



House of Lords  
House of Commons  
Joint Committee on  
Human Rights

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

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**Seventh Report of Session 2007–08**

*Volume I*





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***Volume I***

*Report and formal minutes*

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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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### Current Staff

The current staff of the Committee are: Mark Egan (Commons Clerk), Bill Sinton (Lords Clerk), Murray Hunt (Legal Adviser), Angela Patrick and Joanne Sawyer (Committee Specialists), Jackie Recardo (Committee Assistant), Karen Barrett (Committee Secretary) and Jacqueline Baker (Senior Office Clerk).

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## Summary

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There are growing numbers of adults with learning disabilities in the UK. The extent to which the rights of adults with learning disabilities are being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles. The Committee's inquiry was extended and wide-ranging. The Committee wanted to ensure that its inquiry was accessible and relevant for adults with learning disabilities. This Report is accompanied by an Easy Read summary and an audio version of that summary (paragraphs 1-15).

Despite marked improvements in the past thirty years in the lives of adults with learning disabilities, including the closure of long stay hospitals, there have been a number of recent failures in healthcare, including cases of abuse, neglect and ill-treatment of adults with learning disabilities. These, and a number of recent high profile criminal cases, appeared to confirm that adults with learning disabilities are particularly vulnerable to breaches of their human rights (paragraphs 16-29).

The Committee's inquiry received evidence principally from witnesses in England, and so focuses on the policy framework in the 2001 Government White Paper *Valuing People*. This is based on rights, independence, choice, inclusion and a programme of change, but progress has slowed and there is a gap between the Government's policy and the experiences of people in their daily lives. The Committee expects the Government to give the recommendations in this Report serious consideration when it redrafts the current consultation document *Valuing People Now*. It recommends that *Valuing People Now* should promote a "human rights based approach" and provide practical guidance to public authorities on how human rights principles can be used to secure better treatment (paragraphs 30-43).

The evidence seen by the Committee shows it is still necessary to emphasise that adults with learning disabilities have the same human rights as everyone else. It recommends action to promote awareness and a positive approach to the rights of adults with learning disabilities under the Disability Discrimination Act 1995 (as amended) and the Human Rights Act 1998. The Committee recommends that the Equality and Human Rights Commission and the Government should take steps to help adults with learning disabilities understand what these provisions mean for them. The Committee welcomes the decision of the Government to sign the UN Convention on the Rights of Persons with Disabilities, which presents a valuable opportunity to confirm that people with disabilities, and particularly adults with learning disabilities, are entitled to full respect for their human rights. The Committee recommends the Government should ratify this Convention, and its Optional Protocol, without delay (paragraphs 44-77).

Evidence to the Committee suggests that adults with learning difficulties are more liable to social exclusion, poverty and isolation, and that efforts to improve their lives have had little impact on some. The evidence suggests that public authorities, including local authorities and PCTs, are not fully committed to the implementation of the Government's policy in *Valuing People* and that limited resources are undermining attempts to implement the aims of that policy effectively. The Committee recommends the introduction of a positive duty on public authorities to promote respect for human rights. Taking a positive and proactive

approach to the creation of a culture of human rights will encourage a move away from negative attitudes and stereotypes which have “dehumanised” adults with learning disabilities in the past (paragraphs 78-134).

The Committee is concerned that adults with learning disabilities in health and residential settings suffer neglect, abuse, discrimination and indifference. Although the Committee welcomes the announcement by the Department of Health of an independent inquiry into the healthcare of adults with learning disabilities, it considers that the Department of Health could do much more to promote culture change and a human rights-led approach (paragraphs 135-158).

Evidence to the Committee suggests that children of people with learning disabilities are more likely to be removed from the care of their parents. These removals, unless justified and proportionate to a risk to the child, may lead to a serious risk of a breach of the rights of the child and its parents to respect for their private and family lives, as guaranteed by Article 8 ECHR. The Committee recommends proactive and positive action by the Department of Health (paragraphs 159-181).

Witnesses raised significant concerns about the human rights of people with learning difficulties in the criminal justice system. Evidence suggests that people with learning disabilities are very concerned about crime, including hate crimes against people with learning disability. Witnesses told the Committee that people with learning disabilities are not taken seriously and lack confidence in and understanding of the criminal justice system. Witnesses told us that adults with learning disabilities may sometimes serve longer custodial sentences than others convicted of comparable crimes (paragraphs 182-217).

In the Committee’s view, more should be done to reduce barriers to the enjoyment of ordinary life by people with learning difficulties including through the production of more accessible information and independent advocacy, as well as by measures in relation to areas such as voting, communications equipment and support services. It recommends legislation to ensure that all providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights (paragraphs 218-292).

The Committee’s recommendations in this report are based on its view that stronger leadership is urgently needed to create a more positive culture of respect for human rights in the United Kingdom. It calls for practical steps to be taken to promote the rights of adults with learning difficulties in mainstream public services. It considers that the Department of Health and the Office for Disability Issues should work closely together, including to ensure effective cross Government work to place the aims of *Valuing People* in the mainstream and to ensure respect for the human rights of adults with learning disabilities. It encourages the Equality and Human Rights Commission to ensure that the voices and views of adults with learning difficulties play a central role in its work (paragraphs 293-303).

# 1 Introduction

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## Our inquiry

1. The number of adults with learning disabilities in the United Kingdom is growing. People with learning disabilities are generally living longer. More premature babies and children with learning and other disabilities are surviving into adulthood.<sup>1</sup> Recent figures show that spending on social care for adults with learning disabilities doubled during the past decade, yet there has been a growing campaign recently for increased funding as services struggle to cope with demand.<sup>2</sup> The first national survey of people with learning disabilities found that adults with learning disabilities are often socially excluded, have little control over their own lives, and were “more likely than others to have bad things happening in their lives”.<sup>3</sup>

2. Human rights apply to everyone. We have chosen in our recent thematic inquiries to focus on groups which are particularly vulnerable; whose members may have difficulty speaking up for their rights; or who may have difficulty understanding when their rights under equality, human rights and other legislation are being breached. Over the past two years, stark reports on the treatment of adults with learning disabilities in health and social care settings have been published, by the Healthcare Commission and the Commission for Health and Social Care, Mencap and the Disability Rights Commission. Each of these reports raises substantive issues about the compatibility of such treatment with human rights and equality law under the Human Rights Act 1998 (“HRA”) and the Disability Discrimination Act 1995 (as amended), the European Convention on Human Rights (“ECHR”) and other international legal standards. We most recently considered these issues in relation to the treatment of older people in healthcare, in our Report on Older People in Healthcare.<sup>4</sup> In this inquiry, however we have chosen to consider a broader range of issues of relevance to adults with learning disabilities.

3. The extent to which the rights of adults with learning disabilities are currently being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles. It also raises other important issues of substantive human rights law such as the right to life (as guaranteed by Article 2 ECHR), the prohibitions on inhuman and degrading treatment (Article 3 ECHR) and unjustified discrimination (Article 14 ECHR), and the right to respect for private and family life (Article 8 ECHR). The treatment of adults with learning disabilities by the criminal justice process may engage the right to a fair hearing (Article 6 ECHR) and due process, and the right to liberty (Article 5 ECHR), rights that are also protected by our common law. A number of inquiries and campaigns about the rights of adults with learning disabilities have recently adopted

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<sup>1</sup> Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century, Department of Health, Cm 5086 (“*Valuing People*”).

<sup>2</sup> Care Services Improvement Partnership, “Getting to grips with commissioning for people with learning disabilities”, April 2007.

<sup>3</sup> National Statistics and Health and Social Care Information Centre; Adults with Learning Difficulties in England 2003/04, published on 28 September 2005. (“*The National Survey*”).

<sup>4</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I.

the title “A life like any other”, or variations on that theme.<sup>5</sup> We have decided to use this inquiry to question whether we are meeting our obligations to respect the human rights of adults with learning disabilities and whether, as a result, adults with learning disabilities in the United Kingdom are likely to be able to lead ordinary lives.

## Learning disabilities or learning difficulties?

4. This inquiry also challenged us as parliamentarians to ensure our inquiry was accessible and relevant for adults with learning disabilities. We made the early decision that we wanted to take evidence directly from a range of people with learning disabilities and to reach as many people as possible during our inquiry. We wanted to work in a way which was accessible and enabled people to tell us their views. A summary of this Report and its conclusions and recommendations is being published in Easy Read, and in an audio format, as part of this process.

5. The first problem we faced was whether to talk about “learning disabilities” or “learning difficulties”. We know that some people prefer the term “learning disabilities” and others prefer the term “learning difficulties”. We have used the term “learning disabilities” in the title of our inquiry to reflect the language used by the Government in its policy papers and used by the Disability Rights Commission in its work. We considered that this term would avoid any confusion with specific learning difficulties associated with education such as problems faced by children and adults with dyslexia. We used the term learning difficulties when working with witnesses who used this term themselves.

6. We are aware that there are a number of debates over the definition of learning disability. We did not adopt a specific definition in our call for evidence, but have been guided in writing this report by the definition set out in *Valuing People*, the English learning disability White Paper, issued by the Department of Health in 2001, namely that 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.”<sup>6</sup>

7. This definition covers people with an autistic spectrum disorder who also have learning disabilities, but excludes those with average or above average intelligence who have an autistic spectrum disorder, like Asperger’s Syndrome.

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<sup>5</sup> See for example, the Community Care Magazine Campaign: Community Care, 17 May 2007 (“A life like any other”), Healthcare Commission, “A Life like no other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England”, 3 December 2007.

<sup>6</sup> *Valuing People*, paras 1.4 – 1.7.

## Terms of reference

8. We called for evidence on how human rights principles were relevant to the treatment of adults with learning disabilities and how they were treated in their daily lives. In particular we sought evidence on the following issues:

- the provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities and on 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;
- 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 United Nations Convention on the Rights of Persons with Disabilities ("UN Disability Rights Convention") to promote the rights of adults with learning disabilities.

9. With the help of Mencap, we issued an Easy Read version of our press notice. In this, we asked people with learning disabilities to tell us about their experiences. After we published this Easy Read version, some people with learning disabilities contacted us to tell us that our three-month deadline to respond was too short. We issued another press notice to extend this deadline by several weeks. We agreed to accept evidence after the deadline and extended the length of our inquiry to allow people with learning disabilities to participate and tell us their views.

## Evidence and visits

10. In the course of this inquiry, we have received almost 200 separate pieces of evidence and correspondence from a wide range of relevant charities, service providers, non-governmental organisations, carers and families, Government departments and, importantly, directly from adults with learning disabilities. We are grateful for all of the evidence we received. Most of this evidence is published in full in a separate volume to this Report. However, a number of the submissions we received contained detailed information about the experiences of people with learning disabilities or their families; some referred to individual cases and challenges in which they had become involved; a significant number of submissions raised recurring themes. Some people wrote to tell us that they wanted to know more about human rights or to tell us about the support they received. A summary of the themes and stories emerging from the correspondence which we have not published is contained in an Annex to this Report.<sup>7</sup>

11. We commenced our inquiry by taking advice from the British Institute for Learning Disabilities on how we might make the oral evidence sessions more accessible for witnesses with learning disabilities. The transcripts of our oral evidence sessions are published, as

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<sup>7</sup> Annex 2. Most of this unpublished material can be consulted in the Parliamentary Archives.

usual, with this Report. In addition, a detailed note of an informal meeting with witnesses is published in an Annex to this Report.<sup>8</sup>

12. In October 2007, we met with adults with learning disabilities, their supporters and families in a number of different settings. We visited Lewisham College, where we spoke with learners and staff in their School of Supported Learning; we met with members of a local KeyRing Housing and Support Network in South East London; and we visited people with more complex and profound learning disabilities at an HFT (Home Farm Trust) resource centre in Bidford-upon-Avon and at home, in supported accommodation, in Evesham. We also met informally with Lambeth People First Self-Advocacy Group and their supporters at the Palace of Westminster. We are very grateful to all those who assisted us in the course of our inquiry.

### **Structure of our report**

13. In Chapter 2, we consider the policy framework within which services for people with learning disabilities should be provided. In Chapter 3, we consider the relevance of human rights principles for people with learning disabilities. Chapter 4 examines the broad scope of the evidence we received during our inquiry and identifies the key concerns raised with us; it explains how each of these concerns has implications for the human rights of adults with learning disabilities; and considers whether in some circumstances a better understanding of human rights standards could lead to a better life experience for adults with learning disabilities. In Chapters 5, 6, 7, and 8, we look at four areas where human rights concerns were particularly acute: the treatment of adults with learning disabilities in health and residential care settings; the treatment of parents with learning disabilities and their children; access to justice for people with learning disabilities; and the barriers to an ordinary life routinely confronted by people with learning disabilities. In Chapter 9, we consider the practical application of human rights principles to the treatment of adults with learning disabilities and the role to be played by central and local Government and the Equality and Human Rights Commission in promoting the creation of a culture of respect for the human rights of adults with learning disabilities. We set out our principal conclusions and recommendations at the end of this Report. An analysis of the relevant human rights standards is contained in an Annex to this Report.<sup>9</sup>

### **Specialist advisers and acknowledgements**

14. We record our particular thanks to Professor Linda Ward and Camilla Parker, our Specialist Advisers for this inquiry.

15. We also wish to thank Mencap for their assistance in the preparation of our first Easy Read Press Notice and the British Institute of Learning Disabilities for their advice on making our inquiry more accessible to people with learning disabilities.

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<sup>8</sup> Annex 3.

<sup>9</sup> Annex 1.

## 2 Adults with learning disabilities: the key issues

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Human rights abuses are going on every day in our communities suffered by people with learning difficulties and it is time something was done about it.

*Andrew Lee, Director, People First (Self-Advocacy)<sup>10</sup>*

16. There have been marked improvements in the lives and circumstances of adults with learning disabilities in the 30 years between the 1971 White Paper, *Better services for the mentally handicapped*,<sup>11</sup> and its successor in England, *Valuing People*.<sup>12</sup> As Ivan Lewis, MP, Minister of State for Care Services, reminded us:

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.<sup>13</sup>

17. As a result, many fewer people now live in long stay institutions, segregated away from the rest of society. Many more live in ordinary housing in the community. A minority now have paid jobs, some at a senior level including, for example, the National Co-Director of Learning Disabilities at the Department of Health.<sup>14</sup> Noticeable too is the number of people with learning disabilities who are active in self advocacy groups, speaking their views and getting their voices heard, including at inquiries of this kind, something that was unheard of 30 years ago.

18. But this picture of positive change has been tarnished recently by a string of reports and inquiries which have revealed a darker, and more shocking, side to life for some adults with learning disabilities in the 21st century.

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<sup>10</sup> Speaking at the launch of the Learning Disability Coalition; <http://www.learningdisabilitycoalition.org.uk/aboutus.asp>.

<sup>11</sup> Department of Health and Social Security/Welsh Office, *Better Services for the Mentally Handicapped*, Cmnd 4683, 1971.

<sup>12</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm5086, March 2001.

<sup>13</sup> Q 154.

<sup>14</sup> Nicola Smith and Rob Greig are the Co-National Directors for Learning Disabilities. We invited both to give evidence, but Ms Smith was unable to attend. When we refer to the National Co-Director we refer to the evidence of Mr Greig.

## Abuse and neglect

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 the 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 3 day stay. When challenged the hospital responded by stating that they did not know how to feed him.

Scope<sup>15</sup>

19. In July 2006 the Healthcare Commission (HCC) and the Commission for Social Care Inspection (CSCI) published a joint report following their investigation of abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust.<sup>16</sup> The investigation had been prompted by concerns on the part of East Cornwall Mencap Society. The report described many years of abusive practices at the trust including physical, emotional, environmental and financial abuse and the failure of senior trust executives to tackle it. The investigation team found an over-reliance on medication to control behaviour, as well as illegal and prolonged use of restraint. For example, one person spent 16 hours a day tied to a bed or wheelchair. Institutional abuse was widespread. The report spoke of "whole system failure. The mechanisms that should have protected people living in the trust's services failed."<sup>17</sup>

20. In January 2007 the Healthcare Commission published a report following its investigation of learning disability services provided by Sutton and Merton Primary Care Trust.<sup>18</sup> The investigation was undertaken at the request of the Trust's Chief Executive, following a number of serious incidents including allegations of physical and sexual abuse. The report described outmoded, institutionalised, care which had led to the neglect of people with learning disabilities at the Trust, and generally impoverished and unsatisfactory environments, with lack of space compromising people's privacy and dignity. The inappropriate use of restraint was again identified as a serious matter of concern. Institutional abuse was reported to be prevalent in most parts of the service:

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.<sup>19</sup>

21. In the wake of the Cornwall report, the Healthcare Commission embarked on the first audit of NHS and independent specialist inpatient healthcare services for people with

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<sup>15</sup> Ev 79.

<sup>16</sup> Healthcare Commission and Commission for Social Care Inspection, *Joint Investigation into Cornwall Partnership Trust*, July 2006.

<sup>17</sup> *Ibid*, p 62.

<sup>18</sup> Healthcare Commission, *Investigation into the services for people with learning disabilities provided by Sutton and Mersey Care Trust*, January 2007.

<sup>19</sup> *Ibid*, p6.



learning disabilities in England, in order to identify problems in the sector as a whole, as well as examples of best practice (“the Healthcare Commission Audit”). The report, published in December 2007, found that most services for people with learning disabilities provided poor standards of care, with significant institutional failings depriving people of their human rights and dignity in many instances.<sup>20</sup> Services operated below the radar of the healthcare system, with poor leadership, poor training and no framework to measure the performance of services. People were living in poor physical environments, with few choices in how they lived their lives, and isolated from their communities. While the Commission did not find evidence of physical abuse in any service, it did find that insufficient attention was paid to safeguarding vulnerable people across all aspects of their care.

### Failures in healthcare

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 8cm 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 ten days.

*Mencap*<sup>21</sup>

In general, hospitals’ staff attitudes and awareness of the needs of people with learning difficulties are not good. Some staff are patronising and disrespectful and treat people like children ... 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.

*Monica Hunter, Chairperson, People First (Scotland)*<sup>22</sup>

22. In 2006 the Disability Rights Commission (DRC) published the report of its formal investigation into the inequalities in physical health experienced by people with mental health problems and those with learning disabilities, *Equal Treatment: Closing the Gap*.<sup>23</sup> It showed that people with learning disabilities “die younger than other citizens”, and had

<sup>20</sup> Healthcare Commission, *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*, December 2007.

<sup>21</sup> Ev 140.

<sup>22</sup> Ev 321.

<sup>23</sup> Disability Rights Commission, *Equal treatment: Closing the Gap*, 2006.

high rates of unmet health needs, “which may contribute to early death.” The report highlighted a “fatal complacency” in the NHS which had contributed to this situation.<sup>24</sup>

23. In 2007 a report by Mencap, *Death by Indifference*, described the cases of six people with a learning disability who had died, following unsatisfactory treatment while in the care of the NHS.<sup>25</sup> The report argued that “their deaths were avoidable...and occurred because of discrimination, indifference, lack of training and a very poor understanding of the needs of people with a learning disability”.<sup>26</sup> It prompted the Minister for Care Services to comment that there appeared to be “systemic indifference” in the NHS towards people with learning disabilities.<sup>27</sup>

24. Following these two reports, the Secretary of State for Health ordered an independent inquiry into access to healthcare for people with learning disabilities to identify the action needed to ensure adults and children with learning disabilities receive appropriate treatment in acute medical (hospital) care and general primary care. The inquiry was established on 31 May 2007 and is due to report in June 2008.<sup>28</sup> The Health Service Ombudsman for England is also conducting an independent inquiry into each of the six cases highlighted in the Mencap report.

## Victims of crime

In a particularly disturbing murder case involving a man with profound learning difficulties, a teenage girl and two men tortured 38-year-old Steven Hoskin before forcing him to his death from a 100ft viaduct in St Austell, Cornwall ... Yesterday, they were jailed for murder and manslaughter. As well as drugging him with 70 paracetamol tablets, burning him with cigarettes and forcing him to walk around on a dog lead, the offenders made Mr Hoskin confess to being a paedophile before killing him.

*Guardian, Society, 31 July 2007*

25. In the last year there has also been widespread media coverage of the deaths of a number of people with learning disabilities, following serious assaults and abuse. They include Steven Hoskin (see above); Kevin Davies, who was locked in a garden shed in Gloucestershire, where he was beaten, burned and humiliated before he died; Raymond Atherton, who was subjected to a long campaign of physical abuse at the hands of local teenagers before being beaten and thrown into the River Mersey in Cheshire, where he died; and Brent Martin, who was beaten up and left to die on the street in Sunderland. These cases gained public attention.<sup>29</sup> They prompted increased concern on the part of

<sup>24</sup> Ibid, p29.

<sup>25</sup> Mencap, *Death by Indifference*, 2007.

<sup>26</sup> Ibid, p.4.

<sup>27</sup> Community Care Magazine “Government launches inquiry after Lewis speaker of NHS ‘indifference’” 15 March 2007.

<sup>28</sup> *Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, chaired by Sir Jonathan Michael.

