



House of Commons
Health Committee

Social Care

Written evidence

*Ordered by The House of Commons
to be printed 15 October 2009*

The Health Committee

The Health Committee is appointed by the House of Commons to examine the expenditure, administration, and policy of the Department of Health and its associated bodies.

Current membership

Rt Hon Kevin Barron MP (*Labour, Rother Valley*) (Chairman)
Charlotte Atkins MP (*Labour, Staffordshire Moorlands*)
Mr Peter Bone MP (*Conservative, Wellingborough*)
Jim Dowd MP (*Labour, Lewisham West*)
Sandra Gidley MP (*Liberal Democrat, Romsey*)
Stephen Hesford MP (*Labour, Wirral West*)
Dr Doug Naysmith MP (*Labour, Bristol North West*)
Mr Lee Scott MP (*Conservative, Ilford North*)
Dr Howard Stoate MP (*Labour, Dartford*)
Mr Robert Syms MP (*Conservative, Poole*)
Dr Richard Taylor MP (*Independent, Wyre Forest*)

Powers

The Committee is one of the departmental select committees, the powers of which are set out in House of Commons Standing Orders, principally in SO No 152. These are available on the Internet via www.parliament.uk.

Publications

The Reports and evidence of the Committee are published by The Stationery Office by Order of the House. All publications of the Committee (including press notices) are on the Internet at www.parliament.uk/healthcom

Committee staff

The current staff of the Committee are Dr David Harrison (Clerk), Martin Gaunt (Second Clerk), David Turner (Committee Specialist), Lisa Hinton (Committee Specialist), Frances Allingham (Senior Committee Assistant), Julie Storey (Committee Assistant) and Gabrielle Henderson (Committee Support Assistant).

Contacts

All correspondence should be addressed to the Clerk of the Health Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 6182. The Committee's email address is healthcom@parliament.uk.

List of written evidence

	<i>Page</i>
SC	
1 Department of Health	Ev 1
Supplementary by DoH	Ev 4
2 Mencap	Ev 6
3 Sense	Ev 8
4 Medway Older People Communication Network	Ev 11
5 National Union of Journalists' Pensioners Committee	Ev 15
6 Essex Independent Care Association	Ev 18
7 Royal College of Nursing	Ev 21
8 Mr Ashleah Dean Skinner	Ev 25
10 Local Government Association	Ev 25
11 Home Group Ltd	Ev 28
12 The Hesley Group	Ev 31
13 Nestor Healthcare plc	Ev 33
14 Sanofi Pasteur MSD	Ev 37
15 Association of Directors of Adult Social Services (ADASS)	Ev 40
16 Linda Pickard	Ev 44
17 A Dignified Revolution (ADR)	Ev 47
18 United Kingdom Homecare Association (UKHCA)	Ev 51
19 Parkinson's Disease Society	Ev 55
21 Alzheimer's Society	Ev 57
22 National Pensioners Convention	Ev 61
23 Bupa Group	Ev 67
24 Mind	Ev 71
25 The King's Fund	Ev 76
26 UNISON	Ev 79
27 Care Quality Commission	Ev 84
28 Royal College of General Practitioners	Ev 88
29 Independent Age	Ev 89
30 The LIFT Council	Ev 92
31 Partnership Life Assurance Company Ltd	Ev 97
32 College of Occupational Therapists	Ev 100
33 Leonard Cheshire Disability	Ev 102
34 Mental Health Foundation	Ev 105
35 Sue Ryder Care	Ev 107
36 Macmillan Cancer Support	Ev 110
37 Age Concern and Help the Aged	Ev 113
38 The Princess Royal Trust for Carers	Ev 118
39 Counsel and Care	Ev 124
40 National Care Association	Ev 126
41 City of London Corporation	Ev 128

42	Multiple Sclerosis Society	Ev 129
43	Citizens Advice Bureau	Ev 133
44	Skills for Care	Ev 138
45	The NHS Confederation	Ev 140
46	Social Care Institute for Excellence	Ev 143
47	Professor Pat Thane	Ev 148
48	Professor Anthea Tinker	Ev 153
49	Professor Caroline Glendinning	Ev 157
50	General Social Care Council	Ev 162

Written evidence

Memorandum by the Department of Health (SC 01)

FUTURE OF SOCIAL CARE SERVICES

1. The Department of Health is pleased to have the opportunity to provide evidence to the Health Select Committee on the future of social care services.

2. This memorandum will cover:

- The care and support Green Paper “Shaping the Future of Care Together”
- Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities
- Personalisation of social care services
- More effective, consistent and user-friendly social care services
- Next steps

CARE AND SUPPORT GREEN PAPER

Background

3. “Care and support describes the activities, services and relationships that help people to stay as independent, active, safe and well as possible, and to participate in and contribute to society throughout the different stages of their lives.”¹ This consists of a whole range of support, from families, friends and communities, as well as from state-funded social care services such as domiciliary care (care in home) or residential care, financial support from the benefits system and help with housing.

4. The current social care system unlike the NHS was not created out of one single reform but the product of a series of more limited and incremental steps over time. As a result, the current system provides social care only to people with high levels of need and on low incomes who cannot afford to pay for themselves. Those who can pay for themselves are expected to do so with no support from the state, sometimes having to use up their savings and assets such as their homes to pay for care. For the large number of people who are expected to make provision for themselves, with no help towards the costs of care and support, this system is often seen as unfair.

5. The current care and support system will come under increasing pressure from changes in life expectancy and the changing demographics in England. By 2026, we expect there to be 1.7 million more adults who need care and support, and rising expectations mean that they will expect more choice and control over their services. As the number of people who need care and support increases, and expectations rise, the costs of providing care and support will increase dramatically. This means that the way in which the current state system is funded will no longer be adequate. If the system is left unreformed, this will mean restricting support further and growing numbers of people going without the care and support.

6. During 2008, the Government ran a six-month engagement process with the public, people who use services, and people who work in care and support. The Government listened to their views on the challenges, which face the care and support system in the future, and the problems within the current system.

7. In response to this, the care and support Green Paper for England, “Shaping the Future of Care Together,” was published on 14 July 2009. It set out a vision to build a new National Care Service in England that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs.

8. Shaping the Future of Care Together describes a system where people get care and support wherever they live in England. Under this system, people will be able to know exactly what to expect from the system and what they need to do to get help.

Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities

9. In order to fund the National Care Service and meet the needs of all those who require care in the future, more funding will be needed. The Green Paper explores how to make best use of existing funding within the system, for example through integration of some elements of disability benefits and social care funding and considers possible ways in which new funding could be brought into the system.

¹ HM Government “Shaping the Future of Care Together” 2009.

10. In evaluating options for a new funding system, the Green Paper considers the choices around who should be responsible for providing care and support and paying for people who need care, between the state, the individual and their families and how best to share this responsibility fairly. The Green Paper proposes three options for funding a National Care Service.

- Partnership—In this system, everyone who qualified for care and support from the state would be entitled to have a set proportion—for example, a quarter or a third—of their basic care and support costs paid for by the state. People who were less well-off would have more care paid for—for example, two-thirds—while the least well-off people would continue to get all their care for free.
- Insurance—In this system, everyone would be entitled to have a share of their care and support costs met, just as in the Partnership model. But this system would go further to help people cover the additional costs of their care and support through taking out insurance, if they choose to. The state could play different roles to enable this. The option of purchasing insurance would apply to people taking out insurance upon retirement. People born with a care and support need or who develop a need earlier in life would not be able to purchase insurance. This is because people cannot insure against the risk of something that has already happened. However, many people who were born with a care and support need would probably qualify for all their care free under the Partnership element of this option, since many are likely to be on low incomes.
- Comprehensive—In this system, everyone over retirement age who had the resources to do so would be required to pay into a national scheme. Everyone who was able to pay would pay their contribution, and then everyone whose needs meant that they qualified for care and support would get all of their basic care and support for free when they needed it. We would also look at having a free care system for people of working age alongside this.

11. The National Care Service is intended to provide care and support for all adults who need it. The funding proposals put forward, consider the needs of all adults (both older and working age adults) with disabilities, including those with physical and learning disabilities. However, sometimes in the case of the Insurance and Comprehensive options, different solutions work for people of different ages.

12. All the options will provide help to cover people's basic care and support costs that is needed to help people meet their assessed needs. If people want to go beyond this, they could choose to pay for additional care.

13. In the distinction of domiciliary and residential care costs, the funding options outlined above cover the costs of care, this means people who receive care in the home are covered. However, in all the options people in residential care who could afford to do so would be expected to contribute towards the cost of their accommodation (their care costs would be covered under the new system.) This includes costs such as food, lodging and council tax, which are a normal part of everybody's life, regardless of whether they need care or not.

14. The Green Paper proposes a range of different ways in which people could pay their contribution (either for the Insurance or Comprehensive system) towards the cost of their care for domiciliary or residential care. These include:

- contributing through a lump sum upon retirement or in instalments during retirement;
- deferring their State Pension for a few years, using the money to pay into the scheme
- deferring the whole payment until after death, paying through their estate.

15. To help individuals contribute towards their accommodation costs in residential care, the Green Paper also proposes a universal deferred payment mechanism, allowing these costs to be charged upon a person's estate when they die.

Personalisation of social care services

16. Much has already been achieved in improving care and support. For example, *Putting People First* (introduced in 2007) has begun to address many of the problems that people highlighted during the engagement process. *Putting People First* set out a shared vision and commitment to the transformation of adult social care, with the values and elements of a personalised adult social care system and a description of what help is available to local authorities to support system-wide change.

17. At present every council is working towards the goal of making personal budgets the norm in providing care and support, and the Government has invested £520 million in the Social Care Reform Grant to help them do this.

18. However, some of the problems in the current system will extend beyond the timescale of *Putting People First*. They will need a longer-term, national approach to providing care and support. The Green Paper builds on the approach that *Putting People First* developed and goes further to ensure in future everyone will be eligible for help with finding and paying for the care they need. In addition, an individual's care and support plan, will give much greater choice over how and where they receive support, and the possibility of controlling their own budget wherever appropriate. This means that people will know what resources they have available and that they will be able to make decisions about how it is used. This system will be the same regardless of where people live.

19. Under the new care and support system, local authorities will take the lead in encouraging the development of a much wider range of care services. People will get support to help them decide whether to stay in their own home, move into supported living or move into a care home, according to their own preferences and needs.

More effective, consistent and user-friendly social care services

20. The Green Paper considers a number of reforms to ensure more effective, consistent and user friendly care and support services in the future. These are described below.

More effective services

21. To ensure the reforms to the care and support system will develop a universal and sustainable system, which empowers people to live their lives the way they want to, we will need to deliver more effective services.

22. The Green Paper considers how many different services will need to work together to achieve this. There are three key changes which will need to be made going forward:

- More joined-up working between health, housing and social care services and between social care and the disability benefits system. This will mean that people receive more appropriate care in the right setting, reducing costs, improving outcomes and ensuring that services work together to keep people healthy, independent and well for longer. This would not necessarily involve structural change but improved joint ways of working to help to transform the experience of people who need care. The recently established Ministerial Group on Integration of Health and Social Care Services will help identify what has worked well in places round the country, as well current evidence to help push forward joined-up working.
- A wider range of services in care and support As individuals will have more choice over the care they receive, a greater range of services will be needed to choose from. We will need to help local authorities make sure that the services and ways of working in their area support innovative and high-quality care and understand how existing care and support services will need to adapt as more people begin to have more control over their care.
- Better quality and innovation Improving quality is an important part of making the best use of taxpayers' money and ensuring services, which people want and require. One of the most important aspects of improving quality is supporting the people who work in care and support. We will need to work with providers and the care and support workforce to help equip them with the different skills they may need to support people, in taking as much control as possible of their own lives. The Department of Health recently published a strategy on the future of the care and support workforce. Over the next few months, the Department of Health will develop an action plan to look at how the workforce will need to develop in the medium and long term. This will bring together key partners in the social care sector and elsewhere, to look at the big challenges for the future. In order to improve quality, and understand what care and support services work best we are considering giving an independent organisation the role of providing advice to government on what works best and is best value for money in care and support. Advice from this organisation could guide the decisions made by people commissioning care and support, and people who are choosing care and support services for themselves, helping ensure that services are based on the best and most recent evidence about what works in providing care and support.

More consistent and user friendly services

23. The National Care Service will be more consistent and user friendly across England. In order to achieve this:

- people will know exactly what to expect from the system and what they need to do to get help.
- there will be a fairer, more transparent allocation of funding

What people can expect from the new system

- Everyone in the future will be entitled to a National assessment wherever they are in England. Individuals will have the right to have their care needs assessed in the same way and will have the same proportion of their care and support costs paid for wherever their live. This assessment will be portable, so people will be able to take their needs assessment with them wherever they live in England.
- Services in the future will be joined up and work together more smoothly, particularly when assessing needs to ensure people will only need to have one assessment of their needs to gain access to a whole range of care and support services.
- Everyone will be able to access information and advice about care and support to make informed decisions about the care they need, making the service more user-friendly We want carers and people who need care to have easy access to a local information, advice and advocacy service when they need it—whether they are eligible for state funding or paying for care themselves. This

information will need to be available in a variety of formats, including online and through other digital technologies. One option could be an easily identifiable brand for all materials on care and support. We are currently seeking people's views on how to make information available as part of our consultation.

More fairer and transparent allocation of funding.

24. During the engagement process, many people commented they felt it was very unfair that people with the same needs could get different amounts of care in different parts of the country. In order to ensure a future care and support system that is fair, transparent and consistent in its allocation of funding, national government will set the level at which someone would be eligible for state funding in the future. This means everyone who had this level of need would be eligible for help paying for their care and support, wherever they go in England.

25. Beyond this, the Green Paper also considers who should determine the amount of support an individual receives in any future funding system to ensure a fair and more consistent allocation of funding. There are two options which we are currently seeking views on in our consultation. These are:

- A part-national, part-local system—Under this system, people would know that they were entitled to have their needs met, and a proportion of their care package would be paid for by the state, wherever they lived. But local authorities would be responsible for deciding how much an individual should receive to spend on overall care and support, giving them the flexibility to take into account local circumstances.
- A fully national system—Under this system, national government would decide how much funding people should get, instead of local authorities. The amount of funding allocated could be consistent across the country, or could vary depending on location to take account of the different costs of care across England.

26. Under either system, local authorities would play the key role in delivering care and support. They would continue to:

- be the channel for state funding and support;
- undertake assessments;
- provide information, advocacy and care management for individuals; and
- provide and commission services, and manage the market of care and support providers and
- foster innovation in care and support, using their freedom to decide exactly how services are delivered at a local level.

Next Steps

27. We are currently consulting on the proposals presented within the Green Paper, which is due to finish on 13 November. Once the consultation has been completed, we will use these responses to inform and finalise our proposals, with the intention to publish a White Paper on care and support in 2010.

28. In the mean time we are working to drive forward changes in areas where there is already a strong consensus, ensuring we work closely with the appropriate organisations to take this forward.

29. Care and support covers a range of issues, which are reserved or devolved. During the development of a White Paper, the Department will work closely with officials in the devolved administrations to reach a shared view on how best to ensure proposed changes provide the best possible outcomes for all people in the UK.

September 2009

Supplementary memorandum by the Department Of Health (SC 01A)

SOCIAL CARE

1. The Department of Health is pleased to provide evidence to the Health Select Committee on the recent announcement made by the Prime Minister on free personal care in the home.

2. This memorandum will cover:

- Free Personal Care in the home
- The care and support Green Paper “Shaping the Future of Care Together”
- Next steps

FREE PERSONAL CARE IN THE HOME

3. The Prime Minister announced on 29 September that people with the highest needs will be offered free personal care in their own homes.

4. The Prime Minister's announcement is a move to supporting those most in need in the current system and tackling the rising costs people are facing today. This is a step towards creating a fully integrated National Care Service for the future.

5. The money for this policy will be met from reprioritising central budgets and Department of Health will be working with stakeholders to make sure other services aren't affected. The Prime Minister has stated that this commitment equals £670 million in its first full year. Ministers have indicated that their expectations are that the Department of Health will reprioritise central funding and local authorities will reprioritise and use savings from efficiency measures

6. It is expected that this policy, following legislation, will be implemented in October 2010. We will be working with stakeholders over the coming months and further clarity on the scope of the proposals will be published.

Who will benefit?

7. The move is intended to support all adults with the highest needs in England. It will enable all those people with the greatest care needs to protect their savings, including, for example, many people with serious dementia or multiple sensory impairments.

How will it work?

8. People defined as in the highest need would no longer be charged for the cost of personal care services they receive to meet their high personal care needs in their own homes.

9. People not assessed as having high personal care needs would still be eligible for the current system, where support is means tested and determined by local authorities.

10. We will be working with stakeholders over the coming months and further clarity on the scope of the proposals will be published. We will need to introduce legislation to bring about this change.

What will this mean for local government?

11. This policy will be funded through additional grants and further efficiency gains from local councils. We will be working with councils to ensure that we use the most effective way of distributing this funding.

12. These plans for better-funded care at home should build on the most innovative practices already adopted by leading local authorities and PCTs.

What will this mean for the devolved administrations?

13. Health and social care is a devolved matter in Scotland, Wales and Northern Ireland. This announcement applies to England. Any changes to legislation will apply to England only and will not impact on the Devolved Administrations.

BACKGROUND ON CARE AND SUPPORT GREEN PAPER

14. The current care and support system will come under increasing pressure from changes in life expectancy and the changing demographics in England. By 2026, we expect there to be 1.7 million more adults who need care and support, and rising expectations mean that they will expect more choice and control over their services. As the number of people who need care and support increases, and expectations rise, the costs of providing care and support will increase dramatically. This means that the way in which the current state system is funded will no longer be adequate. If the system is left unreformed, this will mean restricting support further and growing numbers of people going without the care and support.

15. During 2008, the Government ran a six-month engagement process with the public, people who use services, and people who work in care and support. The Government listened to their views on the challenges, which face the care and support system in the future, and the problems within the current system.

16. In response to this, the care and support Green Paper for England, "Shaping the Future of Care Together," was published on 14 July 2009. It set out a vision to build a new National Care Service in England that is fair, simple and affordable for everyone, underpinned by national rights and entitlements and personalised to individual needs.

17. Shaping the Future of Care Together describes a system where people get care and support wherever they live in England. Under this system, people will be able to know exactly what to expect from the system and what they need to do to get help.

NEXT STEPS

18. We are currently consulting on the proposals presented within the Green Paper, which is due to finish on 13 November. Once the consultation has been completed we will use these responses to inform and finalise all our proposals, with the intention to publish a White Paper on care and support in 2010.

October 2009

Memorandum by Mencap (SC 02)

SOCIAL CARE

Mencap is the UK's leading learning disability charity, working with people with a learning disability, their families and carers. We believe people with a learning disability should have choice, opportunity and respect with the support that they need

EXECUTIVE SUMMARY

Mencap is extremely concerned about the current social care system, particularly for people with a learning disability and those who care for them.

The current social care system is underfunded and fails to meet the needs of many people with a learning disability. With a growing demand on services, due to increased numbers of people with a learning disability, this is set to get worse in the future. Mencap strongly urges the Government to inject money into the social care system to meet the rising demand on social care of people with a learning disability. Other concerns in relation to the future of funding include a failure to understand future demand, entrenchment of a postcode lottery of funding and services, and the exclusion of people with mild and moderate needs.

Personalisation is a great way to bring about choice and control in an individual's life. Mencap has been a supporter of the personalisation agenda from the outset, however we have highlighted a number of concerns about how it has been implemented. We urge the Department of Health to urgently address the systematic problems that are excluding people with a learning disability from receiving personalised care.

In order to improve effectiveness and consistency and make services user-friendly, the Government must understand the demand on social care. The Government also needs to ensure there are sufficient funds to meet the demand. We are also calling for general improvement to information and support and give consideration to reforming the social care workforce.

SUBMISSION

Future of funding of long-term residential and domiciliary care for people with a learning disability

1. Mencap believes that the current social care system is inadequately funded, including funding of long-term residential and domiciliary care for people with a learning disability. We strongly urge the government to address the funding gap for care for people with a learning disability, in light of the rising demand. As a member of the Learning Disability Coalition, Mencap fully supports its submission on future expenditure on social care for people with learning disabilities calling for increased funding for learning disability services.²

2. Urgent research needs to be undertaken by the Department of Health to track future demand for health and social care so that certain groups do not get pushed out of the system through inadequate planning and funding. Evidence shows that people with a learning disability are living longer and that more people with profound and multiple learning disabilities are surviving into adulthood.³ Without evidence of the likely future demand for services, any improvements to the care and support system will quickly be dissipated by ever-increasing demands and inadequate funding to meet them.

Postcode lottery

3. The current social care system is entrenched in a postcode lottery of services and funding.

4. In the current social care system, local authorities are responsible for setting eligibility criteria and social care budgets. Each local authority sets its own resource allocation system which has led to local authorities providing variable levels of care, creating a postcode lottery. There must be transparency about how resources are allocated and a commitment to a national resource allocation system, so that the system is fairer.

5. Due to the different resource allocation systems, many individuals are effectively trapped where they live because reassessment in the neighbouring borough would leave them with a smaller budget or they may even be ineligible for any care and support. People should not have their right to live where they choose eroded by the system.

² Submission on future expenditure on social care for people with learning disabilities, 2009 Learning Disability Coalition

³ Estimating the future needs for adult social care services for people with a learning disability, 2008, Eric Emerson and Chris Hatton

6. "Shaping the future of care together" the government's social care green paper presents a significant opportunity to end the current "postcode lottery" of care which has created huge unfairness in the system. Mencap supports a national system of social care which includes national assessment and a basic entitlement to care as suggested in the green paper. We would want a system based on clear entitlement related to need. We support recommendations for a national system of assessment and points allocation.⁴ We urge the Department of Health to conduct extensive research into how a national system of eligibility and entitlement would fit with local variations in the commissioning and cost of care provision. Consideration also needs to be given to how such a system would work in practice and on the implications for local government. The national system must be flexible but it must also be fair.

People with mild and moderate needs

7. During our adult social care consultation, it was heavily reported that people with mild and moderate learning disabilities are slipping through the net of social care. Most people with moderate needs do not receive any services and at least four local authorities only provide support to people with critical needs.⁵

8. Some people only require a small level of care and support, which would enable them to live independently and in many cases lead to employment. Without such support, many are left behind and will become a greater financial burden on social care in the future.

9. The Department of Health have raised this issue in the white paper, *Our health, our care our say*:⁶

10. "There is also a growing evidence base showing that preventative measures involving a range of local authority services, such as housing, transport, leisure and community safety, in addition to social care, can achieve significant improvements in well-being"⁷

11. "Prevention and partnership—adopting a new vision of social care that goes beyond the narrow model that currently predominates. Typically this related to the need for a stronger focus upon prevention and inclusion so that councils and their partners know much more about people who currently fall outside of the system."⁸

12. Mencap believes that this needs to be urgently addressed.

Personalisation of social care services

13. Mencap fully supports personalisation as it reinforces the idea that the individual is best placed to know what they need and how those needs can be best met. Personalisation is about giving people greater choice and control over their lives and replaces traditional and institutional care services.

14. However Mencap has some serious concerns about some aspects of how the personalisation agenda is being implemented.

15. During Mencap's consultation on adult social care, many people with a learning disability and their families told Mencap about how they have been left out of personalisation this was supported by a CSCI report,⁹ which found that many local authorities have failed to make substantial changes to introduce person-centred care, creating unfairness in the social care system.

16. Personalisation, like other aspects of social care, is subject to the post code lottery. The post code lottery extends from assessment, eligibility, resource allocation and service choice. Mencap believes this to be a direct result of local flexibility and a lack of transparency.¹⁰ Mencap strongly calls for a national assessment system, which would increase transparency and alleviate postcode lottery. Mencap also calls for the Department of Health to take on a more proactive approach in monitoring and enforcing the efforts made by local authorities to introduce personalisation in their area.

17. Mencap is concerned that some local authorities will use individual budgets, a practical element of personalisation, to save money. It is widely thought that individual budgets are cheaper than the traditional service provision and could be used to reduce local authority spending. Mencap strongly believes that savings should be reinvested into the social care budget, to cover the cost of the increasing demand and general improvement of social care services.

18. Personalised social care will require a changing role for social care staff. Mencap believes the workforce needs to be given the skills required for this changing role. So far, many local authorities are failing to do this, therefore creating a significant barrier to the introduction of personalisation. A similar issue is that of changing services. During Mencap's consultation on social care, many individuals highlighted the failure to reform care services to meet the aims of personalisation. Mencap strongly urges the Department of Health to urgently address this issue.

⁴ *Cutting the cake fairly: CSCI review of eligibility criteria for social care*; 2008, Commission for Social Care Inspection

⁵ *Ibid 2*

⁶ *Our health Our care Our Say*, 2006, Department of Health

⁷ *Our health Our care Our Say*, 2006, Department of Health

⁸ *Ibid 2*

⁹ CSCI, *The State of Adult Social Care 2007–08*, 2009

¹⁰ Mencap response to the DH consultation: *The case for change—why England needs a new care and support system*, 2008

19. People with multiple and complex needs often require large staff teams, which can be both expensive and complex to run. Funding and support at a high level is necessary to make this kind of staff-heavy support package work for individuals and their families.¹¹ Mencap believes that the Department of Health should ensure that support packages are properly financed, so that people with multiple and complex needs receive the personalised care that they have a right to.

More effective, consistent and user-friendly social care services

20. Ultimately Mencap believes that the way to make social care services more effective, consistent and user-friendly is to understand the true demand. Mencap calls on the Department of Health to commission a study in to the numbers of people with a learning disability and their social care needs. Mencap also sympathises with calls from the rest of the sector to study numbers from other user groups. Without knowing and understanding the current and future demand on social care, local authorities fail to effectively plan for the future.

21. As covered previously, Mencap believes that the current social care system is under funded and this needs urgent attention. Without the appropriate level of funding, social care services will not be more effective, consistent and user-friendly.

22. Mencap has grave concerns about the postcode lottery and lack of transparency in the current social care system. As well as excluding people from the social care that they need, the lack of transparency and severe local variation hinder Parliament from ensuring that the current system is effective, consistent and user-friendly. Mencap urges the government to introduce a national assessment system, which would assist the Department of Health in developing strategic planning for improvements at a national level. It would also enable local authorities to compare themselves with other local authorities to introduce local changes to improve social care services.

23. During Mencap's social care consultation, many individuals told Mencap that one of the greatest barriers to social care is the lack of information and support to the individual and the family. This includes a failure to provide accessible advice and information and often a complete failure to provide any information and support. We urge the government to address this issue and take a pro-active approach to providing a solution to the problems. Mencap believes that local authorities should widely advertise information and support outlets, as well as making it clear to service users who is best to get in touch with.

24. Finally, Mencap strongly believes that the Department of Health needs to strengthen the workforce to make social care services more effective, consistent and user-friendly. In the light of personalisation, the role of the social worker needs to be adjusted.

September 2009

Memorandum by Sense (SC 03)

SOCIAL CARE

EXECUTIVE SUMMARY

Decisions on the future of social care must take account of the needs of lesser heard groups. Deafblindness is a unique disability and the specific needs of deafblind people can often be neglected by mainstream policy-makers. Sense is currently consulting deafblind people, families and professionals on how the Green Paper's proposals could affect them. However we already know that there are some fundamental points that must be explored in order for any new system to work for deafblind people. These include professionals identifying deafblind people, deafblind people's right to a specialist assessment within a national assessment model, meeting the needs of deafblind people with portable assessments, resource allocation systems, and information, brokerage and advice within a personalised care and support system.

1. INTRODUCTION

1.1 Sense

With over 50 years of experience, Sense is the leading national charity working with, and campaigning for, children and adults who are deafblind. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have sensory impairments with additional disabilities.

1.2 Deafblindness

Deafblindness, or dual sensory loss, is a combination of both sight *and* hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, accessing information and mobility. Deafblindness is a unique disability that should not be seen as just a hearing loss plus a sight loss. The two impairments impact on each other and multiply the

¹¹ CSCI, *The State of Adult Social Care 2007–08*, 2009.

total effect. There are many causes of deafblindness. These include premature birth, birth trauma and rubella during pregnancy, which can cause babies to be born deafblind. Some genetic conditions also result in deafblindness. And any of us can become deafblind at any time through illness, accident or as we grow older. People who are born deafblind often have additional disabilities, including learning and physical disabilities. Sense estimates that there are approximately more than 180,000 deafblind adults in England.¹²

1.3 *Deafblindness and an ageing population*

As the population ages, the number of deafblind older people will rise. Indeed in 2029, we estimate that the number of deafblind older people in England will have risen to over 300,000 people.¹³ Government, local authorities and other organisations' plans to address the needs of an ageing population must include identifying deafblind older people and providing appropriate services.

2. THE KEY ISSUES FOR DEAFBLIND PEOPLE

2.1 *Specialist assessment under the Deafblind Guidance*

Deafblind people are entitled to a specialist assessment of their needs and appropriate services.¹⁴ The statutory Deafblind Guidance clearly state that local authorities must:

- Identify, contact and keep a record of deafblind people that live in their area;
- Ensure that a deafblind person is assessed by a suitably qualified person;
- Provide services that are appropriate for deafblind people;
- Provide one to one specialist support as appropriate;
- Provide information and services in a way that is accessible to deafblind people;
- Ensure that a senior manager is responsible for services for deafblind people.

Every deafblind person should be offered a specialist assessment under the Deafblind Guidance. Many deafblind people, their families and mainstream professionals do not know about the kind of positive interventions that can provide support to deafblind people. This is where a suitably trained specialist can offer guidance and advice on making sure support options take full account of the impact of dual sensory loss.

2.2 *Proposals for a national assessment process*

A portable assessment would help deafblind people to move around England much more easily and prevent some of the stress and anxiety around moving to a different local authority area. Deafblindness is a unique disability, not just sight loss plus a hearing loss. It is therefore not enough for an assessment to note sight and hearing loss, it is crucial to explicitly identify a dual sensory loss. As stated above deafblind people are entitled to a specialist assessment of their needs; we are concerned that a standard national system may not highlight the need for a specialist assessment.

2.3 *Meeting specialist needs identified in a portable assessment*

Alongside concerns about national assessment, we also have worries about service provision to meet the needs of deafblind people. The services that many deafblind people need are not uniformly available across the country. This is caused by a range of factors including a local authority's willingness to implement the Deafblind Guidance, the number of deafblind people identified by the local authority, the capacity of national or local providers and rural or urban location. This will mean that in the future a deafblind person may be able to take their assessment with them to a new location but may not have access to appropriate services to meet assessed needs. We accept that needs may not be met in a uniform way throughout England, but fear that a portable assessment will not improve the situation for deafblind people if a process is not in place to ensure their needs can be met when they move.

2.4 *Appropriate support for deafblind people*

We are very concerned that the Green Paper is not explicit enough on the different types of essential support that individuals may need. The Green Paper explores how "basic care and support" needs will be met. Many deafblind people may be able to take care of their own personal care but may need support in performing other essential tasks, accessing information and being active members of their community. Although some deafblind people will need support with personal care, they will still have a range of needs related to their deafblindness. For some people this may require a number of hours of communicator guide or intervenor support. A communicator guide is a worker with specialist knowledge of deafblindness who can support a deafblind person with tasks in the home and in the local community. A number of hours a week of one to one support can transform the life of a deafblind person. An intervenor is a one to one support

¹² Sense, 2008, Numbers of deafblind people explained.

¹³ Based on population projections from the Office for National Statistics http://www.gad.gov.uk/Demography_Data/Population/2006/uk/wuk065y.xls

¹⁴ Department of Health, 2009, Social Care for Deafblind Children and Adults LAC (DH) (2009) 6.

worker who helps a deafblind person make sense of and interact with the world around them. Intervenor usually work with children or adults who were born with severe visual and hearing impairments and who may also have additional disabilities. Intervenor may work with deafblind adults in the home and community environments.

2.5 Personalisation

We share the Government's commitment to a system which allows people to shape and control their own lives. However, we have a number of concerns about the way in which this is currently being put into practice. In partnership with a number of organisations, we have published *Putting Everyone First*, a practical guide for local authorities to ensure that they consider a range of factors that need to be taken into account to ensure that Personal Budgets meet everyone's needs.¹⁵ A move towards RAS or self-assessment tools has meant that some local authorities are not always meeting their duty to provide a full assessment of someone's needs as well as a specialist assessment. This is unacceptable and means that deafblind people's needs are left unmet.

2.6 Personalised assessment and resource allocation systems

The allocation of appropriate funds to a Personal or Individual Budget is critical to its success. There is little point in people being given control of an inadequate budget; this does not give a person the power to shape services to meet their needs. In many ways the use of a standardised questionnaire (as has been used by many local authorities in the form of a RAS) does not represent a personalised approach. Some authorities have taken an "outcomes focussed" approach, which takes people's aspirations for their lives as its starting point. The evaluation of the Individual Budget pilots concluded that there was no consensus about the benefits of RAS questionnaires and called for a debate about the relative merits of RAS, outcomes focussed approaches and the system currently used for direct payments allocations. In the absence of a national debate, we believe that the first issue authorities should consider is whether developing a RAS self-assessment questionnaire is the approach they want to take. If local authorities use a RAS questionnaire in some way, it is vital that a more inclusive range of questions is used; *Putting Everyone First* gives guidance on this. Some RAS questionnaires that we have seen do not ask questions that will identify and award appropriate funding to meet the needs of deafblind people. A RAS questionnaire will be more effective if it asks questions about communication needs, access to information, mobility both within and outside the home and varying levels of need; all of these are key support areas for deafblind people. We welcome that the draft revision of the FACS guidance makes it clear that a RAS should only be used to create an indicative budget that must be flexible in order to meet assessed and eligible needs. This is a crucial point for deafblind people who often have specialist and therefore more expensive to meet needs.

2.7 Information, brokerage and advocacy

As individuals move to direct their own support, it is vital that they have access to appropriate and accessible information. Accessibility for deafblind people means that services will need to have the resources and knowledge to use the appropriate interpreters and communication support, such as sign language and deafblind manual interpreters. Information will also need to be produced in alternative formats such as Braille and audio. Information needs may range from information about the basics of self-directed support, personal budgets or direct payments to thorough and trustworthy advice on employment law. Individuals must be able use accessible brokerage and advocacy services should they wish to delegate some responsibilities or require support in their relationship with their council or service providers. The case study below outlines how one deafblind man is supported by his local direct payments support service.

2.8 Case study of accessible support from a direct payments support

A deafblind man uses his local support service to provide payroll services. He uses Braille and has a Braille screen reader for his computer. The support service use both email and telephone via Typetalk to communicate directly with him. The support service send him monthly emails with details of gross and net pay and details of any deductions such as income tax and National Insurance. They put two staples in the envelope containing the payslips so that he knows they have arrived. They also put Braille labels on the payslips so that he can hand the hard copies out to his different employees and maintain both control and confidentiality.

3. RECOMMENDATIONS FOR ACTION

3.1 Support implementation of the Deafblind Guidance by all local authorities

In order to provide an effective and consistent service for deafblind people, local authorities must implement the statutory Deafblind Guidance. This should be championed by Government and the Care Quality Commission should include implementation of the Deafblind Guidance in their inspection criteria.

¹⁵ http://www.sense.org.uk/help_and_advice/social_services/putting_everyone_first.htm

3.2 *Ensure a national assessment process explicitly identifies dual sensory loss and takes account of specialist needs*

A national assessment system must explicitly identify dual sensory loss and the need to refer individuals for a specialist assessment. Assessors must be made more aware of deafblindness and assessment documentation should provide an opportunity to explicitly record dual sensory loss, not just sight and hearing loss as two separate impairments.

3.3 *Ensure local authorities can meet the portable assessed needs of deafblind people*

Even within a personalised social care system local authorities retain the duty to meet assessed needs and ensure the local market can meet everyone's needs. Deafblind people planning to move to a new area will need to be able to discuss their support needs with their new local authority before they actually move. A support plan can then be drawn up to ensure that their needs can be met as soon as they move.

3.4 *Recognise that care and support needs include specialist support for deafblind people*

There needs to be much greater clarity on what is meant by "basic care and support". The debate about the future for social care must not have support with personal care as its sole focus. It must be clear that eligible needs cover a much broader remit.

3.5 *Ensure personalisation includes everyone*

Good practice in ensuring personalisation include everyone should be collected and disseminated. Government and local authorities should work jointly with Sense to ensure a personalised system meets the needs of deafblind people.

3.6 *Personalisation, assessment and resource allocation*

Government must stress to local authorities that they are obliged to conduct a full assessment of individuals' needs that fulfils their legal duties and that a RAS can only be used to create an indicative budget which must be flexible in order to meet the cost of all eligible needs.

3.7 *Access to information, brokerage and advocacy*

Individuals must have access to these services. Accessible brokerage and advocacy services must be funded to ensure that those who require these services are able to use them.

September 2009

Memorandum by the Medway Older People Communication Network (SC 04)

SOCIAL CARE

SUMMARY OF EVIDENCE

It is unclear as to whether the three areas for Inquiry are stand alone items or an integral part of a whole. We have set out the inputs that are required for each of these aspects. We recognise the basic equality of provision that is required by Human Rights. We noted the huge discrepancy of income and wealth within the Country and note that social conditions have a major impact upon a person's health. We reject the notion that finance should be a driver in provision. We note the defects in the system at present as highlighted by The Patients Report and others. We deal in detail with the question of future funding noting that this is a responsibility of society as a whole. On the question of "Personalisation" we again note the requirement of equality of treatment and call attention to the variety of people involved in care but note the fundamental responsibility as belonging to Government and Health professionals. In discussing Social Care Services we note inadequacies in present performance and call for a return to professional control with these services allied to quality control systems that ensure monitoring and measurement and development of the system.

EVIDENCE

1. The call for evidence from the House of Commons Health Committee Inquiry into Social Care sets out three areas for consideration. These are

- Future Funding
- Personalisation
- Social care service.

It is unclear as to whether the Committee sees these three areas as separate, independent areas for inquiry or whether they are interconnected aspects of the whole. In our evidence we will treat each aspect separately with the proviso that what we have to say will in most cases relate to all three areas.

DESIGN INPUTS FOR FUTURE FUNDING

2. In designing a system it is important to bear in mind the key aspects of design, namely to first consider the various inputs. In considering the three aspects mentioned above, we will first concentrate upon the question of funding and consider the issues that have to be dealt with.

3. The first and major point is that when considering the health, care and support needs of any individual the response to those needs is the same whatever be the status of the person in need. Whether the needy person is a Queen or the meanest commoner the needs for a particular problem are the same. It is a fundamental human right that a person in need be treated according to that need. To consider that one person should have a better level of care, simply because they are able to afford such care whilst denying that care to some other person is a denial of that person's human rights and a breach of human rights legislation.¹

4. The second point that must be made is to draw attention to the major differences in income and wealth between various sections of the community. Whilst at one end of the scale people are talking about salaries in terms of millions of pounds at the other end we have people living on minimum wage or on pensions both of which may in fact have to be supplemented by income support.

5. There is abundant evidence to show the inequalities found in health and medicine are directly linked to the social and economic conditions that govern people's lives. Diseases such as lung cancer, coronary heart disease, stroke, accidents and suicide vary according to whether one is a professional, managerial, skilled non manual or manual, or unskilled. The affect on the unskilled in all of these cases is at around three times as great as the effect on professional people.

6. There is extensive documentary evidence to prove that one's position in society affects one's health².

7. The Green Paper does not make any reference to these points when in fact they are crucial to any discussion of health, care and support. Without taking into account these issues in the design of the new system the Government will be further discriminating against people who have suffered economic discrimination through out their lives.

8. In designing the future system of Health, Care and Support one of the main design features shall be to end the unequal distribution of wealth. Health, Care and Support needs are the same for any one affected irrespective of their income and wealth.

9. The Green Paper states "*But the precise costs will vary depending on how we design the options and decisions made about spending at the time*" This begs the question of what will be the main driver in deciding on the future system of care and Support. The implication behind this comment is that finance will be the main driver in decisions. The Human Rights Act would require that it is the needs of individuals that should have priority in planning such a system.

10. The Green Paper states "*The care and support that is needed to help people to meet their assessed needs. If people wanted to go beyond this, they could pay for additional care if they chose*" This comment is difficult to understand. If a person is assessed with a particular need there follows from that a course of action that needs to be taken. This is true whatever the status of the person being assessed. If that assessment is made accurately then there is no reason to go beyond the course of action prescribed. If there is a possibility that additional treatment could be necessary then that should form part of the original assessment and proposed course of action. Anything less than this implies that only those who are able to afford the full treatment will get that treatment. The proposed new system must be clear in stating that the level of treatment shall be independent of the means of the person receiving treatment.

11. The Green Paper uses many ideas from past legislation without giving evidence and data to substantiate the claims of success that are being made. In 2005, we presented a paper to the Royal College of Nursing Conference on Nursing and Older People: Partners in Care³. In that Presentation we gave many examples how older people were badly treated in clear breach of their human rights.

1. We had expected that things would have improved in the time since we did our work. However, events such as the experience at Maidstone and Tunbridge Wells Trust, Mid-Staffs Hospital, the recent Patients Association Report and information that we have received from "A Dignified Revolution"⁴, an organisation that allows professional nurses and others express their concerns, and from the information that we receive from people whom we know, meet and work with, it is very clear that such behaviour has continued⁵.

2. On a positive note, many more professionals working in Health, Care and Support now have a greater understanding of Human Rights and recognition that these rights have a major part to play in patient care.

3. What we are not so convinced about is the importance that administrators involved in Health care and support attach to the Human rights of those for whom they are caring. To what extent is the view that Human Rights and Health and Safety at Work Acts are a hindrance to the work being done, as was expressed to us by one administrator, held within the administrative sector?

4. The Green Paper sets out the Government's "*vision for a system that is fair, simple, affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs*" The Paper also makes clear that "*these services are likely to affect every one of us in some way during our lives, whether directly, through needing care ourselves, or through knowing or helping to support someone who needs care*".

5. Any plans for the future must address the question of inequality and provide for a redistribution of wealth and resources. We are strongly opposed to any proposals that place greater burdens on working families at any stage in their lives.

6. In designing the future system of Health, Care and Support one of the main design features shall be to end the unequal distribution of wealth. Health, Care and Support needs are the same for any one affected irrespective of their income and wealth.

7. What was clear is that a comprehensive system providing universal benefits according to the needs of the individual and paid for by contributions according to ability to pay is far the best way of providing for these services.

8. Where two systems are allowed to prevail, a national system available to all and a private system available only to the rich then problems will arise with the richer elements able over time to obtain a far superior service whilst the majority will be left with an ever declining service.

9. One of our main fears is that the way care is available will result in those who can pay through which ever way is decided upon will get far higher quality care than those who are means tested.

10. The result of means testing is a denial of human rights not only for those who have to subject themselves to the process of means testing but also for those for whom means testing is a means of denying them access to provisions of which they have need.

11. The only possible way of ensuring that everyone does indeed obtain the situation set out in the Government's vision is to ensure that provision follows the principle that governed the original welfare state that at times of prosperity people should pay into a scheme at a level commensurate with their wealth and income so that at a time of need individuals and their carers receive whatever is related to their need on a level that any other member of the community would receive.

PERSONALISATION

12. The Green Paper fails to recognise that they are providing services for people they are not dealing with commodities as the tenor of the Paper suggests.

13. Care is a culmination of events that have shaped a person's life. It is important that those events be fully included in the process.

14. The provision of care and support is never an individual matter. It is always a communal affair, whether it be family, friends or neighbours or a mixture of all three that actually takes the responsibility for looking after people in need. The "*State*" should mean society in general and society as a whole has a vested interest in caring for individuals within that society.

15. We wish to see that the system adopted fulfils the requirements of Human Rights for each and every individual and be fully convinced that people are able to exercise these rights especially at a time in their lives when their main priority is the alleviation of some form of need.

16. If any one receives then all who need should also receive. If this is not financially possible then no one should receive.

17. The Green Paper talks about personalisation of care, flexibility and choice as though these are the major aspects of health, care and support without really spelling out what they mean by these terms.

18. Each individual who has need for health, care or support is different, they have to be assessed and professionals have to determine the best course of treatment. However, the list of ailments from which people can suffer is not unique to individuals however differently they may suffer. In this sense treatment is common.

19. What we are very concerned about is allowing flexibility to mean that certain people who are in the fortunate position of having wealth to be able to receive necessary treatment that is denied to other who lack that wealth.

20. We are extremely concerned about the matter of accommodation costs. The summary states that "*the cost of care, but do not include accommodation because we would expect people to pay for their own food and lodging whether or not they were in a care home*". This simple statement states, before any other factor is taken into consideration, that the inequalities that exist at present will be carried forward whatever the Government may finally decide upon. One of the basic reasons why health, care and support needs are greater among the majority lower income people is precisely because the money they have available for food

and lodging, whilst they are well and working, is so much less than that available to the rich minority. The cost to this majority of going into a care home will of necessity increase and so they will inevitably have to pay more for the same provision in these terms. We cannot accept this statement.

21. We do not feel that this Green Paper goes any where near far enough to deal with this important issue. People will always care for others whether they are family, friends or neighbours. This does not take away from Society at large or Government and Care Professionals the responsibility of ensuring that the Health, Care and Support system meets the needs of those who have a claim upon it, without placing an undue burden upon those who seek to care for others. As a civilised society that is the least we can expect.

SOCIAL CARE SERVICE

22. The Green Paper talks about *“better quality”*. We always have difficulty whenever words like *“better”* are used. The question arises better than what? What we expect is that organisations providing Health, Care and Support are monitoring their performance and responding to any event which falls short of desired practice. Such events may be major, in which case corrective action should be taken immediately and preventative measures put in place to avoid similar events in the future. What may be termed *“minor”* events will be recorded. If subsequently the event is repeated a sufficient number of times it will become a major event. Such *“Quality Control”* systems are extensively used in industry and should be adopted in the provision of Health, care and support. We understand that ISO has produced standards for use in these circumstances.

23. The Green Paper devotes a whole section to *“joined up working”*. However the context of that section is joining up services at the top, bureaucratic level. What is even more important is to join up working at the day to day operational level. The trend towards separating functions and then hiving them off to private organisations, as in cleaning and provision of food in hospitals, has to be reversed. We wish to see an integrated Health and Social Care and Support system run by a single organisation such as the National Health Service which is democratically controlled and has as its only priority the provision of health, care and support for those who need it. This service must be tax funded.

24. We are concerned about the *“management”* of the service. However our approach is the exact opposite of the trend set out within the Green Paper. We do not believe that the change that has occurred with successive Governments to part privatise and to bring in management practices from commercial businesses has been a success. Rather we believe that such practices are a cause of many of the failings within the health, care and support services.

25. We wish to see nationally agreed standards, verified and enforced, with professionals within the health, care and support services given the responsibility of working to these standards. Within their remit would be a managerial function as part of the overall responsibility to fulfil their professional duties.

26. Allied to this we wish to see processes in place that enable close monitoring of the systems to take place, with collection of information and statistics that can be used to assess the work that is being done, to measure the success of the system, and to bring about a continual improvement in technique and performance. Innovation will be monitored and assessed. It will enable the quality control outlined above to become a reality.

27. We are extremely concerned about the way in which reliance is at present placed on Inspection. As graphically illustrated in the Maidstone and Tunbridge Wells case and at Mid Staffs this can lead to serious delays, possibly in terms of years, before effective action can take place. Time is then lost to see the result of such changes. We believe that the present system is reactive when what is required is for the system to be proactive.

VERIFICATION AND VALIDATION

28. The Government has set out its aim for *“a system that is fair, simple, affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs”*. In seeking to verify the Green Paper proposals we find that the solutions proposed fail to meet the necessary criteria. For such an output we believe that the inputs that we have set out above are necessary.

29. The validation will only come in practice as the proposals we have made for quality control within the new system are adopted.

REFERENCES:

1. United Nations Declaration on Human Rights; European Charter of Human Rights, Human Rights Act.

2. World health Organisation document, edited by Marmot and Richard Wilkinson, *“The Solid Facts”* published in 2003.
The Black Report 1980's
“Capitalism, Health and Medicine” Mike Haynes in the Summer 2009 edition of the International Socialism Journal, Volume 123

3. Challenging Discrimination and Championing the Rights of Older People. Presentation to Royal College of Nursing Conference—Nursing and Older People: Partners in Care November 2005.

4. Documents from “Dignified Revolution”

Sidney Martin
Director

Ralph A. Tebbutt
Director

September 2009

Memorandum by the National Union of Journalists’ Pensioners Committee (SC 05)

THE FUTURE OF SOCIAL CARE

EXECUTIVE SUMMARY

1. The NUJ Pensioners Committee works on a wide range of issues of concern to retired people and works closely with the National Pensioners Convention. We send six delegates to the annual Pensioners Parliament organised by the NPC; two of our members are officers of the NPC and one, Pat Healy, chairs its Health Working Party which deals with health and social care.

2. We believe that the Green Paper represents a missed opportunity to propose a truly fair system of care and support that is fit for the 21st century. Such a system can only be provided by the public sector which can set, regulate and enforce standards and ensure that the staff providing care and support are fully trained and appropriately remunerated.

3. We believe that the future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities should be based on general taxation as the fairest way of sharing the cost across the generations.

4. Personalised care and support should mean that services are designed and delivered around the needs of the individual. We are concerned at the increasing use of individual budgets and direct payments which are suitable for younger, disabled people but not acceptable to most older people with no previous experience of being employers.

5. Social care will become more effective, consistent and user-friendly when sufficient funds are allocated to provide a high quality, comprehensive service and when the people using it are directly involved in the design of the systems used.

SUBMISSION

1. The NUJ Pensioners Committee works on a wide range of issues of concern to retired people and works closely with the National Pensioners Convention. We send six delegates to the annual Pensioners Parliament organised by the NPC and two of our members are elected officers of the NPC.

2. The NUJ has more than 6,000 members over the age of 60 and is in the process of setting up its own retired members organization to broaden its activities. This new organization will be launched in November 2009 and aims to be a research, PR and writing volunteer force and to campaign on the vital issues that affect the quality of life of pensioners.

3. We believe that the Green Paper represents a missed opportunity to propose a truly fair system of care and support that is fit for the 21st century. Such a system can only be provided by the public sector which can set, regulate and enforce standards and ensure that the staff providing care and support are fully trained and appropriately remunerated.

4. The Health Committee seeks views on the options for three topics and we will answer them in turn.

Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities

5. We are deeply disappointed that the Government dismisses the idea of a tax-funded system on the basis of the simplistic idea that “it places a heavy burden on people of working age”. We disagree.

6. We see no evidence that today’s workers are not willing to pay sufficient taxes to pay for the kinds of system that they wish for their own parents and for themselves in due course. We do see a great deal of objection to the idea that any future social care system will rely much more on private care.

7. The current debate is being distorted by notions about the alleged unfairness between the generations that has led to young people leaving university saddled with debt and unable to get their first step on the housing ladder because of distortions in the housing market that has disproportionately benefited older people.

8. Such notions ignore many salient facts. First, today's pensioners have contributed to society throughout their working lives and did so willingly in the expectation that they would receive appropriate levels of care from the "cradle to the grave". This post-war promise has been steadily undermined in recent years and has led to people not knowing what support they are entitled to when the need arises.

9. Second, while some pensioners do benefit from generous, inflation proofed pensions, they are the minority who have enjoyed above average earnings during their working lives. The Government admits that there are still 2.5 million pensioners living in poverty, the same number as when it took power in 1997.

10. The UK has one of the lowest state pensions in the Western world, and one that is falling in value in comparison to average earnings. More than half of today's pensioners depend on the state pension as their main source of income.

11. In 2012, when the Government proposes to restore the earnings link with state pensions, it is estimated that its value will have fallen to 12 per cent of average earnings. This compares with 30–60 per cent of average earnings in many European Union states where social care is provided as a universal benefit.

12. A falling proportion of today's workers are in occupational pension schemes and the benefits from those schemes are diminishing as final salary schemes are withdrawn and pension funds perform poorly, a trend which has been accelerated by the global economic crisis.

13. Population forecasts are notoriously difficult to maintain with any accuracy and are constantly revised. Although current expectations are that the proportion of workers to the dependent population will fall over the next two decades, a rising birthrate is forecast from 2030.

14. Although the dependency ratio has narrowed, productivity has increased year on year except at times of recession. But recessions are of their nature short-lived and the normal pattern of growth can be expected to be restored within a short period of time.

15. We therefore do not accept the underlying premise of the Government's proposals that the current system is unsustainable because of demographic change and rising expectations. We recognize that the population is ageing and that younger people do have higher expectations than previous generations.

16. We believe that the Government should approach those realities by asking what it can do to meet those expectations, rather than by throwing it back to individuals and families and suggesting that they should do more. There is ample evidence that working age people are willing to pay more provided they understand what they will be entitled to when their turn comes. That should be at the core of any new system.

17. We believe that a fully tax-funded system is the fairest way of providing the support people need in a National Care Service worthy of the name.

18. Families and individuals already contribute through income tax during their working lives and through VAT and other indirect taxes throughout their lives. They also save the State vast sums, recently estimated at £87 billion a year, by providing a great deal of informal care in the home.

19. No-one argues that children's services should be paid for by their families alone; services needed by people as they get older should similarly be provided by society as a whole. Those individuals who wish to pay for a higher level of service than can be provided by society should be free to do so. Making a priority of prevention, low level care, and services such as telecare and adaptations to the home can lead to many more people being able to stay longer in their own homes and avoid or postpone much more expensive residential care or long hours of domiciliary care.

20. We remain a rich country. We should provide a high quality, comprehensive system of social care that meets national standards and is available to everyone. The system should not be means tested. This should be established in law so that everyone knows what the system is and what they are entitled to. Anything else is likely to produce a postcode lottery.

Personalisation of social care services

21. The first point we would make is that independence, choice and control can only be a reality if people have sufficient income. As we have already said, the basic state pension, which is the main source of income for most pensioners, has been regularly found to be the lowest in Europe (eg 2007 European Pensions Barometer, published by AON Consulting) and is well below the official poverty line. The chief disadvantages of the Pensions Credit system are that it is expensive to administer (10 times the cost of administering the BSP); it fails to reach at least a million eligible pensioners because they object to means testing; and it is set so low that it does not even bring recipients up to the official poverty level.

22. Therefore, the first thing the Government should do in pursuing its vision for social care is to raise the BSP to at least the official poverty level and make it payable to all pensioners. Then pensioners will be able to afford to maintain their health and mobility by eating healthily and heating their homes.

21. There should also be active promotion of prevention, low level care, advice and advocacy to enable older people to retain their ability to live independent lives as long as possible and to obtain the best personalised services they need. Advice and advocacy should be available both for people who need publicly funded care and for those who under the existing system fund their own care.

22. Self funders will run out of money if they survive into very old age and will at that stage need to rely on publicly funded care. They should be assessed properly when it first becomes clear that they are in need of some form of social care. Assessments should determine whether they need domiciliary care or telecare in order to manage with minimum personal care. Making such advice and assessments universally available would pay for itself by minimising the risk of people going into residential care before they really need to. This, of course, happens under the present system when self funders run out of money without ever having had a proper assessment of their needs.

23. Personalised care and support should mean that services are designed and delivered around the needs of the individual. We are concerned at the increasing use of individual budgets and direct payments. Undoubtedly, they give some recipients greater choice on how the money allocated to them is spent. But these systems are being developed in the context of the assumption that there need to be cuts in social care budgets.

24. We can see many dangers in this. Firstly, the economies of scale available to local authorities through nationally set pay scales will not be available to older people when they employ people directly themselves. The money they are given may not go so far as when it is being administered by well trained professionals who are subject to supervision and scrutiny.

25. Secondly, people in their 80s who have never employed anyone apart, perhaps, from an odd job person or window cleaner, may struggle to learn about health and safety regulations, payment of income tax and National Insurance contributions. There is also a danger of the money being mis-spent, perhaps by relatives or other informal carers, who appear to be helpful but may have other motives. It is also highly likely that many older people as they become more frail and therefore in need of social care, would prefer to be looked after than feel obliged to learn new skills to get the help they need.

26. It is vital, therefore, that advice, advocacy and support must be made available for anyone receiving individual budgets or direct payments. This could undermine the projected savings that such systems are expected to produce. It is not cheap to provide proper advice, advocacy and support. More effective, consistent and user-friendly social care services.

27. Social care will become more effective, consistent and user-friendly when sufficient funds are allocated to provide a high quality, comprehensive service and when the people using it are directly involved in the design of the systems used. Too often consultations are based on already determined ideas of what is best and older people in particular find it difficult to make their voices heard. Or, if their voices are heard, they are often dismissed.

28. Means testing is not acceptable. It creates social divisions and does not provide the services that people need. There is ample evidence to show that “targetting” resources means that some of the most vulnerable people are not reached by the services they need.

29. People who are fortunate enough to have been able to plan and save should have that recognized through the tax system, not in the provision of services. Those who have been unable to plan and save should not be penalized by being denied the care and support services they need. Nor should we fall into the trap of assuming that the poorest and most vulnerable can make do with inferior services.

30. It is a matter for celebration that people live longer. Most will live perfectly healthy lives but society should provide for the needs of those becoming frail, even if it means reordering the priorities for public spending. When the first state pension was introduced 100 years ago, there was no pool of money available to finance it because people had not yet begun to pay contributions towards it.

31. Immediately after the Second World War, when the country had been devastated by bombing, the loss of thousands of its citizens in the conflict, and was facing vast debt because of the cost of the war, we introduced the NHS and much enhanced benefits, such as family allowances.

32. On each of these occasions, the money needed was found because the mood of the country was that it was moral and just to introduce them. We are now a much richer country and should accept our obligation to provide high quality health and social care from the cradle to the grave as was promised in 1948.

33. We also see much public opposition to spending money on fighting wars and replacing nuclear weapons. Reordering public priorities by reducing such spending would both provide sufficient resources for a 21st century social care system worthy of the name, and the money needed to equip our forces properly when they are engaged in overseas conflicts.

34. Older people are much more likely to vote in the coming General Election. The promise of a new National Care Service that fulfils the criteria we have set out could help some to decide to whom they will give their vote.

September 2009

Memorandum by the Essex Independent Care Association (SC 06)

SOCIAL CARE

1. PREAMBLE

2. As a vibrant and progressive voluntary organisation Essex Independent Care Association welcomes the opportunity to submit comments the Health Committee Inquiry into Social Care advised on 20 July 2009.

3. Social Care is now almost exclusively provided by independent, (individual, voluntary or private sector) providers. We are thus best placed to understand the needs of Social care users, their staff, and the providers who are delivering these services. It is our members who day to day deliver these services and know the joys, satisfaction and challenges of that calling.

4. Essex Independent Care Association represents personal, residential home care, supported housing and community support providers in the Southend, Essex and Thurrock local authority areas. The Association was formerly Essex Care Homes Association and is a company limited by guarantee. The Association also works with kindred organisations locally, regionally and Nationally.

5. This submission addresses the three areas set out in the terms of reference. An Executive Summary concludes this submission.

6. *Future Funding of Long Term and Residential and Domiciliary Care for Older People and People with Physical or Learning Disabilities*

7. The request for evidence coincided with the publication of the Government's Green Paper—Shaping the Future of Care Together. The Association has participated in the consultation around this document with representatives attending the road shows. At the conclusion of the Government exercises there will be member consultation and feedback from the road shows and other comments.

8. Whilst our final policy in relation to funding will be developed following these consultation activities, themes and draft policies are emerging.

9. *A Basic Entitlement*

10. The Association is now convinced that there needs to be a nationally agreed basic care allowance. This needs to be an agreed national rate and be available irrespective of resource pleas by local authorities. This would not be a direct parallel with a former Residential Care Allowance as it would apply to home care and residential services. As a start figure, the Association are suggesting that this should equate to 75% of the average cost of residential care bed or the average cost of 20 hours a week of home care. There are sufficient funding models to enable such a principle to be applied. We would be happy to assist wherever is most suitable to develop the final detail.

11. Our concern is that there be a nationally applied and available floor payment not dependent upon the discretion of local authorities. Local authority assessments are of a variable nature and quality and the discretionary actions lead to difficulties and unfair allocation of resources. A simple test such as that applied for the various levels of attendance allowance which is objective and more transparent would help move toward a basic entitlement.

12. *Top Up*

13. Such a move would then provide greater scope for top up arrangements similar to those already in place. Currently, local authorities are not keen on making placements requiring top up. We wish to see a larger role for Top Up.

14. There is clear evidence that, certainly within the next 20 years, there will be a generation of elderly people who will have resources they are likely to want to use to augment their social care needs. We see the system of a basic allowance and top up either via insurance provision, individual provision or in partnership with local authorities as a way forward in terms of funding. We would be happy to elaborate and work as to further refine these models, as appropriate.

15. The Association will be responding in detail to the consultation around the options set out in Shaping The Future Together. Our guiding objectives are likely to be achievement of consistent finance and an improved role in innovation and development funded through support to the entire provider community.

16. PERSONALISATION OF SOCIAL CARE SERVICES

17. *General*

18. We have long welcomed the move toward personalisation of care services. Many of our members have been in the forefront of innovation and imagination in the use of the new flexibility and creativity often only independent providers in day to day contact with service users, can deliver. We have noted with interest its varying application within our designated areas, across the region and nationally. Citizens have over the last few years become much more alert and better educated and therefore able to make informed choices and

arrangement in respect of their lives. Thus the move toward widening personalisation is one we applaud. We are concerned at the continued quest for reduction in the cost of care packages that personalisation is stated to require.

19. *Care Planning*

20. We consider there should be clear, objective and transparent means of personal care planning involving all stakeholders not those designated by the planning entity. We also wish to see swifter moves to care management and planning being subjected to proper tender and open competition. This activity should be brought within the legislation prohibiting municipal trading as soon as possible.

21. We call for a range of care planning options to be available following the award of the basic Entitlement. This would mean a choice between ideally family; an independent care planner from an accredited voluntary agency or a local authority employed care planner. The choice should be fairly put and be that of the service user.

22. *Safeguards*

23. We are concerned that people with personal budgets and employing their own personal assistants are not being required to CRB or ISA check those personal assistants. We consider this is a permit for everybody barred by ISA to offer themselves as “skilled, trained and experienced” in the knowledge that they are not going to be found out. We consider this flaw is a permit to abuse the most vulnerable people in our community.

24. *Summary*

25. Overall, we consider personalisation has many benefits.

26. We are concerned that it is currently seen as a financial device. We are concerned at the lack of requirement for safeguarding service users ie only a guide and not a requirement to check CRB or ISA.

27. We consider that Personalisation could embrace our general comments in respect of funding. Further when combined with a suite of insurance based additions personalisation can help augment resources for individuals and provide more relevant care.

28. We continue to see the public sector whether nationally or locally as an enabler and not provider. The various insurance arrangements alluded to in the Green Paper will immediately require an improved range of skills from local authority staff hence the need to streamline initial assessment and subject continuing planning services to a wider choice, all as noted above.

29. EFFECTIVE SERVICES

30. As a provider organisation, we continue to be concerned about the need for effectiveness of the provision of services. We see current effectiveness is impeded in areas of regulation: intermediary (QUANGO) support and partial and unclear engagement with providers in the development of services.

31. *Regulation*

32. We remain very concerned at the duplication indeed triplication between the role and function of local authority contract compliance staff, local authority quality and monitoring staff and the statutory regulator—The Care Quality Commission. Local authority staff are on record as stating they consider the CQC activity as deficient and have therefore introduced their own elaborate mechanisms. In parts of this area, providers may be subject to the following monitoring activity:

- Statutory Regulator CQC
- Contract Compliance—in some cases up to eleven separate boroughs.
- Quality and Monitoring—similarly eleven boroughs.

33. This is in addition to other statutory regulators eg local authority, health and safety, local authority food and fire.

34. The dichotomy, often conflict, between the various elements of the local authority and the statutory regulator is undoubtedly the largest area for concern. We have now a range of examples where effectively local authorities are deciding that they regard the statutory regulation as inadequate and are therefore adding in their own regulations. We have had to draw attention to the fact that on some occasions their so called local care standards are in breach of statute eg criminal record storage.

35. Local Authority mechanisms do not have the transparency and accountability of the statutory regulator. The development of so called Local Authority Standards has not been the subject of consultation with service users, staff or providers. This is something we would have been keen to support at whatever level. Worryingly these “Standards” have been used in a coercive way to ration the supply of placements and fetter the commercial ability of the provider.

36. Our call for improvement in effectiveness is very simple. We are concerned that the headlines currently evident around reducing the numbers of “Quangos” will impact upon the Care Quality Commission. This is a non-governmental organisation which has already had to take serious budget cuts. One example of this has been the loss of any local presence. As a simple example, providers now have to travel up to 200 miles simply to arrange for a manager to complete a criminal records check as required by the regulations. This is a cost at several levels as a result of reductions in the CQC budgets.

37. Our call is for a regulator remaining transparent but properly resourced, not having to rely upon home working, no local presence and continuing budgeting cuts under the mantra of Quango reduction.

38. It is into this perceived void that the local authorities have enthusiastically jumped.

39. We consider the resources currently devoted by local authorities into these duplication and triplication activities could easily be diverted to CQC. This will enable CQC to undertake effective inspections which could then be used by local authorities in their own contracting activities. This would avoid the need for parallel but not related standards and cease the current proliferation of service standards applying to every local authority National minimum standards and regulations as inspected by the statutory regulator should be the only yardstick.

40. *Support to the Sector*

41. In the same context, we are concerned that duplication of some of the direct support provided to the sector. This is being subjected to other expenditure challenges and is acting to the detriment of the sector. In particular but not exclusively, we have in mind, the position of Skills for Care and the Social Care Institute for Excellence. When taken with the regulatory and statutory powers of the General Social Care Council we again see a situation where providers are uncertain about who will offer best assistance advice and support in their objective of driving up the quality and standing of all social care services.

42. It is our contention that social care will be well served by one strong, effective and properly resourced enterprise able to represent the training and development needs, undertake regulation and develop its own academy. This would most properly be the General Social Care Council. Such a move would reduce all the current drain of servicing three separate almost duplicate organisations. It would enable independent providers to be more actively involved—the enterprises mentioned are dominated by public sector interests, would provide a lighter touch and generally more responsive measure of support to the sector.

43. Such an approach could also include an element of democracy on the General Social Care Council. This is currently missing, all members being Ministerial appointments. Given the future plans for much higher numbers of registrants, it would seem only reasonable for the stakeholders, ie those registered to have a least a number of seats on the Council. This was the case with the Health Professions Council and whilst not as secure at Nursing and Midwifery Council stake holders ie Registrants form a significant Council grouping. There is stakeholder discomfort with the Appointments Commission process. Some element of Democracy could start to address that discomfort.

44. EXECUTIVE SUMMARY

45. In conclusion, the Association wishes to submit the following comments in respect of the Terms of Reference.

46. *Funding*—we seek a flat rate nationally applied care allowance which would be available to all and be subject to light touch or attendance allowance type assessment. This would allow much more creativity and imagination in respect of top up and care planning. This would thus work from more objective criteria established through the initial assessments.

47. *Personalisation*—we applaud the moves towards personalisation. We are disappointed they continue to be seen as financially driven and about delivering financial objectives. We also seek proper and required safeguards against service user abuse through a requirement for Personal Assistants to be subject to CRB and ISA checks.

48. We consider that there should be further exploration to ensure objectivity and transparency. In particular we consider care assessment management and planning should be subjected to proper competitive tendering as soon as possible rather than exclusive municipal, cushioning arrangements such as Essex Care. .

49. *Effectiveness*—We consider the effectiveness of social care could be improved by a couple of simple acts.

50. The first is the diverting of monies used by local authorities for their own quality and development units, contract compliance and kindred inspection style activity to be directed to Care Quality Commission. The Commission is the statutory regulator. The Commission’s budgets and presence have been eroded. With proper funding and as necessary staff movements, the Commission could produce material which would enable local authorities to fulfil their monitoring role. This would be using the output from the Commission using National Standards upon which there has been consultation rather than the prescribed duplicate and often triplicate standards produced in house by local authorities.

51. Independent providers have been keen to participate in the development of National Minimum Standards. We consider them essential. We look forward to continuing to play a full part in their further development by the Care Quality Commission.

52. We also call for the merging of the various intermediary and support bodies particularly Skills for Care and SCIE, under the General Social Care Council. We also seek for more democratic accountability and transparency for that Council especially to its Registrant stakeholders who are funding the organisation.

53. CONCLUSION

54. The Association would be happy to clarify or evidence any elements to the Committee and would be happy to elaborate on any of the matters raised as appropriate.

September 2009

Memorandum by the Royal College of Nursing (SC 07) FUTURE OF SOCIAL CARE SERVICES

1. EXECUTIVE SUMMARY

- The RCN welcomes the publication of the Government's green paper on social care and support. Their commitment to reform provides a historic opportunity to establish fair care under the welfare system in England.
- Any new social care system must be transparent and sufficiently resourced to ensure greater access and equity for users.
- The current system for establishing who pays for long term care is complex and the RCN supports the Government's desire to simplify these arrangements. However, the RCN would strongly oppose any change where long term care funding currently met by the NHS was shifted onto the patient and subject to means-testing.
- The RCN believes the social care system must be made simpler for users and include training for providers, commissioners and advocates to ensure equity and consistency of service provision.
- The care system will only work if individuals understand what care they are entitled to and the system in place for paying for it. To assist this, the roles of both the NHS and local government should be more transparent.
- The RCN believes that the use of quality care outcome measures would be an invaluable tool for a new social care framework. The RCN would like to see a measurable assessment of quality outcomes developed in addition to the availability of good practice guidance for local authorities, practitioners and commissioners.
- Following preventative models of care is essential to providing effective health and social care services. The NHS cannot meet its obligations without an effective social care system. It is important to recognise the value of social care investment in keeping people out of hospital through prevention and intermediate care. However, to do so will require a fundamental shift in resources and provision of care.
- The RCN believes health and social care need to be more closely integrated in order to provide more effective care for those with long-term conditions. The RCN would also like to see greater communication between health and social care professionals through the adoption of co-location schemes and investment in information technology.
- The RCN believes greater investment in community nurses is essential in supporting individuals receiving care in their own homes or in the community.
- The RCN believes that it is critical for all care professionals to work in partnership with service users, including carers.

2. INTRODUCTION

2.1 With a membership of almost 400,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations

2.2 The RCN welcomes the Government's green paper: *Shaping the Future of Care Together*, which looks at possible ways to create a fair and sustainable funding system for adult social care and support in England. An effective social care system is widely considered an essential part of any civilised society and the health

sector cannot meet its responsibilities fully without working in partnership with a strong and capable social care sector. The RCN believes the key principles that should underpin a reformed care and support system are fairness, equality, quality and individualised patient centred care.

2.3 The RCN welcomes the opportunity to make a written submission to the inquiry of the Health Select Committee.

3. *Options for future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities*

3.1 The RCN strongly supports the desire to tackle the area of social care through widespread engagement with the public and key stakeholders. However, with local government budgets under severe pressure and a significant increase in demand for social care services there appears to be a significant gap between this vision and the likely reality.

3.2 The rise in demand for services has left local authorities with limited budgets which could be further exacerbated by the anticipated cuts to local funding over the next two years. The RCN acknowledges the significant economic difficulties that currently exist and the additional burden this places on spending plans. However, unless sufficient resources are committed those requiring social care support will continue to experience difficulties.

