which the custody officer can make such judgements is frequently hampered by detainees who are under the influence of drink and/or drugs or who are violent. The Code places an ongoing responsibility on the custody officer to consider the care and treatment of detained persons (Code C9) and to make appropriate entries on the custody record.

Mentally disordered or otherwise mentally vulnerable people must not be interviewed regarding their involvement or suspected involvement in a criminal offence in the absence of the appropriate adult unless they are dealt with under the urgent interview procedure on the authority of a superintendent at a police station. (Code C 11.15–17 and 11.18–20)

VICTIMS AND WITNESSES

ACPO strongly supported the development and implementation of the use of the intermediary special measure to support victims and witnesses communicate more effectively throughout the criminal justice process. The introduction of intermediaries will open up the criminal justice system to many more vulnerable victims, and will be particularly useful in supporting victims with a learning disability.

No Witness No Justice (NWNJ) introduced a new level of support to victims and witnesses from the point at which someone is charged with a crime. At the heart of this new service is the requirement for victims and witnesses to be seen as individuals and for services to be tailored to meet individual needs. In cases of hate crime this is particularly important. By taking this individualised approach a better and more thorough support network will be put in place for victims of hate crime.

Victims are given a single point of contact within the criminal justice system who will keep them informed about progress of their case after every court hearing as a minimum and more regularly if required. Specialised victim or witness support is arranged by the witness care officer.

Through the undertaking of the detailed needs assessment introduced as a requirement through NWNJ, victims and witnesses now receive an unprecedented level of support throughout the life of their case, and a better consideration of what special measures should apply in each case.

The police service has long recognised its limitations in law in protecting vulnerable adults. It has therefore been actively involved in consultations on the review of 'No Secrets' and wider changes being led by Ivan Lewis MP, through the Department of Health, and has been pushing for the introduction of new legislation, to enable the protection of vulnerable adults to mirror the provisions available for children. Forces are actively developing their protocols with partners for protection and investigative arrangements for vulnerable adults and this is an area that has come under scrutiny in the latest inspection process.

Forces have formulated hate crime policies, determining responses and actions in relation to allegations. This is often supported through the provision of third party reporting mechanisms, such as True Vision.

Forces, as part of the initial police learning and development programme have made a number of links with community groups, so as to develop student officers understanding of community issues, including learning disabilities. Also as part of their training programme, the provisions of the Youth Justice and Criminal Evidence (YJCE) Act 1999 (special measures) are explained, which provide for a number of support measures for those with learning disabilities. Specialists within forces have been trained to obtain best evidence from witnesses, including those with learning disabilities, by way of video recording. This improves the quality of the evidence obtained as well as supporting witnesses in giving their evidence.

It can be argued that there should be further training available for officers to help them identify and deal with learning disabilities. However, this needs to be set against the fiscal climate that the service operates in. There is insufficient funding available for additional training to be developed and delivered to all officers nationally. Whilst it would be desirable that police officers would identify all those with learning disabilities, this would be unrealistic. This is due to the variety and complexities of conditions that exist, and where some may not be readily apparent or the individual shows no sign of suffering from a disability. This has been recognised within the Office for Criminal Justice Reform who are establishing the current skills gap at identifying vulnerability, and are working to develop a package to assist the service in improving its performance in this area. On the 4th December a conference is being hosted for police practitioners to explore these issues, and identify additional improvements that should be made.

The Code of Practice for Victims of Crime, the revised Achieving Best Evidence, the Intermediary Scheme and the NWNJ project are changing the way in which the police and CJS now respond to all victims and witnesses, but particularly those with a learning disability. A better assessment of the needs and support requirements of all victims and witnesses will lead to the provision of better support throughout the investigative and prosecution process.

Further support for vulnerable witnesses is now available through the Intermediary scheme, which is legislated for through the YJCE Act. At present the scheme is progressing through national roll out, with the scheme due to be fully available from April 2008. This will allow officers to further assist those with learning difficulties by improving communication links during both the investigation and court processes. An initial evaluation of the scheme by OCJR was very positive, and these improvements will now be available nationally.

I hope that you find these comments useful. The Association would be happy to assist with the development of any substantive proposals, should there be any, in due course. In the meantime, thank you for affording us the opportunity to comment.

Ken Jones
Chief Constable
President of ACPO

19 November 2007

Letter from Ann McGuire MP, Minister for Disabled People, Department for Work and Pensions

When I appeared before the Committee on 12 November I agreed to write on three matters:

- Raising awareness of the Disability Equality Duty.
- The Easy Read version of the UN Convention on Disability Rights.
- The application of the Disability Discrimination Act to the provision of information for pregnant women who have a learning disability.