<sup>29</sup> See for example; BBC News: ‘Feral boy, jailed for killing’, 3 April 2007 (Raymond Atherton) and BBC News: ‘Boy convicted of £5 bet murder’, 22 January 2008 (Brent Martin).

people with learning disabilities and their organisations about whether the victims had been subjected to crime because they had learning disabilities. The Crown Prosecution Service launched a policy for prosecuting such crimes in February 2007.<sup>30</sup> In December 2007, it was announced that the Home Office planned to produce good practice guidance for the criminal justice system and local authorities to address issues of hate crime against people with learning disabilities.<sup>31</sup>

## Are people with learning disabilities especially vulnerable to infringements of their human rights?

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.

*Speakeasy N.O.W. Self-Advocacy Organisation*<sup>32</sup>

26. In the light of each of these high-profile instances and reports of abuse, ill-treatment and discrimination against people with learning disabilities, we consider that it is timely for Parliament to consider the extent to which the United Kingdom is meeting its domestic and international obligations to respect and protect the human rights of adults with learning disabilities.

27. The evidence we have received confirms that adults with learning disabilities are particularly vulnerable to a lack of respect for their human rights.

- People with learning disabilities may not be aware of their human rights because information about their rights is not easily available in simple, easy to understand formats.<sup>33</sup>
- Expectations have traditionally been low for people with learning disabilities, so that the lack of a job, an impoverished home environment, the absence of social relationships, and a lack of privacy and dignity, are often accepted without comment. As Rob Greig, National Co-Director for Learning Disabilities, told us:

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 ... taught not to have great expectations in life.<sup>34</sup>

- The existence of negative attitudes and prejudice may mean that breaches of their human rights are not treated seriously. For example, Respond, the Ann Craft Trust and Voice UK told us:

<sup>30</sup> Policy for Prosecuting Cases of Disability Hate Crime, Crown Prosecution Service, February 2007.

<sup>31</sup> Department of Health, *Valuing People Now: From Progress to Transformation*, December 2007.

<sup>32</sup> Ev 67.

<sup>33</sup> Ev 232.

<sup>34</sup> Q 120.

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.<sup>35</sup>

- People with learning disabilities are often socially marginalised and isolated. They may live in segregated settings with few, if any, social relationships with people living in the wider community. Infringements of their human rights are thus less likely to be observed or addressed.<sup>36</sup>
- People with learning disabilities tend to be dependent on paid or unpaid carers.<sup>37</sup> This makes it hard for them to challenge the care they receive, even if they feel something is not right.
- Difficulties in understanding and communication may mean that people with learning disabilities may be more susceptible to manipulation and exploitation and so vulnerable to certain kinds of crime and abuse.<sup>38</sup>
- People with learning disabilities are less likely than other people to be aware of whether an action against them abuses their human rights,<sup>39</sup> to make a complaint about any such infringements, or to report a crime against themselves.<sup>40</sup> They consider that they are also less likely to be believed, even if they do so.<sup>41</sup> In the words of one witness:

For many adults with learning disabilities, the violation of their human rights is seen as a normal part of their everyday lives.<sup>42</sup>

28. Witnesses told us that the human rights of some groups of people with learning disabilities are likely to be particularly at risk. These include people with profound and multiple disabilities, who may not be able to communicate through speech;<sup>43</sup> people whose behaviour poses a challenge to the staff and services that work with them;<sup>44</sup> people from black and minority ethnic communities, who may not find accessible information or appropriate and culturally sympathetic support readily available;<sup>45</sup> and people who have been placed in service settings many miles away from their families and communities of origin.<sup>46</sup> Our evidence suggests that such people face additional hurdles in securing support for their human rights or in disclosing infringements of them.

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<sup>35</sup> Ev 279, para 1.3.2.

<sup>36</sup> Ev 247. See also the *National Survey*, Executive Summary, Pages 4 – 11.

<sup>37</sup> Ev 233.

<sup>38</sup> Ev 99; Ev 205, page 6.

<sup>39</sup> Q 2.

<sup>40</sup> Ev 247, Ev 411.

<sup>41</sup> Ev 247.

<sup>42</sup> Ev 247, para 1.1.

<sup>43</sup> Ev 203.

<sup>44</sup> Ev 79.

<sup>45</sup> Ev 216; Ev 222.

<sup>46</sup> Ev 245.

29. In this report we include short examples, or stories, from the evidence we received to illustrate the wide range of ways in which the human rights of people with learning disabilities are not being respected, despite the positive developments in policies affecting people with learning disabilities in the last few years.

## The policy context

30. The overall direction of policy guiding services for people with learning disabilities is similar in all four nations of the UK – a commitment to enabling people with learning disabilities to live as equal citizens in the community alongside their non-disabled peers, with choice and control over their lives, and the support they need to enable this. This policy is set out in England in *Valuing People*,<sup>47</sup> in Scotland in *The Same as You?*<sup>48</sup> and in Wales in the recent *Statement on Policy and Practice for Adults with a Learning Disability*.<sup>49</sup> In Northern Ireland, The Bamford Review of Mental Health and Learning Disability published its final report on legislative reform (including proposals on mental capacity legislation) in August 2007.<sup>50</sup> This was the last of a series of 11 reports produced over a period of five years, including *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland* in September 2005, *Human Rights and Equality of Opportunity* in October 2006, and *Promoting the Social Inclusion of People with a Mental Health Problem or a Learning Disability* in August 2007. The values base and overall policy goals in the four countries are similar, though only the Northern Ireland reports refer explicitly to human rights to any degree. The service frameworks for implementing policy on the ground differ from country to country.

**31. We received evidence from across the UK, but most was from organisations and individuals in England. Consequently, this Report will focus largely on the policy framework in *Valuing People*. However, the human rights standards discussed in this Report are universal. We consider that most of the conclusions that can be drawn from the evidence are equally relevant to all four countries of the UK. Equally, we hope that our recommendations and conclusions will inform the development of policy and practice by each of the devolved administrations, as well as central Government.**

32. Our concern, is that the provisions of the Human Rights Act have not been implemented effectively, or with adequate guidance from Government. As a result, the Act has been insufficiently understood and applied.<sup>51</sup> By taking a positive approach to their human rights obligations under the Human Rights Act, the Disability Discrimination Act (as amended) and the common law, public authorities could improve the delivery of public services for all, particularly for vulnerable groups for whom they should offer protection, like adults with learning disabilities. We consider that the creation of a culture of respect

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<sup>47</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm 5086, March 2001.

<sup>48</sup> Scottish Executive, *The same as you? A review of services for people with learning disabilities*, 2000.

<sup>49</sup> Welsh Assembly Government, *Statement on Policy and Practice for Adults with a Learning Disability*, 2007.

<sup>50</sup> The Bamford Review of Mental Health and Learning Disability (Northern Ireland), *A Comprehensive Legislative Framework*, August 2007.

<sup>51</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 67.

for human rights will help lead towards a society where everyone, including adults with learning disabilities, is treated fairly, with equality and with dignity.

### Where we are now: Are we valuing people?

33. Since 2001, the delivery of services and support for adults with learning disabilities in England has been framed by the cross government *Valuing People* White Paper.<sup>52</sup> Its key message was that people with learning disabilities are, above all else, people and citizens. The role of public services was to help them live full and equal lives in the community. The White Paper had at its heart four underlying principles – rights, independence, choice and inclusion – and an ambitious programme of work to deliver change in these areas. This included commitments to reducing health inequalities, increasing the range and choice of housing available, modernising day services and increasing access to employment. New mechanisms for delivery were also introduced, such as person centred planning, health action planning for individuals, and the establishment of multi-agency Learning Disability Partnership Boards in local areas. All these provisions should have improved the chances of people with learning disabilities becoming enabled to enjoy their human rights. The lack of explicit reference to human rights in the White Paper (apart from a passing reference to the Human Rights Act 1998, along with other relevant legislation, in the section entitled “Our Values”) is noticeable and unfortunate, given the White Paper’s vision that:

All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary.<sup>53</sup>

34. Despite the good intentions of *Valuing People*, and the positive reception to it in the field, a review of progress on its implementation four years later, entitled *The Story So Far*, revealed that not much had changed for many people.<sup>54</sup> Many mainstream public services had not taken its messages on board. Some groups (like those with complex support needs) had missed out on progress. Perhaps, most significantly, the review pointed out that:

Most people’s lives are still not what a non-disabled person would say was OK for themselves. Society is beginning to understand that people are equal citizens – but making this real is quite a long way off.<sup>55</sup>

35. *The Story So Far* revealed progress in some areas. People were being listened to more both about their individual lives and in service planning. Person centred planning, done properly, was making a difference to people’s lives. The Supporting People programme (designed to help vulnerable people retain their housing tenancies) had helped many to live more independently.<sup>56</sup> Direct payments (through which people were given the cash

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<sup>52</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm 5086, March 2001.

<sup>53</sup> *Ibid*, para.2.2.

<sup>54</sup> Valuing People Support Team, *The Story So Far*.,2005.

<sup>55</sup> *Ibid*, para 1.4.

<sup>56</sup> Department of Health, *Valuing People Now*, para 1.6.

equivalent of the cost of the services they were assessed as needing, so they could purchase their own choice of support) had helped to change some people's lives.<sup>57</sup> But in other areas (eg access to paid work and to good quality healthcare) progress had been disappointing.<sup>58</sup>

36. In May 2007, the Government announced its decision to “refresh” its policy with the publication of *Valuing People Now* – a consultative draft of the Government's intentions for improving services for people with learning disabilities between 2008 – 2011.

37. *Valuing People Now* was published after our inquiry concluded and we have not taken evidence on the substance of the consultation document. The Government's consultation process will finish at the end of March 2008.<sup>59</sup>

38. *Valuing People Now* identifies five priorities for action: “... personalisation, what people do during the day, better health, access to housing and making sure that change happens”.<sup>60</sup> A table at the end of each section summarises the different goals, and how progress on each will be measured. **In the light of the evidence which we received on the gap between the aims of *Valuing People* and the experience of adults with learning disabilities, which we consider below in Chapter 4, we are concerned that in *Valuing People Now* there appear to be few measurable targets for action nor precise proposals for monitoring progress on their achievement.**

39. The Minister for Care Services reassured us that this document would focus on human rights.<sup>61</sup> We were disappointed that references to human rights are noticeably absent from the main body of the document, although their salience to what is proposed is recognised in the Secretary of State for Health's “Foreword”:

There is no question that it is a human rights issue that all people with learning disabilities [should] have the choices and control over their lives that so many of us take for granted – a life like any other.<sup>62</sup>

40. **We are pleased to note that the Government is committed to “fully consider and respond to the conclusions” of our Report in the course of formulating their priorities for 2008 - 2011. We expect the Government to give the recommendations and conclusions of our Report serious consideration during preparation of the final version of *Valuing People Now* and in setting its priorities for action for the next three years. We consider that *Valuing People Now* presents a valuable opportunity for the Department of Health to take a positive approach towards the promotion of the understanding and protection of the human rights of adults with learning disabilities. We recommend that, when redrafted after consultation, *Valuing People Now* should explicitly promote a “human rights based approach” to public authorities' duties under**

<sup>57</sup> Ibid, para 1.7

<sup>58</sup> Ibid, para 9.2.9.

<sup>59</sup> Ibid, para 9.2.9.

<sup>60</sup> Ibid, 2007, Foreword.

<sup>61</sup> Q 187.

<sup>62</sup> Department of Health, *Valuing People Now*, Foreword.

**the Human Rights Act; and should provide practical guidance for public authorities on the effective implementation of those duties.**

41. A number of other Government policy proposals have been relevant to our work on this inquiry. The core issue of increasing people's choice and control is central to the government's strategy on *Improving the Life Chances of Disabled People*, both generally and in its wider plans for health and social care reform, contained in *Our Health, Our Care, Our Say*. The former report established the cross government Office for Disability Issues ("ODI") which will publish its five year Independent Living Strategy in 2008. Both reports made commitments to modernising social care and developing independent budgets to give people more choice and control over the supports they need to live independently. "Independent living" was defined as:

all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.<sup>63</sup>

42. We note that a number of new Government proposals have been announced during the progress of this inquiry. For example, in December 2007, after the conclusion of our evidence taking, the Secretary of State for Health announced the government's vision and commitment for the transformation of Adult Social Care. This was to "set out and support the Government's commitment to independent living for all adults" so that:

Over time, people who use social care services and their families will increasingly shape and commission their own services. Personal budgets will ensure people receiving public funding use available resources to choose their own support services.<sup>64</sup>

43. Against the backdrop of this and other policy developments, designed both to improve the choice and control exercised by people with learning disabilities over their support, and to safeguard them where they are vulnerable, there has nonetheless been substantial evidence of strain on local services and carers. Increasing numbers of local authorities have tightened their eligibility criteria as a result of resource constraints and an increase in the numbers of people with learning disabilities needing support. *Valuing People Now* includes a commitment to "work to fully assess the impact of the increasing numbers of people with learning disabilities on demand for, and therefore the cost of, services" but makes no reference to the issue of tightening eligibility criteria. We return to this issue in Chapter 4.

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<sup>63</sup> See Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People*, January 2005, p 17. This is based directly on definition adopted by the Disability Rights Commission.

<sup>64</sup> Department of Health, *Putting People First: a shared vision and commitment to the transformation of adult social care*, December 2007, Press Notice, 10 December 2007.



### 3 Why do human rights matter?

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Training around rights will help people with learning disabilities to get their human rights.

*Cornwall People First*<sup>65</sup>

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 we have over our everyday lives.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>66</sup>

44. In the rest of this Report, we consider the treatment of adults with learning disabilities, and the evidence we have received. **We are disappointed that, at the start of the 21st century, almost ten years after the introduction of the Human Rights Act, and over a year since the introduction of the Disability Equality Duty, this evidence convinces us that we need to emphasise that adults with learning disabilities have the same human rights as everyone else; and that they are entitled to freedom, respect, equality, dignity and autonomy in their everyday lives.** In an Annex to this Report, we outline the various human rights laws and standards which are relevant to our inquiry. In that Annex, we refer not only to the provisions of the Human Rights Act and to the common law, but also to the provisions of the Disability Discrimination Act (as amended), including the positive Disability Equality Duty and the UN Disability Rights Convention.

#### What does the Human Rights Act add?

45. We have consistently expressed our view that the Human Rights Act is important in the development of institutional and Government policies and practices, and in the improvement of public services.<sup>67</sup> For example, in our Report on the *Human Rights of Older People in Healthcare*, we said:

We see the purpose of the Human Rights Act, not as an end in itself, but as a tool that can and should be used in law, policy and practice to enable [...] social justice goals to be achieved.<sup>68</sup>

46. We consider that the Human Rights Act provides ‘a legal framework for service providers to abide by and empower service users to demand that they are treated with

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<sup>65</sup> Annex 2, para 10.

<sup>66</sup> Q 1.

<sup>67</sup> See for example, Sixth Report of Session 2002-03, *The Case for a Human Rights Commission*, HL 67-1, HC 489-I, para 9.

<sup>68</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 69.

respect for their dignity'.<sup>69</sup> The Human Rights Act empowers users of public services who may be placed in situations where they are vulnerable to abuse. We consider that these conclusions apply with equal force to people with learning disabilities.

47. Joanna Perry, from Values into Action, put it well when she told us:

Sometimes for staff, in particular staff working 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 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.<sup>70</sup>

48. She gave us the example of a man who liked to go out in his garden, but who also liked to make a lot of noise. The neighbours complained and the response of his care home staff was to keep him indoors:

We helped the staff use the framework of human rights, which puts everyone's rights on the same footing, to see how his rights were equal to the neighbour's rights ... and to come to a compromise. The staff [went from] 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 from day-to-day stuff like that to life and death decisions.

49. The National Co-Director for Learning Disabilities told us that adopting a rights based approach to *Valuing People* was right. He explained:

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.<sup>71</sup>

50. Witnesses told us human rights had a role to play, but that there were a number of barriers to a better deal for adults with learning disabilities.<sup>72</sup> These included failure by Government to secure the effective implementation of *Valuing People*, lack of funding, and negative attitudes (which we consider in Chapter 4, below).

51. We recognise that it may be particularly difficult to empower people with learning disabilities to speak up for their rights under the Human Rights Act. As Andrew Lee, Director, People First (Self-Advocacy) told us:

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.<sup>73</sup>

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<sup>69</sup> Ibid, para 93.

<sup>70</sup> Q 69.

<sup>71</sup> Q 119.

<sup>72</sup> Qs 8-9.

<sup>73</sup> Q 2. See also Ev 233.

52. We consider that it is part of the role of Government to ensure that human rights principles and standards are accessible. Particular steps may need to be taken to ensure that adults with learning disabilities are assisted to understand human rights, including through the provision of accessible information and advocacy (which we consider below in Chapter 8). Values into Action told us that their “Rights into Action” project had worked with adults with learning disabilities and had:

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.<sup>74</sup>

53. **We recently made a number of recommendations to Government on “the transformative power of the Human Rights Act”. In plain English, we told the Government and others what we thought they needed to do to make the Human Rights Act work for everyone. We have called upon the Government, the Equality and Human Rights Commission, other public bodies and voluntary organisations to champion publicly how a better understanding of human rights principles could improve health and social care services.** Specifically, we recommended that the Equality and Human Rights Commission as part of their duty to “promote understanding of human rights” should ensure that this understanding is widely disseminated.<sup>75</sup> **We consider that when fulfilling this duty, the Equality and Human Rights Commission has a responsibility to engage proactively with those who are most vulnerable to breaches of their human rights and those who are less likely to be able to understand what human rights mean for them, including adults with learning disabilities. We recommend that the Commission take steps to ensure that adults with learning disabilities are aware of their rights under the Human Rights Act and the Disability Discrimination Act (as amended).**

54. However, despite the welcome establishment of the Equality and Human Rights Commission, we consider that Government retains a primary responsibility to ensure that we all understand the human rights framework within which they, and service providers, operate. **We recommend that the Minister for Care Services, the Office for Disability Issues and the Ministry of Justice together develop a strategy on how to help vulnerable people, including adults with learning disabilities, understand what the statutory duties in the Human Rights Act and the Disability Equality Duty mean for them.**

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<sup>74</sup> Q 49.

<sup>75</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I

## Disability, equality and human rights

The Disability Equality Duty is, in my opinion, possibly the single most important piece of policy or legislation that could impact upon the lives of people with learning disabilities, more so than the *Valuing People* policy itself ... The difficulty I see at the moment is there is a low level of awareness of the Disability Equality Duty across the country.

*The National Co-Director for Learning Disabilities*<sup>76</sup>

55. The important connection between human rights and equality was emphasised by the Minister for Disabled People in her evidence to this inquiry:

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 ... is fully consistent with the [UN Disability Rights Convention] aim of protecting disabled people's human rights.<sup>77</sup>

**56. We consider that the statutory duties under the Disability Discrimination Act (as amended), and specifically, the Disability Equality Duty, complement the HRA. Together they form a powerful means of effecting positive change. If both are understood and implemented properly they can underpin and promote the agenda set by the Government for improving the life chances of people with learning disabilities.**

57. Unfortunately, a number of our witnesses confirmed that there is a low level of awareness of the implications of the Disability Equality Duty among people with learning disabilities, their carers and supporters and, more worryingly, on the part of service providers and public authorities. Ms Eve Rank, Disability Rights Commissioner, gave a helpful illustration:

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.<sup>78</sup>

58. She added:

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

<sup>76</sup> Q 135.

<sup>77</sup> Ev 388, para 11.

<sup>78</sup> Q 27.

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.<sup>79</sup>

59. We asked the Minister for Disabled People to explain why, given that the Disability Equality Duty is so important for adults with learning disabilities, there was so little awareness of the requirements of the duty among public authorities. She told us that there was a distinction between awareness and compliance with the duty at a “high level within public authorities”, and formal compliance by, for example, “the publication of a disability equality scheme, etc”, and “a bigger issue” of cultural change. She explained that although the purpose of the Disability Equality Duty was cultural change, radical change could not happen overnight.<sup>80</sup>

**60. We are concerned that, one year after the introduction of the Disability Equality Duty, the evidence we have received suggests a clear distinction between formal compliance by public authorities and a failure to take a positive approach to the duty on the ground.** Despite the Minister’s reassurance that the Government did not consider compliance with the Disability Equality Duty should be a “tick-box” exercise, we are concerned that without proactive work on the part of the Office for Disability Issues and the Equality and Human Rights Commission, this is precisely what will happen. We welcome the commitment of the Minister for Disabled People to work together with the Equality and Human Rights Commission to ensure that the Disability Equality Duty “is not left on a pile somewhere”.<sup>81</sup> However, when we asked for the Government’s plans to improve awareness and ensure positive compliance, we were disappointed to see that the plan includes Ministerial speeches and a “new wave” of other unspecified “activities”. **We recommend that the Office for Disability Issues work closely with the Equality and Human Rights Commission to champion publicly a broad, positive approach to the Disability Equality Duty. This should involve a strategy to ensure that other public bodies, and their staff, understand how the proactive implementation of the duty can improve service provision for adults with learning disabilities and others.**

61. Throughout this inquiry witnesses have highlighted the importance of the Disability Equality Duty and its huge potential to bring about positive change to the lives of people with learning disabilities. Witnesses expressed their concerns that the proposals in the Government’s Single Equality Bill consultation document concerning the public sector equality duties may weaken the existing disability equality duty.<sup>82</sup> **We urge the Government to ensure that any amendment to existing positive equality duties should strengthen rather than undermine their effectiveness.**

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<sup>79</sup> Ibid.