3.3 Under the current system the reality is that the funding of most long-term care is largely met by individuals or, when the value of their savings and other assets has reduced to a certain level (under a means-testing assessment), by a mixture of their own income and the local authority. However, there are large differences in what service users are entitled to according to their income and assets. Long-term care funding has been difficult for the public to understand. Nurses have often found that they have to interpret rules regarding eligibility assessments which has required them to take an increasing “gatekeeper role” in terms of securing care entitlement.¹⁶ Therefore, any new system must be designed so it is transparent to all those involved.

3.4 It is important to recognise that the boundaries of where health care ends and social care starts have become increasingly difficult to define. Nonetheless, one of the most defining features is that services provided by the NHS are free at the point of delivery, and usually charges cannot be made. However, services which are provided or arranged through social services departments of local authorities are means-tested. Moreover, a potential point of conflict in current health and social care systems is the definition of long-term health care and whether this should include all care received by people unable to live at home without support. There has been considerable debate on whether the definition should include long-term care in hospitals, nursing and residential homes, and around the health and social services support people receive in their own homes.

3.5 What is significant at this stage is the absence of firm details in the green paper on what a reformed system would look like. In particular, the green paper has limited financial figures and modelling information in terms of the funding options. There is no clear indication of what a national care service might cost; how much would be paid by the Government; and critically, what care individuals would receive for their contribution.

3.6 In 2006, Sir Derek Wanless’s report, *Securing Good Care for Older People*, set out a series of funding options for social care. Sir Derek expressed a preference for a “partnership model”, which would give a basic, minimum universal level of care to everybody. The RCN would welcome more clarity on whether any of the funding options proposed in the green paper would provide any form of basic universal care.

3.7 The 1999 Court of Appeal judgment for the Coughlan Case laid down a test for deciding when the NHS was responsible for funding a care package if the needs of the patient were primarily health needs.¹⁷ Therefore, the NHS has to meet the costs of providing health care for those who are being cared for in a hospital or a nursing home. The crucial test in determining liability is whether the person’s primary needs are for “health care needs” or for “social care needs”.

3.8 The RCN would strongly oppose any change in the current responsibilities and is concerned that under the broad funding options the costs of health care might be shifted onto the patient and subject to means-testing when it should be free on the NHS.

3.9 The RCN believes that significant demographic and affordability challenges, further increased by the current economic downturn, have now led the Government to look at shifting the funding balance away from collective responsibility (such as taxes or social insurance) towards increasing individual responsibility for costs.

3.10 The RCN accepts that any funding system must be affordable and the Government’s green paper offers an opportunity to address the fundamental flaws experienced in the current system. The RCN is looking in detail at the three funding options outlined in the green paper and is consulting with members to inform the RCN’s response to the paper.

¹⁶ “Guide to fully funded NHS care”—published by Age Concern, the Alzheimer’s Society, Help the Aged and the Royal College of Nursing (March 2006)

¹⁷ *Ibid.*

4. *Options for personalisation of social care services*

4.1 Care for those with long-term conditions must be personalised, so that individuals have access to appropriate health and social care throughout the course of their condition, beginning with diagnosis by a specialist and ending by referral to palliative care if appropriate. Care must also be tailored to the disease area, but the service must avoid assuming patient need based on a stereotype of the condition. Equally, the service must recognise the impact of a long-term condition on the lives of each patient's family, carers or relatives.

4.2 Direct payments, introduced in 1996, have in certain circumstances allowed people to get the cash equivalent of their social care and arrange their own care and support. However, it should be recognised that individual budgets are not right for everybody. They can be problematic and challenging for vulnerable people. For the older person with deteriorating health and fluctuating needs, control of their individual budgets may not be possible, family may not be supportive and reassessment not available. To improve this balance, service users will need to have greatly improved access to information about their condition(s) and there needs to be joint ownership of outcome expectations for both service user and provider. Support options that enable choice and control and which are relevant to and meet the needs and aspirations of the care recipients are crucial. Further work needs to be undertaken to ensure problems with access are identified.

4.3 The Government has acknowledged the important contribution made by unpaid carers such as friends and family. However, the accountability relationships between patients, employees, volunteers and carers will have to be carefully thought through to make clear who is responsible for which part of the individual care package provided under the direct payment. Carers will need education and support to set up individual budgets, including how to negotiate as a commissioner of services. It is also important that individual budgets are monitored to ensure the system is not abused while also making sure there are not excessive controls that could restrict their effectiveness.

4.4 However, despite the need for safeguards there is a significant opportunity for the provision of genuine "care" through the operation of direct payments. Where the circumstances are appropriate, putting the patient in charge of the commissioning process can reduce confusion over roles and provide more clarity around the recipients "actual" needs.

5. *Options for more effective, consistent and user-friendly social care services*

5.1 The current framework for adult social care is now widely recognised as confusing and outdated. It remains a patchwork of often conflicting statutes enacted over sixty years. The RCN believes the system must be made simpler with entitlements made clearer, allowing individuals to be able to plan ahead with greater understanding of what will be on offer. This should include a clearer definition of the national guidelines for eligibility for both the service users and the commissioners and flexibility to respond to individual circumstances. Moreover, there should be appropriate training for the providers, commissioners and the advocates to maintain a fair and consistent provision of care packages nationwide.

5.2 The following sections identify further areas the RCN believes require attention in order to ensure social care is more effective, consistent and user-friendly.

Measuring and improving the quality of care

5.3 The quality of care delivered to patients is coming under increasing scrutiny through the use of explicit measures which seek to judge the process of care against specific standards. This theme was a central element of Lord Darzi's Next Stage Review proposals and the RCN believes that this should also be a core part of care and support provided in residential care and within the community. Good practice guidance for local authorities, practitioners and commissioners should be developed to sit alongside a measurable assessment of quality outcomes.

5.4 The RCN believes that the use of quality care outcome measures, or quality metrics, would be an invaluable tool for a new social care framework. Metrics would indicate where there was a problem with quality and identify significant contributory factors, such as staffing levels, insufficient resources, lack of training and development, inadequate equipment, overload of paperwork/bureaucracy, and inappropriate admissions. Possible core quality assurance indicators are safety measures such as failure to rescue, falls, healthcare associated infections and pressure ulcers.

5.5 In ensuring an individual's care needs are met it is important to not just consider physical care, but to take a more holistic approach to care planning. A core part of holistic care involves seeing the patient as a whole, ensuring that they receive essential care (such as quality care, basic hygiene, nutrition) and the privacy and dignity all should expect. It is important these core features of good person centred care are not neglected in order to achieve financial targets. Principles that protect patient dignity need to be at the heart of the care pathway and be applied across the social care and support system.¹⁸

¹⁸ The RCN's campaign *Dignity: at the heart of everything we do*, was launched on 25 June 2008. The RCN published a range of campaign materials and resources to inspire improvements in practice and boost the quality of care for patients and clients.

Opportunities for early prevention

5.6 Keeping people well and following preventative models of care provides significant benefits, both financial and for the nation's health. Early intervention can potentially prevent problems occurring in patients with long-term conditions and keep an individual stable so that the acute phases of disease (often requiring acute care) are reduced or at least significantly delayed. For the elderly prevention work can focus on avoiding falls and other accidents as well as a range of services to ensure they are safe and secure. However, moving towards preventive models of care will require a fundamental shift in the way services are performed, which can only be achieved through close consultation with those working across the care pathway.

5.7 The RCN believes housing must be considered a key part of the social care system and not just as an "add on" to it. Our members have repeatedly emphasised that good housing contributes to the independence of the care recipient and can also play a part in maintaining an individual's health.

Challenges associated with ageing and long-term conditions

5.8 The RCN considers the most serious challenge to the provision of public services over the next twenty years will be the increase in life expectancy. On average we are living eleven years longer than we were in 1948. The complexity of meeting the care needs of ageing populations will straddle both health and social care systems.

5.9 The individual who has diabetes, a leg ulcer and early on-set Alzheimer's disease will require specialist nursing care to manage their health needs as well as support for normal daily living activities such as shopping and cleaning. However, as conditions change and needs vary, it simply is not possible to draw an absolute line between where nursing care stops and social care starts or indeed where nursing care or social care become personal care.

5.10 The care of those living with long-term conditions has been made complex by the involvement of a wide range of government agencies, improvement schemes as well as a myriad of professional groups. Different strands of policy covering this area have historically been discrete and not well connected. There needs to be a whole systems approach to delivering seamless care for those with long-term illnesses and for this to place the patient at the centre of the care pathway.

Community based care

5.11 The shift of care closer to the community will bring significant change in the way care is provided. Community based services provide the full spectrum of care from primary prevention through to specialist disease management and palliative care. Nurses in the community provide a range of care services, including aspects of assessing and managing conditions, while also working across boundaries and in collaboration with social services and secondary health care. Their challenging role will often require a combination of clinical and case management skills in order to plan, manage and coordinate the care of people with complex long-term conditions and high-intensity needs who live in their own homes and communities. Patients in the community can potentially feel extremely isolated and nurses are often skilled in acting as an advocate for patients and a supporter for carers.

5.12 There is significant concern that the community based nursing service remains under resourced and not able to provide enough support to individuals receiving care in the community. Moving the care of vulnerable individuals into the community will require significant investment in community nursing services with community matrons, district nurses and specialist nurses who have an understanding of social care and can act as "care navigators" across the full length of the care pathway.

Carers and volunteers

5.13 Carers are a diverse group which include people of all ages. Without carers many more people would be reliant on social care and support services. However, the RCN is concerned that social care is often provided by carers who are not trained, who are often paid the minimum wage and do not benefit from a professional regulatory system. Also, there is significant concern that high turnover and vacancy rates have affected the quality of care. If this situation continues it will undermine the effectiveness of any reformed care system. A better rewarded, higher status workforce would raise the quality of services.

5.14 A report by Carers UK, published in September 2007, revealed that the value of this unpaid care has increased to £87 billion a year, more than the annual running cost of the NHS which stood at £82 billion in the year 2006–07. The RCN believes that it is critical for all care professionals to work in partnership with service users, including carers. The hidden contribution of families, carers, the voluntary sector and non statutory organisations are still rarely recognised in the care pathway and this is something that must be addressed.

Integration and seamless care

5.15 Nurses have told us that the disparity in provision of care and support services across the country continues to cause difficulties for many individuals. Many individuals with significant care needs have been unable to access the system due to tightening eligibility criteria being applied by local authorities.

5.16 The patient agenda and patient voice can sometimes be lost in the process of driving forward integrated care. Despite significant attempts at better partnership working there are varying degrees of integration across the UK even within local authorities. Co-location schemes and investment in information technology are examples of initiatives that can improve information flows between health and social care professionals.

September 2009

Memorandum by Ashleah Dean Skinner (SC 08)

SHAPING THE FUTURE OF CARE TOGETHER

Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities.

1. The funding strategy which should be used for future care should be the Comprehensive model, this is because people are treated equally as everyone will get free care when they need it, this should always be the case. The Comprehensive model would require everyone to pay a contribution into a state insurance scheme similar to the way national insurance works.

2. I am in favour of this because the money used to fund the care would be from a system where everyone contributes to irrespective of whether or not they require such support, it would be strongly and wholly disproportionate to use money from welfare benefits for example Disability Living Allowance or Attendance Allowance, as people who do not require such methods of care or who already have a stable care scheme in place, would suffer as a result.

3. However the Government should also equally contribute to the funding, and this should be National Government's responsibility and not local Government because if it is left to local Government, there may be cases where there is a postcode lottery, where some areas get more and some get less funding.

4. On 8 June 2009, the Minister for Disabled People Jonathon Shaw MP, ratified the UN Convention on the Rights of Persons with Disabilities, Articles 25 and 26 of the UN Convention are extremely relevant to the funding and indeed the overall outlook for the future of care.

5. Welfare Benefits were created to provide financial support to those who are in genuine need of financial assistance, the idea of the National Care Service will also be for those who are in genuine need, but one should not be used for the other. It is for these reasons that welfare benefits such as Disability Living Allowance and Attendance Allowance should never be used to fund care, equally funding is only one factor that will be part of the care reforms.

6. Everyone should pay insurance to fund care and this should be funded also from National Government but not used from welfare benefits, unless of course they want to make voluntary contributions, but this should be left to choice.

AREA OF EXPERTISE

Mr. Ashleah Dean Skinner, A.Inst.Pa, holds professional designation by the Institute of Paralegals as an Associate Paralegal, he is also a Disability Advocate and an advisor with Workplace Disability Adjustments; he has previously given written evidence in a Transport Select Committee on the Blue Badge Scheme.

September 2009

Memorandum by the Local Government Association (SC 10)

SOCIAL CARE

EXECUTIVE SUMMARY

1. The LGA has consistently argued for reform of our adult care and support system to meet the challenges of changing demography, insufficient funding and escalating costs. Central to reform must be a fairer funding settlement that:

- recognises the contribution which local government currently makes to adult care expenditure;
- makes the best use of the totality of money available in the wider well-being pot; and
- considers funding for the NHS.

2. Only with consideration of these issues can a funding settlement be designed that best delivers high quality, personalised services. A reformed system must also retain a degree of local flexibility to ensure that local need, local expertise and local knowledge of resources and partners continue to shape such an important local service.

LOCAL GOVERNMENT ASSOCIATION

3. The Local Government Association (LGA) is a voluntary lobbying organisation, acting as the voice of the local government sector. We work with and on behalf of our membership to deliver our shared vision of an independent and confident local government sector, where local priorities drive public service improvement in every city, town and village and every councillor acts as a champion for their ward and for the people they represent.

4. The 423 authorities who make up the LGA cover every part of England and Wales. Together they represent over 50 million people and spend around £113 billion a year on local services. They include county councils, metropolitan district councils, English unitary authorities, London boroughs, shire district councils and Welsh unitary authorities, along with fire authorities, police authorities, national park authorities and passenger transport authorities.

5. The LGA is pleased to submit a written response to the Health Committee's inquiry on social care and would welcome the opportunity to give oral evidence.

INTRODUCTION

6. The LGA has long called for reform of our adult social care and support system. Councils do an incredible job to ensure the vulnerable members of our society get the services they need but the system is not fit for the challenges of the twenty first century. The combination of insufficient funding, increased demand from an ageing society and escalating costs is already placing an immeasurable strain on adult care.

7. The emerging personalisation agenda in social care has great potential to transform the experience of social care through personal budgets and improved opportunities to exercise genuine choice and control—not just about how support is provided, but also over the nature of that support.

8. The LGA shares the commitment to the values of independent living and supports the system-wide transformation that will be required to deliver personalisation, and is working with the government and other partners to transform social care along these lines. We believe personalisation must go beyond social care and include the availability of services which maintain and improve the quality of life for a range of people, not just those with the most intense personal care needs.

9. Any policy reform must address these other dimensions, such as health, housing, education, leisure and transport. Councils are in a position to do this for their localities and believe they have a responsibility to all their residents in the provision of high quality advice and information, and in ensuring the availability of an appropriate range of services.

10. Balancing national consistency and local flexibility is key to the future of a successful, reformed system of adult care and support. Democratically elected local government must be able to decide with individuals what form this support should take, within a national framework and an adequately funded system. This means adequate resources being allocated at a local level to take account of local need, local markets, and the local range of statutory and non-statutory organisations that are involved in care and support and are unique to each area.

FUTURE FUNDING OF LONG TERM CARE

11. Despite many people thinking otherwise, funding for adult social care does not come solely from national taxation. The local government finance system is based in part on the relative resources a council can draw on, and services such as adult social care are funded through a combination of central and local government revenues. In 2008–09, for example, the LGA estimates that councils will have contributed 39%, or £5.3 billion, of the total projected cost of national social care spend—£13.8bn. We further estimate that over the period 2010/41 the adult social care funding burden on Council Tax will more than treble from £5.3 billion to £16.7 billion unless more money is made available. This is not just about councils having to make difficult trade-offs in their budgets; some councils already spend more on social care than their entire general grant from central government.

12. Council tax is one of the local resources but, given different areas of the country have populations with different levels of wealth, the amount raised by council tax varies considerably. The 39% is therefore just an average; for some local authorities Council Tax will be required to fund over 80% of local adult social care expenditure. The amount that Council Tax contributes to local adult services spend can therefore vary considerably depending on the area, council, and the extent to which it is supported by government grants. Despite this pressure, councils are spending, on average, £1.98 million—or £294.2 million in total—(2007–08) on adult social care that people can access when they need it and without a formal assessment, such as information and advice services. This is a rise of 20% on 2006–07, with the overall spend expected to rise further still to £312.4 million in 2008–09—around £2.6 million per authority.

13. Revisiting the funding distribution method for social care will not only be crucial to the success of the system in the future but also the longer term sustainability of council budgets. Based on current levels of adult care funding and provision, Council Tax will simply not be able to support projected levels of future expenditure.

14. A fairer funding settlement must consider the totality of money available in the current system. As supporting older and disabled people is about more than providing services delivered by adult care departments (and includes, for example, consideration of appropriate housing, leisure, transport and health services), we need to define what constitutes a local whole system budget.

15. This must include consideration of NHS funding. Social care expenditure is a fraction of total NHS spending. Total NHS baseline spending for 2007–08 was £90,352 million. Over the three years of CSR07, additional funding for the NHS will increase this spending to £96,430 million, £102,897 million and £109,806 million.

16. If a fraction of this funding was spent on care and support in the community, aligned with social care spending, it would result in a significant increase in care and support locally. Allocating just 10% of the additional NHS funding over the CSR07 period would provide an extra £608 million, £1,255 million and £1,945 million to local care and support services in these three years. Evidence is emerging that this investment would save spending elsewhere in the NHS.

17. In the recent care and support Green Paper, “Shaping the Future of Care Together”, the Government puts forward five models to increase the available funding for adult social care: individuals paying for themselves, partnership, insurance, comprehensive, and fully tax funded. The Government has ruled out individuals paying for themselves and fully tax funded. We believe the Government’s preferred options are the only realistic options of the five put forward. Whatever system might be established in the future, local government will continue to play a crucial role in its operation and success—whether that be helping people to receive good quality financial advice or developing the local market of care service providers.

18. Whatever funding system is established for adult care and support, the change must be used as an opportunity to further shape the overall direction of the care agenda—moving away from a focus on crisis to a much greater focus on prevention and early intervention. There is a growing body of evidence to show the impact this can have—both in terms of allowing people to remain at home, and delivering savings.¹⁹ In North Yorkshire, for example, telecare has diverted 21 people (of 42 in a pilot project) away from residential care. This has resulted in significant savings: gross savings of £6,800 per person and net savings of £4,300 per person. More importantly, such services are improving people’s quality of life. Similarly in Gloucestershire, technology is saving the council £15,000 on just three pilot clients.

NATIONAL V LOCAL

19. The Green Paper also puts forward two models for a revised funding system: fully national and part local/part national. We believe that the bedrock of the care system is local, and inextricably linked with building sustainable communities that tap into the full range of activity needed to support independence. We believe that ensuring a local element in the design and delivery of adult care and support services is important for:

- providing councils with flexibility to commission and design care services around the needs of the service user;
- supporting councils’ ability to join up social care with health, housing and other systems to provide better outcomes for local people;
- ensuring a responsive care and support system;
- ensuring an accountable care and support system; and
- preventing radical changes to the entire local government finance system.

20. Standardising national assessment arrangements, and ensuring a consistent proportion of care costs are met by the state, will help national Government get a real sense of the true costs of care and be a trigger to realistic allocation of funding. This is very much in line with LGA thinking. A national care service will also require greater transparency and consistency in the application of continuing health care criteria; again something for which the LGA has been campaigning.

21. But a prerequisite for the national care offer, and for personalisation, is the right local offer. Councils are working closely with the NHS to develop prevention and reablement services. And behind these, a complex pattern of family, neighbourhood and community support is needed. Those using personal budgets are looking for flexible, local solutions that dip in and out of formal care and support services. Good housing, transport, leisure and community safety are integral.

¹⁹ See, for example, *Facing Facts and Tomorrow’s Reality Today: The Cost of Care*, LGA, 2009, p10–11.

22. Four other important preconditions for the success of the national care service are (i) managing the market and (ii) developing the workforce, together with (iii) good information, advice and advocacy and (iv) good support for carers. The latter two are critical and cannot be standardised against a blueprint. While there should be greater consistency in how a person's share of public funds is calculated, how someone chooses to spend them will be a personal and local decision.

23. We do not yet fully understand how services will adapt and grow under a truly personalised system. We anticipate that services may well be smaller, more organic, and cross the boundaries of health, care and housing. We do know that costs will vary enormously in regional and sub-regional markets.

24. Without pre-empting the national debate, the LGA fears that the local nature of care and support could be overlooked in the technicalities of how funding should be aggregated to support the national care offer.

25. The local offer is a delicate balance of people's own resources, community support, the love and good will of carers, and the contribution of a wide range of local services. These and the council tax subsidise any notional allocation of care funding through the Revenue Support Grant.

26. The national care service offer should bring entitlement and transparency into the care equation, and critically more funding. But it should not be over-prescriptive. Any disruption to this careful local ecology will be damaging and unnecessarily costly.

September 2009

Memorandum by the Home Group Limited (SC 11)
THE FUTURE OF SOCIAL CARE AND SUPPORT

EXECUTIVE SUMMARY

Home Group Ltd welcomes the opportunity to engage in the debate on the future of social care and support. This submission presents the following key points

- Low level interventions such as housing related support assist clients to gain and maintain independence and reduce the need for more costly interventions.
- Voluntary sector providers are well placed to develop and deliver innovative services.
- There is significant local disparity in assessment of care and support needs and allocation of funding.
- Personalised services are important to providing additional choice and person-centred services, but individual budgets are not appropriate in all cases. Commissioned services are still important to providing real choice and control to many clients.
- Younger people with care and support needs often experience financial hardship, leading to additional difficulties eg social exclusion, through inadequate funding. Existing proposals do not indicate how this will be addressed.

In order to create a fair, simple and affordable system of social care and support, we would like to see

- Continued investment in low level care and support and early intervention services (eg housing related support) in order to assist people to gain and maintain independence.
- A more consistent and fair means of assessing care and support needs and allocating funding which is focussed on, and responsive to, individual needs.
- Incentives for local authorities to engage with the voluntary sector to develop and deliver innovative services providing care and support that clients actually want and need.
- More detailed proposals to address the hardships faced by younger people with care and support needs.

1. ABOUT HOME GROUP LIMITED

1.1 This is a submission from Home Group Limited (Home), which includes Stonham (its care and support division) and Home Prime (its older people's services). Home is the largest and most geographically spread provider of supported housing services in England.

1.2 Home provides services to over 15,000 clients every year. We work in cities, towns and rural areas across England from Cornwall to Cumbria providing services for a wide range of client groups including:

- people with mental health issues
- people with learning disabilities
- older people
- young people

- families
- offenders and ex-offenders

1.3 We provide a variety of care and support services including:

- Supported housing services
- Residential registered care
- Domiciliary care
- Sheltered housing and extra care services
- Tenancy support
- Advice and gateway services

1.4 Home has three elements to its purpose:

- to provide affordable housing to our customers—tenants, leaseholders and other residents.
- to provide support to individuals—our clients.
- to secure sustainable neighbourhoods for all our customers and clients.
Our customers and clients are at the centre of all that we do.

1.5 For many of our clients the support we provide enables them to increase and develop independence over time. As Stonham we provide services that work effectively to that aim. We also have clients who require longer term support to maintain a level of independence. Both Stonham and Home Prime offer services that successfully meet this need

1.6 Home is also a provider of general needs social and affordable housing for rent, shared ownership and purchase. As LiveSmart@Home we offer mid-market housing, as Nashayman Housing we provide specialist housing services for Black and minority ethnic communities and wider consultancy services, and as Copeland Homes we manage former local authority housing in West Cumbria. In the south of England we were previously known as Warden.

1.7 Home Group Limited is a Registered Social Landlord and a Charity registered under the Industrial & Provident Societies Act.

2. GENERAL COMMENTS

2.1 Throughout this paper we refer to the people who use our services as “clients”, and Home Group Ltd as “Home”.

2.2 Although the majority of Home care and support services are commissioned under the Supporting People programme, services are tailored very much to the needs, wishes and aspirations of our clients through our comprehensive client involvement programme (Involving You) which involves clients in all aspects of planning and managing services, and our personalised support planning processes (My Way Forward).

2.3 Research and the personal experience of our clients demonstrate that supporting clients to gain and maintain independence through relatively low level interventions reduces the need for more costly emergency and acute services and provides a secure foundation for other interventions. In July 2009, consultants Capgemini published research findings on behalf of the Department of Communities and Local Government which found that investment in packages of support that include housing related support services avoids costs elsewhere and therefore produces a net financial benefit.²⁰

2.4 In many of our supported housing, sheltered housing and other services, the Home staff member offers the most constant support for clients who access a variety of other care and support services in order to meet diverse needs. Our services can be described as the “glue” which holds other services together.

2.5 The committee indicated that the Inquiry would focus on options for

- future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities;
- personalisation of social care services;
- more effective, consistent and user-friendly social care services

Our comments below are therefore structured around these key themes.

²⁰ Research into the Financial Benefits of the Supporting People Programme (Dept for Communities and Local Government, July 2009) [online] accessed on 28 September 2009 at <http://www.communities.gov.uk/publications/housing/financialbenefitsresearch>

3. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

3.1 We believe that any future system of funding for care and support, must address the needs of all those who need care or support. Two out of the three proposals for future funding in *Shaping the Future of Care Together* do not address the needs of adults who need care and support before retirement age. Many of our clients with long term disabilities, or other care and support needs earlier in life face limited choices due to funding restrictions, which in turn impacts adversely on their overall quality of life.

3.2 We would like to see more detailed proposals for funding long term care and support for younger people that will enable a decent quality of life

3.3 *“Funding is really tight here and it’s often short term. I understand that you need to watch where the money goes, but you also need to pay for adequate support. Otherwise it just costs more in the long run.”*
Registered Care Home Manager (Mental Health), West Midlands

3.4 Our clients face additional restrictions in terms of the type and location of service available to them because of local variations in funding arrangements. Clients who may wish to move to a different local authority area in search of work, or to be nearer to family may be thwarted by disparate funding arrangements.

3.5 We welcome proposals for standardised assessment and funding packages that would allow people greater flexibility in where they choose to live. However, we urge that steps are taken to ensure that standardisation does not result in an overall reduction in service quality and that innovation is not stifled in the pursuit of a fair and universal system.

3.6 Whether the system is locally or nationally determined, our key concern is that the system should be primarily responsive to individual need, rather than simply subject to local budget constraint. Safeguards must be built in to ensure that the system adequately meets clients’ needs eg the inclusion of transparent and measurable standards for establishing the efficacy of the system in meeting individual needs. Clients should be directly involved in defining standards and measuring services against them.

3.7 We are concerned that the suggested integration of some disability benefits (eg Attendance Allowance) into the care and support system will remove a valuable source of funding and means of maintaining choice and independence for older people. People on the threshold of means tested care and support funding will lose out to the greatest degree.

4. PERSONALISATION OF SOCIAL CARE SERVICES

4.1 We strongly support the development of person centred services that are designed around the needs, wishes and aspirations of individual clients. Our support practice policy and procedures around supporting clients effectively puts clients at the centre of designing their own support plans and encourages partnership working with other service providers.

4.2 Using supported planning tools developed in consultation with clients (*My Way Forward*), we develop support plans unique to individual clients to assist in their achievement of personal goals and aspirations.

4.3 By involving clients in all aspects of our organisation, from sitting on the management board, to designing services and influencing policy, we can ensure that our services represent what clients actually want and need.

4.4 Individual budgets have an important place for some clients, particularly those receiving long term support from a variety of funding sources. We are working with partners to pilot different models, including a key involvement working with the Housing Association Charitable Trust.

4.5 However, good personalised service does not always equate to holding and managing an individual budget. For some clients, individual purchasing of support is not the most effective way of ensuring real choice and control. Commissioned services are more appropriate to many clients who would chose them because they don’t (or don’t yet) want to exercise a greater degree of choice and responsibility. Some of our older clients, in particular, tell us that they would rather work within existing services using person centred approaches, without having to engage with the processes and bureaucracy of designing and developing bespoke services.

4.6 Individual budget systems which give control of actual or virtual money to clients are not appropriate to many clients with chaotic or addictive lifestyles.

4.7 Whilst commissioned services are still essential to providing choice to clients, care should be taken to commission service models which are not overly restrictive and which permit flexibility to meet individual need. No assumptions or decisions should be made without directly asking clients and potential clients. Clients must be involved in decisions about and the design of future services.

5. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

5.1 We welcome the emphasis on prevention and low level support services that support people to remain independent. Our experience of supported housing services demonstrates the value of supported housing services and other low intensity support in increasing independence, and reducing the need for more intensive and costly interventions eg hospital admission

5.2 In the year 2008–09, over 77% of our clients with physical health issues receiving housing related support, were better able to manage their physical health as a result. Over 75% of clients with mental health issues were better able to manage their mental health as a result of housing related support.

5.3 We welcome the development of new technology to assist in delivering good quality services eg telecare solutions. However, this must be seen as complementary rather than as an alternative to working face to face with a skilled worker, which our clients tell us they value very highly.

5.4 In the year 2008–09, 89% of our clients who used assistive technology/aids and adaptations were better able to manage living independently as a result.

5.5 Our experience of joined up working to best meet client's needs is variable. Many clients with multiple and complex needs and/or dual diagnosis (eg mental health issues and substance misuse) are still subject to funding battles between health and social care services and frequently end up "falling between two stools" with their needs unmet until such disputes are resolved.

5.6 *"Funding loopholes have pushed a lot of people with mental health needs into the community with inadequate support. Their basic needs are not met and I see people walking round the town centre hungry and dirty."* Mental Health Project Worker West Midlands

5.7 We would like to see a more holistic approach to needs assessment, with a clear pathway for funding allocation.

5.8 In spite of the promise of progress in improving access to psychological therapies, clients with mental health issues continue to highlight the lack of access to good quality psychological services and the adverse impact this has on recovery. Again we observe variation across the country with, in some cases, neighboring authorities having wide variation in the availability of services.

5.9 We welcome the government's recognition of the need for joined up services and see supported housing services as playing an important role in achieving cohesive services resulting in the best outcomes for clients.

5.10 *"Often when a client has a lot of carers going in, our scheme manager is the one constant face, and person they turn to when things go wrong, eg if the carer doesn't turn up, or they are putting them to bed at five in the afternoon."* Supported Housing Scheme Manager, North East England

5.11 The voluntary sector has played an important part in developing innovative services (eg extra care services, supported living) which facilitate excellent outcomes for clients, and where this has proved more difficult for statutory services.

5.12 Good quality housing and housing related support services play crucial roles in promoting independence—both generally in terms of meeting basic needs eg shelter and reducing social isolation, as well as in addressing more specific needs such as promoting mental health recovery.

5.13 The involvement of clients in determining what services should be delivered and how services are delivered is key to delivering more effective, consistent and user friendly social care services.

September 2009

Memorandum by the Hesley Group (SC 12)

THE FUTURE OF SOCIAL CARE SERVICES

EXECUTIVE SUMMARY:

- This submission is made on behalf of The Hesley Group, an independent provider of high quality services for people with special needs.
- Our comments are focussed on issues surrounding the future funding of long-term care for people with learning difficulties, the personalisation of their care, and how this care could be made more effective.
- Care and support packages for those with complex needs should be reflective of total costs and the personalisation agenda must lead to increased choice for individuals and their families and not be used to reduce costs.
- Residential care services can be highly personalised and provide the appropriate care pathway to enhance an individual's life.

- There is a need for greater awareness among commissioners for appropriate funding for those with severely complex learning disabilities. A range of services provide the most appropriate care pathways that enhance the individual's life.
- Clarification surrounding the means testing of benefits for those with leaning disabilities when working or having inherited capital is required to ensure that service provision can work as efficiently as possible.
- A greater emphasis on regional funding and commissioning will improve service development and remove the current postcode lottery for specialist services.

1. INTRODUCTION TO THE HESLEY GROUP

The Hesley Group provides specialist residential settings for people with extremely complex and severe needs, arising from autism and severe learning disabilities

A number of settings, including residential schools for children under 19 and specialist residential services that cater for people aged 16 plus, are run by The Hesley Group in the Doncaster area.

Adult services are delivered through two settings, established as “intentional communities”, which provide specialist and dedicated services for people with the most severe learning disabilities.

The purpose built Hesley Village and College comprises houses, flats and bungalows, a restaurant, a cinema, a village hall, a therapy centre, a hair salon, a bank, shops, a sports hall and a mini-market. There is also a vocational centre and field study centre, where residents can learn valuable life skills, such as cooking and gardening: necessary skills for independent living.

The second setting is the Low Laithes Village—a purpose built residential setting located on the outskirts of Barnsley. The village comprises of flats and bungalows, with a café, a shop, a launderette and a community centre. Specially built workshops and rooms can be used by residents to learn vocational skills or to pursue hobbies and interests. Its close vicinity to the town centre enables residents to take part in a wide range of social, educational and occupational opportunities.

2. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

As specialists in residential care for those with complex needs, The Hesley Group argues that the true cost of care and support packages, for those individuals, must reflect all costs. This is especially true where brokers are used to negotiate care packages for local authorities.

To allow this to happen and simplify the procedure, The Hesley Group suggests that National Contracts for services, similar to those created for Children's Services (NASS), are needed in order that providers and purchasers can speed up the negotiation of contracts and improve efficiencies.

To simplify the criteria of funding streams, The Hesley Group believes that regional funding and commissioning would facilitate more logical development of services. This would reduce the perceived “postcode lottery” for specialised services.

3. PERSONALISATION OF SOCIAL CARE SERVICES

In order to achieve true personalisation for adults with learning disabilities a holistic support plan is essential. Local services must have the capacity to provide the required levels of service as needed, not based on waiting times or the availability of professionals or clinicians.

An holistic approach would provide the correct framework for the personalisation agenda to give individuals and their families choice for the most appropriate care. These choices must not be restricted by the use of the personalisation agenda to reduce costs.

The care of individuals with complex learning difficulties should not be lost with the personalisation of social care services. Residential services can be highly personalised within the needed regulated setting for the severely autistic. Access to meaningful social and vocational activities is crucial and a range of provision, both residential and community based, is required to meet those needs.

A range of services is necessary in order to provide appropriate care pathways that enhance the individual's life.

4. More Effective, Consistent and User-friendly Social Care Services

The Hesley Group feels that service users and their advocates need to be listened to in order to create a truly user-friendly social care service.

As a specialised service provider the Hesley Group sees the need for the transition from children's services to adults to be made more consistent. Children's placements, and thus funding, are terminated once the young person reaches 18, however they still have an entitlement to education under their statement of special

needs until age 19. This break in funding and further confusion over the transition process leads to uncertainty and disruption to an individual's life. This is especially important to avoid in a severely autistic young adult, where routine is essential.

Those who lack the capacity to make their own decisions need easier access to independent advocates to assist their decision making and ensure that they do not fall through the gaps in the current system.

5. MEANS TESTING

To achieve full and independent lives many people with learning disabilities work within the community that they live. The Hesley Group feels that there should be no exception for those within residential care.

Work, for those in residential care, is a key learning stage in the care pathway to community living. However many in residential care are unable to work as their earnings affect their means tested benefits, thus limiting the incentives for those who need life experience to achieve independence.

The means testing of benefits is also affected by inheritance. Over 50%²¹ of people with learning difficulties and severely challenging behaviour are cared for by their parents. When these parents die many will disinherit their disabled child because to inherit a large capital sum would affect their means tested benefits.

Confusion around these issues creates unnecessary concerns for an already vulnerable group.

Government should consider changes in the system that would allow for some arrangement covering inheritance regulations so that these disabled people do not suffer further concern and financial discrimination because of their care needs.

6. RECOMMENDATIONS AND CONCLUSION

In order to ensure that care packages reflect the true cost of care for individuals with complex learning difficulties and to simplify the procedure, The Hesley Group recommends that National Contracts for services are needed. These contracts would encourage more regional funding and commissioning and the simplification for this system.

The Hesley Group believes that residential care settings are a necessary part of the care pathway for the severely autistic and that well-managed residential services can be highly personalised for each individual.

To make social care services more effective, consistent and user friendly, the Hesley Group believes that the transition from children's to adult's services needs to be more efficient and ensure that the needs of the service user, rather than the requirements of various funding streams are kept paramount.

Children's placements and Special Educational Needs funding need to be coordinated to lead to improved service provision.

Finally, The Hesley Group believes that to achieve the best outcomes for service users, an individual's capacity to work and gain valuable independence and self esteem should not be compromised by a reduction in their benefits.

The Hesley Group would be delighted to provide more information about their services should that be required, and to provide spokespeople to submit oral evidence to a subsequent hearing of the Committee

September 2009

Memorandum by Nestor Healthcare Plc (SC 13)

SOCIAL CARE

INTRODUCTION

1.1 Nestor Healthcare Plc-Social Care Division welcomes the opportunity to submit evidence to the Health Committees inquiry into the future of social care services. Nestor Healthcare Plc is one of the largest independent organisations dedicated to delivering services to health and social care markets. We deliver domiciliary care and support services through our partner organisations and directly to individuals focussing on individual needs. Established in 1949 we employ a nationwide workforce of around 9000 staff who are employed through our network of 100 social care local offices.

2. BACKGROUND—NESTOR HEALTHCARE PLC

2.1 Nestor Healthcare Plc comprises of a primary care division and social care division. Nestor Primecare is a provider of integrated out-of-hours healthcare providing advice and treatment to patients and Primecare Forensic Medical that delivers clinical services to secure establishments and police forces. Nestor Primecare has been appointed preferred bidder for 5 "Darzi" schemes under the governments extended access scheme.

²¹ CeDR research report November 2008; Eric Emerson and Chris Hatton, Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England.

2.2 Nestor Healthcare Plc-social care division comprises of 18 different brands. Goldsborough/Medico are two of the main domiciliary care brands which operate through a network of 100 branches nationally. Approximately 85% of the domiciliary care activity is generated through contracts with more than 70% of the Local Authorities. The remaining 15% of revenue relates to the provision of domiciliary care and support to private clients. The core services are delivered to predominantly Older People.

2.3 Nestor Healthcare Plc-Social Care Division provides specialised services to Children and Families, supporting children with learning or physical disabilities as well as where the child's carer has social care needs such as drug or alcohol dependency issues. Additionally we provide mental health services for people who may have long standing or transient mental health problems including people who are subject to guardianship and supervision orders under the Mental Capacity Act.

2.4 Four businesses, New Horizons, Pathos, Life Care and Complete Homecare provides support to adults who have learning disabilities and includes provision for people with complex needs. For Service Users who have been described as having "challenging behaviour" our services are strictly related to the needs of the individual. They focus on reducing the negative and promoting positive behaviour so that they are more able to live within their chosen community.

3. EXECUTIVE SUMMARY

- Nestor Healthcare Plc—Social Care Division provides social care and support in partnership with over 70% of Local Authorities employing 9,000 staff in 100 local branches delivering around eight million care hours per annum.
- Our business delivers domiciliary care and support to older people , children , people with physical , learning disabilities and mental health illnesses with 18 businesses forming part of the Nestor Healthcare –social care division parent group
- We welcome the opportunities presented to service users and our organisation by the personalisation agenda but believe the drive for cost saving efficiencies by some local authorities will hamper the progress of personalisation and restrict social care provider's ability to deliver high quality flexible and responsive services in the future.
- To ensure care closer to home remains a real viable alternative to residential care, we support the UKHCAs call for the Government to consider the Low Pay Commissions 2009 report which highlights careworkers pay. We believe Councils commissioning strategies need to reflect the need to provide a fair price for care rather than striving for cost saving efficiencies by capping care delivery rates lower than the cost of service provision. This impacts on the quality of service provision.
- The future of social care requires service users to retain the right to choose. Service users should retain the option to receive traditional domiciliary care services as well as services via direct payments or individualised budgets. This may be particularly relevant for Older People Services. The drive for Local Authority to achieve or exceed 30% targets with CQC inspecting on their compliance may inadvertently stifle the choices service users have.
- The benefits of the Social Care Reform Grants needs to be filtered down to social care providers so that seamless services between health and social care can be delivered
- How personal budgets are spent needs to be scrutinised to ensure users do not neglect their personal care needs in favour of promoting general wellbeing which could have long term impacts on the individuals overall health
- Regulation of personal assistants needs to be considered. Currently this workforce is not subject to CQC inspection and not part of the new vetting and barring system. This poses the risk of abuse for some vulnerable people. Evidence indicates that a significant proportion of service users who are in receipt of direct payments fail to make satisfactory pre-employment checks and some staff in delivering services for DP users do not receive training, contracts of employment or have provision for pensions.
- As a provider committed to providing safe, reliable, person centred care we believe that the personalisation agenda needs to now move from how social care will benefit to how this will be achieved at grass roots level , with providers being supported to effect the change and meet the challenges the transformation presents.

Nestor Healthcare—Social Care Divisions Response to Questions

4. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE

4.1 From a domiciliary care provider's perspective the funding of social care has implications for the shape of the services we will be able deliver in the future. The drive for cost saving efficiencies by local authorities implementing Gershon cost saving efficiencies²² is evident at contract tendering stage with some commissioning strategies impacting adversely on the quality and range of services that can be provided.

²² Gershon Report "Releasing Resources to the Front Line—Independent Review of Public Sector Efficiency" HM Treasury 2004.

Capping care providers' charge rates at tendering stage when a contract is re-tendered makes it difficult to deliver high quality innovative services and results in organisations not tendering because the contract would not be financially viable in terms of being able to deliver quality services for the price set by the local authority. Where this has been the case Nestor Healthcare—Social Care Division has withdrawn from the tendering process rather than compromising the quality of service provision.

4.2 Where this practice is undertaken, local authorities benchmark all social care providers charge rates and fix a maximum charge rate. Tenderers are requested to submit their rates with the highest score going to the provider with the lowest charge rate. This process is often counterproductive when delivering high quality services as it places emphasis on cost/price at the cost of quality or consistency. The commissioning strategy encourages some providers to compromise quality and not reflect the true cost of robust recruitment, training and quality frameworks. This process has a similar negative impact on service quality as the reverse e—auctions that have been highlighted in the press.

4.3 Nestor Healthcare Plc—Social Care supports the UKHCA call for the Government to evaluate local authorities purchasing policies as proposed by the Low Pay Commission Report 2009²³ and believe that local authority commissioning needs to ensure that contract prices reflect the true cost of care including national minimum wage. By doing so Domiciliary Care providers will be able to invest in developing innovative services that reflect the true cost of care provision.

4.4 As an organisation Nestor Healthcare Plc welcomes the opportunities presented by the Social Care Reform Grant to work in partnership with local authorities to develop long term plans and would welcome the opportunity of working with PCTS more closely to release more funding streams enabling a more diverse range of services to be offered. To facilitate a more seamless service the gaps between health and social care needs to be bridged. An understanding of the boundaries which the social care workforce operates within as well as the benefits of working with social care workers in terms of flexibility of work patterns, diversity of the workforce reflecting the local demographics and working with national providers with considerable resources who can evidence best practice across the country would serve to bridge these gaps.

4.5 As Local Authorities push to achieve their targets of 30% of service users receiving direct payments, Local Authorities are moving away from commissioning block contracts to commissioning framework agreements. Although for service users this means they are able to clearly benchmark a range of providers in terms of quality and price, for smaller providers the lack of guaranteed volumes of hours could make their businesses nonviable or push smaller organisations together restricting choice within the social care market. A recommendation is made that a mix of contracts is retained to optimise choice and ensure a stable domiciliary care market.

5. PERSONALISATION OF SOCIAL CARE SERVICES;

5.1 Nestor Healthcare welcomed the “Putting People First”²⁴ vision with its emphasis on delivering person centred care including the strategic shift towards early intervention and prevention and recognises the benefits to some service users the outcome approach to service delivery can bring. The increasingly widespread utilisation of electronic call monitoring in particular call monitoring that focuses on minute by minute payments for service provision that is deployed by some local authorities in an attempt to control costs of direct service user contact time, impacts adversely on the ability to deliver truly outcome focussed services for individuals.

5.2 For a care worker to work in an enabling way when a service is programmed to be exactly 15 minutes does not take into account the fluctuations in service users day to day well being and this serves to promote task based service delivery . Any deviation from the programmed time results in the local authority withholding payment of invoices penalising providers.

5.3 With a significant emphasis by both central government and in turn local government on the need to provide “outcome focussed care” there needs to be an understanding at local authority strategic level that some service users do not want to go down the personalised service route in terms of support plans and managing direct payments or individualised budgets. For example, some Older People may wish just to be told what care they are to receive rather than be involved in deciding what they are eligible to receive, they may also not have anyone to advocate on their behalf to make the considered thoughts that partner personalisation. Balancing the personalisation agenda with more traditional models of service delivery still needs to be considered to ensure that personalisation doesn't become a one size fits all option.

5.4 In areas such as Extra Care Housing where service users choose to move into housing where care is provided on site 24 hours per day, the impact of Local Authorities introducing direct payments for individuals within a scheme could serve to destabilise a service. Providers traditionally have been awarded block contracts to provide a core number of hours. This enables a workforce to be recruited specifically to work within the scheme promoting consistency and quality. Introducing direct payments with service users having the facility to “opt out” of the on site care provision in favour of purchasing care externally could result in providers being unable to maintain its workforce because of no guaranteed hours . Security in the

²³ UKHCA “From Rhetoric to Reality” A Manifesto for Sustainable Homecare Oct 2008.

²⁴ Putting People First Putting People First: a shared vision and commitment to the transformation of adult social care DoH 2007.

scheme could be threatened because of the increase in the number of people entering the scheme and more importantly service users could be put at risk if they need support outside the times their care worker visits and no access to on site care provision.

5.5 As individuals are encouraged to take control of how they spend their budgets there could be potential for the maintenance element of social care being ignored in favour of funding other activities believed to benefit the individuals overall wellbeing. For example, service users choosing not to receive support for ensuring basic cleanliness and using the funding to purchase a holiday or football season tickets. This in the longer term could impact on the service users overall health. More emphasis needs to be placed on service users meeting their basic care needs in terms of washing, dressing and nutrition to maintain a healthy lifestyle.

5.6 Nestor Healthcare-Social Care Division embraces the concept of service users having choice and control over service delivery but believe that Personal Assistants need to be regulated and subject to the same checks as care staff employed by domiciliary care organisations. The onus on the direct payment holder to undertake training, employment checks on individuals they employ exposes some vulnerable people to unnecessary risks. The study by Skills for Care in June 2008²⁵ that found that 48% of people receiving direct payments failed to make CRB checks on their PAs whilst 46% failed to seek references. With the advent of the vetting and barring, system for domiciliary organisations there is potential for careworkers wishing to avoid the ISA processes to migrate into personal assistant roles. In rural areas where the recruitment of personal assistants may be more difficult and the role of PAs is undertaken by family members unregulated support again poses the risk of abuse with research indicating in cases of elder abuse two thirds of incidents are perpetrated by relatives, most often the individuals adult child or spouse.

5.7 Nestor Healthcare-Social Care Division has around 10% business with service users and families with learning disabilities and this figure is increasing. Despite direct payments and individual budgets now being firmly part of the funding options within the sector, families and people with mental health problems continue to require additional support to identify where appropriate care for their family can be sourced as it remains fragmented. Our own research into Autism has found that some parents continue to find it difficult to access direct payments with their children falling between the health and social care gaps.

5.8 The Governments Personalisation agenda has received considerable publicity with stated vision of transforming social care. For providers of social care the agenda now needs to move from “What” to “How” with support at local government level to implement the strategy without comprising quality or choice.

6. MORE EFFECTIVE, CONSISTENT AND USER FRIENDLY SOCIAL CARE SERVICES.

6.1 As a national provider covering England, Wales and Scotland we are exposed to multiple commissioning strategies. Local authorities approach to tendering and contractual obligations vary significantly with each authority interpreting legislation and guidelines differently. This increases overheads for national providers and has the potential if robust quality mechanisms are not in place to affect the consistency and quality of service provision. For example, inconsistencies in Councils’ Medication Policies results in branches working with our own policy that complies with CQC guidelines and our insurance terms and multiple differing local authority policies that repeatedly push the boundaries of the social care worker’s role moving it increasingly into a health support role. For service users this has the potential to present risks. As a social care provider, the inconsistencies are frustrating and a more streamlined approach to contract terms and conditions would be welcomed.

6.2 To have more effective consistent and user friendly services local authorities and central government need to invest their support with provider to develop personalised care. At present tendering opportunities reflect the need for providers to embrace the personalisation agenda but the ability to move forward with it remains a challenge for the majority of home care providers with little evidence of support to make the transition being evident at local level.

7. CONCLUSION

7.1 Nestor Healthcare-social care division welcomes the opportunity to highlight our views on the future of social care. We recognise the benefits that the personalisation can bring to social care and to service users but believe more work is required on promoting the quality of the services, balancing cost with choice and supporting providers to bring about the transformation of services. We recommend a review of Councils commissioning strategies. We believe this should include reviewing the practice of capping contract rates at tendering stage which encourages care worker pay rates to remain at a low level. As stated this impacts on the ability to provide quality services and prevents organisations being able to explore innovative practices that promote choice and quality. As an independent social care provider committed to the delivery of person centred care we would welcome the opportunity to work in partnership with local councils to explore models of service delivery that promote dignity, choice and control to people who use social care services. With 80%

²⁵ Skills for Care “Employment Aspects and Workforce Implications of Direct Payments” May 2008.

of Local Authorities using independent providers to deliver social care and support, we recommend that Councils' are given clear guidelines on working with the independent sector to effect the cultural change that is required by the personalisation agenda and to meet the future challenges.

September 2009

Memorandum by Sanofi Pasteur MSD (SC 14)

SOCIAL CARE

SUMMARY

- Sanofi Pasteur MSD acknowledges the recent Department of Health (DH) Green Paper, *Shaping the Future of Care Together* and agrees that money could often be better invested in prevention in order to keep people healthy.
- Our primary point is that vaccination should be given a more prominent role in the provision of health and social care, as it can reduce the burden of vaccine-preventable diseases among older people.
- This would improve health outcomes, since infectious diseases are a significant cause of morbidity and mortality among older adults (50+ years of age). Without specific vaccination programmes for older people these diseases will continue to be a cause of substantial morbidity and mortality in the coming decades among a growing section of the population. Yet there is a widely held belief that vaccination is only relevant for children. Consequently, there is no systematic approach to immunising adults, despite the fact that more adults than children die each year from vaccine-preventable diseases.
- In order to maximise the effects of vaccination on an individual's health, it is necessary to adopt a "life course" approach, which seeks to prevent disease by the use of vaccination throughout our lives. Vaccination programmes for older people should start from approximately 50 years of age before age-related decline in the immune system begins.
- Support from health and social care professionals will be crucial in implementing the policy and achieving high uptake rates. There needs to be more education and training of professionals to improve their understanding of vaccines. Services need to be more "joined-up" in order that social care professionals can identify opportunities for patients to be vaccinated and involve health professionals as appropriate.
- We support the greater personalisation of services, but in order to make this a reality, patients should be able to choose preventive care, including vaccination.
- If patients are to have control over their personal care budgets, there should be flexibility in the system to allow them to access vaccines at NHS prices in cases where they are outside a universal programme.
- There should be more regular assessment or screening of adults over 50 to check their vaccination status and to prompt appropriate action.
- Underpinning all this is the need to improve patients' knowledge of vaccines to overcome misperceptions and resistance to vaccination.

INTRODUCTION

About Sanofi Pasteur MSD

1. Sanofi Pasteur MSD (SPMSD) is the only company in the UK totally dedicated to vaccines. It was founded in 1994 as a joint venture between Sanofi Pasteur and Merck & Co. Inc. We have a heritage that includes pioneers in vaccination, such as Louis Pasteur (rabies vaccine) and Maurice Hilleman (measles vaccine) and have grown to become a leading supplier of vaccines. Using a combination of research and manufacturing expertise, our purpose is to bring innovative vaccines to the UK, protecting health and preserving quality of life for all ages.

2. Our main way of achieving this goal is to develop and make available innovative vaccines against a wide spectrum of diseases. We are also dedicated to increasing the understanding of the value of vaccines and vaccination by providing relevant and accurate information on their efficacy, quality and safety.

Reforming adult care

3. Sanofi Pasteur MSD acknowledges the recent Department of Health (DH) Green Paper, *Shaping the Future of Care Together*, in particular the recognition of the importance of a more “joined-up” service, health assessments, prevention, information, and personalised care and support.

4. We acknowledge there are macro-funding issues. Our focus is on how giving a high priority to vaccination, together with more personalised services, can lead to more effective care and a healthier population.

5. We concur with the Green Paper that money could often be better invested in prevention in order to help keep people physically active and healthy. If the system fails to provide treatments and support earlier in life, individuals will suffer the burden of avoidable illness, pain, and, in some cases, death. In addition, the NHS and care services will face greater costs.

6. We welcome the introduction of a National Care Service underpinned by rights and entitlements with services that are better value for money and that keep people as healthy as possible. However, to achieve this there needs to be a greater recognition of the role for vaccination as a feature of social care and healthcare provision.

VACCINES AND HEALTH

7. Ageing and age-related disease are mounting challenges to individuals and our health and social care systems. Although much is known about prevention and treatment of a wide range of acute and chronic diseases, many adults do not receive up-to-date care or prevention. Consequently, they can suffer avoidable pain, disability and death. Making vaccination more central in the provision of both social care and healthcare would help avoid these consequences.

8. Vaccination is effective in preventing over 20 infectious diseases and has helped eradicate smallpox. No other health intervention, apart from the provision of safe water has done more to reduce mortality.²⁶

9. There is a strong EU-wide consensus that vaccines are an under-used means for improving healthy ageing. A recent statement by two European geriatric and gerontological societies (European Union Geriatric Medicine Society [EUGMS] and International Association of Gerontology and Geriatrics—European Region [IAGG-ER]) advocated routine vaccination of ageing populations and called for improvement in the uptake of routine vaccinations in adults aged 60 years and over across the EU in order to promote healthy ageing by reducing the burden of vaccine-preventable infectious diseases among older people.²⁷

10. Infectious diseases among adults over 65 years remain a significant cause of morbidity and mortality.²⁸ For instance, in 2001, lower respiratory infections (lung infections) were the fourth most frequent cause of death in high-income countries.²⁹

11. The annual incidence of shingles, also known as herpes zoster (HZ), in the 50+ population is estimated to be 5.23 per 1000 person-years in the UK population.³⁰ The risk of shingles increases with age, beginning at about 50 years and is 8 to 10 times as likely to develop in people 60 years of age or older as in younger people.³¹ One in five patients with shingles will develop the painful and long-lasting complication called post-herpetic neuralgia (PHN).²⁹

12. The treatment of shingles and PHN is a burden to the NHS. Excluding hospitalisations, the average cost to NHS of each shingles case ranges from £60 to £125, and from £167 to £616 per episode of PHN depending on the definition used and pain severity. Pain severity is the main driver of medical resource, and most of the costs are incurred in primary care: 74% for shingles and up to 84% for PHN.³⁰ A recently completed database review to estimate the burden of shingles and PHN in secondary care in the UK found that from October 2006—September 2007, among people aged 50 and older, there were up to 5,297 hospital admissions related to HZ as a primary or secondary reason for admission. This represented a total cost of up to £13.4 million to the NHS. A significant proportion of the costs (31%) was due to excess bed days.³²

13. Yet shingles can be prevented to a significant extent. Clinical trials of a shingles vaccine, developed by Sanofi Pasteur MSD, showed a reduction in the incidence of shingles by 51.3%, a reduction in the incidence of PHN by 67% and a reduction in the burden of illness due to shingles by 61%. It also reduced

²⁶ Plotkin S & Plotkin S. “A Short History of Vaccination,” Chapter 1 in *Vaccines*, Edition 5 by Stanley A. Plotkin, Walter A. Orenstein, Paul A. Offit. Elsevier Health Sciences, 2008.

²⁷ Michel JP *et al.* Advocating Vaccination of Adults Aged 60 years and Older in Western Europe. *Rejuvenation Research* 2009;12:127–35

²⁸ Htwe TH, Mushtaq A, Robinson SB, Rosher RB, Khardori N. Infection in the elderly. *Infect Dis Clin NAm* 2007;21:711–743.

²⁹ Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJ. Global and regional burden of disease and risk factors, 2001: systematic analysis of population health data. *Lancet* 2006; 367:1747–1757

³⁰ Gauthier A *et al.* Epidemiology and cost of herpes zoster and post-herpetic neuralgia in the United Kingdom. *Epidemiol, Infect* 2009;137(1):38–47

³¹ Kimberlin DW, Whitley RJ. Varicella—zoster vaccine for the prevention of herpes zoster. *N Engl J Med* 2007;356:1338–1343

³² Sanofi Pasteur MSD Data on File 2009. UK13473

the incidence of shingles with severe and long lasting pain by 73%.³³ Additionally, the Health Protection Agency (HPA)'s economic evaluation of shingles vaccine found that vaccinating against shingles has been shown to be cost-effective for those age 65 and 70 years of age.³⁴

14. Without specific vaccine programmes for adults, these infectious diseases will continue to be a cause of substantial morbidity and mortality in the coming decades.³⁵ Moreover, the size of the older adult population (60+ years) is predicted to increase across Europe by 160% from 1999 to 2050.³⁶ Therefore, the number of cases of infectious disease in the older population will increase and be a greater burden on the NHS.

15. Yet with the exception of the flu vaccine, there is a widely held belief that vaccination is only relevant for children. Consequently, there is no systematic approach to immunising adults. Adults do not regularly check their vaccination status and vaccination coverage remains low, despite the fact that more adults than children die from vaccine preventable diseases each year.³⁷

PUTTING VACCINATION AT THE HEART OF OLDER PEOPLE'S CARE

16. In the Green Paper, the DH said that we cannot predict who will need high levels of care and support. Yet we do know that injuries and disease can be prevented if there is willingness by policy makers to act.

17. Preventing older people from falling is seen as a key challenge for the NHS and local authorities and the DH has stated that it aims to raise the focus on older people's prevention services and encourage their use.³⁸ Falls are more common in older people with poor balance, and decreased strength and mobility, but they are not inevitable and the risk can be reduced by balance and strength interventions.³⁹

18. But we also know that vaccination can prevent disease. Yet with the exception of the flu and pneumococcal vaccines, it is not given as high a priority in older people's health or social care as falls prevention.

Life course approach

19. As our population ages we need to adopt new approaches to ageing. Public health strategies should include immunisation and be based on a "life course" approach. The main aim should be to promote prevention, in both primary and secondary care, relating to life-threatening diseases and those that can adversely affect patients' independence and quality of life.³⁹ Such an approach would prevent disease by the use of vaccination throughout our lives, rather than concentrating on when we are very young or very old.

20. As the immune system declines with age, it leads to more frequent and more severe infections. Thus, an effective vaccination programme would start from 50 years of age onwards before age-related decline in immune systems begins. This would produce both public health and economic benefits as it would help reduce the need for costly treatments.⁴⁰

Support from healthcare and social care professionals

21. Recommendations from healthcare and social care professionals can be a major influence on adult vaccination rates and the largest cause of missed opportunities is their failure to offer vaccination.⁴¹

22. There needs to be more education and training of professionals in both the health and social care sectors to improve their understanding and use of vaccines and more regular checking of patients' vaccination status. There should be targets for vaccination coverage and incentives to vaccinate, as there are for the flu vaccine.⁴⁰

23. We do not propose that anyone other than appropriate qualified healthcare professionals should administer vaccines, but there should be a role for social care professionals to help maximise the effectiveness of any vaccination campaigns. They can share the responsibility for increasing awareness and coverage of vaccination by raising awareness of the benefits among patients. If the DH is to provide a more joined-up service, then it must find ways for social care professionals to identify opportunities for older people to be

³³ Oxman MN *et al.* A vaccine to prevent herpes zoster and post-herpetic neuralgia in older adults. *N Engl J Med* 2005; 352(22): 2271–84

³⁴ Van Hoek, AJ *et al.* Estimating the cost-effectiveness of vaccination against herpes zoster in England and Wales. *Vaccine* 2009;27:1454–1467

³⁵ Michel JP *et al.* Advocating Vaccination of Adults Aged 60 years and Older in Western Europe. *Rejuvenation Research* 2009;12:127–35

³⁶ Michel JP, Gold G. Coping with population aging in the old continent—the need for european academic geriatrics. *J Gerontol A Biol Sci Med Sci* 2001;56:M341–M343

³⁷ Poland GA, Jacobson RM, Ovsyannikova IG. Trends affecting the future of vaccine development and delivery: The role of demographics, regulatory science, the anti-vaccine movement, and vaccinomics. *Vaccine* (2009), 27:3240–3244

³⁸ Falls and fractures. Effective interventions in health and social care; Department of Health. July 2009.

³⁹ Cruz-Jentoft AJ *et al.* European Silver Paper on the Future of Health Promotion. European Summit on Age-related Disease, 2008. *Eur J Aging* 2009;6:51–7

⁴⁰ Gusmano, Michael and Michel, Jean-Pierre. Life Course Vaccination; Impact of Life Course Vaccination on an Ageing Population. Alliance for Health and the Future Policy Brief Vol 4 No 1.

⁴¹ Motbey C. Pneumococcal polysaccharide vaccination in Australia: an examination of barriers and arguments in support of the hospital based approach. *Hum Vaccin* 2008;4:341–3

vaccinated and to involve health professionals in implementation. Similarly, health professionals working in social care settings, eg nurses in care homes and health visitors, should also be involved in efforts to increase vaccination coverage.

Greater personalisation

24. We fully support the principle that services to patients will be specific to their personal circumstances and need, and that they will have much greater say over how and where they receive support. If this is to be put into practice, patients' should be allowed to make early choices of preventive care, including vaccination.

25. In the Green Paper, the DH raises the possibility of patients controlling their own budgets. In order to promote greater use of vaccination, there should be flexibility in how patients are able to use these personal care budgets. Although these are not intended for use on healthcare, consideration should be given to allowing at least limited flexibility where this could increase prevention. In its vision of the future, the DH says that it "will do more to stop people developing care and support needs in the first place".⁴² Using personal care budgets for vaccination can help achieve this.

26. Patients who meet the age requirement of a vaccine licence, but do not fall within the JCVI's recommendation age limit should be able to access vaccines at the NHS price using their personal care budgets. This would give patients greater control over their own care and help them secure protection that they would not otherwise have had against preventable diseases.

Assessment

27. While young children are seen by doctors as part of their routine health assessments, older adults are more likely only to interact with health professionals when they are sick or injured, which leaves few opportunities to be offered vaccination. Health care professionals are more likely to discuss vaccination with patients during check-up visits than when they have an illness or injury.⁴³ The DH should, therefore, consider the introduction of regular screening or assessment of adults over 50 to check their vaccination status and take appropriate action. With greater use of electronic medical records, this could be done by computerised prompts every time a patient has contact with the health care system. Screening and assessment systems should include social care professionals who can involve health professionals for the actual vaccination.

Patient knowledge and attitudes

28. Even if vaccination becomes more central to older people's care, there will still be a need to overcome reluctance on the part of some patients. Some patients may believe that they will contract the very disease the vaccine is designed to prevent or will suffer serious side effects. Others may believe that they are not at risk and, therefore, do not need a vaccination.

29. Vaccination programmes must be complemented by information campaigns conveying to patients accurate information on the need for and benefits of vaccination. Patients should also be able to monitor their vaccination status through a life-course immunisation record.

September 2009

Memorandum by the Association of Directors of Adult Social Services (SC 15)

SOCIAL CARE

1. INTRODUCTION

1.1. The Association of Directors of Adult Social Services (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of Social Care, ADASS members often also share a number of responsibilities for the provision and/or commissioning of housing, leisure, library, culture arts and community services within their Councils.

1.2. The Association is able to bring together tremendous breadth, depth and accumulated experience on all issues covering managerial policy and professional activities of Adult Social Care departments and cross cutting issues with Children's Services departments and NHS organisations.

1.3. Our members are jointly responsible through the activities of their departments for the well-being, protection and care of thousands of vulnerable people and for the promotion of that well-being and protection through the use of direct services as well as the co-ordination of, and liaison with the NHS, voluntary agencies, private companies and other public authorities.

⁴² Department of Health. *Shaping the Future of Care Together* (p. 50). July 2009

⁴³ Johnson DR, Nichol KL, Lipczynski K. Barriers to adult immunization. *Am J Med* 2008;121:S28-35

1.4. Our members have leadership responsibilities in Local Authorities to promote local access to services and to drive partnership working to deliver better outcomes for local populations. They participate in the planning of the full range of Council Services and influence Health Service planning through formal and informal Local Strategic Partnership arrangements.

2. BACKGROUND

2.1. Despite increased national prosperity, wider opportunity and increasing life expectancy for all, the gap in life expectancy and level of services between and within local authority areas and remains a major challenge. Added to this are the challenges of a changing demography, insufficient funding and escalating costs.

2.2 The challenges identified above have been recognised by Government and they set out their commitment to review long-term care, including funding, in the 2007 pre-budget Report and Comprehensive Spending Review. The Case for Change—Why England needs a new care and support system was subsequently published for consultation in May 2008.

2.3 “Putting People First” was published in December 2007 and was and is a shared Vision and commitment to the transformation of Adult Social Care over a period of three years. The key elements are prevention, early intervention and enablement, personalisation, information, advice and advocacy. ADASS was a co-signatory of the document which was a milestone in a partnerships protocol across government and the major social care organisations.

2.4 The Green Paper “Shaping the Future of Care Together” was published for consultation on 14 July 2009. It has a theme of making care fair, simple and affordable. ADASS welcomes the green paper’s themes. We expect that any new system that emerges must enhance the principles of Putting People First and result in fairer, quality driven services which help individuals take greater control of their lives and care budgets.

3. ROLE OF THE DIRECTOR OF ADULT SOCIAL SERVICES

3.1. Section 6 of the Local Authority Social Services Act 1970 was amended following the introduction of the Children Act 2004. The amendment requires a local authority with social services responsibility in England to appoint an officer as the Director of Adult Social Services (DASS).

3.2. In May 2006 the Department of Health issued Best Practice Guidance on the role of the Director of Adult Social Services. The intention of this guidance is to create, within each Council with social services responsibilities, a post with a strategic responsibility for the planning, commissioning and delivery of social services with all adult client groups.

3.3. The DASS has a leading role in delivering the Government’s wider vision for social care, including delivering better integration between a range of agencies responsible for supporting people with care needs and promoting wellbeing. The postholder champions the wellbeing of adults in the community and in residential care, provides professional leadership and delivers the cultural change necessary to implement person-centred services and to promote partnership working.

3.4. The DASS is responsible for supporting and promoting social inclusion and wellbeing by engaging with mainstream services and other local initiatives to support, build and enable community capacity and reduce inequalities. The DASS role is central in encouraging services to be designed around the needs of individuals, rather than dictated by organisational or professional boundaries—the DASS provides a specific focus on adults and this involves a role in championing the needs of adults that goes beyond the organisational boundaries of adult social care. There is a clear link to close working with PCTs and in particular Directors of Public Health, Commissioners and Providers in joint work to improve health and well-being.

In this context, the Association is pleased to submit the evidence below to the Health Select Committee Inquiry into Social Care.

4. THE INQUIRY—SOCIAL CARE

4.1. *The Inquiry is focussing on the options for:*

Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities.

Personalisation of social care services

More effective, consistent and user-friendly social care services.

4.2 ADASS recognises the need to reform our Adult Social Care and support system. We need a system which puts citizens at the centre of its focus, where basic elements of social care are available to all as an entitlement according to need and circumstances, carefully integrated with health, housing, community and other services, making sure that people are cared for and protected in a much fairer, quality driven way than is currently the case.

We need to recognise the scale of the demographic and social change facing us.

Demographic Change:

- Increased life expectancy: By 2026 population estimates show that there will be double the number of people aged over 85 that there are now and the number of people aged over 100 will have quadrupled.
- People are living longer with disabilities: A few decades ago children born with Down's syndrome would have expected to live into their mid-20s. Now they can live into their 50's : clearly a cause for celebration, but it also presents new issues we must as a society address
- More people with care needs: 1.7 million more by 2026.
- Economic impact: In the 1940s when the welfare state was established there were more than five people under 65 for every person over 65. Currently there are four people under 65 for every person aged over 65. By 2029 there are expected to be three people under 65 for every person over 65
- Social Change: Expectations are increasing

4.3 *Future Funding of Social Care:*

4.3.1 Despite many people thinking otherwise, funding for social care does not come solely from national taxation. The local government finance system is based in part on the relative resources a council can draw on, and services such as adult social care are funded through a combination of central and local government funding. In 2008–09, for example, the LGA estimates that councils will have to contribute 39%, or £5.3 billion, of the total projected cost of national social care spend—£13.8 billion. This is not just about councils having to make difficult trade-offs in their budgets—some councils already spend more on social care than their entire general grant from central government.

4.3.2 Revisiting the funding distribution method for social care will not only be crucial to the success of the system in the future but also the longer term sustainability of council budgets. Council tax will not be able to support the levels of expenditure that it would be required to support based on the current model of social care funding.

4.3.3 ADASS believes that a fairer funding settlement must consider the totality of money available in the current system. As supporting older and disabled people is about more than providing services delivered by adult care departments (and includes, for example, consideration of appropriate housing, leisure, transport and health services) there is a need to define what constitutes a local whole system budget.

4.3.4 This must include consideration of NHS funding. Social care expenditure is a fraction of total NHS spending. CSR07 revealed that NHS total baseline spending for 2007–08 was £90,352 million. Over the three years of CSR07, additional funding for the NHS will increase funding to £96,430 million, £102,897 million and £109,806 million.

4.3.5 If a fraction of this funding was spent on care and support in the community, aligned with social care spending, this would represent a significant increase in care and support locally. Allocating 10% of the additional NHS funding over CSR07 would provide £608 million, £1,255 million and £1,945 million to local care and support services over each of the next three years, and evidence is emerging that this investment would save spending elsewhere in the NHS.

4.3.6 The Green Paper “Shaping the Future of Care Together” outlines five options but puts forward three preferred ways to increase the available funding for adult social care—partnership, insurance and comprehensive. Any new system which emerges after the consultation must be open and transparent about costs and what people are entitled to receive wherever they live. It is premature to rule out the state funded option at this stage. Further thought needs to be given to the issue of citizenship and our collective offer to older people. The Green Paper also needs to focus much more on prevention and early intervention. There is a growing body of evidence to show the impact this can have—both in terms of allowing people to remain at home and lessening the costs to the NHS.

4.3.7 The Green Paper puts forward two models for a revised funding system—fully national and part local/part national. Clarity is needed by what is meant by “national” and what the funding arrangements will be. The paper is silent on the prospects of more state funding even though the options imply increased state expenditure and increased contributions from individuals. As it is largely about older people the green paper sets up the potential of two systems: care free to those of working age but a partnership approach for those over 65.

The national solution to funding would impact dramatically on council tax and the tax base. An alternative is for councils to determine the level of resources an individual requires and be funded depending on the model for the actual costs.

The issue of benefits also needs to be factored into the debate about funding.

