



Promoting Independence, Preventing Crisis

Making social care reform work for disabled adults

2013

A joint inquiry by the:

All Party Parliamentary Local Government Group

All Party Parliamentary Disability Group

Report Authors

Joint inquiry into adult social care reform for working age disabled people

In February 2013, the All Party Parliamentary Group on Local Government and the All Party Parliamentary Disability Group launched a joint inquiry investigating how social care policy, funding and practice could better meet the needs of disabled adults. This was in response to an evidenced trend of disabled working age adults, losing the vital social care support they need to maintain their independence in society.

The inquiry received written evidence from disabled people, organisations and social care researchers, and during March 2013 heard oral evidence from four panels of experts.

Members of the inquiry:

APPG chairs:

Local Government Chair - Heather Wheeler MP (Con)
Disability Co-Chair - Baroness Campbell (Crossbench)
Disability Co-Chair – Rt. Hon. Anne McGuire MP (Lab)

Inquiry panel:

Rt. Hon. Thomas Clarke MP (Lab)
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Acknowledgements

We would like to thank all of the disabled people, organisations and professionals who gave written and oral evidence to this joint inquiry. Your experience and recommendations have helped our all party groups to better understand the importance of social care reform on disabled adults of working age and given us insights into how social care legislation, funding and practice could be improved to better meet people's needs and aspirations, and prevent a backslide into dependency.

Our thanks go to Scope for helping to facilitate the joint inquiry, and to Disability Rights UK and the Local Government Information Unit (LGIU) for their ongoing support of our all party parliamentary groups.

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Accompanying this report are two annexes:

Annex A: Transcriptions of the oral evidence sessions from the inquiry.

Annex B: Written evidence submitted to the enquiry.

Foreword

APPG inquiry into social care for working age disabled people Foreword by Baroness Campbell and Rt. Hon. Anne McGuire MP

One third of social care users are working age disabled people under 65.

Yet, on the eve of the Government's Care and Support Bill entering Parliament, much of the social care debate in both the press and Parliament remains focused on the needs of older people.

Whilst the challenge of delivering care for our aging population has been well documented, less light has been shone on what working age disabled people need from social care reform. This inquiry aims to change that; putting disabled people at the heart of social care policy making.

The evidence we received from disabled people and social care users was clear: good social care and support is the thing that enables them to live as active British citizens, instead of passive clients of care. The evidence reminded us that social care and support must not simply be about basic survival, for example getting up; eating and drinking or going to bed. It must be about supporting people to live, to live independently. Independent living is a universal human right to dignity, fairness and respect. Driven by the principle of independent living, social care can deliver support enabling disabled people to access all of life's opportunities, such as work, leisure and family life – things that non-disabled people take for granted.

It must not be a safety net system which intervenes only at points of crisis. That is why the recommendations made by this inquiry would, if accepted, help to create an ambitious care system fit for the 21st-century. We also believe the recommendations will assist the Government in its own ambition of creating a care service based on personalisation and prevention. The 2010 Coalition Agreement contains the promise to 'break down barriers between health and social care funding' for disabled people. The recommendations contained in this report will also achieve exactly that – a holistic approach which has been talked about for decades but never achieved.

We received a wide range of written and oral evidence which forms the voice of this report. The inquiry therefore offers an up-to-date range of practical and creative solutions that will inform the Government's decision making about social care reform over the coming months and years. Many of the recommendations are simple and cost nothing, others demand a rightful portion of health and social care resources.

This inquiry is totally the product of disabled people's voices and experience and the individuals and organisations, who support their wellbeing and right to independent living, currently underrepresented in the social care debate. Without such diligent contributions, this report would not have been possible – many thanks to them. Lastly but not least, our thanks to Scope who were brave enough to support this exercise in such short time and work with the ever-changing diary of parliamentarians!

Baroness Campbell of Surbiton and Rt. Hon. Anne McGuire MP

Co-Chairs, All Party Parliamentary Group on Disability

Foreword

APPG inquiry into social care for working age disabled people Foreword by Heather Wheeler MP

How to deliver high quality social care in a time of austerity remains one of the biggest challenges facing local government today.

For this reason the All Party Parliamentary Group on Local Government has once again turned its attention towards social care – but this time specifically looking at how the thousands of disabled people under 65 who rely on social care are affected.

There is no doubt that the Government has made significant progress. For the first time, the Care and Support Bill will introduce a single, modern law for adult social care. Accompanying the Bill will be a 'cap' on care costs that will give people more certainty about the costs they face should they need care in the future.

But whilst social care is a national issue, it is local government who must deliver an ambitious care system that meets the very different needs of both older and disabled people, at a time when budgets are tight. And this challenge has yet to be addressed.

This inquiry aims to explore what can be done at a local level to ensure that working age disabled people get the care and support they need. Many local authorities are leading the way, creating a more effective care system. But importantly, this report explores how the Care and Support Bill can boost local authority initiative and innovation and make sure disabled people get the care and support they need.