<sup>80</sup> Q 188.

<sup>81</sup> Ibid.

<sup>82</sup> Department for Communities and Local Government, *Discrimination Law Review A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain*, June 2007. See Annex 3, para 2; Ev 333.

## UN Convention on the Rights of Persons with Disabilities

I don't know much about the Convention on the human rights of people with disabilities but I do feel strongly that everyone with a disability should have equal rights to those who don't have disabilities.

*A person with learning disabilities*<sup>83</sup>

62. The new UN Convention on the Rights of Persons with Disabilities highlights the strong links between human rights and equality. For example Article 4 (General obligations) provides that States are required to take steps in order to:

Ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

63. The Minister for Disabled People succinctly summed up the importance of this new international human rights treaty:

The Convention is a powerful statement that disabled people are fully entitled to the same human rights and fundamental freedoms as others.<sup>84</sup>

64. Sonia Sceats from British Institute of Human Rights ("BIHR") told us that ratification of the UN Disability Rights Convention:

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 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.<sup>85</sup>

65. Inclusion International, an international organisation which represents the interests of people with learning disabilities, told us:

For people with [learning disabilities] and their families, the challenge of this Convention will be to have State parties and other groups recognise that the Convention includes and must protect the rights of people who cannot speak for themselves....For people with [learning 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 structures and organised in order to be inclusive.<sup>86</sup>

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<sup>83</sup> Annex 2, para 11.

<sup>84</sup> Q 155.

<sup>85</sup> Q 73.

<sup>86</sup> Ev 190-191. The quote refers to "intellectual disabilities", a term used by some international organisations to refer to learning disabilities.

**66. We agree that the UN Disability Rights Convention presents a valuable opportunity to confirm that disabled people, including adults with learning disabilities, are entitled to full respect for their human rights.**

67. The United Kingdom has signed the Convention, but has not ratified it. Having stressed the importance of the UN Disability Rights Convention to us, Anne McGuire MP, Minister for Disabled People commented:

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.<sup>87</sup>

68. In her evidence, the Minister told us that it was the Government's intention to ratify the Convention by the end of 2008.<sup>88</sup>

**69. We welcome the Government's commitment to ratify the UN Disability Rights Convention. However, we are mystified by the reason given for the Government's delay in ratifying this treaty.** We wrote to the Minister earlier this year calling on the Government to ratify the Convention and asking for a timetable for ratification.<sup>89</sup> The Minister told us that this was the first human rights treaty that the Government had considered under "which organisations like the European Community share competence with Member States". She explained that "there is a need to coordinate action with the Community...and with other member states ... So the timetable is not within our control".<sup>90</sup> When we asked the Minister to explain whether there were barriers to ratification, such as to cause delay till the end of 2008, she told us: "we also have to ensure that we are in fact compliant and can meet our responsibilities". She said told us that she couldn't tell us about any specific barriers to ratification, but that she was working on plans for ratification with other departments.<sup>91</sup>

**70. We recommend that either the Government ratifies the UN Disability Rights Convention and its Optional Protocol without further delay, or provides clear and unambiguous details of any specific impediments to immediate ratification. We will continue to monitor progress towards ratification. We will be deeply concerned if the Government does not meet the goal that the Minister for Disabled People has set, namely, ratification before the end of 2008.**

## Independent living and human rights

71. Earlier in this chapter we referred to 'independent living', adopting the Disability Rights Commission's definition. Many of our witnesses told us that a right to "independent

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<sup>87</sup> Q 155.

<sup>88</sup> Ibid.

<sup>89</sup> Ev 385.

<sup>90</sup> Ev 386.

<sup>91</sup> Q 190.

living” was important for people with learning disabilities. Some expressed their support for a Private Member’s Bill, the Independent Living Bill, introduced by Lord Ashley of Stoke.<sup>92</sup> For example, both the Disability Rights Commission and Andrew Lee, Director, People First (Self-Advocacy), told us how important they thought this Bill was, as it secured the right of people with learning disabilities to support for independent living.<sup>93</sup>

72. One of our witnesses, Rescare, expressed some concern about the term, ‘independent living’, emphasising that not everyone can live independently. Rescare told us that the extent of the dependency of some people with learning disabilities is often overlooked in considering supported or independent living.<sup>94</sup> When we refer to independent living, we refer to the Disability Rights Commission interpretation, which promotes choice and autonomy for people with disabilities in their daily lives. This may mean different things for different people. It should not be confused with situations where people with learning disabilities have been moved to supported living in the community without adequate support. One of the first things that we learned in this inquiry was that a “one size fits all approach” was not appropriate.

73. We consider that the principles of independent living and promoting the participation of disabled people in community life are core themes of the UN Disability Rights Convention. It has a clear basis in other human rights standards and principles, such as freedom, equality and autonomy. Article 19 (Living independently and being included in the community) of the UN Disability Rights Convention provides that States:

[...] recognize the equal right of all persons with disabilities to live in the community, with choices equal to others and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

74. Sonya Sceats, Policy Officer at BIHR put it well when she said that the concept of independent living ‘is something that you can find resonating in the text of the UN Convention’.<sup>95</sup>

75. The Minister for Disabled People told us:

“All of our policies at the moment are driving towards independent living.”

76. The Minister for Care Services added:

“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.”<sup>96</sup>

**77. We welcome the commitment expressed by the Minister for Care Services and the Minister for Disabled People, to the principle of independent living. We await the**

<sup>92</sup> See for example Ev 85, Ev 289.

<sup>93</sup> Q 1 (Andrew Lee), Q 11 (Andrew Lee), Q42 (Mr Shrimpton)

<sup>94</sup> Annex 3, para 17-18 (Richard Jackson, Rescare); Ev 55.

<sup>95</sup> Q 74.

<sup>96</sup> Q 177.



**results of the Government's Independent Living Review, with interest. We recommend that the Government consider the outcomes of that review, and the need for any further policy or legislative change, as part of their commitment to review the UK's domestic compliance with the UN Disability Rights Convention.**

## 4 Living with a learning disability

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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.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>97</sup>

I moved to [a new home]... where people were bad the staff said they could not stay up. I was there 8 years. I used to run away – it was hell there it was like a prison.

*A person with learning disabilities*<sup>98</sup>

78. We heard examples of both good and bad experiences and received evidence on most aspects of life with a learning disability, including:

- access to public and other services (e.g. access to healthcare, education, transport, benefits, social care and support);<sup>99</sup>
- access to housing and choosing where to live;<sup>100</sup>
- access to paid employment;<sup>101</sup>
- relationships with friends and family and sexual or other personal relationships;<sup>102</sup>
- participation in decision-making, speaking up and making complaints;<sup>103</sup>
- playing a part in the local community.<sup>104</sup>

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<sup>97</sup> Q 1.

<sup>98</sup> Annex 2, para 5.

<sup>99</sup> Ev 48, 50, 52, 66, 68, 82, 408.

<sup>100</sup> Ev 55, 84, 92, 110, 116.

<sup>101</sup> Ev 326, 379, 391, 410.

<sup>102</sup> Ev 50, 56, 242, 256.

<sup>103</sup> Ev 116, 219, 238-239, 241, 411.

<sup>104</sup> We have summarised some of the evidence we received from people with learning disabilities, their families and supporters in Annex 2; See also Ev 56.

## Access to public and other services

When group members can't do something they want to or that is important to them, it is usually not because people don't respect their rights but is usually down to lack of staff or other support or having no transport.

*Summary from a submission from a small self advocacy group<sup>105</sup>*

79. We received a good deal of evidence from people with learning disabilities about their experiences of accessing, or trying to access, a whole range of services. On further and continuing education opportunities we heard concerns about restricted provision for some groups, and the lack of progression available.<sup>106</sup> As People First Scotland said: "Most people are sick of 'life-skills' type courses and want to study something that gives them a better chance of getting a job."<sup>107</sup> People also told us about problems they had with transport to college and classes, for example:

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 9.00am which is a problem. Also, if we have electric wheelchairs we are unable to use the public buses even the new low liner ones.<sup>108</sup>

80. We received so much evidence about people's, often negative, experiences of trying to access healthcare, which we consider in Chapter 5. In addition, a number of witnesses drew our attention to the particular difficulties confronting people with learning disabilities in trying to access dentistry services,<sup>109</sup> and in receiving appropriate optical care.<sup>110</sup>

81. A number of witnesses told us about problems in connection with welfare benefits, including problems if they were contemplating starting a job, and, more generally, the lack of easy to understand information and advice available.<sup>111</sup> For example:

The benefits system is hard to understand. There is a lot of jargon and the forms are hard to fill in.<sup>112</sup>

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<sup>105</sup> Annex 2, para 6.

<sup>106</sup> Ev 53, 94, 222, 299, 304, 310, 377.

<sup>107</sup> Ev 327.

<sup>108</sup> Ev 122.

<sup>109</sup> Ev 194, 359, 391.

<sup>110</sup> Ev 373.

<sup>111</sup> Ev 49, 50, 163.

<sup>112</sup> Ev 327.

## Access and choice in housing

I feel so angry, I've got no choice. I want to move, I feel like I'm ready to move. If I said anything to the staff here, they'd say, "no chance", they'd say, "no way".

I said to Mum and Dad I want to leave home. But they said no. They said I can't cook and I can't clean so I can't be on my own.<sup>113</sup>

82. We received evidence about a range of problems here, including lack of choice and control over where people lived and who they lived with,<sup>114</sup> problems over housing benefit, especially where people needed 24 hour support,<sup>115</sup> little security of tenure,<sup>116</sup> and being prevented by staff or family members from moving on to a new place.<sup>117</sup> Some people felt they were inappropriately constrained where they lived: "how many non-disabled people would be punished (not allowed out) if they left a mortgaged or rented home untidy?";<sup>118</sup> others felt more positive about their housing and support experiences:

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 to, 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.<sup>119</sup>

83. We met members of a KeyRing housing network during the course of our inquiry. They told us how important living on their own in the community was to them, they each needed different levels of support to achieve this. KeyRing staff recognised that theirs was not the only good example of housing support, but they were concerned that local authorities sometimes were too cautious in their approach to enabling adults with learning disabilities to live in the community and that limited resources and suitable housing stock were often cited as barriers to allocating suitable support for people with learning disabilities.<sup>120</sup>

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<sup>113</sup> Submission by Dr Alex McGloughlin, School of Social Sciences, Nottingham Trent University, 16 May 2007, enclosing research findings. Available from Parliamentary Archives.

<sup>114</sup> Ev 50, 57, 58, 328.

<sup>115</sup> Ev 52, 110.

<sup>116</sup> Ev 359.

<sup>117</sup> Ev 121.

<sup>118</sup> Ev 382.

<sup>119</sup> Ev 153.

<sup>120</sup> Committee Visit to Lewisham, Meeting with members of South London Keyring Housing and Support networks, 17 October 2007. See also Ev 390 - 392.

## Access to paid employment

We don't feel we have the same chances of getting a job as other people.<sup>121</sup>

You leave special schools without any qualifications and without the skills you need to work<sup>122</sup>

84. We received evidence on the difficulties faced by young people when they left school and wanted to get a job: “they do not receive the same opportunities as their non-disabled peers.”<sup>123</sup> We heard about the benefit problems people faced if they were fortunate enough to get the chance of a paid job. These problems meant people might have to choose not to work at all, or only very reduced hours.<sup>124</sup> We were told that it appeared to be even harder to get a job if you had a learning disability in Northern Ireland.<sup>125</sup>

85. Our visit to Lewisham College School of Supported Learning confirmed these concerns. Both staff and learners told us how difficult it was to access paid employment for people with learning disabilities. These difficulties meant that it was nearly impossible to find work for people with moderate to severe learning disabilities.<sup>126</sup>

## Relationships with friends and family, sexual or other personal relationships

Our carer says we can't kiss (me and my girlfriend). She says ‘we've got to draw the line somewhere’.<sup>127</sup>

86. People told us about their desire for friends and relationships; the difficulties they had in getting out to meet other people (because of lack of support); and the negative attitudes, strictures, lack of opportunities and privacy they confronted, if they wanted to develop close personal relationships or get married. Although we accept the evidence of the Minister for Care Services that the State does not have “a duty to provide people who are lonely with a friend”, we are concerned that in some circumstances, the experiences of people with learning disabilities engage their right to respect for private and family life

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<sup>121</sup> Ev 69.

<sup>122</sup> Ev 237.

<sup>123</sup> Ev 334.

<sup>124</sup> Ev 69, 222, 327, 347, 359.

<sup>125</sup> Ev 323.

<sup>126</sup> Committee Visit to Lewisham, 17 October 2007.

<sup>127</sup> Ev 65.

(Article 8 ECHR) and participation in the life of the community, as guaranteed by the UN Disability Rights Convention.<sup>128</sup> For example, witnesses told us:

We are stuck in at home with not many friends. I would like to go to the pub or to bingo.<sup>129</sup>

and:

People treat you funny. Some won't let you have a relationship. People against us getting married.<sup>130</sup>

87. We welcome the Government's recognition in *Valuing People* that:

Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature.<sup>131</sup>

**88. We recommend that the Department of Health revisit this issue in their redrafted *Valuing People Now*, in light of the evidence we have received.**

## Participation in decision-making, speaking up and making complaints

[We are].. often treated like children.<sup>132</sup>

89. We asked people how easy it was for them to be involved in making decisions about their lives. Some of our witnesses felt that they did have a say in decisions made: these were largely people who were involved in self-advocacy groups, whose experience had given them more confidence to speak up for themselves.<sup>133</sup> Others thought it was hard to have a say, because not enough responsibility was given to them. Other witnesses told us that far from being enabled to make complaints about their treatment, people with learning disabilities could be excluded from day to day decisions and choices about how they lived their lives:

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.<sup>134</sup>

90. Even those who felt they had a say in decision making themselves felt that “people who have more complex needs often do not because people don't know how to communicate

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<sup>128</sup> Ev 49, 50, 56, 58, 67, 184, 222.

<sup>129</sup> Ev 68.

<sup>130</sup> Ev 49.

<sup>131</sup> *Valuing People*, para 7.39.

<sup>132</sup> Ev 50.

<sup>133</sup> Ev 69.

<sup>134</sup> Ev 68.

with them”.<sup>135</sup> Even if people did have a say it did not necessarily mean that the outcome would be what they wanted:

If we receive services sometimes decisions are made because of money not because of what we need.<sup>136</sup>

91. Most people said it was hard to make a complaint, because the system was difficult to understand or because they did not have the confidence to do so. A number of witnesses talked of being too nervous to complain or worried about what would happen to them if they did so: “If we complain we will get into trouble.”<sup>137</sup> Some people felt there was no point complaining because they would not be listened to. “You can tell someone in authority or a parent, but you are not often taken seriously or believed.”<sup>138</sup>

### Participation in the local community

92. A number of witnesses told us that they thought that the lack of support they received was inadequate to allow them to play any part in their local community.<sup>139</sup> We return to this topic in Chapter 8.

### Families and carers

We are unable to go far as there are no disabled toilets in which to attend to his needs. So as a family we are all restricted in the participation in the local community. He is unable to meet with friends or socialise and without us taking him for a local walk or a short drive in his van we would be completely isolated.

*Mother of an adult with learning disabilities on her family’s experiences*<sup>140</sup>

93. It is estimated that there are around 6 million family carers in the UK.<sup>141</sup> Mencap’s report *No Ordinary Life* found that 60% of parents of children and adults with profound and multiple learning disabilities spent more than ten hours a day on basic physical care. 78% of families received either no support at all or less than 2 hours per week.<sup>142</sup> *Valuing People* stressed the important role that family carers play in supporting people with learning disabilities and enabling them to live more fulfilling lives. *Valuing People Now* records the new commitments by Government to improving the circumstances of family

<sup>135</sup> Ev 69.

<sup>136</sup> Ibid.

<sup>137</sup> Submission from Macclesfield Speaking Up Speaking Out Centre. Available from the Parliamentary Archives.

<sup>138</sup> Ev 50.

<sup>139</sup> Annex 2; See also Ev 57.

<sup>140</sup> Annex 2, para 9.

<sup>141</sup> Ev 287.

<sup>142</sup> Mencap, *No ordinary life*, 2001, p.10, cited Ev 204.

carers but notes that 'life for many family carers remains difficult and further action is needed'.<sup>143</sup>

94. We received evidence from a number of witnesses from carers organisations about their experiences of the denial of human rights to their relatives or themselves.<sup>144</sup> Eve Rank and Richard West, two people with learning disabilities who are themselves carers of other people, said:

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.<sup>145</sup>

95. They pointed out that being a carer can have a major impact on the life of the carer and their own ability to lead an ordinary life: '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.' Unable to work (or only able to work reduced hours) because of their caring responsibilities, family carers are often in a poor position financially.<sup>146</sup> But witnesses told us, that 'carers grants and benefits such as council tax relief go unclaimed' because many people who look after a relative with a learning disability do not think of themselves as a 'carer'.<sup>147</sup>

96. The evidence we received from family carers highlighted the concerns felt by them about many of the issues we identify in this report. There was widespread concern about tightening eligibility criteria and the 'postcode lottery' in the provision of support and services; about the introduction of charging for services provided through adult social care, which could mean that families could sometimes no longer afford to continue their use of them; about services focussing on crisis intervention rather than improving people's everyday lives; and about problems with obtaining a Disabled Facilities Grant in order to get adaptations so that an adult with complex needs could have access to a toilet and shower.<sup>148</sup> We heard of family carers who felt that they were invisible to services until there was a crisis at home and of parents being forced to provide all the personal care needed by their relative when they were hospital inpatients, because of the hospital's reluctance to pay for the additional support required.<sup>149</sup> Witnesses told us of the frustrations they experienced in trying to get adequate help for their relative and the difficulties they faced in trying to keep in touch with them if they were moved away from their home community into out of area placements.<sup>150</sup> They pointed out that: 'many families ... act as powerful, long-term advocates for their sons/daughters, but receive little help themselves.'<sup>151</sup> They

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<sup>143</sup> *Valuing People Now*, para 10.1.3.

<sup>144</sup> e.g. Ev 56, 232, 242, 287, 317.

<sup>145</sup> Ev 317.

<sup>146</sup> Ev 287.

<sup>147</sup> Ev 317.

<sup>148</sup> Ev 287.

<sup>149</sup> Committee Visit to HFT Resource Centre, 24 October 2007, discussions with a parent of two adults with learning disabilities.

<sup>150</sup> Ev 245.

<sup>151</sup> Ev 232.



highlighted the fact that if family carers are not adequately supported it will impact on the lives of their disabled sons and daughters and, that if their relative got ill and they got too old to care for them, it would cost public services a lot of money.<sup>152</sup>

97. Although comments are sometimes made about families holding back their relatives with learning disabilities or being ‘over-protective’, the evidence we received suggested that ‘for most people, most of the time, their families are their greatest and most reliable allies.’<sup>153</sup> As the Foundation for People with Learning Disabilities pointed out:

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.<sup>154</sup>

98. Many witnesses expressed concern about continuing poor treatment, isolation and social exclusion and that the experiences of people with learning disabilities in the United Kingdom illustrated a lack of respect for the human rights of adults with learning disabilities.<sup>155</sup> **We are concerned that the experiences communicated to us by adults with learning disabilities, their families and supporters appear to reflect the findings of the last National Survey, that adults with learning disabilities are more likely than other people to suffer from social exclusion, poverty and isolation.**

99. Not every aspect of the lives of adults with learning disabilities fell within the scope of this inquiry. Indeed, some of the evidence we received did not relate to human rights concerns. However, witnesses consistently told us that there were a number of common themes in the treatment of adults with learning disabilities which cut across a range of issues and which were undermining respect for their dignity and human rights:

- the gap between the Government’s policy on the treatment of adults with learning disabilities and the life experiences of many of our witnesses;
- the difficulties experienced by people with learning disabilities in trying to access services and support; and
- the continuing impact of negative attitudes, assumptions and stereotypes around people with a learning disability.

100. We consider how these themes undermine the ability of adults with learning disabilities to secure respect for their human rights; and whether a human rights based approach could lead to change for the better.

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<sup>152</sup> Ibid.

<sup>153</sup> Ev 217.

<sup>154</sup> Ibid.

<sup>155</sup> See for example Ev 298.

## The gap between policy and practice

The white paper *Valuing People* was full of excellent recommendations, many of which have either been paid lip service, or have been ignored completely. There is a feeling amongst professionals that it was a lot of rhetoric without legislative reach to ensure that its recommendations would be put into practice. There is still a huge gap between what was recommended and what actually happens.