4.3.8 The changed funding arrangements must not diminish the local elements of design and delivery of adult care and support services as this is important for:

- a. Providing councils with flexibility to commission and design care services around the needs of the service user;
- b. Supporting councils' ability to join up social care with health, housing and other systems to provide better outcomes for local people;
- c. Ensuring a responsive care and support system;
- d. Ensuring an accountable care and support system;

4.4 *Personalisation of Social Care Services*

More effective, consistent and user-friendly social care services

4.4.1 ADASS has been leading with the DoH the system-wide transformation of social care to deliver Personalisation. The DoH has funded a three year programme of change—we are in the second year. The five key priorities of the transformation agenda to be achieved by 2011 are:

- That the transformation of adult social care has been developed in partnership with existing service users (both public and private), their carers and other citizens who are interested in these services.
- That a process is in place to ensure that all those eligible for council funded adult social care support will receive a personal budget via a suitable assessment process.
- That partners are investing in cost effective preventative interventions, which reduce the demand for social care and health services.
- That citizens have access to information and advice regarding how to identify and access options available in their communities to meet their care and support needs.
- That service users are experiencing a broadening of choice and improvement in quality of care and support service supply, built upon involvement of key stakeholders (Councils, Primary Care Trusts, service users, providers, 3rd sector organisations etc), that can meet the aspirations of all local people (whether council or self-funded) wanting to procure social care services.

4.4.2 Personalisation means every person, across the spectrum of need, having choice and control over the shape of his and her support, in the most appropriate setting. It includes a strategic shift towards early intervention and prevention. The emphasis needs to be on enablement and early intervention to promote independence rather than involvement at a point of crisis. This needs to be a joint strategy with Health.

4.4.3 People can choose to have their own budget through the Personalisation agenda so that they do have choice and control over their care and support to help them achieve the outcomes that are important to them in the context of their whole life.

4.4.4 The Single Assessment process has not been fully embedded across the Health and Social Care System and needs to be in order to underpin this agenda.

4.4.5 Joint working across housing, transport, leisure and community safety are an integral part of the Personalisation agenda.

4.4.6 Joint working is of particular importance with the NHS. It is a mixed picture across the country. Where it works well it delivers:

- More appropriate care in the right setting
- Reduces costs through reducing hospital admissions
- Improves outcomes for citizens
- Keeps citizens healthier, more active and improves well-being

It needs to be achieved through joint performance measures not by structural change

4.4.7 Personal Health Budgets are a natural progression of personal social care budgets. The DoH began a pilot programme in March 2009. The aim of a personal health budget is to deliver better quality care, especially more responsive care, by enabling people to take more control over the way money is spent on their healthcare. The effectiveness of the pilot will be the decider of a national roll-out of personal health budgets.

4.5 *More effective, consistent and user-friendly social care services*

4.5.1 Good information, advice and advocacy are essential.

4.5.2 The needs of Carers must be an integral part of social care delivery. Their needs, as well as the cared for, must be met. There are at least 6 million carers in the UK, who provide unpaid social care.

4.5.3 Managing the social care market to ensure that there is high quality, accessible and responsive social care availability is essential—Social and Health Care Commissioners need to do this jointly based on the Joint Strategic Needs Assessment.

4.5.4 Crucial to the agenda is the need for a well trained, confident and competent workforce. Without investment in the workforce, the transformational change cannot happen. Working To Put People First: the Strategy for the Social Care Workforce in England identifies six key themes:

- Leadership
- Recruitment, retention and career pathways
- Workforce remodelling and commissioning
- Workforce Development
- More joint and integrated working
- Regulation for quality in services as well as public assurance

It is imperative that the workforce agenda is given high priority and resourced accordingly.

5. CONCLUSION

Social Care is essential to both support and protect the vulnerable to lead full and purposeful lives. Change though is clearly needed.

The change must however continue to deliver prevention, early intervention and enablement and personalisation if we are to deliver the Vision of “Putting People First”!

September 2009

Memorandum by Linda Pickard (SC 16)

THE FUTURE OF INFORMAL CARE AND ITS POTENTIAL IMPLICATIONS FOR SOCIAL CARE POLICY

EXECUTIVE SUMMARY

The aim of this submission is to draw the attention of the Health Committee to new information relating to the future of family care in England. The submission draws on a report carried out for the Strategy Unit (Cabinet Office) and Department of Health (Pickard 2008). The evidence suggests that around 250,000 disabled older people could be left without family care by 2041, opening up an unpaid “care gap” and potentially increasing demand for social care services. The submission discusses the implications of this evidence for social care policy in the context of the Government’s Green Paper on social care (HMG 2009) and latest announcement on free personal care (*Community Care* 2009).

INTRODUCTION

1. The research underlying this submission is concerned with informal or unpaid care provided by the adult children of older people. Over one in three disabled older people in England receives informal care from an adult child, yet the future supply of this form of care seems uncertain. The aim of the research is to compare the supply of informal care to its demand in future years.

2. The study produces projections of informal care for older people to 2041 in England. The analysis focuses on the supply of intense informal care provided for 20 or more hours a week and on demand for social care by disabled older people. Data sources include General Household Survey (GHS) data on both provision of informal care and receipt of care by people aged 65 and over. The research is part of a major study modelling ageing populations in future years, funded under the UK cross-council New Dynamics of Ageing Programme, the MAP2030 project (<http://www.lse.ac.uk/collections/MAP2030/>).

3. Full details of the research reported here can be found at <http://www.pssru.ac.uk/pdf/dp2515.pdf>.

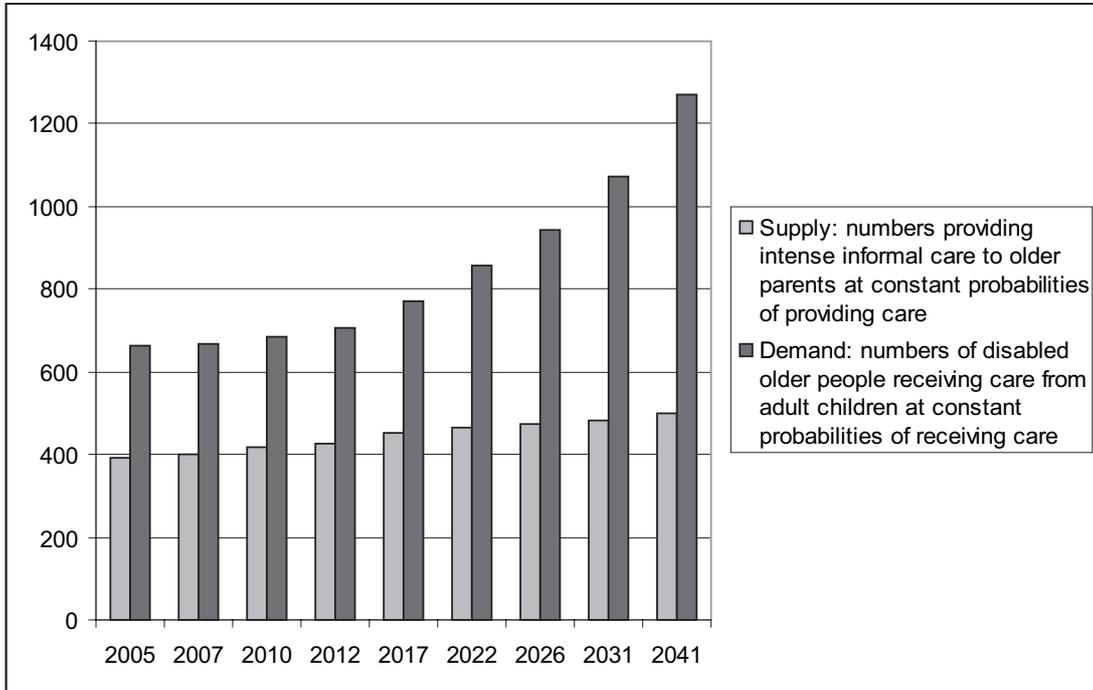
RESULTS

4. The results show that, on the assumptions used, the supply of intense informal care to disabled older people by their adult children in England is unlikely to keep pace with demand in future years (Chart One). On the demand side, currently around 600,000 disabled older people receive informal care from adult children and this is projected to rise by 90% to 1.3 million in 2041 (Wittenberg *et al* 2008). On the supply-side, there are currently 400,000 people providing intense informal care to parents and this is projected to rise by 27.5% to 500,000 in 2041 (Pickard 2008). Therefore, the care-receivers: care-providers ratio is projected to fall from 0.6 in 2005 to 0.4 in 2041 (Chart One).

5. This projected change will result in a shortfall of approximately 250,000 intense carers or 250,000 fewer disabled older people receiving intense informal care by 2041 (Chart Two). These results are obtained by comparing the projected increase in intense care provision to older parents, shown in Chart One, with the projected increase in this form of care provision if supply were to keep pace with demand (that is, if the current care-receivers: care-providers ratio stayed constant in future years).

6. The “care-gap” is primarily driven by demographic changes, in particular, rising old age dependency ratios.

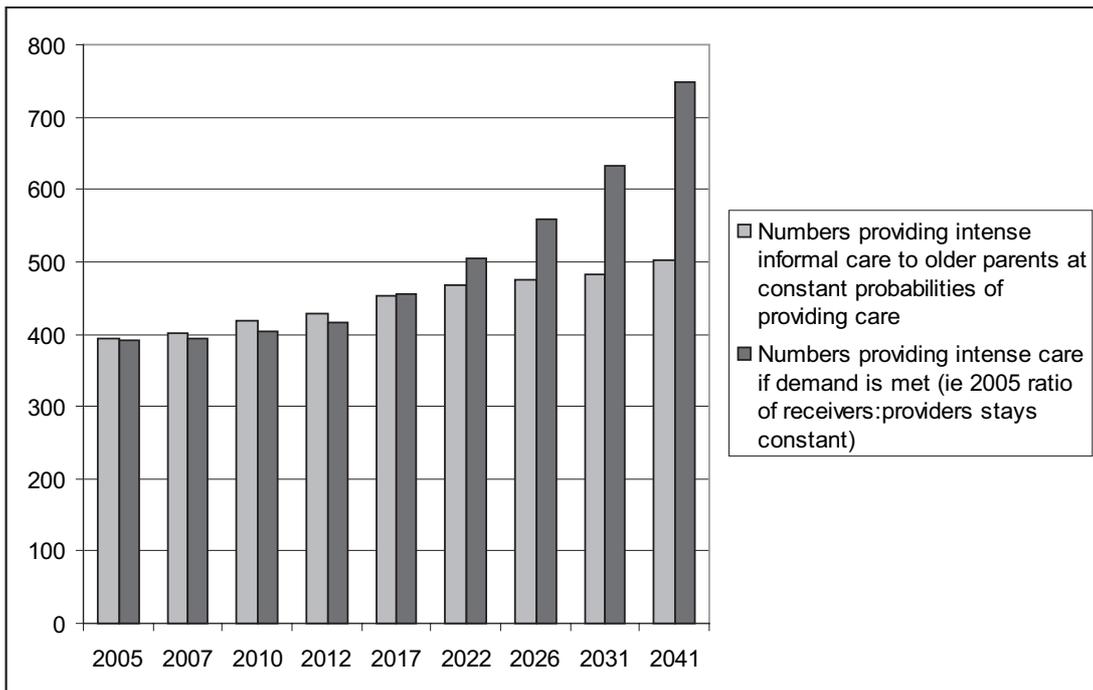
Chart One
Will the future supply of intense intergenerational care in England keep pace with demand for care by disabled older people?



Key sources: 2000–01 GHS, 2001–02 GHS , 2006-based Government Actuaries Department (GAD) population projections, 2003-based GAD marital status projections, 2001 Census, PSSRU modelling.

Note: Numbers are in thousands.

Chart Two
The “care gap”: difference between supply of intense intergenerational care & demand for care by disabled older people, England 2005–2041



Sources and notes: see Chart One.

POLICY IMPLICATIONS

7. The policy implications are that, to keep pace with demand, either more people will need to provide intense informal care or more formal services for disabled older people will need to be provided. Because the majority of people providing intense care to older parents are of “working” age and providing intense care is negatively associated with labour market participation, any increase in intense care provision may be associated with lower labour market participation. The “care-gap” may then have implications for demand for formal long-term care services for older people in future years.

8. The research raises questions about long-term care policies that rely heavily on informal care in future. The options proposed in the Government’s Green Paper vary in the extent to which they are likely to rely on informal care (HMG 2009: 17–18).

9. The “partnership” and “insurance” options are both likely to lead to heavy reliance on informal care. In the case of the “partnership” option, a quarter to a third of personal care costs would be publicly funded (HMG 2009: 17), leaving most care costs to be met by the individual. In this situation, many of those without sufficient financial resources to purchase care services would seek support from their families. In the case of the “insurance” option, the purchase of insurance would be voluntary (HMG 2009: 17) so that, where older people had chosen not to purchase insurance, then again many would seek support from their families. In the light of the evidence presented here, these options are likely to present problems in the future because informal care is unlikely to be available for substantially more disabled older people than at present and an inability to purchase care is likely to mean that substantial levels of unmet need will remain.

10. Only the “comprehensive” option proposed in the Green Paper would potentially reduce reliance on intense informal care and therefore protect against a decline in the availability of this form of care in the future. This is because it would ensure that everyone over retirement age with the resources to do so would pay into a state insurance scheme and would then receive care and support when they needed it (HMG 2009: 18). It is not clear, however, that a “comprehensive” option should necessarily be funded only by the resources of older people themselves, as is suggested in the Green Paper (HMG 2009: 18). There are many organisations representing older people who feel that tax-funding of social care should not be ruled out and that “costs must be shared fairly across the generations” (Age Concern and Help the Aged 2009; National Pensioners Convention 2009).

11. Most recently, the Prime Minister has announced a new policy of free personal care, to be introduced in the autumn of 2010 (*Community Care* 2009). According to information available at the time of writing, this proposal would apply to older people with the highest needs living in private households. If eligibility for free personal care was based on functional disability, this policy would reduce reliance on intense informal care and protect against a decline in the availability of informal care in the future.

REFERENCES

Age Concern and Help the Aged (2009) *Green Paper Sets out Reform Challenge* (ageconcern.org.uk/AgeConcern/release-care-green-paper-140709.asp, dated 14 July 2009 (Accessed 4 September 2009))

Community Care (2009) Gordon Brown makes free personal care pledge. *Community Care*, 29 September 2009.

HMG (HM Government) (2009) *Shaping the Future of Care Together*. Cm 7673. London: HMG

National Pensioners Convention (2009) *An Alternative National Care Service for Older People*. <http://www.npcuk.org/articles/Alternative%20National%20Care%20Service.pdf> (Accessed 29 September 2009)

Pickard L (2008) *Informal Care for Older People Provided by their Adult Children: Projections of Supply and Demand to 2041 in England. Report to the Strategy Unit (Cabinet Office) and the Department of Health*. PSSRU Discussion Paper 2515. London: PSSRU at LSE. <http://www.pssru.ac.uk/pdf/dp2515.pdf>

Wittenberg R, Pickard L, Malley J, King D, Comas-Herrera A, Darton R (2008) *Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care for Older People in England. Report to the Strategy Unit (Cabinet Office) and the Department of Health*. PSSRU Discussion Paper 2514. London: PSSRU at LSE. <http://www.pssru.ac.uk/pdf/dp2514.pdf>

Linda Pickard
Research Fellow
Personal Social Services Research Unit (PSSRU)
London School of Economics & Political Science

October 2009

Memorandum by A Dignified Revolution (SC 17)

SOCIAL CARE

1. EXECUTIVE SUMMARY

1.1. A Dignified Revolution (ADR) was founded by nurses appalled by declining standards in nursing care both in hospitals and in other settings, especially for older patients

1.2. In response to an article by a founder member of ADR, published in the *Daily Mail* in 2008, the organisation received 94 items of correspondence—nearly half of these from past or present nurses or other health professionals—detailing similarly harrowing experiences

1.3. Whilst many writers referred to bad attitudes and poor care in the hospital setting, several mentioned social care. In addition, other cases brought to the attention of ADR concern the treatment of older adults outside the hospital setting. They share numerous similarities. Analysis of the core themes from these e-mails is presented in this document.

1.4. A trained nurse indexed and analysed the 94 responses received according to the following criteria:

- The main issues/themes where care is failing
 - Reasons for lack of care, in view of letter writer
 - Lack of Tender Loving Care (TLC)/professionalism
 - Lack of physical care
 - Dangerous practice
- How things could be improved and glimpses of good care
 - Suggestions for improvement
 - Positive comments
- The resulting findings speak to the following two bullets from the Committee’s Terms of Reference:
 - Personalisation of social care services
 - More effective, consistent and user-friendly social care services

1.5. Results are as follows:

1.5.1. Lack of TLC/professionalism was cited by 34% of respondents and mostly related to bad attitude of nursing staff towards patients and their relatives

1.5.2. Poor physical care topped the league of complaints made in correspondence with ADR; overall, 87% of respondents wrote about this aspect and:

- 26% cited poor nutrition/hydration—rising to 28% when a disregard for special dietary needs is included
- 21% cited poor hygiene issues, of which 15% related directly to poor hygiene of the patient themselves
- 9% of patients were receiving inadequate or no pressure area care

1.5.3. Dangerous practice was reported by 12% of respondents.

1.6. What respondents recommend:

1.6.1. Of 41 respondents who gave reasons for declining standards, the vast majority (44%) cited the move from vocational to academic nursing training; 42% of respondents who made suggestions for improvement cited a return to vocational training as a solution to declining standards

1.6.2. 30% of respondents made positive comments about nursing standards, though these were usually qualified as being the exception

1.7. What ADR recommends:

1.7.1. That the Committee should consider the experiences of older adults using both social and health services holistically, since bad attitudes towards them and poor care are common to both settings. In fact, ADR is aware of significant issues of poor care at the interface between hospital and social care settings

1.7.2. That inquiries, as well as care, should be holistic and person-centred

1.7.3. That there should be a return to hands-on, vocational “on the job” training for health and social care professionals, instead of the current focus on university degrees and academic study

2. About *A Dignified Revolution* (ADR)

2.1. ADR is a group of individuals, the majority of whom are nurses, who want to improve the care of older people in hospital. It was launched in January 2008. The impetus to establish the initiative was driven by:

2.1.1. The distress that these individuals had experienced because of the poor care that their elderly relatives had received whilst in hospital, and their concern that others might find themselves in the same situation

2.1.2. The realisation that the lack of dignity and respect that older people tolerate when in hospital is not a recent phenomenon. The issue was first publicised in 1997. Ten years on, despite extensive media attention and numerous reports and guidance from government, little has changed

2.2. Many nurses provide outstanding care. However, the attitude and behaviour of other nurses when caring for vulnerable older people—be this in hospital or elsewhere—does not reflect the duty of care that they have towards their patients

2.3. Many of the poor experiences being shared are being reported by health professionals who work in various parts of the NHS and Social Care sector. The systems seems to inhibit them challenging practices which are demeaning their professions

3. INTRODUCTION TO OUR SUBMISSION

3.1. In December 2008 the Daily Mail published an article by a founder member of ADR. It was about the experiences of an elderly relative's hospital care. The article struck a chord with many readers who had seen and experienced similar examples of negligent, unprofessional and uncaring practice. As a result, 94 people wrote to ADR with their own examples of either being a patient in hospital or witnessing their loved one's distress.

3.2. Of these spontaneous respondents, nearly 50% were nurses or other health professionals (43 out of a total of 94), some retired but many still studying the profession or in employment. All of these individuals agreed with the sentiments expressed in the Daily Mail article with many of them offering support along with their own opinions of what they perceived to be contributory factors to the provision of poor care.

3.3. ADR considers that poor care of the type illustrated by these 94 unsolicited case studies is not confined to a hospital setting. Indeed, it has several examples on file of equally poor care in the context of the care home environment. In making this submission we ask the Committee to consider care provision for older people in the context of the individual and not by the setting—the common denominator is the older person and his or her needs rather than where these needs are being met. If personalised care is the goal, this principle should therefore drive all inquiries and related activities.

4. EXPERIENCES OF OLDER PEOPLE IN HOSPITAL

4.1. A trained nurse indexed and analysed the 94 responses received according to the following criteria:

- The main issues/themes where care is failing
 - Reasons for lack of care, in view of letter writer
 - Lack of TLC/professionalism
 - Lack of physical care
 - Dangerous practice
- How things could be improved and glimpses of good care
 - Suggestions for improvement
 - Positive comments

4.2. This memorandum presents some top-line key findings, supplemented by materials appended to the cover e-mail and listed at the end of this document. These speak to the following two bullets from the Committee's Terms of Reference:

- Personalisation of social care services
- More effective, consistent and user-friendly social care services

4.3. Lack of TLC/professionalism was cited by 34% (34/94) of respondents and mostly related to bad attitude of nursing staff towards patients and their relatives. Typical quotes include:

4.3.1. My mother died at home. When I called a night nurse because her breathing had changed she said "*there's no point in us coming, she's dying, there's nothing we can do.*"

4.3.2. I saw things happen to my mum while I was there and dread to think what they did to her when I was not there. She begged me not to make a fuss—she was terrified of the people who were supposed to be "caring" for her

4.3.3. She was in great pain from suspected bowel cancer and needed to lie flat—the nurse got her out of bed for a wash, ignoring her pleas not to, whilst telling her: “*the bed won’t make you better.*” She was also often left without her call button within reach, then told off when she consequently wet the bed

4.3.4. ...perhaps the worst sight was to see the young English nurses who smiled and appeared to show nursing skills and compassion, but as soon as it was just down to the elderly patients many of them just did little or nothing—for example chatting at the nurses station whilst patients begged for bed pans or a drink

4.3.5. The whole time dad was in that ward he was treated rudely by most, but not all of the staff. Above his bed was a large sign declaring that abusive behaviour from patients or relatives would not be tolerated. It said nothing about abusive behaviour by staff

4.3.6. Nurses that were too busy gossiping about boyfriends [sic] and holidays to give an elderly lady a drink of water. For two hours that lady cried, had I not been so ill I would have helped her myself

4.3.7. A couple of weeks went by and we were informed that mum could not return home and would need to go into residential care. I was devastated but both my sister and I started to look round residential homes. The one we chose was lovely, the staff were first class, but I was informed by the social worker that there wasn’t [sic] a place at that time and that we had four days to find somewhere before mum was discharged. I felt by this time we were being bullied and I told them under no circumstances would mum be discharged to anywhere but the chosen home. Suddenly a place was available!!

4.4. Poor physical care topped the league of complaints made in correspondence with ADR; overall, 87% (82/94) of respondents wrote about this aspect, of whom (worryingly, given recent extensive publicity on this issue):

- 26% (21/82) cited poor nutrition/hydration—rising to 28% when a disregard for special dietary needs is included
- 21% (17/82) cited poor hygiene issues, of which 15% (12/82) related directly to poor hygiene of the patient themselves
- 9% (7/82) of patients were receiving inadequate or no pressure area care

4.5. Dangerous practice was reported by 12% (11/94) of respondents. Some typical examples include:

4.5.1. ...she was concerned because the little old lady in the bed opposite could not reach the tablets left on the locker the night before...

4.5.2. That same day a nurse was feeding a lady in the bed next to Mum who needed encouragement to swallow and when this lady started to choke the nurse walked away and left her on her own!

4.5.3. I never saw a member of staff wash their hands or use the gunge-stuff despite containers on their belts, the bed, the ward sink, entrance etc.!!

4.5.4. ...one nurse had to be stopped by a doctor who told the nurse that the food was piling up in the patient’s mouth and she was not swallowing. The next day I overheard that that patient had pneumonia

4.5.5. I reported two colleagues for serious breaches of professional conduct. One was secretly obstructing administration of prescribed fluids to patients she thought would die anyway. “*Giving fluids is just killing them slowly*”, she called it

5. THE HEART OF THE PROBLEM

5.1. Of 41 respondents who gave reasons for declining standards, the vast majority (44%, 18/41) cited the move from vocational to academic nursing training. Unsurprisingly therefore, 42% (13/31) of respondents who made suggestions for improvement cited a return to vocational training as a solution to declining standards. Some typical comments include:

5.1.1. I found that nursing really changed for the worse, when nurses starting doing University courses. They appeared to spend so little time actually learning about the ability to be with patients. I have had NAMED nurses on admissions—NEVER to see them again! In the late 70s’ through to the end of the 80s’ I remember nurses having information on the underside of their aprons. They were given their daily report by SISTER, on ALL patients, not their so called NAMED patients

5.1.2. I feel what has been lost in Nursing is the idea of CARING. In becoming a more academic profession—and I have no complaints about that—something about the whole essence of the job of nursing has been completely lost

5.1.3. As I approach the end of my teaching career I now reflect on the changes that have occurred in the profession over the last few decades and wonder if the move into higher education has, in fact, benefited the profession. Compassion and caring, concern and attention to detail do not require diplomas and degrees

5.1.4. I think until you bring back the SEN and the SRN you will continue to have those NURSES who think that they are too important to do things with REAL PEOPLE

5.1.5. I support any initiative that encourages nurses to focus on the traditional areas of care and attention but am not holding my breath

5.1.6. Sadly what happened to your aunt is, and will continue to happen, unless, in my opinion, matron is brought back to the wards

5.1.7. Nurses can't [sic] be trained in universities. Nurse training needs to go back to the school of nursing run by trained nurses

5.1.8. Universities spend a lot of time teaching skills in a plastic setting, our only experience comes from placements. At University, academically we are encouraged to use reflective writing skills to enhance our learning, something which I am struggling with, I would rather spend time with "real" patients than spending hours writing reflections, I am sure I can learn more from being with a patient than what I would gain out of writing about my thoughts and feelings. I want to be a good nurse, and I want to be there for my patients

5.1.9. What can we do? How can we raise the standard of patient care to the level at which we were taught? Simple, give the training back to the hospitals. Take nurse education out of universities. Project 2000 (I think that's what it was called?) is a nonsense! Once a nurse has the RGN qualification from their hospital then—if they want to specialise—they can go to University to study further. But the basic, all-important nurse training must be given back to the hospitals. It inspires loyalty and on-the-job training that is much more relevant than learning from a distance in a university lecture hall. Then nurses might not think themselves too grand to empty a bedpan. You cannot "degree" caring

5.1.10. I am hoping to advertise locally to the care sector the R.C.N course as I feel having visited many care establishments in the [sic] course of my work that whilst't [sic] there are is [sic] good training being carried out I feel there are some poor practises [sic] also being taught. Although the NVQ programme [sic] has units which cover Dignity and should meet the standards unfortunately the method of some training persons leaves quite a lot to be desired and I feel this is a good place to start improving dignity and all that relates to it

6. GLIMMERS OF HOPE

6.1. Encouragingly, 30% of respondents made positive comments about nursing standards, though these were usually qualified as being the exception and often followed a battle for better care. Examples include:

6.1.1. Thankfully there have always been a number of dedicated nurses who give one hope, and are beacons in an otherwise bleak landscape. Ironically these nurses are actually quite ordinary in that essentially they perform role for which they are trained. But such is the paucity of care; their commitment to their profession stands out

6.1.2. After many months of chasing a meeting was arranged for me to meet with various people at the hospital. It was acknowledged that the hospital fell down badly in this instance and yet another apology was given. My aim was to get things changed so that this did not happen to other patients. The outcome of this meeting was that a new menus [sic] is now in place and that there are now allegedly chefs to prepare food for patients with special dietary needs. Also regimes are in place to assist patients who need it to eat also the nursing practices are to be reviewed

6.1.3. There were some good nurses and care assistants and I was grateful for these people. They were usually older, I noticed

6.1.4. ... I would like to commend the nursing staff who cared for me. During a recent admission their courtesy and professionalism [sic] shone. I would also thank the social work team for their excellent efforts on my behalf, producing unexpected and pleasing results

6.1.5. It was a great relief when Mum was transferred to a Sue Ryder Home where she received the kindest, most efficient care possible, we cannot thank the nurses and staff enough, they are amazing

6.1.6. Mum seemed very happy at the home and the staff were fantastic with her, they would sit and talk to her and made sure she was comfortable

7. ADR RECOMMENDATIONS

7.1. While the Committee's Terms of Reference are restricted to consideration of social care services, ADR believes that issues surrounding care of older people cannot be constrained by boundaries. Older people's experiences of health and social services share a common denominator of impersonal treatment and bad attitudes, and these issues can only be addressed holistically

7.2. ADR therefore advises the Committee to consider the following two bullets from its terms of reference in the essential context of all services with which older adults have contact, as relevant issues concerning personalisation, consistency and accessibility are common to these:

- Personalisation of social care services
- More effective, consistent and user-friendly social care services

7.3. Better vocational training instead of university-oriented academic qualifications and more "joined up working" across health and social care are urgently needed and would benefit older people and their families. Zero tolerance for bad attitudes towards older people should be implemented by all professionals and indeed, by everyone who sees it

8. SUPPLEMENTARY INFORMATION

8.1. The following documents have been appended to the same e-mail as this submission memorandum:

- Uncaring. Slovenly. Some of our nurses are a disgrace (... and I can say it, because I'm a nurse myself) <http://www.dailymail.co.uk/health/article-1091005/LORRAINE-MORGAN-Uncaring-Slovenly-Some-nurses-disgrace---I-say-Im-nurse-myself.html>—copy of the Daily Mail article which initiated the responses and subsequent analysis presented here
- Food and drink: the basic requirements of life—written from Daily Mail correspondence
- Good personal hygiene: a basic human need, fundamental to health and well-being and essential to reduce the risk of hospital acquired infections—written from Daily Mail correspondence
- Growing old in Britain—Maria's Story.pdf—an example of one of the case studies ADR holds on file, which spans both social and health care issues and exemplifies the commonalities

October 2009

Memorandum by the United Kingdom Homecare Association (SC 18)

SOCIAL CARE

EXECUTIVE SUMMARY

1. UKHCA is the professional association of homecare providers from the independent, voluntary, not-for-profit and statutory sectors. Our written evidence to the Health Committee largely focuses on the challenges facing the independent homecare sector and the implications these will have for the future of social care. The challenges fall under three headings: workforce issues, commissioning issues and personalisation issues.

2. Workforce issues:

- The average rate of pay for a homecare worker in England is just £6.80 an hour. This headline figure masks considerable regional differences. For example, the average rate of pay in the North East of England is only £5.85 an hour. Can we therefore be surprised that for the whole of England homecare has—at 24.9%—the highest staff turnover of all care services?
- A major reason for low pay in the independent sector is that local authorities act a near monopsony (a single buyer) for the purchase of homecare in their local area. Because of this they can exert a downward pressure on independent providers' prices, impeding their ability to pay wages sufficient to ensure adequate recruitment and retention of staff.
- The Low Pay Commission has recommended on four separate occasions that the Government ensures that the commissioning policies of local authorities and the NHS reflect the actual costs of social care, including the National Minimum Wage. The Government has accepted the recommendation, though we have yet to hear of any firm proposals from the Department of Health on how this will be taken forward.

3. Commissioning issues:

- Providers are coming under increasing pressure from local authority commissioners exercised by efficiency savings and reducing costs of services; a pressure likely to grow as local authorities attempt to pass on reductions in social care funding because of the current economic downturn. Annual contract price reviews already barely recognise homecare providers' additional statutory costs.
- There is a pattern emerging of E-tendering processes, with local authorities employing a "Dutch auction" approach, where care contracts are won by the lowest bidder. This then impacts on pay levels and exacerbates recruitment and retention difficulties.
- In England, Wales and Northern Ireland a new vetting and barring scheme will be introduced in phases from 12 October 2009. The membership fee will be £64 per careworker in England and Wales, and £58 in Northern Ireland. Local authorities are unlikely to recognise this new regulatory burden in their contract prices, creating a disincentive for employers to pay their workers' fees, with the potential to impact on recruitment and retention further.

4. Personalisation issues:

- There are significant risks and threats for homecare providers from personalisation. Organisations that have been largely dependent on local authority purchasing may lose contracts across the board, leading to a rapid reduction in guaranteed volume and therefore income. For many, this loss of income could lead to closure.
- The low level of direct payments paid by some local authorities limits the ability of service users to buy care from a regulated provider unless they can afford to "top up" their care.

- As a consequence, service users are directly employing people or poaching the care worker introduced to them by their homecare agency. They are able to do this because they incur none of the agency's overheads for training, registration and regulation. Self-directed employers are not required to provide training for their staff or to carry out security checks.
- It seems entirely illogical that government should have brought about a highly regulated sector in 2002, with proposals for further regulation while, at the same time, promoting a cash payment system for the engagement of untrained, unqualified, unsupported and unregulated personal assistants

5. The Green Paper *Shaping the Future Together*

- The success of the new care and support system as outlined in the Government's Green Paper will be dependent on it working effectively, irrespective of what ever funding system is in place. However, the structure of the care and support system is not creating the right circumstances for local homecare services to thrive.

SUBMISSION

1. We welcome this opportunity to submit written evidence to the Health Committee's inquiry into the future of social care services. UKHCA is the professional association of homecare providers from the independent, voluntary, not-for-profit and statutory sectors. The association represents over 1,800 organisations across the United Kingdom.

2. The independent sector is the major provider of state funded homecare. It is the largest employer of the homecare workforce, with around 274,000 people employed in the sector (compared with around 48,000 local authority employees).⁴⁴ The sector has grown from providing just 5% of state funded care in 1993 to its current level of providing 81% of state-funded care.⁴⁵

3. Homecare is an important service for many people. In 2007–08, an estimated 577,000 people and over in England received homecare arranged through their local authority.⁴⁶ The independent sector and its workforce therefore have a crucial role in frontline delivery of services.

4. We do not wish to comment on the future funding of homecare services for older people or the various funding options presented in the Government's Green Paper *Shaping the Future of Care Together*, as all raise major issues of fairness and equity outside UKHCA's role as a professional association. However, we recognise that significantly more funding is required to address the urgent demographic challenge the country is facing and to ensure that people who use services receive genuine choice about their personal care. What providers need above all else from the reform of social care is security of demand for the services they supply, which will allow them to plan and deliver suitable services.

5. Instead, our submission focuses largely on the challenges facing the independent homecare sector and the implications these challenges have for the future of social care. The challenges fall under three headings: workforce issues, local authority commissioning issues and personalisation issues.

WORKFORCE ISSUES

6. Despite the centrality of the workforce to high quality care, Skills for Care data has found the average rate of pay for a homecare worker in England is just £6.80 an hour.⁴⁷ This headline figure masks considerable regional differences. For example, the average rate of pay in the North East of England is only £5.85 an hour.⁴⁸ A report by the Social Care Employers Consortium has recently found that voluntary sector careworker wages lag behind other public services such as refuse collection or road sweeping.⁴⁹ Can we therefore be surprised that for the whole of England homecare has the highest staff turnover of all care services—at 24.9%—meaning that providers have to replace their entire workforce every 3.5 years?⁵⁰

7. A major reason for low pay in the independent sector is that local authorities act as a near monopsony (a single buyer) for the purchase of homecare in their local area. Because of this they can exert a downward pressure on independent providers' prices.⁵¹ Also, local authorities do not always increase the prices they pay to homecare providers in line with inflation, new legislation or the minimum wage. A survey by the Low

⁴⁴ The State of the Adult Social Care Workforce in England, 2008, Sills for Care (2008). P.33–35. www.sillsforcare.org.uk/view.asp?id=977

⁴⁵ Community Care Statistics 2007, Home care services for adults. NHS Health and Social Care Information Centre (2008). p.4. <http://www.ic.nhs.uk/webfiles/publications/Home%20Care%20%28HH1%29%202008/HH1%20Final%20v1.pdf>

⁴⁶ Community Care Statistics 2007–08. Referrals, Assessments and Packages of Care for Adults, England. National Summary, NHS Health and Social Care Information Centre (2008), p6. <http://www.ic.nhs.uk/webfiles/publications/Social%20Care/RAP%20National%20Summary/Final%20National%20Summary%20Report.pdf>

⁴⁷ Skills for Care. NMDS-SC briefing Issue 8—pay. (2009), p3. <https://www.nmds-sc-online.org.uk/Get.aspx?id=184207>

⁴⁸ nmds-sc briefing, Issue 8—Pay. p.4. Skills for Care. <https://www.nmds-sc-online.org.uk/Get.aspx?id=184207>

⁴⁹ Social Care Employers Consortium. Social Care—Has Anything Changed? (2008). scec.rowan.tincan.co.uk/SOCIAL%20CARE%20%20Has%20Anything%20Changed%202008.doc

⁵⁰ Skills for Care. "NMDS-SC Briefing, Issue 2—Turnover and Vacancy Rates". (2007). www.nmds-sc-online.org.uk

⁵¹ For more information on the dominant purchasing power of local authorities and the downward pressure on prices see Media Briefing 1: Homecare Providers England.

Pay Commission found that social care was the least successful sector providing services to the public sector in negotiating their contracts with local authorities over the October 2007 increases in the minimum wage, with two-thirds reporting an unsuccessful result.⁵²

8. The Low Pay Commission has recommended on four separate occasions (2005, 2007, 2008 and 2009) that the Government ensures that the commissioning policies of local authorities and the NHS reflect the actual costs of social care, including the National Minimum Wage.⁵³ This year, the Government has accepted the recommendation,⁵⁴ though we have yet to hear of any firm proposals from the Department of Health on how this will be taken forward.

9. Increasingly homecare staff are being asked to undertake complex tasks and medication related activities that were previously the domain of District Nurses. Regrettably, there's little appetite among local authorities for rewarding providers who supply careworkers who have achieved a National Vocational Qualification (NVQ) in health and social care. This further limits providers' ability to reward their staff with an enhanced wage rate, with the gain for qualified workers unlikely to exceed 5% of their colleagues at entry level.⁵⁵

10. Meanwhile, local authorities have proved themselves an unreliable distributor of national training grants. In 2006–07, the majority of the National Training Grant—63%—was spent on local authority staff and there was a £26 million under-spend.⁵⁶ Since April 2008 such grants are not ring-fenced and may be used for other local priorities than social care, so there is even less of a guarantee that national money will be used for training the social care workforce.

11. Ultimately the flux in the workforce is costly in terms of the recruitment and induction costs for social care staff but also fails to provide the continuity of care which is so valued by service users. It also prejudices the completion of qualifications, reducing the effectiveness of training funding. The cost of the required training package for a new careworker is likely to be around £980.⁵⁷ Averaging these investment costs and turnover across the social care sector, the annual loss to the sector is £78 million.

LOCAL AUTHORITY COMMISSIONING ISSUES

12. Providers are coming under increasing pressure from local authority commissioners exercised by efficiency savings and reducing costs of services; a pressure likely to grow as local authorities attempt to pass on reductions in social care funding because of the current economic downturn.

13. If discussions do take place between providers and commissioners, they centre on how providers can aid authorities to achieve annual “Gershon review” savings of 2.5%, rather than how providers can contribute to the personalisation agenda. However, Sir Peter Gershon's review of public sector efficiency was never designed as a way of cutting back on front line services, but rather to set out the scope for further efficiencies within the public sector's back office, procurement, transaction service and policy making functions.⁵⁸

14. Annual contract price reviews are barely recognising homecare providers' additional statutory costs. In 2007, UKHCA's survey of local authorities indicated that 38% would not be implementing any contract increase, despite new statutory holiday entitlement from October 2007 alone estimated to add 2% to the wage bill.⁵⁹

15. In England, Wales and Northern Ireland a new vetting and barring scheme will be introduced in phases from 12 October 2009. The membership fee will be £64 per careworker in England and Wales, and £58 in Northern Ireland, with all care staff phased into the scheme over five years from November 2010.⁶⁰ There was no public consultation on the proposed costs of the scheme.

16. It is significant that the costs of the Vetting and Barring scheme are payable by the worker themselves. We estimate that the additional cost to the workforce (or providers who choose to pay the costs on behalf of their workers) is an additional £18 million over five years, above those already incurred. A similar scheme is proposed in Scotland for introduction at a yet unspecified date in 2010, and scheme membership costs have not yet been announced.

⁵² *National Minimum Wage Low Pay Commission report 2009* (2009). p.285. <http://www.lowpay.gov.uk/lowpay/report/pdf/7997-BERR-Low%20Pay%20Commission-WEB.pdf>

⁵³ *National Minimum Wage Low Pay Commission report 2009* (2009). p.74. <http://www.lowpay.gov.uk/lowpay/report/pdf/7997-BERR-Low%20Pay%20Commission-WEB.pdf>

⁵⁴ Press release 12 May 2009. Government Approves New £5.80 Minimum Wage Rate. Department for Business Enterprise and Regulatory Reform. <http://nds.coi.gov.uk/environment/fullDetail.asp?ReleaseID=401122&NewsAreaID=2&NavigatedFromDepartment=True>

⁵⁵ Skills for Care. “NMDS-SC Briefing, Issue 3—Pay”. (2007). www.nmds-sc-online.org.uk

⁵⁶ Skills for Care, *The State of the Adult Social Care Workforce* (2008). P.11 www.topssengland.net/view.asp?id=977

⁵⁷ Skills for Care. NMDS-SC Briefing, Issue 2—Turnover and Vacancy Rates. (2007). P.1 www.nmds-sc-online.org.uk

⁵⁸ *Releasing resources for the frontline: Independent Review of Public Sector Efficiency*, H.M. Treasury (2009). P42. http://www.hm-treasury.gov.uk/d/efficiency_review120704.pdf

⁵⁹ A fair price for homecare, UKHCA media release (2007). www.ukhca.co.uk/mediastatement_information.aspx?releaseID=22

⁶⁰ The figure excludes the administrative charge made by Umbrella Bodies for carrying out criminal record checks

17. This is an “individual” one-off registration fee that follows the worker in their career with vulnerable adults and children, but it is a considerable amount in a low paying sector and staff will inevitably look to their employers to help them pay the fee. We are extremely pessimistic that local authorities will recognise the burden of registration fees in their contract prices, creating a disincentive for employers to pay their workers’ costs.

18. If local authority commissioners do not recognise these costs in their contracts, homecare workers may have to pay for their own registration costs. This has the potential to impact severely on homecare worker recruitment and retention even further and as a “flat fee” unrelated to income will have a greater impact on poorer paid sections of society.

19. Other “cost saving” mechanisms used by local authority commissioners include only paying for contact time—sometimes only by the minute—or using short care episodes of 15 minutes for personal care. This will inevitably impact on the wellbeing and job satisfaction of the workforce, and satisfaction with care received. These cost saving approaches limit the ability of the workforce to adopt a more proactive and enabling role.

20. It also limits providers’ ability to pass on higher wage costs for careworkers undergoing training, or travelling between clients, as they are only able to derive fees for billing for services provided. If the price paid genuinely does not take into account the cost of provision, and providers are forced to not pay staff for training, or ask them to pay for their own criminal records bureau disclosure checks (£36 per person), they are then pilloried for being complicit in bad practice or in it “for the money”.

21. The result is a workforce which is typically pay sensitive, characterised by an undesirable “churn” as workers change employers for relatively small increases. This is costly in terms of the recruitment and induction costs for care staff but also fails to provide the continuity of care which is so valued by service users. It also prejudices the completion of qualifications such as NVQ’s, thereby reducing the effectiveness of training funding.

22. The Gershon efficiency agenda also plays out in market management practices with two patterns emerging at odds with the Government’s personalisation agenda. Firstly, there has been a distinct trend amongst local authorities re-tendering block contracts to reduce the number of providers with which they trade and keep a downward pressure on prices, as part of efficiency savings. Ultimately people may find that the suite of services and expertise of workforce available to them are lost under this rationalisation agenda.

23. Secondly, there is a pattern emerging of E-tendering processes, employing a “Dutch auction” approach, where care contracts are won by the lowest bidder. E-auctions are a particular problem for small and medium enterprise homecare providers who may feel that their survival is based entirely on the public sector purchaser and that they are effectively forced into winning the contract at any price however low. This then impacts on pay levels and exacerbates recruitment and retention difficulties.

24. Where contracts for homecare services are re-let following re-tenders, there appears to be an unrealistic expectation that careworkers will migrate en masse to employment with successful contractors. This is not necessarily the case, and can be a significant barrier to the retention of workers and has the potential to destabilise the local care economy.

PERSONALISATION ISSUES

25. UKHCA was a signatory to *Putting People First* and we support the delivery of more personalised services. However, it is important to recognise there are significant risks and threats for home care providers from the Government’s plans for transforming social care. Until now have been little acknowledged but could potentially have important unintended consequences for the sector. At its most extreme, it “*could spell large-scale destruction of the sector.*”⁶¹

26. Organisations that have been largely dependent on local authority purchasing may, within a relatively short period of time, lose contracts across the board, leading to a rapid reduction in guaranteed volume and therefore income. The Commission for Social Care Inspection (succeeded by the Care Quality Commission in April 2009) estimates that 78% of independent sector homecare providers’ business is from local authorities.⁶² For many, this loss of income could lead to closure.

27. A critical question is the impact that the changes will have on social care capacity. There is no guarantee that staff will move to other providers when agencies close. They may move out of social care altogether, thereby reducing overall capacity. Even where providers survive, some of the planned changes may make staff retention more difficult. Public sector contracts make it possible for providers to guarantee their front-line staff at least some work.

28. With the possibility of these guarantees gone or reduced there is likely to be more instability in the social care labour market and an increase in the churn of workers between employers. There is also likely to be less overall work on offer and possibly more fluctuation, which may lead to some careworkers being lost to the industry.

⁶¹ L. Sawyer (2008) *The personalisation agenda: Threats and opportunities for domiciliary care providers*, in *Journal of Care Services Management*, Vol. 3, No.1, pp 41–63, Henry Stewart Publications. <http://www.ukhca.co.uk/members/pdfs/personalisationagendaLS.pdf>.

⁶² *Time to Care?* Commission for Social Care Inspection (2006), p28. No longer available to download from CQC website.

29. One consequence of moving to self-directed care is that formal domiciliary care providers may lose staff to direct payment users. There is much anecdotal evidence that this is already happening. Providers say that the direct payment rates received by service users who have previously been their clients are usually not enough to enable them to continue to purchase their agency's service.

30. A UK wide survey of direct payments has found substantial variation in the rates paid to service users, with many local authorities stating that payment rates were lower than the average costs of homecare providers. The surveyors found the average hourly direct payment rate to an older person in England was £8.70.⁶³ This limits the ability of service users to buy care from an independent provider unless they can afford to "top up" their care, ironic given the principle of direct payments is to extend service user choice.

31. As a consequence, some service users are directly employing the care worker introduced to them by their homecare agency. They are able to do this because they incur none of the agency's overheads for training, registration and regulation. Self-directed employers are not required to provide training for their staff or to carry out security checks.

32. It seems entirely illogical that government should have brought about a highly regulated sector in 2002, with proposals for further regulating by the General Social Care Council (GSCC) and Independent Safeguarding Authority (ISA), while at the same time, promoting a cash payment system for the engagement of untrained, unqualified, unsupported and unregulated personal assistants

THE GREEN PAPER *Shaping the Future Together*

33. The Green Paper says that to make the social care reforms a reality any new system will be dependent on a number of factors including developing the workforce, personalisation of services, more joined up services and changing people's mindsets. Also, local authorities will need to take the lead in things like market shaping, helping private sector organisations adjust to a different way of responding and having good commissioning practices. In effect, the success of the new care and support system will be dependent on it working effectively, irrespective of what ever funding system is in place.

34. As discussed above, we do not believe that the structure of the care and support system is creating the right circumstances for local homecare services to thrive. In particular, local authority commissioners are exerting pressure on independent providers to reduce their costs and make efficiency savings while at the same time annual contract price reviews barely recognise additional statutory and regulatory costs, thereby limiting their ability to reward their staff and develop the workforce.

October 2009

Memorandum by the Parkinson's Disease Society (SC 19)

FUTURE OF SOCIAL CARE SERVICES

1. SUMMARY

We would like to highlight the following areas for particular attention:

- The PDS would like to highlight the flexibility provided to people with Parkinson's by Attendance Allowance and other disability benefits. It is important that these benefits are not lost in seeking ways to fund social care in the long-term
- There is a clear need for better information and signposting to social care services
- Long waits for aids and equipment needs to be addressed as a priority
- There is a need for ongoing support for all people with a long-term condition, with an identified point of contact.

2. ABOUT THE PARKINSON'S DISEASE SOCIETY

2.1 Parkinson's Disease Society (PDS) was established in 1969 and now has 30,000 members and over 330 local branches and support groups throughout the UK. It provides support, advice and information to people with Parkinson's, their carers, families and friends. It also provides information and professional development opportunities to health and social services professionals involved in their management and care.

2.2 This year, the Society is expected to spend £4 million on research into Parkinson's Disease. The Society also develops models of good practice in service provision, such as Parkinson's Disease Nurse Specialists, community support, and campaigns for changes that will improve the lives of people affected by Parkinson's.

⁶³ Direct Payments Survey: A national survey of direct payments policy and practice, Personal Social Services Research Unit. (2007). P.57 www.pssru.ac.uk/pdf/dprla.pdf

ABOUT PARKINSON'S DISEASE

2.3 It is estimated that 120,000 people in the UK have Parkinson's. Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden "freezing".

2.4 Parkinson's affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson's is between 50–60 years of age, though one in seven will be diagnosed before the age of 50 and one in 20 will be diagnosed before the age of 40.

ISSUES AND EVIDENCE

3. *Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities*

3.1 The PDS recognises that in order to secure an acceptable level of social care services in the long-term future, additional sustainable funding must be identified. We do not have a preference as to how this additional funding should be achieved, though we are currently surveying members about their views of the options put forward by the government in the social care Green Paper and would be pleased to submit the results of this consultation to the Committee as additional evidence later this year.

3.2 However, the PDS is extremely concerned at proposals in the Green Paper to abolish Attendance Allowance to help pay for care. We know how important this benefit is to maintaining the independence of people with Parkinson's, giving people the flexibility they need to meet the additional costs of their disability. In effect, Attendance Allowance is the perfect direct payment, and is one of the strongest elements of the existing care and support system.

3.3 Attendance Allowance is also clear and transparent—if the claimant can demonstrate sufficient incapacity they will get benefit and be paid at the same rate wherever they live in the UK, avoiding the local inconsistencies that people experience in social care. Because it is non means tested, people know the exact amount they will qualify for if they meet criteria.

3.4 It is essential that the future care system builds on the positive benefits of Attendance Allowance and incorporates these advantages into any new system.

4. *More effective, consistent and user-friendly social care services*

4.1 The All Party Parliamentary Group for Parkinson's disease recent Inquiry report⁶⁴ highlighted inconsistencies in access to health and social care services across England, Wales and Northern Ireland.

4.2 We welcome the commitment by the current Government to introduce a National Care Service, that would deliver a system of care and support across England "which is not subject to a post code lottery."⁶⁵ Addressing the post code lottery in social care is an important commitment that we would like to see taken up by all political parties and we look forward to scrutinising the detail of the Government's proposals in the forthcoming White Paper.

5. *Provision of information*

5.1 The APPG for Parkinson's disease Inquiry identified poor information provision and signposting to services, especially with regard to signposting to social care support. The Inquiry Report⁶⁶ highlighted the need for health professionals working with people Parkinson's to provide information about relevant social care services and how to access these. It recommended that commissioners of health and care services must be required to provide information and signposting, with effective monitoring to ensure that this is delivered.

5.2 The PDS members' survey⁶⁷ highlighted the impact of this poor information on people with Parkinson's and their carers. For example, over half (52%) of carers identified "getting expert advice on health and social services"; as "very important", but only a fifth (20%) were actually receiving this, and only a third of carers were aware of their right to a carers' assessment.

5.3 There is a clear need for an improved structure for ensuring that people know where to go to receive information and signposting to services, including support for those organising their own care, with a clear point of contact for every client.

⁶⁴ *Please mind the gap: Parkinson's disease services today*, All Party Parliamentary Group for Parkinson's Disease, 2009.

⁶⁵ Prime Minister and Leader of the Labour Party Gordon Brown; speech to the Labour Party conference, 29 September 2009.

⁶⁶ Please mind the gap, *op cit*

⁶⁷ *Life with Parkinson's today—room for improvement*, Parkinson's Disease Society, 2008.

6. *Equipment and aids to daily living*

6.1 The APPG for Parkinson's disease Inquiry report highlighted the benefits of aids and adaptations in enabling individuals to maintain independence and continue living in their own homes.

6.2 Long waits for aids and equipment has been identified by people with Parkinson's as a major problem in many parts of the UK, which can result in deterioration in the health of the person with Parkinson's. We also frequently hear from carers who have developed back problems through having to manage whilst waiting for hoists to be fitted.

6.3 The PDS members' survey found more than one in ten (11%) respondents felt that their home was not suitable for them, 7% reported that stairs or steps were a problem and 4% needing other adaptations. The survey also found that many people with Parkinson's are purchasing their own equipment, and many of these were doing so without advice. For example, of the 41% of respondents who had purchased bathroom aids, over half had done so without professional advice.

6.4 Quality Requirement 7 of the NSF for long-term neurological conditions relates specifically to providing equipment:

6.5 "People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life."

6.6 However, the evidence from our members' survey and the APPG Inquiry report demonstrates that this is not being delivered in many areas. Proper implementation of existing policy drivers, such as the NSF, is essential. The PDS supports the APPG for Parkinson's disease's call for a review of the NSF for Long-term (Neurological) Conditions to measure progress made towards implementation at its half-way point, against its 11 quality requirements for health and social care.

7. *Need for ongoing support for people*

7.1 We would also like to see ongoing support and regular review of all people with an identified long-term condition. People with Parkinson's tell the PDS that they lose all contact from their social services after a one-off intervention, such as a respite break or the provision of a piece of equipment, and in many cases they are not given a named contact and phone number to call in emergency.

October 2009

Memorandum by the Alzheimer's Society (SC 21)

FUTURE OF SOCIAL CARE SERVICES

Alzheimer's Society is the leading care and research charity for people with Alzheimer's disease and other forms of dementia, their families and carers. It is a national membership organisation and works through nearly 230 branches and support groups. The Society has expertise in providing information and education for people with dementia, carers and professionals. It provides a helpline and support for people with dementia and carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia. We are pleased to be able to respond to the Health Committee's inquiry into the future of social care services.

EXECUTIVE SUMMARY:

- The impact of dementia is vast and will only grow. There are 700,000 people with dementia in the UK and this is forecast to increase to 940,110 by 2021 and 1,735,087 by 2051.⁶⁸ All aspects of the social care system must support and address the needs of people with dementia.
- Two thirds of people with dementia live in their own homes in the community and one third live in residential care.⁶⁹
- Early intervention in dementia offers an excellent opportunity to provide much higher quality care and deliver efficient spending.⁷⁰ These are central concerns in the current economic climate. At present, the majority of dementia services are skewed towards those with higher needs when more intensive support is needed, which necessarily comes at a higher price.
- Better dementia services promise value for money. The National Audit Office (NAO) 2007 report on dementia highlighted that significant money is wasted because the response to dementia has

⁶⁸ Alzheimer's Society (2007) *Dementia UK*, a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society: London.

⁶⁹ *Ibid.*

⁷⁰ National Audit Office (2007) *Improving services and Support for people with dementia*: London.

- been inadequate. The NAO report due in November will come to similar conclusions. Improvements to the quality of dementia care and services could shift care closer to people's homes, promote a more integrated approach, and potentially yield efficiency savings.
- People with dementia are big users of social care services.⁷¹ Because the majority of the package of care that people with dementia receive is typically provided through local authorities and is means tested, people with dementia end up paying significant amounts towards their care and often for a long period of time. They deserve high quality care at a fair price.
 - An effective, rigorous regulation system is an essential part of promoting and supporting good quality care for people with dementia. Currently the Society is very concerned that the compliance guidance from the Care Quality Commission will not assure good quality care.
 - Hospital admissions have a severe impact on people with dementia and poor hospital care brings increased avoidable costs. Hospital admissions and the associated negative impacts can be reduced by providing support to maintain people's health in their own homes and communities.⁷²
 - The goals of personalisation must be realised for all people, and not just those who find it easiest to access the system. People with dementia need adequate information and support to use individual payment schemes.
 - The National Dementia Strategy for England is key to improving social care services for people with dementia. Full implementation of the Strategy must take place within five years.

1. *Future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities*

1.1 People with dementia and their carers are among the hardest hit by the current charging system. Because the majority of the package of care that people with dementia receive is typically provided through local authorities and is means tested, people with dementia end up paying significant amounts towards their care and often for a long period of time. Government has recognised that the question of who pays for care is a dementia issue. Any new system that does not address the needs of people with dementia will fail.

1.2 In 2007 the Society published *The Dementia Tax*, a report on the current charging system on people with dementia. It drew on the experiences of 2,300 people with dementia and carers across England. The report showed that the current system of charging for social care is particularly unfair on people with dementia. The majority of their essential care comes from social services, is means tested and is required over a period of many years. Social care for people with dementia is effectively a tax.

1.3 Key statistics from the *Dementia Tax* include:⁷³

- Four fifths of people are making a contribution towards the cost of care at home.
- Over half of people contribute over £300 per week for care home fees.
- One quarter of people with dementia pay the entire cost of the social care services they use in their own home.
- Despite the amount that people pay, the quality of care is often poor.

1.4 Charging affects people from all kinds of backgrounds, including those on low incomes because of the means-test thresholds. In the last 10 years the numbers of people from all social groups who are having to pay for care has increased.

1.5 One of the priority areas for a new system of care and support must be creating a system that is transparent and simple to understand. Creating differential responses according to types of need for care and support will seriously jeopardise that intention and should be resisted. Any new system must address the specific needs of people with dementia and their carers.

1.6 It has become routine for local authorities to develop high quality packages for children and younger adults with learning disabilities, but for older people's services to be significantly under resourced. Cost comparisons show that in 2006–07 local authorities were spending an average of £759 per week on care for children in foster care or children's homes, with the cost rising to an average of £2,402 per week for care in a children's home. For adults with learning disabilities the average is £971 per week. This compares to an average of just £444 paid for residential care of older people and £451 paid for care of older people in nursing homes.⁷⁴ All of these groups deserve good quality care. There must be a system that does not discriminate.

⁷¹ Alzheimer's Society (2008) *The Dementia Tax*. Alzheimer's Society: London.

⁷² Ibid.

⁷³ Alzheimer's Society (2008) *The Dementia Tax*. Alzheimer's Society: London.

⁷⁴ The Government Statistical Office, *Personal Social Services Expenditure and Unit Costs England, 2006–07*, published 2008.

1.6 *Recommendations for the future system:*

- Scrap the dementia tax: move to a system where risk is shared beyond people with a specific medical condition like dementia.
- A new system must deliver good quality care at a fair price. The quality of care must be improved if people are to buy into making a contribution. People are willing to make a contribution but only if care improves.
- Replace the current fair access to care system which means no one with lower level or moderate needs gets help. Deliver a new national resource allocation system.
- End age discrimination in funding of care which sees much more generous packages of care for children and younger adults with disabilities than for older people with dementia.
- Recognise the role that carers play and make sure that they are not financially disadvantaged by caring.

2. *Personalisation of social care services*

2.1 Alzheimer's Society supports the personalisation agenda. It has the potential to radically change the quality of life of people with dementia and carers.

2.2 Direct payments, individual budgets and personal budgets—which are the main approaches to delivering the personalisation agenda—enable people with dementia and their carers to exercise more choice over their care. Because of the potential benefits, strategies should be put in place to enable people with dementia to take advantage of them.

2.3 There is evidence to suggest that individual payment schemes are much more accessible to younger people.⁷⁵ Older people requiring social care, many of whom have dementia, experience greater difficulties taking up such schemes. In research older people reported lower levels of psychological wellbeing than those not using individual payment schemes.^{76 77} The way a younger person may choose to use direct payments can be very different from the choices of an older person. To fully meet the goals of personalisation, older people must not be excluded by a system that is geared only to the preferences of younger people.

2.4 Currently there is limited evidence about how to make personalisation work for people with dementia. Some people with dementia and carers have made use of direct payments but there have been significant obstacles, including much lower budget allocations for older people. This necessarily restricts the range of options. In the next 3–5 years priority needs to be attached to understanding personalisation in the context of dementia. The Society will be focussing energy on this area of work.

2.5 To make choice and control a reality there must be increased supply of services. We know that dementia services can be limited in both quantities and range of types of service. If the services available do not support effective choices for people then personalisation will not work.

2.6 Personalisation is central to the National Dementia Strategy for England. The Strategy's central premise is that people with dementia and carers are the experts and must be involved and engaged throughout their care and support journey, to ensure that individuals are empowered and in control. Making personalisation work for people with dementia and their carers is critical to the success of the Strategy.

2.7 Making personalisation work for people with dementia is also critical for the success of the agenda as a whole. People with dementia currently form a large proportion of all those who need support to live independently. This number will increase substantially. Without improving care and support for the large number of people living with dementia to promote empowerment and choice, the personalisation agenda will not deliver the type of change envisaged by the Government.

2.8 *Recommendations:*

- Develop clearer evidence and information about how personalisation can work for people with dementia and their families
- Awareness raising and training for health and social care professionals on involving people with dementia and carers in the personalisation agenda.
- Increased opportunities for people with dementia and their carers to access direct payments, individual budgets, personal budgets and personal health budgets (where available).
- An effective support service to be available for all people with dementia, which is tailored to their individual needs, flexible and highly accessible.
- An improvement in the supply of services for people with dementia which work towards increasing independence, choice and control.

⁷⁵ Department of Health (2008) *Evaluation of the Individual Budgets Pilot Scheme*. London.

⁷⁶ National Centre for Independent Living (2009) *Direct payments in the NHS*. London.

⁷⁷ Department of Health (2008) *Evaluation of the Individual Budgets Pilot Scheme*. London

3. *More effective, consistent and user-friendly social care services*

3.1 Early intervention in dementia offers an excellent opportunity to provide much higher quality care and deliver efficient spending. These are central concerns in the current economic climate. Recent research⁷⁸ shows that low-level support available in the community at an early stage has great potential to improve the experiences of people with dementia. Providing tailored care packages in people's own homes helps to maintain independence and dignity. At present, the majority of dementia services are skewed towards those with higher needs. The range of social care options available for people with dementia and their families is often limited, particularly in the early stages of dementia. Waiting until crisis point to intervene means that people with dementia and their carers endure poor quality of life for an extended period of time. It is also a far less cost-efficient use of public money.

3.2 The needs of a person with dementia will change over time as their condition progresses and they will require increasing input from both health and social services. It is very important that services are planned and commissioned jointly to provide the best care for people with dementia. The need for joined up services is strongly felt by people with dementia and their carers, who can experience great frustration and poor quality services where joined up working is not as effective as it should be. Dementia stands to be an exemplar of the benefits of joined up working between health and social care and provides great potential as an example and model. A key feature of effective planning and services provision is strong evidence and research regarding the local population and their needs. We recommend this be commissioned. This evidence base should involve people with dementia and their carers.

3.2 People with dementia occupy up to one quarter of hospital beds.⁷⁹ The 2007 NAO report on dementia highlighted research showing people with dementia were often unnecessarily admitted to hospital, stayed longer and were discharged later than they should have been.⁸⁰ When discharged from hospital, people with dementia are at an increased risk of entering a care home often because they are deemed ineligible for intermediate care services which could support them returning to their own homes. Length of stay in hospital could be reduced through better training for staff on dementia and improving access to intermediate care services. Poor dementia services in the community could also contribute to increased hospital admissions. Improving community dementia services could potentially save funds.

3.4 A skilled, aware and capable workforce is critical to providing effective, user-friendly services. People with dementia and their carers will come into contact with a vast range of professionals throughout their journey with dementia. Those giving dementia support must understand the behavioural and psychological symptoms unique to dementia. Professionals need to understand how to communicate effectively with a person with dementia, including reading non-verbal signs and working with family carers. Many health and social care workers still have the mistaken belief that little can be done to improve the quality of life of people with dementia. It is crucial that all health and social care workers understand how a person with dementia can live well, and the central role they play in this.

3.5 People with dementia are not a homogenous group—there will be a broad range of needs, expectations and preferences. Some people will require only a small amount of support once or twice a week, whereas others will require more intensive services. Services must be tailored to the individual and their situation—they must be flexible and able to fit in with people's family lives and social commitments. Most importantly, services must be reliable.

3.6 Carers know the person with dementia better than anyone else. Where a person with dementia has lost capacity to communicate, carers offer a valuable insight into what the person with dementia may be experiencing or communicating. Despite this, many carers told of being left out of care decisions and not included or treated as part of the care planning process, often to the detriment of the person with dementia. Carers must be treated as partners in care to ensure the social care services a person with dementia uses are effective.

3.7 Choice and control over care are important levers to providing user-friendly care. Dementia does not mean that individuals can no longer make decisions about their care. The Mental Capacity Act 2005 provides a framework for ensuring people with reduced capacity can continue to have a say in their own lives. It is very important that all people involved in social care are aware of the Mental Capacity Act. Widespread awareness and understanding of the Act is crucial.

3.8 An effective, rigorous regulation system is an essential part of promoting and supporting good quality care for people with dementia. People with dementia are significant users of health and social care services, and yet a great deal of evidence reveals the poor standards of services provided for people with dementia. A robust regulatory system of care services with strong registration requirements is key to changing this situation. Currently the Society is very concerned that the compliance guidance from the Care Quality Commission will not assure good quality care.

⁷⁸ National Audit Office (2007) *Improving services and Support for people with dementia*: London.

⁷⁹ J Holmes, K Bentley, I Cameron (2003) A UK survey of psychiatric services for older people in general hospitals. *International Journal of Geriatric Psychiatry* 18:716–21

⁸⁰ National Audit Office (2007) *Improving services and Support for people with dementia*: London.

3.9 Dementia has suffered under misunderstanding, stigma, and low status from all sections of the population. Improving awareness and understanding about dementia is essential to improving the experiences and quality of life for all people living with dementia. Public awareness work must reach out to all sectors of society. This includes transport workers, the police, postal workers and people from utilities companies.

3.10 Recommendations:

- The National Dementia Strategy for England is key to improving social care services for people with dementia. Full implementation of the Strategy must take place within five years.
- Collate evidence on what people want and need to experience effective, user friendly services and develop best practice models.
- Prioritise early intervention in dementia care and services to promote high quality services and deliver cost efficiency, including services to support people with dementia leaving hospital.
- Ensure the national awareness campaign promised in the National Dementia Strategy for England is far-reaching.
- Carers must be true partners in care—this will include adjusting of professional attitudes.
- Services must be flexible, reliable and provide greater choice.
- Commissioners must develop a thorough evidence base of the needs of people with dementia and use this to deliver joined-up working
- People with dementia and carers should be involved in workforce development planning to ensure that the needs of service users are met.
- Social care professionals must be able to treat people with dignity and respect, and there must be a culture of non-discrimination.
- The workforce must have communication skills and know how to involve people with dementia in everyday choices.
- Training for the dementia workforce must emphasise a holistic view of dementia, to ensure a true understanding of dementia and enable person-centred care.
- Care Quality Commission inspectors must have an up to date knowledge of best practice in dementia care and inspect to a consistently high standard.
- Care Quality Commission must give strong direction on how all dementia services should provide good quality care must be explicitly linked to regulatory requirements. This will support a regulation system that drives up quality.

October 2009

Memorandum by the National Pensioners Convention (SC 22)

SOCIAL CARE

SUMMARY

- Social Care has long been the “Cinderella Service” of the welfare state; often finding itself overlooked and under-funded. The publication of the new green paper entitled *Shaping the Future of Care Together* offers the chance to properly address these issues.
- The proposal to create a National Care Service which will clearly set out entitlements is welcome, but the green paper’s instant dismissal of a tax-funded payment option undermines such a proposal. The fairest and most equitable way of providing a universal, free at the point of need National Care Service is through general taxation (rather than through any of the other models put forward or the use of existing care or disability benefits) and there is wider support for this amongst the public and other stakeholders than the government seems prepared to acknowledge.
- The personalisation of care must not be seen as the same as individual budgets. Individual budgets raise serious concerns about personal safety, the quality of care and unacceptable burden of responsibility that will be placed on many vulnerable older people.
- There needs to be greater recognition of the role and value carers provide, including payment of the carer’s allowance to older people.
- There should be an acknowledgement of the changing and weakening nature of the regulation of care services that has taken place. Any new National Care Service should be properly regulated with regard to registration, standards, monitoring and inspection of care providers and those employed in the care sector.

1. INTRODUCTION

1.1 For years, social care has been the “Cinderella” service of the welfare state; often lacking sufficient funds or enough political interest to raise its profile. Now, with the publication of the long awaited green paper on care, entitled *Shaping the Future of Care Together*, it is finally the focus of national debate. The green paper identifies a number of problems with the existing care system, namely its complexity, the unfairness of means-testing, a postcode lottery of funding and standards and its lack of personalised services. Alongside this is the perceived growing pressure of an ageing population. The one issue on which there can be little doubt, is that the existing social care system is failing the most vulnerable members of our society and needs urgent attention.

1.2 A snapshot of social and long-term care provision in England shows the following:

Domiciliary Care

- Around one million older people receive some form of care in their own home
- The private and voluntary sector care providers receive around £9.3 billion a year in public funding
- An estimated £5.9 billion is spent by individuals on social care either through private contributions or through charges
- A huge unmet need and care gap exists between the services older people require and what they actually receive because services are being rationed. As a result, only those with high care needs qualify for assistance. This unmet need places an additional burden and strain on many relatives and friends who provide unpaid care (eg. 1.2 million men and 1.6 million women over 50 are unpaid carers)
- All care in the home is means-tested, and individuals need an annual income of less than £13,000 to receive services free
- The charges for those with income above this level, vary widely depending on each local authority area, thus creating an unfair postcode lottery

Long-term residential care

- In 2003, out of 500,000 care places: 69% were in the private sector, 17% in the public sector and 14% in the voluntary sector
- Private care is worth around £6.9 billion a year
- One in four care workers leave their jobs every year and this high turnover is almost entirely due to poor pay and conditions of employment
- Within care homes, only one member of staff is required to have an appropriate care qualification (but even they do not have to be situated on-site)
- Those with assets (including the value of their property) of more than £23,000 must fund their own care. Those between £13,000 and £23,000 are means-tested and pay a proportion whilst those below £13,000 have their charges paid by their local authority. Average charges are around £800 a week

1.3 This submission will conclude by proposing an alternative vision of social care provision which acknowledges that the real challenge facing today’s social care system is a lack of funding and a short-term political approach to the care of older people in their own homes and the wider community.

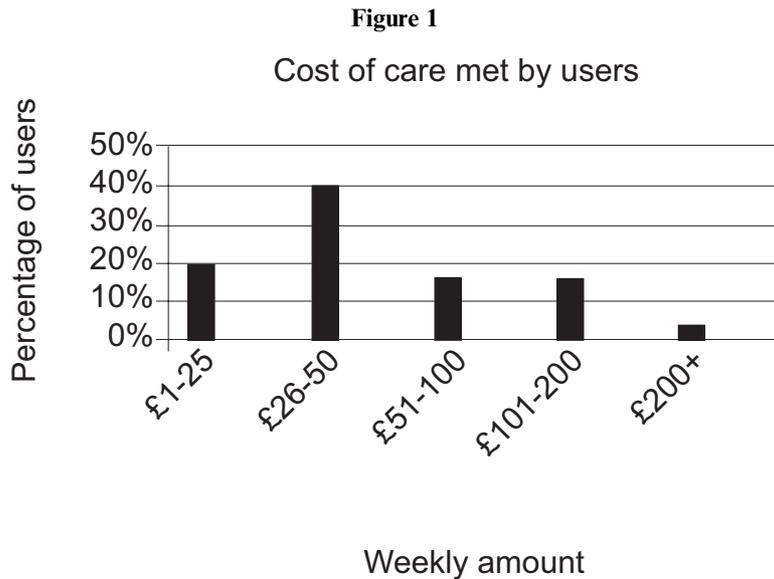
2. THE COST OF SOCIAL CARE

2.1 In the year 2006–07, local authorities spent £14.2 billion on social care for all adults, of which 61% went on services for older people. The amount spent on home care was around £2.3 billion, reaching just over 1 million adults, with around £6.3 billion being spent on residential services. From 2001–02 to 2005–06, the percentage of gross expenditure on care services with private and voluntary providers grew from 59% to 72%—amounting to £9.3 billion in total. Further grants were also made by local authorities to over 5000 voluntary organizations providing care services in the community.