The information is in the enclosed annex.

I hope you find the responses helpful. Please let me know if I can be of further assistance.

ADDITIONAL INFORMATION REQUESTED BY THE COMMITTEE FOLLOWING THE HEARING ON 12 NOVEMBER 2007

1. RAISING AWARENESS OF THE DISABILITY EQUALITY DUTY (DED)

The Committee asked for more information about future awareness raising activity. The note below outlines what the Office for Disability Issues (Department for Work and Pensions) has done and what more is being planned.

In the run up to 4 December 2006 when the Duty came into force, the Office for Disability Issues (ODI) undertook a comprehensive awareness raising exercise, as did the Disability Rights Commission (DRC). The main aim of this was to raise awareness of the DED across the public sector, and with senior civil servants in particular, by outlining the purpose of the DED, and explaining what public authorities needed to do, and by when.

Specifically, the ODI hosted a major conference which was attended by senior managers and policy makers from public bodies as well as senior representatives from Disability organisations. John Hutton (then Secretary of State for Work and Pensions), Meg Munn, Ivan Lewis, and Anne McGuire all spoke at the event. Anne McGuire also gave the key note address at many conferences organised by the Disability Rights Commission (DRC) and other organisations such as the Local Government Association.

Anne McGuire and Bert Massie (Chair of the DRC) wrote jointly in February and November 2006 to the majority of public authorities, other than schools, which are subject to the specific duties reminding them of their responsibilities.

Articles on the DED by DWP Permanent Secretary Leigh Lewis were placed in Whitehall and Westminster World and Public Servant magazines. Anne McGuire also wrote articles for a wide range of publications such as, Public Service Reform News, Public Service Director, with the targeting of specific sectors through articles in People Management, Local Government News, Nursing Management and Police Profession. Disabled people were served through articles being placed on the BBC's Ouch Website and Hope.

The ODI also commissioned a compliance audit in January 2007 on the requirement for certain public authorities to publish a disability equality scheme. A series of events were held across the country to disseminate the findings of the audit and spread best practice. This was followed up with an events report being distributed to all delegates as well as being published on the ODI website.

The raising awareness work continues and recently ODI have contributed to events organised by the Department for Children, Schools and Families to prepare primary schools for the DED.

Ministers continue to address events. The ODI will shortly be embarking on a new wave of activities to ensure that public bodies are aware of both their obligations and the benefits that can be achieved. Through this the ODI plan to target, with tailored messages, three key groups: Central Government, key parts of the wider public sector such as health, education, criminal justice and local authorities, and the Voluntary and Community Sector (VCS). In particular VCS organisations that could benefit from using the DED as a tool for influencing change in the public sector, for example disability organisations and umbrella bodies such as Volunteering England will be included.

2. EASY READ VERSION OF THE UN CONVENTION ON DISABILITY RIGHTS

As the Committee is already aware an Easy Read version of the negotiation text of this Convention was produced. The ODI are now in the process of finalising the text to accord with the text of the Convention. There is a need to be satisfied that the final text is as accurate as it can be without compromising accessibility for its intended audience. It is expected that the revised version will be ready by the end of the year. It will be placed on the ODI's website and will also be made available to the Committee.

3. INFORMATION FOR PREGNANT WOMEN WITH A LEARNING DISABILITY

The information below deals with the application of the Disability Discrimination Act 1995, as amended, to the provision by a healthcare Trust of information for pregnant women who have a learning disability.

The application of the DDA is a matter for the Courts and not Ministers. However, in general terms, under the DDA the provision of information such as this is likely to be seen as a service to the public. The duty is to make reasonable adjustments to enable disabled people to access that information. Legally the duty applies if the service provider has a policy, practice or procedure which makes it "impossible or unreasonably difficult" to access the service in question. A reasonable adjustment might be the provision of

an Easy Read version, but equally it might be somebody providing the information verbally. Thus a healthcare Trust should be able to defend its position if it ensured that it took reasonable steps to provide the information in a form or manner that made it accessible to people with a learning disability.

27 November 2007

Letter from Michael Wills MP, Minister of State, Ministry of Justice

Thank you for your letter of 29 October 2007 about the Ministry of Justice Guide to the Human Rights Act for people with learning disabilities. I am sorry for the delay in sending this reply.