*An NHS Clinical Psychologist in Learning Disability Services*<sup>156</sup>

101. Many witnesses expressed their support for *Valuing People*, and for the existing legal framework, including the Human Rights Act and the Disability Equality Duty, but regretted that it has not made much difference on the ground. For example:

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 and a lack of political will to deliver the improvements which the policy framework appears to promise.<sup>157</sup>

and

*Valuing People* was a document that amongst other things states “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 be a lack of commitment within services to change the way they work.<sup>158</sup>

102. In its evidence, the Department of Health accepted the conclusion of *The Story So Far* that “mainstream policy and delivery areas such as employment, housing and education have still not effectively taken on the *Valuing People* agenda”.<sup>159</sup> The National Co-Director for Learning Disabilities told us that the primary reason there was a gulf between the Government’s policy and what was happening to people with learning disabilities was the lack of “levers” for the implementation of 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 on persuading people that they want to make those changes. Obviously things like the Disability Discrimination Act, and in particular, the

<sup>156</sup> Annex 2, para 7.

<sup>157</sup> Ev 136.

<sup>158</sup> Ev 407.

<sup>159</sup> Ev 97.

Disability Equality Duty, add additional new important levers, but I would say that is the major reason.<sup>160</sup>

103. The Minister for Care Services accepted that, although significant progress had been made, work was still necessary to implement the policy effectively.<sup>161</sup> He confirmed that, until now, he had experienced problems promoting the rights of people with learning disabilities, even within his own Department:

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...Beyond that, in terms of 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.<sup>162</sup>

**104. We are concerned by the evidence that the framework for improving the lives of adults with learning disabilities does not appear to have had much impact in Government departments other than the Department of Health or the wider public sector; and that the impact of *Valuing People* on the experiences of adults with learning disabilities in their dealings with local authorities and individual service providers has been so patchy.**

**105. We were dismayed to hear the Minister for Care Services describe the National Director for Learning Disabilities as a “lone-ranger” on mainstreaming learning disabilities, rights and policy even within the Department of Health. We are extremely concerned that the Department, which has responsibility for cross-Government policy on learning disability, has failed to take seriously access to mainstream services for adults with learning disabilities, despite the existence of its statutory duties under the Disability Discrimination Act (as amended), the Disability Equality Duty and the Human Rights Act.**

106. The Minister for Care Services told us that the Government was taking a number of steps to close the gap between rhetoric and reality. He told us that, for the next Comprehensive Spending Review period, the Government had not only agreed the money, but also agreed the performance assessment framework.<sup>163</sup> He said that current funding arrangements had to change, with funding moving away from the NHS to local authorities. He told us that *Valuing People Now* would remind people that:

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 about fulfilling statutory obligations.<sup>164</sup>

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<sup>160</sup> Q 118.

<sup>161</sup> Q 154.

<sup>162</sup> Q 158 (Mr Lewis).

<sup>163</sup> Ibid.

<sup>164</sup> Q163. See also Q164.

107. The Minister told us that *Valuing People Now* would involve Government using the levers that were available at a national level to secure better services locally.

108. **We welcome the Government’s recognition that further work needs to be done to implement policy effectively, so as to support the rights of adults with learning disabilities as individuals. We also welcome the Minister’s frank acknowledgement that more pressure needs to be placed on both central and local Government to deliver the policy of *Valuing People*.**

109. In *The Story So Far*, the National Co-Director explained that some local authorities were happy to treat the policy in *Valuing People* as “optional.”<sup>165</sup> **We are concerned that the National Co-Director for Learning Disabilities and the Government have been searching for “levers” to implement a policy designed to ensure that adults with learning disabilities can live their lives in a way which promotes dignity and respect for their rights. We are particularly concerned that the National Co-Director did not appear to consider that public authorities’ duties under the Human Rights Act would hold much sway. We reiterate our concern that the Department of Health and other Government departments should be proactive in promoting a positive approach to the Human Rights Act and to the Disability Equality Duty. We see the value of using these obligations to support or explain a particular policy choice as a ‘lever’ for implementation. However, this should not undermine the binding nature of these duties.**

## Inability to access services and support

When group members can’t do something they want to or that is important to them, it is usually not because people don’t respect their rights but is usually down to lack of staff or other support.

*A small Bedfordshire self-advocacy group*<sup>166</sup>

110. Many witnesses told us that they believed that the inability of people with learning disabilities to access appropriate services and support was indicative of a fundamental lack of respect for their human rights. In particular, witnesses told us about:

- local authority restrictions on eligibility for support by social services, within the Fair Access to Care criteria (discussed below);
- poor care management and planning; particularly on transition into adulthood (i.e. when responsibility for support moves from children’s services to adult services within local authority social services departments);<sup>167</sup>

<sup>165</sup> *The Story So Far*, Foreword.

<sup>166</sup> Annex 2, para 6.

<sup>167</sup> Ev 53, 74, 76, 94.

- out of area provision of support, away from families and communities, for people with complex and profound learning disabilities;<sup>168</sup>
- difficulties co-ordinating support across local authority boundaries;<sup>169</sup> and
- reluctance on the part of some of local and health authorities, supporters and families to enable individuals to take risks in their daily lives.<sup>170</sup>

## Is it all about the money?

The White Paper *Valuing People* talks about the importance of community presence and participation, but £1.75 per week to spend is not enough to enable anyone to do that.

*Parent and carer of an adult with a learning disability.*<sup>171</sup>

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 in our midst.

*Andrew Lee, Director of People First (Self-Advocacy)*<sup>172</sup>

111. A significant number of witnesses told us that funding for services and support was the key reason that *Valuing People* was not being implemented effectively. Dame Jo Williams, Mencap, told us that more information was required on the need for services and funding, which they hoped to feed into the Comprehensive Spending Review:

The evidence that we have to date 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 are hearing about cuts in services which are affecting people's lives.<sup>173</sup>

112. The evidence we have received on this issue focused principally on access to social and community care services provided by local authorities. Witnesses raised two issues of concern:

- tightening local authority eligibility criteria undermining *Valuing People* and putting the rights of people with learning disabilities and their carers at risk; and

<sup>168</sup> Ev 114, 160-161, 181.

<sup>169</sup> Ev 392.

<sup>170</sup> Ev 219.

<sup>171</sup> Annex 2, para 7.

<sup>172</sup> Q 17.

<sup>173</sup> Q 13.

- inadequate provision for people who could benefit disproportionately from a low level of support, because of the prioritisation of people with more complex support needs.

113. We asked the National Co-Director for Learning Disabilities how the tightening of local authority eligibility criteria would impact on people with learning disabilities and the implementation of *Valuing People*. He told us:

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.<sup>174</sup>

114. When making assessments of need and decisions about service provision, councils must act in accordance with *Fair Access to Care* Guidance, issued by the Secretary of State. In setting eligibility criteria, councils must take account of their resources, local expectations and costs and agreements with the NHS. They should also consult users and others. Councils are advised in *Fair Access to Care* that they “should have regard to” their legal obligations under the Sex Discrimination Act 1975, the Disability Discrimination Act, 1995, the Human Rights Act 1998, and the Race Relations (Amendment) Act 2000.

115. Recent figures released by the Commission for Social Care Inspection show that the proportion of councils planning only to support people with substantial or critical needs was likely to rise from 53% to 62%, before the end of 2007.<sup>175</sup>

**116. Difficult questions about allocation of resources may be involved when deciding whether to provide support in specific cases. However, we consider these questions must be answered within the context of the legal obligations of local authorities and other public authorities, to respect the dignity and rights of service users. Local authorities must act in accordance with the Disability Equality Duty.<sup>176</sup>**

117. We previously considered the positive duties of public authorities under the Human Rights Act in our recent report, *The Human Rights of Older People in Healthcare*.<sup>177</sup> The Government has since rejected our recommendation that it should legislate to make explicit that all public authorities, including councils, are under a positive duty to take active steps to protect and respect human rights, where the ECHR imposes a positive obligation so to do. The Government said that such a positive obligation was unnecessary, in the light of the duties of the Equality and Human Rights Commission to encourage public authorities to comply with the Human Rights Act.<sup>178</sup> **We are deeply concerned about the Government’s negative response to our recommendations on the need for an**

<sup>174</sup> Q 126.

<sup>175</sup> Figures provided following a request by Mencap, published by the Learning Disability Coalition. [http://www.learningdisabilitycoalition.org.uk/news/news\\_9.asp](http://www.learningdisabilitycoalition.org.uk/news/news_9.asp).

<sup>176</sup> The High Court recently ordered Harrow London Borough Council to reconsider a decision to change their eligibility criteria, because they had not shown that they had considered the Disability Equality Duty: *Chavda v Harrow* [2007] EWHC 3064.

<sup>177</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 146 – 153.

<sup>178</sup> First Report of Session 2007-08 ‘Government Response to the Committee’s Eighteenth Report of Session 2006-07: the Human Rights of Older People in Healthcare’ HL Paper 5; HC 72.

**express positive human rights duty for public authorities. The creation of a positive duty to respect human rights would help kick-start a change of attitude to the role of the Human Rights Act and to rights more generally. We doubt that, at least in the short term, oversight by the Equality and Human Rights Commission will encourage individual authorities to take a more proactive approach. On the other hand, witnesses to this inquiry, including the Minister for Care Services and the Minister for Disabled People, stressed their view that the potential impact of the Disability Equality Duty will be to change fundamentally the way that public authorities look at disability rights. We remain persuaded that the same is true of positive duties and the Human Rights Act. We reiterate our recommendation that the Government consider the introduction of an express positive duty on public authorities to promote respect for human rights, where the European Convention on Human Rights imposes a positive obligation on the State.**

118. The Minister for Care Services told us he was not persuaded that we were getting the best use of investment in services for adults with learning disabilities.<sup>179</sup>

119. The National Co-Director for Learning Disabilities told us that increasing respect for the rights of adults with learning disabilities was not principally an issue of expenditure.<sup>180</sup> He explained that a more positive approach to the rights of people with learning disabilities could be achieved by changing attitudes towards learning disability (we consider this issue below). We asked a number of our witnesses about how to make improvements, if no more additional resources were available. Suggestions ranged from increasing awareness of the Disability Equality Duty and the Human Rights Act,<sup>181</sup> through better control over care planning and management, to more individualised support with greater flexibility.<sup>182</sup>

120. We asked the Minister about tightening eligibility criteria and the balance which councils were required to strike between cheaper support for those with low support needs and more expensive intervention when their needs became critical. In the latest Comprehensive Spending Review, the Government committed to a process of consultation on a Green Paper on the long-term funding of social care.<sup>183</sup> *Valuing People Now* proposes the transfer of responsibility for learning disabilities from Primary Care Trusts (“PCTs”) to local authorities. Associated budgets will also be transferred. Only specialist learning disability healthcare commissioning will remain with PCTs.<sup>184</sup> Shortly after giving evidence to us, the Minister for Care Services published *Putting People First*, a proposal for individual, or personalised, budgets for the care and support of elderly and younger disabled people, including adults with learning disabilities.<sup>185</sup> This programme has a ring-fenced budget of £520 million which will be distributed between 150 councils in England, over three years.

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<sup>179</sup> Q 171.

<sup>180</sup> Q 129.

<sup>181</sup> Q 62–3.

<sup>182</sup> Q 20.

<sup>183</sup> *Comprehensive Spending Review*, October 2007, para 6.9.

<sup>184</sup> *Valuing People Now*, 16.2.

<sup>185</sup> *Putting People First: a shared vision and commitment to the transformation of adult social care*, Department of Health, 10 December 2007.

121. The recent initiatives by Government to grapple with funding in social care, particularly in relation to learning disabilities, seem like a step in the right direction, although they were announced at a late stage in our inquiry, after we had finished taking evidence. We heard some positive support for the introduction of individual budgets, but have also heard concerns about the adequacy of those budgets and the need for separate funding for independent, effective brokerage.<sup>186</sup> **We strongly recommend that guidance to local councils should remind them that decisions about funding must be taken in a way which is compatible with the Disability Equality Duty and the Human Rights Act. We recommend that the Government rewrite its Guidance, including *Fair Access to Care*, to ensure it provides clear, straightforward and accessible examples of a human rights based approach, explains how social care funding decisions could lead to a breach of Convention rights and sets out how to comply proactively with the Disability Equality Duty.**

### Negative attitudes, assumptions and stereotypes about people with a learning disability

Some people take the mick out of me and I used to get bullied, but I know people know about my learning disabilities ... my girlfriend does not have a learning disability. She gets treated fairly more than me because I have a learning disability. People laugh at her when she is with me, but she just says "he is the same as any one else".

*A person with learning disabilities*<sup>187</sup>

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.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>188</sup>

122. Witnesses told us that providers of mainstream services and people on the street often had negative attitudes, assumptions and stereotypes about people with learning disabilities which made it difficult for people with learning disabilities to gain respect for their human rights. These attitudes and assumptions could lead directly to the denial of individual rights, for example through bullying or hate crime, or they could underlie decisions by others which marginalised people with learning disabilities and undermined their ability to speak up for their rights. Mencap told us:

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

<sup>186</sup> Annex 3, para 25 (Philippa Russell).

<sup>187</sup> Annex 2, para 5.

<sup>188</sup> Q 1.



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.<sup>189</sup>

123. Negative attitudes and assumptions can be a particularly significant problem for certain groups, such as people with complex and profound learning disabilities. For example, the PMLD (Profound and Multiple Learning Disabilities) Network told us:

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 more innovative forms of support, such as individual funding, because some people do not think that they will benefit...But these negative attitudes can also be life-threatening – for example if they result in the denial of medical treatment.<sup>190</sup>

124. Other witnesses confirmed the difficulties they encountered as a result of negative attitudes on the part of professionals and service providers. For example, in seeking access to healthcare (which we consider below, in Chapter 5):

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.<sup>191</sup>

125. They also told us how negative attitudes could cause difficulties in the wider community:

People felt that there was a general lack of tolerance 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 understanding of people with learning disabilities to the more worrying abuse of rights such as intolerance and discrimination.<sup>192</sup>

and

People treat you funny. They won't let you have a relationship. People against us getting married.<sup>193</sup>

and

We have experiences, seen and heard, about lots of bullying happening in the community. People with learning disabilities are often scared to go out. We're often called names or people take the mickey in a really nasty way.<sup>194</sup>

126. Andrew Lee, Director, People First (Self-Advocacy) told us:

<sup>189</sup> Ev 137.

<sup>190</sup> Ev 204.

<sup>191</sup> Ev 69.

<sup>192</sup> Ev 88.

<sup>193</sup> Ev 49.

<sup>194</sup> Ev 69.

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.<sup>195</sup>

127. **We agree with our witnesses that one of the most distressing and worrying things about the investigation by the Healthcare Commission and CSCI into the treatment of people with learning disabilities in Cornwall was that “many of the staff did not believe and understand that what they were doing was wrong”. This episode provides a most harrowing example of how a lack of awareness of the rights of people with learning disabilities can have a devastating effect, leading to situations where the right to be treated with respect for private life is ignored (Article 8 ECHR), and the rights to life and to be free from inhuman and degrading treatment are endangered (Articles 2 and 3 ECHR).**

128. Some witnesses told us that training for professionals and others on learning disability by people with learning disabilities would be needed to change the situation. For example:

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 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 into their community.<sup>196</sup>

129. The National Co-Director for Learning Disabilities told us that changing attitudes would involve promoting the rights of people with learning disabilities:

Those negative attitudes will often come from people who have only ever experienced people with learning disabilities in a negative, passive role in society...It is only when society sees what people are really capable of that I think we will begin to make some major changes.<sup>197</sup>

130. The British Institute of Human Rights said that the promotion of a human rights based approach could improve the treatment of people with learning disabilities, not only by empowering people with learning disabilities but by promoting change within service providers:

We 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 a way that enables them to flourish as human beings.<sup>198</sup>

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<sup>195</sup> Q 1.

<sup>196</sup> Ev 51.

<sup>197</sup> Q 129.

<sup>198</sup> Ev 131.

131. We welcome the recognition by the National Co-Director for Learning Disabilities of the importance of educating people, and particularly service providers, to see people with learning disabilities as people with human rights which need to be respected. He told us:

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 would treat a non-disabled person ... 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, [such] attitudes ... [which] are not acceptable in modern society.<sup>199</sup>

132. We welcome the recognition of both the Minister for Care Services and the Minister for Disabled People, that while the Government has a responsibility to ensure public authorities meet their duties to respect the rights of adults with learning disabilities under the Disability Discrimination Act and the Human Rights Act, a move away from negative attitudes and assumptions is required:

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 no 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.<sup>200</sup>

**133. We agree that taking a human rights based approach to service provision could contribute to reversing negative attitudes, assumptions and stereotypes. We again stress that the Department of Health and the Office for Disability Issues should take a lead in creating a positive approach to the implementation of both the Human Rights Act 1998 and the Disability Equality Duty. However, “taking a human rights based approach” means more than using the appropriate language in policy documents or in statements to parliamentary committees. A proactive and practical approach to the implementation of individual rights for people with learning disabilities is needed to replace the existing culture, which has allowed society to “dehumanise” people with learning disabilities for centuries.**

Helen continued to be distressed and her confusion increased. She was sent to a psychiatric ward, where 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 ... they believed that the pain ... was the most likely explanation for her change in behaviour. Doctors informed her family that Helen was “just doing this for attention”.

*Mencap Case Study*<sup>201</sup>

<sup>199</sup> Q 138.

<sup>200</sup> Q 164 (Mrs McGuire).

<sup>201</sup> Ev 139.

134. The evidence that we have received in this inquiry strongly suggests we are failing adults with learning disabilities, by failing to afford adequate respect for their human rights. In the following chapters, we focus on four areas which we consider provide the starkest illustrations of adults with learning disabilities being treated without dignity and respect for their human rights:

- The treatment of adults in health and residential care settings, an area that has already had a significant amount of public attention in the light of high profile cases (Chapter 5);
- The experience of parents with learning disabilities (Chapter 6);
- The treatment of adults with learning disabilities in the criminal justice system (Chapter 7); and
- Barriers to an ordinary life confronting adults with learning disabilities (Chapter 8).

























161. The United Nations Convention on the Rights of the Child confirms that every child has the right not to be separated from its parents, unless separation is necessary to meet that child's best interests (Article 9). In this connection, the Convention on the Rights of the Child provides that the State:

[S]hall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities (Article 18).

162. The UN Disability Rights Convention, although not yet ratified by the UK, makes similar provision and adds that no separation should take place solely on the basis that the parents of a child have a disability. State Parties to that Convention will have a duty to consider alternative care for the child within a wider family setting (Article 24(3)).

**163. Social Services departments, courts and other public authorities working with parents with learning disabilities and their children are subject to the duty to act compatibly with the right to respect for family life, as guaranteed by Article 8 ECHR. The State has a positive, human rights based obligation to protect children from harm and to promote their development. However, any decision which impinges on the relationship between a parent with learning disabilities and his or her children could have very serious implications for the right to respect for their family life. In such circumstances, particular care must be taken to ensure that any restrictions on the development of ordinary family relationships must not only be in the best interests of the child, but must also be a necessary and proportionate response to the level of risk posed to the child or to its parents through continuing care at home. This assessment must take into account all of the relevant facts of an individual case, including the potential for additional support to meet the needs of the parents and the child.**

**164. The Minister for Care Services told us that “political correctness” should not prevent the removal of a child simply because a parent has learning disabilities. We agree that the assessment of whether a child should or should not remain with its parents is a complex one, requiring the careful consideration of many factors, including the best interests of the child and the rights of the child and its parents. We welcome the Minister’s acknowledgement that, unless justified and proportionate in all the circumstances, removal of a child could pose a significant risk to the rights of the child and its parents to respect for family life.<sup>262</sup>**

165. Unfortunately, we received evidence that decisions about the future placement of children of parents with learning disabilities are regularly taken without adequate information, arrangements or support being put in place to allow parents to demonstrate that they can look after their children satisfactorily. We were told that adult social services and children's services often did not work well together to ensure that families had the support that they needed. We were also told that:

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the needs of the children, the State had not considered whether greater levels of support could be appropriate. The Court also considered that the parents had very limited opportunities for visitation and that the children had been independently placed with different foster parents. The Court considered that although the State has a wide margin of appreciation in relation to individual decisions on child protection, that in this case, the State had acted in breach of Article 8 ECHR.

<sup>262</sup> Q 215.













**supported by community teams for people with learning disabilities, and the numbers of their children taken into care, each year.**













- it can be particularly difficult for people with learning disabilities to raise their concerns if they have communication difficulties;<sup>307</sup>
- it is difficult if the complaint is about the person providing care as a person with learning disabilities may fear the loss of care, accommodation or other support if they make a complaint and/or make a report to the police;<sup>308</sup>
- even if they report a crime, a care provider may not take the issue any further or may (as discussed above) investigate the matter themselves instead of involving the police;<sup>309</sup>
- police can be unhelpful;
- people with learning disabilities are not confident in talking to the police when they have been victims of a crime;<sup>310</sup>
- the police can be reluctant to accept that a crime has been committed if the victim has a learning disability;<sup>311</sup>
- alleged crimes might not be investigated or prosecuted because people with a learning disability, are not considered to be reliable witnesses. This is particularly the case where the person has communication difficulties;<sup>312</sup>
- information is not provided in a format that is accessible to people with learning disabilities and frontline police officers do not receive sufficient training to enable them either to identify someone with a learning disability or know how to meet their needs;<sup>313</sup>
- the police do not always consider using the special measures available under the Youth Justice and Criminal Evidence Act 1999 and may assume that the individual with a learning disability cannot give evidence;<sup>314</sup>
- once a complaint has been made, the Crown Prosecution Service may think that the complainant with learning disabilities will not be able to give credible evidence, or that it will be too stressful for them to do, which may reduce the likelihood of a successful prosecution.<sup>315</sup>

199. Witnesses drew our attention to a number of recent, positive developments, including:

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<sup>306</sup> Ibid.