2.2 The green paper states that: “Two in every three women and one in two men can expect to have high care needs (difficulty getting dressed, bathing etc) during their retirement.” It goes on to argue that the average lifetime care cost for a 65-year-old in England is currently £30,000—claiming that at least 50% of pensioners have costs of £25,000 to £100,000 and over. For example, just four years of care and accommodation in a care home could cost over £100,000.

2.3 An estimated £5.9 billion is already spent by individuals on social care either through private contributions or through charges. In a recent NPC social care survey⁸¹ (see Fig 1), almost half of all users were paying up to £50 a week for home care; with up to 20% paying between £100 and £200.

⁸¹ NPC Survey of Social Care Users and Providers 2007



2.4 In the Comprehensive Spending Review 2007, the government announced a 1% real terms increase to the revenue support grant for local government—with Department of Health funding for adult social care of £190 million by 2010–11. However, these amounts are insufficient to provide care for all those in need and the fact that the government’s introduction of individual budgets is actually anticipated to save 3% continues to show how little financial and political priority this issue is given.

3. FAIR ACCESS TO CARE SERVICES?

3.1 In 2003, the Fair Access to Care Services (FACS) guidelines were introduced as a response to the outcry against the “postcode lottery” which allowed local authorities to use different criteria for assessing the need for care. The guidelines state that every local authority in England must use four standard criteria: critical, substantial, moderate and low to assess and deliver social care. These are described as being:

- Critical—where life is in danger; or serious abuse or neglect has or might occur
- Substantial—where abuse or neglect has occurred or might occur; or the individual is unable to carry out the majority of personal care or domestic routines and there is no-one available to assist
- Moderate—where the individual is unable to carry out several personal care or domestic routines; or several of their family and social roles
- Low—where the individual is unable to carry out one or two personal care or domestic tasks; or one or two of their family and social roles

3.2 However, the Commission for Social Care Inspection (CSCI)⁸² in one of its last reports before it became part of the Care Quality Commission, stated that “most councils now only help people with substantial or critical needs, leaving many needing help to fend for themselves or rely on friends and family for support.” Furthermore, the CSCI found that:

- 75% of local authorities do not provide the moderate and low criteria
- 160,000 households are denied help
- 1.2 million men and 1.6 million women over 50 are unpaid carers, saving the country £87 billion

3.3 The recent National Coalition on Charging report⁸³ also revealed that rising charges for people receiving care in their own homes, were causing disabled and older people in England to reduce or even stop their support services. The report found that:

- 80% of people surveyed who no longer use care services say charges contributed to their decision to stop their support
- 29% of respondents did not feel their essential expenditure (related to impairment/health condition) was taken into account in financial assessments to pay charges, meaning they have to choose between essential support and equally essential food, heating or utility bills
- nearly three quarters (72%) of people surveyed believe the government should think about the charges people pay for support at home in any plans to reform adult social care
- a fifth (22%) of people surveyed who currently use support suggested they would stop if charges increased further

⁸² The State of Social Care 2006–07, Commission for Social Care Inspection.

⁸³ Charging into Poverty, National Centre for Independent Living, 2008.

3.4 By contrast, those with low and moderate needs are forced to either rely on voluntary organisations or family members to help, or go without. Naturally, this situation can lead to a worsening of their condition and their needs may eventually reach a substantial or critical level. The cost of providing this extreme level of care is therefore more expensive in the long term than would have been the case with earlier intervention; when needs are at a lower level.

3.5 This point was clearly evidenced by the Prime Minister's recent announcement at his party's conference, when he stated that in the interim from next October those with the highest needs would receive free personal care in their own homes. However, the estimated annual spending of £670 million would work out at just £38 of care a week for each of the 350,000 people affected—far short of the estimated £165 cost of the average 11-hour package of domiciliary care provided in 2007. Furthermore, the failure to also help those with less severe needs will ultimately lead to a worsening of their condition and a subsequent greater demand on higher levels of care and support.

3.6 In addition to providing care to all in need, there should also be the active promotion of prevention, low level care, advice and advocacy to enable older people to retain their ability to live independent lives as long as possible and to obtain the services they need. Advice and advocacy should be available both for people who need publicly funded care and for those who under the existing system fund their own care.

4. THE CARE GAP

4.1 A shortfall in care can occur when people either do not access services (eg. due to cost or ineligibility) or when the services they do receive fall short of their requirements. This is particularly a problem amongst those with moderate or low care needs. Over a three year period up to 2006, the number of older people using services dropped from 867,000 to 840,000—at a time when the population aged 75 and over increased by nearly 3%. Since 1997, the number of households receiving supported home care has fallen from 479,000 to 358,000 in 2006.⁸⁴ It is also further estimated that the number of older people who get no care or informal care, despite being in need, is 381,000.

4.2 Even more concerning, is the poverty of expectation expressed by many older people. The CSCI found that individuals had low expectations and modest desires about what help they might get when entering the social care system. Many said they were receiving less support than they felt they needed—or were trying to muddle through the system without any help or guidance.

4.3 The exclusion of lower bands of eligibility means that people have particular difficulty in getting support with practical—yet vitally important tasks—such as housework, gardening and shopping. The NPC social care survey found the care gap included a lack of help with cooking, gardening, housework, visiting day centres, going out, shopping, DIY/maintenance, adaptations to property (ramps, showers etc) and bathing.

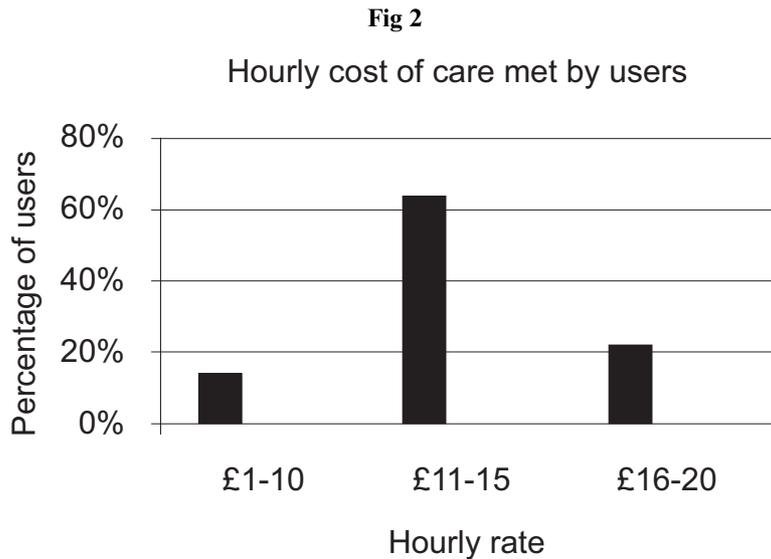
4.4 Recent changes to the Supporting People Fund allocated to local authorities have also led to cuts in care services and support for older and disabled people. The decision not to ring-fence budgets has, amongst other things, hastened the unpopular removal of many on-site wardens from many sheltered housing complexes.

4.5 Ultimately, the burden of the care gap is felt by the individual's family and carers. Despite a commitment to “valuing” carers through a Carers' Strategy which will come into reality by 2018, there is no suggestion of changing the current rules on the carer's allowance which prevents someone in receipt of a state pension from claiming. Many support services are also unavailable to existing carers. This can lead to passive neglect of their loved ones, because they are unable to cope.

5. A POSTCODE LOTTERY IN CARE CHARGES

5.1 Despite the introduction of the FACS, a postcode lottery within the provision and cost of social care still exists. The NPC social care survey found there were clear variations in the amounts charged for an hour's worth of care (see Fig 2).

⁸⁴ The State of Social Care 2006–07, Commission for Social Care Inspection.



5.2 For example, whilst in one London borough the charge for home care was £17.50 an hour, in another it was £25. What is also clear from the survey is that the lack of a nationally agreed set of care charges (including a maximum charge) damages the legitimacy and credibility of the whole social care system.

6. FUNDING OF CARE

6.1 The green paper outlines five possible funding options, two of which; individuals paying for everything and tax-funded care are instantly ruled out of the debate. The three remaining options, Partnership, Insurance and Comprehensive all continue to involve an element of means-testing and unfairness. By contrast, the Caring Choices Report⁸⁵ in 2008 found widespread demand for change. In particular 90% rejected the present means-tested system, preferring a stronger universal element determined by care need rather than income or wealth.

6.2 It is our view that the state should provide a high quality, comprehensive system of social care that meets national standards and is available to everyone, based on their care needs. Despite the green paper's claim, the tax-funded option should therefore be reintroduced into the debate.

7. THE PERSONALISATION OF CARE

7.1 The new care green paper makes it clear that the personalisation of care is at the heart of the government's proposals for reform. Under the Conditional Resource Enhancement (CRE) scheme, an assessment is made of the user's needs in terms of hours, which is converted into the £s required to deliver that care, and this is provided in the form of an individual budget which is given to the user to spend as they choose. Local authorities are therefore gradually handing over responsibility to individuals to enter into the commissioning process.

7.2 However, the introduction of individual budgets raises serious concerns. Many people will be met with a bewildering choice of care providers, consisting of local authority services, private companies and the voluntary sector. The individual budget holder therefore has to be directed to the "experts" offering advice and services and is inevitably drawn into the growing "market" where private companies, the voluntary sector and charities compete for contracts to supply such services.

7.3 Ultimately, this will transfer risk and responsibility either to the individual who needs social care or to their relative(s). They must now take on management tasks or deal directly with the private companies which will provide their advice or care for profit. However, there is no clear guidance for the individual when becoming an employer.

7.4 Fundamentally, expecting some of our most vulnerable older people to take on the responsibility of employers—recruiting, dealing with payroll matters, contracts, employment rights and discipline—is simply unrealistic. In effect, rather than giving choice, individual budgets open up opportunities for abuse by those who manage the individual's affairs and those organisations who see it as a chance to win contracts and make profits.

7.5 In addition, individual budgets raise serious concerns about the safety and protection of vulnerable individuals who will be responsible for employing their own care workers, who at present are exempt from registration, regulation and inspection. This dangerous and alarming situation must therefore be addressed as a matter of urgency, particularly when considering that such a major shift in policy has never been approved by Parliament.

⁸⁵ The Future of Care Funding: time for a change, Caring Choices Consortium, 2008.

8. MONITORING AND REGULATION

8.1 In recent years there has been a systematic weakening of the rules and regulations surrounding the provision of care. The CQC would seem to have uprated many care homes in an attempt to reduce the number of site inspections required, whilst at the same time downgrading the standards for regulating and inspecting domiciliary care in an individual's own home.

8.2 It is estimated that 60–70% of home care in future will be provided by individuals (either directly employed by the user or self-employed) because they will be able to get more money than if they worked for an agency or contractor. However, they will not be regulated by the CQC and there will be no requirement for a CRB check, training or qualifications.

8.3 A return to proper regulation and standards is therefore essential to any proposals for reform. New requirements for registration of care providers should be re-introduced (drawing on previous CSCI guidelines) for 50% of staff in care homes and all new staff working in domiciliary care to be suitably qualified. In addition, care staff who are employed either by an individual, local authority, agency or care home company should have an appropriate qualification as a minimum standard as an essential requirement for registration and the General Social Care Council should be required to register, inspect and regulate all paid care workers.

9. AN ALTERNATIVE NATIONAL CARE SERVICE

9.1 It is a matter for celebration that people live longer and that this demands that society should provide for their needs, even if it means reordering the priorities for public spending. We see no evidence that today's workers are not willing to pay sufficient taxes to fund the kind of system that they wish for their own parents and for themselves in due course. Reordering public spending priorities and addressing the need for increased taxation, diverting money from private health care and introducing a windfall tax on their profits would provide sufficient resources for a 21st century social care system worthy of the name. Such an alternative National Care Service is summarised below:

1. *Prevention services*

Care, support and advocacy will be available to enable individuals and their carers to stay independent, well and socially included for as long as possible in their own homes, including sheltered housing.

Those living in their own homes, or *prior* to returning home from hospital or residential care, will receive the necessary preventative and care services and support appropriate to their needs. This should include home adaptations and equipment, as well as domiciliary care, support and leisure services that would help individuals and their family carers to manage in their own homes.

2. *National assessment*

There will be nationally determined assessment criteria which will be used throughout England to assess care needs.

Individuals will have the right to have their needs (critical, substantial, moderate and low) assessed and receive the appropriate care from a universal menu of services. At the same time family carers' needs will also be assessed. The postcode lottery in the quality, availability and cost of services will cease under the tax-funded National Care Service.

3. *A joined-up service*

Individuals and their family carers will be entitled to receive a variety of care services from a range of regulated providers, which will be of the highest standard.

There will no longer be a divide between health and social care provision and the process of accessing care will be transparent and easily understood. All services will operate to nationally agreed standards which will be properly regulated and enforced. These shall include issues of staffing, pay and training requirements.

4. *Information and advice*

Individuals and their carers will be able to easily access straightforward information and advice about their entitlements to services at every stage of their care, and advocacy when required.

Whether in the community, care home or hospital, individuals and their family carers will be entitled to receive information which clearly explains their entitlements to care, how to access the services available and their rights as a service user. Recognition will also be given to those who need assistance from a third party/advocate/friend to help them exercise their entitlements.

5. *Personalised care and support*

There will be a range of care and support services made available that can be tailored to individual personal circumstances and needs.

Care and support will be designed and delivered around an individual's needs through a regulated provider, whilst the responsibility for managing budgets will lie with the local authority or NHS. Additional financial and practical support will also be available to family carers.

6. <i>Fair funding</i> Society will share the cost of providing care for those in need.	A tax-funded universal National Care Service will entitle individuals to free non-means-tested care, support and accommodation appropriate to their needs.
--	--

October 2009

Memorandum by Bupa Group (SC 23)
SOCIAL CARE

EXECUTIVE SUMMARY

- Bupa is an international healthcare leader which, among our other activities, is a leading UK based international provider of social care.
- Given the wide scope of the inquiry and the size limitation on the written submission we have focussed our evidence on:
 - demonstrating the urgent need for additional social care funding to meet current needs and future demographic trends;
 - explaining why we believe the “Comprehensive” option set out in the Green Paper is in our view the only option which will adequately address the issues the English social care system faces;
 - making some observations on how such a scheme might operate successfully; and
 - giving some examples of successful social care reforms from our international experience.
- Clearly there are many other aspects of social care reform which are important, such as personalisation and the operational effectiveness of the system, but we believe these are secondary to the central question of adequate funding. We have not therefore addressed those issues in this evidence.
- The English social care system is currently significantly under-funded. This results in:
 - the needs of those requiring social care not being met,
 - additional financial and capacity pressure on the NHS’ and
 - underinvestment in social care facilities and staff.
- Without reform these effects will worsen in the future because we can expect the number of people needing care and support to increase rapidly over the next 20 years.
- Fundamental to tackling this is getting more *new money* into social care on a *sustainable* basis.
- We believe the projections of the average costs of care of £31,700 per person (excluding accommodation and food costs) represents a realistic estimate of these costs and if that amount of funding is made available it will represent a step forward in social care funding.
- We oppose the proposal in the Green Paper to exclude the accommodation and food costs of residential care from the support that is to be provided under a reformed social care funding regime because:
 - This will preserve a large element of the current substantial financial burden on service users and thereby undermine the nature of the reform.
 - It is inequitable to exclude the accommodation and food costs of residential care (which cares for service users with the highest care needs) as these form an integral part of their care.
 - It will result in further complexity because the (already complex) current system will continue to exist to fund accommodation and food costs alongside whatever new funding regime is introduced.
 - It will retain the large incentive in the current system to seek care through the NHS (which is free to the user) rather than use the social care system.
- We have reviewed the proposed sources of funding referred to in the Green Paper in order to determine which is likely to sustainably deliver the additional funding which the Green Paper recognises is essential for improved social care. Our experience as providers of care in the UK and overseas leads us to conclude that:
 - The current system has failed to provide adequate funding and has had the inequitable result that the whole risk of high social care costs falls on a large minority. This is an historical accident, is unnecessarily complex and creates large incentive on service users to seek to obtain NHS funding.

- A more equitable system would spread the costs more evenly across society and thereby eliminate the need for those who find themselves needing high levels of care to run down their assets to pay for it.
 - We agree with the Green Paper that it is improbable that sufficient additional funding can be obtained at all or on a sustainable basis from general taxation. Therefore the only identifiable sustainable source of the necessary funding is the assets people have built up by the time they retire.
 - To ensure that the costs are spread more equitably and to make contributions affordable, contributions will have to be shared on a risk pooled basis.
 - Private social care insurance products have failed in the past because people underestimate the cost and likelihood of requiring social care and also self select so the necessary risk-pooling has not been achieved.
 - This is why we favour the “Comprehensive” option in the Green Paper.
 - We believe that to gain public support for such a system the funds must be held separate from general government receipts and ring fenced for the provision of social care.
 - This contribution could be funded at an approximate cost of around £35 per month through an appropriate insurance policy taken out at the age of 40.
 - We believe that any new funding system must incorporate a major extension of Individual Budgets to give people control over their care
- There have been successful reforms overseas in social care, so change in the UK is possible. Some examples of key features of those reforms are summarised in paragraph 6.

1. BUPA

1.1. Bupa is an international health and social care leader which has no shareholders, allowing us to reinvest our surpluses in providing more and better care for our customers. We serve customers in 190 countries and can compare best practice across different markets.

1.2. Bupa provides residential social care to 18,500 residents in our 301 UK care homes and employs 27,000 people in the UK. We are the biggest UK provider of specialist dementia care—our spending on dementia care training has trebled since 2004. Approximately 75 per cent of our UK care home residents receive some state funding.

1.3. Bupa also provides care to 12,500 NHS patients with complex care needs in their own homes and out of hospital. Virtually all of these patients are NHS funded.

1.4. We also own and operate 38 homes in Spain, 49 homes in Australia and 48 homes in New Zealand.

1.5. Bupa also covers the lives of 3.25 million UK customers through private medical insurance which represents 40% of the UK market.

1.6. We take our responsibilities in this debate seriously.⁸⁶

2. THE CHALLENGE FOR SOCIAL CARE IN ENGLAND

2.1. The social care system is currently under funded which results in unmet need, pressure on the NHS and underinvestment in social care facilities. There have been various reports which have established this such as:

2.1.1. *“We recognise that the size of the “cake” is limited, whilst the number of people who want a “slice” is increasing. In the long term, there is no alternative to radical reform of the way the social care system is funded, and this report sets out a range of possible options and their impact on eligibility. However, we are unable to avoid the conclusion that the key issue is not simply the criteria used to assess people’s eligibility for publicly funded care and support, but the amount of resources currently allocated—the size of the cake itself.”⁸⁷*

2.1.2. *“In essence, the conclusion to be drawn is that the fees that are typically on offer from local authorities are fairly close to being adequate for unmodernised care home stock. But they remain inadequate to fund a modernised care home sector meeting the physical standards set by the government for new homes registered after April 2002.*

The potential additional cost to the public sector of an England-wide commitment to pay a fair price for a fully modernised care home sector, in terms of physical environment, is estimated at approximately £540 million per annum at 2008–09 prices and volumes of demand.

⁸⁶ That is why we have instigated our own debate amongst the whole community about what social care should seek to achieve and have launched our own manifesto for older people, which can be found at <http://www.bupa.co.uk/redirects/caredebate/>.

⁸⁷ Cutting the Cake Fairly—CSCI review of eligibility criteria for social care—October 2008 http://www.dhcarenetworks.org.uk/_library/Cutting_the_cake.pdf

If the concept of “fully modernised” is extended to include a professionalised workforce, paid accordingly, then the additional cost would be substantially greater ... every extra £1 per hour paid to carers and domestic and catering staff would add £280 million per annum to local authority costs; and implementation of the proposal within the 2007 Pensions Bill for a minimum 3% employers’ pension contribution (subject to opt-out) could add £52 million per annum to local authority costs.”⁸⁸

2.2. In 2006 people aged over 65 accounted for 43.1% of NHS spending.⁸⁹ We estimate that the spending per head is 3.4 times the average for the over 65’s, four times for the over 75s and 8.3 times for the over 85s based on similar statistics from other countries.

Age Group	Total Expenditure (£bn)	% Total Expenditure
Age 65–74	5,890	15.4
Age 75–84	6,763	17.7
Age 85 +	3,818	10.0
Totals	16,471	43.1

The demographic pressures which provide a further impetus for reform will be familiar to the committee: *“By 2026, population estimates show that there will be double the number of people aged over 85 that there are now, and the number of people aged over 100 will have quadrupled. In the 1940s when the welfare state was established, there were more than five people under 65 for every person aged over 65. Currently, there are around four people under 65 for every person aged over 65. By 2029, there are expected to be three people under 65 for every person over 65.”⁹⁰*

2.3. It is estimated that between 2005 and 2041, the numbers of users of non-residential formal services would need to rise 102% from 1.5 million to 3.1 million, to keep pace with demographic pressures and the numbers of older people in care homes (and long-stay hospital care) would need to rise by 139% from 345,000 to 825,000.⁹¹

2.4. The key issue for social care is therefore a deficit in the funding required to improve the quality of services today and at the same time drive an increase in the volume of all types of social care.

2.5. In addition the percentage of older people in care homes is higher in many comparable countries than in the UK where only 5% of the UK’s over-65 population were in care homes in 2003. This compares with 6% in Australia, 8% in Sweden, 9% in Holland and 12% in Norway. This indicates that it will not be possible to save costs by substantially reducing the proportion of older people in residential care. In addition, a survey has found that, on admission to a UK care home, a third of residents had dementia, a quarter were frail and a fifth had had a stroke.⁹²

3. THE CURRENT SOCIAL CARE FUNDING SYSTEM

3.1. The current system of funding has the result that the whole risk of high social care costs falls on a minority group who have:

- 3.1.1. some (but a relatively low level at over £23,000) of assets including housing equity,
- 3.1.2. high care needs,
- 3.1.3. but not high enough care needs to qualify for NHS funding.

3.2. This is purely an historical accident, appears illogical and unnecessarily complex, and also creates large incentive on residents and their families to seek to obtain NHS funding (which is free to them). A more equitable system would spread the costs more evenly across society and eliminate the need for the large minority who find themselves in this position to run down their assets to pay for care.

4. The proposed exclusion of accommodation and food costs of long term residential care from the new funding regime

4.1. We oppose the proposal in the Green Paper to exclude accommodation and food costs of residential care from the support to be provided under a reformed social care funding regime because:

4.1.1. In our experience people don’t distinguish between care and accommodation and food costs (which represent about half of residential social care costs) as both are a financial burden.

⁸⁸ Calculating a Fair market Price for Care—Third Edition—Joseph Rowntree Foundation—September 2008 <http://www.jrf.org.uk/sites/files/jrf/2252-care-financial-costs.pdf>

⁸⁹ House of Commons Select Committee report, public expenditure on health and personal social services 2006, table 47 page 120

⁹⁰ Shaping the Future of Care Together Green Paper http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102732.pdf

⁹¹ Future Demand for Social Care, 2005 to 2041: Projections of Demand for Social Care for Older People in England—PSSRU Discussion Paper 2514 (2008) <http://www.pssru.ac.uk/pdf/dp2514.pdf>

⁹² Bowman, C., Whistler, J., & Ellerby, M. (2004). A national census of care home residents. Age and Ageing.

4.1.2. The reason why an individual is in a residential care setting is because it is more cost effective (even after the additional accommodation and food costs) to care for them in that setting than to provide an equivalent level of care in their own homes. So as the aggregate costs are lower, it is inequitable to exclude the accommodation and food costs of care home residents (who by definition have the highest care needs) from protection under the new funding system.

4.1.3. The provision of care and accommodation is part of an individuals' assessed care needs (by analogy the NHS doesn't charge separately for food and accommodation in hospital as that is an integral part of the care that NHS service users require). Given the frailty of residents and the long-term nature of the care provision, food and accommodation are a fundamental part of the care provided and have a significant impact on care quality.

4.1.4. It at least doubles the complexity of the funding regime because there will need to be a separate system to pay for accommodation and food costs of residential care alongside whatever new funding regime is introduced. This will mean that the large incentive in the current system to obtain care through the NHS will be preserved.

5. *Why Bupa supports the comprehensive funding option*

5.1. We believe that the current level of social care funding provided by the state should be preserved as a contribution to social care costs from general taxation is appropriate but this will clearly not be sufficient to meet the current demands for care and the substantial additional demand in the future.

5.2. We agree with the Green Paper that to be sustainable the necessary additional funding can only come from participants in the system and not general taxation.

5.3. We believe that for such a system to be equitable and affordable there will need to be "risk-pooling" on as wide a basis as possible. This would involve pooling the contributions from a large part of the population, not all of whom will need substantial amounts of social care. This cannot be achieved through voluntary social care insurance policies because the public underestimates the cost and likelihood of needing social care and, as a result, they do not believe such policies offer good value for money. In addition, the costs of those policies have been driven up because only those with a high probability of needing care have taken them out which substantially reduces the benefit of risk-pooling.

5.4. We believe that the Comprehensive option set out in the Green Paper is the only proposal which will deliver the required reform of the social care system. There would be a cost (which the Green Paper estimates at between £17,000 and £20,000 per person) but in return:

5.4.1. The necessary improvements in the social care system would be delivered to the benefit of service users, informal carers and to the NHS.

5.4.2. Older people would have confidence in their ability to obtain high quality social care when they needed it without having to spend all their assets.

5.5. Clearly for such a system to be politically acceptable the funding contributed by participants must not form part of general government funding and would need to be ring fenced to provide the social care they need when they need it.

5.6. This contribution could be funded in a variety of ways. For example it would be advantageous to allow it to form part of the tax free lump sums payable from private pension arrangements.

5.7. Another cost effective, voluntary alternative for those planning for the need to make the contribution payment would be for people to take out insurance policies with a face value of the necessary contribution, payable only if the insured survives to the end of the stated policy period (the date the contribution becomes due, assumed to be at 65). No benefit would be paid if the insured died before the date the contribution became due.

5.8. The following table summarises indicative monthly costs of these policies for a range of personal circumstances assuming a contribution of £20,000 payable at 65.

<i>Category</i>	<i>Age at which policy first taken out</i>	<i>Monthly cost</i>
Male	40	£34.42—36.63
	45	£47.97—50.74
Female	40	£35.25—37.15
	45	£48.99—51.39

6. OTHER INTERNATIONAL SOCIAL CARE REFORMS

6.1. There have been successful reforms in social care overseas, so change in the UK is possible. Some examples of key features of those reforms which have been successful are:

6.1.1. National assessment and payment systems based on care needs. This provides a solid financial basis for care provision by eliminating unwarranted local funding variations.

6.1.2. National capacity planning to help predict the numbers of older people requiring care in the future and help plan for the consequent increase in social care capacity which is required.

6.1.3. The accommodation bonds system in Australia has been a cost effective and palatable way to introduce new money into the system and to drive the introduction of a large volume of additional high quality services. Bonds have successfully stimulated the investment of private capital to develop new and high quality replacement capacity in care homes. The bond structure is acceptable to potential residents because they are asked to make the contribution at a time when they themselves recognise they have a need for care and because the bulk of their capital is returned to them or their family when they leave the care home. This has substantially reduced the amount of money required from general taxation.⁹³

6.1.4. The increased availability of social care through the introduction of a comprehensive scheme in Japan has resulted in reduced demands on family carers and the acute hospital sector.

6.1.5. In Germany service users can pay relatives to provide social care to them. The rates of contribution are substantially less than those which apply for formal care but many people still prefer this option, which helps control the costs of care provision.

7. CONCLUSION

7.1. We welcome the debate that the Green Paper has initiated on this key issue. Our international experience leads us to believe that change is possible provided that the central issue of adequate funding is addressed. Critically, we believe that the proposal to exclude the accommodation and food costs of residential care from the new funding regime threatens to undermine the basis of the proposed reform.

October 2009

Memorandum by Mind (SC 24) SOCIAL CARE

MIND'S MISSION

Our vision is of a society that promotes and protects good mental health for all, and that treats people with experience of mental distress fairly, positively, and with respect.

The needs and experiences of people with mental distress drive our work and we make sure their voice is heard by those who influence change.

Our independence gives us the freedom to stand up and speak out on the real issues that affect daily lives.

We provide information and support, campaign to improve policy and attitudes and, in partnership with independent local Mind associations, develop local services.

We do all this to make it possible for people who experience mental distress to live full lives, and play their full part in society.

EXECUTIVE SUMMARY

Effective social care services for people with mental health problems are vital. Currently, services provided by local authorities do not always meet the needs of people with mental health issues. People who need support to live independently but do not meet high eligibility criteria for social services are often neglected by services. Those who do get services can find them inflexible. Although personalisation has been shown to improve outcomes, too few people with mental health problems receive direct payments and individual budgets.

Mind is highly concerned that current funding models proposed by the Department of Health may only work for older people, not for people who develop a condition in adulthood.

Mind believes there are a number of issues for people with mental health problems that need addressing in the reform of the social care funding system. Our recommendations are summarised on page three.

Mind has consulted extensively through its networks of people with direct experience of mental distress on this issue and the views of respondents inform this consultation response. All quotes in this document are direct quotes from people with experience of mental distress who have participated in our research.

Mind's recommendations

- (a) The Government must ensure that any future funding system does not have a further negative impact on people with mental distress, who are already a disadvantaged group in society.
- (b) The Government should reconsider both the economic and equity benefits of a funding option based on general taxation or national insurance contributions.

⁹³ A useful summary of the operation of accommodation bonds from a care user's perspective can be found at <http://www.health.gov.au/internet/main/publishing.nsf/Content/3916407DB6A554CA256F19001007B2/SFile/Info%20Sheet%2016.pdf>

- (c) The Government must not adopt a funding system based on private insurance; as such an option would discriminate against people with mental health problems.
- (d) The Government should clarify its proposals for funding preventive care
- (e) The Disability Living Allowance and Attendance Allowance must be retained.
- (f) The Government must address the bureaucratic and systemic barriers to pooled budgets, including diverse eligibility criteria, assessment processes and restriction on spending across different funding streams
- (g) The Government must make personalisation a reality by allowing people who wish to do so the right to access traditional models of support (rather than pushing everyone to receive support through a direct payment); and ensuring new services are nurtured, and existing service providers are supported to evolve.
- (h) The Government must provide clear guidance about safeguarding and risk, and highlight the role of professionals in ensuring the safety of people who may at times be vulnerable or at risk.
- (i) The Government must make accessible funding, universal advocacy, information, advice and brokerage, which is a prerequisite to take up of personalised approaches.
- (j) The Government must provide multi-agency training and cross-sector working at all levels.
- (k) Recent progress in pooling budgets for mental health and social care services must not be lost as the modernisation of social care services takes place.
- (l) The Government should provide social care services for those with lower needs, as this is cost-effective and can prevent crises.
- (m) The care and support system must meet the distinctive needs of people with mental health problems, especially those whose needs fluctuate over time.
- (n) The care and support system should promote user involvement and be responsive to what service users say.
- (o) The current review of FACS criteria must result in a fairer system where people with low level or fluctuating needs can access the right level of support and are not simply excluded from the care and support system.
- (p) The right to access a social care assessment must become a reality for all.

1. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

1.1 *A fair funding model*

1.1.1 Mind welcomes the Government's aim to clarify the status and role of social care services within the welfare system, including people's entitlements and responsibilities.

1.1.2 Mind is concerned that the Health Committee does not refer to mental health when looking at future funding. Social care services are vital for people with mental health problems. Mind is concerned the funding models proposed focus on older people and would not work for those who may develop an unanticipated disability in early adulthood, and therefore could not plan and "save" for it.

1.1.2 People with mental health problems are more likely than others to face serious financial disadvantage⁹⁴ and often live on lower than average incomes: over 75 per cent rely on welfare benefits⁹⁵ and unemployment rates are high.⁹⁶ Mental health problems can act as a pathway to debt, and debt can lead to mental distress.

1.1.3 Mind opposes any funding model based on private insurance. Aside from being unable to afford insurance payments, people with mental health problems could be doubly penalised for their needs by discriminatory insurance policies that categorise them as "high-risk". Despite the existence of the Disability Discrimination Act, there are instances where insurers can still justify discrimination on the basis of a mental health problem.⁹⁷

1.1.4 It is essential that any future settlement for care and support does not create a disincentive to access services for this group, nor penalise those who are least able to contribute to the cost of care.

1.1.5 Mind's consultation with social care service users shows that most people believe social care for adults and older people should be funded by general taxation and be free at the point of delivery for everyone.

1.1.6 Services for people with mental health problems do not easily fit into health and social care boxes and often work towards the same outcomes. It is difficult to rationalise why some services are free at the point of delivery, while others are charged for because they are defined as social care.

⁹⁴ Mind (2008) *In the red: debt and mental health*.

⁹⁵ Office for National Statistics (2002b), *Labour Force Survey, LFS*, London

⁹⁶ Office for National Statistics (2003), *Labour Force Survey, LFS*, London

⁹⁷ Mind (2005) *Insurance cover for people who have mental health problems*

1.1.7 There are a number of possible funding systems whereby individuals would be required to contribute directly to the cost of their care, largely irrespective of their means: partnership arrangements, private insurance, care savings accounts, and “limited liability” (where the individual contributes only for a certain length of time).⁹⁸ Yet for many people with mental health problems, learning difficulties or physical disabilities, care and support may be needed for the same reason they are unable to work and save money. No future funding system should put people with mental health problems at further financial disadvantage.

Mind’s recommendations:

- (a) The Government must ensure that any future funding system does not have a further negative impact on people with mental distress, who are already a disadvantaged group in society.
- (b) The Government should reconsider both the economic and equity benefits of a funding option based on general taxation or national insurance contributions.
- (c) The Government must not adopt a funding system based on private insurance, as such an option would discriminate against people with mental health problems.

1.2 *Prevention and recovery*

“Prevention is better than treating the symptoms, which is very expensive. Like putting ambulances at the bottom of a dangerous cliff instead of erecting a fence at the top.”

1.2.1 Mind is concerned that the current care and support system is based on an assumption that people’s needs and conditions are permanent, and ignores the reality that mental ill-health can be overcome or prevented. A modern system must adapt to the specific challenges posed by mental distress. This includes recognising that funding decisions in social care have an impact on spending elsewhere in the system.

1.2.2 There is a strong economic argument for providing affordable, subsidised social care to people with fluctuating needs: the increased economic contribution that could be made by this group if they are supported to live independent lives, potentially return to work, and avoid the need for costly acute health interventions. For mental health specifically, the care budget cannot be disentangled from the benefits bill, employment rates and health spending. Mind is concerned that these wider cost-benefit arguments are not yet reflected in the Government’s care and support debate and that funding for prevention and re-ablement services are not clearly costed in the social care green paper.

Mind’s recommendation:

- (d) The Government should clarify its proposals for funding preventive care

1.3 *The additional costs of disability*

“Many people with mental health conditions rely on DLA because they cannot gain access to the social care that they need. Social care eligibility criteria are often way too high and bar people with serious anxiety and depression from accessing their services. If I lost my DLA, I would be left with nothing.”

1.3.1 People with mental health problems may also incur other costs, such as private treatments where there are long waiting times on the NHS, and prescription charges. Mind’s research shows the importance for the Government to meet these costs, which are distinct from the provision of care and support. Disability Living Allowance and Attendance Allowance are extremely important benefits for people with mental health problems, helping to cover these extra costs of living with a disability and providing independence and personal flexibility. Under no circumstances should DLA/AA be pooled with general local authority social care funding in a future care and support system.

1.3.2 Mind’s research has found that most people who received DLA/AA use it for social activities to reduce isolation, transport costs, and to help with basic living costs.

1.3.3 The Wanless report on social care suggested that two-thirds of the current expenditure on Disability Living Allowance and Attendance Allowance could be transferred into the social care budget to allow for greater spending on support.⁹⁹ Our research shows over three-quarters (78 per cent) of respondents disagreed with the proposal, and only 13 per cent agreed.

⁹⁸ King’s Fund (2006) Securing good care for older people: Taking a long-term view

⁹⁹ King’s Fund (2006) Securing good care for older people: Taking a long-term view

Mind's recommendation:

- (e) The Disability Living Allowance and Attendance Allowance must be retained.

2. PERSONALISATION OF SOCIAL CARE SERVICES

2.1 *Choice and control—Mind's "Putting us first" project*

2.1.1 Mind supports the aims of the personalisation agenda to bring about greater choice and control for disabled people. The individual budgets pilots show people with mental health problems benefit from having a greater say over their care.¹⁰⁰

2.1.2 Mind is currently leading Putting us First, a Department of Health funded project to increase uptake of personal budgets in mental health. Enclosed with this response are publications produced so far from this project.

2.1.3 Fewer people with mental health problems benefit from personalisation in social care than other disability groups with around 3,500 people using a direct payment—far fewer than other groups.

2.1.4 Evidence suggests that the transformation of mental health services has encountered more challenges and generated more resistance from professionals than in other sectors. The key issues that have been identified include:

- The difficulty, in mental health, of separating out what is a mental health need (paid for by NHS money) from social care and other support needs
- How to manage personal budgets for people with fluctuating needs
- Concerns over the risks which might be posed by giving people control over their care and budget
- Lack of awareness and resistance by care coordinators creating a barrier to uptake.

2.1.5 Appropriate infrastructure is imperative in the development of future social care initiatives. Where personalised approaches are already being rolled out in social care, this infrastructure should be developed as a priority. For example, the lack of investment in advice, advocacy and brokerage in social care has severely hampered progress.

2.1.7 Much of the infrastructure should be developed at a national level to avoid duplication of effort and a postcode lottery. This will enable disabled people across the country to know exactly how personal budgets will work, and how to access them.

2.1.8 The provision of information, raising awareness, developing local networks and ensuring service users are involved is central to the success of personalisation. This is also important in changing professional cultures and assumptions about people with mental health problems (and other disabled people).

2.1.9 Mind's Putting us First project is building capacity at local level through "personalisation champions" who have experience using a direct payment. Their work will involve developing networks and discussion forums, providing training for professionals and user groups, and disseminating learning to increase uptake and tackle barriers to implementation.

Mind's recommendation:

- (f) The Government must address the bureaucratic and systemic barriers to pooled budgets, including diverse eligibility criteria, assessment processes and restriction on spending across different funding streams
- (g) The Government must make personalisation a reality by allowing people who wish to do so the right to access traditional models of support (rather than pushing everyone to receive support through a direct payment); and ensuring new services are nurtured, and existing service providers are supported to evolve
- (h) The Government must provide clear guidance about safeguarding and risk, and highlight the role of professionals in ensuring the safety of people who may at times be vulnerable or at risk.
- (i) The Government must make accessible funding, universal advocacy, information, advice and brokerage, which is a prerequisite to take up of personalised approaches.
- (j) The Government must provide multi-agency training and cross-sector working at all levels

¹⁰⁰ IBSEN (Individual Budgets Evaluation Network) (2008) Evaluation of the Individual Budgets pilot programme: final report

3. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

3.1 *Joined up services*

“Too much emphasis is on medication and traditional talking therapies and not enough on all-round needs, both physical, emotional, spiritual and social and in terms of personal goals or aspirations”

3.1.1 Mental health problems do not fit neatly into “health” and “social care” issues. There is currently poor integration between the two services and differences in service funding and delivery are arbitrary and unhelpful. People experiencing distress and receiving health services may find their social care needs are not always identified or prioritised because their care tends to be led by medical professionals. People who have complex needs—such as those who have a substance misuse issue—do not always receive a joined up services response.

3.1.2 Greater provision of services for people with lower level needs would reduce the need for expensive, acute services and corresponds with a public health agenda focused on prevention and wellbeing. For mental health service users, this means a shift away from risk assessment, crisis management and acute healthcare interventions, to preventative social care services aimed at keeping people well, safe, in work and an active part of the community.¹⁰¹ Mind believes services across health and social care (and other public services) should be resourced on the basis of cost-benefit analysis across health and social care (and other public services)—and such analysis would find that preventative services would be cheaper in the long run.

Mind’s recommendations:

- (k) Recent progress in pooling budgets for mental health and social care services must not be lost as the modernisation of social care services takes place.
- (l) The Government should provide social care services for those with lower needs, as this is cost-effective and can prevent crises.

3.2 *Flexibility and responsiveness*

“I work full time, but because of this am discriminated [against] as being fully able; I’m not fully able all the time and could really do with being able to shout for a hand sometimes!!”

3.2.1 The care and support system is currently built around the needs of people with permanent conditions. Assessments, eligibility criteria and services are not designed to respond quickly to changing levels of need or to provide a service that is flexible over time. The current FACS (Fair Access to Care Services) eligibility framework does not accurately reflect the circumstances of people whose needs fluctuate over time. People with severe depression, bipolar disorder or psychotic illnesses may have periods where they live independently and experience few or no symptoms. Equally, there may be periods where the same person’s mental distress is extremely debilitating and has a serious effect on their ability to look after their health and welfare.

3.2.2 A fairer and more responsive assessment process that responds to an individual’s identified needs is required, in contrast to the current assessment criteria which are restrictive and rigid. Personalised approaches should place emphasis on service users assessing their own needs.

3.2.3 Application procedures are considered extremely inflexible by mental health service users. Forms, bureaucracy and cut-off dates can be stressful and intimidating for people already in distress. Support should be given to those who have difficulty filling in forms.

Mind’s recommendations:

- (m) The care and support system must meet the distinctive needs of people with mental health problems, especially those whose needs fluctuate over time.
 - (n) The care and support system should promote user involvement and be responsive to what service users say.
 - (o) The current review of FACS criteria must result in a fairer system where people with low level or fluctuating needs can access the right level of support and are not simply excluded from the care and support system.
-

¹⁰¹ The Future Vision Coalition (2008) A new vision for mental health

3.3 Access to services

3.3.1 Currently, many people whose social care needs fall short of the “substantial” or “critical” FACS thresholds still may not be able to sustain employment, social support systems and family relationships, but are unlikely to receive social care services in most local authority areas.

3.3.2 Many people experiencing mental distress are unaware they are entitled to a social care assessment. Where people do seek help from community services, they are often turned away without an assessment. In some cases, people are denied a social care assessment because professionals anticipate they would not be eligible for free care, or because the Care Programme Approach is being unlawfully used as the gateway to social care services.¹⁰²

Mind's recommendations:

- (p) The right to access a social care assessment must become a reality for all.

September 2009

Memorandum by The King's Fund (SC 25)

FUTURE OF SOCIAL CARE

INTRODUCTION

This paper is a response by The King's Fund to the Health Select Committee inquiry into the future of social care. The King's Fund seeks to understand how the health system in England can be improved. Using that insight, we help to shape policy and transform services. Our work includes research, analysis, leadership development and service improvement. We also offer a wide range of resources to help everyone working in health and social care to share knowledge, learning and ideas.

BACKGROUND AND OVERVIEW

The case for major reform of the current system of social care funding is well established. The current system is complex, financially unsustainable, and perceived as unfair.

The system's complexity means that many potential beneficiaries do not understand what they are or will be entitled to. A recent survey for the Department of Health found that almost a third of respondents believed (incorrectly) that social care services would be entirely free at the point of need (Samuel 2008). In the case of funding for older adults, this means there is a serious risk that a significant number of individuals will not be prepared financially for the care costs that up to a third of them are likely to incur in older age.

There are considerable local variations in services, with a trend towards funding only those with critical needs—in 2007–08 72 per cent of councils were excluding those in the low or moderate needs bands (CSCI 2008). It is widely accepted that this is a system that has a high level of unmet need. Taken together with the fact that some individuals have to sell their homes to pay for residential care, it is not surprising that the current arrangements are perceived to be fundamentally unfair (Caring Choices 2008).

Yet despite all these failings, it has been estimated that without reform, the current system could result in a state funding shortfall of £6 billion per year by 2026, even assuming annual budget increases of 2 per cent (HM Government 2009).

Over the past decade a number of authoritative reports have proposed alternative funding systems. The majority report of the 1999 Royal Commission on Long Term Care advocated “free personal care” paid for out of general taxation as the most efficient way of pooling the financial risk of long-term care (Royal Commission on Long term Care 1999). The review of social care funding for older adults commissioned by The King's Fund in 2005 favoured a “partnership model” of funding, combining a universal state entitlement with a top-up scheme in which the state matched individual contributions (Wanless 2006). The Joseph Rowntree Foundation recommended in 2006 that there should be a universal state entitlement covering 80 per cent of costs, supplemented by a 20 per cent contribution by individuals (Hirsch 2006).

Such approaches were supported by the findings of a nationwide consultation conducted by Caring Choices, a coalition of 15 organisations led by The King's Fund. In 2007 the coalition held a series of consultative events with older people, carers, social care staff and commissioners and found wide dissatisfaction with the current system and broad support for a funding model that involved contributions from both the individual and the state, and that was easier to understand (Caring Choices 2008).

Despite this activity, progress in bringing about reform has been slow. Initially the government insisted that no further changes were needed in the system of social care funding, and it was not until the publication of The King's Fund Review that it announced its intention to bring about fundamental reform. Even after

¹⁰² For more information: Mind (2008) Response to CSCI review of FACS eligibility criteria for social care services

this pledge, it has taken almost two years for a Green Paper to be published and legislation will not be possible in this parliament. The financial context in which the debate will now take place is of course very different from the one that existed when The King's Fund review was published.

Nevertheless, The King's Fund strongly welcomes the opportunity for debate and engagement offered by the Green Paper. The funding environment may have changed, but the needs of older people and disabled adults are as great and in some cases greater than ever. The Green Paper provides an opportunity to engage the public, the political parties and other groups with an interest in this issue, and if at all possible, the chance to establish a consensus that could secure an enduring agreement on the shape of future funding.

SHAPING THE FUTURE OF CARE TOGETHER

The Green Paper offers a compelling analysis of why radical reform is needed, recognising funding pressures, demographic change, higher expectations and widespread dissatisfaction with the current system.

The government's vision for a new system that is "fair, simple and affordable" (Secretary of State for Health 2009) aligns closely with the four key tests The King's Fund developed to assess any proposed new funding arrangements: that it be fair, understandable, effective and enduring (The King's Fund 2009).

A National Care Service: the idea of a National Care Service is for there to be nationally defined entitlements based on need. It should be noted that four of the six elements of the proposed new service—prevention, advice and information, personalised support and joined-up delivery—are already being implemented by local authorities as part of the "Putting People First" programme. In this sense the Green Paper connects funding reform with a better model of delivery, which is to be welcomed—the objective is not just to find a better way of funding but to provide a different way of responding to people's need.

We welcome the proposal for a national assessment process in which help is determined on the basis of what people need rather where they live. Research has shown that those who use or are affected by the service and also the wider public regard the current variations as unfair—tackling the so-called postcode lottery is entirely justified. However, the experience of the NHS after more than 60 years is a useful reminder that a national approach alone is not enough to ensure geographical consistency.

Funding choices: the "partnership model" of funding favoured in the Green Paper follows some (though not all) of the principles advocated in The King's Fund's review, and supported by the Caring Choices consultative events. We believe that a system in which responsibility for funding is shared between the individual and the state is the right starting point.

The government is also right to consider how Attendance Allowance might be considered as a future source of funding; it has been described by some as the original personal budget (Hunter 2009), and it makes sense for it to form part of a single funding stream for social care, as we advocated in our 2006 Review. However, there are other options; for example, Attendance Allowance could be retained in its current form but be subject to a means test, thereby focusing it on those with lower incomes or fewer assets. The major challenge is to ensure that as far as possible any new system offers the freedom and flexibility enjoyed by current recipients, and that it represents a genuine enhancement of the service and is not a way of shifting from a cash payment to a rationed and prescribed service.

We also agree that it is fair to expect those who are able to pay for their accommodation costs to do so, and we support the government's proposals to introduce universal deferred payment mechanisms that will allow these costs to be met through charges on someone's estate once they have died. Local authorities have powers under section 55 of the Health and Social Care Act 2001 to take a legal charge on a care home resident's main or only home instead of seeking contributions from the individual. Take-up appears low for a variety of reasons.

Although the Green Paper refers to the extent to which funding arrangements should be the same for working age adults and older people, it does not directly address the different needs of these groups nor how each option would work in practice. As a result there is a view that the funding options focus largely on older people. Two of the three options involve insurance that would not be relevant to most younger adults with disabilities whose need for care will already be apparent. And, unlike older people, many of them will not have had the opportunity to accumulate significant savings or assets. For these reasons, under the proposed "partnership" option, many adults with disabilities would continue to receive their care free. This would also be the case under the "insurance" option (because they would qualify for free care under the "partnership" element). The "comprehensive option" is described by the Green Paper as being "for people of over retirement age" but there is a commitment to "look at having a free care system for people of working age alongside this". The implication appears to be that by default under all three options, adults of working age would continue to receive "free" personal care either through means-testing or a new system funded by general taxation.

It is worth noting that councils are experiencing severe pressures on their budgets for learning and physical disabilities and this will be increased by further improvements in life expectancy in these groups. The rise in demand is not just because the population is ageing, and any assessment of need and the resources required to fund it must address demand across the whole age range.

None of the options in the Green Paper deals specifically with one widely expressed concern about the unfairness of the current system—the plight of those with modest means who have saved prudently throughout their lives. The proposal for a basic entitlement will, of course, be of benefit to this group but our original partnership model proposed that in addition to the basic entitlement, the state would match individual contributions pound for pound. This was designed to reward thrift and provide an incentive for individuals to contribute to the costs of their care.

TOWARDS A NEW SYSTEM

The Green Paper marks an important milestone on the journey to a reformed system, and the promise of a White Paper next year is encouraging. But realistically attention must focus on what can be done to support change in the next parliament.

The surprise announcement by the Prime Minister at the Labour Party conference that the government plans to introduce free personal care at home for those in highest need may have some merit as a transitional measure but it does not reduce the urgent need for comprehensive reform. We are concerned too about various aspects of this proposal and the fact that there has been no discussion or debate about the implications before it was announced. This is all the more surprising as it emerged halfway through consultation on a Green Paper that had taken more than a year to develop and that had explicitly ruled out free personal care as an affordable option.

Economic recession and the inevitable squeeze on public spending will make radical reform harder to achieve. The imminence of the general election makes reaching any form of political consensus unlikely within the next year. Yet the underlying demographic and funding pressures will continue unabated, and there is a desperate need to maintain the momentum for reform. In the meantime there are steps that could be taken to ameliorate some of the more blatant flaws in the current system, such as raising the ceiling on current assets, which determines whether an individual in a care home is entitled to local authority support, from £22,250 to £42,500, and lifting personal allowances, as recommended by the Joseph Rowntree Foundation (JRF 2009).

Despite efforts to transform the way social care is delivered through personalisation and the “Putting People First” programme, the system remains largely unreformed and significantly underfunded. The real terms increase in adult social care spending over the past 10 years has been half that of the NHS and less than many other public services. It is clear that the options and costs set out in the Green Paper are indicative and will change according to public spending decisions and priorities.

For that reason alone there needs to be much greater openness and clarity about the costs of each of the options and the impact they would have on individuals. We need to understand more clearly how benefits will be brought into the new system and how this will affect future claimants. The Green Paper has left the position of working age adults unclear; unless this is addressed it is likely to encourage suspicion and hostility rather than open engagement.

There is much to do before the aspirational goals of the Green Paper can be translated into specific and detailed proposals; as a consultation document it is perhaps inevitable that it has raised more questions than answers, but the options must be firmed up before anyone can take a definitive view about whether there is one that should be taken forward. The proposal for a National Care Service, and getting the right balance between national consistency and local flexibility, have elicited particular comment. The promise that people will enjoy “joined-up services” is laudable but the means whereby this will become a consistent reality have yet to be specified.

The King’s Fund intends to contribute to the development of a consensus on reform of social care in several ways.

- The King’s Fund will play a continuing role in highlighting the issues and seeking to influence policy thinking across the political spectrum.
- We are revising our original partnership model to take account of developments and policy changes since our 2006 Review. We are exploring whether this has the potential to offer a credible and financially viable option that would also address current concerns about the extent of unmet need; this would then be evaluated and, as far as we are able, costed alongside the options proposed in the Green Paper.
- The King’s Fund is working with the Social Care Institute for Excellence to look at how a National Care Service might operate in practice and the implications for other areas of policy, for example, the NHS. In his speech to the Labour Party conference, the Prime Minister placed a rather different and more integrated meaning on the term “National Care Service” than that set out in the Green Paper.
- We are considering how to develop further ideas about offering joined-up services in the light of past efforts to integrate health and social care and what can be learnt from international experience.

We would welcome the opportunity to discuss The King’s Fund work in all of these areas.

REFERENCES

Caring Choices (2008). *The Future of Care Funding*. Available at: www.kingsfund.org.uk/research/publications/the_future_of_2.html (accessed on 22 September 2009).

Commission for Social Care Inspection (2008). *Cutting the Cake Fairly: CSCI review of eligibility criteria for social care*. Newcastle: Commission for Social Care Inspection. Available at: www.scie-socialcareonline.org.uk/profile.asp?guid=a859d15f-afc1-4939-a821-0a637e706f4d (accessed on 30 September 2009).

HM Government (2009). “Technical note: The £6 billion funding gap for adult social care”. Care Support Independence website. Available at: <http://careandsupport.direct.gov.uk/wp-content/uploads/2009/04/technical-funding-doc-0807081.pdf> (accessed on 22 September 2009)

Hirsch D (2006). *Paying for Long-term Care: Moving forward*. York: Joseph Rowntree Foundation. Available at: www.jrf.org.uk/publications/paying-long-term-care-moving-forward (accessed on 22 September 2009)

HM Treasury (2008). *Pre-Budget Report 2008: Facing global challenges: supporting people through difficult times*. Cm 7484. London: The Stationery Office.

Hunter M (2009). “Campaigners say no to green paper’s proposal for attendance allowance”. *Community Care*, 19 September. Available at: www.communitycare.co.uk/Articles/2009/09/11/112560/campaigners-say-no-to-green-papers-proposal-for-attendance.html (accessed on 30 September 2009).

Joseph Rowntree Foundation (2009). *Options for Care Funding: What Could be Done Now?* Available at: www.jrf.org.uk/sites/files/jrf/care-funding-options.pdf (accessed 22 September 2009)

The King’s Fund (2009). *Parliamentary Briefing: Forthcoming Green Paper on funding social care in England*. Available at: <http://www.kingsfund.org.uk/document.rm?id=8304> (accessed 22 September 2009)

Samuel M (2008). “DH survey reveals one-third believe future care will be free”. *Community Care* website. Available at: www.communitycare.co.uk/Articles/2008/11/28/110095/dh-survey-reveals-depth-of-public-ignorance-about-care-funding.html (accessed on 30 September 2009).

Secretary of State for Health (2009). *Shaping the Future of Care Together*. Cm 7673. London: The Stationery Office. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102732.pdf (accessed on 22 September 2009).

Wanless D (2006). *Securing Good Care for Older People: Taking a long-term view*. London: The King’s Fund. Available at: www.kingsfund.org.uk/publications/the_kings_fund_publications/securing_good.html (accessed on 22 September 2009).

October 2009

Memorandum by UNISON (SC 26)

SOCIAL CARE IN ENGLAND

1. PERSONALISATION OF SOCIAL CARE SERVICES

1.1 Our research to support UNISON’s response to the Green paper “Shaping the Future of Care Together” shows that Councils are facing an impossible task of delivering personalised care and support to meet growing demand with no extra funding whilst also trying to generate efficiency savings.

Please also see attached in support of our inquiry response:¹⁰³

Appendix A: *Cash or Care? 10 essential questions for councils on personalisation* UNISON June 09

Appendix B: *Who cares about Homecarers?* UNISON June 2009

We also have concerns on how social care provision is developing within the transitioning period between now and the phasing in of a new proposed National Care Service in 2014.

As a result of underfunding personalisation is becoming synonymous with less choice, increased privatisation and growth of an unregulated care service.

¹⁰³ Not printed—contact UNISON for further information.

1.2 We have set out key areas of concern in relation to the impact of personalisation of services:

(i) The provision of consumer choice in opting for either a personal budget, direct payment or individual budget has in some areas decreased the choice of services rather than increased or diversified the care market. Some local authorities have been unable to deliver requested services they have traditionally provided.

For example there has been an increase in local authorities claiming that the introduction of Direct Payments is forcing them to close day care centres. The evidence from our members is that Councils are unwilling to provide services at a reduced capacity and are blaming Direct Payments as a result. However UNISON believes that this could be averted if recipients of Direct Payments were allowed to purchase local authority services along with Personal Budget holders. Direct payments can not be used as an excuse to close down local services.

These services need to be maintained as local authorities still retain a duty of care for those they support and are therefore responsible for making alternative arrangements when services are interrupted or break down, or needs suddenly change.

UNISON believes that certain local authority services need to be ring fenced to protect and guarantee local well run services as a sustainable choice for people wanting a Personal Budget and not a Direct Payment. Direct Payment holders should be free to purchase local authority services if they wish.

(ii) Our research shows that some local authorities are not offering people the choice of arranging and providing a service (Personal Budget) but only offering them a Direct Payment and therefore asking people to arrange their own care services or activities.

“Personal budgets are great for younger people and older ones who have need of detailed services and have the ability and desire to organise them...helping them do this can be very satisfying but cannot always be done rapidly. The principle that all service users have to have individual budgets for a minimal service is inappropriate. Most frail elderly people just want a service arranging.”—Social worker and UNISON member

UNISON believes that care recipients need assurance and a guarantee on their right to choose which type of budget they want and which type of service they want. This will further help to nationally standardise local access and provision of equal quality services and end the post code lottery in the proposed National Social Care Service.

(iii) UNISON would like to see a guarantee that Direct Payments and Individual Budgets will be uprated each year to reflect rising costs so they maintain their real value. Currently some local authorities do not have any agreed indexing of rates, leaving it to individuals to seek to negotiate uplifts.

UNISON would like to see the proposed “efficiency board” (Social Care Green paper 2009) to focus on monitoring costs of best value and quality of services. The board should implement a transparent annual review of rates or tariffs and provide recommendations and guidance for all stakeholders.

(iv) UNISON believes that service users also need to be guaranteed the time they need to work with qualified and accountable adult social workers in assessing needs and deciding how to meet them. UNISON branches are reporting that some local authorities are using the personalisation agenda to remove, reduce and not replace professional adult social care workers in care teams. Instead less qualified staff are taking on the role of social workers who are now required to behave more like brokers than managers of care.

“Social workers...are key to supporting self-assessments, understanding people’s aspirations and ensuring they have access to personalised support Self-assessment was widely viewed as a misleading term, and in practice it was found that self-assessment entailed intensive support from care managers...it was more demanding of staff time and skills than traditional professional assessment.”—CSCI, The state of social care in England 2007–08

(v) Many people want to be able to direct their care more but do not want to be an employer or have the responsibility of managing their budget. Yet it seems many councils are only directing people to poor quality agencies as an alternative to direct employment, where they have to pay a core fee out of their budget for the provider to manage their budget.

UNISON believes more guidance and support for Local Authorities is needed to assist those who don’t wish to take up the responsibility of being a micro employer. The emerging evidence suggests that Local Authorities have not been provided with guidance in developing models to manage Personal Budgets and instead have developed budget management systems with private agencies.

The emergence of Individual Service Funds (ISFs) in some authorities has assisted those who would like to have budgets managed on their behalf by agency providers. However the core management and support costs charged by providers for this service are currently 10–15% of an individual’s budget which means that they don’t get the same amount of money to buy services as an individual employer may through direct payments (particularly if they have multiple ISFs with different providers). In other words they are financially penalised for not wanting to take over the responsibility of direct management and employment responsibilities of their personal budget. The claims of efficiency savings on funding social care needs using this type of service delivery model must be questioned.

Local authorities should be able to keep support and budget brokerage services in-house which could be modelled in many different ways but most importantly retain the accountability and risk of care provision.

UNISON believes that there is a need to pilot and review a service delivery model based on Local Authority management of Personal Budgets. This brokerage and budget management role should be serviced by an in-house (employed directly by local authority) pool of Personal Assistants (PAs) meet individual assessed support plans and with established good practice and terms and conditions for care workers.

Like mortgage brokers and financial advisors we believe that there is a need for the regulation of the roles of “support brokers” and budget managers with clear national guidelines with risk assessment and training requirements.

(vi) There need to be standard national guidelines to ensure that people using Direct Payments to employ care workers are fully equipped to meet all their legal responsibilities as employers and employees are clear of their employment rights and responsibilities.

UNISON branches, Employment Tribunals and Citizens Advice Bureaux are all reporting casework involving workers employed under direct payments. In some cases the individual employer has no liability insurance, in many cases individuals were not aware of the full range of employment responsibilities, and often there is no agreement as to who will pay tribunal awards. Other evidence shows that service users often feel ill-equipped to deal with aspects of the employment relationship.

“There were a significant number of employees who did not enjoy their minimum employment rights and there were a significant number of employers who were at risk of having awards given against them at Employment Tribunal”

Scottish Personal Assistants Employers Network and UNISON, Creating and supporting an informed employer and employee relationship within the self directed support sector, 2009

UNISON would like to work with employers, service users, the government and local authorities to establish a Code of Practice on the employment of Personal Assistants and a framework for pay and conditions. This would include direct payment tariffs and model contracts which would enable a decent employment package for PAs with access to training and development, using local authority pay and conditions as the benchmark.

All the evidence suggests that without this there will be increasing casualisation with a risk to creating a quality National Care Service.

(vii) UNISON believes that more guidance is needed to assist local authorities in their obligations to safeguard vulnerable people and ensure that providers and micro employers have been involved in establishing how risk management works and where lines of accountability lie. There is currently uncertainty around risk elements of personalisation.

“Managing risk—putting more choice and control in the hands of people with support needs increases flexibility but has reduced the control the council has over services. This requires a closer working relationship with providers involving more trust than has always been the case in the past.”

Managing risk is also more complicated where providers have been selected in a locality basis delivery framework. Here the providers use further subcontracting to ensure that they meet their requirement to cover all levels of support needs.

(Contracting for personalised outcomes. Learning from emerging practice DH August 2009)

Staff are also concerned about the potential for targeted abuse of people who are receiving cash for care and employing their own PAs without requirements for PAs to be registered with the Independent Safeguarding Authority (ISA) and go through the vetting and barring disclosure.

“Not enough thought had been given to protecting people using self-directed support. CRB checks on potential employees were not offered automatically to each vulnerable person, but only if they specifically asked. There had been no strategic consideration of the council’s duty of care versus the less formal arrangements that self-directed support brings.”—CSCI, The state of social care in England

(viii) In conclusion with regard to personalisation operating through the proposed National Care Service UNISON believes that

- cash for care (Direct Payments) should allow for users to opt for in-house (local authority run) services
- personal budgets holders should have the choice of local authority support and budget brokerage services and be serviced by an in-house employed personal assistant if requested
- councils should have the genuine choice to retain and develop a comprehensive in house service which delivers genuinely personalised care
- cash for care should be subject to the same regulation regimes, vetting and barring schemes, financial scrutiny, employment law, health and safety, and training requirements as other forms of home care

- certain local authority services, such as day care centres, need to be ring fenced to protect and guarantee local well run services as a sustainable choice for people just wanting a Personal Budget and not a Direct Payment
- a Code of Practice on the employment of Personal Assistants, and a framework for pay and conditions needs to be developed involving unions, service users and local and central government
- national guidelines on risk and vulnerability are needed to end the current uncertainty of where boundaries of risk assessment and responsibility lie

2. *More effective, consistent and user-friendly social care services.*

2.1 The level of privatisation in homecare exceeds that in almost any other public service and has created many problems for our members and service users. Among the most obvious are:

- Under-funding and the profit motive in the private sector, leading to poor pay and conditions and lack of training and high turnover affecting quality of service to many clients
- The use of “spot” contracting, which prevents application of the TUPE Regulations which protect pay and conditions of staff who transfer between employers
- The exclusion of spot contracting from the Local Government Code of Practice on the Two Tier Workforce, which aims to stop low paid contract workers being started on lower pay and conditions than transferred staff from Local government

2.2 There is growing evidence to suggest that privatisation has not generally improved the quality of the homecare service. Indeed, there is growing evidence to the contrary which suggests that highly fragmented, outsourced care is unpopular with many users and that the independent home care sector is struggling to recruit and retain staff. UNISON is receiving increased examples from its branches of poorly managed care services run by large UK care agencies.

“Understandably, these practices have contributed to very high turnover rates. Norma estimated that there were 50 unfilled vacancies in the service, requiring the company to bring in agency staff from elsewhere in the country. Ironically, these staff were much more expensive to employ, earning £90 a day, with the company paying to house them in hotels and transport them to calls by taxi.”— UNISON submission to Low Pay Commission 2009

2.3 In its 2009 report the Low Pay Commission raised concerns about the pressure on public authorities to keep costs down by commissioning care as cheaply as possible. “We continue to be concerned by the shortfall in funding experienced by many social care providers,” and recommends that “the commissioning policies of local authorities and the NHS should reflect the actual costs of care, including the National Minimum Wage”. National Minimum Wage Low Pay Commission (2009)

The case study below indicates that pay practices in the sector may be in violation of the National Minimum Wage.

“But the pay practices of Model Care still left many workers struggling to earn a decent wage. Rather than being paid a straight-forward hourly rate, the workers were paid a set amount per call, with different rates for calls of 15, 30, 45 or 60 minutes. Crucially, five minutes of travel time between calls was unpaid, so staff could lose as much as 15 minutes pay per hour. A typical rota of 14 calls shown below, totaling just over just over eight hours work, would earn the home carer just £46.20 or £5.71 an hour for staff TUPE’d over from the previous contract. The rate was even lower for new staff taken on by Model Care. They would earn an average of £5.40 an hour for the same 14 calls.”—UNISON submission to Low Pay Commission 2009

There is clearly a major problem with a system that seeks to outsource its home care provision and then underfunds it both for the users and the workers.

2.4 UNISON has concerns that in the transition to the National Care Service the continued underfunding, personalisation and privatisation will result in poor quality private services.

2.5 UNISON believes that now is the time for local authorities, service users and the local workforce to develop a positive alternative by actively working to invest in and re-build homecare services which are responsive and tailored to service user control—recognising the advantages of in-house provision when it comes to reliability, accountability and quality. We believe that this can include a range of models of care and will require a move away from commissioning processes which repeatedly seek out the providers which can provide a 15-minute homecare visit for the lowest price.

Critical to the success of this will be having a stable, flexible, well-trained workforce with capacity and time to respond to individual needs, employed on decent pay and conditions.

WORKFORCE ISSUES

2.6 There are stark differences in terms of pay and conditions between employees in the private and public sector. For example in the 2009 UNISON “Time for change” survey it found that 43% of staff received unsociable hours payments compared to the norm of 24/7 zero hours payments in the private sector.

2.7 As the table below demonstrates, the private sector is the lowest payer by some distance and the differential between “care worker” and “senior care worker” is the lowest, suggesting little incentive for workers to undertake training (and limited opportunities for career development).

Median pay rates by sector (source NMDS-SC, December 2008–February 2009)

<i>NMDS-SC job role</i>	<i>Private</i>	<i>Voluntary</i>	<i>Statutory</i>	<i>All sectors</i>
Care worker	£6.30	£7.04	£6.80	£6.56
Senior care worker	£6.75	£8.34	£9.11	£7.00
Registered manager	£26,000	£26,734	£28,270	£27,175

2.8 With such low pay and poor conditions it remains difficult for the social care sector to recruit, retain and develop a skilled, committed and stable workforce. As at April 2008, the NMDC-SC reported that in England, care worker turnover rates are highest in the private sector—23.6%—and considerably lower in the statutory sector—9.6%.

2.9 UNISON believes that the problem with recruitment and retention of staff is particularly aggravated in home care services because of the generally very poor pay levels, training and lack of career development opportunities.

The government must also acknowledge the crucial role currently played by migrant workers in the care sector and ensure that its desire to take a “tough stance” on immigration does not undermine quality and continuity of care

2.10 The right to training for home care workers is vital because of the skills required to do the job and only a well trained workforce can provide a high quality of care for users. A clear career progression path must be embedded in local workforce development plans.

2.11 UNISON supports proportionate and effective forms of professional registration and regulation to ensure the safety and wellbeing of care users and to drive up training levels and care standards in the care sectors. UNISON would like further clarification over the proposals of domiciliary care workers and personal assistants to register with the General Social Care Council (GSCC). UNISON believes that employers need to pay fees if they are to recruit and retain staff and homecare workers. UNISON is also campaigning for employers to meet the costs of Independent Safeguarding Authority (ISA) vetting and barring registration.

2.12 Home care is one of the best examples in local government of a service that has responded to the changing needs of the service and service users. UNISON wants to work with all UK governments to develop adequate investment in the service and workforce measures, to tackle the vicious circle of high vacancy levels, high turnover and chronic recruitment difficulties. We believe that all those involved must also seek to raise the visibility and status of social care work.

UNISON believes the following action is required:

- an adult workforce programme developed in partnership with unions, employers and government and funded to at least the same levels as the children’s workforce
- statutory enforcement of the Code of Practice for Social Care Employers so that employers are held to account for their responsibilities to skill and equip their workers to deliver high standards, just as workers are held to account against their professional code
- an extended focus on workforce issues and standards within the inspection and enforcement work of the Care Quality Commission
- the inclusion of specific requirements on qualifications and training in any revised National Minimum Standards for care, extending targets for NVQ2, introducing requirements for the provision of NVQ 3 training and other core training requirements
- migrant labour to have the same opportunities as non migrant labour to prevent a two tier workforce happening
- 50,000 apprenticeships to be embedded in future career structures
- paying previous unpaid informal carers as personal assistants
- employment rights and responsibilities and vetting and barring to be regulated and addressed for micro employers and personal assistants

3. FUNDING OPTIONS

3.1 UNISON has put forward in its Green paper response that the personalisation agenda, the increase in privatisation at a time of volatility in the home care private market and the desire to create a national social care service make this an ideal time to rebuild in-house (local authority run) homecare services.

3.2 UNISON supports a universal (National Insurance) model of national social care based on the principles of the NHS. The Government's funding settlement must support good quality care services by improving working conditions and addressing staffing shortages.

3.3 UNISON believes that the role of local government as set out in the Green paper:

- Channel state funding and support
- Undertake assessments
- Provide information, advocacy and care management
- Provide and commission services and manage the market of care and support providers
- Foster innovation in care and support

should be supplemented with the increased roles of local authority in-house services as set out within this inquiry response.

*“Personal experience shows that the main choice service users want is to receive consistent services that are arranged and managed professionally. With the right political will, it should be possible to integrate services, employing trained (and unionised) carers whose services could be flexibly input according to an individual need. This would also solve some other problems such as safeguarding, risk and monitoring.”*UNISON branch 2009

October 2009

Memorandum by the Care Quality Commission (SC 27)

FUTURE OF SOCIAL CARE SERVICES

1. EXECUTIVE SUMMARY

1.1 The Care Quality Commission has a key role and unique perspective to assess the impact or potential impact on people, councils and services of proposed system changes.

1.2 We would like to stress the urgency for progress in taking the proposals forward, and the need for cross-party support and engagement to take this forward.

1.3 Social care policy has been developed in the context of an aim to make care better for everyone underpinned by safeguarding, the development of the quality ratings system, and reviews including Putting People First, and the personalisation agenda. There are different understandings of—and commitment to—“personalisation” by councils, partner agencies, people who use services and carers.