I am grateful to you for pointing out that the Guide has not been available to download from the Ministry of Justice website. I am sorry for that oversight, which I have asked my officials to rectify immediately. The Guide is now available as a downloadable document, via the following link: <http://www.justice.gov.uk/guidance/humanrights.htm>.

You also asked for information on the production of the Guide, and what the Ministry of Justice has done to make it available to people with learning disabilities and low literacy. It was checked for accessibility by MIND and for accuracy by our Departmental legal advisers.

The Guide attempts to relate the complex nature of the Articles of ECHR to the day-to-day experience of its intended audience. It was not designed to provide precise legal definitions. However, we are satisfied that it does provide an accurate and helpful account of the Act—though it does now need updating to take account of machinery of government and other changes.

I regret to say that, having produced this useful publication, we have not perhaps done as much as we should to bring it to the attention of disabled people and their supporters. However, we would like to use your enquiry as a springboard to promote it more energetically. I have asked my officials to see what help might be available across the Government to give the Guide wider prominence and ensure that it reaches those it is intended to help.

Michael Wills MP

**Letter from Ivan Lewis MP, Parliamentary Under Secretary of State,
Department of Health**

At the evidence session for the Joint Committee on Human Rights Investigation of Human Rights on Monday 12 November 2007, the committee asked when the evaluation of the human rights work being taken forward by Mersey Care NHS Trust in the Department of Health project “Human Rights in Healthcare” would be completed.

The “Human Rights in Healthcare” project has now sourced an independent evaluator to assess the effectiveness of the human rights based approaches being developed by the five Trusts involved in the project including Mersey Care NHS Trust. The evaluator is scheduled to produce a report that will be published by the Department of Health in Autumn 2008.

Ivan Lewis

29 November 2007

Letter from Roger Hill, Director of Probation, Ministry of Justice

Thank you for your letter of 3 December to Phil Wheatley, the Director General of the Prison Service which was copied to me. In your letter you raised a number of issues related to the inquiry being conducted by the Joint Committee on Human Rights concerning the treatment of people with learning difficulties by criminal justice agencies. I have seen the responses provided to the Committee by colleagues from the Crown Prosecution Service and the Office for Criminal Justice Reform (OCJR), and I would like to provide you with some information on behalf of the National Probation Service.

Provisions in the Criminal Justice and Courts Services Act 2000, which were renewed and extended by the Domestic Violence Crime and Victims Act 2004, place a duty on Probation Boards to make contact the victims of offenders convicted of violent or sexual offences who are sentenced to 12 months or more in prison. This Victim Contact Scheme fulfils a variety of objectives, but the purpose defined in the legislation is to firstly provide victims with information during the offender’s sentence and, secondly, to give victims the opportunity to make representations to the body setting the conditions of the offender’s release once they have completed the custodial element of their sentence.

Rather than specific types of crime, such as hate crime, the range of offences which “qualify” for post-conviction victim contact are taken from the list of violent and sexual offences at Schedule 15 of the Criminal Justice Act 2003 and include offences of murder, manslaughter, rape, assault and theft and a large number of sexual offences. There is also scope for providing contact to the victims of offences which fall outside the scope of the definition on a discretionary basis where the offence that was perpetrated has caused particular physical or psychological damage to the victim that warrants ongoing support during the offender’s sentence.

I note that the OCJR have provided the Committee with comprehensive information about the Code of Practice for Victims of Crime so I will not go into any more detail about the obligations that it sets out for the Probation Service, suffice to say that they largely reflect the duties established by the legislative framework.

Once a conviction has been secured against the offender, the Code sets out a process where victims are referred to the Probation Service by the staff in the criminal justice agency that have been their main point of reference during the offender’s trial. This will usually be the joint CPS/Police Witness Care Unit, but will sometimes be a Police Family Liaison Officer, if one has been appointed to work with the victim. In referring a victim to the Probation Service, the referring agency should provide the Probation Victim Contact Unit with any information relevant to ensuring that victim contact is established appropriately. This should include whether or not the victim has been identified as being vulnerable or intimidated or whether there are any other specific issues such as whether the victim has mobility, language or learning difficulties.

The Victim Policy Team in the National Offender Management Service (NOMS) Public Protection Unit is currently in the process of drawing up revised policy and practice guidance and they have undertaken to ensure that wherever it is appropriate issues related to the accessibility of the criminal justice system to people with learning difficulties will be identified and addressed throughout the National Probation Service.