<sup>307</sup> Ev 247.

<sup>308</sup> Ibid.

<sup>309</sup> Ibid.

<sup>310</sup> Ev 80, 142.

<sup>311</sup> Ev 122, 142.

<sup>312</sup> Ibid.

<sup>313</sup> Annex 3, para 41-3.

<sup>314</sup> Ev 142-144,; 170.

<sup>315</sup> Ev 268, para 9.

























































## Conclusions and recommendations

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### Adults with learning disabilities: the key issues

1. We received evidence from across the UK, but most was from organisations and individuals in England. Consequently, this Report will focus largely on the policy framework in *Valuing People*. However, the human rights standards discussed in this Report are universal. We consider that most of the conclusions that can be drawn from the evidence are equally relevant to all four countries of the UK. Equally, we hope that our recommendations and conclusions will inform the development of policy and practice by each of the devolved administrations, as well as central Government. (Paragraph 31)
2. In the light of the evidence which we received on the gap between the aims of *Valuing People* and the experience of adults with learning disabilities, which we consider below in Chapter 4, we are concerned that in *Valuing People Now* there appear to be few measurable targets for action nor precise proposals for monitoring progress on their achievement. (Paragraph 38)
3. We are pleased to note that the Government is committed to “fully consider and respond to the conclusions” of our Report in the course of formulating their priorities for 2008 - 2011. We expect the Government to give the recommendations and conclusions of our Report serious consideration during preparation of the final version of *Valuing People Now* and in setting its priorities for action for the next three years. We consider that *Valuing People Now* presents a valuable opportunity for the Department of Health to take a positive approach towards the promotion of the understanding and protection of the human rights of adults with learning disabilities. We recommend that, when redrafted after consultation, *Valuing People Now* should explicitly promote a “human rights based approach” to public authorities’ duties under the Human Rights Act; and should provide practical guidance for public authorities on the effective implementation of those duties. (Paragraph 40)

### Why do human rights matter?

4. We are disappointed that, at the start of the 21st century, almost ten years after the introduction of the Human Rights Act, and over a year since the introduction of the Disability Equality Duty, [the] evidence received convinces us that we need to emphasise that adults with learning disabilities have the same human rights as everyone else; and that they are entitled to freedom, respect, equality, dignity and autonomy in their everyday lives. (Paragraph 44)
5. We recently made a number of recommendations to Government on “the transformative power of the Human Rights Act”. In plain English, we told the Government and others what we thought they needed to do to make the Human Rights Act work for everyone. We have called upon the Government, the Equality and Human Rights Commission, other public bodies and voluntary organisations to champion publicly how a better understanding of human rights principles could

improve health and social care services. (Paragraph 53) We consider that when fulfilling this duty, the Equality and Human Rights Commission has a responsibility to engage proactively with those who are most vulnerable to breaches of their human rights and those who are less likely to be able to understand what human rights mean for them, including adults with learning disabilities. We recommend that the Commission take steps to ensure that adults with learning disabilities are aware of their rights under the Human Rights Act and the Disability Discrimination Act (as amended). (Paragraph 53)

6. We recommend that the Minister for Care Services, the Office for Disability Issues and the Ministry of Justice together develop a strategy on how to help vulnerable people, including adults with learning disabilities, understand what the statutory duties in the Human Rights Act and the Disability Equality Duty mean for them. (Paragraph 54)
7. We consider that the statutory duties under the Disability Discrimination Act (as amended), and specifically, the Disability Equality Duty, complement the HRA. Together they form a powerful means of effecting positive change. If both are understood and implemented properly they can underpin and promote the agenda set by the Government for improving the life chances of people with learning disabilities. (Paragraph 56)
8. We are concerned that, one year after the introduction of the Disability Equality Duty, the evidence we have received suggests a clear distinction between formal compliance by public authorities and a failure to take a positive approach to the duty on the ground. (Paragraph 60) We recommend that the Office for Disability Issues work closely with the Equality and Human Rights Commission to champion publicly a broad, positive approach to the Disability Equality Duty. This should involve a strategy to ensure that other public bodies, and their staff, understand how the proactive implementation of the duty can improve service provision for adults with learning disabilities and others. (Paragraph 60)
9. We urge the Government to ensure that any amendment to existing positive equality duties should strengthen rather than undermine their effectiveness. (Paragraph 61)
10. We agree that the UN Disability Rights Convention presents a valuable opportunity to confirm that disabled people, including adults with learning disabilities, are entitled to full respect for their human rights. (Paragraph 66)
11. We welcome the Government's commitment to ratify the UN Disability Rights Convention. However, we are mystified by the reason given for the Government's delay in ratifying this treaty. (Paragraph 69)
12. We recommend that either the Government ratifies the UN Disability Rights Convention and its Optional Protocol without further delay, or provides clear and unambiguous details of any specific impediments to immediate ratification. We will continue to monitor progress towards ratification. We will be deeply concerned if the Government does not meet the goal that the Minister for Disabled People has set, namely, ratification before the end of 2008. (Paragraph 70)

13. We welcome the commitment expressed by the Minister for Care Services and the Minister for Disabled People, to the principle of independent living. We await the results of the Government's Independent Living Review, with interest. We recommend that the Government consider the outcomes of that review, and the need for any further policy or legislative change, as part of their commitment to review the UK's domestic compliance with the UN Disability Rights Convention. (Paragraph 77)

### Living with a learning disability

14. We recommend that the Department of Health revisit this issue [of how can support adults with learning disabilities to form relationships] in their redrafted *Valuing People Now*, in light of the evidence we have received. (Paragraph 88)
15. We are concerned that the experiences communicated to us by adults with learning disabilities, their families and supporters appear to reflect the findings of the last National Survey, that adults with learning disabilities are more likely than other people to suffer from social exclusion, poverty and isolation. (Paragraph 98)
16. We are concerned by the evidence that the framework for improving the lives of adults with learning disabilities does not appear to have had much impact in Government departments other than the Department of Health or the wider public sector; and that the impact of *Valuing People* on the experiences of adults with learning disabilities in their dealings with local authorities and individual service providers has been so patchy. (Paragraph 104)
17. We were dismayed to hear the Minister for Care Services describe the National Director for Learning Disabilities as a "lone-ranger" on mainstreaming learning disabilities, rights and policy even within the Department of Health. We are extremely concerned that the Department, which has responsibility for cross-Government policy on learning disability, has failed to take seriously access to mainstream services for adults with learning disabilities, despite the existence of its statutory duties under the Disability Discrimination Act (as amended), the Disability Equality Duty and the Human Rights Act. (Paragraph 105)
18. We welcome the Government's recognition that further work needs to be done to implement policy effectively, so as to support the rights of adults with learning disabilities as individuals. We also welcome the Minister's frank acknowledgement that more pressure needs to be placed on both central and local Government to deliver the policy of *Valuing People*. (Paragraph 108)
19. We are concerned that the National Co-Director for Learning Disabilities and the Government have been searching for "levers" to implement a policy designed to ensure that adults with learning disabilities can live their lives in a way which promotes dignity and respect for their rights. We are particularly concerned that the National Co-Director did not appear to consider that public authorities' duties under the Human Rights Act would hold much sway. We reiterate our concern that the Department of Health and other Government departments should be proactive in promoting a positive approach to the Human Rights Act and to the Disability



Equality Duty. We see the value of using these obligations to support or explain a particular policy choice as a ‘lever’ for implementation. However, this should not undermine the binding nature of these duties. (Paragraph 109)

20. Difficult questions about allocation of resources may be involved when deciding whether to provide [funding for] support in specific cases. However, we consider these questions must be answered within the context of the legal obligations of local authorities and other public authorities, to respect the dignity and rights of service users. Local authorities must act in accordance with the Disability Equality Duty. (Paragraph 116)
21. We are deeply concerned about the Government’s negative response to our recommendations on the need for an express positive human rights duty for public authorities. The creation of a positive duty to respect human rights would help kick-start a change of attitude to the role of the Human Rights Act and to rights more generally. We doubt that, at least in the short term, oversight by the Equality and Human Rights Commission will encourage individual authorities to take a more proactive approach. On the other hand, witnesses to this inquiry, including the Minister for Care Services and the Minister for Disabled People, stressed their view that the potential impact of the Disability Equality Duty will be to change fundamentally the way that public authorities look at disability rights. We remain persuaded that the same is true of positive duties and the Human Rights Act. We reiterate our recommendation that the Government consider the introduction of an express positive duty on public authorities to promote respect for human rights, where the European Convention on Human Rights imposes a positive obligation on the State. (Paragraph 117)
22. We strongly recommend that guidance to local councils should remind them that decisions about funding must be taken in a way which is compatible with the Disability Equality Duty and the Human Rights Act. We recommend that the Government rewrite its Guidance, including *Fair Access to Care*, to ensure it provides clear, straightforward and accessible examples of a human rights based approach, explains how social care funding decisions could lead to a breach of Convention rights and sets out how to comply proactively with the Disability Equality Duty. (Paragraph 121)
23. We agree with our witnesses that one of the most distressing and worrying things about the investigation by the Healthcare Commission and CSCI into the treatment of people with learning disabilities in Cornwall was that “many of the staff did not believe and understand that what they were doing was wrong”. This episode provides a most harrowing example of how a lack of awareness of the rights of people with learning disabilities can have a devastating effect, leading to situations where the right to be treated with respect for private life is ignored (Article 8 ECHR), and the rights to life and to be free from inhuman and degrading treatment are endangered (Articles 2 and 3 ECHR). (Paragraph 127)
24. We agree that taking a human rights based approach to service provision could contribute to reversing negative attitudes, assumptions and stereotypes. We again stress that the Department of Health and the Office for Disability Issues should take a

lead in creating a positive approach to the implementation of both the Human Rights Act 1998 and the Disability Equality Duty. However, “taking a human rights based approach” means more than using the appropriate language in policy documents or in statements to parliamentary committees. A proactive and practical approach to the implementation of individual rights for people with learning disabilities is needed to replace the existing culture, which has allowed society to “dehumanise” people with learning disabilities for centuries (Paragraph 133)

### **The treatment of adults with learning disabilities in health and residential care settings**

25. We are concerned, but not surprised, that the evidence we received shows that people with learning disabilities face similar problems in healthcare as older people, including: (Paragraph 136)
- Malnutrition and dehydration (Articles 2, 3 and 8 ECHR):
  - Abusive and degrading treatment (Articles 2, 3 and 8 ECHR):
  - Neglect or carelessness by health and social care services (Articles 2, 3 and 8 ECHR):
  - Lack of privacy in health and social care settings (Article 8 ECHR):
  - Lack of dignity in respect of personal care needs (Article 8 ECHR):
  - Inappropriate use of restraint and/or medication (Article 8 ECHR):
  - Problems with communication, particularly where patients have complex or profound learning disabilities (Article 8 ECHR):
  - Negative, patronising and infantilising attitudes towards people with learning disabilities (Article 8 ECHR):
  - Discriminatory treatment of adults with learning disabilities in access to mainstream services on grounds related to their disability (Articles 2, 3, 8 and 14 ECHR):
  - Fear and difficulties in making complaints (Article 8 ECHR):
26. We are extremely concerned that adults with learning disabilities undergo degrading experiences in health and residential care settings, which closely mirror the experiences of older people, on which we reported in August 2007. This implies that poor treatment and neglect of some of the most vulnerable people in our society, at the times when they are ill, in need of care and support, and most dependent on others to secure their most basic and fundamental rights, is endemic. Treatment involving abuse, neglect or carelessness of the kind uncovered by the Healthcare Commission and the Commission for Social Care Inspection in Cornwall and Sutton and Merton and by Mencap in *Death by Indifference* involves serious and severe human rights breaches. The task of securing the dignity and self-respect of this vulnerable group, which is central to the fulfilment of their human rights, is the

responsibility of us all. The creation of a more positive human rights culture in service provision is vital to securing respect for adults with learning disability in need of health and social care services. (Paragraph 139)

27. We made a series of recommendations on how to meet these concerns, in our Report on the *Human Rights of Older People in Healthcare*. In the light of the evidence that human rights problems extend beyond older people to a broad range of vulnerable people, we are extremely concerned that the Department of Health has offered few concrete commitments in its response to our previous recommendations on the implementation of a human rights based approach in the NHS (Paragraph 142)
28. While we agree that the HRA is an important 'lever for change', care must be taken when using such descriptions to ensure that the legal obligations of the Human Rights Act are not undermined or misunderstood. (Paragraph 146)
29. We welcome confirmation by the Department of Health that an independent evaluator has been appointed for its Human Rights in Healthcare project. It is disappointing that the report of the independent evaluator will not be available until Autumn 2008, which will be almost eight years after the HRA was introduced. Nonetheless, we recommend that the findings of the evaluation are published and disseminated widely within the Department of Health (including to Strategic Health Authorities, PCTs and providers of health and social services) and across Government. (Paragraph 147)
30. Despite our view that the Human Rights in Healthcare project has potential, we are concerned that the Department of Health may see this exercise as a panacea that will lead to a positive culture of respect for dignity and human rights in service provision. In our view, this is only one of a range of initiatives that is needed in order to achieve this aim. We recommend that the Department of Health should use the sixtieth anniversary of the NHS to gain maximum exposure for its positive commitment to ensure that "Human rights are at the centre of the values of the health and social care system in this country". We consider that the adoption of a clear strategy on human rights in policy making by the Department of Health would set a positive example on the type of culture change which will be necessary to ensure that human rights are really at the heart of service delivery. (Paragraph 148)
31. We welcome the positive commitment by the Healthcare Commission and CSCI to a human rights based approach to regulation and inspection. We also welcome the commitment of the Healthcare Commission and CSCI to work together to implement the conclusions of the recent Healthcare Commission Audit. We recommend that the Healthcare Commission and CSCI use this process to promote a positive approach to human rights and to the National Minimum Standards by hospitals and care homes. (Paragraph 150)
32. The Health and Social Care Bill proposes to merge the regulatory and inspection systems for health and social care. The Care Quality Commission will assume the responsibilities currently held by the Healthcare Commission and CSCI in 2009. The Government proposes to merge the National Minimum Standards for health and social care, in registration requirements for registered providers of health and social

care. It proposes that “human rights will be an important feature in the requirements, and we expect that they will also feature prominently in the regulator’s criteria”. We will consider these proposals as part of our scrutiny of the Health and Social Care Bill. (Paragraph 151)

33. We welcome the early Government commitment in *Valuing People Now* to use the forthcoming NHS Operating Framework to require Strategic Health Authorities, PCTs and Trusts to deliver action plans to address the shortcomings identified by the Healthcare Commission’s audit of learning disability services. (Paragraph 152)
34. We welcome the frank acknowledgement by the Minister for Care Services that more needs to be done to ensure that adults with learning disabilities can access health services on an equal basis. We consider that practical steps must be taken to meet the recommendations of the DRC Formal Inquiry, not only by the Department of Health, but by other public bodies, including Strategic Health Authorities, PCTs, and local authorities. We are disappointed that progress on implementing the recommendations by the DRC Formal Inquiry has been slow. We welcome the commitment in *Valuing People Now* that work will continue until “nationally led responses to the DRC recommendations are in place”. We urge the Department of Health to provide visible national leadership on the recommendations of the DRC Formal Inquiry, by taking steps to assess progress on each recommendation and to provide a detailed strategy and timetable for implementation. We support the recommendation of the DRC Formal Inquiry, that this should take place with much greater urgency. We recommend that the Equality and Human Rights Commission continue the work of the DRC on this issue and monitor progress closely over the next year, with a view to taking enforcement action if no progress is made. (Paragraph 156)
35. We welcome the Department of Health announcement of the independent inquiry into the healthcare of people with learning disabilities. We also welcome the Government’s commitment in *Valuing People Now* to consider seriously the recommendations of that inquiry on hospital and acute care. We welcome the Government’s decision to highlight the duties of PCTs and general hospital trusts under the Disability Discrimination Act 1995 (as amended). This includes ensuring that their Disability Equality Schemes address those bodies ability and resources to meet the needs of people with learning disabilities. We regret that such a reminder is necessary. (Paragraph 157)
36. In the light of the evidence gathered in this report, we call on the independent inquiry to adopt a human rights based approach to its work. We trust that it will endorse our call for a positive approach to the implementation of the statutory duties in the Human Rights Act and the Disability Discrimination Act 1995 (as amended). We will follow the progress of this inquiry with interest. (Paragraph 158)

### Parenting and family life

37. Social Services departments, courts and other public authorities working with parents with learning disabilities and their children are subject to the duty to act compatibly with the right to respect for family life, as guaranteed by Article 8 ECHR.

The State has a positive, human rights based obligation to protect children from harm and to promote their development. However, any decision which impinges on the relationship between a parent with learning disabilities and his or her children could have very serious implications for the right to respect for their family life. In such circumstances, particular care must be taken to ensure that any restrictions on the development of ordinary family relationships must not only be in the best interests of the child, but must also be a necessary and proportionate response to the level of risk posed to the child or to its parents through continuing care at home. This assessment must take into account all of the relevant facts of an individual case, including the potential for additional support to meet the needs of the parents and the child. (Paragraph 163)

38. The Minister for Care Services told us that “political correctness” should not prevent the removal of a child simply because a parent has learning disabilities. We agree that the assessment of whether a child should or should not remain with its parents is a complex one, requiring the careful consideration of many factors, including the best interests of the child and the rights of the child and its parents. We welcome the Minister’s acknowledgement that unless justified and proportionate in all the circumstances, removal of a child could pose a significant risk to the rights of the child and its parents to respect for family life (Paragraph 164)
39. We welcome the acknowledgement in the Government’s *Good Practice Guidance on Working with Parents with a Learning Disability* that people with learning disabilities “have the right to be supported in their parenting role, just as their children have the right to live in a safe and supportive environment.” We also welcome the acknowledgement that while children have the right to be safe from harm, children’s needs are usually best met by support for their parents, to look after them. (Paragraph 169)
40. We consider that if the recommendations for good practice in each of these areas were implemented effectively, this could significantly reduce the risk that parents and children would be separated, in breach of [their human rights]. (Paragraph 170)
41. We welcome the recognition in *Valuing People Now* of the need to do more to improve support to parents with learning disabilities and their children. But we remain concerned that there are few concrete proposals for action or measurable targets regarding improving support to parents with learning disabilities and their children in that document. (Paragraph 177)
42. Although we welcome the commitment of the Department of Health and the Department for Children, Schools and Families to the provision of information [to parents] in an accessible way, the Minister for Disabled People has accepted that it is likely that this commitment is no more than the Disability Discrimination Act already requires of those Departments. (Paragraph 178)
43. While we recognise the potential of the *Good Practice Guidance* to improve support for parents with learning disabilities and their children, its effectiveness will depend entirely on positive dissemination and widespread implementation by local authority adults’ and children’s services, NHS Trusts and others. We are disappointed that the

active dissemination of this important Guidance has so far relied principally upon the work of an independent parenting network, albeit supported by the Office of the National Director and his colleagues. We welcome the proposed involvement of the Care Services Improvement Partnership in further dissemination of the Guidance. We call upon the Government to set out clearly its proposals for ensuring that all local authority social services departments, including children's services and NHS Trusts are aware of the *Good Practice Guidance* and, importantly, that relevant professionals have training in its effective implementation. (Paragraph 179)

44. We note that although *Valuing People Now* refers to the need for independent advocacy for parents with learning disabilities, it makes no proposals for action to ensure and increase the availability of such provision. We call upon the Government to take action on this issue in our discussion of advocacy in Chapter 8 below. (Paragraph 180)
45. We consider that the proposals for monitoring progress in [this part of] *Valuing People Now* are particularly weak and lack precision. Public authorities have binding duties under the Disability Discrimination Act and the Human Rights Act to provide services without discrimination, to implement effectively their positive duties to disabled people, and to uphold the rights of parents with learning disabilities and their children to respect for their private life. In the light of these duties, we recommend that the Department of Health requires Learning Disability Partnership Boards to report annually on local commissioning of services to support parents with learning disabilities; and ensures that data is collected locally on the numbers of parents with learning disabilities supported by community teams for people with learning disabilities, and the numbers of their children taken into care, each year. (Paragraph 181)