1.4 Our evidence demonstrates that most people are still experiencing a “one-size-fits-all” model of care that is not geared towards people's individual needs—particularly for self-funders, for people under the age of 65 with long term care needs, and those falling below eligibility criteria. There is an expectation that access to provision will get worse before getting better for people in this latter category as financial pressures may lead to eligibility criteria being tightened even further leading to more people having to rely on family, friends, carers, with additional costs and pressures being passed to the NHS when people are unable to cope or their needs change. Building on the finding of our predecessors, CQC's priorities are: ensuring care is centred on people's needs; championing joined-up care; identifying poor quality care and ensuring swift action to help eliminate it; and promoting high quality care for all.

2. ABOUT THE CQC

2.1 The Care Quality Commission (CQC) is the independent regulator of all health and adult social care in England. We came into operation on 1 April 2009, combining the functions of the Healthcare Commission, Commission for Social Care Inspection and the Mental Health Act Commission. We inspect all health and adult social care services in England, whether they're provided by the NHS, local authorities, private companies or voluntary organisations. We also seek to protect the interests of people whose rights are restricted under the Mental Health Act.

2.2 We make sure that essential common standards of quality are met everywhere care is provided, from hospitals to private care homes, and we work towards their improvement. We promote the rights and interests of people who use services and we have a wide range of enforcement powers to take action on their behalf if services are unacceptably poor. We aim to make sure that better care is provided for everyone.

3. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

3.1 The government commissioned a comprehensive review by the Commission for Social Care Inspection (CSCI) into the current eligibility criteria for social care services. The recommendations from the review were published in the CSCI report “Cutting the Cake Fairly” in January 2008. These recommendations included the proposal to replacing the Fair Access to Care System (FACs) with a system under which resources were allocated to individuals at three levels of “priority for intervention”:

- Immediate—without immediate support a person’s well-being would be seriously threatened.
- Early intervention—well-being may be threatened within six months without support.
- Longer-term intervention—well-being may be threatened within a year without support.

3.2 The government did not adopt this recommendation in the draft eligibility criteria guidance it issued for consultation in July, and which will apply until the Green Paper’s proposals are implemented in around 2014.

3.3 People who use services tell us that it is not always easy to get information and advice about care services. We also know that care assessment practices and outcomes vary from area to area. CQC therefore strongly supports the aspects of universality set out in the green paper: information, advice, advocacy, as well as a national assessment. This helps add clarity to what can be a highly complex and stressful process whilst levelling the playing field.

3.4 On changing the current system of care and support, there is a real need for urgency about moving not only the debate forward, but also reform right through to implementation. People who are denied access to care and support now will find it even tougher as financial circumstances tighten, and they will be joined by more people as eligibility criteria for accessing care services potentially rise. This is a crucial time to secure cross party support to drive reform.

3.5 Given the important role the Government has given regulators in improving quality and getting at the root of people’s experience of services, it is surprising and disappointing that regulation hardly features in the Green Paper. We hope to focus our work on these issues by including it in our corporate priorities to “identify poor quality care and ensure swift action to help eliminate it.

3.6 It is important that whichever funding option is decided it is simple, fair and sustainable. Also that it is clear about the help available to all people and not just those who are aged 65 and over. Younger adults with long-term care needs make different choices from people who are preparing for the end of their lives: choices about going to university or entering employment therefore also need to be factored in to issues around funding, including links to the benefits system. There also needs to be a minimum level of care assured to help minimise the current postcode lottery, and reduce health inequalities.

3.7 A new funding deal needs also to increase the level of funding available for social care, not only to address demographic pressures but also to tackle current unmet need, low quality care and low wages in the care sector. It is unlikely that sufficient funding could come from a purely tax funded solution; there will be a need also to address the total picture of welfare benefits, taxation from working age contributors and means related contributions from retired age groups.

3.8 Flexibility in support—we want to see an end to the one size fits all approach which still exists. Support needs to be good quality, flexible, personalised and adaptable to anticipate and meet people’s changing needs and lifestyle choices. Support also needs to be consistent wherever people live. Systems should not get in the way of people moving from one area to another and needing new assessments and then losing some or all of their care package. Fairness and transparency in funding should underpin flexibility in support.

3.9 An issue that remains unclear is the relationship between the National Care Service and the National Health Service. For example, we would like to see greater emphasis on a requirement for the NHS and Councils to have to work much more closely to tackle the challenges of delivering greater personalisation, managing demands given the demographic changes and delivering care closer to home.

3.10 CQC welcomes the proposal for a stronger research body to establish the evidence base for social care. CQC believes that the Social Care Institute for Excellence is well-placed to take on this role. We would be happy to continue to work in partnership with SCIE to contribute evidence from our regulatory activities to help inform and strengthen the social care evidence base for the benefit of people who use social care services.

3.11 As cited earlier, the ongoing social care needs of people below the age of 65 are very different to those above 65, and as such did not receive the prominence in the Green paper that they warrant. Their different needs, choices and aspirations require very different choices, including education, employment, where and how they live being supported by tailored services which assist them to make the right choices for them. Any system reform needs to ensure these needs are acknowledged and integrated from the start.

4. PERSONALISATION OF SOCIAL CARE SERVICES

4.1 There are different understandings of—and commitment to—“personalisation” by councils, partner agencies, people who use services and carers. CQC is strongly committed to this agenda and we are using a definition of personalisation put forward by our predecessor the Commission for Social Care Inspection, which is that “personalisation” means putting people at the centre of the design and delivery of services, acting to respect their rights and choices, and providing support to enable people to live their lives the way they wish.

4.2 In the State of Social Care in England 2007–08 CSCI found that councils and partners are adapting to the personalisation agenda, however they are still at an early stage in transforming social care. There has been progress over the last six years, with steady improvements. More people are able to control and choose their support through, for example, direct payments, individual budgets and good person-centred assistance, with some outstanding examples of people’s lives being radically improved. We have also found that personalised care does not always automatically mean direct payments and budgets—service users want to be in the driving seat by shaping their care but not always controlling their budget or becoming an employer. Ongoing support and follow-up are an important issue which we will continue to monitor, particularly for people being given a direct payment by the council and then basically left to fend for themselves.

4.3 Our evidence, however, shows that most people are still experiencing a model of care that is not geared towards people’s individual needs. In particular, people with multiple and complex needs, and people under the age of 65 are often still having little if any choice about their care. As with direct payment recipients, ongoing support and follow-up are important issues we will be monitoring closely.

4.4 We have concerns regarding the impact of the recession upon quality. With the expected reduction in budgets post 2010 we believe that these factors could combine and be used as excuses for quality being compromised, rather than challenges which need to be considered and addressed to produce innovation and transformation. This will also mean less capacity for self-funders, as their assets and income are squeezed. We are currently scoping a special review on the impact of the financial downturn on the quality of care, and expect to publish more information on this in late spring 2010. We would of course be happy to share this work with the committee. We will be looking at how pathways across health and social care can be re-engineered to reduce costs and improve quality, through avenues such as pooled budgets, joint commissioning and much closer integration of care pathways.

4.5 Safeguarding is another important consideration in the future of social care services and for all aspects of our work. We use our unique perspective across social care and health to report on our findings about safeguarding issues, including along care pathways where for many people boundaries between social care and health are not real. It is essential that partners are working together and sharing appropriate information at the right time to help keep people safe.

4.6 Whilst we welcomed the Department of Health’s work with the No Secrets consultation earlier this year, in November 2008 CSCI published a study on the effectiveness of arrangements to safeguard adults from abuse,¹⁰⁴ which found that there was:

- Uneven progress in developing effective safeguarding arrangements by councils and care services
- Variability in the quality of support to people who experience abuse and a lack of clarity about the outcomes for victims of abuse
- More attention is needed to establishing appropriate and individually tailored safeguards for people directing their own support
- Variability in the focus on preventing abuse and long term support to people who have been subject to abuse
- a big difference between the best and worst performing councils in relation to their responsibility for establishing and co-ordinating local multi agency safeguarding procedures (best councils have active leadership and strong partnership working)

4.7 In terms of our regular inspections against minimum standards, the evidence shows that quality ratings are improving. Today a higher proportion of services are rated good or excellent and a smaller proportion rated poor. For example poor and adequate ratings have reduced by 33% (from 24% to 16%) from August 2008 to September 2009 and good and excellent ratings have increased from 72% to 79% in the same period.

4.8 The State of Social Care in England 2007–08 report highlighted that information and advocacy services still require improvement. People, whether they fund their care or are publicly funded, are not

¹⁰⁴ CSCI, *Safeguarding adults: A study of the effectiveness of arrangements to safeguard adults from abuse*, November 2008, [http://www.cqc.org.uk/_db/_documents/safeguard\[1\].pdf](http://www.cqc.org.uk/_db/_documents/safeguard[1].pdf)

always getting the advice and support needed to make decisions about their care. These services need to be extended to all sections of the community, including people with multiple and complex needs. The Green Paper proposal to ensure universality of information and access to advocacy is therefore welcome.

4.9 In addition, the CSCI report “Supporting Disabled Parents” published in February this year highlighted that only 17% of councils we surveyed had collected any information about disabled parents and their families living in their area so few are planning and commissioning services on a basis of knowledge.

4.10 Another concern in relation to personalisation are the slim references to carers within the green paper. There is acknowledgement of the support that carers need, how they also need to have choice, including staying in employment, but there is hardly the clear recognition that their embedding in all functions is required. We are working with our Carers Advisory Board on a strategy to advance carers issues, particularly on recognition. One of the ways that we are currently considering doing that is through their greater involvement in our inspections, which allows them to play a role in calling councils and PCTs to account.

5. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

5.1 CQC’s five year strategic plan—to be consulted on from September 2009—identifies five objectives, four of which have important resonance for future social care services:

- Ensure care is centred on people’s needs
- Championing joined-up care
- Identifying poor quality care and ensuring swift action to help eliminate it
- Ensuring and promoting high quality care

5.2 Championing joined up care is one of these key priorities, and one of the ways we are currently assessing this, and responding to an identified need, is through our special review into meeting the healthcare needs of people (adults of all ages) in care homes. This review is an in-depth analysis looking at the commissioning and procurement of services as well as service provision for people living in care homes across the NHS and within care homes. We are aiming for the local assessment reports from this to be published in summer 2010, with the national report published in late autumn 2010.

5.3 The broader remit of the Health and Social Care Act (including making the provision of certain social care services a public function under the Human Rights Act 1998) helps to ensure that human rights are at the heart of our work. We promote and protect the rights and interests of everyone who uses health and adult social care, particularly the most vulnerable people, for example people who are held under the Mental Health Act.

5.4 We will introduce a new registration system for the NHS from April 2010 and re-registration for independent healthcare and adult social-care in October 2010. We believe that this system will bring the following benefits to adult social care services, and also health care services:

- people who use services can expect all registered health and adult social care providers to meet essential common quality standards and respect their dignity and rights.
- the same set of standards will apply right across the care sector, making it easier for one provider to be compared to another and for providers to work together.
- it marks a change from regulation based primarily on policies, systems and processes to regulation based primarily on outcomes—what constitutes a quality experience for people who use services. It is being introduced in direct response to what people who use services, providers and stakeholders said was needed.
- Continual monitoring and checking will make sure that potential problems are identified early and that swift action is taken where services are failing people.

6. CONCLUSION

6.1 Based on our evidence, and the evidence of our predecessors, most people are still experiencing a model of care that is not geared towards people’s individual needs—particularly for self-funders, for people under the age of 65 with long term care needs, and those falling below eligibility criteria. There is also the growing expectation that access to provision will get worse before getting better for people in this latter

category as financial pressures increase. We are using this evidence to shape our work programme, particularly our performance assessment and special reviews.

6.2 We would be pleased to provide oral evidence to the Committee. For further information or if you have any queries, please contact the Care Quality Commission.

October 2009

Memorandum by the Royal College of General Practitioners (SC 28)

SOCIAL CARE

1. The College welcomes the opportunity to contribute to the Health Committee's Inquiry into Social Care.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the "voice" of GPs on issues concerned with education, training, research, and clinical standards. Founded in 1952, the RCGP has over 38,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

Comments on specific areas of the inquiry:

1. *Options for future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities*

3. The care and treatment of those who are significantly sick should be state funded; otherwise those without financial resources are likely to be disadvantaged. Dementia care should be a priority within nursing home care. However, a balance should be struck between clinical, treatment based care and non-treatment based holistic care. We must avoid an over-reliance on technical or drug-based solutions, especially if this is at the expense of person-orientated care. The latter can be far more important and effective for many patients, and resources should be allocated with this in mind.

2. *Personalisation of social care services*

4. Personalisation and choice should be encouraged, as long as the mechanisms of choice, such as personal budgets tariff systems, do not favour the articulate and motivated (or their relatives) at the expense of those who lack the confidence and capability to use such systems. There is a danger that with increased personal budgetary control of social care services, some people may deny themselves or a family member's treatment in order to avoid debt. For people on very low incomes with poor job prospects, the impact of debt would be crippling and would leave them open to possible manipulation and exploitation, as well as harming their self-esteem.

3. *More effective, consistent and user-friendly social care services*

5. Interpersonal contact between the patient and the carer produces the best care. However, such care requires continuity and time, and despite systems and controls there is a great deal of variability in quality.

6. With the decline in the communities and families, isolation has become a major societal problem, especially in urban environments. The form of and coordination of services is crucial in terms of strengthening communities. The general practice surgery is one of the only facilities left where individuals engage with their community. Consideration should therefore be given to reorganising facilities, including social care, around the general practice, in a process analogous to the Federated Practice.¹⁰⁵ Furthermore, local inpatients nursing (intermediate care) could be sited alongside practices with other services, such as community outreach. The co-location of services is explored in a paper by Dr Angela Jones, Chair of the RCGP Health Inequalities Standing Group, submitted to the Marmot Review on behalf of the College.¹⁰⁶ Such localism is likely to make a large difference to the problem of social isolation.

7. I gratefully acknowledge the significant contribution of Dr Andrew Spooner towards the above comments.

Dr Maureen Baker
Honorary Secretary of Council

October 2009

¹⁰⁵ Primary Care Federations: Putting patients first (RCGP, 2008) <http://www.rcgp.org.uk/PDF/Primary%20Care%20Federations%20document.pdf>

¹⁰⁶ Strategic Review of Health Inequalities in England Post 2010 (Marmot Review): An RCGP paper on the role of primary care in the reduction of health inequalities <http://www.rcgp.org.uk/pdf/Sept%2008%20Marmot%20Review%20Paper%20-%20for%20web%20gkm.pdf>

Memorandum by Independent Age (SC 29)
THE FUTURE OF SOCIAL CARE SERVICES

ABOUT INDEPENDENT AGE

Independent Age works to keep older people independent and out of poverty by providing them with practical support, financial help and lifelong friendship.

We focus on supporting those who are:

- Over 70
- In financial need
- Lonely or isolated
- Have made a sustained and significant contribution to society, particularly through voluntary work

The charity has around 6,000 current service users across the UK and Ireland. It is currently developing its services in order to better meet the needs of older people in today's society. Our aim is make sure that all those we help are receiving their entitlements from statutory and other providers and then to provide additional support tailored to the individual's particular needs. This support is likely to be a combination of:

- Regular befriending and support from an Independent Age volunteer visitor
- Financial help in emergencies
- Additional practical support, such as providing household items and toiletry packs for hospital visits
- Membership of the Independent Age community, including regular correspondence, magazines and cards on birthdays and at Christmas
- Increasingly, the opportunity to meet and correspond with other members of the Independent Age community

OUR RESEARCH

At Independent Age our experience is specifically in the context of older people. Our answers draw on the results of the following research:

- I. Our Annual Survey 2008 and our Interim Survey 2009, in which a series of topical questions on life, society, and our services were posed to 6,500 and 3000 of our beneficiaries respectively, to which 3,315 and 1,579 responded.
- II. A series of focus groups and interviews conducted by a research agency on behalf of Independent Age in 2008. Seven focus groups were held comprising between three and seven beneficiaries, and lasted between one and a half to two hours. Eighteen depth interviews were conducted involving one interviewer and one respondent, and in some cases respondents were paired, involving some couples. These interviews lasted between 45 minutes and an hour and a half. In total, 69 respondents were interviewed across three regions in England, including the North East, the Midlands and the South West.

We are currently in the process of conducting a series of 12 focus groups and in-depth interviews in six localities across the UK, and have included some preliminary evidence from our findings to date.

SUMMARY

This response will address the bullet points specified in the inquiry as follows:

1. The future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities

The implementation of any funding system must necessarily take into account the following:

- There is a current lack of awareness in society about the need to make provision for social care in later life.
- There is considerable confusion about the distinction between health and social care.
- Any new system must account for, and detail how, it will educate individuals about what is available and how it can be paid for.
- Individuals must be made properly aware of what the government will provide, and what they are expected to contribute.
- Regardless of the funding options considered, it is vital to take into account the totality of an individual's needs.
- Cost saving must not become the driving force behind the implementation of the personalisation and individual budget agenda.

2. *Personalisation of social care services*

- Independent Age welcomes the move towards personalisation in social care, but would like to highlight that poor implementation will negate any potential benefits.
- The concept of personalisation is a new one for many people. A new system must, as a matter of course, properly educate older people about what is on offer, how this will become available to them, and how they will be supported during the process.
- The system must be streamlined to ensure that those in need of care do not suffer from the burden of excessive paperwork and bureaucratic delays.
- It must be made clear to the recipients of social care what will happen if their needs change or increase, and how this will be addressed.
- Brokerage support is a key issue here, and specifically relates to the implementation of direct payments. The level of brokerage required may not be suitable in all situations.
- The right to have “choice” must include the right *not* to choose. We must consider what help individuals will need to make use of the choice available to them.
- Advocacy services are currently very limited in most areas and will take significant time to develop.
- The government must account for the time and cost of building and sustaining a new market.
- The nature of support required by the personalisation agenda will vary from the current forms of social work available in the present system. A culture change must be effectively facilitated.
- The current system of assessment and care management does not allow sufficient time for staff to develop the type of in-depth relationships with social care recipients that will be required to fully take advantage of the personalisation and individual budget agenda.
- Further support from families and/or the voluntary sector is likely to be essential, and the development of greater expertise in the voluntary sector will be required to support this.
- Increased flexibility may enable care providers to utilise the knowledge they have obtained about a person’s needs over a prolonged period of time in order to tailor support more effectively.
- Safeguarding must be an intrinsic part of any new social care infrastructure that involves the use of a variety of different services, providers and people, including friends and family.
- Safeguarding mechanisms must apply to both the care giver and the care receiver.

3. *More effective, consistent and user-friendly social care services*

- The personalisation agenda presents a number of opportunities to provide a more effective, consistent and user-friendly social care service.
- Less joint *working* between health and social care departments, and more joint *departments* could ensure clearer central guidance and increased resources for direct services than are evident in the current system.
- Older people need and want access to comprehensive, face-to-face advice on the social care system.
- Telecare services could cut the costs of providing social care. However, an increase in telecare services could also result in social care recipients receiving less social contact.
- Savings made by the use of telecare services should be used to fund an increase in services geared towards reducing the social isolation of older people.

The future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities

1.1 The implementation of any funding system must necessarily take into account the following:

1.2 There is a current lack of awareness in society about the need to make provision for social care in later life. There is also considerable confusion about the distinction between health and social care. Any new system must account for, and detail how, it will educate individuals about what is available and how it can be paid for. Individuals must be made properly aware of what the government will provide, and what they are expected to contribute.

1.3 Advice and information are key to the successful implementation of a new funding system. If required to make a contribution to their own social care, individuals should be presented with clear options on exactly how they can do this.

1.4 Regardless of the funding options considered, it is vital to take into account the totality of an individual’s needs and the true cost of these. A clear illustration of how the current system fails to take a holistic and therefore effective approach to older people’s needs is in the case of residential or nursing care. Members of Independent Age staff have found that the Personal Expenses Allowance is insufficient to meet an older person’s basic needs. The PEA does not enable older people living in these circumstances to

maintain a reasonable quality of life. For example, older people in residential care frequently find it difficult to obtain appropriate equipment, such as specialist chairs, or afford services to meet their basic needs, such as foot care.

1.5 Importantly, although in some circumstances personalisation has led to a degree of cost saving, this must not become the driving force behind implementation. To create an effective and sustainable system providing the level of brokerage and advocacy support, advice and information that is required to enable individuals to make the most of the choices available to them, an initial increase in funds is likely to be required. In addition, if the system is to adequately address the needs of those with low to moderate care needs, an increase in cost will also arise. Personalisation must not be seen as a cost cutting exercise, but rather a new concept that will better meet the needs of our ageing population, that has potential cost benefits in the long term.

Personalisation of social care services

2.1 Independent Age welcomes the move towards personalisation in social care, but would like to highlight that poor implementation will negate any potential benefits. We would like to draw attention to a number of points:

2.2 It is important to recognise that the concept of personalisation is a new one for many people. A new social care system must, as a matter of course, properly educate older people about what is on offer, how this will become available to them, and how they will be supported during the process. Anecdotal evidence received at Independent Age suggests that many older people are confused by the current system of social care and this can, and does, have a negative impact on their lives. It is vital that adequate advice and information is provided to prevent unnecessary confusion. The system must also be streamlined to ensure that those in need of care are not suffering from the burden of excessive paperwork and bureaucratic delays. It must be made clear to individuals exactly what will happen if their needs change or increase, and how this will be addressed.

2.3 Brokerage support is a key issue here, and in particular relates to the implementation of direct payments. Independent Age staff and volunteers working with older people in receipt of social care have expressed considerable concern about this method of support. As an individual in receipt of a direct payment, an older person will assume the role of employer, and will be expected to identify the services they need, find the appropriate providers of these services, and negotiate a service representing good value for money that adequately meets their needs. While Independent Age supports the notion of choice essential to the concept of personalisation, and would like to see older people empowered to shape their care to best suit their needs, the level of brokerage required may not be appropriate in all situations. Indeed, the right to have “choice” must include the right *not* to choose. For example, the system must cater for the needs of older people managing at crisis point. Some older people would rather *not* assume the kind of responsibility required by direct payments. We must consider what help individuals will need to make use of the choice available to them.

2.4 Advocacy services are currently very limited in most areas and will take significant time to develop. The government must account for the time and cost of building and sustaining a new market before personalisation can work effectively for all people with varying support needs.

2.5 The nature of support required by the personalisation agenda will vary from the current forms of social work available in the present system. A culture change must be effectively facilitated, which will necessarily include the adequate training of social care professionals. In the experience of Independent Age care professionals, the current system of assessment and care management does not allow sufficient time for staff to develop the type of in-depth relationship with social care recipients that is required to fully take advantage of the personalisation and individual budget agenda. Social care staff providing support to enable older people to make the most of the choices available to them, will need more time to acquire a greater understanding of an individual’s history, previous choices and preferences, and what is important to them. The concept of personalisation is centred upon recognising an individual’s needs, and developing the best way to facilitate those needs. This will often require actions which are currently outside the remit of the social care system, and will extend beyond our current perceptions of what constitutes “care”. Further support from families and/or the voluntary sector is therefore likely to be essential, and the development of greater expertise in the voluntary sector will also be required to support this.

2.6 It is important to recognise the opportunities presented by enabling care providers greater flexibility in designing care packages. In providing a service to individuals, providers often have a greater relationship with the people in receipt of social care services and support. The knowledge they have obtained about a person’s needs over a prolonged period of time could be used to tailor support more effectively.

2.7 Safeguarding must be an intrinsic part of any new social care infrastructure that involves the use of a variety of different services, providers and people, including family and friends. It is essential that vulnerable people are not exposed to a deregulated social care market. In the case of the employer-employee relationships occurring as a result of direct payments, it is also important to recognise that this is a two-way relationship. To ensure not only quality, but continuity of care, both parties must be treated fairly and professionally. Mechanisms must be firmly in place to ensure fair treatment for all.

More effective, consistent and user-friendly social care services

3.1 The personalisation agenda presents a number of opportunities to provide a more effective, consistent and user-friendly social care service. A number of these opportunities are described above. In addition, we would like to add the following:

3.2 Less joint *working* between health and social care departments, and more joint *departments* could ensure clearer central guidance and increased resources for direct services than are evident in the current system. More joint departments would eradicate the need for two separate commissioners responsible for joint working, and would lessen the level of bureaucracy involved in the decision making process.

3.3 It is clear from our research that older people need and want access to comprehensive, face-to-face advice on the social care system. Independent Age has consistently observed discontent with signposting, and a strong desire for more personal services that allow individuals the time they need to ask questions and come to terms with how the system will work for them.

3.4 We would also like to note the potential economic and social benefit represented by the increased use of telecare services. Reductions in staff time and home visits could cut costs in providing social care. However, we are concerned that an increase in telecare services could result in social care recipients, many of whom are already lonely and isolated, receiving less social contact. Savings made by the use of telecare services should be used to fund an increase in befriending and other services geared towards reducing the social isolation of older people.

October 2009

Memorandum by the LIFT Council (SC 30)

SOCIAL CARE

1. INTRODUCTION & SUMMARY

1.1. The LIFT Council welcomes the opportunity to respond to the Committee's inquiry into the future of social care and this submission seeks to address the three issues raised in the terms of reference. In addition, this submission seeks to set out The LIFT Council's position on what type of reform needs to take place and why LIFT is ideally placed to enable local authorities and others achieve many of the key objectives of reform, including:

- Improving the commissioning of social care on a locality basis and strengthening local authorities' commissioning function.
- Moving away from a focus on the bare minimum to a focus on personalisation, choice and quality.
- Taking advantage of private sector expertise to push reform, drive up standards, realise efficiencies and ensure a plurality of services.

1.2. Whilst The LIFT Council does not feel it necessary to put forward one-size-fits-all for the involvement of LIFT in social care we would like to draw to the Committee's attention that there are a number of benefits of making use of existing LIFTCos and the new Express LIFT framework. One of the greatest advantages of the LIFT model is that LIFTCos exist across defined geographical areas, meaning that they already have a wealth of local knowledge and understanding. These could be usefully drawn upon more broadly in supporting the commissioning and provision of social care support, particularly as we see particular benefit in ensuring the care and support system has a strong local basis. The LIFT Council would be keen to see Government taking more active steps in promoting LIFT as an option in this area and we would like to see the Department of Health look at how Express LIFT might be used to deliver social care facilities and how local authorities (LAs) might be able to access PFI credits through Express LIFT.

1.3. It is The LIFT Council's position that there is greater scope to involve private sector partners in social care commissioning and to take advantage of their expertise in this area. As a meaningful partnership between the public and private sectors and a vehicle which enables the public sector to take advantage of private sector expertise in commissioning, contracting and performance-management, LIFT is ideally placed to support the commissioning of social care at the local level as well as supporting local authorities with their role of managing the market of care and support providers. In addition, there is a key role for LIFT to play in enabling local authorities to work with other local partners in terms of rationalising and deriving value from the strategic deployment and management of local estate, in the context of local targets and priorities.

1.4. This submission is accompanied by a bank of case studies to illustrate where LIFT is already being used to integrate health and social care services and improve provision across the country.

2. BACKGROUND TO LIFT AND THE LIFT COUNCIL

2.1. Local Improvement Finance Trusts (LIFT) are a Government-endorsed finance scheme based on long term joint ventures at national and local level to improve investment in primary and social care services in England. Already around £1.8 billion of funding has been injected into GP premises and community facilities across the country in this programme, with over £1 billion in the pipeline. To date, over 240 LIFT buildings are either in construction or open to patients. LIFT facilities often co-locate a wide range of services, including GP practices; podiatry services; occupational therapy; physiotherapy; multi-purpose diagnostic and treatment clinics; and mental health services. In addition, Children's Centres, libraries, leisure facilities and social care facilities including residential, day-care and nursing supported housing schemes are just some of the premises that have been built through Local Authorities under LIFT.

2.2. Each local joint venture company (the LIFTCo) is owned by representatives of the local Primary Care Trust (PCT), Community Health Partnerships¹⁰⁷ and a private sector partner. Projects are overseen by a Strategic Partnering Board, comprising representatives of stakeholders from the local health economy including in some areas Local Authorities. Unlike Private Finance Initiative (PFI) deals, LIFT schemes are based on the local LIFTCo owning and maintaining the new premises and leasing space to PCTs, General Practitioners (GPs) and other social care or voluntary sector tenants, offering a real partnership approach between the public and private sectors. LIFT was first introduced by the Department of Health (DH) in 2000 with the aim of attracting a total of up to £1 billion of private investment by 2010; a level of primary care investment unprecedented in the history of the NHS.

2.3. In August 2008, the DH officially launched the Express LIFT framework, which will reduce the time and cost in appointing LIFT partners for Primary Care Trusts (PCTs) and local authorities. Express LIFT accelerates the LIFT process even further, offering PCTs and local authorities who have not yet conducted their own procurement the opportunity to select a pre-approved LIFT partner more quickly and cost effectively from the list. Local procurements from the Express LIFT framework can be completed within three or four months as opposed to two years as is currently the case and will allow the benefits of LIFT to be realised in more areas across the country.

2.4. The LIFT Council (formerly LIFT LOBI) is the representative trade body for private sector investors in LIFT schemes. Our membership comprises 13 organisations; over 95% of the private equity investors in LIFT ventures around the country. The LIFT Council acts as a forum for debate and decision-making for members on all issues relating to LIFT and represents the interests and consensus opinion of its members.

3. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

3.1. The LIFT Council welcomes the Government's Social Care Green Paper as we believe the current social care system requires fundamental reform. We feel a major reason for this is the projected £6 billion funding gap identified in the future provision of social care, mainly due to changing demographics, a situation exacerbated by the current state of the economy and the impact this is having on public finances. Whilst The LIFT Council does not feel it appropriate to take a particular position on the options set out in the Green Paper on how to create a partnership system of funding between the state and service users, we do believe that a move to co-payment of some description is inevitable in order to improve quality in social care provision and to create incentives for improved standards.

3.2. The LIFT Council's vision for social care is one in which the market incentivises a drive towards improved quality, where integrated packages of support are commissioned for those with social care needs and where there is real choice. Clearly this type of system will have cost implications. The LIFT Council therefore supports a wider-use of self-payments in the social care system and is pleased that this is the direction of travel set out in the Government's Green Paper.

3.3. A widening of the use of self-funders and personal budgets will enable the system to become more efficient as cost savings are made through lower transaction costs from a reduction in bureaucracy and non productive overheads. Integrated commissioning will also enable joined-up health and social care packages to be put in place, such as enabling a greater focus on rehabilitatory care, which also has the potential to reduce costs over the long term. The LIFT Council also believes localities would benefit from putting in place flexible infrastructure to meet short-term care needs, such as "step up/step down" beds. Much of the work that LIFTCos have done in supporting the transformation of primary health care already supports more preventive health care practices which will help to maintain people in independence for longer and hence reduce demand on social care services. LIFTCos can assist in mapping demand and working to ensure localities have the relevant strategic infrastructure in place as well as deriving efficiencies from a more strategic approach to the estate.

¹⁰⁷ Community Health Partnerships (CHP)—known until autumn 2007 as Partnerships for Health (PfH)—is an independent company, wholly owned by the Department of Health. Its main activity has been to deliver the Local Improvement Finance Trust (LIFT) Initiative which provides clean, modern, purpose-built premises for health and local authority services in England.

4. PERSONALISATION OF SOCIAL CARE SERVICES

4.1. It is widely recognised that the current social care system is not fit for purpose, with particular public concern over the perception of a “postcode lottery” and a lack of personalised services. This can also be applied to the capacity with which local authorities discharge their commissioning responsibilities. There is also the perception, acknowledged by Government, that the current system is unfair and is characterised by a focus on the “minimum standard” across the board, with the commissioning decisions of local authorities often largely dictated by costs rather than need leading to a lack of focus on personalisation. The LIFT Council is pleased that a key focus in the Green Paper is an expectation that care and support is personalised.

4.2. There is a vital need to move the social care system away from provision based simply on minimum standards of care. Clearly local authorities are facing a difficult challenge as budgets are squeezed and demand increases, a problem exacerbated by ongoing issues around pay equalisation. In addition, local authorities operate in an environment of significant financial pressure and are budget driven—75% of a local authority’s budget is spent on staffing, its largest single cost. The second highest cost is the day to day running of buildings, offices, residential homes, commercial properties and libraries which represents about 8–10%.

4.3. Local authorities must be encouraged to commission not just on the basis of “need”, but on the basis of “want”. Effectively mapping local demand in this way will more effectively identify the provision that is needed by self funders whose interests are poorly represented by many local authorities at present. This more strategic approach to commissioning will allow those who want to use their own resources to purchase higher-quality packages of care, which in turn will drive standards up across the board. Current approaches to commissioning create perverse incentives for the private sector to adopt investment strategies which reflect high volume low quality service provision at a minimum unit price. The fragmentation of the independent sector for social care provision further weakens the opportunity for a more strategic dialogue—The LIFT Council’s experience positions it well to support the development of a more strategic interface between local commissioners and both private and not-for-profit suppliers.

4.4. Better joint working between PCTs and local authorities is critical to improving commissioning, as recognised in the Green Paper. This must continue to happen and should be encouraged, for example by the increased pooling and joint management of budgets and the co-appointment of key personnel such as Directors of Public Health. Joint Strategic Needs Assessments have an important role in identifying the needs of the least advantaged but should do more to reflect the concerns of those who aspire to support themselves in independence with the minimum of help from the state. We believe budgets and decision making should be devolved on the basis of locality areas, subject to commissioned services meeting national standards.

4.5. There is currently a lack of real choice for those accessing social care, again often linking back to the issue of cost. The LIFT Council believes that a focus on a more integrated package of care will enable real choice and therefore opportunities for users. Focusing on holistic packages of care will also allow perverse incentives in the current system to be addressed, for example, incentivising preventative and rehabilitatory care rather than paying providers to keep users in care for long periods of time. In such a system of plurality, The LIFT Council identifies a potential role for the state in providing or commissioning a brokerage role, linking demand with regulated suppliers—another role with which LIFTCo can assist. Providing real choice and empowering users in this way is the best way in which to drive up standards across the board.

4.6. The LIFT Council would also support the implementation of national standards clearly defining what is an acceptable level of commissioning and the minimum variety of provision in a locality. These standards must stipulate that commissioning responds to all local demand, including that for high quality care. In addition, these standards must place a responsibility on commissioners to put in place a variety of packages, services and options rather than opting for the bare minimum. It is vital that these standards are not used to justify a minimum standard of provision. The range of services that are identified must be based on an objective analysis of need and demand. The Green Paper proposes the establishment of the equivalent of a National Institute for Health and Clinical Excellence (NICE) for social care which would provide advice on the effectiveness and cost-effectiveness of different types of care and support. The LIFT Council supports this proposal and believes the body should also have responsibility for promoting best practice in social care commissioning, with the Care Quality Commission auditing this process. We also believe there is a key role for LIFTCo in working with local authorities to identify, improve and, where appropriate, provide purpose-built facilities which meet the whole range of local need. The LIFT Council is willing to work with any new national body to share experience of good practice and build in measures of effectiveness into future work programmes.

4.7. Most local authorities have moved away from direct provision towards a system where they contract with suppliers whose terms and conditions for employees are less expensive. Public policy is in danger of being dominated by the voices of the increasing number of older people who do not feel that they should have to use their own resources to meet social care costs in later life. We support an approach which seeks to achieve a step change in public attitudes by building a wider acceptance that people are encouraged to plan for a higher quality of care by sharing a greater proportion of the cost. In effect the debate should centre on a level of state funding or co-funding that provides adequate state care but develop a stronger analogy

with pension provision. You can choose to accept a defined state pension and a standard level of social care funded through national insurance but you are wise to invest in additional private schemes for a more comfortable time in later life.

5. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

5.1. The previous sections set out in detail how The LIFT Council believes the care and support system can become more effective, consistent and user-friendly.

5.2. In addition, The LIFT Council believes that there is greater scope to involve private sector partners in social care commissioning and to take advantage of their expertise in this area. As a meaningful partnership between the public and private sectors and a vehicle which enables the public sector to take advantage of private sector expertise in commissioning, contracting and performance-management, LIFT is ideally placed to support the commissioning of social care at the local level as well as supporting local authorities with their role of managing the market of care and support providers.

5.3. This is already happening to some extent in the health arena and guidance published for PCTs on the Government's *Transforming Community Services* programme explicitly states that PCTs should view the LIFTCo option as their delivery vehicle of choice in terms of forming a strategic partnership to realise their Commissioners' Investment and Asset Management Strategy (CIAMS) to better align commissioning priorities and estates management.¹⁰⁸ Indeed, there is already evidence from our members that they are already starting to assist their PCT partners in delivering CIAMS.

5.4. This submission has already identified a number of areas in which LIFTCo can play a significant role in improving the commissioning and provision of social care services in England. This includes taking advantage of LIFTCo expertise in commissioning of social care to take advantage of expertise in commissioning, contracting and performance-management and the management of care and support providers and assisting with the mapping of local demand and ensuring commissioning and existing infrastructure is able to meet this demand and is flexible enough to do so.

5.5. The flexibility of LIFT means that whilst support can be provided to PCTs and LAs, there is also potentially a role for LIFTCo in mentoring social enterprises to deliver care and support services. For example, the social enterprises can focus on delivering the care and LIFTCo can assist in a business mentoring sense, providing advice on contracting, demand management etc.

5.6. Whilst many LIFTCos are already working closely with local authority partners on social care and wider community projects, The LIFT Council would be keen to see Government taking more active steps in promoting LIFT as an option in this area. The LIFT Council therefore calls on the Government to promote the use of LIFT with LAs and as a mechanism by which to realise joint-working between PCTs and LAs. We would also be keen to see LIFTCos better integrated in Local Strategic Partnership arrangements. In particular, we would be keen to see the Department of Health look at how Express LIFT might be used to deliver social care facilities and how LAs might be able to access PFI credits through Express LIFT.

October 2009

Annex

A SELECTION OF CASE STUDIES

1. LIFT PATHFINDER FOR SOCIAL CARE—SHEFFIELD INTERMEDIATE CARE CENTRE

Community 1st Sheffield are actively progressing a pathfinder project for health and social care services in Sheffield. Although it is still early days, Community 1st is acting as the lead conduit to develop a new intermediate care facility which will ensure a fully integrated approach between NHS Sheffield, Sheffield City Council, adult social services, Sheffield Teaching Hospitals NHS Trust and GP's.

A joint commissioning board has been established with representatives from the above to develop the commissioning and service proposals for this exciting new development.

This development for the heart of Sheffield will support local service redesign and will form part of a whole "Health" pathway change for people requiring intermediate care, ie care for patients who require nursing care, including managing/caring for patients in their own home as well as being a hub for the multi agency teams that will manage patients across the whole pathway. It will be a 120-bed facility, equivalent to the current number of intermediate care beds provided across multiple sites throughout the city, but with the new centre it is hoped that the length of patients' stay will be reduced by 50%.

The preparation for this has been based on the "Pathways for Intermediate Care in Sheffield" report, written by Dr Tom Downes, who is involved in the planning stages for the new centre.

As well as the in-patient bed facilities, services are likely to include therapy, specialist nursing, x-ray facilities, minor surgery, podiatry, ophthalmology and rehabilitation services, a gym, and day surgery.

A site options appraisal has been undertaken, though as yet the site for the new centre has not been confirmed, but it is hoped the facility will be built by the end of 2012, with service commencing mid 2013.

¹⁰⁸ A separate policy paper is available on request detailing how LIFT can assist in commissioning in the NHS more broadly.

2. EAST HAM CARE CENTRE, NEWHAM, EAST LONDON

East Ham Care Centre provides an excellent example that demonstrates a truly integrated and holistic approach to care services for older people.

The Centre replaces the Frail Elders Centre at Plaistow Hospital and the Sally Sherman Nursing Home and delivers cohesive services designed to improve the standard of life. Without the Care Centre, many of the service users in need of respite, continuing and intermediate care would be admitted in to acute care to address their needs. With the remodelled services, the 78 beds at the centre are used flexibly to accommodate the needs of the admitted users.

The building has given both the PCT and Local Authority the opportunity to provide seamless joint services, which deliver improved care for the service users, whether they are utilising the day centre, one of the 78 beds or the Elders Resource Centre.

The successful planning of the East Ham Care Centre was built on the firm partnership between Newham PCT and Newham Council that existed prior to the LIFT development. The successful implementation of this integrated model demonstrates the enormous potential for delivering community services in the future, meeting the changing needs of the local population. It demonstrates what can be achieved if health and community organisations join forces to work in partnership.

3. THE PARTNERSHIP PRIMARY CARE CENTRE

The Partnership Primary Care Centre is a £4.1 million project that not only aims to cater for a diverse range of needs, but also hopes to provide a focal point for the vibrant community of Islington.

Within Islington there are stark inequalities in health. For example, there is a much higher mortality rate from heart disease among the manual social classes and a much higher rate of diabetes among the Bangladeshi population. Also primary care services suffer from poor accommodation with many premises being old, cramped and inaccessible. The aim of this project is to enhance the health and well-being of patients and staff, while remaining flexible and adaptable to meet the changing needs of health and social care and broader community based services.

Set to house various essential healthcare facilities as well as a GP practice that will serve some 60,000 patients, the centre will also be home to 10 one-bedroom social housing flats being built for the Mosaic Housing Association.

Lorraine Robjant, Camden & Islington LIFT Project Director, said: “The setting up of Camden and Islington LIFTCo is a major step for primary care facilities in the two boroughs. It will now mean we can start to realise our vision of developing more than 20 new primary care centres over the next five years.”

Owned by the Corporation of London and leased on a long-term basis to the Mosaic Housing Association, one of the conditions of the permission to develop the site is that the existing single-storey Community Hall being demolished must be re-provided.

This project is part of a Public Private Partnership (PPP) agreement between Community Solutions for Primary Care (CSPC), Partnerships for Health (PfH), Camden Primary Care Trust (PCT) and Islington Primary Care Trust (PCT).

The “LIFTCo” that was formed as a result of this agreement (Camden & Islington Community Solutions Limited) has entered into a 25 year Lease Plus Agreement with Islington Primary Care Trust (PCT) for the facilities, which will include:

- 645 sq. m. of accommodation space
- The Fairweather House practice, which will gradually expand to four “whole time equivalent” GPs and become a training practice
- A practice nurse consulting room
- A minor surgery treatment room with utility areas
- A child health facility
- Office space for visiting community nursing staff
- A multi-purpose meeting room and a library/resource/teaching room to develop training and education facilities for both clinical and non-clinical staff.

4. GRACEFIELD GARDENS HEALTH CENTRE, LAMBETH

The 4,280 square metre Gracefield Gardens Health Centre in Streatham is home to one of Lambeth’s one stop shop Joint Services Centres, as well as the health facilities run by Lambeth Primary Care Trust.

The new Centre is part of a site developed by Lambeth Primary Care Trust in partnership with Building Better Health. This is a result of the PCT working closely with Lambeth Council to provide integrated healthcare and Local Authority Services under one roof. The Centre forms an important focal point for the community, giving local residents direct access to their council and healthcare.

Healthcare facilities at the centre include two GP surgeries, multi purpose clinics and sessional suites. Ancillary facilities include offices for primary care outreach and other staff, together with meeting rooms, a library and other shared resource spaces for healthcare and social workers.

The centre is designed around a central courtyard, which serves as a source of daylight and a central focus, helping users with orientation around the building. Public access is via a principal entrance leading to the main reception/waiting area, which forms the ground floor of the central courtyard. Large waiting areas are situated next to the courtyard at both ground and first floor levels, again helping users with orientation around the centre.

Externally, the four-storey building is designed to provide an attractive and striking presence for users and staff alike. The design features bold and attractive colours to the entrance façade, with large welcoming windows at ground and first floors. The entrance is enhanced by the cutting back of the upper façade to create an inviting civic element within the neighbourhood.

Services provided by Gracefield Gardens include:

- Benefits, housing and council tax
- GP practices
- Nursing
- Foot health
- Midwifery
- Therapy services
- Teams based at the centre will include:
 - Adult and Community Services
 - Children and Young People’s Services
 - Town Centre Managers
 - Team Around the Child

“Residents will benefit from being able to access health services and council services under one roof. This is a great example of partnership working to make life better for local people. The centre is bound to be popular with the community.”—Jackie Meldrum, Deputy Leader of Lambeth Council.

“As a Streatham resident, I feel the whole community will be proud of Gracefield Gardens. It is a wonderfully welcoming place, and is a strong statement of our partnership with the council.”—Caroline Hewitt, Lambeth PCT Chair.

Memorandum by Partnership Life Assurance Ltd (SC 31)

THE FUTURE OF SOCIAL CARE SERVICES

EXECUTIVE SUMMARY:

This submission is made on behalf of Partnership Life Assurance Company Ltd (Partnership), the market leading provider of immediate needs care annuities (long term care insurance) in the UK.

Our comments are focussed on issues surrounding the future funding of long-term residential and domiciliary care, with particular reference to the 41% of older people in the system who have to pay for their own care and are classed as “self funders”.

The submission argues for better financial advice to help older people, and their families, effectively fund residential and domiciliary care costs at the point of need and therefore to underpin the personalisation process.

We make clear the negative impact currently felt by older people and their families as a result of a lack of reliable and appropriate independent financial advice and guidance, and the significant cost to the public purse which results.

Demonstrates how greater awareness of immediate needs annuities and appropriate financial advice could provide greater security for older people, and could generate significant savings for local authorities.

Recommends that the Committee calls on the Department of Health to encourage local authorities to calculate the cost, to them, of “self funders” running out of money so that a true picture of expenditure on elderly care can be created.

Calls for amendment to the Charging for Residential Accommodation Guide (CRAG) to include information on where to gain appropriately qualified independent financial advice for self funders.

1. INTRODUCTION TO PARTNERSHIP:

Partnership Life Assurance Company Ltd (“Partnership”) is the longest established company offering annuities for people with health conditions, both in Care and Retirement.

Partnership provides immediate care annuities. These are designed for clients who need immediate financial support with care costs.

Clients are provided with an individually underwritten quotation and are then guaranteed to receive an agreed income to help fund their care costs for the remainder of their lives in return for a single premium.

Partnership has over 10 years of experience in this market and has insured over 5,000 lives.

2. LOCAL AUTHORITIES’ DUTIES:

In order to qualify for local authority funding for social care services potential users are means tested. Those with assets (including property) of less than £14,000 are eligible for full state funding. Those with assets between £14,000 and £23,000 are eligible for partial funding, whilst those with assets over £23,000 are generally required to fund their own care.

Approximately 41%¹⁰⁹ of older people using care services are classified as “self funders”.

Self funders are able to choose which care home they are resident at or which domiciliary agency to use.

However once their personal income or family support is exhausted and their assets fall below the £23,000 threshold then the local authority is required to start contributing to their care costs.

3. ABOUT SELF-FUNDERS:

41% of older people in receipt of residential care services are self funders who rely on their own income including pensions or savings, family contributions, the sale of the family home, or investments to pay for their care.

Yet with the estimated average stay in a care home at around four years and with the average annual fees for residential care for 2009–10 being £24,908 increasing to £34,788 if nursing care is required,¹¹⁰ this could mean an average cost of £139,152. It should also be noted that one in ten people in care will live for eight years.

Inevitably the cost of care is not static. This year’s figures have increased by 5.1% and 3.3% respectively from last year.

Many care homes can cost more than £50,000 per year.

Domiciliary care is also costly. The average cost of home care is £16.85 an hour.¹¹¹ So just two hours of daily home care could amount to a cost of more than £12,300 a year; without taking account of higher rates for weekends and public holidays.

There are 150,000 “self funders” in domiciliary care in England.

Once an older person’s assets fall below the £23,000 mark, through paying for their own care, they then become reliant on the state to cover their care costs.

Once a local authority takes over responsibility for funding care, they may require an older person to move care homes, potentially causing instability, upset and further health complications.

4. FINANCIAL IMPACT ON LOCAL AUTHORITIES:

Many self funders outlive their funds, thus falling below the £23,000 means test limit, requiring local authorities to finance their care.

An estimate of the financial impact on local authorities is demonstrated in a recent report by Nottinghamshire County Council (NCC).

NCC’s average cost of weekly nursing care for former self funders is £387 and £294 for residential care.

In 2008–09 there were an estimated 317 former “self funders” now being supported financially by NCC. These self funders are costing NCC an estimated £1.8 million in nursing care and £4.3 million in residential care. A total of £6.1 million per annum is being paid as a result of “self funders” running out of money.

If this estimate was applied to the 152 Councils that fund adult social care in England alone, the total cost to local authorities and ultimately the tax payer would be just short of £1 billion per year. However, without more accurate data, it is impossible to calculate the cost of “self funders” running out of money to local authorities.

Partnership recommends that the Committee calls on the Department of Health to encourage local authorities to measure such expenditure so that a true picture of cost for elderly care can be created.

¹⁰⁹ Laing and Buisson “Care of the Elderly People UK Market Survey Report”.

¹¹⁰ Laing Buisson, Care of Elderly, UK Market Survey, 2008.

¹¹¹ Laing Buisson, Care of Elderly, UK Market Survey, 2008.

5. HOW DO IMMEDIATE NEEDS ANNUITIES HELP?

Immediate needs annuities allow older people receiving care—be it nursing, residential or domiciliary—the peace of mind that they will receive a guaranteed income to help pay for their care costs for the remainder of their lives.

Each individual policy is designed so that after a one-off premium has been paid, the client receives a monthly income to help meet the cost of their care for the rest of their lives—no matter how long they live.

A 0–8% or RPI inflation factor can be added to the quotation to ensure that care home inflation is covered.

In addition, a six month Money Back Guarantee is also offered as a standard feature to provide clients and their families financial protection in the form of a premium refund, should they die within six months of taking out the policy.

Further additional capital protection can also be purchased if required.

6. BETTER ADVICE WOULD HELP SELF FUNDERS:

The Charging for Residential Accommodation Guide (CRAG) provides guidelines for Local Authorities on the amount of funding an older person receives for their care, and what should be taken account of when mean testing individuals.

Under the CRAG guidelines Local Authorities “must ensure that the resident is given a clear explanation, usually in writing, of how their assessment of his ability to pay has been carried out”¹¹²

Currently there is no requirement on local authorities to provide self funders with information about where to gain independent financial advice, information on immediate-care annuities, or how else the Local Authority can help with their care payments.

The Guide acts to place restrictions on the State’s role in funding care for the elderly, yet does not provide those who have more than £23,000, with any assistance to secure financial advice.

Due to the delicate nature of the circumstances surrounding both the individuals and supporting family needing advice it is imperative that they should only be given access to appropriately qualified financial advisers. Only those with a CF8 qualification from the Chartered Institute of Insurers or those who are Members of the Society of Later Life Advisers (SOLLA) should be recommended.

Section 6.003 of CRAG states that those with more than £23,000 are liable to pay for their accommodation.¹¹³

We assert that the following should be inserted after this section: *“Where an individual is required to pay for their own care in either a Local Authority (LA), independent sector or their own home, they (and their families or powers of attorney if appropriate) should be directed towards a reliable and suitably qualified source of independent financial advice, in order to gain information about immediate needs annuities and other relevant financial products.”*

We believe that by making this simple amendment to the CRAG, the long term care needs of older people would be addressed in a planned and cost effective way. This would provide self funders with the funding for care they require without causing reliance on the state.

7. CONCLUSION

In conclusion, we recommend that the Health Select Committee’s report into the future of social care services makes clear the need for local authorities to provide information on the funding options available for self funders.

Furthermore, we recommend that the Committee calls on the government to amend the “CRAG” to ensure older people, and their families, are directed towards qualified financial advisers if their assets are such that they are classified as a “self funder”. These recommendations would, we believe, provide better outcomes and peace of mind for older people and their families and more efficient use of resources for local authorities.

Partnership would be delighted to provide more information about their services should that be required, and to provide spokespeople to submit oral evidence to a subsequent hearing of the Committee.

October 2009

¹¹² CRAG guidelines, April 2009.

¹¹³ CRAG guidelines, April 2009.

Memorandum by the College of Occupational Therapists (SC 32)

FUTURE OF SOCIAL CARE SERVICES

INTRODUCTION

1. The College of Occupational Therapists (COT) is pleased to provide written evidence to the Health Committee, which has been informed by a selected group of COT's members working in the field of social care.

2. The College of Occupational Therapists is the professional body for occupational therapists and represents over 28,000 occupational therapists, support workers and students from across the United Kingdom. Occupational therapists work in the NHS, Local Authority social care services, housing, schools, prisons, voluntary and independent sectors, and vocational and employment rehabilitation services.

3. Occupational therapists are regulated by the Health Professions Council, and work with people of all ages with a wide range of occupational problems resulting from physical, mental, social or developmental difficulties.

4. The philosophy of occupational therapy is founded on the concept that occupation is essential to human existence and good health and wellbeing. Occupation includes all the things that people do or participate in. For example, caring for themselves and others, working, learning, playing and interacting with others. Being deprived of or having limited access to occupation can affect physical and psychological health.

GENERAL COMMENTS ON THE GREEN PAPER AND GOVERNMENT PROPOSALS

5. COT has concerns regarding the style of language in the Green paper. We feel that it risks promoting a sense of passivity amongst those needing care. Linked to this suggestion is a concern that "care" is being reduced to a bare minimum making it of little value in terms of quality of life.

6. However, having noted this comment, we believe that much of the content of the Green Paper supports the practice and aims of occupational therapy which was warmly welcomed. We feel strongly that the occupational therapy workforce could be a helpful champion for some of the initiatives detailed such as Re-ablement, Telecare and Housing options.

7. The six principles of the National Care Service are welcomed.

8. COT supports the plan to remove the post code lottery approach to service delivery but recognises the need for services to be locally developed. The importance of having assessments and services provided by a well supported workforce is however missing from the list.

ISSUES FOR THE FUTURE

9. COT would like to see an improved IT infrastructure, with an expectation of assessment data being shared appropriately across agencies. Discussion regarding service users holding their own assessment and intervention/care records would also be welcomed.

10. COT would want an explanation regarding whether the national assessment will be acceptable in all four UK countries, and perhaps Europe, plus clarification on how a national assessment will bring an end to the postcode lottery.

11. We would also seek clarification regarding how the Green paper's aspirations fit with existing legislation and policies (for example, Housing legislation controlling access to the Disabled Facilities Grant, and Fair Access to Care criteria) which will need to be thought through before any legislation is proposed.

12. COT urges further consideration of different models of prevention services. Prevention is a broad term and can refer to generic prevention of ill health. The provision of well being services or targeted (secondary) prevention services (eg falls services). It is also felt that the principles of Early intervention and Re-ablement may be hard to apply to those living with long term conditions; for these groups the provision of condition management services is important.

13. Consideration should be given to providing preventative services outside of traditional statutory service structures and the funding of such services needs to be reviewed and trialled.

14. COT wishes to support the concept of "upstream" health promotion and prevention and we are confident that the occupational therapy workforce can make a considerable impact on the health and well being of the population (Please see the COT publication Health Promotion and Occupational Therapy" COT 2008 for more information).

15. The Government will need a better understanding of, and support for, improved and inclusive design, particularly of the built environment, with Life Time Home standards becoming the norm for new builds and major refurbishments.

16. Making the six principles of the NCS a reality will require a focus on the existing workforce and improved planning regarding the shape and size of future workforces. We know that Occupational Therapists currently make up between 1–2% of the social care workforce in the UK, and yet they handle between 25–40% of all social care referrals (“Occupational therapy in Adult Social Care in England. Sustaining a high quality workforce” DH 2008).

17. Workforce planning for occupational therapy is managed via NHS structures and it is vital the potential of the occupational therapy workforce within social care is not only included in the planning calculations, but also appropriately funded. Furthermore, as the only profession within social care that has been educated in, and expects to work across, organisational boundaries, occupational therapists should not only form an essential part of front line services, but should also be involved in the development and implementation of policies developed to make the NCS a reality.

INTEGRATION OF SERVICES

18. Joined up services may sound like a tall order, and has been talked about, but not brought about, for too long. COT published an integration strategy for occupational therapy services in 2002 as it has always been clear that occupational therapists are very familiar with working across agency and local departmental structures and can usefully facilitate joined up working. For example, many occupational therapists are currently working across health/social services/education/housing and the third and private sector boundaries as part of their daily activity.

19. Innovations in service delivery must not lead to fragmented services that make no sense to those that need them.

20. One stop shops are a familiar concept within local government structures and the NCS will require a new partners to become part of the one stop shop concept.

21. Experience of the Transforming Community Equipment roll out has led COT to believe that the location of a single access point for multiple services is very important, and must promote visibility and ease of access.

22. Joining up a range of services, including those that are not traditionally seen as Health/Care services may make these new style services more attractive to service users and would facilitate the inclusion of prevention services that are available to all, regardless of age and disability.

23. An evidence-informed approach to such services would be welcomed, not only to build on what we know is successful but also to support the idea of adopting evidence informed practice.

24. COT has been a supporter of integrated service delivery for many years (see “From Interface to Integration” COT 2002). Joined up service provision sits comfortably with the profession’s holistic philosophy and, as previously stated, the occupational therapy workforce has been trained to work in both health and social care settings and it equally productive within both agencies.

IMPLEMENTATION OF FUTURE STRATEGIES

25. The experience of the impact of Agenda for Change on occupational therapists working in the NHS as opposed to those working in Local Authority services makes us very aware of the need for equitable pay and conditions across the key sectors. If this is not addressed the ability to recruit and retain the appropriate workforce will be severely compromised.

26. The skills mix within the workforce will also be key. Whilst occupational therapy staff are well placed to carry out generic assessments of need, they must have the time and resources to carry out occupational therapy specific assessments in order to ensure that the NCS offers holistic and comprehensive assessments of the person within their life context.

27. Joined up services will require a mature approach to sharing information. Clearly the protection of sensitive data must remain, but it must for service users, rather than other professionals, to decide what can be shared and under what circumstances. In addition, resources that have traditionally been held by one Council department (eg the Disabled Facilities Grant provided under Housing legislation) may have to be pooled to allow innovative solutions and deliver improved economies of scale.

28. There is a level of change fatigue within the existing social care workforce and this will have to be countered in order to drive through the NCS. It will be important that change is managed, without undue distraction by other requirements/demands.

FUNDING OF SOCIAL CARE

29. COT has no favoured funding model especially as we are unclear how the Insurance model will operate.

30. We have a degree of scepticism about whether the insurance industry would be prepared to take on the risks associated with those with Long Term conditions, and we are concerned that the industry may be overly motivated by business opportunities rather than individual need. The insurance industry’s approach to people with HIV/AIDS for has not been a shining example of success. In addition it is felt that in order to be financially viable, the insurance model would require wholesale buy in, which could not be guaranteed.

31. It was suggested that a clearer definition of what is included within the term "Care" is required in order to help clarify any preferred funding model. For occupational therapists, a key question is whether care needs included equipment and adaptations provision.

32. The provision of personalised advice for people making decisions regarding provision for the future care needs is also a concern especially for people who may lack mental capacity.

33. COT also has some anxiety over how "safe" individuals' contributions would be, and whether they were a risk that they might be "lost" amongst other funding streams, or used to offset other government funding shortfalls.

October 2009

Memorandum by Leonard Cheshire Disability (SC 33)

FUTURE OF SOCIAL CARE SERVICES

EXECUTIVE SUMMARY

1.1 Leonard Cheshire Disability is actively campaigning for reform of the social care system and we are pleased that both the Government and the Health Select Committee are investigating ways in which the system can be improved. Our response focuses on how social care currently works and should work for disabled people of working age.

1.2 Disabled people are twice as likely to live in poverty as non-disabled people and twice as likely to be out of work.¹¹⁴ Appropriate, affordable and timely social care can support many disabled people into work, to care for their families and to see their friends. Yet for too many disabled people this does not happen.

1.3 Currently three quarters of councils only provide social care to those with substantial and critical needs; this is expected to rise to over 80% of councils in the next financial year. Those with low and moderate needs are left without financial support and often without advice on how to make alternative arrangements. With the majority of disabled people on low incomes, many are unable to pay for the care they need.

1.4 The social care system works very well for some disabled people and does not work at all for many others. The postcode lottery within social care means that what support you get is not necessarily dependent on your needs or means but rather on the local authority in which you live. This leads to wide variations across the country which are neither fair nor sustainable.

1.5 The charging rules of the current system can leave many disabled people trapped in poverty, unable to go out to work or to accrue savings because these can be taken away to pay for care services. This can leave disabled people and their families with no way to escape the poverty trap.

1.6 Of the funding options set out in the Green Paper a fully tax funded system comes closest to an equitable solution for all. Of the options the government is considering the comprehensive model meets more of our aims than any other, but only if social care is free for working age disabled people regardless of their needs or means.

1.7 The personalisation agenda is key to empowering disabled people to take control of their lives, and it needs further embedding in the discussions which are surrounding the options for reform.

1.8 Reform of the social care system must focus on supporting all disabled people to live their lives, to go out to work, to care for their family and to see their friends. Decisions on funding should not be based on an assumption that the majority of disabled people will continue to be poor, as implied in the Green Paper, but rather designed to support disabled people to escape poverty.

1.9 Leonard Cheshire Disability would not support disability benefits such as Attendance Allowance and Disability Living Allowance being subsumed into wider social care funds as these very important benefits cover more than just social care costs.

INTRODUCTION

2.1 The provision of timely, affordable and appropriate social care has numerous financial and social benefits for disabled and older people. It can mean that disabled people can go out to work, can see their friends and care for their family. Where this support is not available it can leave people trapped in their own homes and trapped in poverty.

2.2 249,800¹¹⁵ disabled people a year receive social care support from their local authority. An unknown number pay for their own care, often referred to as self funders. A further unknown number must go without the care and support they need because they cannot afford to pay for it and they do not meet their local authority's stringent eligibility criteria.

¹¹⁴ Parckar G, "Disability Poverty in the UK", (Leonard Cheshire Disability, 2008).

¹¹⁵ "The state of social care in England 2007-08" (Commission for Social Care Inspection, 2009).

2.3 Over three-quarters of local authorities only provide social care support to those with substantial or critical needs, leaving those with low or moderate needs and their families to cope as best they can. Disabled people are twice as likely to live in poverty as non-disabled people making it more likely that they will be unable to afford to pay for adequate care privately. Soon to be published research by Leonard Cheshire Disability has found that around the country even disabled people who have a weekly income of less than £100 are being required to pay for some or all of their social care support.¹¹⁶

2.4 It is important to note that just because needs are described as “low” or “moderate” it does not mean that they are not essential needs.

2.5 It is clear that reform of the social care system is urgently required. We have a number of concerns however about the way in which the government proposes to go about this.

3. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

3.1 For the social care system to truly meet the needs of disabled and older people it is essential that any new funding system must meet the following criteria:

- 3.1.1 It must not charge people into poverty, making it impossible for people who use social care services to build up savings or undertake employment. Currently working age disabled people in receipt of social care services can see all or some of their income taken away to pay for care services if they go out to work, especially if they live in a residential home. Such a rule actively dissuades many disabled people from earning a living, effectively trapping them in poverty.
- 3.1.2 It must be and be seen to be equitable: financial support must be received based on need not on where you live. Local authorities have considerable discretion in setting their own charging policies, creating a “postcode lottery”. One person may receive all their care for free but their friend in a different local authority with similar means and needs may have to pay for all their social care support. Such discrepancies are clearly unfair and can prevent disabled people of working age from moving because there is no certainty that they would continue to receive the same care package at the same cost.
- 3.1.3 It must be available to everyone who has social care needs whether they are low, moderate, substantial or critical. Three quarters of councils with social care responsibilities only provide social care support to those with substantial or critical needs, and, according to recent reports, this is set to increase to over 80% in the next financial year. Without the right support many of those with low and moderate needs will see their situation deteriorate until their needs have become substantial or critical and they qualify for support, placing an unnecessary financial burden on social services, the NHS and their families.
- 3.1.4 It must support those with limited assets to ensure that they are not left without the social care that they need, whilst also not penalising those who have built up savings over time. Disabled people are twice as likely to live in poverty as non-disabled people and twice as likely to be out of work.¹¹⁷ The DWP has a stated aim to increase the number of disabled people in work and a commitment to ending disability poverty. Yet the levels of disabled people in work are only slowly increasing and even when in work disabled people, on average, earn less than non-disabled people, all of which means that many disabled people will find it difficult to build up assets.

3.2 Of the five options set out by the Government in the Green Paper it is not clear how each system would work for disabled people of working age. Based on the available information and on the principles above, we would make the following observations:

3.3 *Option 1: Pay for yourself*

3.3.1 This option would meet none of our criteria. It would lead to increased levels of poverty amongst disabled people, and further exacerbate the inequality of the current system. It would not support everyone who needs social care, nor would it support those with limited assets. At best this would place an even larger burden on families, and at worst it could lead to shocking cases of neglect and long-term hospitalisation.

3.4 *Option 2: Partnership*

3.4.1 Ensuring a guaranteed basic level of state support could potentially represent some improvement on the current social care system, but we are not convinced that the Partnership model offers the step-change that is needed. The current means-test can make it difficult for disabled people of working age to build up assets. The moment assets reach a certain level they begin to be taken to cover care costs. This system can actually make it impractical to take on work, all but preventing someone of working age from taking up employment. We are very concerned that a means-test in the partnership model could have exactly the same effect as now, actively discouraging saving among disabled people who use care and support services, preventing many from going out to work and leaving more trapped in poverty.

¹¹⁶ Gore, E *et al* “Disability Review 2009” (Leonard Cheshire Disability, 2009).

¹¹⁷ Parckar, G, “Disability Poverty in the UK” (Leonard Cheshire Disability, 2008).

3.4.2 Whilst the introduction of a means-test does bring problems for younger disabled adults, it is worth noting that for the Partnership model to work at all for younger disabled people it is essential for some sort of means test to exist. Without it those with high-level support needs throughout life would simply be unable to top-up their part of the co-payment, leaving them with only a proportion of the care package they needed. This would make the system even more unfair than the current system. Whilst the Partnership model helps to challenge some of the difficulties faced by older people in the social care market, we have some serious concerns about how the Partnership model, on its own, would function for working age disabled people.

3.5 *Option 3: Insurance*

3.5.1 It is not clear how this system would work for disabled people of working age, particularly for people who have social care needs throughout life. The government has a stated aim to reduce disability poverty throughout the UK. We would strongly oppose the introduction of any funding system for social care that would perpetuate the current levels of poverty amongst disabled people, or would rely on the fact that disabled people of working age will receive free care because they live in low income. There is no indication that this funding model would work to expand the social care system, meaning that it could potentially continue to leave many disabled people without the care and support they need. We would be concerned that this option offers little clear improvement on the Partnership model.

3.6 *Option 4: Comprehensive*

3.6.1 The only way in which it will be possible for younger disabled adults with social care needs to make use of this scheme would be if they receive free social care throughout life and so were not prevented from saving by means-testing, or prevented from working by social care regulations. In essence the social care system for disabled adults of working age would be designed to create the fairness needed for the system for older people to function for all.

3.6.1 The free social care system for disabled people of working age must extend to all disabled people, whatever their means, and whether they have low, moderate, substantial or critical needs, to ensure that they are able to go out, live their lives and acquire the assets needed to pay for care in later life. However this brings its own complexities with regard to a subsequent point of transition being created between working age and older people's services, by requiring individuals to start paying for some or all of their care at the point when they are no longer earning a monthly income from work.

3.6.2 Although there are drawbacks to this system, it might be possible to use the "comprehensive" model to meet our criteria to a greater degree than the other systems above.

3.7 *Option 5: Tax-funded*

This is the only model with the potential to fully meet our criteria. The government has already rejected this model on the grounds that the tax burden will be too much. Leonard Cheshire Disability feels strongly that for a proper debate on the future of social care funding to take place the public must be able to discuss what they think a fair taxation burden would be and whether they would be prepared to pay for it. Simply being told that it is "too much" is disingenuous if the ambition is to create a funding model based on consensus, which will last for at least another 50 years.

4. PERSONALISATION OF SOCIAL CARE SERVICES

4.1 We strongly support the personalisation of social care for disabled people. Empowering service users to choose the right type of care and support for them, to choose who provides that support and when it is provided will go a long way to ensuring that social care better supports disabled people to fulfill their potential.

4.2 For disabled people of working age flexible, personalised social care can make the difference between whether or not someone is able to work. If an individual is unable to work then benefit levels are not sufficient to lift someone out of poverty. It is critically important that care and support services offer disabled people of working age genuine choice and independence. The care and support system can play a decisive role in narrowing the poverty gap between disabled and non-disabled people.

4.3 It is important to recognise that a key part of the personalisation agenda must be for disabled people to be able to choose to maintain their current care and support arrangements if they are the best arrangements for them.

4.4 We are concerned that the government's vision for how social care provision will work in practice has not yet been made clear to the general public. Many people still consider social care to be residential care homes and care at home for older people, all organised by the local authority. The shift in commissioning from local authorities to individuals is likely to have a profound impact on the ways that local authorities, and social care organisations, whether charities or private providers, operate. The implications for this should not be missed from the current debate on funding and the creation of a National Care Service. The debate should be about how to fund and arrange this new way of delivery rather than finding ways to perpetuate the current system.

5. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

5.1 The Green Paper proposes a new National Care Service to help standardise the social care services that are available across the UK, and to help raise the profile of social care. Leonard Cheshire Disability is strongly supportive of measures which would end the postcode lottery in social care provision. However we would seek clarification on exactly what the remit, structure and powers of any new body would be.

5.2 Working with the MS Society and Demos, Leonard Cheshire Disability has produced a “Constitution for Social Care”, which sets out the key principles on which the care and support system should be founded. The document sets out our position on many of the issues raised in the Green Paper. We are delighted to see that some of the principles in our “Constitution for social care” are present to some extent in the Green Paper’s description of the National Care Service. A copy of the constitution has been submitted to the Committee for information.

5.3 The current situation means that many thousands of disabled people around the country do not get the care and support that they need because they do not meet their local authorities ever-tightening eligibility criteria. For social care services to be more effective they need to be available to all disabled people with social care needs. Providing care and support when needs are “low” or “moderate” can prevent a disabled person’s situation from deteriorating and can support them to stay in their own homes, to go out to work, and to care for their family. It is essential that a way is found for all disabled people who need social care support to receive it.

6. DISABILITY BENEFITS

6.1 The Green Paper refers throughout to the possibility of bringing “disability benefits, such as Attendance Allowance” into the overall pot of funding for social care. At present benefits like Attendance Allowance (AA) and Disability Living Allowance (DLA) are paid directly to the individual, regardless of means or personal circumstances, and are designed to help cover some of the extra costs that disabled people can face in managing their impairments.

6.2 Whilst eligibility for DLA care component and AA is determined through an assessment that looks at social care needs, neither benefit is intended solely to cover the costs of social care. DLA is an “extra cost benefit”, which is designed to cover the extra costs that arise from having an impairment and that may or may not involve social care. The assessment for the benefit is intended to identify those people with extra costs, not specifically to identify social care requirements. There are many people who receive DLA, but who do not receive social care services. For many people DLA provides an absolutely vital resource in helping to challenge disability poverty and overcome the additional costs of disability.

6.3 For all of these reasons Leonard Cheshire Disability would very strongly oppose such benefits being drawn into the social care system. Whilst we recognise the need to ensure that extra funding gets into the social care system it simply does not make sense to look to remove elements that are actually working most successfully at present.