In respect of NOMS’ response to disability hate crime I can advise you that the Offender Assessment and Management Unit are currently undertaking a review of hate crime and disability hate crime is being included in that review.

Whilst there is no centrally co-ordinated strategy for relationships between local community learning disability services and local probation areas, there is liaison with learning disability services at a local level according to need. Some areas have formed partnerships with local services to meet the need identified.

People with learning difficulties have the same access as other offenders to appropriate probation services, including community based sentences. Any offender with learning difficulties is placed where staff are aware of their needs and interventions are tailored to fit the assessed needs.

Roger Hill
Director of Probation

19 December 2007

Letter from the Chair to Mr Phil Wheatley, Director General of HM Prison Service, HM Prison Service

CRIMINAL JUSTICE AND LEARNING DISABILITIES

The Joint Committee on Human Rights is currently conducting an inquiry on Human Rights and Adults with Learning Disabilities. Although our initial terms of reference made no specific reference to criminal justice issues, we have received a number of submissions which directly refer to the treatment of people with learning disabilities, whether as victims of crime, accused or defendants or as prisoners, by the criminal justice system. Witnesses have raised particular concerns about:

PEOPLE WITH LEARNING DISABILITIES AS VICTIMS OF CRIME

- Failure to identify people with learning disabilities/offer support.
- Investigation of crimes against people with learning disabilities in residential or other settings (eg care homes or hospitals).
- Crimes against people with learning disabilities as an adult protection issue.
- The Government review of “No Secrets”: involvement of criminal justice agencies.
- Theft and people with learning disabilities.
- Responses of criminal justice agencies to disability hate crime.
- Prosecution decisions in cases involving victims or witnesses with a learning disability.
- Accessibility: Supporting people with learning disabilities to report crime.
- Accessibility: Assistance during interview and trial.
- Accessibility: Special Measures and the Youth Justice and Criminal Evidence Act 1994.

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- Use of Intermediaries.
 - Training for police, lawyers and judges in vulnerability and learning disability.
 - Relationships between local community learning disability services and local criminal justice agencies.

PEOPLE WITH LEARNING DISABILITIES AS SUSPECTS OR AS DEFENDANTS

- Failure to identify people with learning disabilities and offer specialised support.
- Access to justice and people with learning disabilities (eg ability to understand arrest, questioning or trial and to engage effectively with the process).
- Training for police, lawyers and judges in vulnerability and learning disability.
- Accessible information on the criminal justice system.
- Extension of special measures to suspects and defendants.
- Compliance with PACE1984 and people with Learning Disabilities.
- Access to well-trained “Appropriate Adults”.

PEOPLE WITH LEARNING DISABILITIES AS PRISONERS

- Failure to identify people with learning disabilities in prisons.
- Should people with learning disabilities serve custodial sentences?
- Access to community based sentences for people with learning disabilities.
- Recent research by the Prison Reform Trust, “No one knows” (2007).
- Accessible information in prison.
- Accessing support in prison.
- Relationships between prisoners with learning disabilities and their families (ie distance from support and difficulties securing visits through visiting orders).
- Ability of prisoners with learning disabilities to engage with rehabilitation programmes; and to access early release.
- Access to appropriate probation services for people with learning disabilities.

Although the deadline for evidence in our inquiry passed sometime ago, I would like to invite you to submit written evidence on these issues in order that our consideration of the evidence in this area may take into account your views. I have also extended this invitation to the Director of the National Probation Service, Mr Roger Hill (to whom I have copied this letter).

It would help inform our inquiry if you could ensure that any written evidence you would like to submit is received before 18 December 2007.

If you have any questions about this inquiry, or would like further information about submitting evidence, please contact our Committee Specialist.

3 December 2007

Memorandum from Mr John Pearson

I am writing in response to the call for evidence the committee has made in respect of the above subject.

I, along with my wife, am a family carer for my 23 year old son James who has severe learning disabilities and mobility problems.

James, our son, has no speech or communication skill, is doubly incontinent, suffers from epilepsy, has autistic spectrum disorders and can present very challenging behaviour from time to time.

One thing you soon realise as either a carer or a person with a learning disability is that you have to fight to get services and support, and even when you do get help it is invariably rationed.