### Treatment of people with learning disabilities in the criminal justice system

46. We recognise that not all abuse against adults with learning disability will amount to criminal behaviour. We recognise that in many circumstances, individuals who uncover abuse and criminal behaviour against vulnerable adults will rightly treat the protection of the victim as a priority. Where an individual has been seriously assaulted or where his or her life has been endangered, there is a clear obligation on the State, secured by that individual's ECHR rights, to conduct an effective investigation of the circumstances of the abuse. This includes an obligation to provide for the prosecution of the individual responsible, if appropriate. These important human rights obligations apply to everyone, including people with learning disabilities, unless there are objective reasons why an investigation or a prosecution should not go ahead. (Paragraph 195)
47. We recommend that in the review of *No Secrets* and the proposed *Valuing People Now* guidance on crime and people with learning disabilities, the Government provides clear and accessible guidance on protecting people with learning disabilities (and other vulnerable adults) from abuse and ensuring that if a crime is suspected, effective steps are taken to inform and involve the police. We urge the Government to ensure that the relevant criminal justice agencies, including the Association of Chief Police Officers, the Crown Prosecution Service, the Home Office and

organisations of and for people with learning disabilities, are closely involved in shaping this guidance. (Paragraph 196)

48. We are disappointed that the Government has not agreed to create a duty to report abuse, as we previously recommended. We call on the Department of Health, as part of their review of the *No Secrets* Guidance, to reconsider our recommendation that there should be a duty on those working with vulnerable adults, at least within the NHS and in care homes to report suspected abuse. (Paragraph 197)
49. People with learning disabilities, in common with the wider population, may have mixed experiences of dealing with the police, the courts and other parts of the criminal justice system. Every part of that system has an obligation to promote equal access to their services for disabled people, including those with learning disabilities, as part of their duties under the Disability Equality Duty. (Paragraph 200)
50. We welcome the Government's commitment to meet the concerns of people with learning disabilities about hate crime, in *Valuing People Now*. We welcome the proposal that the Home Office should lead on the production of guidance to address hate crime and to increase the safety of people with learning disabilities in their communities. We recommend that people with learning disabilities, their carers and supporters, ACPO, the Police Federation and the CPS are closely involved in the production of this guidance. We consider that more accurate information would better inform the Government's policy on this issue. As part of the Government's commitment to address hate crime and the personal safety of adults with learning disabilities, we recommend that steps be taken to gather more consistent data on the level of crime against people with learning disabilities, either through a survey sponsored by the Home Office, or as part of the British Crime Survey. (Paragraph 204)
51. We welcome the recent steps taken by ACPO and the CPS to improve their policy on crimes against victims with disabilities and hate crime, including against adults with learning disabilities. We were disappointed to hear that the CPS had not initially worked closely with the National Co-Director for Learning Disabilities. We recommend that, where any public sector agency is considering a policy which is relevant to disabled people, steps are taken to ensure that people with learning disabilities are specifically considered as part of the policy formulation, and if possible, involved in the preparation of that policy. We welcome the proposal by the CPS to amend their charging guidance to ensure that they are involved at an early stage in the investigation of crimes against people with a learning disability where hate crime is suspected. Whilst any decision on prosecution must be based upon the evidence available and should take full account of the rights of the defendant, we consider that this would be a positive development which could increase the confidence of adults with learning disability in the police and the criminal justice system, by ensuring that any element of hostility or prejudice towards them is properly investigated and considered as part of any prosecution. (Paragraph 209)
52. We are concerned that the problems highlighted by this evidence could have potentially very serious implications for the rights of people with learning disabilities to a fair hearing, as protected by the common law and by Article 6 ECHR. Some of

this evidence also suggests that there are serious failings in the criminal justice system, which give rise to the discriminatory treatment of people with learning disabilities. (Paragraph 212)

53. The evidence which we have received on the treatment of people with learning disabilities in prison and their inability to secure equal access to parole, raises one of the most serious issues in our inquiry. We are deeply concerned that this evidence indicates that, because of a failure to provide for their needs, people with learning disabilities may serve longer custodial sentences than others convicted of comparable crimes. This clearly engages Article 5 ECHR (right to liberty) and Article 14 (enjoyment of ECHR rights without discrimination). It is also an area that falls within the Prison Services' responsibilities under the Disability Equality Duty. (Paragraph 215)
54. We welcome the publication of the Government's consultation, *Improving Health, Supporting Justice*. We recommend that the Government ensures that people with learning disabilities are able to participate effectively in that consultation. We recommend that each of the relevant criminal justice agencies, including the police, the Crown Prosecution Service, the Court Service, the Prison Service and the Probation Service undertake an audit of their services for compliance with ECHR rights, the Disability Discrimination Act and, specifically, the Disability Equality Duty, in order to inform the Government's *Improving Health, Supporting Justice*, when it is finalised next year. (Paragraph 217)

### Barriers to an 'ordinary life'

55. Under the Disability Discrimination Act 1995 (as amended), the statutory obligation on providers of goods and services to the public to make reasonable adjustments to enable disabled people to use their services may, in some circumstances, require that information is made available to people with learning disabilities in an easy to understand, written, or other appropriate format. We consider that the provision of accessible information for people with learning disabilities should be standard practice for public bodies such as the Government departments, NHS bodies and local authorities, who are all subject to this duty to make reasonable adjustments, and are also subject to the duty to promote disability equality. (Paragraph 225)
56. With the introduction of the Disability Discrimination Act (as amended) and the duty on providers of goods and services to make reasonable adjustments to meet the needs of people with learning disabilities, we believe that adults with learning disabilities should be able to obtain the information they need in formats they can understand. We consider that the statutory obligation to make reasonable adjustments includes ensuring that information is available in an easy to understand format. This duty is reinforced in relation to public authorities, by the Disability Equality Duty. We are deeply concerned that this does not reflect the experiences of our witnesses. (Paragraph 226)
57. We are disappointed by the lack of specificity and at the absence of any reference to goals, targets or identifiable commitments to increase the provision of accessible information in the Action Summary relating to this section of *Valuing People Now*



[on accessible information]. It is not clear how progress is to be made or measured in the absence of any specific commitments. We recommend that such commitments are included in the revised version of Valuing People Now to be produced later in 2008, following consultation. (Paragraph 231)

58. We recommend that [the issue of accessible information] receive appropriate attention in the ODI's forthcoming Independent Living Review Strategy. (Paragraph 232)
59. In addition, we call on the ODI to ensure that statutory authorities and others are fulfilling their duties under the Disability Discrimination Act and the Disability Equality Duty by making information available in formats that are accessible to people with learning disabilities. This can be through providing it themselves, by commissioning it from others, or requiring it as part of contractual agreements. The ODI should monitor and review progress as part of an overall strategy for the provision of accessible information. (Paragraph 233)
60. We also call upon the Healthcare Commission and the Commission for Social Care Inspection to ensure that scrutiny of the availability of accessible information (including easy to understand information on what is abusive practice and what people can do about it) is routinely included in the course of their inspections of providers of health and social care. (Paragraph 234)
61. Empowering people with learning disabilities to stand up for their human rights is important. Although, in some places in this report, we have described this group as vulnerable, we have been particularly impressed by the role played by self-advocacy groups and our individual witnesses with learning disabilities, in telling us how their rights could best be protected. We are aware that some people with learning disabilities will not be able to understand information about human rights by themselves, even if it is in an easy read, illustrated or audio format. They will need to have the information explained and have support to understand it (Paragraph 238)
62. These concerns are indicative of a disappointing lack of central leadership on this issue. We were deeply disappointed that the Office for Disability Issues could not provide an accessible summary of the United Nations Convention on the Rights of Persons with Disabilities until more than a year after the Convention was agreed. We were equally concerned that the Easy Read guide to the Human Rights Act, prepared by the Ministry of Justice, was not available to be downloaded from the Ministry of Justice website for some time. We raised these concerns with the Minister for Human Rights and the Minister for Disabled People and both of these problems have now been resolved. (Paragraph 241)
63. We welcome the recent publications from the Office for Disability Issues on improving information for disabled people, including the document aimed at public sector communicators and practitioners. These set out five principles for producing better information for disabled people: (Paragraph 242)
  - Principle 1: ensure that disabled people are involved from the start.
  - Principle 2: provide information through a range of channels and formats.

- Principle 3: ensure your information meets users' needs.
- Principle 4: clearly signpost other services.
- Principle 5: always define responsibility for information provision.

These principles should be followed both within and beyond Government.

64. We were dismayed by the Minister's frank admission that not only is there no Government strategy on the provision of accessible information on rights, there is no wider cross-Government strategy on providing information in an accessible format. We accept that it can sometimes be difficult to provide information in this way quickly, consultation with relevant stakeholders will often be appropriate and necessary, and that, sometimes, the most appropriate format will not be the written word. Nevertheless, we expect central Government to provide a lead and to set a good example by ensuring that people with learning disabilities have equal access to information in appropriate formats, as required by the Disability Discrimination Act and the Disability Equality Duty. (Paragraph 244)
65. We recommend that the Office for Disability Issues work with the Office of the National Director for Learning Disabilities at the Department of Health and the Cabinet Office to formulate and implement a cross-Government strategy for the provision and distribution of easy to understand, accessible information, by Government (and other) bodies, as a matter of urgency. We recommend that a specific strategy on accessible information about human rights and equality is formulated by the Office of Disability Issues, working with the Ministry of Justice. The Equality and Human Rights Commission should be closely involved in the development of these strategies and should monitor their implementation in practice. (Paragraph 245)
66. We call upon the Government to review the availability of Independent Mental Capacity Advocate services. (Paragraph 255)
67. We recommend that parents with learning disabilities should have access to independent advocacy when subject to safeguarding procedures, particularly before any court proceedings. We call upon the Government to review current provision of advocacy services for parents with learning disabilities, to ensure that such services are available in these situations. (Paragraph 258)
68. We are aware that resources are limited, but are persuaded that for many people with learning disabilities access to independent advocacy may be the only realistic means of securing their human rights, not least if family carers are no longer around to advocate on their behalf (Paragraph 260)
69. We consider that adults with learning disabilities, particularly those who are most vulnerable (including parents, adults with complex and profound learning disabilities and those involved in the criminal justice system), would benefit greatly from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society. (Paragraph 261)

70. We welcome this commitment [*Valuing People Now*: on the national advocacy fund], but call upon the Government to review the availability of independent advocacy for people with learning disabilities whose needs fall outside the scope of the Independent Mental Capacity Advocate services provided under the Mental Capacity Act 2005, or the proposed reform of health and social care complaints procedures. We recommend that as part of their proposal to support advocacy to have an increasing impact, the Government ensures that independent advocates, including independent mental capacity advocates and others, have an understanding of human rights principles and the positive duties of public authorities and service providers towards adults with learning disabilities. (Paragraph 263)
71. People with learning disabilities should be subject to the same test for capacity to vote as people without learning disabilities. However, assumptions that adults with learning disabilities lack capacity may prevent them from exercising their right to vote and to participate in the democratic process. (Paragraph 272)
72. We recommend that the Electoral Commission and the Ministry of Justice, working with the Office of the National Director for Learning Disabilities and the Equality and Human Rights Commission, produce guidance for Presiding Officers on the test for capacity to vote and how to assess this. The Electoral Commission should work together with the Equality and Human Rights Commission to take steps to make voting more accessible for people with learning disabilities. As part of this process, we recommend that the Government consider the role of the proposed Care Quality Commission, and whether it should monitor how registered providers of care facilitate, or undermine, service users rights to vote. (Paragraph 273)
73. We recommend that when *Valuing People Now* is revised, after consultation, local commissioners and service providers should pay greater attention to how they organise services, in order to maximize, rather than limit, people's opportunities for social relationships and inclusion in the community (Paragraph 282)
74. We recommend that the final version of *Valuing People Now* consider the devastating impact which poor access to communication aids can have on the ability of some adults with learning disabilities to communicate with others, and thus participate in social relationships and the life of the community. (Paragraph 284)
75. We recommend that the Department of Health gathers and publishes information on the nature and numbers of out of county placements, and on the significant impact such placements have on individuals with learning disabilities, to inform its work on the revised version of *Valuing People Now*. (Paragraph 288)
76. In light of the significant role commissioners and service providers will play in the protection and promotion of the human rights of adults with learning disabilities, we were disappointed that the recently published Department of Health Good Practice Guidance for Commissioning Specialist Adult Learning Disability Health Services fails entirely to mention "human rights" or a "human rights based approach" or to provide any practical guidance to commissioners on how to use commissioning agreements to secure respect for the rights of adults with learning disabilities. (Paragraph 291)

77. The Minister told us the Government intended to ensure that the new Care Quality Commission would be under a responsibility to regulate to the “standards that would be expected if the Human Rights Act were to apply to those providers”. The Human Rights Minister recently told us that a statutory solution which will extend the full protection of the Human Rights Act to service users who receive support from a private sector provider will not happen until after the conclusion of a consultation on its forthcoming Green Paper on a Bill of Rights for Britain. We consider that this presents a significant retreat from the Government’s earlier commitment to provide a solution for private care homes as soon as possible. We are concerned that this change of view will leave a significant gap in the protection of vulnerable people receiving support in the private sector, including adults with learning disabilities. We recommend that the Government legislate to ensure that all private providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights. (Paragraph 292)

### Conclusions: Putting human rights principles into practice

78. Although we were impressed by the passion for a human rights based approach expressed by the Minister for Care Services and the Minister for Disabled People, we are persuaded that real change for adults with learning disabilities will only happen if practical steps are taken to promote a more positive approach to the rights of adults with learning disabilities on the ground, in mainstream public services. (Paragraph 295)
79. Public authorities should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under the Disability Equality Duty) as optional. (Paragraph 296)
80. We urge the Department of Health and the Office for Disability Issues to consider opportunities for joint-working to meet the aims of *Valuing People* and *Valuing People Now*. As part of this process, we recommend the amendment of *Valuing People Now*, to remind all public authorities, including Government Departments, local authorities and NHS Trusts, that the aim of the Government’s policy is grounded both in the need to respect the human rights of adults with learning disabilities, and in the binding obligations of the Human Rights Act 1998 and the Disability Discrimination Act (as amended). We consider that this would send a strong message to mainstream services that implementation of this policy is not optional. (Paragraph 301)
81. We consider that the Equality and Human Rights Commission has a crucial role to play in the creation of a broad culture of human rights. (Paragraph 303) We encourage the Equality and Human Rights Commission to ensure that it monitors the performance of the Government and other public bodies in relation to the treatment of adults with learning disabilities, and take steps, including through active involvement with their statutory Disability Committee or otherwise, to ensure that adults with learning disabilities play a central role in its work and that their views and voices are heard. (Paragraph 303)



















(Article 5), the right to life (Article 10), respect for privacy (Article 22), respect for home and the family (Article 23), the right to education (Article 24) and the right to the enjoyment of the highest attainable standard of health (Article 25). Article 19 provides for the right of 'living independently and being included in the community'.

35. States are expected to be proactive in ensuring respect for the rights set out in the UN Disability Rights Convention. For example, Article 4 requires States to take steps to '...ensure and promote the full realization of all human rights and fundamental freedoms' of disabled people 'without discrimination of any kind on the basis of disability.' A wide range of actions is listed. These include adopting legislative and other measures for the implementation of the rights under the UN Disability Rights Convention and modifying existing laws, regulations and practices that constitute disability discrimination. When undertaking such work, governments will be required to 'consult closely with and actively involve' disabled people. Governments will also be required to promote training on the UN Disability Rights Convention for staff and professionals who work with disabled people.

36. To date, 123 States have signed this treaty (including the UK) and 13 States have ratified this Convention. It is anticipated that in the next year or so it will come into force once the requisite number ratifications has been achieved (20 States). Anne McGuire, MP, Minister for Disabled People, informed us that the UK Government intends to ratify the Disability Convention by the end of 2008, if not before.

37. An Optional Protocol to the UN Disability Rights Convention provides for individuals to submit complaints about alleged violations of their rights under Convention to the Committee on the Rights of Persons with Disabilities.

38. Although ratification of the UN Disability Rights Convention will not incorporate it into domestic law, this Convention has the potential to be highly influential. For example national courts and the European Court of Human Rights regularly refer to international human rights treaties to assist in the interpretation of the ECHR and may therefore use the UN Disability Rights Convention for this purpose in relation to disability issues.

## **Themes arising from human rights standards and legislation**

39. The following themes emerge from the human rights standards and legislation discussed above and are relevant to people with learning disabilities.

### ***Positive obligations to promote human rights and equality***

40. Human rights standards are not just about requiring states to refrain from interfering with individuals' human rights or ensuring that where rights have been infringed, appropriate legal redress is available. In certain circumstances States are also required to take action in order to ensure that individuals' rights are protected. This is of crucial importance because during this inquiry we have been given many examples of how people with learning disabilities are excluded from society (these barriers are discussed in Chapter 8).

41. Both the ECHR and the Disability Discrimination Act 1995 (as amended) require that public authorities be proactive in certain cases if they are to comply with their statutory





## Annex 2: Contributions to the inquiry from members of the public

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1. We received a significant number of submissions from members of the public, including people with learning disabilities and their families or carers and professionals working in the field of learning disabilities. Some of these submissions have been published as part of a separate volume of evidence. However, a number of submissions gave examples of individual cases and enclosed correspondence about those cases. Some submissions included copies of our call for evidence, in Easy Read, with hand-written additions and comments. Some people have asked for anonymity or for their submissions to remain private. We have not published such submissions but instead offer a summary of the main points they raise.

### Themes and concerns

2. A number of themes and concerns were raised in the correspondence we received from the public, including:

- A lack of understanding towards people with learning disabilities, by service providers and in the wider community;
- Discrimination, abuse and bullying;
- Access to funding for services and support;
- Gap between policy in *Valuing People* and reality;
- Importance of advocacy and Easy Read information;
- Supported or independent living (including access to housing and employment);
- Human rights, education and training.

3. These themes are explored in more detail below. We also received a number of submissions from people with learning disabilities who told us that although they are happy with their lives, there are other people with more complex needs or more profound learning disabilities who may not be.

### *A lack of understanding for people with learning disabilities*

4. A number of submissions referred to the lack of understanding towards people with learning disabilities. These discussed a range of negative attitudes ranging from fear, bullying and dissociation to misunderstanding and unhelpful stereotyping. See for example:

She feels useless and is bullied – she always gets the blame if anything goes wrong. They are not used to working with people with learning difficulties. [She] needs to be shown (sometimes a number of times) before her brain registers any new tasks. She is determined to live independently and has a constant struggle to be accepted.



*A parent of an adult with learning disabilities discusses her daughter's experiences.*

[Our local Mencap] was preparing to purchase a 5-bedroom house in a local estate for four people to live in with overnight sleep-in cover. The local community learnt about this and a large group requested a meeting with our Chairman. He said it was the nastiest group he had ever been confronted by. They expressed their strong objections to the purchase.

*A parent of an adult with learning disabilities and Trustee of local Mencap group.*

### **Discrimination, bullying and abuse**

5. A number of submissions referred to discrimination, bullying and abuse. These range from submissions on discrimination faced by adults with learning disabilities in their attempts to participate in the community to stories of physical and sexual abuse, by carers or by others, including other people with learning disabilities.

I moved to [a new home] where, when people were bad the staff said that they could not stay up. I was there 8 years. I used to run away – it was hell there it was like a prison. I had to go to bed at 6 o'clock and missed the soaps. Other people had boyfriends. I had two breakdowns because of it...They treated me like dirt. In my thirties, I lived at Mill Road. I had another breakdown as again people would not let me do what I wanted to do.

*A person with learning disabilities describes her previous experiences.*

I answered a phone call from [the police force local to my son's school], who told me they suspected [my son] and two other pupils at [his school], had been sexually assaulted, and that they were passing the case onto [our local police] – which they did. Although [our local police] were sympathetic they categorically refused to interview [my son]. This was because he had mental health issues and extreme challenging behaviour.

*Mother of an adult with learning disabilities.*

Some people take the mick out of me and I used to get bullied, but I know people know about my learning disabilities ... my girlfriend does not have a learning disability. She gets treated fairly more than me because I have a learning disability. People laugh at her when she is with m, but she just says he is the same as any one else.

*A person with learning disabilities describes his previous experiences.*

Making this work is down to attitudes, and, as many of the group members are over 50, they were brought up in a time when people thought very differently about what is possible if you have a learning disability. Parents were given very different advice and information and maybe people's hopes were pitched a bit lower.

*Summary from a submission from a small self advocacy group.*

As a carer I have found that judgmental attitudes are a barrier to good planning. As a family carer I would have to 'field' not only my son's distress but the attitudes of those who are supposed to help. People are too quick to judge 'a behaviour' without the knowledge of the disability.

*A parent of an adult with learning disabilities describes his concerns.*

I'm the one

Are you listening?

I'm the one that school described as hopeless

I'm the one that you described as friendless

I'm the one that kids described as useless

I'm watching

You're the one who writes my care plan

She's the one that limits my pocket money

You're the one that manages my lifestyle

He's the one who controls what I watch on TV

You're the one who tells me I have a choice

They're the ones that write my menu

You're the one that insists I explore my inappropriate behaviour

He's the one that swears at me

Is there anyone there?