7. CONCLUSION

Leonard Cheshire Disability welcomes the opportunity to submit evidence to the committee, and the recognition that the social care system urgently needs reform. With the right social care support many disabled people can be active members of their community and contribute financially to the economy. Without it, or because of the current charging rules, many disabled people remain trapped in poverty with no route out. It is essential that at the end of these reforms all disabled people who need social care can receive it and can find a route out of poverty.

Leonard Cheshire Disability supports over 21,000 disabled people in the UK and works in 52 countries. We campaign for change and provide innovative services that give disabled people the opportunity to live life their way. Visit www.LCDisability.org

October 2009

Memorandum by the Mental Health Foundation (SC 34)

FUTURE OF SOCIAL CARE SERVICES

EXECUTIVE SUMMARY

The publication of the Green Paper is welcome as a way of debating how to pay for social care in the future. The debate needs to take into account the care needs of people of all ages, not just older people.

People who may at no point in their lives be able to contribute financially towards the costs of their care—including many people with more serious mental health problems and some people with learning disabilities—must still be guaranteed to have their care needs met.

We support the principles behind the proposed national care service, and a national assessment of needs.

We regret that the option of a wholly tax-funded system has been rejected, as we believe this would be the fairest and most affordable option. We believe this option should be reopened.

We would have concerns about any transfer of disability benefits into the social care pot. These benefits are a lifeline for tens of thousands of people with mental health problems and people with learning disabilities, and is money they can control and spend as they think best.

1. We are grateful for the opportunity to submit evidence to the Health Committee's inquiry into the future of social care.

2. Founded in 1949, the Mental Health Foundation (MHF) is a leading UK charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems, whatever their age and wherever they live. The Foundation also incorporates the Foundation for People with Learning Disabilities (FPLD).

3. We are preparing our full response to Social Care Green Paper and the views we set out below should be considered as provisional. Our comments are focused on the proposals set out in the Green Paper—which primarily concern funding issues—rather than on a wider discussion of the future of social care services.

OVERVIEW OF THE GREEN PAPER

4. The Foundation welcomes the debate on how we should pay for social care in the future. We know that the gap between available funding and future costs will increase unless it is addressed—meaning that increasing numbers of people will go without their needs being met.

5. We have a strong interest in ensuring that people with mental health problems and people with learning disabilities receive what social care they might need at any time in their lives. It is particularly important to recognise that there will be people within these groups of all ages who may at no point in their lives be able to contribute financially towards the costs of their care, but that this should not mean their care needs are not met equitably.

6. There is a tension between the desire for a national system of assessment and eligibility and the autonomy of local services to meet the needs of their local populations as they think fit within their allocated resources. This tension is not resolved in the Green Paper.

7. The Green Paper focuses very largely on how to meet the social care needs of an increasingly aging population. But in doing so it we need to remember that a great deal of social care is targeted at children and working age adults (for example, people with a learning disability or chronic mental health problem), and solutions to the funding gap need to take into account all groups that use social care, not just older people.

8. The Green Paper makes little or no reference to the health care needs of people, which are very closely tied into the social care needs, and how the proposed National care Service (NCS) might work alongside the NHS to provide a joined-up response to the care needs of individuals.

NATIONAL CARE SERVICE

9. The current social care system is not fit for purpose, being a patchwork of services and creating a postcode lottery. From the user's perspective it is unfair, overcomplicated and inflexible. The Foundation believes the focus of reform should be on sustainable entitlement of social care, adequate to meet assessed needs.

10. The Foundation agrees with the vision of an NCS that is based on “a system that is fair, simple and affordable for everyone, underpinned by national rights and entitlements but personalised to individual needs”. However it is unclear whether the NCS proposed will have a formal structure like the NHS, or whether it is simply a catch-all title for the way services are provided by local authorities and others, as at present. The terminology may cause confusion in that the National Health Service is paid for out of general taxation and is (with some exceptions) free at the point of contact while that option has been discounted (in our view wrongly) for the National Care Service.

11. We support the principle of a national needs assessment and the provision of services to meet needs that is consistent wherever a person lives, and regardless of whether they move to another part of the country.

12. We agree with the six things that all disabled adults should be able to expect from a National Care Service. Much of this—prevention, joined-up services, personalised care—is not new and already embedded in the rhetoric of social care if not yet consistently applied in practice throughout the country. It would be good, though, to add a reference to quality of care received.

FUNDING OPTIONS

13. As the Green Paper states (p.104), the fundamental issue is how to get new money into the social care system. The present pot of money is already inadequate to meet people's needs, and the imbalance between needs and costs will increase if nothing is done.

14. We regret that the option of a wholly tax-funded system has been rejected, as we believe this would be the fairest and most affordable option. We believe this option should be reopened. While this would clearly place a heavier tax burden on working adults, we do not see why social care should necessarily be seen as different to, for example, health care, education, policing and the criminal justice system, which are all services paid for out of general taxation. Taxpayers and their families, including older generations who are already retired, would themselves benefit from getting any social care they need at any time without having to pay for it at that time. It might also be argued that the other funding options that require people to contribute in one form or another towards their (and others') care are no different to taxation except in name.

15. It is essential that those who cannot afford to contribute towards the costs of their social care needs (which will include many people with serious mental health problems and many people with learning disabilities) do not have to, and are able to receive the same level of care against assessed needs as anyone else. We are reassured by the Green Paper's statements that this will be the case regardless of which funding option is chosen.

16. If the Green Paper is serious about prevention (one of its six key areas) then the solution to the funding question will need to ensure that people with mild to moderate needs also receive the support they need to help prevent their needs escalating along with the cost of care. The Green Paper states that "Money could often be better invested in prevention, rehabilitation and keeping people active and healthy" (p.9) but there is little in the Green Paper that demonstrates how this might be done, and the likely constraints on public sector funding in the next few years put the health promotion and illness prevention agenda at serious risk.

17. The Partnership model, preferred by the Government, is in effect a means-tested model. Those who can afford it will pay more; those on lower incomes will pay less (or nothing). However it is unclear where the new money necessary to boost the overall pot is coming from as it appears that everyone is as well-off or better-off under this system.

18. We have concerns about the involvement of private insurance companies in any social care funding arrangements, as the need for companies to make a profit may militate against the most cost-effective use of resources for care. It should also be noted that insurance companies may at any point become victims of future financial crises (meaning some people may find their insurance cover wiped out) in the way that a State-run insurance system does not.

TRANSFER OF DISABILITY BENEFITS

19. We would have concerns about any transfer of disability benefits into the social care pot (this would in any case simply move resources from one pot to another). These benefits are a lifeline for tens of thousands of people with mental health problems and people with learning disabilities, and is money they can control and spend as they think best. The Green Paper states that "people receiving any of the relevant benefits at the time of reform would continue to receive an equivalent level of support and protection under a new and better care and support system". However given the discretion of local authorities to spend their resources where they consider best to meet the needs of their local population, there appears to be no way of guaranteeing this. The proposal also runs counter to the current policy aim of personalisation, which looks to increase people's control and choice about where to spend their care and support money.

October 2009

Memorandum by Sue Ryder Care (SC 35)

FUTURE OF SOCIAL CARE SERVICES

1. ABOUT SUE RYDER CARE

Sue Ryder Care is a leading third sector provider of specialist palliative care and long term-neurological care in the UK. It operates hospices, neurological care centres, homecare and community based care services.

Its vision—"Care that liberates lives"—means that the charity cares for all of a person's needs, be they physical, emotional, psychological or spiritual, and is dedicated to helping people get the best from their lives, while living with chronic and life-limiting conditions and illnesses.

Sue Ryder Care's specialist palliative care services are based around consultant led inpatient units and comprise day hospice facilities, specialist community nurses, social work and bereavement services, which integrate with the NHS and other organisations, including oncology units, GPs and social services. In 2007, its six hospices provided 1,800 episodes of in-patient care and 5,500 attendances at our day care hospice services.

Its neurological care services provide specialised long term care and support for people with conditions including Multiple Sclerosis, Stroke, Parkinson's Disease, Motor Neurone Disease, Huntington's Disease, Brain Injury and Dementia, with most centres recognised as preferred providers of respite care by the MS Society. Admission is based on referral by NHS or Social Services and individual assessment by the charity. Its eight neurological centres provide care for over 400 people, with a further 3,750 people receiving care through neurological day services.

Sue Ryder Care homecare provides social support for people with a range of care needs in the community. The majority of the people the service cares for, often in partnership with other agencies, are adults with a high level of need, recognised following assessment by a social worker. Sue Ryder Care provides 12,000 hours of homecare every week through these services.

Sue Ryder Care services are funded through a combination of statutory funding, personal funding and voluntary donations. In order to provide these services, which provided over four million hours of care last year, the charity relies on generous donations from the public and statutory funding from the government via local authorities and primary care trusts for commissioned services.

2. EXECUTIVE SUMMARY

Sue Ryder Care supports the personalisation agenda. We are concerned however that to implement it successfully it must be accompanied by a robust support structure. We want to ensure that as people are given more choice and control over the services they receive and the ways in which these are purchased, there are advocacy and brokerage services in place to assist them.

Care must be taken to ensure there is not a "one size fits all" approach to the agenda and individuals need support to think about what is best for them; be it residential care, care in their own homes or community based solutions.

To ensure the services are as effective as possible, more joined-up working needs to be undertaken between health and social care.

3. PERSONALISATION OF SOCIAL CARE SERVICES;

3. Sue Ryder Care supports the personalisation agenda. As a charity, we strive to provide services for people centred around their needs and wishes. Giving people the appropriate support to enable them to make decisions about the care they receive is central to every part of our work and not easily identifiable as a separate policy.

As a specialist provider of care for people living with neurological conditions our experience has shown that though not everybody we care for will have the capacity to make decisions about every aspect of their care. Choice is vital even if it relates to things that most people take for granted such as what they eat and what activities they take part in on a day-to-day basis.

3.1 Increasing the availability of personal budgets will not ensure personalisation for all as they are not suitable for everyone in need of care. Those who are not able to manage their own budgets in this way as a result of their illness/disability may also be less likely to make decisions about the care they receive. It is this group that will need extra support to ensure that they received services tailored to their needs and wishes. There must not be a "one size fits all" approach and the services in place must be able to respond to changes in people's circumstances.

3.2 It is clear that elements of the personalisation agenda such as the provision of personal budgets will provide more choice and control for many. There are elements of this scheme that still need to be examined in greater detail though. The issue of safeguarding is an important one. Giving people increased control over where they get the services they require means relinquishing some control over ensuring they are cared for by reputable service providers and individuals.

Simply handing over a personal budget to someone and allowing them to get on with purchasing their own services would only be suitable for a small minority of those receiving care. For others, advocacy, advice and brokerage services would enable the local authority and the individual to ensure they are properly represented and as protected as possible without restricting choice. Sue Ryder Care's service users that have had experience of using personal budgets complained that while the system worked in principle, they did not feel that there were advocacy and support services in place to assist them in the event of a problem.

3.3 Sue Ryder Care recently spoke to its service users and their relatives about the government's social care green paper. The people we spoke to criticised the current support services that are in place for them and called for improved advice and advocacy services at all stages—from diagnosis to death. The feeling that "those who shout loudest" get what they want left many feeling isolated (and those who had battled for the support they needed were left exhausted).

3.4 Sue Ryder Care's services have responded to the personalisation agenda in different ways around the country. Local Authorities are approaching implementation of the personalisation agenda in a number of different ways and at different paces. This means that creating a model for personalised services that can be adapted to the needs of each local area is not always possible (or desirable). The challenges for providers are now localised—though no doubt this will change in the future as larger frameworks for the agenda come into existence.

3.5 Looking to the future, it is clear that we are entering a period of great change in the manner in which services will be provided as the practice moves into place behind the new policy, and that we will find that some models will succeed while others fail.

It is important the principles of quality and choice win out and that economies of scale for services that are currently successful for many people do not become unviable as small numbers choose alternative choices. This is only one among a number of challenges

We are already seeing a positive impact of choice for home care services users in the Trafford area, which recently introduced individual budgets. While Sue Ryder Care was not added to the local preferred provider list by the local authority, 100% of current users of the service requested to remain with Sue Ryder Care.

4. MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES.

4. In order to ensure any future system is user-friendly, it will need to be simple and independent advice, brokerage and advocacy will need to be available to ensure that people have the support they need.

4.1 From the work we have undertaken recently with our service users and their relatives, it is clear that they believe standards need to be improved among those providing and advising people on care. Almost everyone we spoke to in residential care related problems they had experienced with carers in their homes. Time and again we heard stories of carers turning up hours late, not staying for the allotted time and not having the necessarily skills to provide the care needed. They would like training to be improved for people on the front-line of service delivery.

4.2 Many of the people Sue Ryder Care cares for have a severe neurological condition. The effects of these conditions can be complex and caring for these people can often be very different to caring for people living with other conditions.

One possible side-effect of neurological conditions such as Huntington's Disease can be behavioural issues for example. The people we spoke to did not feel it was appropriate for carers to be coming into their homes without knowledge of the sort of side-effects their condition can cause.

Also it is reported by people living with fluctuating conditions such as Multiple Sclerosis that while their health is good services operate well, but when it fails it is difficult to gain the additional support required.

4.3 Sue Ryder Care is currently discussing the introduction of step-up-step-down projects with Commissioners. These would enable people to receive different levels of care depending what their needs were at any one time. It should help to remedy problems surrounding inappropriate hospital admissions which can be distressing for a patient and their family, as well as being costly and without merit for the NHS. It would also assist with the prevention agenda as people's situations would not have to reach crisis point before they received extra support.

4.4 More joined-up working between social care, health and housing services would ensure a better experience for people who need the support of more than one agency. In some areas such as Oxfordshire, we have seen joint-commissioning for fast-track funding of end of life care patients. This experience is not widespread though even though the benefits for the patients are great (they are able to move more smoothly between health and social care funding without being reassessed each time).

5. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

5. Many perceive the current funding of residential and domiciliary care as being unfair. Postcode lotteries operate, people are forced to use their savings to pay for their care and do not receive appropriate information and advice. The government's social care green paper aims to address these inconsistencies and to create a National Care Service to sit alongside the NHS. Sue Ryder Care believes that any reform of the social care funding system will have to address these inequalities.

5.1 The government's social care green paper sets out proposals to create a "National Assessment". Some organisations have argued that this may not go far enough; if Local Authorities are able to respond to local needs and offer varying services, the same postcode lotteries and inconsistencies may still exist. We have worked with the Fair Access to Care Guidance since it was introduced, and are aware that it is interpreted differently throughout the country. The government must ensure that the same does not happen to the National Assessment if it is created.

There is a debate about whether social care funding should be allocated centrally or locally. If it were to be allocated to individuals by central government, there could be a problem responding to the needs of local communities, and the personalisation agenda could suffer. However, if the Local Authorities retain control of the social care budgets and a National Assessment is introduced, both eligibility for services and the level at which they are delivered need to be portable.

5.2 The funding of those with complex needs must be taken into account. Sue Ryder Care works with people who have both health and social care needs. Too often, the transitions between the two funding streams are complex, and those needing care suffer. This is also true of those with changing needs or at the

end of their life. The dividing line between health and social care can be difficult to navigate which means the two funding streams try to “shunt” costs on to one another. A “joined up” social care service must therefore work more closely with healthcare services to ensure people in need of care do not suffer.

5.3 In the current climate, it is unsurprising that there are concerns over the quality of domiciliary services. The marketplace is extremely price sensitive with local authorities cutting contract costs and organisations and private companies bidding against each other to provide a service. In some instances, Sue Ryder Care has chosen to withdraw from the bidding process as the parameters within which we would have to operate under the contract would not enable us to provide a quality service. In the case of Walsall, after Sue Ryder Care removed itself from the process the next two incumbent service providers were suspended by CSCI. Local authorities must ensure they do not encourage this “reverse bidding war” with organisations vying to offer the lowest price as it puts the quality of the service at risk.

October 2009

Memorandum by Macmillan Cancer Support (SC 36)

SOCIAL CARE

EXECUTIVE SUMMARY

- There are over 1.6 million people in England living with a cancer diagnosis.¹¹⁸ It is a cause for celebration that, due to advances in detection and treatment, more people are now receiving high-quality cancer treatment within the NHS and surviving following a cancer diagnosis. However, although cancer treatments are becoming more effective, patients and carers are not receiving the supportive care services they need.
- Macmillan knows that many people affected by cancer need access to appropriate practical support services (such as help with housework or childcare), emotional support services (such as counselling), financial information and advice, and other information and support services.
- However, at the moment they are not being referred to social care services for assessment and struggle to access services. Even if people do receive an assessment, due to the current level of social care resourcing, people with cancer with low or moderate needs are not receiving the support that they need.
- Local authorities should be supported by the Government to invest in services for people with low or moderate needs and recognise that some services can be effectively delivered by innovative partnership services involving volunteers.
- Supporting cancer patients with low or moderate needs in the community can help them to manage their own conditions, potentially preventing emergency admissions to hospital if conditions escalate.

KEY RECOMMENDATIONS

- Health and social care priorities should be aligned to ensure that all the needs of cancer patients are considered and supported, not just their clinical needs.
- Every cancer patient and carer should automatically have a holistic assessment of their needs, including their social care needs, at key points in the cancer journey.
- PCT and local authority commissioners should work together with the voluntary sector to ensure that universal information services are available to everyone and can help to support people with cancer and other long-term conditions and carers.
- The Attendance Allowance funding stream should not be used to make up a shortfall in social care funding. This is an important benefit for cancer patients as it helps them meet the extra cost of their disability, such as a special diet or travelling to hospital, not just to pay care costs.

1. INTRODUCTION

1.1 Macmillan improves the lives of people affected by cancer, providing practical, medical, emotional and financial support. We help people to help themselves, and each other, by signposting to the network of cancer self help and support groups and offering good practice based training and support. We fund services to support practical and emotional needs and provide grants and benefits advice to people living with cancer, and carers. In 2008, we invested over £30 million in social care and information services. At the end of September 2008, there were 216 Macmillan Information professionals, 102 Macmillan social work professionals and 167 Macmillan welfare benefit advisers, plus 65 carers schemes, 81 information centres, 93 benefit advice schemes and 11 befriending or bereavement schemes.

¹¹⁸ King’s College London, Macmillan Cancer Support and National Cancer Intelligence Network (2008). *Cancer Prevalence in the UK, 2008*.

2. SOCIAL CARE NEEDS OF PEOPLE AFFECTED BY CANCER

2.1 *Practical*: Having cancer and being treated for cancer can leave people feeling tired, weak, in pain, and ill. The frequency of treatment can limit what people can practically do, and surgery can affect people's physical strength and mobility, either temporarily or permanently. They can find it difficult to do household chores like shopping and cooking. Getting around can become more difficult as they have trouble driving or managing stairs. They may also have problems getting up and going to bed, dressing and undressing, and maintaining personal hygiene. Four out of ten cancer patients (41%) say that the physical effects of their cancer or treatment are difficult to cope with.¹¹⁹

2.2 *Emotional*: Being told that having cancer is a possibility, and actually having it, is both frightening and distressing for the person with the disease and their family and friends. Nearly half of people with cancer (49%) say they experience depression as a result of their cancer diagnosis,¹²⁰ and more than four in ten (45%) say that the emotional aspects of cancer are the most difficult to cope with, compared to physical effects.¹²¹ Studies have shown links between depression and cancer survival; across 26 studies on cancer patients and the effects of depression on survival, mortality rates were up to 25% higher in patients experiencing depressive symptoms.¹²²

2.3 *Financial*: 91% of cancer patients' households suffer loss of income and/or increased costs as a direct result of cancer.¹²³ People with cancer can find it hard or impossible to work during their treatment and beyond, because they feel tired, weak, in pain, and ill. They can encounter unexpected expenses, like the increased cost of travel to and from treatment, and hospital car parking charges.

2.4 *Other care needs*: In addition to the effects of cancer and/or treatment on cancer patients, nearly half of all cancer patients have at least one other long-term condition, and nearly a quarter have at least two.¹²⁴

3. PEOPLE AFFECTED BY CANCER ARE STRUGGLING TO ACCESS SERVICES

3.1 Cancer is perceived as a "health" issue, rather than a health *and* social care issue. This was highlighted by the comments from the Health Secretary and others during the launch of the Green Paper.¹²⁵ In recent research, commissioners confirmed that local authorities tend to view cancer as primarily a health issue and PCTs traditionally do not see social care as a core service in relation to cancer care in general.¹²⁶ The emotional, practical and financial needs of cancer patients are "falling between the gap" in health and social care services, with neither one taking responsibility for addressing these needs. Over a quarter of cancer patients (26%) say they feel abandoned by the system when they are not in hospital.¹²⁷

3.2 Levers for encouraging joint working between local authorities and health services are not sensitive enough to the needs of people living with cancer. Local Area Agreements (LAAs), which set out the priorities for local authorities, very rarely mention the needs of people with cancer. Health priorities, such as the Cancer Reform Strategy, which has a strong emphasis on supporting cancer patients' social care needs, cannot be incorporated into LAAs. Our concern is that if LAAs do not include any of the indicators which could improve services for people living with cancer, then their needs will continue to "fall between the gap" in health and social care provision.

3.3 Our research shows that, as a result of little or no joined up working, people with cancer are often not referred by health services to social care services for an assessment.¹²⁸ As an indication, of the 32 people affected by cancer questioned at recent Macmillan Cancer Voices conferences, 25 had not received an assessment of their social care needs.¹²⁹ It is clear that cancer patients who are not even assessed for their social care needs in the first place cannot be receiving the support and services they need to help them cope with their condition in the community.

3.4 Even in cases where cancer patients do receive assessments, they often still do not access support services, because they are classed as having "low" or "moderate" needs (as defined under the Fair Access to Care Services criteria). Because social care in England is so under resourced, local authorities focus on people with "substantial" and "critical" needs, leaving people with low or moderate needs without the support they need.^{130 131}

¹¹⁹ Macmillan Cancer Support (2006). *Worried Sick—the emotional impact of cancer*.

¹²⁰ Ibid.

¹²¹ Ibid.

¹²² Jillian R. Satin, Wolfgang Linden, Melanie J. Phillips (2009). *Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis*.

¹²³ Macmillan Cancer Support (2006). *Cancer costs—the hidden price of getting treatment*.

¹²⁴ Macmillan Cancer Support (2008). *Health and well-being survey*.

¹²⁵ "We need a care system that people can rely on, that does not penalise people for their prudence and that ends the cruel lottery of older people facing financial hardship because they happen to get dementia, for example, rather than cancer." Health Secretary, Andy Burnham, 14 July 2009.

¹²⁶ Macmillan Cancer Support (2008). *Social care for cancer*.

¹²⁷ Ibid.

¹²⁸ Macmillan Cancer Support (2008). *Social care for cancer*.

¹²⁹ Macmillan Cancer Voices conferences in London and Bromwich, 2008. Of 32 people questioned, 25 had not received an assessment, 4 had, and 3 did not answer.

¹³⁰ Commission for Social Care Inspection (2008). *The state of social care in England 2007–08*.

¹³¹ Commission for Social Care Inspection (2008). *Cutting the cake fairly: CSCI review of eligibility criteria for social care*.

3.5 Local authorities are also not signposting to services which may be able to provide social care support even where statutory services cannot. Over a third of cancer patients (35%) say they do not feel confident about how to access social care and support.¹³² The Commission for Social Care Inspection found that in six councils that it studied in depth, signposting to services appeared to be dependant upon the skills of individuals,¹³³ and was therefore patchy and inconsistent.

3.6 Not supporting cancer patients in the community can lead to their conditions escalating, and potentially to inappropriate hospital admissions. Of the 14,500 cancer patients in hospital at any one time (at a cost of £2.9 million per day to the NHS), 60% have been admitted as an emergency.¹³⁴

4. A NEW MODEL FOR SOCIAL CARE

4.1 Health and social care services should work together to provide services to meet the emotional, practical and financial needs of cancer patients. We believe that a new model for social care will only be effective if joint working between health and social care is encouraged by aligning priorities, targets and performance measures more closely. Joint working not only creates a better experience for patients, but can potentially also produce cost savings.

4.1.1 Local Area Agreements should be more flexible and responsive to the NHS annual operating framework, so that initiatives like the Cancer Reform Strategy, which is a priority for the NHS and has a strong focus on supporting the social care needs of cancer patients, are considered in the commissioning of social care services.

4.1.2 Joint Strategic Needs Assessments and local strategic partnerships should be required to consider the health and social care needs of people affected by cancer specifically.

4.1.3 Joint commissioning and the use of pooled budgets should be used to encourage joint working between health and social care. Currently these practices are not being used as much as they could be: in 2007–08, councils only contributed an average of £12.52 million to pooled budgets, yet spend an average of £100 million a year on adult social care.¹³⁵

4.1.4 Health and social care services should work together to commission for whole care pathways, instead of for discrete services, and shared outcome measures should be developed across health and social care, which could be incorporated into Local Area Agreements. The Year of Care pilots for diabetes services showed the benefits of commissioning for whole care pathways. The pilots aimed to strengthen the relationship between healthcare professionals and people with diabetes by working to jointly plan their care and to ensure that the local support services were identified and available. Feedback from the pilots has been extremely positive; one service user commented: “*My doctor wants my input as well, he wants to know how he can help me, so it really is a two-way conversation. I now know how I can help myself and how they can help me. As well as the support of my husband and my family, I feel like the practice is also fully behind me.*”

CASE STUDY—MACMILLAN SOCIAL CARE COORDINATOR, NORTHAMPTON

In February 2008, Macmillan began funding a Social Care Coordinator based at Northampton General Hospital in the Centre for Oncology. The post aims to enhance and improve the experience of people living with cancer across the health and social care journey by streamlining services, facilitating timely hospital discharge and preventing avoidable admissions to hospital.

The service places the patient at the centre of their care. The social care needs of patients, carers, children and families are assessed, advice and information offered and support services co-ordinated.

During the first year of the post, 226 patients accessed the service. By coordinating services and promoting joined up working between health and social care, in this time the Social Care Coordinator is estimated to have facilitated 113 hospital discharges, influenced 18 avoidable admissions and saved 287 excess bed days. Based on a cost of £321 for an oncology bed day, this equates to an estimated £92,127 saving to the NHS on bed days alone.

4.2 As well as working together, health and social care services should work with service users to develop services. User involvement is a key lever for improving the quality of patient care in health services and delivering a patient-centred NHS, and should be similarly so across the care pathway.

4.3 All cancer patients should receive holistic assessments of their needs at key points in their cancer journey. Holistic assessments of needs, including social care needs, for both cancer patients and carers, should be automatically undertaken at the point of diagnosis, and repeated at key points throughout the cancer journey. These should be part of a process of personalised care planning, which puts the needs of the patient at the centre.

¹³² Macmillan Cancer Support (2006). *Worried Sick—the emotional impact of cancer*.

¹³³ Commission for Social Care Inspection (2008). *The state of social care in England 2007–08*.

¹³⁴ http://www.improvement.nhs.uk/cancer/presentations/survivorship_launch/11.50am%20Breakout/Ann_Driver_11th_September.ppt

¹³⁵ York Consulting (2008), *Local Government Association/Association of Adults Social Services Report on Adults Social Services Expenditure on 2007–08*. and Leeds: York Consulting 47 Source: Information Centre (2008) *Personal social services expenditure and unit costs. England 2006–07, section 5*

4.4 More support should be provided to people with cancer and their carers who are assessed as having low or moderate needs. Anecdotal evidence suggests that providing people with low or moderate needs with appropriate support can help to prevent their needs escalating into substantial or critical needs, and potentially avoid inappropriate hospital admissions. This should include:

4.4.1 Signposting and referral to support services for all people affected by cancer, regardless of their level of need. We welcomed the announcement in *Putting People First*, which was reiterated in the recent Green Paper, to create a universal information, advice and advocacy service available to everyone irrespective of their eligibility for public funding. However, our research suggests that few such services are currently being planned,¹³⁶ and we urge PCT and local authority commissioners to work together with the voluntary sector to ensure that these services are available to everyone and can help to support people with cancer and their carers.

4.4.2 More value placed on volunteer and peer-to-peer schemes in providing support to cancer patients and carers with low level social care needs. In addition to increasing funding for social care, another way of increasing resource would be to develop volunteering opportunities for people who are not carers but wish to volunteer in health and social care. We see volunteering as a way of providing simple practical and emotional support, such as befriending and help with DIY. We would caution that volunteer schemes, whilst increasing resource, are not free, or a way of providing social care “on the cheap”, and volunteers should not be seen as a substitute for appropriate professional care.

CASE STUDY—OXFORDSHIRE BEFRIENDING NETWORK

Macmillan has funded the Oxfordshire Befriending Network (OBN) for a number of years. The service provides trained volunteers to offer practical and emotional support to anyone with a terminal diagnosis or life-threatening illness, at home, in hospital or in a hospice. Befrienders meet weekly to listen, talk, and just be with their befriending partner. They can accompany their partner on hospital visits or other trips, provide a link with local health and social services, and provide much-needed breaks for carers.

In 2004, the OBN won The GlaxoSmithKline Impact Award. The judges praised the way the service benefits both befriender and partner and helps people deal with the taboo surrounding death.

“I am so grateful for the learning I have had from knowing my befriending partner and her sharing some of her life and experiences with me. I have realised how important this has been to both me and her, to see what a difference we have made for each other.”—Volunteer

“When I am with my befriender, I forget I have cancer... she is my friend and I love her to bits!”—Befriending partner

5. FUNDING

5.1 Macmillan believes that the Government needs to increase resourcing and ensure that resources are used more effectively in order to realise a new vision for social care. It was not the intention of this response to comment on proposals for new funding models but suggest how the social care system needs to work better.

5.2 However, we are strongly opposed to the proposal contained in the Care and Support Green paper to merge the Attendance Allowance (AA) funding stream with current social care funding streams to pay for the new National Care Service. As the Disability Minister himself said in a written answer on 23 July 2009, “Attendance Allowance provides help with the disability-related extra costs of people who experience the onset of disability after age 65”,¹³⁷ it is not intended to pay for the cost of care. Cancer patients we spoke to confirmed that AA helped them to pay for, for example, the cost of travelling to hospital for treatments, for car parking charges, for a special diet, special clothes, and extra heating, all of which were extra costs incurred because of their cancer.¹³⁸ This benefit should not be taken away to pay for the cost of care.

October 2009

Memorandum by Age Concern and Help the Aged (SC 37)

SOCIAL CARE

EXECUTIVE SUMMARY

The Green Paper:

- We strongly welcome the government’s vision of a National Care Service and moves to a system of national entitlement. This is the best aspect of the Green Paper.
- Overall the Green Paper lacks sufficient detail for us to judge whether any of the reform options are superior to the current system. It is a disappointing document.

¹³⁶ Macmillan Cancer Support (2008). *Social care for cancer*.

¹³⁷ Deb, 23 June 2009, c816W

¹³⁸ Macmillan held thirteen in-depth interviews with people affected by cancer during the last week of August and the first week of September 2009.

- Proposals to integrate Attendance Allowance into the care and support system are worrying and vague. Details are needed now.
- The Green Paper proposals are broadly “revenue neutral” (except for the “comprehensive” option). But the care and support system needs more resources—even to respond to the needs of people who meet today’s means-test—in order to achieve better quality and earlier availability of services.
- We support moves to a less means-tested “partnership” model where everyone in need receives some help with the cost of care. But this should only be pursued if there is first enough money to adequately fund good quality care for the poorest.
- In principle, we welcome the idea that people should pool the risks of needing to pay for care. But our research shows that the proposal for a “care charge” outlined in the “comprehensive” option is very unpopular. We were disappointed that the less obtrusive option of taxation was ruled out, which could include taxes targeting older people not just younger adults through a combination of income and wealth taxes.
- The Prime Minister’s very welcome announcement that personal care will be free for those in the highest need living at home is a move towards a “comprehensive” approach funded from general taxation. We are unsure how this will affect the proposals in the Green Paper.

The transformation agenda:

- Further investigation is needed on the reasons why older people are less satisfied with personal budgets than other groups.
- The personalisation agenda needs to take account of unstable and unpredictable conditions, as well as crisis situations, which might make needs more difficult to manage with a personal budget.
- Personal budgets must be adequate to meet assessed needs. With age discrimination legislation imminent, resource allocation must not replicate discriminatory practices that have evolved where by older peoples services are geared around less ambitious outcomes than services for younger people.
- Care must be taken to ensure there is genuine market choice for budget holders.
- One of the biggest stumbling blocks to consistent user friendly services is tight eligibility criteria which means many people are refused state support—and in many cases then receive no help in finding their own services.
- Care must be taken to ensure that in the new world of personal budgets and less traditional services quality and safeguarding is at the centre—and this implies money for training and support for both users and workers and clear access to advice, information and brokerage.

1. INTRODUCTION.

1.1 Age Concern and Help the Aged welcome this inquiry by the Health Select Committee on the future of social care. The inquiry comes half way through the Putting People First transformation programme and in the midst of the current Green Paper consultation. It is an opportune time for the committee to examine the proposals and take stock of how far the vision of personalised care and choice is working in practice. In this paper we address the first bullet point in some detail and address the second two bullet points together under the heading of the transformation agenda.

2. FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

2.1 Age Concern and Help the Aged is currently in the process of consulting with older people about their views of the proposals in the Green Paper and will be submitting a full response to the Department of Health in November. We have produced campaign material which gives our initial thoughts on how far the Green Paper meets our ten tests for reform. The booklet is attached to this memorandum.

2.2 However having had the opportunity to examine the Green Paper and all the accompanying papers we have some considerable concern about how we will be able to respond meaningfully to it. The Green Paper lacks sufficient detail for us to judge whether any of the reform options are superior to the current system. It is a disappointing document.

2.3 We warmly welcome the proposals for a National Care Service. The offer of six national entitlements should be the “architecture” for any model of reform: prevention—joined up services—personalised care—a national assessment—information and advice—fair funding.

2.4 We agree with the government that there should be a move away from local discretion towards a more national system. This should combine features of social security (clear national entitlements) and the NHS (national standards but local discretion on how outcomes are achieved). This proposal is the most positive new development in the Green Paper.

2.5 Other elements of the “offer” set out in the Green Paper are familiar from previous policy statements. Indeed a commitment to prevention and service integration dates back to the 1980/90s. The challenge is to turn good ideas into consistent practice throughout the country. To turn the principles into reality, new resources are needed.

2.6 On 29 September the Prime Minister announced that the process of building a National Care Service would begin with the offer of free personal care at home for those in highest need. We very much welcome this statement, although it is unclear how it will interact with the Green Paper’s funding options or with its costings. At present we do not have any detail about what will constitute highest need or how the policy will be implemented.

2.7 In general, we believe the starting point for the discussions about funding should be a clear debate about what proportion of GDP our society will want or need to spend on care over coming decades. This approach was adopted when reforms to the NHS and the pension system were being discussed—and informed Derek Wanless’s report on care for the King’s Fund. This is an essential backdrop for discussions about what balance there should be between spending by the state and the individual—as well as for analysis of detailed funding models.

2.8 The Government has published little detail on the financial assumptions behind its proposals. But overall by the 2020s ministers expect to spend a little less with the reforms in place than under the status quo (except if care is made free for all, which would be paid for by a new charge). Although the details aren’t available, we don’t believe these spending assumptions are compatible with two essential reforms needed to help people who already qualify for state-funded care under today’s means-tested system: (1) improved quality and (2) earlier availability of care. We will oppose any proposals which do not improve the availability and quality of care for the poorest.

2.9 Before we can make any meaningful comment on the funding options proposed in the paper we need more detail on the costing assumptions: the level at which eligibility criteria will be set; how much resource will be available per person; and the nature of the means-test for both the partnership proposal and for the cost of accommodation under the “comprehensive” model.

2.10 The Government says the reforms might be paid for by integrating Attendance Allowance benefit payments into the new care and support system. The Green Paper is worryingly vague about what this will mean and many frail and disabled people are rightly anxious about the future of the benefit. It may be that integration will preserve the essential features of Attendance Allowance. But without any detail in the public domain people are right to fear the worst. There is also much confusion about whether Disability Living Allowance would be included. Treating the two benefits differently would widen existing age discrimination.

2.11 A technical publication accompanying the Green Paper indicates that “integration” could involve disability related payments such as Attendance Allowance becoming means-tested in order to exclude 60% of people from entitlement. We are seeking clarification about the details of the analysis and the status of this proposal.

2.12 One extremely important aspect of Attendance Allowance is that the payment is “carer blind”—that is the payment is made regardless of whether the person has a carer. In contrast the new system might make payments or provide services after any help that is offered by a carer has been taken into account. This could mean that someone who would receive Attendance Allowance under the current system, could get little or nothing if they have a carer who is willing to undertake the care themselves.

2.13 We consider that the following positive features of the benefit should be guaranteed in the new system before we could consider integration:

- A statutory, national entitlement to cover the costs of ill-health and disability for all who need extra help
- A minimum weekly payment worth no less than now, with indexed annual uprating
- Complete flexibility over how the payments are used to maintain health and independence
- Entitlement regardless of whether a family member is providing care
- No extension of age discrimination in disability related payments or in the outcomes they are intended to secure.

2.14 Although we support greater risk pooling we are sceptical about the “comprehensive” option, the guarantee of free care in exchange for a compulsory charge of around £20,000 paid by all older people except those without assets. Our research shows that in principle richer people would prefer to pool the costs of care. But we do not believe this “deal” is politically acceptable, not least because it would pay for services which are free in Scotland. The Prime Minister’s announcement on free critical care in the home also begs the question why one universal entitlement to care should come from general taxation and another from an earmarked charge.

2.15 The care charge would buy people protection from the unlikely but catastrophic risk of needing to pay for many years of care. But in addition to the payment many people would also lose thousands of pounds in foregone Attendance Allowance; and the charge would not cover “board and lodging” in care

homes which comprise at least half their costs. Taking these two factors into account, the government's "offer" looks little cheaper than insurance people can already buy to cap their costs, once they know they will need care. We think few older people will see the care charge as a "price worth paying".

2.16 We recognise that older people should contribute to the costs of the public services they use but we believe that there are less obtrusive ways of raising revenues from assets. The government should also continue to promote longer working lives, so that earnings can be taxed for longer. We were disappointed that the tax option was ruled out, which could include taxes targeting older people not just younger adults through a combination of income and wealth taxes.

3. TRANSFORMATION AGENDA

3.1 Age Concern and Help the Aged support the moves towards more personalised care services for older people. Older people should have more choice and control over the outcomes they want and the support in place to achieve them. We also support the idea that personalisation should go beyond social care services, to all services that an individual receives, including housing, transport and community services.

3.2 The focus of the personalisation agenda has been on personal budgets. There is evidence that older people's satisfaction with personal budgets is not as high as other user groups. Further investigation of the reasons for this is needed. It might be that older people who just want services arranged for them are being pressurised into accepting cash payments, or because insufficient advice and support is available, or because the budgets older people are given are not adequate and only meet the cost of the essential elements of their care. Personal budgets were developed with younger disabled people in mind. They share many of the same type of needs as older people, but may have more stable conditions and are less likely to move into the care system in a crisis. The delivery of personal budgets therefore needs to be altered so that it fits more closely the needs that older people might have. Account needs to be taken of unstable and unpredictable conditions, as well as crisis situations, which might make needs more difficult to manage with a personal budget.

3.3 Local Authorities need to continue to carefully monitor outcomes among older people who receive personal budgets. They should also ensure that family carers who accept the responsibility of managing a budget on a day to day basis for a relative are making a positive, informed choice rather than taking on a burden reluctantly.

3.4 Resource allocation for personal budgets should be fair, transparent and focused on outcomes. The level of the personal budget needs to be adequate to buy care which meets the assessed needs. There is growing evidence to show that older people are discriminated against in the systems which allocate the money (Resource Allocation Systems) compared to other user groups. It appears that historic differences in the way that budgets are allocated are being built into the new systems to distribute the money to individuals.

3.5 We are concerned that some councils are pursuing an overly mechanistic approach to resource allocation. In some areas there have been simplistic assessments which award points which translate into a cash amount. In a recent court ruling (*J.L. v. Islington*) the Judge concludes that; "I find it hard to see how a system such as this one, where points are attributed to a standard list of factors, leading to banded relief with a fixed upper limit, can be sufficiently sophisticated to amount to a genuine assessment of an individual child's needs". Although referring to a child, the same point applies to adults.

3.6 Our view is that Resource Allocation Systems should only provide an "indicative budget" for use as a planning tool and should not be a final determination of a person's support needs—which depend on a number of factors including the cost of care providers' fees.

3.7 Although the final decision about personal budgets remains with the local authority, the information gathering is often passed to other agencies, as is the "brokerage" services of helping the person arrange their care in the way that they wish. We welcome this as it provides people with more choice, although we are concerned that what used to be a free services undertaken by the local authority in the form of assessment and care management might become chargeable if provided by other organisations. Our preference is that local authorities should fund these services so that they are provided free. An alternative approach would be for people who receive personal budgets to have an amount included in their budget in order to purchase support services, but there are several problems with this:

- The role of brokers and care managers would have to be rigorously separated as the latter cannot be charged for;
- There is no guarantee that budgets would be adequate;
- If a means testing system is developed that involves a service user contribution based on the overall size of the budget people may end up paying towards brokerage.

3.8 A critical "unknown" is how personalisation will affect the market for care services. Personalisation, for example, could result in consolidation of the market because purchasers will favour large "household name" providers that they know and trust, or people could opt for very local or "grey market" solutions. It is hoped that there will be more varied options tailored to people's preferences rather than "one size fits all" services. But with increasingly fragmented demand providers may lack the confidence and economic security to innovate.

3.9 Much work is being done through the transformation agenda and it is clear from inspection reports that services are improving. However the biggest stumbling block to user-friendly services is that so many local authorities have had to raise their eligibility criteria to “substantial” and “critical”. This means that the experience of many is that they approach adult services in the expectation of getting help and find that they are turned down. This experience often then colours any future contact.

3.10 Likewise, Age Concern and Help the Aged still too often hears of cases where financial assessments are taking place at the initial stage and thus older people are missing out on needs assessments. Indeed one document from a local authority which was sent to us states “If, following a financial assessment, you are considered to have sufficient capital or income to purchase your own care, the provision of care by Council may cease. If this happens the care package arranged by Council will end four weeks after the date of the financial assessment and, if necessary, you will be assisted to purchase your own care directly.” This is a direct contradiction to guidance for home care where it is clear that regardless of wealth individuals should be able to have their home care arranged by the council if this is what they wish. The fact that the person may well be very happy with the care that has been provided, could mean considerable disruption if they have to change provider merely because they have too much money.

3.11 Age Concern and Help the Aged is interested in how quality can be driven up and has produced 20 drivers which interact and help drive up quality. We have attached them to this submission. Some are market drivers but others are compensations for market deficiencies.

3.12 With more and more people managing their own care packages there is an expanding and increasingly diverse workforce of personal assistants who may not have gone through traditional training in social care. It is important that funding for training and support is in place for both users and workers in this new environment.

October 2009

APPENDIX

20 DRIVERS OF QUALITY CARE AND SUPPORT

Choice and control drivers

- | | |
|---|---|
| 1. Consumer choice (i): home care | This can be achieved through direct payments or increased choice and control over commissioned services using notional budgets. Consumer choice allows people to personalise services, which should increase satisfaction; budgets may also create market incentives for providers to improve quality. |
| 2. Consumer choice (ii): care homes | Most families are already involved in selecting a care home. However there is poor information and constrained choice when people decide whether they need a care home and which to select. Whilst there are steps that could be taken to improve this older people often have to choose care whilst in hospital or in a crisis situation, so will inevitably face barriers to acting as empowered consumers. Once people are in a home, choosing to move to another is rarely practical. |
| 3. Enforceable rights | Service users have rights under community care, consumer protection, criminal and human rights law which they can personally enforce. Awareness and use of these rights is low. There is ‘soft law’ for local authorities to safeguard adults. The current review of ‘No Secrets’ means there is likely to be intensive discussion about whether legislation is needed to support the guidance. |
| 4. Involvement of service users and carers | It is good practice for commissioners and providers to involve service users and carers in planning, commissioning, providing and evaluating services. |
| 5. Information, advice, advocacy, brokerage | This can be a mechanism for improving quality via either consumer choice or upholding enforceable rights. Services provide support to make informed choices and help people with limited capacity make decisions. |

Financial drivers

- | | |
|------------------------------------|--|
| 6. Size of care packages | Commissioning care packages with more contact time (or proving equivalent money through a personal budget) is shown to be linked to improved outcomes. |
| 7. Financial rewards and penalties | In some circumstances high quality care and support can reduce costs for the NHS. In principle, the system could include financial incentives to reward commissioners or providers for generating these savings. |

Commissioning drivers

- | | |
|--|---|
| 8. Assessment and care planning | Everyone is entitled to an assessment of their care needs. Care plans are statements of the outcomes people should achieve and the services people require to meet these. Provision and outcomes can be measured against these plans. |
| 9. Local authority and NHS commissioning | Commissioners are responsible for assessing local need and for planning, developing and evaluating services, as well as managing provider contracts. They must ensure that agreed levels of quality are delivered and they also have duties under equality and human rights legislation. Local authorities have responsibilities, under current “No Secrets’ guidance” to take action where they are aware that so called “vulnerable adults” (defined as people who may be in need of care services) are at risk of abuse. Poor quality services may be a basis for action to prevent abuse or neglect. Government policy now emphasises joint commissioning focused on improving outcomes and preventing the need for acute services. . |
| 10. ‘Market shaping’ powers | Local authorities are charged with developing provider capacity and the local workforce. Both are essential for effective procurement and consumer choice. |

Workforce drivers

- | | |
|---------------------------------------|---|
| 11. Higher pay | Most frontline care workers earn little more than the National Minimum Wage. This has implications for recruitment, retention and the quality of the workforce. |
| 12. Training and qualifications | Training and qualification requirements are included in the current regulatory standards that providers need to meet. |
| 13. Professional standards and ethics | Social care has less of a culture of professional self-regulation and standard setting than health services. |

Regulatory drivers

- | | |
|---|--|
| 14. Regulation and inspection (i): registration standards | Inspection and data collection is used to assess whether providers meet minimum regulatory requirements to operate. |
| 15. Regulation and inspection (ii): consumer information | Inspection and data collection is used to assess quality, including through the “star rating” system. This information can facilitate consumer choice. |
| 16. Regulation and inspection (iii): market supervision | Economic regulators like the Office of Fair Trading are responsible for ensuring that the care market is competitive and efficient. There is no financial or economic regulator with specific responsibilities for independent care providers. |
| 17. Quality assurance systems | Care providers are expected to operate their own quality assurance systems as a condition of registration. |
| 18. Complaints procedures | Complaints procedures enable service users and carers to enforce their rights without resorting to the courts. They can also be a key element in quality assurance, regulation and inspection systems. |
| 19. Age equality standards | Care services are covered by the Department of Health age discrimination standard, however unequal treatment on grounds of age persists. The government has committed to legislation to outlaw age discrimination in social care. |

Good practice drivers

- | | |
|--|--|
| 20. Development and dissemination of good practice | A wide range of statutory and voluntary organisations test and research models of good practice, and disseminate new ideas for delivery. |
|--|--|
-

Memorandum by The Princess Royal Trust for Carers (SC 38)

FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

1.1 The social care Green Paper “Shaping the future of care together” proposes various funding methods to create a sustainable social care system. The majority of carers we have consulted with have advised that they wished that the option of funding social care wholly through general taxation should have been an option.

1.2 We recognize that there are financial restrictions on public funding but we think it is important that the public are given an opportunity to discuss whether funding for social care is as important as other government spending priorities. It is noticeable that whilst the integration of health and social care is seen as vital to improving the lives of those who need care and support, it is only health care that political parties have said that will be protected from future funding cuts.

1.3 The public are generally ignorant that they may have to pay for social care due to the belief that the NHS funds all care “from cradle to grave”. The distinction between health and social care is not obvious to them.

1.4 The Comprehensive model proposed within the Green Paper appears to be the most popular of the three models that the government has proposed according to our surveying of carers and meetings attended. This funding method could also be the best to support the integration of health and social care as it would remove the conflict of some services being provided free of charge, whilst others need to be charged or subject to means testing. Where all services were free at the point of need, as they would be in the comprehensive model, it would allow the most appropriate range of services to be provided improving the quality of life outcomes of those receiving care.

1.5 What the Green Paper recognizes but does not address is that any care system is only sustainable because of the free care provided by carers—someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

1.6 The demographic and financial pressures on health and social care funding will push more people to be cared for at home and in community settings. This will increase the number of carers, which is expected to rise by 3.4 million carers over the next three decades.¹³⁹ Research has found that carers already save the Department of Health between £67 billion¹⁴⁰ and £87 billion¹⁴¹ and the Green Paper accepts that it is not “affordable to have a system which completely replaced family care with state-funded care and support”.¹⁴²

1.7 Therefore, no matter what future funding systems of long-term residential and domiciliary care are created, it will not be viable without the in-kind contributions made by carers. This is true of the social care system as a whole but the Green Paper only looks at one half of the equation of creating a sustainable social care system—the financial contributions that people should make and not the in-kind contributions made by carers.

1.8 The Government does propose that since many couples provide care and support for each other, couples could be asked to contribute lower amounts in the Comprehensive model proposed within the Green Paper.¹⁴³

1.9 We agree with the suggestion that the provision of care and support should be recognized and given value by a reduction in financial contributions. This benefit should be extended to all carers, not just those in couples. It would be unfair to restrict any benefit to co-habiting carers as there are many carers who do not live with the person they care for yet provide substantial care and support. It would also be unfair for a carer not to receive such a benefit because they are not part of a “couple” but rather care for a friend or relative. Such measures would help the Government achieve its aim of creating a fair system, recognizing the irreplaceable value that carers provide in the social care system.

PERSONALISATION OF SOCIAL CARE SERVICES

Putting People First without putting carers second

2.1 The Princess Royal Trust for Carers and Crossroads Care published *Putting People First without putting carers second* in February 2009. Over the next three decades, the number of carers will increase by around 60% or 3.4 million carers. In this way, we will rely increasingly on ordinary people to deliver the ambitious reforms set out in *Putting People First* and this report provides local solutions that already exist to help carers and personalization change lives.

2.2 Much material from this report will be included in evidence given. The full report can be downloaded for free or a hard copy can be posted:

<http://www.carers.org/professionals/social-care/>

Current fringe event

3.2 We are currently holding a fringe event at Labour, Liberal Democrat and Conservative party conferences entitled *Personalising care: the choices we face*. Each fringe event consists of group discussions focusing on:

- Choice and equality in a personalized system

¹³⁹ Pg. 7, *Putting People First without putting carers second*, The Princess Royal Trust for Carers & Crossroads Care, 2009

¹⁴⁰ Just Care, IPPR, 2008

¹⁴¹ Valuing Carers—calculating the value of unpaid care, Buckner and Yeandle of the University of Leeds, published by Carers UK, 2007

¹⁴² Pg. 119, *Shaping the Future of Care Together*, HM Government, 2009

¹⁴³ Pg. 114, *Ibid*

- What parts or structures of the system needs to change to allow personalization to work
- Financial implications of personalisation

3.3 The feedback was then followed by a response from the Minister or shadow minister for Health with questions from the audience. We will be compiling a report at the end of the last conference and will gladly make this available to the Committee if they so wish.

Our view of Personalisation

4.1 We must make personalisation work for whole families and communities, not just individuals. Individuals do not live in a vacuum. Where families wish to, they should have the option of being assessed for eligibility as a whole family, rather than having to negotiate separate assessments and eligibility for each individual. For most, it would be easier to achieve a package that tackled all of their needs in a coherent way. This would give the reach choice and control rather than juggling different arrangements.

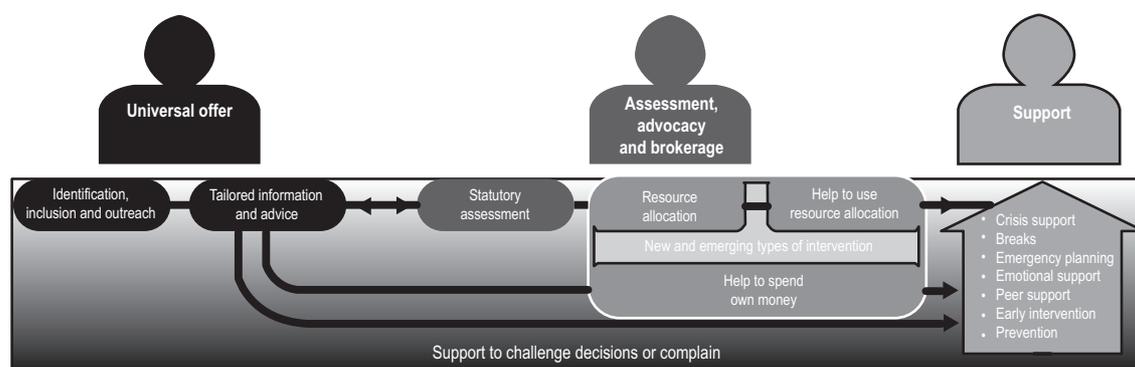
4.2 Independence should not be conflated with living alone. Some of the policy development around independent living risks overlooking people, such as many older people with dementia, whose goal is to live with dignity in a family unit. We should not aim towards a system that works only for the young disabled person who wishes to live in their own home or only for the elderly person with dementia who wished to be cared for by their family, but towards a system that works for both these kinds of choices.

Creating an effective system for Personalisation

5.1 We developed a pathway that considers the strands of Putting People First¹⁴⁴ which sets out the personalisation programme. This pathway has been included in the guide Commissioning for Carers, of which we were the lead author and has been published by the Department of Health.¹⁴⁵ It shows how needs can be met by ensuring that there are available personalised services at each stage.

- Greater choice, control and independence for everyone who uses services and carers
- Everyone able to make informed choices through a “universal offer” of advice and information
- Development of “community capital”: people and families becoming expert care partners
- Early intervention and prevention as well as support at the point of crisis.

Carers have a voice in local planning: all organisations and professions are carer-aware



PERSONALISATION PATHWAY PART 1: IDENTIFICATION AND INFORMATION

6.1 *Putting People First* advocates a “universal offer” of advice and information for carers and those requiring care, whether or not they are likely to be eligible for state-funded support. A family should be able to get help and guidance to understand every stage of the care system and find their way through the “care pathway”. However, there are many people, especially carers, who are unknown to social services and fund their own support but could benefit from advice and information. Only 25% of carers receive an assessment to ascertain their eligibility for services or a personal budget.¹⁴⁶

Identification services

7.1 To ensure that these people and carers have access to information and advice, services performing outreach work to identify them must be in place. Outreach work requires a range of partnerships which cannot be funded through personal budgets; nobody would pay from their personalisation budget for identification services that they no longer need.

¹⁴⁴ Putting people first: a shared vision and commitment to the transformation of adult social care, HM Government, 2007

¹⁴⁵ Commissioning for Carers, The Department of Health, 2009

¹⁴⁶ Carers Speak Out, The Princess Royal Trust for Carers, 2002

7.2 It is essential to continue to use core funding to finance services that successfully identify potential service users and carers to offer them information and advice. Decommissioning services to allow the use of personal budgets should not be to the exclusion of the development of universal services that will identify people who will need a personalised intervention. Understandably, nobody would pay from their personal budget for identification services that they no longer need.

7.3 Experience shows that rates of carer recognition rise dramatically when there is a core funded specialist carers' service in their area. One of the most successful methods is working closely with GP practices. The Carers' Centre covering Harrogate and Craven working closely with a practice identified nearly 140 carers whilst another practice who chose not to work with the Carers' Centre identified fewer than ten carers in the same period.¹⁴⁷

7.4 Other examples in the report include an East Sussex Carers' Centre working with the NHS Trust to help their staff identify and support carers.¹⁴⁸ Hertfordshire Carers' Centre has created a core information offer that local agencies have signed up to which can trigger signposting to the Carers' Centre.¹⁴⁹ Some people doubt that outreach services are done adequately by statutory bodies as they could result in more expense due to increasing demand for services. Therefore, it is Third Sector organisations that are often prominent in performing this role.

Information services

8.1 Like any market, people need information about services available and this universal offer of information should be available to all regardless of their level of need. There needs to be a variety of information gateways, national and more locally targeted. For example, there is a national carers' website and helpline that provides standardised information for carers.

8.2 However, there needs to be locally tailored information suited to communities that can be accessed by all ethnicities and sections of the population. One stop shops are not always the most efficient way as they give only one opportunity that you may not know about; if you miss the door, then you've missed the chance.

8.3 Many carers value the informality of small third sector carers' organisations that help them understand their information and support needs and find a comfortable and useful way into the system. This kind of personalised information service remains essential alongside local single gateways for information and national phone and web services.

8.4 Third sector organisations remain trusted sources of information that people feel able to approach and listen to. This is contrasted with the suspicion that people sometimes view local authorities with, especially if some communities come from traditions where authorities are feared. Some are also less reluctant to be open with local authorities for fear of the information being shared or "used against" them.

8.5 The Brighton & Hove Carers' Centre has a service to:¹⁵⁰

- Inform carers about opportunities available for direct payments and personal budgets.
- Supports carers' involvement in individualised support planning
- Inform carers of their right to an Assessment and enable them to access respite and legal, financial and emotional support
- Advocate for carers if services are not being delivered as planned

PERSONALISATION PATHWAY PART 2: ADVOCACY AND BROKERAGE

9.1 Advocates can represent the interests of people who may find it difficult to be heard or speak out for themselves. These can include older people, those with disabilities and those with mental health problems. This gives a voice to people who need support to make their own choices because they are frail or disabled or because of financial or social circumstances. It also enables them to have their individual needs and views respected and acted upon.

9.2 We believe that Third Sector advocacy organisations can play an impartial role in helping budget holders in their relations with providers, including statutory bodies. Many people prefer to have choice and control but find it hard to manage the budget, and prefer to leave it to others. Organisations or individuals can be nominated as Appointees to take on this role. Brokerage services can also be utilized in a similar fashion to help purchase the services they want.

9.3 Often these services are performed by the budget holder's carer and there is evidence that carers are key to positive outcomes of Individual Budgets¹⁵¹ There is also evidence that the responsibility for managing and co-ordinating the budget holder's support arrangements falls to the carer at the risk of experiencing increased stress.¹⁵² It is necessary that support is given to carers and families to help them manage services purchased.

¹⁴⁷ Pg. 24, Putting People First without putting carers second, The Princess Royal Trust for Carers & Crossroads Care, 2009

¹⁴⁸ Pg. 25, Ibid

¹⁴⁹ Pg. 11 Ibid

¹⁵⁰ Pg. 15, Ibid

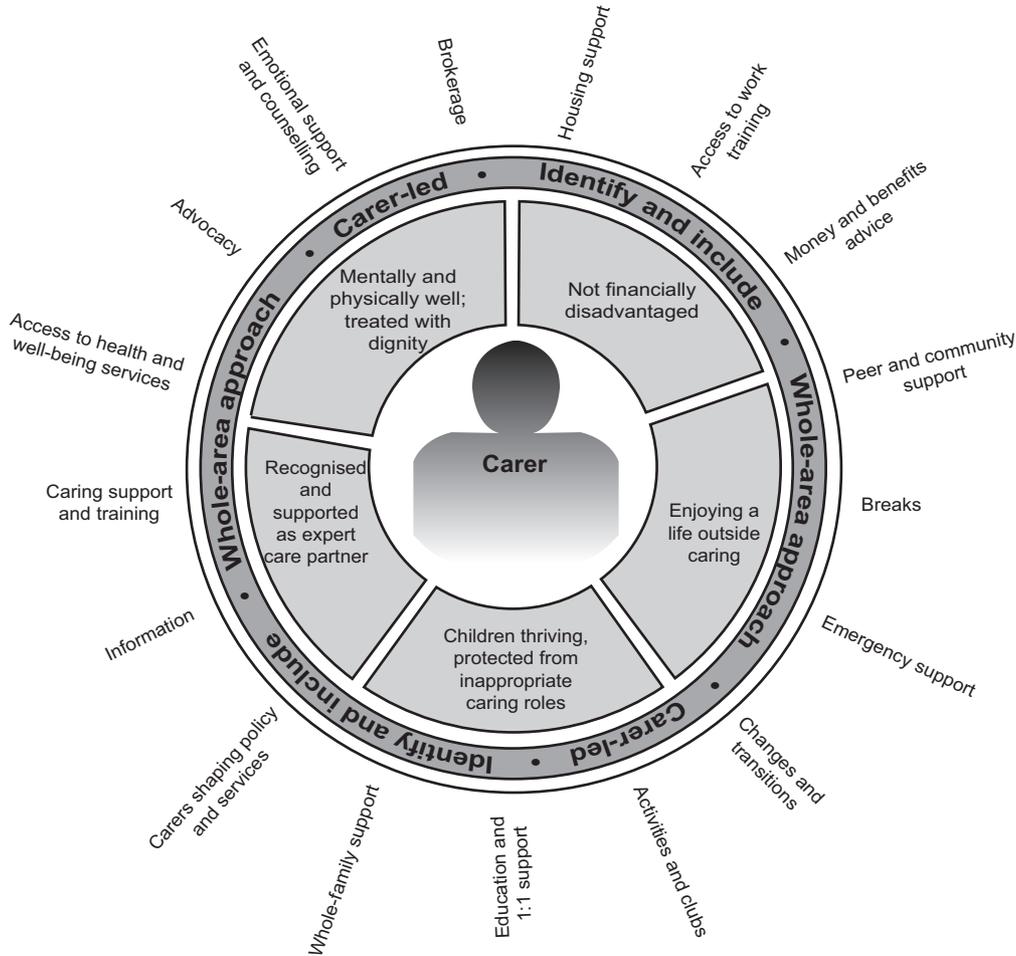
¹⁵¹ Pg. 6, The Individual Budgets Pilot Projects: Impact and Outcomes for Carers, Glendinning, Arksey, Jones, Moran, Netten and Rabiee, University of York and University of Kent, 2009

¹⁵² Pg. 8 Ibid

9.4 Crossroads Care North East England supports carers to identify and access the services needed, and helps to recruit staff chosen to deliver it. Crossroads Care remains the employer responsible for training, maintaining professionals' standards and payroll thus taking the pressure off the carer, whilst the carer and budget holder still enjoy choice and control.¹⁵³

PERSONALISATION PATHWAY PART 3: SUPPORT SERVICES

10.1 Offering choice and personalised services relies upon local areas building and sustaining a diverse market of third sector providers who can offer personalised support, but which also includes organisations which ensure that users and carers are fully involved in local decision making.



10.2 Commissioners should take a whole area approach to assessing need which Third Sector organisations and service users should inform. In relation to carers, we have developed a model of how to ensure that comprehensive support services exist.

10.3 The model has a carer in the centre of a series of concentric circles. The five outcomes identified in the Government's Carers Strategy (2008) are in the next circle. The outer circle includes a range of services that could be needed by carers to achieve the five outcomes.

10.4 Commissioners have a responsibility to ensure that all of these services exist within a locality. Such a range of services might not be available if left to provision by personal budget acquisition. This wheel has been incorporated in a Commissioning for Carers Guide that we were the lead author for and was published by the Department of Health.¹⁵⁴

Having a real choice

11.1 There are many who do not want to choose a personal budget and would rather that they received a social care package. This choice is also dependent on there being enough centrally commissioned services available for people who do not want to purchase their own.

¹⁵³ Pg. 15, Putting People First without putting carers second, The Princess Royal Trust for Carers & Crossroads Care, 2009

¹⁵⁴ Pg. 13, Commissioning for Carers, The Department of Health, 2009

11.2 In relation to carers, a person's independence through using personal budgets can be at the expense of a carer taking on the management of that budget, or providing more care. Carers must also have a choice and not have extra caring duties placed upon them. Peter (name changed) used to attend five days at a community centre. He was approached about a direct payment and being able to choose to do what he wanted.

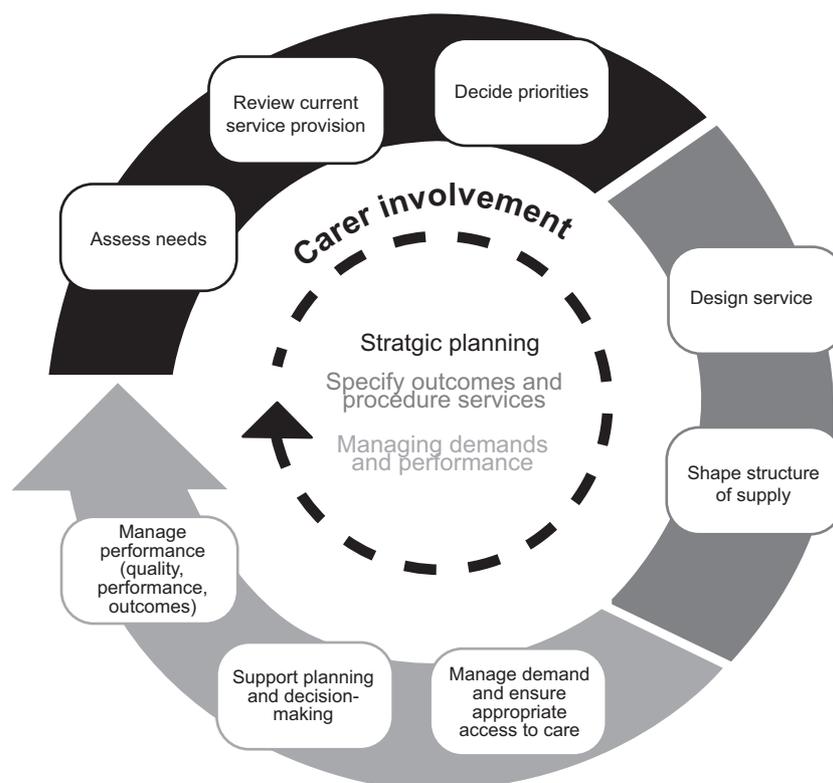
11.3 His family was not involved in planning at the start and using the budget allocated to him, he cannot pay for support five days a week. This means his mother had to reduce hours at work and cover when the support worker is off sick or on holidays. The independence had not been considered meaning the carer took on a greater burden. This is further explored in our report *Putting People First without putting carers second*.

11.4 With any bold new reform, energy and commitment is needed to push forward change. This must be balanced with the flexibility and thoughtfulness required to avoid "throwing the baby out with the bathwater".

MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

12.1 In thinking about service user participation, services should recognise that paid professionals and service interventions are often only a small part of an individual's support network. Services should recognise that individuals exist within a complex structure of family and community relationships and it is important to take a holistic, whole-family view of achieving well being.

12.2 This means recognising carers and family members and ensuring that their participation is supported as well. This is a diagram depicting carer involvement in planning and monitoring services.¹⁵⁵



12.3 For example, our Northampton Carers' Centre has a mental health project based within the Community Mental Health Teams. A reference group ensures care involvement in all development of the project and local services. Key local professionals also attend. They recently worked together to devise a new Carers Assessment form, which is now being used by the CMHTs as well as leaflets and information pack.¹⁵⁶

The Princess Royal Trust for Carers and Crossroads Care

We are the two biggest providers of services for carers in the UK and work together at a national level to promote policies and guidance that will support carers.

¹⁵⁵ Pg. 10, Ibid

¹⁵⁶ Pg. 26, *Putting People First without putting carers second*, The Princess Royal Trust for Carers & Crossroads Care, 2009

The Princess Royal Trust for Carers operates throughout the UK with 144 carers' centres & 85 young carers' services.

Their core offer includes:

- finding hidden carers via outreach in GP surgeries, hospital wards and schools;
- finding the right information for every carer, whatever their circumstances;
- making sure carers' voices are listened to by local decision makers;
- supporting carers emotionally and practically throughout their caring journey;
- helping to make caring a positive experience by helping carers to share experiences and by ensuring access to breaks, education, training and employment.

Crossroads Care operates throughout England and Wales with 120 local and regional schemes.

We are the largest provider of respite care amounting to 4.6 million hours every year. We have 35 years of unparalleled experience and expertise in providing personal care and vital support for the carer. A Crossroads service is about giving time—improving the lives of carers by giving them a break from their caring responsibilities. Our aim is to provide a reliable, tailored service for each carer and the person they care for. A trained Carer Support Worker will take over from the carer to give them “time to be themselves”.

October 2009

Memorandum by Counsel and Care (SC 39)

THE CASE FOR CHANGE: WHY ENGLAND NEEDS A NEW CARE AND SUPPORT SYSTEM

Counsel and Care is delighted to submit evidence to the Health Committee inquiry into social care. The Green Paper, *Shaping the Future of Care Together*, is a once in a generation opportunity to create a new care and support system that is simple, fair, consistent, transparent and flexible, and transforms the lives of millions of people.

Our submission takes the form of four papers published by Counsel and Care in 2008 and 2009. The papers move from problems with the current system and principles for reform to a vision for a new care and support system and lessons from successful reform in other countries.¹⁵⁷

1. *Finding and Financing Care in Hard Times: The top issues reported to Counsel and Care's Advice Service in 2008*

This paper highlights a care system in crisis and reports the difficulties older people and their families have finding and paying for care in their own homes or moving into residential care. It demonstrates the need for radical reform.

2. *A Charter for Change: Reforming care and support for older people, their families and carers*

This paper starts with evidence from Counsel and Care's advice service that demonstrates the growing care gap and the crisis of funding, fairness and confidence in the current system. It sets out five principles for reform: any new care system must be simpler, fairer, transparent, consistent and flexible, and poses ten tests for any new model of care.

3. *Lifelong: A new vision for the wellbeing of all older people, their families and carers*

This paper sets out an ambitious vision for reform of the care system. Lifelong is a universal entitlement to a comprehensive package of services and support integrated at a local level and focused on prevention, topped up by additional contributions to pay for higher levels of need. The paper explores different funding options and suggests that collectively paying for care through sharing the risks and the costs is the best way forward. In particular the paper encourages further exploration of the national care fund proposal.

4. *Reforming care and support: learning from Japan*

This paper looks at the Japanese care system and how it is funded following reform in 2000. It highlights how successful reform in Japan and elsewhere has a number of key characteristics: a strong national framework and local delivery; universal access; a single funding stream; integration of health and care locally; recognition and support for family carers; and system-wide not piecemeal reform.

Taken together these papers and other material published by Counsel and Care and with our partners, particularly through the Right care Right deal campaign, point towards the following answers to the three major issues flagged up in the pre-Green Paper consultation process:

¹⁵⁷ <http://www.counselandcare.org.uk/influence/publications/>

1. the need for a strong national framework of entitlements and standards to deliver simplicity, fairness, consistency and transparency, with local delivery providing flexibility
2. the creation of one system meeting the needs of everyone and used by everyone, with an emphasis on universal access and universal entitlements
3. the sharing of the risks and costs of care while recognising that some people will be better placed than others to pay their contribution. There are a number of different ways to facilitate collective funding of care—from taxation and national insurance to new models of social insurance.

COUNSEL AND CARE WELCOMES THE GREEN PAPER PUBLISHED IN JULY 2009

Sixty-one years after the NHS was founded, the care Green Paper gives us the chance to develop the next frontier of the welfare state. Creating a national care service on a par with the NHS is what this country needs to meet the demands and expectations of our ageing population.

The Government has recognised that we have to address the care implications of our ageing society. Filling the care gap is one of the biggest challenges we all face. We simply can't do nothing and ignore the needs of this and future generations of older people.

Bold new proposals to end the postcode lottery in care and make paying for care fairer for everybody have been widely welcomed. The Green Paper, "Shaping the Future of Care Together", presents radical long-term proposals to pay for the better care older people and their carers urgently need, particularly for the growing number of older people with dementia, disabilities and long-term conditions.