Health: In Lancashire we have for as long as I can remember had little or no physiotherapy or hydrotherapy service for adults with learning disabilities. James needs both these services. We have to fight to get and retain podiatry and dental services for our son. The local primary care trust have refused to commission a health strategy plan and challenging behaviour training course for unpaid family carers. Originally, on the basis of legal liability and now on the basis of cost and reorganisation. Vulnerable young adults with LD are left in the community to be exploited and abused because they do not meet eligibility criteria for services. Acute hospitals have few, if any staff with training in learning disabilities. The family carer is generally regarded as a lay person and scant regard is paid to their views by professionals. When

ever our son has been admitted, either myself or my wife have had to stay with him to provide basic care. I have yet to find a hospital ward with incontinence pads available or the staff who either the time or inclination to change them. The older the individual with a learning disability gets the worse it gets.

Education: In Lancashire for the last 25 years or more we have had a structured approach to education of people with learning disabilities. However this is now being systematically dismantled. Child Development Centres which set the first setting stones in the education of individuals with a learning disability are being run down. These centres owned and operated by the local PCT and staff by a multi-agency multi-disciplinary team were vital in assessing, recording and advising whether children with LD would be better placed in either a special school or if they should attend a normal mainstream facility with the proper support. This vital service is not being replaced by any comparable service and specialist staff post have been dis-established by the Local Authority, who seem to know the price of everything and the value of nothing! Invariably people with a learning disability in a main stream school will often be subjected to bullying and abuse by fellow students. When and if young adults with LD attend further education colleges they are likely to come up against problems finding a suitable course. They also tend to find it virtually impossible to integrate with “normal” students and tend to congregate in isolated groups. Again they are subject to exploitation, abuse and often have money taken from under duress.

Housing: Adults with a learning disability should be able, as far as possible to live independent lives and participate fully and equally within their local communities. However if this is to be achieved there has to be an adequate stock of suitable affordable housing in the locality. Here in Preston the City Council is responsible for housing, but there is a chronic shortage of affordable housing and if people with LD want to move on, they have to look at other areas, which in my view is unacceptable.

Welfare: Family carers have to carry the main burden of caring for the person with LD. This is exploited by services, who tend to adopt a strategy of reaction to a breakdown rather than provide adequate support to prevent people reaching breaking point. There is scant provision for respite care and breaks for carers. For example in the whole of Preston there is only ONE respite care bed for an adult with learning disability who has complex needs and/or is a wheelchair user. There is a totally long winded and complicated for means tested provision of aids and adaptations. We have just had to subsidise our son’s provision of a ramp and a new bathroom shower to the tune of £1,500, which we can ill afford. Modernisation of day services has proceeded without hardly any thought for the social and recreational needs of adults with LD. In many cases day centres are being run down and closed without a properly thought out plan as to what will replace them.

Recreation & Leisure: My son has gone along with 3/4 other young adults with LD, accompanied by support staff to a local leisure centre on a regular basis for the last year or so. Two weeks ago they were denied access, because “SERCO”, the company who operate the centre on behalf of the local council had reduced the number of lifeguards and were unable to allow more than 25 bathers in the 25 metre pool at any one time. They are now requesting the names and addresses of the support workers, sight of their qualifications and risk assessments for each of the service users.

It is very hard for people with LD to have a say in decisions which affect their lives. Valuing people was a document that amongst many other things stated “NOTHING ABOUT US WITHOUT US”. Unfortunately despite the guidance given in this white paper, in my view, implementation has been patchy and there seems to a lack of commitment within services to change the way they work and “blur” the barriers between each other areas of responsibility.

Complaints procedures are overly complicate and not impartial.

In conclusion I feel that there is a serious disregard for the basic human rights of both adults with LD and the family carers. My wife and I are socially excluded and suffering from tiredness and ill health. Too many people with learning disabilities find their way into the criminal justice system in the UK, simply because the system fails them!

We have to change things.

John Pearson

11 May 2007

Memorandum from Ms Veronica Dunn

I am taking this opportunity to submit on behalf not only of a member of my own family, but for any individual who has no family and has no one to represent their interests, as I am aware my family member will one day be in this position.

There can be no doubt that the culture for those with learning disabilities has improved immensely over the last thirty years, the terminology used to refer to them, or being asked to classify your loved one as, imbecile idiot or feeble minded on a hospital form are thankfully in the past.

Hopefully parents are no longer asked on a regular basis “when are you putting him/her in to a home” and there is now a recognition that those with learning difficulties are not a homogenous group and that they are just as individual as the rest of us.

These radical improvements have always been a great source of hope for me as the parent of a son with learning difficulties, however, there are areas that cause great concern if you are required to deal with specific difficulties.