Because I'm the one whose life you're supporting

I've the one you are paid to care for

I'm the one who is a challenge

Because I'm the one who is asking you to listen

*Poem written by Champions*

*A Group of Trainers on Abuse, who are also People with Learning Disabilities.*

### ***Access to funding for services and support***

6. A significant number of submissions focussed on funding, access to services and support. These covered areas including:

- adequacy of assessment by Social Services and difficulties in relationships with local councils;

Poor assessment leads to poor care plans leading to incorrect funding. Assessments seem less to do with person centred plans and the individual than with cost cutting. ... Assessed and written in many cases by 'professionals' with little knowledge and training.

*A family carer expresses her concerns.*

- overcomplicated systems for accessing benefits;
- difficulties associated with access to direct payments, or other support. For example;

It annoys me when I hear the Government saying that people are not claiming all the money that they are entitled to because time after time we have had to fight, sometimes reapplying three times before we have got the allowances we were entitled to.

*A family carer expresses her concerns.*

When group members can't do something they want to or that is important to them, it is usually not because people don't respect their rights but is usually down to lack of staff or other support or having no transport.

*Summary from a submission from a small self advocacy group.*

- eligibility criteria and exclusion from service provision;

We are concerned the drift away from local community support is showing signs of a return to an institutional mind set and that a person with learning disabilities is losing the basic human right of respect and access to services.

*Chair of a local action group expresses her concerns.*

- closure of existing services;

Surely it is an infringement of their human rights to take their facilities away from them without consultations and without any alternatives in place, it has been said that the private sector will provide day centres and facilities, but at present, there are not private sector facilities available at all.

*Person involved in a local campaign against day centre closures.*

- inability to access care and support in health and social care, including in hospitals. For example;

I have been advised by carers [that] nursing staff on wards do not provide adequate care to ensure that adults with learning disabilities are able to go to the toilet, have access to food and water and in very rare circumstances pass [on] important information [...]

*A submission on standards in healthcare.*

In the past when we've used our GP we found we were not listened to or even believed. We had to persist and the community nurses helped get us referred to the hospital.

*A family of people with learning disabilities.*

When I go to the doctors or to hospital they always talk to my mum about what is wrong and not me. The dentist is better he talks to me as well as my mum. I think they would all tell me what is happening.

*A learner from Linkage Community Trust expresses their views.*

I am not happy because the government are not doing their jobs properly because the doctors are not talking to me as a person because I have special needs.

*A person with learning disabilities expresses her view.*

Each time he has been in hospital I or my husband has had to stay with him as the care he requires is not provided in local hospitals. Also there are no facilities (slings/hoists/changing bed) to help with his personal care, he is doubly incontinent. In hospital he has to spend all day in bed as there is no way of transferring him to a chair/wheelchair.

*A parent of an adult with learning disabilities describes her experiences.*

### ***The gap between the policies in Valuing People and reality on the ground***

7. Although the policies in *Valuing People* could in principle lead to respect for the human rights of adults with learning disabilities, the reality is far from the ideal envisaged by the Government's policy. This was reflected in some of these submissions:

From my own personal experience, I am convinced, that any legislation or procedures brought in to enhance the Human Rights of Adults with a Learning Disability will only be as effective as the Support Worker at the sharp end, on duty at that time.

*Support Worker, Mencap.*

While the situation for many people with learning disabilities has improved dramatically over the last twenty years, there is still a long way to go before they will be in a situation which parallels that of most other members of the community. The White Paper *Valuing People* was full of excellent recommendations, many of which have either been paid lip service, or have been ignored completely. There is a feeling amongst professionals that it was a lot of rhetoric without legislative teeth to ensure that its recommendations would be put into practice. There is still a huge gap between what was recommended and what actually happens.

*An NHS Clinical Psychologist in Learning Disability Services.*

*Valuing People* was a document that amongst other things states “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 be a lack of commitment within services to change the way they work

*A parent of an adult with learning disabilities expresses his views.*

The White Paper *Valuing People* talks about the importance of community presence and participation, but £1.75 per week to spend is not enough to enable anyone to do that.

*A parent of an adult with learning disabilities expresses her views.*

### **Importance of advocacy and Easy Read information**

8. We heard significant evidence on the importance of access to Easy Read information and to the services of an independent advocacy service. A number of these submissions also address these issues:

I think we don't get enough help when filling in council forms because I don't understand the forms. This makes me feel very frustrated because I am a non reader with learning difficulties. I feel that social services do not make things easy for me. My social worker bosses me around and does not include me in decision making, this may be because I don't like saying anything because he makes me feel stupid ... This makes me feel that I am not treated fairly as an adult.

*A learner from Linkage Community Trust expresses their views.*

As an elderly carer now, I would also like to promote the concept of individual advocates for those in residential care, at the moment we ensure that the provision is good, but when we are no longer around, someone who is actively independently concerned with my daughter's quality of life is of paramount importance, so could this also be part of your considerations.

*A parent of an adult with learning disabilities expresses her views.*

What would help people with learning disability get their human rights? More self advocacy workers to help people speak up for themselves; more representational advocates to take up specific cases and act on peoples behalf; more investment in getting the right sort of information out there in a form that people understand

*Submission on behalf of two people with Learning Disabilities*

### **Supported or independent living**

9. A number of submissions focused on the barriers adults with learning disabilities met when seeking to live independently or to play an active part in their community. These related to:

- inability to access appropriate supported housing;

- employment and education;

Being a contributing member of one's local community doesn't just mean going to the local, mainstream leisure centre or buying one's own groceries; it should mean the opportunity to do meaningful, paid, work, for those who want to and are able.

*Mother of an adult with learning disabilities expresses her views.*

- inability to access day activities or appropriate residential care, or respite care for carers;
- supporting people with learning disabilities to form relationships with family, friends boyfriends and girlfriends and their children;

[Her] father and I now supplement [her] income, in order to enable her to participate in community life, and maintain her friendships. Without our help, [she] would have a life of poverty, and social isolation.

*Mother of an adult with learning disabilities on her daughter's experiences.*

I think it is harder for the learning disability person who is gay.

*A learner from Linkage Community Trust expresses their views.*

We are unable to go far as there are no disabled toilets in which to attend to his needs. So as a family we are all restricted in the participation in the local community. He is unable to meet with friends or socialise and without us taking him for a local walk or a short drive in his van we would be completely isolated.

*Mother of an adult with learning disabilities on her family's experiences.*

Services are not supporting relationships. Families are regularly disrespected even in public arenas such as conferences. Family connections are not supported, families have to make all the running. For people with a learning disability, having ordinary relationships that involve sex (like everyone else) is not supported in fact often subverted or prevented.

*Mother of an adult with learning disabilities expresses her views.*

### **Human rights, education and training**

10. A number of submissions talked about human rights in terms of their relevance to people with learning disabilities, including where training and education had made a difference to the way that they had been treated. Some people thought that further training and education was needed to make people with learning disabilities and their support workers aware of their rights. See for example:

We don't know much about it and would like to learn more.

*Advocacy West Lancs.*

Training around rights would help people with a learning disability get their human rights. Twelve of the Forum Members sit on the Cornwall Learning Disability Partnership Board. They are called The Get Real Team. Have had training around rights and feel that it is easier to speak up

*Cornwall People First  
Bodmin Forum.*

I have recently left employment at a residential home for adults with learning disabilities. During my two years there and since leaving, I believe that these adults do not get to exercise their human rights in several aspects. They are not informed of their rights in a manner which they can understand, therefore are not aware that they have such rights.

*Former support worker expresses her views.*

I care for an adult with a learning disability and feel it is very important that his human rights are met and that he should be treated no differently in this respect to any other person.

*A carer expresses their views.*

People who have learning difficulties should have the same rights as any other person and the Government have rules in place to make this happen.

*A person with a learning disability expresses their views.*

Protecting the Human Rights of People with Learning Disabilities: This will not be achieved by rhetoric and fine words. Unless there is a way of giving the legislation some teeth, then changes will not occur.

*Consultant Clinical Psychologist*

11. We asked people for their views on the recent UN Convention on the Rights of Persons with Disabilities. A number of submissions commented on the ability of the UN Convention to make a difference to the way that people with learning disabilities are treated.

I don't know much about the convention on the human rights of people with disabilities but do feel very strongly that everyone with a disability should have equal rights to those whom don't have disabilities.

*A person with learning disabilities expresses his views.*

The Convention on the Rights of Disabilities can help them (and should help them) to have their rights – BUT, they must realise their special needs, which are different to other disabilities.

*A family with learning disabilities express their views.*

Most of the principles in the Convention are already stated in other places but it does pull everything together and really highlights that people with a learning disability have the same rights as everyone else.

*A small self advocacy group in Bedfordshire.*



## Annex 3: Note of Informal Meeting: 23 July 2007

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### Panel 1: Relationships, carers and support

Richard Jackson MBE, Founder and Honorary Chairman, Rescare.

Alison Giraud-Saunders, Co-Director, Foundation for People with Learning Disabilities.

Philippa Russell CBE, Disability Rights Commissioner and Disability Policy Adviser, National Children's Bureau and Viv Cooper, Chair of Trustees, The Challenging Behaviour Foundation, for the National Family Carers Network.

### *A human rights based approach*

#### *Awareness and human rights*

1. In response to questions about whether taking a human rights based approach to the provision of services for people with learning disabilities would make any difference, Alison Giraud-Saunders told the Committee that people with learning disabilities speak more about rights since the publication of *Valuing People*, but that they will talk more generally about 'rights', rather than specific human rights. Although this change in focus was clear, she was concerned that practical follow through was lacking. People with learning disabilities are not sure how to enforce their rights or are scared to press for their rights in case it will affect the services they receive. It would help if there was better access to advocacy services for people with learning disabilities.

2. Philippa Russell told the Committee that people with learning disabilities are concerned about rights and entitlements, but the concept of human rights is often expressed in a very abstract way. People with learning disabilities may use the language of 'rights', but may have an inexact view on what rights are and how to achieve them without access to appropriate information and an understanding of how 'human rights' inter-relate with rights and entitlements under other legislation. Although a lot more work needs to be done on implementation, the HRA and disability legislation can be used to give people enhanced rights and create positive expectations. She expressed her grave concern that, although the Disability Discrimination Acts had made significant improvements in people with learning disabilities' access to (and expectations of) services, the Disability Equality Duty on public services might be weakened if proposals within the Government's current consultation on the Discrimination Law Review were incorporated in the forthcoming Single Equality Act. Where the Disability Equality Duty works well, there is better awareness of rights by providers and recipients, because both are active partners in the development and delivery of the Disability Equality Scheme and related action plan to progressively improve the quality of the public service in question.

3. Richard Jackson told the Committee that while a human rights based approach is an important element in the 'care scenario', RESCARE is concerned for those people with severe and profound learning disabilities who are without capacity to make considered life affecting decisions or to activate rights on their own behalf. For them and their families, the new Mental Capacity Act 2005 will prove invaluable, with a parent or close family member able to apply to be appointed to the role of deputy to act on behalf of their dependent son, daughter or relative, including acting to ensure that they benefit from the protection of the various human rights instruments.

### *Human rights training*

4. Philippa Russell told the Committee that more training is needed for people with learning disabilities and their carers on the Disability Discrimination Act and HRA and how to use and maximise their potential. However, any training must be supplemented by regular updated information and by improved access to advice and advocacy services. She considered that misunderstanding and lack of information often negate the good intentions of human rights legislation.

### *Family carers and independent living*

5. Committee members asked about the role of family carers and service providers in supporting independent living. The Committee also asked whether family carers were likely to stand in the way of independent living for people with learning disabilities. The following points were made in discussion.

6. Philippa Russell noted that worrying about the safety of their children is common to all parents. She was confident that the vast majority of parents of people with learning disabilities are not over-protective and want a good life for their children, with maximum independence. She and her husband were committed to encouraging their son to develop maximum independence and to take sensible risks so that he could cope in adult life, in particular when his family were no longer able to support him. She thought that this approach was typical of most family carers. Often, if parents (whether parents of those with or without learning disabilities) sought to prevent their children from pursuing a particular course of action it would be well-intentioned and with a view to ensuring that their child did not follow a path that would lead them into danger. However, she felt that family carers and people with learning disabilities should be encouraged to be more ambitious about the future – particularly when planning for transition to adult life. She noted that she and her husband had 'fought tooth and nail' to enable their son to move out of a group home into a house of his own. The family was now supporting him in setting up a small business of his own. In effect, the family was determined to give him the same life chances enjoyed by his siblings but many families did not have the information, the opportunities or the encouragement to go down this road. She felt strongly that we should follow the example of the USA, where family carers and people with learning disabilities see each other as 'allies', working towards the common goal of 'ordinary lives'.

7. Viv Cooper told the Committee that currently there are some exciting developments in service provision, but that good provision and access to services are not typical. Often families would need to work very hard to achieve the appropriate care and services for their relative with learning disabilities. Although sometimes there is tension between family

members (i.e. between the person with learning disabilities and their family carer), working together as allies is the way forward.

8 Richard Jackson expressed the concern of RESCARE that not everyone with learning disabilities can live independently. RESCARE consider that the extent of their dependency is often overlooked in considering supported or independent living. Family input (70% of caring is within the family home) is very important and families have a prime role to play. For people with learning disabilities, the one stable lifelong relationship they have is with their families. This was acknowledged in *Valuing People*. RESCARE consider that this importance was further evidenced when the widespread abuse events in Cornwall's supported living service were brought to light by 5 families who refused to be intimidated and ignored.

9. He told the Committee about the effects of Fragile X syndrome on his family. He has a 57 year old son, two grandchildren and a great nephew with varying degrees of learning disability and/or autism. He stressed that he has a close and happy family, but that it is important to recognise that the needs of each of his relatives with learning disabilities are different. His family had to fight for each of their relatives with learning disabilities to get appropriate services. For example his great nephew after 3 years at a residential school, on leaving at 18 with no care planning or transfer to adult services after 3 days he was sectioned into the Acute Psychiatric Ward of the local General Hospital. After 18 months he was freed when the Ombudsman admonished the local authorities, fined them £30,000 and commended the perseverance of the family who challenged the authority.

10. The needs of each individual are different, but RESCARE consider that local authorities increasingly impose supported living and refuse funding or referrals to other options, and so, a dangerous "one size fits all" is developing. RESCARE agree that there should be supported living for those who can cope and respond but seek to have '*Valuing People*' and its choice in housing options implemented in full (i.e. small scale ordinary housing, supported living and village and intentional communities, as well as residential care). They were concerned that no option should be ruled out.

### *Independent living and care planning*

11. Philippa Russell stressed the need to have good quality person-centred planning for people with learning disabilities. Person-centred planning should actively involve people with learning disabilities and family carers and should focus upon improving life chances rather than on crisis intervention. She noted widespread concern about changes in the funding of further education and the loss of courses which had historically often enabled people with learning disabilities to acquire both skills for independent living and for vocational training and subsequent employment. She also noted growing concern at the 'postcode lottery' experienced by many families, with wide variations in the provision of high quality local services for people with complex disabilities. She emphasised the point that people with high individual support needs can live in local communities but the growing inappropriate use of 'out of area' provision for people with complex needs demonstrates the need for better investment at local level in developing a wider range of services. She also referred to a recent Disability Rights Commission/Guardian roundtable discussion on the future of social care, where local authorities argued that PCTs (Primary Care Trusts) were increasingly expecting local authorities to cover care costs which should



transition of young people with complex needs, or for ageing family carers. They are very unusual. However, they probably still do not know of everyone who may have a learning disability in Sheffield.

### *Independent living and people with complex support needs*

17. When asked about independent living and people with complex support needs, Richard Jackson told the Committee about his concern that some people with learning disabilities are without capacity from birth. In these circumstances, the role of families is very important. Little is said about family advocates. However, RESCARE believe that families are the natural decision makers on the behalf of people with learning disabilities.

18. Richard Jackson expressed his concern that independence is not the prerogative of supported living. He told the Committee that there are some people with learning disabilities who are not going to be independent. RESCARE believes primarily in the right to choose. People with learning disabilities and their parents should have choice between a variety of service options. RESCARE are seriously concerned about the declining service with the closure of special day and residential schools, day centres and the recent movement campaigning against all residential care provision. They consider that thousands of people with severe learning disabilities and their families are being marginalized and sidelined as a 'crisis led' rather than a 'needs led' service develops.

19. Both Viv Cooper and Philippa Russell told the Committee that their sons, both of whom had complex needs were living in homes in the community, although it had taken an enormous amount of work to make this happen. Viv Cooper told the Committee that her son has learning disabilities, including challenging behaviour and has high support needs. She does not believe that her son is unable to live independently. She stressed that families can co-ordinate, organise, support and manage packages of care. Although families need help and support to do this, it is possible for people with complex needs to live within the community. Although it is possible, it is not typical and the systems are stacked against making it happen. Philippa Russell emphasised that 'independent living' did not mean living in the community without appropriate support.

### *Housing*

20. The Committee asked about the barriers faced by people with learning disabilities who were trying to access housing for supported living. Alison Giraud-Saunders thought that there were three problems: (i) a shortage of suitable housing; (ii) a lack of prioritisation of people with learning disabilities within the system; and (iii) a lack of creative commissioning. She told the Committee that people with learning disabilities are at the bottom of the queue for social housing provision. There are not enough new houses being built allowing people to live with support. An individual with a learning disability who needs support at home may well need a bigger place to live than an individual without a learning disability, such as a two bedroom place rather than one bedroom to accommodate overnight support and allow space for bulky equipment. There is a great shortage of suitable housing. She had heard from families told to evict their son/daughter so that they become eligible for housing assistance. There is currently a lack of creativity in housing provision. For example, in one case, where necessary adaptations could not be made to a family's home to allow their relative with learning disabilities to live there, the PCT sent the

person to distant residential accommodation, rather than move the family to a house that could be adapted. The adaptations would have been cheaper than sending the person to residential care.

### ***Funding, eligibility and access to services***

21. In response to a number of questions about funding, eligibility and access to services, the following points were made in discussion.

22. Philippa Russell told the Committee that having people live in homes in their local communities rather than in specialist out of county residential care could represent a major saving for the local authority. However, she considered that local authorities and PCTs must ensure that there is a strong infrastructure of services to support a successful move towards independent living. Placement breakdowns and crisis intervention are expensive and in many cases could have been avoided.

23. Richard Jackson told the Committee that there is enough money in the system but raised his concerns that it is not reaching the front line of care as intended, and is not ring fenced. For example, money from selling off former hospital sites for people with learning disabilities has not gone back into the service for people with learning disabilities although this was promised. He told the Committee that people with learning disabilities are at the bottom of the Government's funding priorities. RESCARE considers that supported living conveniently moves the burden of caring for people with learning disabilities from local authority budgets to the benefits system and the budget of central Government.

24. The other witnesses expressed their disagreement with this view. Alison Giraud-Saunders told the Committee that currently there was inadequate funding to meet demographic changes (including increased life expectancy) and increasing demand for services.

25. When asked by Committee members to explain how the current system could be improved without further funding, Viv Cooper told the Committee that the answer lay in the proper management of transition from childhood to adult services, individual budgets and direct payments. It was a real problem within the current arrangements that funding streams couldn't or wouldn't mix. She considered that the system needed to be made simpler in order to maximise current levels of funding and that there needs to be someone responsible for co-ordinating services on behalf of any person with learning disabilities. Philippa Russell added that where a person had access to individual budgets there should be an element of funding within their individual budget allocation for someone to coordinate it. However, people need advice and information and training about what the options are. Currently, too many disabled people and family carers lack the information, advice, training and support necessary in order to understand all possible options and to make informed choices.

26. Alison Giraud-Saunders told the Committee that there are already some good examples of bringing together funding streams well. In order to improve services within current funding limitations, she said local Authorities need good information on people with learning disabilities within their areas of responsibility so that planning can start early. People need to start thinking from early in a child's life.

27. There needs to be more creative thinking and a change in attitudes. Specifically, there is not always as much creative thinking in mainstream services, which people with learning disabilities use, as there is in the better services which are particularly for people with learning disabilities.

### **Carers**

28. When asked about people with learning disabilities acting as carers for others, Alison Giraud-Saunders told the Committee that more often, as the population ages and people with learning disabilities continue to live for longer, people with learning disabilities are undertaking a primary caring role. However, they are not being recognised as carers and often don't get a carers assessment. There was insufficient data available to give interested parties an accurate view of the breadth of this problem.

### **Concluding statements**

29. Philippa Russell told the Committee that there needed to be a wider debate and shared understanding about what we mean by 'human rights'. The concept of 'human rights' should be associated with high expectations of public services and of society as a whole. The shortfall in advocacy services means that many people with learning disabilities lack the support they need in order to make best use not only of human rights legislation but also of disability discrimination and other legislation which might enable them to access services and get a better quality of life. Family carers have human rights too, but sadly understanding and ability to use the human rights legislation to best effect are still limited.

30. Richard Jackson told the Committee that people with learning disabilities need life long care, support and protection to a varying degree according to the extent of their disabilities. It is not a case of one type of provision versus another but a comprehensive service with each having a part to play. There should not be a battle but a united front seeking the implementation of *Valuing People* in full with its choice of options. He told the Committee that parents and relatives are concerned that we are witnessing, and in danger of allowing, an abdication by the State of any meaningful care of those who cannot care for themselves and that this could only be against their human rights.

## **Panel 2: Access to justice**

Kathryn Stone, Chief Executive, VOICE UK.