Counsel and Care favours the comprehensive care funding option—paying for care from people's estates, for example, via a "care duty" would be a much fairer option than the current system which means that many older people and their families lose their homes. People on lower incomes currently struggling under the burden of huge care costs would be better supported by the new system.

The proposals meet many of Counsel and Care's tests for a new system which must be simpler, fairer, consistent, transparent and flexible, meeting the needs of older people wherever they live. We particularly welcome:

- the proposal for a National Care Service with a universal entitlement to care and national assessment and portability to end the postcode lottery
- much better provision of information, advice and advocacy to give older people and carers greater choice and control
- closer joint working between health, housing and care services to make the best use of resources
- the emphasis on promoting healthier later life, investing in prevention and supporting older people earlier through schemes like telecare to improve quality of life and save money
- support for better regulation, improved training and career development for the care workforce to deliver better quality care.

The proposal to merge Attendance Allowance into a single pot with other care funding moves towards creating a single funding stream (as in successful reform elsewhere) but it has caused alarm among older people and their organisations because Attendance Allowance is an extremely popular benefit. It needs to be clear what older people would get under a new care system before any change is agreed. More also needs to be done to improve support and income for carers.

The care challenge is an issue for every citizen. We need a huge public debate and national consensus about the best way forward for all of us. How we share the risks and the rising costs of care must be debated in every family and every community as well as through the media. It is an issue that touches the lives of everyone in our society.

What can't be ducked though is that care will cost us all more. So we need to find new ways to pay for the growing bill. Any new funding system must be fairer, simpler and transparent for all. A care duty on people's estates as a one-off payment to fund the comprehensive care option has the hallmarks of a better system.

Better care is key to building a better country for everyone. Economic success as well as meeting our collective social responsibilities will be determined by how well we support older people and their carers today and tomorrow.

October 2009

Memorandum by the National Care Association (SC 40)

SOCIAL CARE

1. INTRODUCTION

1.1 National Care Association represents the interest of independent sector registered providers of social care. The membership comprises primarily SME's

1.2 The provision of services by members covers a wide spectrum of the categories of care including care of older people, people with dementia, people with learning disabilities, people with physical disabilities and children, both in care homes and having the care delivered in their own homes.

1.3 National Care Association is committed to:

- The raising of standards for the benefit of those in receipt of care
- A trained and skilled workforce
- The recognition of Social Care as a profession alongside Healthcare and Social Work.
- Delivering a flexible service tailored to the needs of individual service users rather than delivering the services that have always been delivered.

1.4 The Officers of the Association are:

Chairman—Nadra Ahmed OBE

Chief Executive—Sheila Scott OBE

2. FUTURE FUNDING OF LONG TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

2.1 The current system of funding for people who do not have the assets to self-fund their care has been known to fail to deliver appropriate care to individuals with the highest level of assessed need.

This is particularly evident now as the demographic trend is for an increasing number of older people in their 80s, 90s and many more over one hundred years old.

2.2 The main cause of this is due to the fact that Local Authorities often have to manage a finance led service rather than a needs led service.

2.3 National Care Association believes that the funds available for the delivery of social care should be prioritised for spending on those with the highest level of assessed care need before money is allocated to lifestyle choices.

2.4 There is a clear difference in the methodology used to fund the care services of older people as opposed to younger adults.

Younger adults are almost always funded by the State.

About 50% of older people are funded by the State but the proportion of State funded recipients can vary dramatically around the country. For instance, in the South East it is recognised that as few as 20% may be State funded whereas in parts of the Midlands and the North East the figure can be as high as 80% of recipients being State funded.

2.5 We believe that there is a misconception that people who self-fund their care often have less choice than those whose care is arranged by the state: we do not accept this. People with their own funding can make a positive choice about the type of care they arrange. It is our belief that state funded service users are disenfranchised by the two tier system.

2.6 National Care Association has been considering the issues relating to the future of long term care since its inception in 1981. It is our considered opinion that funding for the majority of people in receipt of care is inadequate. Furthermore, it is wholly unfair that self-funders are penalised through the financial assessment process because they have made provisions for their old age.

Had they not made those arrangements the State would have paid.

2.7 National Care Association has always believed that there needs to be a system that is:

- Fair
- Equitable
- Transparent
- Sustainable

2.8 The proposal that is most likely to meet the above criteria when looking to service delivered in a care home is for the fee to be split into two elements:

- Board and Lodging
- Care

2.9 Everyone has to pay for their board and lodging at home. They may pay it themselves or through the benefits system. People entering care homes are actually moving into their new home and should therefore be able to pay for that part of the arrangement in the same way as if they were living at home. Clearly, this will need to vary taking account of the quality of the accommodation.

2.10 People in receipt of benefits are able to claim a range of benefits; housing benefit, Council Tax allowance etc. These should be made available to people living in care homes who have been through the assessment process and are in receipt of benefit.

2.11 The expectation of the public is that the care element should be paid for by the State.

2.12 There must be absolute clarity about the funding that would be available. This would undoubtedly assist individuals and their families to navigate through the complex care system.

2.13 When the Royal Commission on Long-Term Care reported in 1990, there was much debate about whether or not there was any real understanding of the costs of caring for older people in different ways and therefore the cost to the state. This is as true today as it was then.

2.14 Although the cost of care in a care home to the state is well documented, this is not the case for people living in their own homes particularly where the costs are spread over many Government Departments. It would be helpful if all the state funded costs relating to this area of care could be documented so that real comparisons can be made.

2.15 The areas that might be covered would include the State Pension, any Income Support payments, Attendance Allowance, NHS related costs, Housing Benefit, Council Tax support etc.

2.16 The care paid for by the State might pay for the basic provision of care.

2.17 If people want to buy an enhanced care service they should be allowed to do so.

2.18 We are beginning to hear reports from around the Country that Primary Care Trusts are reassessing patients previously assessed as needing Continuing Health Care funding. If the funding is withdrawn there are huge ramifications both for the care home and for the Local Authority.

2.19 There needs to be urgent consideration given to what the impact of decisions to withdraw Continuing Health Care funding will have both on a Council's adult care budget and on the care home.

2.20 Providers who set their fees in advance and plan around the spread of fees that their businesses attract cannot suddenly be forced in to reducing fees for what is absolutely the same level of care down to the spot contract council rate.

2.21 Potentially providers are going to be faced with service users who may have nowhere to go.

2.22 We are seeing NHS funding being denied more and more to patients with many decisions blatantly ignoring national guidance about National Health Service responsibilities to fund continuing care.

3. PERSONALISATION OF SOCIAL CARE SERVICES

3.1 The implementation of the personalisation agenda for people with significant needs can vary dramatically depending on age.

3.2 With an expectation among younger people with disabilities of a move toward increasing independence, they are more likely to enthusiastically embrace the personalisation agenda.

3.3 Where this philosophy fails is when independent living is adopted and any other form of provision is no longer acceptable.

3.4 There will always be younger adults with disabilities with such profound needs that can only be met within a residential setting.

3.5 There have been worrying reports of local authorities saying that in the future all younger adults will be housed in independent living centres with no respect for the wishes of the individual and their families.

3.6 A range of choices must surely be the key within the personalisation agenda.

3.7 Older people in need of care often do not want to have to be bothered with managing their own services; they are often tired of trying to manage things on their own and are looking for someone else to manage things for them. Having said that, they certainly do want to receive a personalised and individual service.

3.8 This does not mean that the services provided cannot be personalised, they most certainly can be and there are many examples of this:

- Putting service users first
- The wide variety of provision available to meet the needs of people.

4. MORE EFFECTIVE, CONSISTENT AND USER FRIENDLY SOCIAL CARE SERVICES

4.1 So often it is the small things that transform a service and not a major reorganisation.

4.2 It is widely agreed that information is the key to achieving user friendly social care services.

4.3 There needs to be some form of one stop shop available in each local authority area.

4.4 This should be an independent source of information not a centre run by the council.

4.5 The source of information can just be a point that signposts people towards the information they need for instance, an important part of the advice that most people need relates to finance and funding. Such information must be give by appropriately trained advisers. It would be easy for the advice centre to direct people to one of the specialist financial advisers who understands how the systems works.

4.6 A well run information centre would both empower people and make their journey through the complex world of health and social care so much easier.

4.7 There are many options for where the advice centres might run from:

- A doctor's surgery
- A care facility
- A local shopping centre.

4.8 Consistency of provision of services for people who are funded by the State is very patchy.

4.9 For absolute clarity it would be helpful if there were one assessment tool in use and that the criteria for assessing care were set nationally and not locally (to fit in with availability of funds).

5. CONCLUSIONS AND RECOMMENDATIONS

5.1 Independent information centres should be piloted as soon as possible.

5.2 Research should be undertaken to ascertain the true cost of the various models of care.

5.3 A national assessment tool connected to national criteria for accessing care should be adopted as soon as possible.

October 2009

Memorandum by the City of London Corporation (SC 41)

FUTURE OF SOCIAL CARE SERVICES

Whilst not being one of its mainstream functions, the City of London Corporation takes seriously its role in providing quality social care for its residents and, while it is unable to respond to all areas of the inquiry, welcomes the opportunity to input into the Committee's deliberations following the publication of the *Shaping the Future of Care Together* Green Paper.

In particular, the Corporation is keen to highlight some of the work being done to provide services for older residents through successful inter-agency communications. One example of this is the recently established monthly meetings City of London officers hold with representatives of the Bengali community. Discussions range from issues of rent arrears that may indicate a deterioration in a resident's ability to care for themselves and manage activities of daily living, to monitoring of individuals who are displaying episodes of mental illness or showing signs of suffering from dementia. The referrals made from these meetings have formed a large part of the prevention strategy that encompasses all the agencies' safeguarding agenda and, more widely, they provide an opportunity for new initiatives, such as the City's Safeguarding Procedure which ensures that any changes in provision do not detract from the services provided to residents, to be discussed with all the agencies involved, allowing any issues or problems to be raised and dealt with in a timely fashion.

In addition to the services provided to residents within the City of London, the Corporation has established a range of initiatives, such as the Community ICT Project, for older people to engage more actively with their communities and prevent isolation. This provides weekly "Silver Surfer" training sessions, giving participants free access to the internet, new skills (getting email addresses/learning to send and open emails/learning internet search/sending emails with photograph attachments), help with getting up-to-date news, assistance with staying in contact with friends and families and the ability to plan day trips. One of the longest running and most successful initiatives provided for older residents is the City of London's over 50s "Young at Heart" which aims to help members increase their physical and mental fitness through activities such as swimming, guided walks, short mat bowls, line dancing, ballroom dancing, table tennis,

badminton, day trips and quiz nights. The impact of these sessions should not be underestimated as recent health checks showed that 81% of members had lowered or stabilised their body mass index, 92% of members had normal blood pressure and 100% had a normal pulse rate.

October 2009

Memorandum by the Multiple Sclerosis Society (SC 42)
SOCIAL CARE

1. INTRODUCTION

1.1 This paper is a response by the Multiple Sclerosis Society to the Health Committee Inquiry into the future of social care.

1.2 Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults. Around 100,000 people in the UK have MS. For some people, MS is characterised by relapses followed by periods of remission while for others it follows a progressive pattern. The causes of MS are unknown, there is no cure and the treatments that are available are effective in only certain cases and for some of the time. MS symptoms include loss of mobility, pain, fatigue, visual impairment, numbness, loss of balance, depression and cognitive problems. MS can lead to severe and permanent disability.

1.3 The MS Society is the UK's largest charity for people living with MS, with almost 40,000 members, over 320 local branches, four respite care centres and a 10 bed residential unit for people aged 20 to 60, focused on independent living. We provide grants to individuals, for home adaptations for example, and to public sector organisations to co-fund specialist nursing posts. The MS Society is the UK's largest funder of research into MS, investing approximately £7 million in 2008 alone.

2. FUTURE FUNDING OF THE CARE SYSTEM

2.1 Care and support services are vital to support people with disabilities or a long-term condition like MS to live full and independent lives. The MS Society believes that such services should be delivered free at the point of need. This view is supported by people with MS: a survey carried out by the MS Society showed that 87% of people with MS want to see a system which provides free care to people with all level of needs and regardless of income.¹⁵⁸ The Government has an immediate responsibility to address the unmet need currently being experienced by older and disabled people. This responsibility is based on the principle that the state has a positive obligation to promote the independence and equal citizenship of older people and people with a disability.

2.2 However, the MS Society recognises the serious problems with the current care and support system, and the enormous and growing pressures faced by changes in life expectancy and demographics. We accept that a new way of funding this rising demand must be found. The real test of any new system of funding is whether it increases resources in the system as a whole, ensuring that both younger and older disabled people are able to access the care that they need to live full and independent lives.

2.3 Currently, many people do not receive the care that they need because many local authorities have raised their eligibility criteria to try to ration social care spending in the face of increased demand. In 2007–08, 72% of councils gave care and support services only to those who were deemed to be at “substantial” or “critical” level of risk.¹⁵⁹ We also know that people with fluctuating conditions often struggle to pass the eligibility test to access the care that they need. In their analysis of eligibility criteria, the Commission for Social Care Inspection stated that addressing the needs of people with fluctuating conditions should be an urgent priority.¹⁶⁰

2.4 While we welcome a national set of eligibility criteria, the bar needs to be set at a level that ensures that more working age and older disabled people with any level of need are able to access care and support services. The Health Committee may like to consider whether any of the funding options put forward in the current Green Paper will bring sufficient resources into the social care system for this aim.

2.5 We are currently undertaking an online survey of people affected by MS to establish their preferred system of funding for the future social care system, and will be submitting a more detailed response to the Green Paper regarding the funding issue in November.

3. PERSONALISATION OF SOCIAL CARE SERVICES

3.1 The MS Society ascribes to the Independent Living model and supports the self-directed provision of services. Individuals are the experts on their own situation, and therefore people have the right play a central role in the design and delivery of their care and support services, including how resources are allocated.¹⁶¹

¹⁵⁸ Woodroffe, K; Dodd, M, Care and Support Services Consultation: Voices of People Affected by MS, MS Society, 2008

¹⁵⁹ Commission for Social Care Inspection, Cutting the Cake Fairly: Review of eligibility criteria, 2008, p. 26.

¹⁶⁰ Ibid.

¹⁶¹ Gillinson, S; Green, H; Miller, P; Independent Living—the right to be equal citizens, Demos, 2005

3.2 Personalisation offers a real opportunity for people with MS to control the services they need to enable them to live the life of their choice. The additional flexibility provided by personalised services can be particularly beneficial for people with complex and fluctuating conditions such as MS. This is supported by the results of the Individual Budget pilots, which show particularly positive results for younger people with a physical disability.¹⁶²

3.3 A direct payments recipient from Leicestershire told us:

“Flexibility is a fundamental part of care and carers need to be able to fit in with your needs.

There have been many changes in my life since I was first diagnosed [with MS] but I lead a full and active life [since getting direct payments].

I try to tell people how much better it would be if they went on direct payments or the new individual budget. It may be a bit scary to start with and you may not make the right choices at first, but when it all comes together it is life changing.”¹⁶³

3.4 Key benefits of a more personalised approach for people with a long-term or fluctuating condition like MS include the opportunity to be creative and take innovative approaches, alongside traditional care, and the ability to arrange more flexible and responsive services.

3.5 The MS Society supports the human rights approach taken by the draft revised Fair Access to Care Services (FACS) guidance, and the increased emphasis on outcomes.¹⁶⁴ The express assertion that there is no hierarchy of needs is an extremely important one. More personalised services can and should address the full spectrum of people’s needs. For example, at a conference on the subject of personalisation organised by the MS Society in conjunction with Devon County Council, participants discussed the need for “enablers”, capable of supporting people in hobbies and interests, which might include outings and other activities. Opportunities for social and other engagement were seen as essential to an individual’s general well-being and to their independence.

3.6 In another much-publicised example, Gavin Croft, diagnosed with MS at age 35, used his individual budget to buy some equipment to help him to get around easier at home, as well as a season ticket so that a friend could take him to the football. This in fact served as an innovative and enjoyable form of respite care. Gavin stated:

“[Going to the football is] my respite, and the only time of the week [my wife and carer] Karen can rely on having to herself.”

3.7 Flexible and responsive services are particularly important to people with fluctuating conditions like MS. In a major survey carried out by the MS Society in 2008, people with MS told us that the lack of responsiveness in social services means that people with relapsing remitting MS rarely receive care services during a relapse. 95% of people with MS said that better services during a relapse or sudden deterioration of their condition would help them maintain their independence, and 81% of people with MS wanted to be able to plan their care and support in advance of a relapse or sudden deterioration of their condition in advance of the care being required.¹⁶⁵ A respondent to our consultation told us:

“The professionals should be able... to provide a forward care plan for each patient. Of course, that plan would have to be flexible and would need revising constantly. It may even involve abortive planning, but at least, the needs could be provided quickly.”¹⁶⁶

3.8 Personalising services should include giving individuals with long-term conditions the opportunity to plan their care and support in advance, even as early as the point of diagnosis.

3.9 A number of pilots have shown that an effective way for Local Authorities to develop innovative services to increase the choice and flexibility available to individuals in using their direct payments is to work in partnership with voluntary and community sector organisations.

3.10 For example, the MS Society is currently working in conjunction with East Sussex County Council to run an innovative relapse support service during 2009–10. The County Council has provided each person on the pilot scheme with a sum of money to enable them to determine what support would be best for them in the event of a relapse, and to choose when to purchase this support. Each individual has completed a relapse support plan detailing the type of support they would like to use if they have a relapse. This service is being independently evaluated but early discussions with participants have shown that the scheme is highly valued and is enabling people to feel secure, knowing that support will be readily available when they need it. Participants have stated that having this support will enable them to continue working when, due to a relapse, they are, for example, unable to drive and to continue to carry out their parental responsibilities.

¹⁶² Glendinning, C; Review of the Individual Budgets Pilot Programme: Final Report, University of York, 2008

¹⁶³ Roberts, A; Living my own life at last. MS Matters, Issue 84, March/April 2009, England.

¹⁶⁴ Department of Health. Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care. Guidance on Eligibility Criteria for Adult Social Care, (consultation stage), England 2009 at Para 47 and 72–73. Available at http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_102362

¹⁶⁵ Full copies of the research report and the MS Society submission to the Government consultation are available at: http://www.mssociety.org.uk/get_involved/policy_campaigns/key_issues/social_care/case_for_change.html

¹⁶⁶ Ibid.

3.11 Other excellent examples of partnership working delivering better outcomes for service users and carers are the projects carried out by Neurological Commissioning Support (NCS). This joint initiative, led by the MS Society, the Motor Neurone Disease Association and Parkinson's Disease Society, is helping Primary Care Trusts (PCTs) and Local Authorities across the country to ensure that people living with long-term neurological conditions are at the heart of commissioning.¹⁶⁷

3.12 The MS Society is concerned by the Green Paper's suggestions that we should consider integrating some elements of disability benefits, for example Attendance Allowance, into the funding of a new National Care System. Disability benefits, including Disability Living Allowance (DLA) and Attendance Allowance (AA) provide a perfect example of a personalised approach to care and support which promotes independence. These non-means-tested benefits help people to manage the extra costs of living with a disability however they choose. They also support the prevention agenda by providing extra support to individuals, particularly those with low-level needs, to remain independent for as long as possible. Respondents to our survey stated:

"Disability benefits ensure that the money can be used in the way that best helps the person maintain independence and quality of life. No care system could be flexible or responsive enough to assist someone with a fluctuating and unpredictable condition like RRMS. My needs change not just weekly or daily but often hourly. I may be able to feed myself in the morning but unable to do so in the evening for example or vice versa. DLA allows me the control to adapt to an ever changing situation and affords me a little dignity, which is a rare commodity when battling a condition like MS. I can assess my care needs better than any care manager or social worker and at no cost. DLA gives me the freedom to pay for help as and when I need it and in a much more cost efficient way than any formal or centralised system ever could. It is such a small amount of money in the overall scheme of things but for a person like me, it means the difference between surviving and living. That is something you can not put a price on."

"One of the most important factors re DLA is that you can still work and receive it. It gives someone the financial security they need so that if working ever becomes too difficult to continue due to an increase in fatigue or symptoms at least you know you have your DLA income to fall back on.

...Also, DLA is often received by those who haven't reached the point where they need paid carers coming into the home. It acts almost as a preventative measure. It gives enough for people to be able to pay someone for a little help from whatever source, which then means they can reserve their limited energy for other tasks such as working, being a mum or dad, a home keeper etc.

... What does it mean to mean me? It's the difference between having a life and not having a life... The care component of DLA is spent on ready meals, pre-chopped veg and fruit and salad, sandwiches, hair, nail, pedicure appointments, waxing (...I can no longer dry my hair, paint my nails or shave my legs, I wish I could), special clothes and shoes, good quality bedding (as it's washed so often), alterations to house, door knobs, taps etc, wet wipes, incontinence pads, underwear, lights, flooring in house (I cannot walk on carpet) washing powder, tumble dryer and cost of use (I cannot peg out washing and daily have to wash clothes and bedding due to continence issues)."

3.13 Almost 20% of current respondents to our survey say that they would be happy for disability benefits to be used to fund a new social care system if the new National Care Service improves services and provides all of the things that disability benefits currently pay for. However, over 60% of people affected by MS state that they do not think disability benefits should be used under any circumstances, as they provide the choice and support for independence and that is at the heart of the personalisation agenda.¹⁶⁸

4. MS SOCIETY RECOMMENDATIONS FOR AN IMPROVED, PERSONALISED CARE SERVICE

4.1 Good quality advice, information, advocacy and brokerage are crucial to support individuals to make the best use of their funds, and to take on all of the additional responsibilities of managing their own funds.

One direct payments recipient told us:

"I had some support from a local advocacy service, which helped me with things like making sure I got the right amount of care, deciding how many carers I would need, and working out the money for my direct payments and Independent Living Fund. I had to find out about employment laws myself, and I now do rotas, wages, tax, sick pay, holidays, contracts and dismissal—all that is involved with being an employer."

People with MS need specialised, skilled support planners with an intimate knowledge of the system. Feedback from the Individual Budget pilots found that specialist support planners made people's experience more positive and offered "a personal touch that built up a bond between planner and user".¹⁶⁹

¹⁶⁷ For more information on the Neurological Commissioning Support initiative, visit www.csupport.org.uk

¹⁶⁸ Full results of the survey will be published in the MS Society response to the Green Paper on the Future of Care in November 2009

¹⁶⁹ Glendinning, C. Review of the Individual Budgets Pilot Programme: Final Report, University of York, 2008

According to the MS Society's recent research,¹⁷⁰ people with MS want a universal, locally-based "one-stop shop" to provide good quality, independent information to all those with a care need. They also need support planners who could:

- Be a single point of contact to ensure accessibility, continuity and to build trust in the process;
- Build a personal relationship with service users—understanding the way a condition can affect the individual;
- Really understand a person's individual care and social needs, including family circumstances;
- Promote a range of different options, not simply existing Local Authority services; and
- Offer impartial advice, preferably as someone from outside social services—potentially from a peer support network or voluntary or community group.

Other types of support that may help people to exercise choice in managing their own personalised care and support include the following:¹⁷¹

- Mentoring from others
- Examples and stories
- Guides and toolkits
- Training

People affected by MS suggested that many of these could be provided by building capacity in community and voluntary organisations, provided that they are given appropriate support in the form of additional training and financial support.

Support provision could also be improved by the continued expansion of Centres for Independent Living across the country, to ensure that people in all areas of the country have access to a support centre, as recommended in the Prime Minister's Strategy Unit publication, "Improving the Life Chances of Disabled People".¹⁷² These developments should be underpinned by a stronger focus on information provision within local authorities, as proposed in the current Green Paper on Social Care, and strongly recommended in the draft revised "Fair Access to Care Services" guidance.¹⁷³

4.2 People also need guidance as to how far they can "think outside the box" in spending their budgets: where are the boundaries as to what Local Authority care money can be spent on?

4.3 The MS Society welcomes in principle the extension of personalisation beyond social care, as suggested in the Government's Right to Control proposals.¹⁷⁴ However, this additional flexibility and choice must be backed up with appropriate advice, information, advocacy and brokerage as above. The Right to Control trailblazers will require careful planning, and a thorough evaluation to decide what really works for disabled people.¹⁷⁵

4.4 The MS Society welcomes the Government's draft revised FACS criteria as a positive step towards improving the care and support system for all. However, adequate funding must be available to ensure that Local Authorities are able to implement the new guidance fully

4.5 Disability benefits are very much in line with the personalisation agenda, giving people with all levels of care needs a core amount of support to choose their own personalised support to remain independent for as long as possible. Any new system which integrated the funding from these benefits would need to provide a similar level of support, choice and control to all those who could receive such benefits. The Health Committee may like to consider whether rolling these funds into the care and support system would bring any advantage for disabled people, particularly those with low level needs who are currently eligible for disability benefits but not for social care services.

4.6 There is a need for Local Authorities to encourage the development of innovative new services to ensure that people who take on personal budgets have the maximum choice and flexibility in how to use them. The MS Society urges Local Authorities to work closely with service users and user-led groups to develop these services.

October 2009

¹⁷⁰ Woodroffe, K; Dodd, M, Care and Support Services Consultation: Voices of People Affected by MS, MS Society, 2008

¹⁷¹ Duffy, Stansfield, Moffatt, Guide to Self-Directed Support: Guide 2: Planning and Brokerage, In Control, November 2006. Available at <http://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=98&cc=GB>

¹⁷² Improving the Life Chances of Disabled People, Prime Minister's Strategy Unit, January 2005, Recommendation 4.3.

¹⁷³ Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care: Guidance on Eligibility Criteria for Adult Social Care, England 2009 (consultation stage), Department of Health, July 2009. Available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102437.pdf

¹⁷⁴ Office of Disability Issues, Making choice and control a reality for disabled people. Consultation on the Right to Control, June 2009.

¹⁷⁵ See Consultation on the Right to Control MS Society response. Available at http://www.mssociety.org.uk/get_involved/policy_campaigns/policy_parliamentary_work/consultations/index.html

Memorandum by Citizen's Advice (SC 43)
ADULT SOCIAL CARE IN ENGLAND

SUMMARY

1. Adult social care services are struggling to meet the demand that they face. As a result, many people with care and support needs are currently not receiving the services and financial support that they need. Some of them receive financial support through social security benefits, such as Disability Living Allowance (DLA) or Attendance Allowance (AA), but both these benefits are underclaimed leaving eligible people without benefits to which they are entitled.¹⁷⁶ In this situation, a heavy burden of caring falls upon relatives and friends, often at considerable financial sacrifice to the carer.

2. We welcome the Government's recognition in the green paper "Shaping the Future of Care Together" that it needs to take a radical look at how care and support can be available to adults in a fair, simple and affordable way. It will clearly be a major challenge to achieve this goal in the face of a large increase in the number of older people in the population. This evidence draws on the experience of our clients to suggest features which will need to be part of any new system.

3. The green paper sets out a vision for a National Care Service based on six components:

- Prevention services
- National Assessment
- A joined-up service
- Information and advice
- Personalised care and support
- Fair funding

4. In general we very much support this vision. However, we consider it fails to give enough recognition to the importance to frail and disabled people of suitable housing, and of assistance with practical needs such as cleaning, shopping and transport. We also feel that it pays too little attention to the contribution of carers and the support they need.

5. Some aspects of the funding proposals give us great concern—we do not believe it is desirable to abolish attendance allowance (AA) and we are concerned that the green paper narrows the discussion of future funding to only three options. We would not support charging arrangements that treat older people less favourably than those who are of working age. We are concerned that such an approach appears to countenance discrimination against people on account of their age. We do not consider such discrimination is ever justified.

INTRODUCTION

6. The CAB service in England and Wales saw 1.93 million clients in 2008–09. Of these 28,000 brought in issues connected with adult social care. 10 bureaux have Legal Services Commission contracts to provide advice in relation to community care or mental health. There are also locally funded CAB services involved in social care issues. The Devon Welfare Rights Unit, which is part of the CAB network, provides financial assessments for adult social care clients in the county, and Tameside CAB provides an information and advice service about local care and related services for older people, and also an advocacy service for care home residents.

7. Bureaux send in reports on issues which are of policy or practice relevance and we received several hundred reports relating to adult social care in the year to September 2009. This evidence is based on those reports and on the experience of specialist CAB services which work in the adult social care field.

FUTURE FUNDING OF LONG TERM RESIDENTIAL AND DOMICILIARY CARE

8. Under the present system, the individual requiring residential care is required, by rules that apply across England, to contribute almost all her or his income to the fees, and to run capital down to £13,500. This includes the value of their house in many cases. For non-residential care, charges are set by local authorities, following national guidance. The green paper recognises that there is widespread dissatisfaction with the current rigorous means testing regime. It suggests that there are five options for charging for social care:

- Pay for yourself
 - Partnership, with a proportion of basic care costs paid for everyone, and all costs paid for the least well off
 - Insurance—promotion of private insurance to supplement the partnership model
 - Comprehensive—compulsory payments by all people over retirement age to insure them against possible future care costs. Free care for people of working age.
 - Fully tax funded
-

¹⁷⁶ "Tackling pensioner poverty: Encouraging Take Up of Entitlements" National Audit Office November 2002

The government rules out the first and last options, as too mean and as unaffordable. We are unclear how the Prime Minister's recent announcement of free home care for all older people with severe care needs fits into these options.

9. We are not convinced that these options fully cover the practicable choices. The emphasis is on the older population providing the resources for partnership and for the risk sharing of the insurance and comprehensive options. Older people would lose their disability benefits, and give up some of their income and capital in case they need care in later life. We suggest that a wider debate is needed on how to generate the resources necessary to provide the growing amount of care and support for the older population. Key aspects of this debate should be:

- Is full tax funding really unaffordable? If the figures were set out people could choose if they were willing to pay more taxes or national insurance for the peace of mind of a free service like the NHS.
- Should people of working age also be encouraged or obliged to start preparing for possible care costs before they retire? As with pensions, the earlier you start, the less painful it is.
- Could private and occupational pension schemes be adapted to meet the care costs of members who need care and support?
- If older people in general are to pay more towards the cost of care services for those who need them, might they prefer to do so by foregoing existing benefits and concessions to older people such as the winter fuel payment, free bus travel, free prescriptions and the higher personal allowance in income tax?
- Should care charges be tax deductible?
- Could the contribution of care provided by family and friends be better supported by the state in ways which enables these carers to maximise their contribution?

THE ROLE OF DISABILITY BENEFITS

10. In view of the threat to disability benefits in the green paper, it is important to discuss them at this point. For many years people with care needs have been able to claim DLA or AA to provide them with some financial help towards the extra costs they incur because of those needs. Receipt of a disability benefit may also result in a larger award of means tested benefits to those who qualify for them. For people with mobility problems arising before the age of 65, the mobility component of DLA is available. There is no equivalent benefit for people whose mobility problems arise from the age of 65. This is because successive governments have considered such age discrimination to be justified, a view we do not share.

11. The green paper says that the government is considering abolishing AA for new clients and transferring the budget to local authorities. It remains unclear what ideas the government has about the future of DLA. Many people who currently qualify for disability benefits would be assessed by their local authority as having insufficiently severe needs to receive services or financial support.

12. The CAB service identifies eligibility for disability benefits amongst many of its clients and helps them to make a claim. These disability benefits are a great help to the recipients in meeting extra costs which they face on account of their disabilities. Like individual budgets, disability benefits enable the recipients to spend money on the things that they consider they need most, rather than on what the local authority can provide. But they have one big advantage over direct payments—they are an entitlement and not subject to the exigencies of the local authority budget. To abolish AA would greatly reduce the independence, choice and control for older people with care needs which the government wishes to promote. We would strongly oppose any proposal to abolish either AA or DLA, and transfer the budgets to local authority control.

INSURANCE AND COMPREHENSIVE OPTIONS

13. Both of these options would allow people choices of how they pay—lump sum, regular payments in retirement, or by deduction from the estate after death. For insurance there will also be the question of whether or not to subscribe. The amounts of money involved are very large and it will be essential that arrangements are made for people to be able to get reliable independent advice on their choices.

CHARGES FOR USERS OF CARE AND SUPPORT SERVICES

14. The need for social care could be seen as the same sort of expensive unanticipated need as the need for health care. Health care is largely free and it could be argued that there is no reason in principle why social care should not also be free. We believe that this would be the best solution, but we realise that the government considers free social care unaffordable. We have suggestions for “fair” social care charging, if charging is to continue.

15. The partnership option in the green paper would see everyone get a proportion of their care and support costs paid. However, abolition of AA would leave people who do not need residential care or expensive domiciliary packages worse off than at present. Whichever future funding options are adopted for residential care, we believe the charging assessment system should remain a single national system. We would like it to avoid the problems of the current system:

- The personal expenses allowance of £21.90 a week is too small and should be increased.

- It is unfair that self-funders are generally charged higher fees than local authority sponsored residents
- It is unfair that sponsored residents or their families often have to pay top up fees to obtain suitable residential care
- CABs see many people who have been self-funding and do not realise they should apply for local authority sponsorship if their assets fall below £23,000 We recommend that local authorities should be obliged to track such care home residents to ensure that they check with them about becoming sponsored as their capital falls towards £23,000.
- If a person has assets above £13,500 they will be charged a tariff income of over 20% a year on savings above this level, so will run assets down to £13,500. The tariff income rate is much too high and should be reduced.

16. For non-residential services, local authorities have their own charging systems, which must follow national guidance.¹⁷⁷ The guidance allows scope for considerable local variation, for example in whether they take disability benefit income into account, and whether they have a maximum charge. In neighbouring authorities in the north of England, one has a maximum charge of £85 a week, while in the other it is £254 a week. Where there is no maximum charge, a person with an extensive home care package could be liable for charges of over £500 a week. We believe that it would be fairer to have a national charging scheme for community and home based services. This would need to recognise the higher living costs experienced by people with disabilities, and should not require any contribution from their benefit income.

EXTRA COSTS OF DISABILITY—NON-CARE COSTS

17. There is little consistency in the provision of help with non-care costs incurred by people as a result of frailness and disability. For services such as cleaning, transport and shopping—which local authorities do not generally provide—the recipient of the service or their family must meet the full cost, unless there is a volunteer service in their locality. For transport, recipients of the mobility component of DLA receive financial support, and all over 60s are entitled to free local bus travel. Older and eligible disabled residents of London enjoy free use of all public transport within London. Many places also have a range of schemes for disabled travellers. It is disappointing that the green paper does not recognise that help with these extra costs needs to form part of the package of support for frail and disabled people. Recipients of disability benefits often use these benefits to meet these essential non-care costs, and the threat to abolish attendance allowance in the green paper would greatly diminish their quality of life.

A CAB client lives alone. She had a leg amputated and is supposed to rest the other foot, making cleaning and cooking a problem for her. After a two month stay in hospital she requested a visit from social services. They concluded that she did not need any help with personal care and said if she needed help with cooking and cleaning they could give her the name of an agency but she would have to pay for the care herself. She had not been able to work for several months and her only income is £77 per week statutory sick pay. She is applying for DLA. She is struggling to pay for her essential bills and could not afford to pay for any home help—the agency suggested charges £11 + per hour.

SUPPORT FOR CARERS

18. The green paper acknowledges the huge contribution made to care and support by families and friends—one in ten of the population are carers. However, beyond stating that the better care and support services envisaged will have benefits for carers, the green paper offers no analysis or suggestions on how carers could be assisted to help contribute to avoiding a care crisis. We had hoped to see proposals for better financial and practical support for carers.

19. Many carers make financial sacrifices because of their caring responsibilities. The 2001 National Census revealed that the vast majority of carers (80%) are of working age.¹⁷⁸ One in five carers give up work to care¹⁷⁹ and many more will reduce their hours—with part time working having a long-term impact on earning ability.¹⁸⁰ The financial support currently given to carers is very limited. In order to qualify for Carers Allowance of £50.55 a week you must be caring for a disabled person for at least 35 hours a week, have earnings below £95.00 a week, and not be in receipt of another earnings replacement benefit such as State Retirement Pension. Carers are also entitled to have their needs assessed by the local authority, to identify assistance and support they require, but it can be difficult to actually get an assessment, and the support provided to carers is often inadequate.

PERSONALISATION

20. The government has set out its commitment to individual budgets as the preferred way to provide more personalised care and support.¹⁸¹ We fully support choices for people who need care and support. However, the offer that is made to an individual needs to take account of the capability of that individual, and where relevant her or his family, to manage an individual care and support budget. Local authorities

¹⁷⁷ “Fairer Charging Policies for Home Care and other non-residential Social Services: Guidance for Councils with Social Services Responsibilities.” Department of Health September 2003

¹⁷⁸ Office of National Statistics (2001) Census

¹⁷⁹ www.eoc.org.uk

¹⁸⁰ *ibid.*

¹⁸¹ “Putting People First: A shared vision and commitment to the transformation of adult social care” H M Government 2007

need to assess whether direct payments or an individual budget suits the individual better than the provision of services, and to provide any necessary support to the individual in securing and monitoring services purchased. Bureaux have seen situations in which a cared for person was not aware of the need to ensure that a prospective carer was properly trained and checked for a criminal record. They did not always realise that they had assumed the role of employer of their carers, and were not equipped to fulfil this role.

A CAB in the South East saw a client who was in receipt of direct payments to employ carers. However, he had not been offered any support or advice on how to deal with employing staff, filling in time sheets, paying tax, obtaining national insurance numbers or fulfilling holiday pay requirements. He got into difficulties with an ex-employee who was seeking to enforce her statutory rights to payslips and holiday pay. This was causing the client worry and anxiety—he explained that he did not intend to deny his carer any of her rights but lacked the information to fulfil his obligations as an employer.

A Northern CAB saw a client who had been verbally bullied by the disabled woman who employed her through direct payments for the past three years. The client had been working 60 hours a week, seven days a week and was told she was not allowed holidays as there was no one to cover her. She had also had cups of tea thrown at her and was aware that her employer was spreading unpleasant rumours about her in the small town they live in. She had never received written terms and conditions of employment. She felt too scared to raise any grievances as she was unaware of any independent body that could investigate her employer and had tried to complain to her employer's social worker without success.

Also we are concerned that local authorities may be tempted to regard direct payments or individual budgets as an opportunity to walk away from the responsibility of monitoring whether an individual's care and support needs are continuing to be met, and to safeguard them from financial abuse.

MORE EFFECTIVE, CONSISTENT AND USER FRIENDLY SOCIAL CARE SERVICES

What's Wrong with the Current System?

21. Currently adult social care has two major failings: underfunding which results in rationing (as discussed in paragraphs 29 and 30) and confusion about responsibilities. As a result it is not easy for a person needing care and support, or their family to know what services or financial help are available to them.

CONFUSION OF RESPONSIBILITY

22. Most care and support needs arise from a health condition, and particularly for people with more severe needs, the boundary between what is the responsibility of the NHS and what should be provided as social care can be difficult to understand. However, the implications for the patient/client are profound. Services provided by the NHS are currently mostly free to the user but social care is subject to a means test, with self-funding of residential care required for most people who own their home, and the possibility of fees of hundreds of pounds a week for those receiving domiciliary care.

23. The green paper says (page 11):

“Services will be fully joined up between the NHS and the new National Care Service. This will mean that people receive more appropriate care in the right setting, reducing costs, improving outcomes and ensuring that services work together to keep people healthy and active wherever possible”

This looks highly desirable, but the difficult question is how this is to be achieved. The green paper has little to say about this beyond saying that people should be assessed for all forms of support at a single assessment, which only addresses one aspect of the issue. It appears that we must wait to see what the new Ministerial Group on Integration of health and Social Care Services comes up with.

24. Currently, there is lack of clarity about the respective responsibilities of the NHS and local social care authorities, including undue pressure on individuals and families around hospital discharge

A bureau in the South West saw a client whose husband could not be discharged from hospital as there was not an adequate care plan in place. The client's husband had MS and a broken hip. After a four month wait, the client received a visit from the district nurse who noted what equipment was required and the order was placed. Two months later the client's husband had still not been discharged, despite numerous calls to the local council from the client and the CAB. It was difficult to find out who had overall responsibility for the case and the council did not return calls. The client still had to travel to the hospital twice a week as no home visits had been arranged and she was extremely disappointed that her husband could not come home for Christmas.

A client of 73 is concerned about her husband's care costs. Social Services told her she would not be charged for the costs of her husband's care when he went into a home following his stay in a mental hospital. She accepted this assurance and agreed for his stay in care on that basis. No action was taken until 3 years later when she was given a bill for £12,000. She has also now been sent a bill for his current care costs even though she has a written contract saying there is no charge. The council says that any verbal agreement can be overridden if they have a legal right to charge costs.

25. The availability of appropriate housing is crucial for people with care and support needs, as is the availability of practical support such as help with cleaning, shopping and transport. If good housing and practical support are not available, people with the severe social care needs who get local authority support, are likely to have a very poor quality of life even though their personal care needs are being met. It is disappointing that the green paper goes no further than mentioning housing services as part of the services that need to be joined up. There is no analysis of the contribution housing can make in this field, nor any suggestions on how better joined up working involving housing can be achieved. Nor is there a recognition that disabled people need more than just personal care, they need practical assistance as well.

26. CABs are often approached by people needing social care and support, and their families, asking what services are available and how they can access them. The answer is not usually simple—the following case is based on the experience of CAB clients:

Who does the son of an elderly woman who is becoming increasingly frail at home need to approach?

1. *The local county council for assessments of social care needs and need for aids and adaptations in the home, which will be followed by a financial assessment if she qualifies for help.*
2. *If she is not assessed as having enough priority for social services assistance, or receives this as a direct payment rather than services, it will be necessary to shop with local care services providers for the services she needs.*
3. *The local district council for a disabled facilities grant (subject to means test), or discretionary help with repairs and adaptations.*
4. *Local voluntary agencies who may offer befriending, shopping and transport services.*
5. *Local private providers for paid provision of domestic help, handyman and gardening services.*
6. *DWP Pensions, Disability and Carers Service to claim Attendance Allowance.*

27. These arrangements are excessively complex and place unreasonable pressure on the people needing services and their families, and make it likely that they will miss out on services that they need. The green paper proposals for an integrated assessment procedure and easily accessible information and advice services for people seeking care and support services would help. For people coming out of hospital the proposed re-ablement service could help ensure people get access to all the services they need.

INFORMATION AND ADVICE

28. At a national level, the internet and telephone service provided by First Stop is a valuable resource. Many people will, however, be looking for a local service, and a good example of the type of comprehensive information service that is needed is provided by Tameside CAB.

Tameside CAB operates “ChoicE”, a one-stop shop that provides information on care options for adults, with financial support from Tameside MBC. ChoicE provides information on local care and nursing homes, personal care providers, home support services, sheltered accommodation, aids and adaptations, supported holidays, transport and frozen meal suppliers. The service is available six days a week to personal and telephone callers, and also has a website. ChoicE gets very good feedback from its customers who greatly appreciate being able to obtain clear and concise information on a wide range of services all in one place.

29. We do not think that it is helpful that responsibilities for care and support are split between county and district councils in non-unitary areas. In order to simplify matters we suggest that all local authority responsibilities and powers for care and support should rest at the same level in areas with two tier local authorities.

THE PROBLEM OF RATIONING

30. For budgetary reasons, most local authorities ration provision of social care, first by having long waiting times for assessments, and secondly by restricting the provision of services or payments to those with substantial care needs. The Department of Health has set out¹⁸² 4 bands of eligibility for social care—Critical, Substantial, Moderate and Low. The report “Cutting the cake fairly” by the Commission for Social Care Inspection¹⁸³ describes the tightening of eligibility criteria by local authorities in the face of increased demand. During 2006–07 the proportion of councils restricting eligibility to people in the “substantial” and “critical” bands rose from 53% to 62%, and in 2007–08 this rose to 72%. This leaves large numbers of people with significant care and support needs depending on friends, families and voluntary schemes for help with their needs.

A CAB client contacted social services to ask for a stair lift to be installed for his father, who was in his 80s and could no longer use the stairs. He was told that his father may have to wait a year to be assessed, and it could take another four years to be installed. The client asked if he could pay to have one installed and then be reimbursed but was told this would not be possible.

¹⁸² “Fair Access to Care Services—Guidance on Eligibility Criteria for Adult Social Care” Department of Health 2003

¹⁸³ “Cutting the cake fairly” Commission for Social Care Inspection, October 2008

A CAB in the North West saw a client in his late seventies who had been discharged from hospital without social services being informed, despite the fact that he had difficulties getting in and out of the bath. The CAB adviser arranged a needs assessment, which recommended a free standing shower. The client was then informed that he would have to wait at least two years for the unit to be provided. The client's wife cares for him but cannot continue to lift him in and out of the bath.

31. This rationing means that people with lower care needs, or most people with support needs must run down their savings, or depend on friends, families or voluntary groups to provide or pay for those services. People who have access to none of these will go without their care or support needs being met unless they qualify for a disability benefit.

Timely, free assessments

32. In our view, the responsibilities of local authorities to assess needs, and to provide or secure care and support for people who need it should be far more clearly defined, and local authorities need to be financed to meet these responsibilities.

33. The green paper proposal to have a national assessment standard is welcome, providing it is properly resourced. Currently bureaux report widespread delays for clients seeking social care assessments from their local authority.

A CAB in the East saw a client with terminal cancer who was in need of adaptations to enable her to shower or bathe. The CAB adviser rang the local council to arrange an assessment and was told that there would be a 10–15 week waiting time. The client was in desperate need of a shower at a time when she was really feeling the cold and was enduring so much treatment.

34. We suggest that a requirement should be placed on local authorities to carry out assessments within a fixed time—perhaps six weeks—of the request for assessment. There should be a similar requirement for assessments of carers' needs. There should also be fast track procedures for people needing urgent care following an accident or medical event such as a stroke. The use of telephone assessments seems to be growing, and we fear that many of these are of inadequate quality.

A CAB client is in her 80s and has an income of £128 per week. She has memory problems which affect her taking her medication and remembering to eat. She applied for help from social services but the assessment, which was done on the phone, found her not eligible and no further investigation was made.

A man in his late 70s is caring for his wife who is in her 90s and very frail. He asked for a community care assessment as he was struggling to cope with caring for his wife, and was told that the waiting list for an assessment is eight months. The couple were left feeling isolated and without support.

October 2009

Memorandum by Skills for Care (SC 44)
FUTURE OF SOCIAL CARE SERVICES

SUMMARY

Skills for Care welcomes the opportunity to provide evidence to this review. The following comments reflect discussions with employers across the social care sector and build on evidence from recent research. Our evidence suggests that the sector is ready to deliver a 21st century service for adult social care, however we also know that employers must be engaged at all stages of the policy making process so that they can continue to deliver the highest level of care.

In response to the Government's Green Paper: *Shaping the Future of Care Together*, Skills for Care is engaging with over 1,000 employers of adult social care services in a debate about implications to the workforce. Our consultation survey opened on 16 September 2009 and will close on 22 October 2009. We are in the process of collecting the voices of employers and we will therefore be able to provide further evidence during the select committee's oral evidence sessions.

INTRODUCTION

1. Skills for Care, as the Sector Skills Council for adult social care, represents the voice of some 35,000 employers and our work has a significant effect on many of the 1.5 million people employed in the sector.

2. Skills for Care aims to improve the lives of adults and carers by ensuring that those who work with adult service users have the best possible training and qualifications. We help the adult social care sector deliver the best possible care.

3. We work with employers to gather data on the social care workforce through our National Minimum Data Set for Social Care (NMDS-SC) that provides robust evidence so that we can analyse emerging issues for the social care sector. NMDS-SC and our research projects are designed to create a well trained workforce capable of meeting the challenges our sector faces.

4. Our New Types of Working and Workforce Development Strategy help employers and their staff to be innovative and flexible in order to capitalise on future business development opportunities. Between 2003 and 2006 we ran the first phase of our New Types of Worker (NToW) programme which will aim to find out what support, training and qualifications will be needed by new types of workers. The second phase has begun and this will spread what has been learned across all services and across the country.

5. We have been a key partner in developing the new Qualifications and Credit Framework (QCF) as a simpler, more flexible way of recognising and rewarding skills and knowledge in the social care workforce. Once the QCF is introduced in 2010 our *common induction standards* and *knowledge sets* will be linked into the framework.

6. Skills for Care's nine supporting regional committees contribute to the improvement of social care through workforce development activities in each region of England. Skills for Care's regional committees act as brokers for funding for workforce development and training. Regional committees also develop partnerships with employers to help them to get the best out of resources available for social care workforce development in their region.

FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

7. As part of the "1000 Voices" project, we have asked employers to identify which of the funding systems, outlined in the Green Paper, would best assist with their work. We will listen to the voices of employers and relay these to the Government through our response to the consultation.

8. From responses we have gathered so far, employers believe that any new system will have to be fair and represent local needs so that service users are provided with the best care possible.

PERSONALISATION OF SOCIAL CARE SERVICES

9. With high public expectation, comes the need for a better trained, better resourced and a more flexible workforce. This could mean raising the standard of the workforce by providing them with opportunities for development.

10. Delivering a National Care Service, which offers greater personalisation will also require joined up working across sectors, so that people can access appropriate information, advice, guidance and advocacy. We believe that it is vital that a holistic approach to individuals' needs is adopted.

11. Skills for Care believes that there should be greater engagement with wider sectors to promote training in personalisation and working with those at risk.

12. Skills for Care works closely with Skills for Health in developing and delivering a joint approach to workforce development and joint working. Jointly we have developed *Common Core Principles to Support Self Care* as part of our contribution to the Long Term Conditions agenda. We have also developed Common Core Principles—and a competency framework—for End of Life Care which underpins the development of a joint value base for both adult social care and health workforces to deliver the transformation of services.

13. Skills for Care is working in partnership with Skills for Health and the Department of Health on a project that will develop the skills of adult social care staff, health and other workforces to better support carers. In partnership we are developing principles and training materials to make adult social care, health and all other relevant sectors receive effective training to better support carers.

MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

14. Skills for Care believes that an essential component of the delivery of a 21st century adult social care system is that providers are required to work alongside a number of different partner organisations, including the National Health Service, housing associations, Local Authorities and the benefits system, as well as others who would not traditionally been seen as supporting the delivery of adult social care.

15. The current system is often criticised as users sometimes have to navigate a disjointed system, which can often be frustrating and expensive. For employers, the relationships with other organisations can vary, with some establishing strong links with their partners, whilst others struggle to engage with key organisations, which can often cause delays in providing invaluable services to those who need it the most.

16. Skills for Care believes that there is an untapped opportunity to train the workforce in integrated working. It is essential that everyone who works with adult social care service users, including leaders and managers, is adequately trained.

We trust the above points will be of interest to, and considered by, the select committee as part of its inquiry into the future of social care services.

October 2009

Memorandum by the NHS Confederation (SC 45)

FUTURE OF SOCIAL CARE SERVICES

EXECUTIVE SUMMARY

The NHS Confederation represents more than 95% of the organisations that make up the NHS. We are the independent membership body for the full range of organisations that make up today's NHS across the UK. Our members include Primary Care Trusts, NHS Trusts, NHS Foundation Trusts and independent providers of NHS services. We also work closely with a range of other national bodies including the Local Government Association and Association of Directors of Adult Social Services on areas of mutual interest such as social care.

The NHS Confederation welcomes the opportunity to give evidence to the Health Select Committee on the future of social care services, particularly in the areas of the funding of long term residential and domiciliary care for older people and people with physical or learning disabilities; the personalisation of social care services; and the delivery of more effective, consistent and user-friendly social care services.

- The NHS Confederation supports the overall direction of the Green Paper on the future of care and support services (at present under consultation) and its principles.
- We believe that the sustainable funding of social care is an issue that must be tackled now to ensure the long term future of both the care system and the NHS.
- Whichever funding model is agreed, the NHS Confederation would urge that administration costs and accompanying bureaucracy are kept to a minimum to ensure value for money is maintained.
- Whilst supportive of the principles of personalisation, we believe that more work will be needed in the development of the local care market (particularly for third sector and niche providers), of care navigation and information services and of the evidence base particularly around preventative services.

INTRODUCTION

1. Over 70% of the interventions undertaken by the NHS are with people over 65 years old and these are also the individuals most likely to have long term conditions or disabilities, co-morbidities and a degree of social isolation that are best supported by personalised care packages between health and social care. In most cases, these care packages are designed with the twin aims of:

1.1. promoting and supporting independent living for as long as possible and

1.2. reducing the risk of rapid deterioration or a health or care crisis leading to unplanned admissions into high cost NHS services or residential care.

2. Many of these services are basic support/low cost but enabling interventions, including support with food preparation, medication, mobility or personal hygiene. For these supportive services to be most effective in enabling independence, high quality social care needs to be available on a universal and easily accessible basis. The NHS Confederation believes, therefore, that the options held within the Green Paper on the reform of the care system are to be welcomed in so much as they are all based on a core, nationally guaranteed and universal offer of care and support.

3. We believe that "health" and "care and support" services are two sides of the same coin and, as such, are at their most efficient and effective when working together, both as commissioners and providers. Their ethos and the mechanisms for their delivery may be different but overall both contribute greatly to supporting the most vulnerable members of communities. It follows, therefore, that the barriers which reduce effective partnership working between them should be reduced to a minimum and options that do not address these issues will not produce a sustainable and integrated system long term. These barriers include:

3.1. The means testing of elements of social care which, at present, excludes individuals from state funded support and may dis-incentivise self funders from getting the support they need at an early stage for fear of the cost and its impact on their long term financial security.

3.2. The application of eligibility criteria which mean that the provision of low level, preventative services has been severely reduced over the past few years even for those fulfilling the means test assessment, as thresholds have risen.

3.3. The lack of information and advice services which enable self funders, including those with low level needs, to navigate their way smoothly around the local care and support system.

3.4. Differences in the commissioning and policy environment for health and care and support which mean that services are not always prioritised to the same extent by local partners.

3.5. A lack of information sharing between service commissioners and providers which may mean that a more coherent approach to offering care locally is not in place.

3.6. Confusion about the extent to which top up funding can be used to supplement NHS and local authority services to develop a coherent individual care package.

4. The NHS Confederation supports the current transformation programme for adult social care outlined in *Putting People First* and believes that personalised health and care packages will help to enable greater coherence and clarity in the provision of care.

5. However, it questions whether the timing of the Green Paper on the future of the Care and Support system will enable urgently needed decisions on the future funding of care to be taken. Given the current projected constraints in both health and social care budgets over the next five years, we believe that delays now in firming up options could have a major impact on the ability of the system to both produce the efficiencies and improved productivity needed and still deliver high quality personalised and sustainable services.

The future funding of long term residential and domiciliary care for older people and people with physical or learning disabilities.

6. In a previous Futures Debate paper "*Funding tomorrow today*" published by the NHS Confederation in March 2008, we outlined a potential policy prescription for the funding of social care by setting out some core principles. Our view that these should be the basis for reform of the care system has not changed. These principles are:

- 6.1. A standard minimum entitlement in the form of a national benefits package for social care
- 6.2. Cost-sharing between the state and individuals including such schemes as equity release and co-payment models
- 6.3. Bringing together different funding streams including benefits to produce a unified personal budget
- 6.4. Adopting the partnership model developed by Sir Derek Wanless to protect assets and remove the disincentive to save apparent in the current system.
- 6.5. Topping up partnership with social insurance, possibly compulsorily albeit with an opt out for the most wealthy and tax funded top ups for the poorest
- 6.6. Insurance plans providing individual choice which enable diversity of need to be addressed and the extent of co-funding to be set in advance
- 6.7. Rethinking social care commissioning in light of the principle of a minimum entitlement and new delivery mechanisms such as individual budgets and direct payments

7. The NHS Confederation continues to believe that a universally accessible and funded system of care is essential to meet the future demographic challenges of increased longevity along with the improved survival of children with severe and complex needs to adulthood. This should include a core and consistent offer of service, possibly along the lines of the NHS Constitution so that rights, expectations and responsibilities for both users and service commissioners and providers can be more transparent. This should help to hold the system to greater account, particularly for those at present excluded from care and support services on the grounds of assessed need or means.

8. The NHS Confederation would agree that a core level of funding provided by the state is necessary but does not favour any one of the proposed methods of topping up outlined in the Green Paper. However, we do believe that whatever system is preferred, it will need to address the barriers outlined earlier in this evidence. New funding models must ensure that as little as possible is taken in administration costs and bureaucratic processes. They must also ensure that local flexibility in the commissioning of service provision to meet local circumstance can still be delivered.

9. The NHS Confederation would urge that integrated commissioning pathways are as important as integrated provision in developing sustainable and personally responsive services. We welcome the government's efforts to integrate the language and substance of central commissioning guidance to local partners and believe that it will be important to take into account the development of the Total Place pilots as these are evaluated later on this year, particularly in the joint commissioning of preventative services. However, we believe that there is more to be done to ensure that all commissioners, particularly practice based commissioners, are involved in the development of the Local Area Agreement and Sustainable Communities Strategy.

10. Whilst we understand the requirement to have locally responsive services, tailored to jointly assessed need, the NHS Confederation believes that people want and need consistency in the offer available to them and a clear idea of the amount being spent and the value for money available from individual services. We would therefore support the proposal in the Green Paper that a national and portable assessment should be undertaken. However we realise that account will need to be taken of local variations in costs and in the diversity and deprivation of the local community when determining allocations. The presence of a national system may help also to relieve some of the inconsistencies particularly felt at the boundaries of local authorities where the entitlements of people may vary despite close physical proximity.

11. The NHS Confederation would agree that the funding of "hotel" services should be considered separately from the funding of care, although with the caveat that people on low or benefit supported incomes would need these to be covered as part of the overall cost of the package. We believe that the current debate needs to be clear that offsetting the charges (both for hotel costs and for care), so that they are taken off the person's estate, will still put the cost burden on the individual and their family and reduce the amount

which can be transferred as inheritance. The way in which such costs are recouped must ensure that current collection systems for deferred payments are used or modified to make them fit for purpose and that transaction costs and bureaucratic processes are at least not increased and preferably reduced when the new system is in place.

12. The Green Paper is less clear on any differences in the systems required for those working age adults with care needs unable to work as a result and older people who have personal assets as a result of a full working life. The NHS Confederation believes that the same range of services should be available for all with state funding where necessary to top up the core offer. We do feel, however and in line with our previous paper, that the range of benefits would need to be reviewed to ensure that an equitable and affordable solution could be found across the range of care groups.

Personalisation of social care services.

13. Public polling repeatedly shows that people want services that are fair and consistent as well as responsive to their individual needs. The NHS Confederation is supportive of the personalisation of both health and care and support services as we believe that this will give rise to:

- Improved personal control and empowerment
- Greater choice and responsiveness to need
- Improved cost effectiveness of complex or co-ordinated services
- Improved recognition and co-ordination of a single integrated experience and
- A new approach to service redesign and transformation

14. Work on the development of Personal Health Budgets being undertaken by the NHS Confederation in conjunction with the Department of Health's National Mental Health Development Unit and the Association of Directors of Adult Social Services has shown that, whilst there is widespread support for the concept of personalisation, there is much to learn from the experience of social care to date, particularly around staff communication and involvement and the development of new cultures within organisations.

15. In terms of the broader issues of personalisation, we believe that there are some areas where caution is needed to maximise the impact of its implementation.

16. Firstly, there is more work to be done, particularly in the current climate of financial constraint, on the development of the provider market by local commissioners and the consolidation of relationships with a range of providers, including third sector and niche provider organisations, to ensure their longer term sustainability. Without this, users may still find their choices curtailed by the supply market available in local areas and this, in itself, may continue to give rise to an inconsistent service offer across the country.

17. Secondly, the personalisation of budgets may push some rationing decisions down to the individual receiving care and support systems need to be in place so that sufficient information is available from trusted professionals at the point of care planning. The NHS Confederation believes that care navigation is a core part of the role of primary care professionals and social workers and that this may need further development as part of professional training and development. This may require a revision of the time necessary for a full assessment and more support to develop "care literacy" in more deprived communities. We would not support the development of new roles to deliver care navigation but recognise that local information systems may need further investment to make more comprehensive and accessible information a reality in some areas.

18. Finally, however much personalisation becomes the norm for the delivery of care and support services, commissioners will also need to focus on the development of more evidence and population based preventative measures, for example falls prevention services, assistive technology, which aim to maintain independence and encourage self care. The use of joint commissioning mechanisms to ensure that this is adequately funded over the next few years when budgets are under pressure will be key to ensuring the longer term affordability of a more personalised service offer. The NHS Confederation supports the suggestion in the Green Paper on the development of an equivalent body to the National Institute for Health and Clinical Excellence. However, we would urge that NICE and the new body, if not formally connected, work together to ensure that potential synergies are realised and consistent advice and guidance is available across the health and care and support systems.

Delivery of more effective, consistent and user-friendly social care services.

19. The NHS Confederation believes that the development of a National Care Service will enhance the consistency of social care although there are pros and cons to the two suggested mechanisms for devolving money through the system. The wholly national model would be helpful in ensuring that a consistent range of services are available in all local authority areas. However, this would also involve the development of funding formulae with adjustments to take account of demography and differences in service costs in different parts of the country which could increase the overhead costs of the new system and reduce its responsiveness to local needs. On the other hand, the part national, part local hybrid model would deliver greater local responsiveness of service to local need but increase the variation of experience of service users across the country. We would argue that both would have impacts on the development of integrated services

at local level. Bearing in mind the financial constraints which will impact on both health and care and support over the next few years, the ability to innovate will also be necessary to obtain best value and high quality services and we would suggest that this too should be considered when deciding on which of the two systems is finally adopted.

20. Along with the development of navigation and the transparency of the core offer, we believe that the thrust towards greater integration will improve the effectiveness of social care services. However, we would suggest that attention will also be needed to streamline and simplify the infrastructure and processes around joint commissioning and provision to encourage this and that this should be part of any future redesign of local and regional partnership arrangements. The continuing development of more integrated regulatory systems will also support the development of more integrated approaches to service delivery and is to be welcomed in this context.

CONCLUSIONS

21. The NHS Confederation welcomes the opportunity to give evidence on the future of social care services in England. We remain positive about the overall direction outlined in the Social Care Green Paper and the opportunity to enhance current delivery to bring together health and care and support services in ways that make a difference to patients and users. However, we believe that the current opportunity to change the system must be grasped if the NHS and care system are to be fit for purpose to meet the changing demographic and fiscal challenge that the system faces.

October 2009

Memorandum by the Social Care Institute for Excellence (SC 46) FUTURE OF CARE SERVICES

INTRODUCTION

1. SCIE is pleased to be able to offer evidence to the Health Select Committee in relation to its Inquiry into the Future of Care Services. SCIE has been actively working with the Department of Health, organisations of service users and carers, and a range of other stakeholder groups to develop and prepare for implementation of a number of policies relating to care services. These include:

- “Putting People First” concordat, which SCIE signed and which heralded the start of the strategy to transform adult social care
- “Shaping the Future of Care Together” Green Paper on reforming care and support
- “Working to Put People First” Adult Social Care Workforce Strategy
- Dementia Strategy, Carers’ Strategy, Independent Living Strategy, Valuing People Now
- Implementation of the recent Mental Health and Mental Capacity Acts.

2. The Select Committee has asked for short submissions in relation to the following questions:

- future funding of long-term residential and domiciliary care for older people and people with physical or learning disabilities;
- personalisation of social care services;
- more effective, efficient, consistent and user-friendly social care services.

FUTURE FUNDING ARRANGEMENTS

3. There is general agreement, backed up by increasingly robust evidence from regulators and others, that funding for long-term care is inadequate, nor is the present system likely to be sustainable into the future when faced with serious demographic pressures and rising expectations. The funding options in the Green Paper have, as intended, generated substantial comment and debate. Widespread public misunderstanding of, or indifference to, the operation of the current social care system, and its associated charging regimes, has hampered the serious debate which the Green Paper is now seeking to promote. We therefore welcome the fact that the political profile of these issues is rising, as a critical precondition of progress. In this submission we touch on the different implications for older and working age adults.

4. *Older people*

- The Green Paper deals in general circumstances, typical likelihoods of needing care and support, and average costs and benefits. This is appropriate for modelling purposes, but options need to be translated into a system that is workable, affordable and feels fair to individuals. In insurance models, generally the smaller the risk pool, the higher the premium. Insuring against a one-in-four or one-in-three chance of needing care and support may balance out in aggregate but is unlikely to find favour with many older people, not least because they have contributed through taxation,

-
- national insurance and pension schemes throughout their working lives. This is despite their relative affluence, through housing assets particularly, as the Green Paper points out. This suggests that any preferred option will need careful “selling” and may need to be backed by compulsion.
- Combining an insurance principle with assessment-based resource allocation is likely to be controversial. People who thought they were paying for peace of mind at 65, by insuring against lifetime care costs, may still find themselves turned away at 85 or 90 because their need for care and support either does not meet qualifying criteria or, conversely, rises above any set ceiling. In addition, excluding accommodation costs from residential care settings will be hard to explain, though private insurers might respond to that requirement with more affordable products.
 - Incentives require further consideration. Would being insured for long-term care costs discourage people from engaging with prevention, self-care and reablement schemes, and lead to earlier admission to residential care or longer-term dependency on higher levels of domiciliary support? Would it act as a disincentive to family carers, whose contribution greatly exceeds in value the scale of public spending on social care? Could there be a provision similar to a “no-claims bonus”, creating incentives for relatives to extend their care and defer the need for individuals to enter the care system? How far would insurance for social care encourage or undermine joint provision with the NHS?
 - Relative costs and benefits also need careful examination. Group care in a residential or nursing home may on the face of it look cheaper per head than maintaining people with similar levels of need in their own homes; but home care solutions offer much more scope for co-production between relatives, neighbours and formal services in the provision of support, and so may be more economical in some cases. Raising eligibility thresholds for people entering group care may reduce numbers, but consequent higher levels of need are likely to increase unit costs. Conversely, a residential care place may tend to be more costly than, say, extra-care housing if available; but it will be significantly less expensive than hospital care, and better value if that is the alternative.

5. Working—age adults

- In relation to this group, a Green Paper focussing on broad principles and approaches has inevitably raised a significant number of important questions and issues to be resolved. For example, it argues that most eligible disabled people of working age would qualify for free care and support. This is because they tend in the main to live on low incomes or benefits, and to have few or no capital assets. Similarly, older people with few means or assets would receive most of their care free. It is not clear whether wealthier disabled people under 65 would be eligible or required to participate in some of the funding options but it is important that the preferred approach does not fall prey to charges of age discrimination.
- In the current system, some disabled people are caught in a bureaucratic trap, requiring high-dependency care, capable of working but unable to move off benefits and into employment because they could not command an income to cover their care costs.
- This difficult area of policy, where care charges, personal income and assets and benefit rules interact in highly complex ways, is prone to perverse incentives. Government policy is to encourage into employment disabled people, those with learning disabilities, and people with severe and enduring mental illness. Many in these groups have unexplored potential and, with appropriate personal support and reasonable adjustments in the workplace, might be able to access reasonable levels of income once the jobs market improves. They may be wary however of thereby crossing the threshold from free care and support to chargeable care services. On the other hand, for some people, provision of free care and support might create disincentives to using preventive and rehabilitative services to achieve more independent living in their own homes.
- The implications of other aspects of the Green Paper funding proposals for working age adults need further consideration. The overarching model, devised primarily with older people in mind, assumes the 6-part universal offer prevents the need for higher level care and support as long as possible, until with rising needs people may eventually cross the threshold to longer-term care. For younger groups, that process will often be reversed. They may have received high levels of support and care in the family home, or residential school or college, and be aiming to graduate from high-level care to more independent settings. Experience indicates that with the right types of support, many will become increasingly capable, skilled, independent and able to manage their own lives and their support arrangements.
- This is particularly true for people with learning disabilities—just 10 per cent of people with learning disabilities receiving adult social care services are employed. The development of a dedicated employment strategy aimed at people with moderate to severe learning disabilities, provides an important opportunity to support adults with learning disabilities into work. Personal budgets can and should be used for this (Department of Health 2009a).

 PERSONALISATION AND THE SOCIAL CARE TRANSFORMATION AGENDA

6. The personalisation of public services has been a strong thread in recent policy making across government. It became a central concept in the drive for social care transformation in the *Putting People First* concordat of December 2007, which came with £520 million of ring-fenced funding to local authorities to support reform (HM Government 2007).

(a) *Choice*

7. In social care, the traditional service-led approach has often resulted in people not receiving the right help at the right time and unable to shape the kind of support they need. Personalisation is about giving people much more choice and control over their lives in all social care settings and is far wider than simply giving personal budgets to people eligible for council funding.

8. Indeed, the personalisation agenda goes beyond social care and is linked to the “place shaping” function of local authorities. This means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing, health and opportunities for meaningful occupation. Policies such as the Independent Living Strategy and the proposed New Horizons mental health policy reinforce this message. The overall aim is to maximise independent living without the need for more formal care services for as long as possible and to ensure that, once care services are required, they are shaped more by recipients than providers. SCIE strongly supports this agenda and produces a range of resources to inform, encourage and support change by managers and staff in councils, providers and elsewhere. These include “Personalisation: a rough guide” setting out the history, context and key messages of this approach and a range of short At A Glance briefings for specific groups, such as home care providers, Personal Assistants and care home providers.

Universal services

9. *Cutting the Cake Fairly*, the Commission for Social Care Inspection’s review of eligibility criteria for social care, endorsed the notion of “progressive universalism” which is key to “Putting People First”. All citizens should expect some level of assistance and those with the greatest needs can access additional help. Included in the universal offer is information, advice, advocacy and brokerage, as well as prevention and early intervention services. Importantly, self-funders should be actively included in this universal approach—well over 30% of new residents in care homes are paying their own way and should be supported both to remain healthy for as long as possible and to make informed care choices. (Commission for Social Care Inspection 2008: 7).

(b) *Commissioning*

10. In order to stimulate supports in the local community, personalisation will require changes in both commissioning strategies and the range of those from whom councils and individuals (using their own resources, direct payments or personal budgets) commission. Achieving the vision spelled out in *Putting People First* requires a transformation in the commissioning role in terms of the investments (and dis-investments) commissioners make, the markets they work to influence and shape and the relationships they seek to build.

11. As councils disaggregate increasing proportions of their investments to individuals to make their own purchasing decisions, commissioners will need to find ways of working in partnership with providers to ensure a good range of choices and the right types of support for personal budget holders and self-funders. Commissioners will also need to make decisions based firmly on local evidence and intelligence. This should include a knowledge of the local population, equality and diversity issues and what services already exist, particularly in the third sector (SCIE 2009). This should be set out, with health, in an area’s Joint Strategic Needs Assessment. Commissioning strategies should also, importantly, take account of good practice and evidence of what works.

(c) *Advocacy, brokerage and personal budgets**Advocacy*

12. Until relatively recently there was no legal right to advocacy. The Mental Capacity Act 2005 and Mental Health Act 2007 have introduced for the first time statutory access to advocacy services to protect the rights of those subject to decisions involving loss of liberty and where they lack capacity.

13. Advocacy services have been shown to work best where service users can access peer support. Research from the UK into the implementation of direct payments found that support services for people using the scheme were essential, with Centres for Independent Living run by and for disabled people at the forefront on this. User-led organisations (ULOs) such as these are able to offer support and models of working that promote choice, control and empowerment based on people having a shared experience of disability and independent living (Carr and Robbins, 2009; Murray, Tyson and Murray-Neill, 2006). The PPF agenda seeks to increase the number of ULOs across England.