HEALTH

The rights that most of us enjoy are not afforded in the same way to individuals with learning difficulties, specifically in the area where a second opinion is required, where there is an unsatisfactory situation, most of those termed “normal” would have little hesitation in asking for the opinion of a doctor or specialist and we are in fact made very aware of our rights in this area.

This is not the case for those with learning difficulties.

A situation currently exists where they have restricted access to this service, clear guidelines that are contained within NICE and are targeted at those with learning difficulties are not adhered to, and where flagrant disregard has been paid to those guidelines, medical practitioners are extremely reluctant to support, in a positive way, the rights of the individual concerned, and a softly, softly approach is taken.

There is also a situation where the number of professionals working within this specialist field appear to be limited. I know from experience just how difficult it is to get a specialist to even accept an individual for assessment.

The position for those with elderly or less able parents/carers seeking this type of service would almost be impossible.

This is a situation that would not be tolerated in main stream medicine.

SOCIAL SERVICES

There are many good people working at the “coal face” however they appear and in many cases are quite frank that they are working at crisis level for most of their working day, and that doesn’t bode well for those requiring on going support.

The management of social services at a local level has in my experience been, autocratic and totally devoid of what most clients and their families would expect, of what is in effect a caring body.

Decisions that have devastating effect on an individual’s life are taken with no consultation and are delivered as a “Fate a Compli” The process of consultation or discussion is sacrificed when it is expedient to do so, and leave those caring for individuals with the very strong impression that the “bad old days” are really not that far behind us.

DAY SERVICES

The provision of relevant and adequate day services is a crucial area for the clients and their parents/carers.

This service has deteriorated in many areas and is a “sitting service” where no real effort is made to enrich the lives of those attending. Watching videos and television seem to figure to a greater extent in the curriculum than one would wish.

However, there is another area that is of great concern and that is for those who for whatever reason fall out side of the normal day services.

A process where individual care homes with the support of various local services should be required to establish a worthwhile programme for that individual—this is an area where “lip services” is paid, and requires close scrutiny and accountability.

IN CONCLUSION

Men and women with learning difficulties are judged more harshly than those deemed normal, they live in group homes sharing their every day lives, in many cases, with people they have nothing in common with other than their disability and where they are continually reviewed, judged and written about in a regime that none of us would find acceptable and in many cases produces no tangible benefit to that individual.

Ms Veronica Dunn

Memorandum by Joanne Hickinbotham and Steven Parkes

Joanne's and Stevens comments on the provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities, the ability of individuals to access such services and the quality of provision

- Experience of using services:
 - Good for education. Joanne is on lots of courses.
 - Good use of health services, such as community nurse.
 - Happy in their home. Lots of improvements being made.
 - OK experience with debt and welfare offices.
- Chances to have relationships:
 - Partners—in happy relationships.
 - Family—have regular contact.
 - Children—no chance to build any relationship. Feel let down by children services. No communication between each Social Services teams (Children and LD).
 - Help given to maintain/establish relationships:
 - Care Manager—Learning Disability Team.
 - Community Nurse.
 - Midwife.
 - Advocates.
 - Solicitors.
 - Community Learning Disability Team at Beech Mount.

The opportunities for people with learning disabilities to participate in the life of their local community and the state's obligation to facilitate participation and the potential of the convention on the rights of persons with disabilities to promote the rights of adults with learning disabilities

- The ease for people with a learning disability to have a say about decisions:
 - Can make decisions to go on courses. They Just need the support to complete them.
 - Joanne and Steve feel listened to but feel things can take a while to happen. However, they understand that other people can experience difficulties.
 - Regarding their children, Joanne and Steve felt they were not involved in any major decisions. They felt ignored when they asked for help with tasks like feeding and washing the baby.
 - Joanne and Steve feel that the decision to take away their children was made for them and felt that there was nothing they could do to change their mind. This still causes them a lot of anguish.
- How easy it is to make a complaint about a service.
 - My advocate can help us to make and understand the stages of a complaint.
 - Joanne and Steve feel comfortable to speak to people about any concerns.
 - To be listened to more.
 - To be treated fairly and as equal people in society.
 - Not to feel labelled.
 - Other Social Services teams to wok alongside Learning Disability Team.

These points were discussed with Aoife at Mencap.