Robin Van Den Hende, Policy and Campaigns Officer, Respond/VOICE UK/Ann Craft Trust.

Jenny Talbot, Programme Manager, Prison Reform Trust.

### **Human rights and crimes against people with learning disabilities**

31. The Committee asked whether the introduction of the HRA had made any difference to the way that people with learning disabilities were treated by the criminal justice system

and whether “taking a human rights based approach” to the provision of public services could help reform negative attitudes. The following points were made in discussion.

32. Robin Van Den Hende told the Committee that the HRA had led to no significant change in the attitudes of the general public towards people with learning disabilities. However, people with learning disabilities have started talking more about human rights and asking for their human rights to be respected. He thought that the HRA has had some effect on professionals in that discussions relating to people’s welfare increasingly use both the language of human rights and a human rights framework. He added that good practice aims to, and does, ensure respect for human rights, even if the language of good practice is not the language of human rights.

33. Kathryn Stone thought that the low number of prosecutions for crime against people with learning disabilities raised an interesting and important point. People with learning disabilities are seen to be different and they are treated differently by the media if they are murdered. People know the name of Victoria Climbié, but not the names of vulnerable people with learning disabilities who have been recently killed. The abuse of people with learning disabilities is a crime and needs to be treated as a crime, not just called abuse and dealt with as a disciplinary issue. The point is that if people with learning disabilities are seen as having human rights, they will be seen as being the same as other people.

### ***Bullying, Harassment and Hate Crime***

34. Committee members invited the witnesses to expand on how people with learning disabilities are treated by the criminal justice system and by the police. The following points were made:

35. Robin Van Den Hende told the Committee that “abuse” of adults with learning disabilities is not generally treated as a crime, even when that abuse does involve a breach of the criminal law (e.g. assault, sexual assault or fraud). The police are often called late in the process when evidence has degraded and it has become difficult to take statements from witnesses. Recently produced figures on adult protection referrals to Cornwall Adult Protection Committee illustrate this. Between October 2006 and March 2007 62% of adult protection referrals to the Cornwall Adult Protection Committee were either substantiated or partly substantiated. However, the Police were only involved in 9% of those investigations. Only 1% of these allegations led to a prosecution. Part of the problem is that people do not see adults with learning disabilities as people with equal rights to protection by the law.

36. Kathryn Stone told the Committee that research shows that police can fail to identify that a person has learning disabilities and they are reluctant to accept that a crime has been committed because a person has a learning disability. There is some good work being done by police forces to raise awareness about how to identify people with learning disabilities, and support them in giving evidence, including the introduction of the intermediary scheme under the Youth Justice and Criminal Evidence Act. Robin Van Den Hende told the Committee that the answer to the problem is in training in learning disabilities which is uniform across the country. He showed the Committee a copy of the Police Vulnerable Witness Pocket Guide, a credit card sized, fold-out guide for police officers on how to identify and help people with learning disabilities who had experienced crime. The Pocket



Guide was produced by VOICE UK, Respond and the Ann Craft Trust in conjunction with the Association of Chief Police Officers and has been distributed to every front line police officer in England and Wales.

37. Kathryn Stone told the Committee that VOICE UK have been campaigning for a long time for people to have equal access to the criminal justice system. This should be put in the context of the development of good practice. The treatment of people with learning disabilities could be compared with the treatment of children in the criminal justice system who are witnesses. While the need to assist children in giving evidence is widely recognised and acted upon, there is not the same recognition that people with learning disabilities can give good evidence providing they receive appropriate assistance. We need to think how to treat people in the criminal justice system if they are “different” and need different treatment to access justice.

38. The report *Behind Closed Doors* shows that people with learning disabilities sometimes do not know that what is being done to them is a criminal act. Instead, many people with learning disabilities believe that the crime that they suffer is simply a normal part of life. Even if people recognise that a crime has taken place, it can be difficult for people with learning disabilities to communicate their concerns if they have a communication difficulty. It is also difficult if the complaint is about the person providing care as a person with learning disabilities may fear the loss of care, accommodation or other support if they make a complaint and/or make a report to the police. Once a complaint has been made, the CPS may think that the complainant with learning disabilities won't be able to give evidence, or that it will be too stressful for them to do so and this may reduce the likelihood of a successful prosecution.

39. Since the publication of *Behind Closed Doors*, a number of publications have been produced and there are drives by grassroots advocacy organisations to improve the situation. Their effectiveness is demonstrated by the Sutton and Merton inquiry.

## **Training**

40. Committee members asked whether training needed to be provided to the police and others working within the criminal justice system. The following points were made.

41. Robin Van Den Hende added that the principle reasons why people with learning disabilities were more likely to be victims of crime and abuse are (i) the failure of the public to understand and empathise with people with learning disabilities and (ii) the vulnerability of people with learning disabilities. This vulnerability comes about because crime against this group are seen as being easier to commit and to get away with. This, in turn, is because (a) people with learning disabilities may have different communication needs that may not always be recognised by those to whom they could report crime and (b) the fact that some people with learning disabilities maybe too trusting of other people. The police need training and increased awareness if they are to help people with learning disabilities who have been the victims of crime. Police want to help vulnerable individuals, but some officers simply do not understand learning disabilities and the help that is available to let people with learning disabilities give their best evidence. Kathryn Stone added that any training scheme should be rolled out across the country.

42. Committee members asked whether training also needed to be provided to people with learning disabilities. Robin Van Den Hende stated that it should. He explained that change and training was needed on many levels as there are multiple hurdles that a victim with learning disabilities has to overcome to get justice. Many adults with learning disabilities won't recognise that even serious offences are a crime. They may be too scared and intimidated to report it, especially if the crime has been committed by someone working in their home or service. They may not know how to report it. Education for people with learning disabilities would address this. However, even if they report a crime, a care provider may not take the issue any further. Social care professionals may want to sweep it under the carpet and not go to the police. They may investigate the matter themselves instead of involving the police. Even if the crime is reported to the police, the police do not always consider providing special measures and may think the individual with a learning disability can't give evidence. At prosecution level, the CPS may decide not to pursue a prosecution as they consider that the victim cannot give evidence or that it would be too distressing for them to do so.

43. Training is not currently available across the board or at national level. Police officers may only receive a couple of hours of training on disability during their basic training. Training should be given to police officers on identifying people with learning disabilities so that they can be identified at an early stage in the criminal justice process. The police need to realise what having a learning disability means and how they can meet the needs of people with learning disabilities. The police also need to be aware of the special measures currently available to them.

### ***People with learning disabilities as accused***

44. The Committee asked about the problems facing people with learning disabilities accused of crimes. Jenny Talbot stressed the similarities with the difficulties faced by victims. She considered that there needed to be an increased focus on training and awareness. In particular, police officers in custody suites should undertake awareness training to assist in the identification of people with learning disabilities. In addition there needs to be a systematic screen to identify those people who might have learning disabilities. However, it is important to recognise that people often have developed coping mechanisms to hide their learning disabilities which makes it harder for police to identify this group of people. Offending behaviour is not always reported if people live in care homes. The Police may only be called when offending behaviour has got out of control when people with learning disabilities might have benefited from earlier intervention by the police, for example by being cautioned.

45. The Prison Reform Trust consider that the criminal justice system should provide support mechanisms for both suspects and defendants with learning disabilities. A failure to provide this support leads to a significantly increased risk of an unfair trial and miscarriage of justice for defendants with learning disabilities.

46. The Committee asked if the difficulties faced by people with learning disabilities were commensurate with the problems faced by those with mental health problems. Jenny Talbot told the Committee that, if we lifted all people with mental health problems out of prison, there would not be an overcrowding problem and that this would ease the pressure on the system. However, not all people with learning disabilities have mental health

problems, although some do. There is also the question as to whether prison is the most appropriate place for helping people with learning disabilities to stop offending.

47. By far the biggest group of people with learning disabilities in prison are those with mild learning disabilities, many of whom are unlikely to ‘qualify’ for support from community learning disability teams and/or local authority social services departments. People with learning disabilities are likely to need additional support to help them to understand what is happening to them at various points within the criminal justice system. The Prison Reform Trust considers that there needs to be more trained “appropriate adults” working in the criminal justice system to support this group of people.

48. On a practical level, the Prison Reform Trust considers that the following changes are necessary:

- Police should consistently be able to identify suspects who might have a learning disability and should be able to make an appropriate referral for assessment;
- People with suspected learning disabilities should not be interviewed without an appropriate adult;
- Appropriate adults should be accessible 24 hours a day, seven days a week; they should be statutorily funded and appropriately trained
- The appropriate adult scheme should be extended into attendance at court with the suspect/defendant ;
- There needs to be reform of the court process to assist people with learning disabilities (and others) to both understand and to participate in their own trial. For example, allowing for court visits pre-trial and providing accessible information at court. These reforms need to be part of a systematic national programme of change.
- Greater opportunities for community orders for people with learning disabilities should be explored and provided.
- Significantly improved data sharing between the different departments of the criminal justice system so that once a suspect has been identified as having learning disabilities the appropriate support can be put into place throughout the criminal justice process.
- Prison regimes should be made fully accessible to the whole prison population. In particular there should be full access to information, offending behaviour programmes and opportunities for education, training and employment

49. The Committee asked why there appeared to be breaches of PACE in the anecdotal evidence provided by the Prison Reform Trust in their written submissions. Jenny Talbot told the Committee that the possibilities included a lack of training, poor policing, busy custody suites, lack of time and pressure to process people quickly. Another reason might be that if the police identify someone as needing support, they would take more time and resources to deal with them, so it might be easier not to identify them.

50. When asked whether prosecution lawyers have training on how to modify their behaviour when dealing with people with learning disabilities, Kathryn Stone told the Committee that it is the role of the lawyer to challenge evidence. However, she advocated the use of intermediaries for defendants as well. Lawyers and judges need additional skills and training. There are examples of where people have not been asked the right questions in court e.g. when asked “do you follow?”, a person with learning disabilities might think that they have to physically follow someone somewhere. They will understand “do you understand?”. Similarly a person did not understand a whole series of questions that they were asked about the weather (Was it cloudy/sunny/rainy etc?), but did understand when they were asked “what was the weather like?”. Language can be moderated and it does not cost anything. There was a risk of unfair trial if someone could not understand what was going on. She considered that there should be an extended use of intermediaries along the lines currently being piloted in some places.

51. Kathryn Stone confirmed that VOICE UK were involved with the Judicial Studies Board on raising awareness of learning disability among judges.

### ***Prisoners with a learning disability***

52. Jenny Talbot told the Committee that, to be considered for parole, prisoners need to demonstrate that they understand their crime and show remorse and are often required to have participated in relevant offending behaviour (cognitive skills) programmes. People with learning disabilities may be excluded from participating in such programmes and may spend longer in prison as a result. This is because offending behaviour programmes tend only to be for people with an IQ of over 80 and with a certain degree of literacy. Cognitive skills programmes are often not accessible for people with learning disabilities. There is also a problem with accessing support services in prison, for example it is not clear what support should be made available from PCTs and social services. She told the Committee there is a problem of ‘silos of information’ in prisons, for example information isn’t shared between departments, often to the extent that prison staff do not know what support is available at their prison for this group of prisoners if it is provided by another department within the prison. She considered that, in some of the new contracts between PCTS/prisons/social services, the rules on sharing of information are not clear; staff sometimes hide behind patient confidentiality because they are unsure about what information they may share and what they may not.

53. Jenny Talbot told the Committee that, in her opinion, there were potentially more miscarriages of justice for people with learning disabilities than for those without.

# Formal Minutes

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**Tuesday 22 January 2008**

Members present:

Mr Andrew Dismore MP, in the Chair

Lord Dubs

Dr Evan Harris MP

Lord Morris of Handsworth

Baroness Stern

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Draft Report [A Life Like Any Other? Human Rights of Adults with Learning Disabilities], proposed by the Chairman, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 303 read and agreed to.

Annexes read and agreed to.

Summaries read and agreed to.

Several Papers were ordered to be appended to the Report.

*Resolved*, That the Report be the Seventh Report of the Committee to each House.

*Ordered*, That the Chairman make the Report to the House of Commons and that Baroness Stern make the Report to the House of Lords.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

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[Adjourned till Monday 28 January 2008 at 4pm.]

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<b>Monday 25 June 2007</b>	
<b>Dame Jo Williams</b> , Chief Executive, MENCAP, and <b>Mr Andrew Lee</b> , Director, People First (Self-Advocacy).	<b>Ev 1</b>
<b>Ms Eve Rank</b> , Commissioner, and <b>Mr Mark Shrimpton</b> , Assistant Director, Legal and Operations, Disability Rights Commission.	<b>Ev 6</b>
<b>Monday 9 July 2007</b>	
<b>Ms Sonya Sceats</b> , Policy and Research Officer, British Institute of Human Rights; <b>Ms Anne Lofthouse</b> , Lead Officer for Service User and Carer Involvement in Learning Disabilities; <b>Ms Lindsey Dyer</b> , Director, Service Users and Carers, Mersey Care NHS Trust; and <b>Ms Joanna Perry</b> , Board of Trustees, Values Into Action.	<b>Ev 9</b>
<b>Ms Ruth Scott</b> , Head of Policy and Government Affairs, Scope; <b>Professor Tony Holland</b> , Health Foundation Chair in Learning Disabilities, Department of Psychiatry and <b>Ms Amy Forgacs</b> , Cambridge Centre for Participation; <b>Ms Philipa Bragman</b> , Director, and <b>Mr Shaun Webster</b> , Project Co-Ordinator.	<b>Ev 15</b>
<b>Monday 22 October 2007</b>	
<b>Mr Rob Greig</b> , National Co-Director for Learning Disabilities and Co-Chair of the National Task Force for Learning Disability.	<b>Ev 22</b>
<b>Monday 12 November 2007</b>	
<b>Mr Ivan Lewis</b> , a Member of the House of Commons, Minister for Care Services, Department of Health, and <b>Mrs Anne McGuire</b> , a Member of the House of Commons, Minister for Disabled People, Department for Work and Pensions.	<b>Ev 31</b>

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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](mailto:archives@parliament.uk)

# Reports from the Joint Committee on Human Rights in this Parliament

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## The following reports have been produced

### Session 2007-08

First Report	Government Response to the Committee's Eighteenth Report of Session 2006-07: The Human Rights of Older People in Healthcare	HL Paper 5/HC 72
Second Report	Counter-Terrorism Policy and Human Rights: 42 days	HL Paper 23/HC 156
Third Report	Legislative Scrutiny: 1) Child Maintenance and Other Payments Bill; 2) Other Bills	HL Paper 28/ HC 198
Fourth Report	Government Response to the Committee's Twenty-First Report of Session 2006-07: Human Trafficking: Update	HL Paper 31/ HC 220
Fifth Report	Legislative Scrutiny: Criminal Justice and Immigration Bill	HL Paper 37/HC 269
Sixth Report	The Work of the Committee in 2007 and the State of Human Rights in the UK	HL Paper 38/HC 270
Seventh Report	A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Volume I Report and Formal Minutes	HL Paper 40-I/HC 73-I
Seventh Report	A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Volume II Oral and Written Evidence	HL Paper 40-II/HC 73-II

### Session 2006-07

First Report	The Council of Europe Convention on the Prevention of Terrorism	HL Paper 26/HC 247
Second Report	Legislative Scrutiny: First Progress Report	HL Paper 34/HC 263
Third Report	Legislative Scrutiny: Second Progress Report	HL Paper 39/HC 287
Fourth Report	Legislative Scrutiny: Mental Health Bill	HL Paper 40/HC 288
Fifth Report	Legislative Scrutiny: Third Progress Report	HL Paper 46/HC 303
Sixth Report	Legislative Scrutiny: Sexual Orientation Regulations	HL Paper 58/HC 350
Seventh Report	Deaths in Custody: Further Developments	HL Paper 59/HC 364
Eighth Report	Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005	HL Paper 60/HC 365
Ninth Report	The Meaning of Public Authority Under the Human Rights Act	HL Paper 77/HC 410
Tenth Report	The Treatment of Asylum Seekers: Volume I Report and Formal Minutes	HL Paper 81-I/HC 60-I
Tenth Report	The Treatment of Asylum Seekers: Volume II Oral and Written Evidence	HL Paper 81-II/HC 60-II
Eleventh Report	Legislative Scrutiny: Fourth Progress Report	HL Paper 83/HC 424

Twelfth Report	Legislative Scrutiny: Fifth Progress Report	HL Paper 91/HC 490
Thirteenth Report	Legislative Scrutiny: Sixth Progress Report	HL Paper 105/HC 538
Fourteenth Report	Government Response to the Committee's Eighth Report of this Session: Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9 order 2007)	HL Paper 106/HC 539
Fifteenth Report	Legislative Scrutiny: Seventh Progress Report	HL Paper 112/HC 555
Sixteenth Report	Monitoring the Government's Response to Court Judgments Finding Breaches of Human Rights	HL Paper 128/HC 728
Seventeenth Report	Government Response to the Committee's Tenth Report of this Session: The Treatment of Asylum Seekers	HL Paper 134/HC 790
Eighteenth Report	The Human Rights of Older People in Healthcare: Volume I- Report and Formal Minutes	HL Paper 156-I/HC 378-I
Eighteenth Report	The Human Rights of Older People in Healthcare: Volume II- Oral and Written Evidence	HL Paper 156-II/HC 378-II
Nineteenth Report	Counter-Terrorism Policy and Human Rights: 28 days, intercept and post-charge questioning	HL Paper 157/HC 394
Twentieth Report	Highly Skilled Migrants: Changes to the Immigration Rules	HL Paper 173/HC 993
Twenty-first Report	Human Trafficking: Update	HL Paper 179/HC 1056

#### Session 2005–06

First Report	Legislative Scrutiny: First Progress Report	HL Paper 48/HC 560
Second Report	Deaths in Custody: Further Government Response to the Third Report from the Committee, Session 2004–05	HL Paper 60/HC 651
Third Report	Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume I Report and Formal Minutes	HL Paper 75-I/HC 561-I
Third Report	Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume II Oral and Written Evidence	HL Paper 75-II/HC 561-II
Fourth Report	Legislative Scrutiny: Equality Bill	HL Paper 89/HC 766
Fifth Report	Legislative Scrutiny: Second Progress Report	HL Paper 90/HC 767
Sixth Report	Legislative Scrutiny: Third Progress Report	HL Paper 96/HC 787
Seventh Report	Legislative Scrutiny: Fourth Progress Report	HL Paper 98/HC 829
Eighth Report	Government Responses to Reports from the Committee in the last Parliament	HL Paper 104/HC 850
Ninth Report	Schools White Paper	HL Paper 113/HC 887
Tenth Report	Government Response to the Committee's Third Report of this Session: Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters	HL Paper 114/HC 888
Eleventh Report	Legislative Scrutiny: Fifth Progress Report	HL Paper 115/HC 899
Twelfth Report	Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9) Order 2006	HL Paper 122/HC 915
Thirteenth Report	Implementation of Strasbourg Judgments: First	HL Paper 133/HC 954

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Fourteenth Report	Legislative Scrutiny: Sixth Progress Report	HL Paper 134/HC 955
Fifteenth Report	Legislative Scrutiny: Seventh Progress Report	HL Paper 144/HC 989
Sixteenth Report	Proposal for a Draft Marriage Act 1949 (Remedial) Order 2006	HL Paper 154/HC 1022
Seventeenth Report	Legislative Scrutiny: Eighth Progress Report	HL Paper 164/HC 1062
Eighteenth Report	Legislative Scrutiny: Ninth Progress Report	HL Paper 177/ HC 1098
Nineteenth Report	The UN Convention Against Torture (UNCAT) Volume I Report and Formal Minutes	HL Paper 185-I/ HC 701-I
Twentieth Report	Legislative Scrutiny: Tenth Progress Report	HL Paper 186/HC 1138
Twenty-first Report	Legislative Scrutiny: Eleventh Progress Report	HL Paper 201/HC 1216
Twenty-second Report	Legislative Scrutiny: Twelfth Progress Report	HL Paper 233/HC 1547
Twenty-third Report	The Committee's Future Working Practices	HL Paper 239/HC 1575
Twenty-fourth Report	Counter-Terrorism Policy and Human Rights: Prosecution and Pre-Charge Detention	HL Paper 240/HC 1576
Twenty-fifth Report	Legislative Scrutiny: Thirteenth Progress Report	HL Paper 241/HC 1577
Twenty-sixth Report	Human trafficking	HL Paper 245-I/HC 1127-I
Twenty-seventh Report	Legislative Scrutiny: Corporate Manslaughter and Corporate Homicide Bill	HL Paper 246/HC 1625
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Twenty-ninth Report	Draft Marriage Act 1949 (Remedial) Order 2006	HL Paper 248/HC 1627
Thirtieth Report	Government Response to the Committee's Nineteenth Report of this Session: The UN Convention Against Torture (UNCAT)	HL Paper 276/HC 1714
Thirty-first Report	Legislative Scrutiny: Final Progress Report	HL Paper 277/HC 1715
Thirty-second Report	The Human Rights Act: the DCA and Home Office Reviews	HL Paper 278/HC 1716