Personal budgets

14. Support is a crucial aspect of personal budgets. Individual Budgets (IBs) sought to bring together a number of different funding streams and offer a transparent way of allocating resources to individuals. (Many of the lessons of IBs are being utilised in the move to personal budgets—PBs—which are more tightly focussed on social care resources.) Knowing the level of resources at their disposal can help individuals plan and control how their support needs are best met (Glendinning *et al.* 2008). However, the national evaluation of individual budgets (IBSEN) showed substantial variation in the reactions of users, and specific challenges in integrating health and social care services and in developing staff skills and practice. Older people were more cautious about such budgets, raising questions about the way this service innovation is presented and negotiated with both the older person and their carer/s, and what supports are required to make personal budgets attractive to this group.

15. By contrast, people with mental health problems reported a significantly higher quality of life and improved psychological well-being. However, the success of PBs for people with mental health problems needs to be set against certain barriers to take-up and the difficulties in integrating funding streams from health so that support remains unified and effective. Questions about perceived risk and professional decision-making, purchasing non-traditional services and negotiating innovative support choices may also need to be considered for people with mental health problems (Spandler and Vick 2005). SCIE has recently commissioned some work on behalf of DH to enable better understanding of the issues in relation to developing personal budgets for older people and those with mental health problems. This will report in 2010.

16. Evidence is now emerging from local authorities, as they build this new approach. Current evidence suggests between six and 40% of local service users are now using PBs. The average is around 10% and the aim is for at least 30% of eligible service users to have a PB by April 2011, the end of the current reform phase.

17. Personal health budgets, as recommended by Lord Darzi, offer scope for more integrated health and social care support, and more effective partnership working between social care, primary health care and public health. The Ministerial Group on integration of health and social care is considering what are the key obstacles—and possible incentives—to closer joint working.

Brokerage

18. Personalisation is about service users determining their own needs and planning their own support. Many people will find that challenging and will benefit from the support of others who are in a similar situation. Support brokerage is an integral part of personal budgets. However, the IBSEN study indicated that its role and definition need to be clarified and understood by people using social care, their carers and social care staff (Glendinning *et al.* 2008). Brokerage, as defined by In Control is interpreted to cover advice, and administrative support, if needed, from a range of locally identified organisations (for more information, please visit <http://www.in-control.org.uk>). The values of brokerage are seen as linked—not just to accessing specific services—but to a vision of full citizenship and quality of life to which recipients are entitled (Carr and Robbins 2009: 15).

19. Research suggests that the support service infrastructure does not have the capacity to deal with the present number of direct payments users, suggesting urgent investment is needed to take account of increasing numbers of personal budget holders. For example, only half of current direct payments users are in touch with support services. Support services staffing levels have been found to be very small, with most organisations employing three people or less and many caseloads were found to be at the high end of the recommended maximum. It is reckoned that caseloads would increase by 60 per cent if all current direct payments users were accessing support schemes. Many local authorities did not tailor support service funding in relation to volume of users.

(d) Place—and market-shaping

Micromarket development

20. The success of the transformation programme partly depends on the availability of a wider range of services. DH funded a three year NAAPs¹⁸⁴ project to test a business model designed to support and stimulate the development of a range of micro care and support services in order to provide real choice for people that need care or support. This work has shown problems due to growing regulatory, legislative and other barriers and that the number of micro-providers is actually falling. NAAPs recommend a support model that gives current and potential providers the information, advice and help that they need in order to set up a small enterprise or adapt a current service to meet new local requirements (<http://www.naaps.co.uk/en/news> accessed 24 August 2009). Identifying and addressing this issue at local level, and facilitating entry of new providers meeting particular needs, should be addressed by Directors of Adult Services in their capacity as shapers of local care and support markets.

¹⁸⁴ Formerly, the National Association of Adult Placement Schemes, now called “Shared Lives”.

Micro-providers and personal assistants (PAs)

21. Research shows that the market of high-quality, trained and skilled personal assistants is not yet sufficiently developed to offer the type of choice required. Skills for Care England estimated that in the present “maximising choice” scenario, the number of personal assistants and others involved in self-directed care would need to increase nine-fold by 2025. However, there are some concerns about the wider consequences of expanding numbers and roles of personal assistants. These focus on risk, balancing the need to safeguard adults with increasing their choice and control, the emergence of unregulated “grey” markets, the effects of migrant labour, quality assurance and employment and training conditions (cited in Carr and Robbins 2009: 11) These concerns need to be discussed with people employing and planning to employ PAs, representatives of PAs who are becoming a significant part of the social care workforce, and the workforce and service regulators who will need to consider new approaches to regulation that fit the new diversified world of personalisation.

Building Social Capital

22. People using services are also themselves major contributors to social capital, and citizenship models of participation in civil society should replace the deficiency and dependency drivers in the current system. Seebom’s vision of “the largest possible number of people giving and receiving support” is still relevant. This is reflected in the concept of “co-production” (Needham and Carr 2009). This approach emphasises that service users do not just have needs that must be met but have assets such as skills and expertise to contribute to transformation. User led organisations are well placed to articulate those assets and forge dynamic relationships with public services to the benefit of all (Department of Health 2009b).

23. Both the Disability Movement and the broader work of people who use services has been built on the premise that a shared common experience can be utilised to support each other and shape the direction of future policy and service developments. Peer support is the bedrock of user-led organisations. Through training, employment, networking, providing a range of services and promoting civic participation, social capital is built (Cabinet Office 2005)

Carers and social capital

24. Planning and policy implementation need to take a comprehensive view of the care economy, not focusing only on council social care resources, but on the inputs from individuals, their family and neighbours, the responsibilities of allied services such as housing, training, employment and the NHS, the value that mainstream businesses and services represent, the extent of mutual inter-generational support, and the contribution of the huge range of voluntary and community networks. The council’s roles include supporting, enabling, coordinating and orchestrating this range of inputs. In other words, Joint Strategic Needs Assessments, strategic commissioning plans and brokerage systems need to take account of the full range of community supports available to people, not just care services provided by the state and independent sector.

MORE EFFECTIVE AND EFFICIENT SERVICES

25. SCIE welcomes the proposal in the Green Paper for an “independent body to provide advice on what works best in care and support. This will help to make sure that, in future, services are as cost-effective as possible and that they are based on evidence.” This role builds on SCIE’s existing remit as a body charged with obtaining and disseminating evidence of what works in social care.

What personalisation means for costs

26. One example of this approach to cost-effectiveness is the assessment of Individual and Personal Budgets. The IBSEN work suggests that individual budgets have “the potential” to be more cost effective and there is improved satisfaction for some groups of people who use services. Reliable evidence on the long-term social care cost implications is not yet available (Glendinning *et al.* 2008). This is an area which needs urgent attention to sustain confidence.

27. Another cost-effectiveness issue emerging from the international research on personal budgets is that social care may be saving the NHS money at its own expense. The Cash and Counselling pilot in the US reduced nursing intervention by about 17% but this was a saving to health and not to social care. Hence the need for some pooled funds—possibly for mental health, long-term conditions and older people who need both social and health care (Carr and Robbins 2009).

REFERENCES

Cabinet Office (2005) *Improving the life chances of disabled people*, London: Cabinet Office: Prime Minister’s Strategy Unit.

Carr S. And Robbins, D. (2009) *SCIE research briefing 20: The implementation of individual budget schemes in adult social care*. London: Social Care Institute for Excellence.

Commission for Social Care Inspection (2008) *Cutting the Cake Fairly: CSCI review of eligibility criteria for social care*. London: Commission for Social Care Inspection.

Brindle, D. (2008) *Care and support: a community responsibility?* York: Joseph Rowntree Foundation.

Department of Health (2009a) *Valuing employment now: real jobs for people with learning disability*, London: Department of Health.

Department of Health (2009b) *Putting People First: Working Together with User-led Organisations*, London: Department of Health.

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., Manthorpe, J., Moran, N., Netten, A., Stevens, M., Wilberforce, M. (2008) *Evaluation of the Individual Budgets Pilot Programme: Final Report*, York: Social Policy Research Unit, University of York.

HM Government (2007) *Putting People First a shared vision and commitment to the transformation of adult social care*, London: HM Government.

Murray K, Tyson A, Murray-Neill R (2006) *Increasing the Uptake of direct payments*, London: Department of Health.

Needham, C. and Carr, S. (2009) *SCIE research briefing 31 Co-production: An emerging Evidence Base for Adult social Care Transformation*. London: Social Care Institute for Excellence.

SCIE (2009) *SCIE At a glance briefing 6: Personalisation briefing: Implications for commissioners*. London: Social Care Institute for Excellence.

Spandler, H. and Vick, N. (2005) Enabling access to direct payments: an exploration of care co-ordinators decision making practices *Journal of Mental health* 14 (2) pp145–155.

SCIE

October 2009

Memorandum by Professor Pat Thane (SC 47)

HISTORY OF SOCIAL CARE IN ENGLAND

SUMMARY

- The principle that publicly funded health services, administered under the Poor Law, were free of charge but charges might be made for social services administered by local authorities, was established in the nineteenth century. Independent, mainly voluntary (non-profit), organizations played a significant part in the provision of health and social care for older and disabled people, often collaborating with local and Poor Law authorities.
- This broad framework was carried forward into the post-war Welfare State. From 1948, all health services were “free at the point of delivery”. Local authorities had responsibility for social care, either directly delivered or through independent institutions supervised by the LA, for which charges could be made.
- From 1950s emphasis shifted from institutional to community care due to: client preference; belief that this improved the quality of life of older and disabled people; improved medical knowledge and treatments; belief that community care cheaper when demand for and costs of services growing. Continuous concern at inadequacy of community services and difficulty of defining and co-ordinating health and social care.
- Shift both to community care and to private sector provision accelerated in 1980s for all of the above reasons, plus government preference for private sector provision. Increasing charges for social care due to private sector charges and reduced public expenditure. Concerns did not diminish, and have continued despite government efforts through the 1990s and 2000s to improve community support.

BEFORE 1939

Statutory Services

Before World War 2 the only publicly funded social care for older and physically disabled people was through the Poor Law (named Public Assistance following Local Government Act, 1929). From 1601, the Poor Law required each parish to levy rates to care for destitute people without family support. Those deemed unable to work due to old age or disability were regarded as deserving, but the level and type of care varied considerably locally and over time. At best, it funded a family member or a pauper woman to house and care for an older or disabled person or provided regular weekly payments, clothing and health care to enable them to stay in their own homes. At worst, Poor Law “relief” was extremely limited and stigmatizing.

The Poor Law was drastically amended in 1834 to withdraw relief from the “able-bodied” (those deemed capable of work). If they were destitute they could be admitted to deliberately bleak and punitive workhouses. In theory, “non-able-bodied” paupers—mainly older and disabled people deemed unable to work—should be allowed separate, more comfortable workhouse accommodation or granted adequate

weekly benefits. Again, the practice was locally variable, biased towards minimal provision. Generally, the “non able-bodied” were not granted more comfortable accommodation and husbands and wives were separated. In the community they received minimal benefits in cash or kind (food, clothing). The reformed Poor Law rarely funded carers in the community.¹⁸⁵

From 1885 free Poor Law health care was available to all who could not afford to pay for it, whether or not they received poor relief. Separate Poor Law hospitals were built and out-patient services expanded, due to growing awareness that sickness among the poor diminished their capacity for work, increased their dependence on public funds and spread infection in the community. Again, implementation was patchy: fastest in London and large towns.¹⁸⁶

Public concern about the extent of poverty among older people, and recognition that many older people in severe need shunned the Poor Law, led in 1900 to a directive that Poor Law Unions should provide more comfortable, non-punitive separate accommodation for older people, where husbands and wives could share rooms. Again implementation was uneven.

Some mentally disabled people were separately cared for with public funding, though definitions of mental disability were uncertain and shifting (unmarried motherhood could still be a reason to place women in mental hospitals in the 1930s, homosexuality still in 1950s). By 1845 two-thirds of English and Welsh counties provided publicly funded “asylums”, often large and bleak. From 1845 this was required of all local councils. Patients who could afford it were charged, others were funded by Poor Law authorities, establishing the principle that publicly funded care not administered through the Poor Law could incur charges.

The Local Government Act, 1929, transferred all Poor Law powers to public assistance committees of local councils. In many places little changed, but, especially in larger towns, Poor Law hospitals were integrated with other medical services. This revealed the large numbers of older and disabled long-stay hospital patients, in often very bleak conditions, receiving little medical care, with no access to rehabilitative services (eg, following a stroke) which could enable them to leave and live in the community, or lacking a home or support in the community. This led to the expansion of geriatric medicine, focussed on rehabilitation and reducing the numbers of “bed-blockers”. This developed further after the establishment of the NHS.¹⁸⁷

Voluntary and Family Care

From medieval times residential care was provided for older and disabled people in almshouses and care institutions, run by faith organizations or other voluntary associations, often charitable and/or charging fees to those who could afford them. Particularly in the nineteenth century, voluntary visiting associations provided care in the community. Voluntary organizations, the Poor Law and local authorities often collaborated to maximize support for the “deserving poor”. It is impossible to quantify the extent of activity but it was unavoidably locally diverse and unable to meet all needs. Voluntary hospitals, especially numerous in London, provided free treatment to the poor, while charging others, but treated only “acute” not “chronic” conditions, hence the consignment of the long-term sick and disabled poor to workhouse hospitals. Particularly in the 18th and 19th centuries, private mental hospitals, generally fee-paying, developed. The voluntary sector, often collaborating with public authorities, was well-established in the provision of care before World War 2.

Family care for older and disabled people in “the past” should not be romanticized. Again, evidence is not systematic, but suggests that, then as now, families gave such care as they could.¹⁸⁸ At any time before the 1920s there was a high probability that older people would have no children living or available to provide care, due to high death rates, higher levels of non-marriage/partnership than since World War 2, infertility and high emigration rates of younger people.

SINCE 1939

In 1955 187,000 people were registered as “substantially and permanently handicapped”. People over 65 were c. 10% of the population of England and Wales in 1951. There was concern about the high and rising proportion of older people and the resulting costs due to rising life expectancy and the pre-war fall in the birth-rate.¹⁸⁹ This concern diminished in the 1960s and 70s due to the post-war rise in the birth-rate, only to return from the 1980s.

¹⁸⁵ Pat Thane *Old Age in English History* (OUP, 2000), 165–193

¹⁸⁶ M.A. Crowther *The Workhouse System, 1834–1929* (Batsford 1981)

¹⁸⁷ Thane, 436–457.

¹⁸⁸ Thane, 287–307, 407–435.

¹⁸⁹ Pat Thane “The debate on the declining birth-rate in Britain: the ‘menace’ of an ageing population, 1920s–1950s” *Continuity and Change* 5 (2), 1990, 283–305.

Statutory Care

Wartime surveys revealed extensive “secret need” among older people living in the community with minimal or no care. Inadequate, means-tested pensions had been available since 1908. Following the wartime revelations, more generous supplementary pensions were introduced. The campaigning group now known as Age Concern was founded in 1940 and put pressure on government for improved care for older people. There was heightened awareness of the needs of disabled people, whose numbers were increased by war service and bombing. This led in 1944 to the Disabled Persons’ Employment Act, requiring employers of more than 20 persons to employ at least 3% from a newly instituted Disabled Persons Register. In 1946 the National Association for Mental Health (now MIND) was formed to campaign for better provision for the mentally disabled.

1948. CARE IN THE NEW WELFARE STATE: THE NATIONAL HEALTH SERVICE AND THE NATIONAL ASSISTANCE BOARD.

The National Assistance Act, 1946, implemented 1948, abolished the Poor Law/Public Assistance and established the National Assistance Board (NAB), which took over its institutions and responsibility for means-tested benefits. However, all hospitals were absorbed into the National Health Service, also established 1948. Older and disabled people were divided into the “sick”, who were placed in hospitals (c. 90,000 people) and those needing “care and attention” (c. 42,000) who were placed in residential homes, overwhelmingly former workhouses.

The NA Act required local authorities, under the control of the NAB, to provide residential accommodation for older and disabled people “in need of care and attention which is not otherwise available to them”.¹⁹⁰ They were empowered also to register and inspect Homes run by charitable (non-profit) and private (for profit) organizations and to contribute to independent organizations providing “recreation or meals for old people” or themselves provide these, or day centres, clubs etc.¹⁹¹ Local authorities retained their established public health responsibilities, including for health visitors, home helps, child welfare clinics, though were not required to provide them. Whereas all NHS services were “free at the point of delivery” local authorities could levy means-tested charges for residential and community social services, but not for services defined as health care, such as health visitors. They could also commission fee-charging independent services. The NAB funded residential care for those unable to afford charges.

A substantial role for voluntary action and personal payments, supplementing comprehensive basic services and protection for the poorest, was consistent with William Beveridge’s vision of the new “Welfare State”.¹⁹² These principles were not explicitly endorsed by Attlee’s government, but nor did they designate public social services “free at the point of delivery” or discourage co-operation with voluntary agencies.

The NAB was responsible to the Minister of Health, but semi-independent and required to work also with the new Ministry of National Insurance, whose benefits it supplemented. The National Assistance Act was piloted through the Commons jointly by the Minister of Health, Aneurin Bevan and the Minister of National Insurance, Jim Griffiths. The boundary between health care and social care was far from clear and could not easily be for older and disabled people. In 1966 the NAB was abolished and replaced by the Supplementary Benefits Commission. In 1968 this was absorbed into a new Department of Health and Social Security which replaced the Ministries of Health and National Insurance, where it remained until 1988, when a separate Department of Health was established. Responsibility for local government moved permanently from the Ministry of Health to a separate department in 1951, further complicating the relationship between health and social care.

1950s AND 60s. MOVES TOWARDS COMMUNITY CARE.

Few new Homes or hospitals were constructed until the late 1950s due to financial constraints. Surveys in the 1960s found deplorable conditions in both hospitals and Homes for older and disabled people.¹⁹³ The distribution between sectors of residential care for older people in 1960 is indicated in the following Table:

Table 1
NUMBER OF INSTITUTIONS AND HOMES OF VARIOUS TYPES

<i>Type of Institution</i>	<i>Number of institutions</i>	<i>Number of beds</i>
Former public assistance	309	36,934
Other local authority	1105	36,699
Voluntary	815	25,491

¹⁹⁰ National Assistance Act 1948, Part III, Section 21 (1) and (2).

¹⁹¹ Ibid. Section 29 (1), (2) and 31.

¹⁹² William Beveridge *Voluntary Action* (London, 1948).

¹⁹³ E.g. JH Sheldon *Report to the Birmingham Regional Hospital Board on its Geriatric Services*, Birmingham Regional Hospital Board, 1961. P. Townsend *The Last Refuge* (London, Routledge 1964). Barbara Robb *Sans Everything* (London, Nelson, 1967).

<i>Type of Institution</i>	<i>Number of institutions</i>	<i>Number of beds</i>
Private	1106	11,643
Total	3335	110,767

Source: Peter Townsend *The Last Refuge* (Routledge 1964) p. 24.

There was a trend from the 1950s towards the replacement of in-patient with out-patient treatment for the mentally disabled, influenced by the increasing awareness of psychiatrists of the harmful effects of long-term institutional care for some people, and by the costs of institutions. In 1953 half of all NHS beds were occupied by people who were mentally ill or mentally disabled. The Mental Health Act, 1959, aimed to enable “mentally ill people to live, as far as possible, in the community”, but support services were limited.

The National Assistance Act 1948 (Amendment) Act 1962 encouraged local authorities to provide meals, recreational workshops and day centres for older and disabled people and they were required to draw up 10 year plans for health and welfare services “designed to help them remain in their own homes for as long as possible”. Advances in medical knowledge and care enabled more older and disabled people to live in the community. It was also thought to be in their best interests and in line with their expressed preferences. And it was believed that community care was cheaper—an important consideration as costs rose. The Health Services and Public Health Act 1968 increased local authority powers to provide care services, including visiting, laundry, social work and wardens, to inform older and disabled people about services and to make adaptations to their homes . Provision of domestic help became mandatory. Charges could be made for these services. Local authorities could provide them directly or through independent providers. The Act came into force in 1971, when also Attendance Allowance was introduced for older and disabled people needing frequent attention or constant supervision if they were to remain in the community.

There was growing concern in the 1960s about the lack of co-ordination of health and social services. This led to the appointment of the Seebohm Committee on Local Authority and Allied Personal Social Services which reported in 1968 commenting that “Although for many years it has been part of national policy to enable as many old people as possible to stay in their own homes, the development of the domiciliary services which are necessary if this has to be achieved has been slow”, partly due to the shortage of appropriately trained social workers. It recommended new, unified social services departments to assess local needs and resources and plan accordingly, taking account of and supporting the contributions of independent organizations , relatives and neighbours. The report stated: “Services for old people in their own homes will not be adequately developed unless greater attention is paid to supporting the families who in turn support them...If old people are to remain in the community, support and assistance must often be directed to the whole family of which they are members”.¹⁹⁴

1970s. FURTHER MOVES TO COMMUNITY CARE: PROBLEMS OF COORDINATING HEALTH AND SOCIAL CARE.

The Local Authority Social Services Act, 1970, established a single social services department in each local authority, emphasizing the need for a co-ordinated and comprehensive approach to social care, supporting families, detecting need and encouraging people to seek help. The departments became responsible for domestic help, residential accommodation, meals and recreation services (for all of which charges could be made), registration of independent residential homes and social work support.

A succession of measures in the 1970s were designed to assist older and disabled people to remain in the community, partly impelled by activism by disabled people. The Chronically Sick and Disabled Act, 1971, required all local authorities to register disabled people and publicize services. It encouraged, but did not require or adequately fund, expanded community-based services such as home helps and day centres. Also, in 1971 Invalidity Benefit was introduced, supplemented in 1975 by means-tested Invalidity Pensions. In 1975 Invalid Care Allowance was introduced for people of working age (only) acting as care assistants to older and disabled people, but not married women caring for close relatives (until 1986, following judgement by the European Court of Justice) ; or people above state pension age, the great majority of carers. The allowances were low in relation to average earnings. From 1976 Mobility Allowance covered such expenses as transport.

Both local government and the NHS were reorganized in 1974, into larger, tiered units. One aim was closer integration of preventive and after-care services between the NHS (including GPs) and the local authorities. Local authorities took over certain services from the NHS, such as medical, including psychiatric, social work. The new local and health authorities were required to establish joint consultative committees to advise on planning and operation of services of common concern and were recommended to establish joint care planning teams. In 1976 joint financial arrangements were introduced to assist co-operation, enabling NHS funds to be used on collaborative projects with local authorities. Collaboration was never fully effective partly because the new authorities were not very successful and were reorganized again in the 1980s; and to financial constraints in the crisis of the 1970s.

¹⁹⁴ Home Office *Local Authority and Allied Personal Social Services* (Report of the Seebohm Committee) , (London, HMSO, 1968), 96.

In 1975 the White Paper, *Better Services for the Mentally Ill*, described the direction the Labour government wished to take, prefaced by a statement that little progress could be made until the economic situation improved. It emphasized the need to provide a comprehensive range of community services in place of mental hospitals, stating:

It will not normally be possible for a mental hospital to be closed until the full range of facilities described has been provided throughout its catchment area and has shown itself capable of providing for newly arising patients a comprehensive service independent of the mental hospital.¹⁹⁵ Between 1970 and 1975 the population of mental hospitals fell from 107,977 to 87,321; that of mental handicap hospitals from 55,434 to 49,683.¹⁹⁶ There was concern that adequate community support services were not in place.

1980s AND 90s. FASTER MOVES TO COMMUNITY CARE AND PRIVATE SECTOR PROVISION.

The shift from institutional to community care moved even faster in the 1980s due to a government commitment to cutting public spending and its preference for private over public provision. In 1983 District Health Authorities were empowered to provide increased funding for services for people moving from hospitals to the community-funding local authorities or independent organizations to support people leaving hospitals. Local authorities were reluctant to take this up perhaps due to fear that it would ultimately increase their costs.¹⁹⁷

A succession of documents in the 1980s emphasized the need to improve services for older and disabled people and promoted care and improved services in the community.¹⁹⁸ There were also acknowledgements, eg, in the 1981 White Paper *Growing Older*,¹⁹⁹ that substantial numbers would continue to need institutional care, that good community care was not always cheaper and there was shortage of skilled carers, such as district nurses. A Report of the House of Commons Social Services Committee in 1985 criticized services for mentally disabled people, many of whom were older people. It wholly supported community care but was concerned that people were leaving institutions at a growing rate when there were inadequate community support services. It recommended that no-one should leave an institution without a community care plan. The 1986 Disabled Persons Representation Act attempted to give disabled people more input into policy-making at local level. It placed a duty on local authorities to assess the needs of disabled people for social services, take account of the needs and capacities of carers and inform disabled people about services. In the following year, the Audit Commission also criticized the slow, uneven progress of community care pointing out that hospital care was still more generously funded than domiciliary care, which put pressure on local authorities to raise charges and devolve services to the independent sector if they were to expand. These concerns were reinforced by the Griffiths Report, 1988, commissioned by the Secretary of State for Social Services, which concluded: “community care is a poor relation: everybody’s distant relative but nobody’s baby”. It had always been under-funded and there was still poor co-ordination between health and social services. Sir Roy Griffiths recommended, among other things, a clear framework for coordination between health and social services.

The 1989 White Paper, *Caring for People*, acknowledged these problems, reaffirmed the commitment to high quality community care, but put greater weight than before on the independent sector. It stated “The Government will expect local authorities to make use whenever possible of services from voluntary, ‘not for profit’ and private providers insofar as this represents a cost effective care choice”.²⁰⁰ Local authorities were encouraged to identify areas of their own work which could be “floated off”. In 1990 the DoH stated that it was “expected that local authorities will institute arrangements so that users of services of all types pay what they can reasonably afford towards their costs”. These charges varied locally and were rising

The National Health Service and Community Care Act, 1990, followed and attempted to implement these recommendations, without providing substantially increased funding, and, more vigorously than before, encouraged local authorities to become “purchasing” (from independent agencies) rather than “providing” authorities. It required social services departments to inspect services, establish complaints procedures and prepare Community Care Plans. Users became entitled to a Community Care assessment of needs.

Local authorities found it increasingly difficult to provide affordable care with the funding available to them. The number of private sector residential homes grew from 18,800 in 1975 to 119,900 in 1990.²⁰¹ Until 1980 voluntary sector homes received public funding from local authorities in addition to means-tested payments by the residents themselves. From 1980, means-tested board and lodging supplementary benefit allowances became available for residents of all independent sector homes, which encouraged the expansion of the private sector.

¹⁹⁵ *Better Services for the Mentally Ill*, (London : Department of Health and Social Services , 1975) para 11.5.

¹⁹⁶ *In-Patient Statistics*, (London: DHSS, 1975.5.7).

¹⁹⁷ *Anthea Tinker Elderly People in Modern Society* (London, Longman 1992), 99

¹⁹⁸ *Ibid.* 97

¹⁹⁹ *Ibid.* 98

²⁰⁰ *Ibid.* 170

²⁰¹ AH Halsey & J. Webb eds *Twentieth Century Social Trends* (London, Macmillan, 2000), 526.

By the late 1980s services were increasingly targeted on the most disabled, to cut costs, and by 1990 it was becoming difficult for older and disabled people to access help with tasks such as cleaning and shopping if they did not have intensive care needs and could not afford private services. Services were still highly variable across authorities. There was evidence of much unmet need, most commonly for home helps and chiropody.

Further measures sought to assist community care: Disability Living Allowance from 1992; the Carers (Recognition and Services) Act, 1995; the Mental Health (Patients in the Community) Act, 1995; the Disability Discrimination Act, 1995; the Community Care (Direct Payments) Act, 1996 enabled local authorities to make payments to disabled people to assist them to buy community services according to their needs. The Disability Rights Commission (DRC, established 1999, since 2007 absorbed into Equality and Human Rights Commission). Nevertheless, in 1998 another Audit Commission report, *Home Alone: the Housing Aspects of Community Care* again criticized the inadequacy of community, especially housing provision, recommending improvements, with examples of good practice. The criticisms were repeated in another Audit Commission Report in 2000 *Forget Me Not: Mental Health Services for Older People*. This recommended that local authority health and social services departments should work more closely together and submit annual joint plans. Again, it found wide local variation in the provision of services, and often patchy and uncoordinated support for users and their assistants.

Further measures since 2000 have sought to improve support for older and disabled people in the community and their carers, including the Carers and Disabled Children Act 2000, amended 2004; the Special Educational Needs and Disability Act, 2001; the Private Hire Vehicle Act, 2002 and the New Deal for the Disabled, all consolidated in the Disability Discrimination Act 2005 followed by the Disability Equality Duty (DED), 2006.

Family care has continued to be vital for the survival in the community of many older and disabled people. Assertions about declining family responsibility over time are not supported by research evidence.²⁰²

CONCLUSION

The current system of division of social from health care, commissioned and funded by local authorities, subject to means-testing and charging came into being in 1948, with roots in the pre-war system. Over the period since 1948, especially in the 1980s and 90s, responsibility for the care of older and disabled people shifted from institutions to the community and from the public to the independent sector, while charges rose. Despite well-meaning statements and efforts by successive governments criticisms of under-funding of social care and poor integration of health and social care have continued.

Pat Thane

Leverhulme Professor of Contemporary British History, Director *History & Policy*,
Centre for Contemporary British History,
Institute of Historical Research, University of London.

October 2009

Memorandum by Professor Anthea Tinker (SC 48)

THE FUTURE OF SOCIAL CARE SERVICES

1. EXECUTIVE SUMMARY

This paper is divided into:

- General comments about social care where it is argued that there is a lack of links between services, and suggestions about how this can be achieved, and the lack of acknowledgement of the contribution of housing and income.
- Specific observations on the Green Paper. These include general points, likely points of agreement (such as the underlying principles that any future service should be fair, simple and affordable) and notable absences (such as virtually no references to the need for a reasonable income, the role of housing, the value of good medical care and the need for good basic social services).
- Some controversial issues that are not adequately explored. These include the role of local government (which is likely to change dramatically if a national care service is adopted), the dismissal of a tax funded solution, the difficult issues of the balance between priorities for those with the greatest level of need and the need for a preventive service.
- Some other issues which need clarification. These include the implications of a national assessment, personal budgets, prevention, staff issues, costs and benefits, differences between areas and the need for research.

²⁰² Among others: H. Qureshi and A. Walker *The Caring Relationship* London, Macmillan, 1989); J. Finch *Family Obligations and Social Change* (Oxford, Polity, 1989); *Ageing and Society*. Special Issue, Family Support for Older People, 10 (11), 2006.

2. INTRODUCTION

I am responding to an invitation to submit evidence to this Committee. My areas of expertise are in Social Policy and Ageing where I have undertaken research on a wide range of topics including housing, long term care, technology, abuse, older workers and carers.

3. GENERAL COMMENTS ON SOCIAL CARE SERVICES

3.1. *The lack of links between services*

The most consistent theme of research on the needs of people who need care is the absence of links between services—or, in today’s jargon, a lack of “joined up” services. Until about 20 years ago this link, or rather lack of, was particularly focused on the relations between social care and health. Since then there have been many policy initiatives aimed at addressing this problem from financial incentives, such as joint finance and joint funding, to official guidance and persuasion. Research now shows that there is much more collaboration between these two services but that it is patchy and still leaves a great deal to be desired. The use of generic health and social care workers with enhanced skills is one way of achieving service efficiencies which could help to overcome gaps in, for example, rural services. There are still lacks of links with housing (see 3.3).

3.2. *How links can be made*

The links between health, social care and housing need to be made at all levels including:

- At a policy level between government departments—and the co-ordination at Ministerial level by the Department of Work and Pensions (DWP) is to be welcomed.
- At a policy level within government departments including the crucial involvement of research departments. Their input does not always seem to be obvious in government statements.
- In funding. A clear way to encourage co-operation is the bait of a grant. However, there is a major problem when funding comes to an end.
- At a regional and local level. There may be many ways in which this can be done including joint strategy initiatives or placing departments and/or key staff together. What research shows is the crucial importance of the relations between individuals and their personal commitment.
- Training of staff. While many training programmes at undergraduate and postgraduate level eg for doctors, are overloaded subsequent opportunities should be given for course, conferences and workshops to enable staff to be given the chance to hear about other areas of work. Also useful are secondments of staff.

3.3. *The lack of acknowledgement of the contribution of housing*

What is less obvious is the importance of taking housing into account. While lip service is often paid to the desire of people to remain at home (whether this is in their existing home or in mainstream or specialised housing) this does not always seem to be translated into practice. For example the Department of Health (DH, 2005) in “Independence, Well-being and Choice” suggested “exciting models” (page 54) to help older people to live independently in their own accommodation. These included extra care housing, homeshare, adult placement and technology enabled services. All of these, while of importance and some of which are discussed below, are for the minority. Of fundamental importance is the acknowledgement that a home that is safe and appropriate enables people to have a firm basis for care and support. The Audit Commission’s report “Don’t stop me now” (Audit Commission, 2008) gives plenty of examples of how this can be done including how health can be brought in. (See also 4.3.)

3.4. *The lack of acknowledgement of the role of income*

The other remarkable absence in the Green Paper and in policy and discussions, despite the views of older and disabled people, is that of the need for a reasonable income. There is a strong argument in favour of higher levels of pensions and disability allowances to enable people to make their own choices for services. There are the beginnings of this in the provision of personal budgets. For example someone with a personal budget may prefer to use this money to eat at the local pub rather than at a day centre.

4. SPECIFIC OBSERVATIONS ON THE 2009 GREEN PAPER “SHAPING THE FUTURE OF CARE TOGETHER”

4.1. *General points*

The Green Paper is to be warmly welcomed as it builds on “Putting People First: A Shared vision and commitment to the transformation of Adult Social Care”(The Social Care Concordat (HM Government, 2007). Both consider care with all the relevant government departments participating and signing off the documents. I have read the Green Paper in conjunction with the very helpful other papers which were released with it (“Equality Impact Statement” and “Summary of Intervention and Options”). Indeed it would have been useful to have had some of the evidence presented in these latter papers in the main body of the Green Paper. It is also important to note that the legal framework for care and support is itself the subject of a Law Commission review (Law Commission, 2008).

The Green Paper, while very clearly written, is very repetitive and could have been reduced to half the size and some of the other very important evidence included. I do not plan to go through all the points made or arguments rehearsed but will concentrate on what I see as either key points or where there appear to be issues that are either not addressed or need clarification.

4.2. *Likely points of agreement*

There is very unlikely to be disagreement about the underlying principles of any future Social Care Service ie that it should be fair, simple and affordable. Nor that all who need care and support should get a national assessment, information and advice and personalised care and support. The key role of GPs, the importance of advice and information and the valuable role played by carers are other conclusions based on well researched findings. On the first two points most people are known to local GP practices and primary care teams will have a major role to play in linking individuals to appropriate care and support services

4.3. *Notable absences*

There is virtually no reference to the following:

- The importance of the need for a reasonable income either for older people with a pension or for disabled people with benefits. This must underpin any social care provision as it allows the person who needs care to make choices.
- Housing (and see 3.3). The case for both mainstream and specialised housing should have been made and this is only referred to in brief on pages 51–52. Within this the importance of aids and adaptations is crucial for many people who need care. It is within this context that care can be provided. This care will be much more difficult if the home is unsatisfactory. For example helping someone to wash may take the time of two carers if there is not a special shower or adapted bathroom. Even simple aids may help.
- The value of good basic medical care is noted in the “Summary of Interventions and Options” but more could have been made of this.
- The need for good basic social services, which underpin social care, is not made except in passing by the Summary paper. Research consistently shows that help with housework and with foot care and dealing with problems of incontinence are basic and should have a high profile in preventive services.

4.4 *Some controversial issues not explored*

There are at least two important themes which need to be challenged:

- The role of local government

The basis of the Green Paper is that there should be a National Care Service. If this is to be achieved by means such as a common assessment process and grants this will almost inevitably mean some mechanism for ensuring that this is achieved. Will this mean tighter financial control, more regulations, more inspections or what? Or will there be a light touch with perhaps the Care Quality Commission having a stronger role? The Green Paper can be read as assuming a greater degree of centralisation and the implications of this need to be considered carefully. Much is made in the introduction to the Green Paper about the difference with the National Health Service where there has always been a centralised service. But local services are responsible to a local electorate. There needs to be discussion on whether the public would prefer to have less local say in order to gain a more even service which is centralised.

- The dismissal of a tax funded option

A tax funded option where the public pay for the service through general taxation is dismissed. This is mainly on the grounds that it would be paid for by a generation of working people which is not only expected to decline as a proportion of the population but which has not enjoyed the advantages of, for example, free tuition fees and subsidised mortgages that the older generation have. This needs to be tested in a more rigorous way. For example many people of working age do have relatives for whom they either provide care or are likely to do so in the future and may not take this kind of generational approach. Addressing the issue in terms of their parents and grandparents may bring out a different set of priorities to those noted in the Paper. They may for example prefer to pay higher taxes not just for their own security in old age but also to prevent them having to jeopardise their own jobs by having to give a great deal of personal help.

This option also needs to be addressed in the light of a likely growth in the number and proportion of older workers who will not only contribute to the economy through their work but also through taxes.

- The balance between those with the greatest level of need and the need for a preventive service which will focus on those who do not have such needs. The withdrawal of home helps from people who need “just that bit of help” and the concentration on those with the greatest need is a logical one on the face of it and can be justified on many grounds. However, the longer term implications on less dependent people needs examining and also public discussion on priorities. Another interesting example of this is given on page 73 where it is suggested that choice might be exercised by someone with a Personal Budget who chooses to use this for paying for a football season ticket

and transport. That might raise some eyebrows about the needs and assessment of that person although it is possible to imagine conditions where this is an appropriate use of money. It is suggested that Personal Budgets may offer opportunities for individuals to find alternative solutions to long-standing problems of care supply. This includes the employment of personal assistants. However, in social care debates, concerns have been raised regarding the regulation of services and care standards, and the protection of service users and care workers if the unregistered social care workforce expands as the result of personalization. This will require careful monitoring. The Equality Impact Assessment for the Green Paper highlights the ongoing debate about the extent to which older adults will want, or be able, to take control of their care and support in future. The degree to which people will feel confident to do so will depend on individual health and capacity and the range of care and support available within any given locality.

4.5. *Some other issues which need clarification*

— National assessment

There is no reference to the Single Assessment Process and Procedures recommended by the Department of Health and research on common assessment tools.

— Personal budgets

More research is needed on this. As the Equality Impact Statement so rightly points out (page 26) there is the possibility of financial abuse where a system is not subject to regulation and inspection. The recent prevalence study of older people in the community found that 2.6% of older people living in their own homes were subject to abuse by a family member, friend or care worker (O’Keefe *et al* 2007 “UK Study of Abuse and Neglect of Older People: Prevalence Survey”). The predominant type of mistreatment was neglect (1.1%) followed by financial abuse (0.7%). If the prevalence is widened to include neighbours and acquaintances the overall prevalence rises to 4.0 %.

— Prevention

The “Summary: Intervention and Options” touches on the importance of services to address the serious problems of incontinence and foot care (page 59) and these could have been referred to in the Green Paper and given more prominence. The initiatives such as telecare and telehealth are stressed (eg page 78) but they are unlikely either to be provided or used by the majority of older people compared with needs that have a lower profile.

— Staff issues.

While there are important references to staff (eg pages 76–77 on the care and support workforce, on page 12 that people who work in the sector should be supported and on page 83 that staff should be “respectful and friendly”) other important ones are not mentioned. These could have included the projected shortage of workers in the social care field (and their low status and pay) and issues to do with training (including the value of some multidisciplinary ones).

— Costs and benefits

Apart from some evidence in the “Intervention and Options” paper there is little on the expected costs or benefits of the proposed system of care and support. Not only is more research needed but what is already known needs to be drawn together. In particular local authorities possess very different in-house capacity for carrying out social care research and detailed service evaluation. This has implications for the type of comprehensive and resource-intensive research that will be required in order to ensure that outcomes can be effectively monitored. Support from the regional social care improvement teams will be crucial in this regard.

— Differences between areas.

While rural proofing has a section in its own right in the Equality document, and is mentioned on one or two occasions in the Green Paper, there is little on the plight of older people in inner cities. There will be other areas, such as those measured by indices of multiple deprivation (as the report by the Office of Deputy Prime Minister, 2006 “A Sure Start to Later Life”) reveal.

The different approaches needed by various areas are demonstrated by current research being undertaken by one of our PhD students. She is showing that the rural population is ageing more rapidly than in urban areas and it is widely predicted that the future demand for health and social services is likely to increase. It is also recognised that there may be particular problems such as the lack of access to transport and the closure of local shops and post offices. There is also be lack of information which has led to the under claiming of benefits. This research with three local authorities and other rural commentators confirms findings from other studies that local care markets may be historically under-developed in more remote rural locations.

— The need for research

The need for research is clear at all levels. For example local authorities and health authorities have a statutory obligation to prepare and publish a local Joint Strategic Needs Assessment.

4.6. *Some imponderables*

It is difficult in the current political climate to predict future policy interventions with any degree of certainty. Two recent examples include: (i) the recent surprise announcement by the Government to offer free personal care for people with critical needs in the Autumn of 2010 and (ii) the Conservative party proposal to offer free residential care after payment of a one-off premium. The absence of political consensus and detailed costs makes it difficult to predict future policy implications with any degree of certainty.

5. SUGGESTED RECOMMENDATIONS TO THE COMMITTEE

It is suggested that the Committee may wish to explore these issues:

1. Some controversial issues. These include the role of local government (which is likely to change dramatically if a national care service is adopted), the dismissal of a tax funded solution, the difficult issues of the balance between priorities for those with the greatest level of need and the need for a preventive service.
2. Some other issues which need clarification. These include the implications of a national assessment, personal budgets, prevention, staff issues, costs and benefits, differences between areas and the need for research.

ACKNOWLEDGEMENT

The input of Lynne Livsey, a PhD student at the Institute of Gerontology, King's College London who is researching Social Care in Rural Areas, is acknowledged.

Professor Anthea Tinker, CBE, PhD, FKC, AcSS
Professor of Social Gerontology
King's College London

October 2009

Memorandum by Professor Caroline Glendinning (SC 49)

THE FUTURE OF ADULT SOCIAL CARE: WHAT CAN ENGLAND LEARN FROM THE EXPERIENCES OF OTHER COUNTRIES?

EXECUTIVE SUMMARY

1. This paper discusses the funding, organisation and delivery of adult social care by drawing on the experiences of other advanced welfare states.
2. A commitment to principles of universality—equal access to social care by affluent and poorer, younger and older people—is the striking feature of many other countries' approaches to social care. Access to social care depends only on the level of disability or help needed, regardless of age, means or assets. Universal schemes use a single assessment of eligibility that determines similar levels of support and is applicable across the country and for disabled people of all ages. However universal arrangements can be combined with principles of fairness, so that those who can afford to contribute to their care do so.
3. Social care arrangements in many other countries meet the principles of diagnostic, spatial and inter-generational equity.
4. Cash allowances, as alternatives to social care services in kind, are common. However, evidence that cash allowances or vouchers stimulate social care markets is limited and family carers may suffer if few services are available. Choice and market development can also be facilitated where social care is provided through in kind services.
5. Help from families is essential to the sustainability of social care. In many countries, access to and levels of social care do not take into account the availability of relatives. Moreover, support for family care can be an integral part of comprehensive social care arrangements.
6. Economic sustainability can be achieved by capping levels of provision; excluding certain types of help (eg domestic help) from public funding; or cutting prices paid to providers. Political sustainability may be helped by high levels of public confidence that help will be available when needed.
7. Even in federal constitutions, central governments have an essential role in ensuring universality, equity and sustainability in social care.

1. INTRODUCTION

1.1 This paper discusses the funding, organisation and delivery of adult social care by drawing on the experiences of other advanced welfare states. Examining other countries can:

- reveal different values, assumptions and principles underpinning the funding, organisation and delivery of social care and prompt fundamental questions about the principles on which future reform should be based

- shed light on the potential political and social factors that could constrain or facilitate implementation of reforms.

2. Universal or targeted social care?

2.1 A commitment to principles of universality—equal access to social care by affluent and poorer, younger and older people—is the striking feature of many other countries’ approaches to social care. Access to social care depends only on the level of disability or help that is needed, regardless of age, means or assets.

BOX 1: UNIVERSAL ACCESS TO SOCIAL CARE

Germany’s long-term care insurance scheme provides benefits for severely disabled people of all ages, regardless of income or assets. One reason for the introduction of the scheme in 1994 was the stigma experienced by older people having to “spend down” assets in order to qualify for means-tested social assistance to pay for care. Membership of care insurance is compulsory, with almost the entire population covered.

In Austria, a cash Care Allowance funded from taxation was introduced in 1993. It is paid at one of seven levels, determined solely by the amount of help needed and regardless of income or assets. The Care Allowance can be used to pay for care at home or in an institution.

Danish social services are the responsibility of local municipalities. All services are free of charge, regardless of the number of hours care received or the income of the recipient. In nursing homes, user fees are levied only on services for which commercial charges would normally be paid.

2.2 Universal schemes use a single assessment of eligibility, conducted by a care worker from the local municipality, a national body or agency working on behalf of a social insurance scheme. Eligibility for German long-term care insurance depends on assessment of the amount of help needed with personal hygiene, eating, mobility and housekeeping. Claims are assessed by medical boards on behalf of the care insurance funds and the amount and frequency of help needed determines the level of benefit payable, at one of three “care dependency” levels.

BOX 2: JAPAN’S LONG-TERM CARE INSURANCE SCHEME

Everyone aged 65-plus is eligible for benefits, as are people aged 40+ suffering from age-related conditions (eg Parkinson’s Disease). There are transparent, nationally-uniform eligibility criteria; income, assets or the availability of family care are not taken into account. Municipal officials administer a 79-item questionnaire about activities of daily living and answers are scored using a computer algorithm to create seven levels of need; these determine the level of benefits. Benefits are provided in the form of services—institutional care, home help, nursing and bathing services, day care and respite care, equipment and adaptations. All beneficiaries are expected to contribute a standard ten per cent charge, regardless of income, with subsidies for poorer older people.

2.3 Universal arrangements offer equal access and similar levels of provision to people of all ages. The social insurance schemes funding social care in Germany and the Netherlands cover working age and older adults and disabled children, as do municipal social care services in Denmark. In contrast, Australia and Japan illustrate the difficulties that can arise from schemes developed specifically for older people. In Australia in the 1980s, the Commonwealth Government’s Aged Care Reform Programme was successful in limiting the growth of expenditure on nursing homes and encouraging home and community services for older people. However, there has been mounting concern about the chronically under-funded and severe shortage of specialist and rehabilitation services for younger disabled adults. Young adults, particularly with complex or severe needs, are often admitted to residential and end-of-life care facilities intended primarily for older people. A major 2006–07 public enquiry by the Australian Senate called for a National Disability Strategy and co-ordinated policies for working age disabled people and their families. New funds of A\$1.8 billion announced in 2008 were the first step in this Strategy. Similarly, in Japan long-term care insurance benefits are generally only available to older people; however the equity of this arrangement is now being questioned (see below).

2.4 Universal social care arrangements can be combined with principles of fairness, so that those who can afford to contribute to their care do so. User charges bring in revenue and hence contribute to economic sustainability. They also contribute to political sustainability, by reducing arguments that those who could afford to pay for their own social care are receiving it free of charge. The French universal *Allocation Personnalisée d’Autonomie* allocates service provision at one of six levels of dependency. People with incomes below a minimum threshold pay no charges; people with incomes above this level pay charges according to their income.

3. EQUITY

Equity has a number of dimensions.

3.1 Diagnostic equity—this requires that people with similar levels of impairment are treated equally, regardless of medical condition or reason for needing social care. Achieving diagnostic equity depends on the assessment used to determine eligibility for social care. In Germany, eligibility for long-term care has been criticised for a bias towards people with physical impairments and the unequal treatment of people with cognitive impairments. In Japan, the computer algorithm determining benefit levels was adjusted during the first two years of the long-term care insurance scheme in response to criticisms that people with cognitive impairments were assessed as needing less care than those with physical impairments.

3.2 Spatial equity—this means that people with similar levels of care needs are treated equally regardless of where they live. In other countries, local variations in access to and levels of social care provision have been major drivers of reform, even involving constitutional challenges to the traditional autonomy of local provinces and regions. In Austria there were marked regional differences in social services, with virtually no services in some provinces. The introduction of the national Care Allowance in 1993 required a new constitutional agreement between federal and provincial governments, setting out their respective responsibilities for funding and providing services. In Japan the introduction of compulsory, public long-term care insurance was also prompted by widespread concern at previous highly variable local decision-making; great importance was attached to transparent, national eligibility criteria. In contrast, Denmark combines universalist approaches with continuing local municipal autonomy. There is no national eligibility threshold and the legislative requirement to provide social care according to individual needs is open to local interpretation. There is nevertheless a widely accepted principle that everyone in the same municipality should be treated equally and have equal access to services.

3.3 Intergenerational equity—this means that the costs of social care do not fall disproportionately on one generation. This is a challenge in situations as at present, where older people and demands for care are growing faster than the working age population. Some countries have adjusted the respective financial contributions of working age and older people. Thus since 2004 retired people in Germany have been required to pay full contributions to long-term care insurance, rather than these being subsidised by pension insurance funds (to which working age people make major contributions).

BOX 3: CHALLENGES OF INTERGENERATIONAL EQUITY IN JAPAN

Long-term care insurance contributions are payable by everyone from age 40. Because of their higher incomes, people aged 40–65 contribute double the level of premiums as those aged 65-plus. However, because only 45–60-year olds with age-related disabilities can claim long-term care insurance, this age group receives only four per cent of benefits. Moreover, half the long-term care insurance scheme is funded from general taxation, to which those under 40 also contribute but are not eligible for benefits. These age limits are under review.

4. Promoting quality and choice—cash or services?

4.1 Where services are under-developed cash payments such as care allowances may aim to stimulate service provision by incentivising providers to develop the range and quality of their services and compete for the business of care allowance holders.

4.2 Cash payments can also aim to support family care. German long-term care insurance beneficiaries can choose a (lower value) cash payment or (higher value) services in kind. The cash payment has consistently proved more popular and is widely used to support informal carers, but this has reduced pressures on providers to increase the volume and quality of services. The Austrian Care Allowance was also intended to stimulate the supply of care services, but has largely failed in this aim; older people choose more rather than less informal care, using formal services only to supplement informal care.

4.3 Cash payments may also be a response to consumerist demands for greater choice, including choice to recruit and employ care workers privately.

BOX 4: PERSONAL BUDGETS IN THE NETHERLANDS

Social care in the Netherlands is funded through the AWBZ social insurance scheme. Cash personal budgets were introduced in 1995. These are similar to English direct payments and are set according to the number of hours care needed, with a standard 25 per cent deduction on the grounds that informal care does not incur the same overheads as formal provision.

Personal budgets fund home nursing and personal care, in line with needs identified at assessment. Budget holders can employ close relatives, including spouses; this is particularly popular with older people, although overall older people are less likely to choose personal budgets than younger disabled people.

4.4 Cash payments are not the only way of offering choice. People qualifying for long-term care insurance in Germany, Japan and the Netherlands can choose between different service providing organisations. Japanese older people are reported to try several providers before finding one they are satisfied with and providers actively compete for users. As prices are fixed by the insurance scheme, marketing focuses on quality issues.

BOX 5: “FREE CHOICE” REFORMS IN DENMARK

Since 2002, municipal services have competed with new, private organisations to provide domestic help and personal care. However, the availability of choice varies, with far fewer providers offering personal care in rural areas. Public attitudes have shifted markedly in favour of free choice of provider. Moreover, users of private services are significantly more likely than users of municipal services to report satisfaction (though this may partly reflect the more complex care typically needed by those choosing municipal services).

4.5 Increasing opportunities for user choice and provider competition are common features of social care reforms in many countries, particularly where services are traditionally underdeveloped or have been dominated by municipal or other monopoly suppliers. However, evidence from across Europe indicates there are major challenges in encouraging new service providers into rural or sparsely populated areas. Moreover, while competition between providers may help drive up quality, there is no evidence that it drives down costs; on the contrary, for a number of reasons, costs may actually rise.

5. *Family and informal care*

5.1 Help provided by families is by far the largest source of care and support in all countries, developed and less developed. However, there is also widespread evidence of the adverse health, well-being and financial consequences of family care-giving.

5.2 In many countries—including Japan, Austria, Germany and France—eligibility and assessments for social care do not take account of the availability of family carers; only the level of disability or help needed by the older or disabled person is considered. In Denmark, assessments for social care take account of whether a partner can provide domestic help, but not the availability of adult children or other family members outside the household; personal care remains a welfare state responsibility.

5.3 In many countries, support for family care-giving is built into the design of social care arrangements, albeit in radically different ways. The German care insurance cash payment option was always intended to support family care and is accompanied by a range of other measures to support carers, including:

- funding for four weeks respite care a year;
- funding for substitute care if the carer is ill;
- payment of pension and accident insurance contributions of family carers;
- carer training and employment retraining opportunities;
- rights to unpaid leave from paid work for six months (with the care insurance scheme covering the carer’s pension contributions);
- rights to unpaid emergency leave from work for ten consecutive days.

5.4 In Australia, carers enjoy extensive concessionary rates for State and municipal services, plus a two-tier system of cash benefits to which they are entitled in their own right. A means-tested Carer Payment is available to working age carers unable to take paid work because of care responsibilities (similar to the UK Carers Allowance). In addition, the Australian Carer Allowance is paid to all carers supporting someone at home, to cover the extra costs of caring. It is not dependent on the carer’s income or assets, not taxable and is unaffected should the carer leave or re-enter the labour market. Carers can receive Carer Allowance for each person they care for (but only one Carer Payment to replace lost income). In the Netherlands the “Carer’s Compliment”, worth €250 tax free, can be claimed by a carer supporting someone eligible for AWBZ long-term care insurance, solely in recognition of this responsibility.

5.5 Whether social care is provided as cash or services can have dramatically different impacts on carers. As noted above, cash payments may offer incentives to begin, or continue, providing family care. In the Netherlands and Flanders, personal budgets have attracted some new family members into care-giving roles. However, relatives employed in this way can also experience increased obligations, difficulties negotiating boundaries to their responsibilities, and are vulnerable should the relationship with their employing relative break down.

5.6 If social care is provided mainly through cash payments with few services in kind, the pressures on carers correspondingly increase, as do threats to the quality of the care provided. This was explicitly acknowledged in Japan, where older people had traditionally depended on unpaid daughters-in-law, prior to the introduction of long-term care insurance.

BOX 6: CASH VS CARE—JAPANESE DEBATES

Some argued that insurance benefits should be in the form of cash payments as these would:

- Maximise consumer choice.
- Recognise and reward family carers.
- Avoid poor quality care by strangers.
- Be cheaper because family care-giving has no overhead costs.

Others argued that insurance benefits should be in the form of services because cash payments:

- Would inhibit demand for, and supply of, services.
- Prolong oppressive patterns of care-giving by daughters-in-law.
- Prolong poor quality family care, because professional services can be quality-regulated.
- Cost less because demand for services would be lower than demand for cash payments.

6. Economic and political sustainability

6.1 Reforms in other countries show that a strong lead role for central government is crucial for economic sustainability, by combining resources from diverse sources to fund care; setting eligibility criteria; and setting levels of provision for people with given levels of need.

6.2 One way of ensuring sustainability is to cap levels of funding for any individual. In Germany, long-term care insurance benefits have fixed ceilings; any changes require federal legislation. Similarly the Austrian Care Allowance is paid at standard rates for given levels of disability. The disadvantage of capped entitlements is that rising service costs lead to a growing shortfall to be met from personal resources (or social assistance for the poorest). This became a major problem in Germany between 2000 and 2008 and led to increases in the private purchase of services and gaps in the amount of social care received by individuals.

6.3 Other countries restrict the range of help funded through mainstream, universal schemes. In the Netherlands, 2007 legislation transferred responsibility for funding domestic (home) help services from the AWBZ social insurance scheme to municipalities. Domestic help had constituted 42 per cent of total AWBZ spending on domiciliary care, so was a major source of expenditure. Municipalities are now responsible for devising and conducting assessments for domestic help, with widespread local variations; and for issuing competitive tenders to new cleaning companies.

BOX 7: COST CONTAINMENT IN JAPAN

Concerns about the rising costs of Japanese long-term care insurance have prompted restrictions on the services funded by the scheme.

- From 2005 most nursing home hotel costs were removed from coverage. The new out-of-pocket charges are income-related, with the poorest paying no increase.
- Between 2006 and 2008, social care services for people in the two lowest eligibility categories (ie with lowest needs) were restricted and partially replaced by preventive health promotion programmes and social activities. Home help services were also withdrawn from these two lowest eligibility categories.

These (and other) measures will limit contribution increases until 2012.

6.4 A third approach is to cut prices paid by public sector purchasers. The new cleaning contracts issued by Dutch municipalities are much cheaper than the domestic care services previously funded from AWBZ. Germany and Japan have also cut the prices paid by their respective social insurance schemes to service providers. But these measures—and the capped care allowances paid in Austria and Italy—place downward pressures on the social care workforce and increase the risks of provision by a growing “grey” labour force of unskilled and unregulated workers. Employment of new non-EU migrant workers has recently increased more rapidly in health and social care than across the EU as a whole.

6.5 Increases in contributions may be politically easier to secure if the electorate is confident of long-term stability and the prospect of benefitting in the future if and when social care is needed. Thus in 2008 contributions to German long-term care insurance were increased for the first time in 15 years, from 1.7 per cent to 1.95 per cent of gross salary for people with children and from 1.95 per cent to 2.2 per cent for childless people. However, these contribution increases were accompanied by increases in benefits and additional funding for new care management, advice, respite and dementia services. The latter improvements, along with the widespread popular stake in the insurance scheme, may have helped mitigate opposition to increased contributions.

7. CONCLUSIONS

7.1 Experiences from western European, Scandinavian and other developed welfare states show that sustaining social care provision is not an insurmountable challenge; indeed it appears surprisingly resilient in the face of fiscal constraint and population ageing.

7.2 There are widespread commitments to developing and/or maintaining universal and equitable social care arrangements. Previous fragmented, uncoordinated and locally variable arrangements are being replaced with national schemes in which eligibility and benefit levels are the same across the country and for younger as well as older disabled people. Few recent reforms have excluded the well-off or targeted social care services only on the poorest.

7.3 Cash allowances, as an alternative to services in kind, are widespread. However service providers do not always respond to consumer demands with a wider range of flexible, individualised services. Moreover, while cash allowances may empower service users, the implications for informal carers may be less positive if the care they provide is regarded as a substitute for formal service provision.

7.4 Central governments have crucial roles to play in ensuring universal, equitable and sustainable social care. In Germany, Austria, Spain and Australia, regional governments have considerable autonomy, including responsibilities for raising taxes and regulating services. Nevertheless social care policy, resources, eligibility criteria and quality regulation are determined by federal governments. Only central government can reform regional variations in resources, eligibility criteria and levels of service provision and ensure spatial equity. Central government responsibility for social care maximises risk pooling; safeguards budgetary controls; safeguards spatial, diagnostic and inter-generational equity; ensures that regulation and quality control mechanisms apply across the country; and is consistent with principles of universality.

7.5 Central governments also provide political legitimacy by championing the rights and social inclusion of people needing social care and their informal carers, and by defending public expenditure on social care that might otherwise lose out to, say, the acute health sector. Meanwhile local authorities have vital roles to play in conducting assessments; helping social care users plan and access preferred support arrangements; and working with service providers to ensure a wide range of good quality service options are available in response to local demand.

DISCLAIMER

This paper draws on research funded by the Department of Health and published as C Glendinning and N Moran (2009) *Reforming Long-Term Care: Recent Lessons from Other Countries*, Social Policy Research Unit, University of York. Any views or opinions are the author's own.

Caroline Glendinning ACSS
Professor of Social Policy
Research Director, Adults, Older People and Carers
Social Policy Research Unit
University of York

October 2009

Memorandum by the General Social Care Council (SC 50) FUTURE OF SOCIAL CARE SERVICES

INTRODUCTION

ABOUT THE GENERAL SOCIAL CARE COUNCIL (GSCC)

1. The General Social Care Council is the social care workforce regulator for England. The GSCC is a Non Departmental Public Body established in October 2001 under the Care Standards Act 2000. It is sponsored by the Department of Health (DH) but also works closely with the Department for Children, Schools and Families (DCSF) in delivering the children's and young people's care agenda.

2. The GSCC works to improve the quality of social care services for the benefit of people who use services through regulation of the workforce and through its contribution to social work education. It has three main functions:

- it issues and distributes codes of practice for social care workers and their employers;
- it maintains the register of social care workers; and
- it regulates social work education and training.

3. The GSCC exists to improve the quality of social care for the benefit and protection of people who use services in England by:

- acting as a guardian of standards in social care practice by requiring the highest standards of conduct from social care workers and compliance with the GSCC codes of practice;

- promoting and developing a high quality workforce by ensuring the highest standards of initial and ongoing training for social care workers;
 - upholding the value of a committed workforce and the contribution it makes to society
4. The GSCC currently registers almost 100,000 social workers and social work students.

OPTIONS FOR FUTURE FUNDING OF LONG-TERM RESIDENTIAL AND DOMICILIARY CARE FOR OLDER PEOPLE AND PEOPLE WITH PHYSICAL OR LEARNING DISABILITIES

Funding and the workforce

5. As the social care workforce regulator it is not our place to comment on the arrangements for the future funding of the care and support system. It is essential, though, that the debate regarding funding produces a settlement that will deliver a care and support system that meets the expectations that have been raised through the vision the Government has outlined.²⁰³ Crucially, this includes funding that will ensure a flexible, responsive and highly skilled workforce. The debate regarding the future funding of the care and support system needs to be joined-up with the debate regarding the future of this workforce.

6. To give one example, any decision regarding the future funding of the care and support system must also take into account the workforce implications of the drive towards personalisation. There is considerable evidence that the use of direct payments will have significant implications for workforce training. Recent research found that only 7%²⁰⁴ of direct payment recipients had paid for their personal assistants to have any form of training. Serious consideration, therefore, needs to be given to establishing a mechanism that will ensure that funding is available for the education and training needs of this part of the workforce.

OPTIONS FOR PERSONALISATION OF SOCIAL CARE SERVICES

7. The introduction of personalisation is leading to a very different care workforce, and our support of this agenda is crucial if we are to continue to perform our function of maintaining a high quality workforce, which is ready to meet the challenges of personalisation.

Personalisation and Social Work

8. The values that underlie social work training are based on principles of human rights,²⁰⁵ and the intervention skills which students are helped to develop are well fitted for the key tasks necessary to promote effective forms of self-directed support. Social work training is based on the National Occupational Standards for Social Work, which include "[working] with individuals to help them make informed decisions" and "[advocating] with and on behalf of individuals families (and) carers".

9. We believe that the skills and knowledge that registered social workers have make them ideal candidates to act as advocates and to take on the new roles aimed at supporting people to design their own care packages, and to perform the wider role of supporting families. They can add value to personalised services by ensuring that service users have better knowledge of, and access to, the services that will meet their needs and will be what they want.

Personalisation and Regulation

10. The care workforce is set to grow dramatically, from 1.4 million to between 2 and 2.5 million in 2025,²⁰⁶ with a significant growth in non-traditional care roles. *The Strategy for the Adult Social Care Workforce in England*²⁰⁷ highlights the importance of remodelling the workforce, to ensure that it has expertise "not only in providing support directly, but also in providing and brokering access to wider services, advice, advocacy and information." Crucial work is currently being undertaken by Skills for Care in their New Types of Worker project, to understand how the workforce is changing.

11. This raises important issues for workforce regulation as existing roles change and new roles appear, and there is a need for Government and ourselves to continue to monitor the transformations in the workforce.

²⁰³ Department of Health, *Putting people first: a shared vision and commitment to the transformation of adult social care*, December 2007.

²⁰⁴ IFF Research (2008) *Employment Aspects and Workforce Implications of Direct Payments*, page 101. Available online: [http://www.topssengland.net/files/Employment%20Aspects%20of%20Direct%20Payments%20Report—v9%20FINALwith%20foreword\(1\).pdf](http://www.topssengland.net/files/Employment%20Aspects%20of%20Direct%20Payments%20Report—v9%20FINALwith%20foreword(1).pdf)

²⁰⁵ *Estimating the future needs for adult social care services for people with a learning disability*, 2008, Eric Emerson and Chris Hatton

²⁰⁶ Skills for Care (2008), *State of the Adult Social Care Workforce in England, 2008*, Executive Summary page 11. Available online: <http://www.cwdpartnership.co.uk/downloads/doc—download/17-annual-social-care-workforce-executive-summary-2008.html>

²⁰⁷ Department of Health, April 2009, *Working to Put People First, the Strategy for the Adult Social Care Workforce in England*, page 32. Available online: <http://www.dh.gov.uk/prod—consum—dh/groups/dh—digitalassets/documents/digitalasset/dh—098494.pdf>

12. Whilst we approach the question of extending registration with an open mind, we firmly believe that registration should only be introduced if there is evidence that it will add value for people who use services, and if it can strike a balance between giving people the freedom to make choices about their own care, and providing them with safety, protection and assurance of high quality services.

Service User Involvement

13. In order to ensure that the personalisation of social care services fulfils its aim of putting people first, it is crucial that the practice of consulting with and involving people who use services and carers is integrated into every stage of the development and implementation of the personalisation agenda. As well as necessary funding, this requires the dedication of local and national bodies involved in the sector to overcome the barriers to involvement which currently prevent many people from participating.

14. A seminar run jointly by the GSCC, the Commission for Social Care Inspection, Skills for Care, the Social Care Institute for Excellence, and Shaping Our Lives National User Network in December 2007²⁰⁸ identified the serious negative impact that benefit rules have on involvement, from people being unable to accept even minimal fees for involvement for fear that it will take them over the earnings limits, to Jobcentre plus stopping incapacity benefits because they mistakenly classified involvement as work.

15. We, along with the other social care bodies who took part in the seminar, have developed payment policies to minimise the risks which involvement poses to people's benefits. We have also made some progress with Government with support for the Department for Work and Pensions to amend elements of benefits legislation. State benefit rules have been adjusted for involvement so that service users and carers may be reimbursed their out of pocket expenses and may keep within benefit earning limits by accepting a lower amount for involvement than offered, without benefit reductions. These changes have eased some benefit barriers enabling local and national bodies to improve delivery of the involvement agenda, which is fundamental to ensuring that personalisation achieves its goals. We will continue to work with Government, and with our health and social care partners, to bring about the remaining legislative changes to enable people to get involved without putting their benefits at risk.

OPTIONS FOR MORE EFFECTIVE, CONSISTENT AND USER-FRIENDLY SOCIAL CARE SERVICES

Service regulators, workforce regulator and employers working together

16. Following the "Baby Peter" case in Haringey, which came to public attention in November 2008, social workers, their employers and the institutional architecture surrounding the profession (the educational system, professional bodies, regulators etc), have come under intense scrutiny. This scrutiny has included Lord Laming's Progress Report on Child Protection, the Children's Schools and Families Committee investigation into the Training of Children and Families Social Workers and the work of the Social Work Task Force. This scrutiny has identified a number of areas where weaknesses currently exist. For instance, with respect to education the initial report of the Social Work Task Force observed that:

17. *"social workers need to take personal responsibility for their professional development, but they need to be supported to do so through their initial training and at every stage of their careers. This requires employers and educators to also commit to investing in and supporting the development of each generation of social workers, throughout their professional lives".*

18. Or, to take another example, with respect to supervision Lord Laming noted in his progress report that:

19. *"Regular, high-quality, organised supervision is critical, as are routine opportunities for peer-learning and discussion. Currently, not enough time is dedicated to this and individuals are carrying too much personal responsibility, with no outlet for the sometimes severe emotional and psychological stresses that staff involved in child protection often face."*

The GSCC's Codes of Practice for Employers of Social Care Workers

20. The nature of the problems identified through these reports provides evidence that currently the relationship between the service regulators (the Care Quality Commission and Ofsted), the workforce regulator (ourselves) and employers of social care workers is not as close as it should be. Taking action to strengthen this relationship would be an important step towards the goal of more effective, consistent and user-friendly social care services. One means to this end would be ensuring employer compliance with the GSCC's Codes of Practice for Employers of Social Care Workers (Employers Code), as recommended in Lord Laming's report and accepted in principle by government.

21. The Employers Code sets out the responsibilities of employers in relation to the safe recruitment, management, support and development of their social care workers and how employers should co-operate with the care councils to help support public protection by the maintenance of rigorous standards in social care practice.

²⁰⁸ CSCI, *Benefit barriers to involvement: finding solutions*, October 2007

The GSCC's Role in Regulating the Delivery of High Quality Training

22. A crucial area where employer support is essential is ensuring ongoing high quality training. A key statutory function of the GSCC is to regulate the training of social workers and assure the quality of education from the entry into the profession through to courses delivered under the GSCC's post-qualifying framework, ultimately to ensure the safety of people who use services.

23. After allowing time for the Social Work Degree, introduced in 2003, to establish itself we have been undertaking an in-depth review of our model of regulation to ensure it is fit for the purpose. The GSCC has shared with the Social Work Task Force our proposals to strengthen our model of assessing the delivery of the social work degree to a more interventionist and rigorous process.

Ensuring High Quality Practice Placements

24. An essential part of the social work degree is practice placements and currently we require students to undertake 200 days of placement during their initial training. We have recommended that there should be greater cooperation between employers and HEIs through the introduction of formal local partnerships to help ensure that there are appropriate high quality practice placements for all students.

Strengthening Post Registration Training and Learning

25. As part of our registration requirements, registrants have to undertake fifteen days or ninety hours of post registration training and learning every three years (PRTL). These requirements are not prescribed and we want to strengthen the system so that social workers are given more stringent guidelines about what needs to be covered. We would also like to see social workers undertake a greater amount of assessed training and to explore introducing requirements for people in particular roles, such as child protection, to undertake specialist qualifications in that area.

26. For these proposed changes to be effective, however, it will be essential that employers protect the funding allocated for social work training. A Learn to Care funding survey of local authority employers of social workers published last year reported that only 20 per cent of respondents actually secured all the National Training Strategy and Human Resources Development grants.²⁰⁹ Of those who estimated that they would not retain all of the grants, they thought that they would only be able to spend just over half on social care workforce development.

Summary of Key Messages:

- the debate regarding the future funding of the care and support system needs to be joined-up with the debate regarding the future of the social care workforce;
- the unique skills and knowledge that social workers have means that they should play a central role in the personalization of social care services;
- it is crucial that a debate takes place including everyone involved in social care in order to identify the correct balance between choice and safety in terms of personalization and regulation;
- achieving the vision set out by the government in 'putting people first' requires that service user involvement is integrated into every stage of the development and implementation of the personalisation agenda;
- recent scrutiny provides evidence that in the social care sector the relationship between the service regulators, the workforce regulator and employers is not as strong as it should be. Ensuring employer compliance with the GSCC's Employers Code would be an important step in strengthening this relationship;
- through carrying out our statutory functions, the GSCC has a crucial role to play in initial and ongoing social worker training. We are working closely with the Social Work Task Force with respect to our proposals as to how our model of regulation of the Social Work Degree, the provision of practice placements and our requirements around PRTL can be strengthened;
- funding for social work training must be protected.

October 2009

²⁰⁹ Learn to Care, *Funding Survey Report 2008*, December 2008.