Steven Parkes

J Hickinbotham

19 July 2007

Memorandum by Simon Cramp

**SUBMISSION BY SIMON CRAMP, PERSON WITH A LEARNING DISABILITY WHO WORKS
AS A FREELANCE CONSULTANT, SUPPORTED TO SEND IN THIS EVIDENCE BY
JACKIE LAWLEY**

“As a person with a learning difficulty myself, I work with and for people with learning disabilities, enabling them to get the right support and information. I offer expert advice on all issues to do with learning disability, based on my extensive experience working as a consultant throughout the learning disability sector.”

My evidence has been provided from my own personal experiences of living my life with a learning disability.

I have used the questions in the easy read call for evidence documents to structure my comments.

DECISIONS: How easy is it for people with a learning disability to have a say in decisions which affect them?

Its not easy—unless you are someone like me who is able to speak up for themselves, I try to speak up on behalf on people with a learning disability. This is hard for me to do sometimes, but I have had more experience at this and have got more confident to speak out for myself and for others.

It has taken me some time to develop my confidence, over time.

There are barriers—people are not always given opportunities to have a say in decisions that affect them, it sometimes feels that people are not made welcome to have a say.

Sometimes I have seen people forget to ask people with a learning disability what they think, and neglect to let people have a say or involve people.

People with a learning disability are not always involved in directing the decisions about themselves or even helped by others to make their voice heard. People need the right support from people who have the right attitudes, people who take time to get to know the person and help them to take part in the decisions that affect them everyday.

It takes time for people to feel comfortable with having a say as often people have not been asked or consulted to make choices about their lives, sometimes people have taken this right away and have made decisions for them. This is not how it should be. Everyone has the right to have a say and to be involved in making decisions that affect them.

There are some good things happening around people getting individual budgets to lead the life they want to do, and get control over their lives, to make decisions for themselves, sometimes with support as well. This is only happening for a few people and this should be a right for all if they chose to want to direct their own support.

People should work together and respect that a person with a learning disability should have the same human rights as everyone else, people should respect people with a learning disability and people should be treated as equal.

MAKING COMPLAINTS

How easy is it for people with a learning disability to make a complaint about a service?

Again it is not that easy to come forward and make a complaint about a service, often I find that the complaints process is too hard to go through, complicated and puts people off. They can be hard to understand and services can fob you off.

I have experience of recently moving into my own house and have found myself trying to help my brother who has a learning disability to make a complaint about our phone supplier.

We have found this to be a very upsetting experience, when we wanted to try to make things go as smooth as possible and get a phone line installed so we can keep up with our emails and also to use the internet, but this has gone all wrong and we have been without a phone line, we are now making a complaint but its already taken up a lot of our time and we have had help from our family to keep complaining.

I have found this to also be very frustrating and have seen how angry, upset and let down this makes you feel. The complaining does not always seem to help either.

People need to have complaints in easy to read or understand formats or to have a way of providing support to help people make a complaint, otherwise people just won't do it or they will give in.

THINGS ABOUT PUBLIC SERVICES

Health Care

I know of an example where someone close to me who has a learning disability had to have coronary care, after the operation and shock of finding out they had heart problems they felt left out in the dark, they were offered group support but could not really cope with going to a group session, they needed to have some individual support to learn to understand what was wrong with them and how to live a healthy lifestyle but were basically told to take the group session or leave it. The only way this person got some support was by getting hold of someone they used to know in the NHS who “pulled a few strings” and got a bit of extra support involved.

Some people with a learning disability need more time to understand and feel Ok about information about their health; it can be a very frightening time.

I know that people with a learning disability do not get the best support with their health and would want to see that the JCHR tries to do something to make access to health care better for people with a learning disability.

Getting out and about and mixing in the local community

People with a learning disability are held back from getting out and about, from experience people pick on you if you look or behave a bit different. I have had experience of going for a walk and people making fun at me, I was wound up by this and got very stressed, they thought it was funny and a big game. They did this because they knew no one would do anything about it.

This has knock on health issues, bullying can make you feel ill and depressed.

The human rights of people need enforcing and people need protection from bullying and crime on the streets.

Relationships

Often a hard one to speak up about.

Finding and keeping friends can be difficult, past experiences of being let down or used can make people very frightened about making friends or getting into a relationship.

People might need more support to develop friendships, and to learn how to cope with being let down and how to deal with emotions.

When relationships go wrong, I find it makes me feel depressed, despondent, rock bottom and it affects my health, I don't feel like eating much and want to be left alone.

Apart from family I only have a few people who I can call my friends; most people are colleagues and acquaintances. This can be difficult to face.

It can be hard to trust people.

Sometimes people might think you are really confident person but inside you might feel useless at some things, and can mean you keep away from trying to make friends.

Housing

I have just moved into a house with my brother, we are both tenants, this has taken ages and ages to get sorted out. We are in now but it is a very unsettling time, with loads of things to sort out which has been stressful and knocks your confidence a bit.

I have had to speak up for myself about what support I think I need and don't need, sometimes this has been difficult as people have tried to give me support from someone who I have had no choice about, this would not work for me.

People with a learning disability want houses and homes the same as everyone else, there should be more choice about where and who people live with.

There are still far too many people living in big places, some people are still living in NHS places that don't need to be and still too many people getting abused and not treated properly by the people who are paid to care and support them.

More should be done to protect people and for people to be given the dignity and respect they deserve.

Everyone is different and should be listened to about how they want to be supported or helped to make these decisions by someone who they trust or someone that knows the person really well.

Education and getting work

My experiences are that people who might be really good at doing certain jobs are not given the opportunities to get into jobs or to have a chance to trial jobs like work experiences.

In my experience I had very little supervision when I had a job, I was told that I had to do an NVQ to keep the job, but I was told I was not up to standard for an NVQ and pulled off the programme, with no help or support to work it through. With the right support I think I could have achieved this.

Benefits

It is very hard for people to understand just what benefits they can get, in my experience some people did not think I had a disability and was questioned on many occasions. I have probably not claimed all the benefits I have been entitled to in the past. Trying to manage money is also hard for some people, trying to make sure you have enough money to pay your bills, your rent and eat properly.

It is also very hard for families to get through the mine field of information and claim forms. This could be made a bit easier.

Some other thoughts

Human rights need enactment in legislation, for example when people are discriminated there are few cases won by individuals or were they feel they get a good outcome.

The only way things will change for people is when people are treated as equal citizens in their local community, respected for who they are and valued.

It will be good to see the human rights convention really mean more than words, something to ensure the human rights of people with a learning disability and act on making sure people are protected and making sure people are treated with dignity and respect.

Simon Cramp

2 August 2007

Memorandum by Miss Heather Crozier, Community Learning Disability Nurse

HUMAN RIGHTS AND PARENTS WITH LEARNING DISABILITIES

I am a Community Learning Disability Nurse working in Leicester City with 10 years community experience. My experience in working with parents has been gained very much through “hands-on” work with, initially, no formal training. Years ago there was a definite reluctance to accept that PWLD had rights to continue with family life and consequently there did not appear to be appropriate training courses to access. This work was also not seen as core business within the Trust and funding to attend any course would have been difficult to obtain.

I have now worked with a number of families and have used my experience to encourage and assist others in supporting PWLD. Much of my work has been focused within the Child Protection arena working with professionals and colleagues from a variety of areas. The information and examples I would like to forward are my own personal experiences, thoughts and comments (in no particular order).

- The Learning Disability Service works with people with a learning disability who have associated health care needs however there are now more PWLD as trends appear to have changed. PWLD can struggle in many ways which then has an impact on their mental health and general well being.
- PWLD can have a Children’s and Family Social Worker allocated if needed but it has only been recently that the parent would be allocated a Social Worker in their own right. There has also been a reluctance to accept that a parent’s needs cannot be dealt with by a Family Social Worker.
- Children’s and Adult services have poor communication systems and information which should be shared and discussed can be missed or misinterpreted.
- Agencies are often not familiar with the specific roles people play and are unsure of who they should be focusing on for example the parent or child.
- PWLD often don’t receive the appropriate or timely assessments they should for example Occupational and Speech and Language Therapies in enough time for correct plans and pro-active work to be carried out.
- Not enough time is given to allow appropriate work to be carried out for example parents who are offered a parenting assessment usually have to work through the same process as another parent; different levels of comprehension and ability are not considered The assessment is only altered if someone argues successfully enough on that parents behalf.

- Agencies working with PWLD often don't have specific experience or training in Learning Disabilities as the focus is on the parenting skills.
- Lack of resources for example appropriately trained staff/time/accessible information/computer software to assist with accessible information are major issues. Much of our work needs to be consistent and intensive and without the resources the work can become a "fire-fighting" exercise.

I have started a research project (with a Speech and Language colleague) to try and obtain information from agencies who work with PWLD. The project is to try and gather clear, concise information on how our area supports PWLD. It is also to highlight any difficulties or problems agencies may encounter.

Miss Heather Crozier
Community Learning Disability Nurse