Familiar themes have emerged – innovation, integration and prevention remain watch words for a care system of the future. But what became clear is that a preventative care system must be the chief outcome of reform. Without a truly preventative system, councils will have little choice other than to intervene only at crisis points – when the personal and financial cost is far too great.

We are grateful to all the individuals and organisations that gave up their time to submit both oral and written evidence to this inquiry, which we hope have been done justice in this report.

All members of this inquiry are clear that this report will prove to be a vital resource for MPs and Peers as the Care and Support Bill progresses through Parliament. But we hope it goes beyond that and contributes to creating a care system that is fully integrated, with local authorities working together with other agencies to empower disabled people to live full and independent lives.

Heather Wheeler MP

Chair, All Party Parliamentary Group on Local Government

Executive summary

Care and support is vital for people of all ages. But the debate on social care funding has been almost exclusively about how the system should respond to the demands of an ageing population.

Important as this debate is, one in three people who use social care services are disabled people of working age, whose needs are not always the same as those of older people.

Whilst social care is very much a national issue, the challenge of delivering an ambitious care system for disabled people is one that rests with local government. At a time when budgets are tight, it is imperative that we look at ways in which we can boost local authority initiative and innovation to deliver real social care reform for working age disabled people.

It is these dual challenges that we hope to address in our inquiry and this report.

Chapter 1: The right to independent living

There is widespread concern from a range of organisations and individuals cited within this report to indicate that the current social care system is still too-often focused on the 'nuts and bolts' of provision and isn't yet able to ensure that disabled people can live truly independent lives.

- **Social care represents more than the basics of care and must enable disabled people to live fully independent lives, putting disabled people at the centre of their care. This is key to social care being able to achieve the wellbeing principle set out on the face of the Care and Support Bill.**
- **The list of wellbeing outcomes currently outlined in the draft Bill should be extended to include the right to participation in work, education, training or recreation, social and economic wellbeing, personal relationships and the contribution to society.**
- **Personalisation should represent more than simply tailoring social care to an individual and should be about breaking down the barriers between care, housing, transport, leisure and community involvement that currently face disabled people.**
- **The Government must ensure the continuity of care packages when an individual moves from one local authority area to another.**

Chapter 2: The impact of changes to eligibility

The evidence we received paints a picture of local authorities striving to innovate to achieve the best outcomes possible. However, we also heard that the growing social care funding problem has resulted in local authorities raising their eligibility criteria for social care. With fewer disabled people captured in the formal care system this can result in an escalation of need and can have a damaging result on the independence and wellbeing of disabled people. It also places additional strain on local authority budgets as they orientate around providing expensive, crisis care.

- **The current Fair Access to Care Services (FACS) criteria should be replaced by a system that is more objective and coherently implemented across the country.**
- **The current eligibility criteria has led to many thousands of disabled people falling out of the care system altogether and this must be rectified.**
- **The new national eligibility threshold for care must be set at a lower level to ensure that disabled people are able to receive the support needed in order to live independently.**
- **The use of Resource Allocation Systems should be reviewed to ensure fairness and consistency in reflecting the true cost of care for disabled people. To achieve this, Healthwatch England must take steps to assess the extent to which people are subsidising the cost of their care. Clause 25 of the Care and Support Bill must be strengthened to underline the duty of local authorities to be transparent about resource allocation decisions related to social care.**

Chapter 3: The value of preventative care and support

It is time for a new concept of social care that works towards creating a truly preventative care system, able to offer tailored support at an earlier stage, producing better outcomes for working age disabled people and reducing the need for costly crisis care provision further down the line.

- **Without access to social care, disabled adults' needs escalate, and many risk reaching crisis point. The impact of this on the everyday lives of disabled people can be devastating, leaving many at risk of social isolation.**
- **This escalation of need impacts financially on other bodies such as the health and criminal justice systems.**
- **Disabled people falling out of care often re-enter the system at a later stage and at a greater level of support need.**
- **It is time for a new concept of preventative care to be developed that provides early and adequate support to disabled adults to ensure their needs do not unnecessarily escalate, and to make efficiency savings for local authorities.**
- **Health and social care bodies must be more closely integrated and pooled budgets utilised in order to provide a more effective route to promoting independence and preventing crisis.**
- **The new Health and Wellbeing Boards represent the appropriate vehicle through which Government can deliver effective preventative services.**

Chapter 4: Paying for care and relevance of the Dilnot funding proposals to disabled adults

It is especially important at this time of financial austerity to ensure that the Government identifies a solution to address the existing funding gap for social care.

By more closely integrating the health and social care systems through the use of Health and Wellbeing Boards, the Government can ensure that local authorities are empowered to implement positive change in a financially viable manner.

- **The Dilnot Commission recommendations will help to cap care costs and protect assets for older age people, but these reforms will not positively benefit working age disabled people.**
- **The majority of working age disabled people will not have had the chance to acquire assets, and many have faced the competing financial pressure of dealing with other care costs.**
- **The age at which an individual starts contributing to the cost of their social care has yet to be properly evidenced, and will be a key factor in determining the true value of the Dilnot Commission proposals.**
- **The previous transfer of health care funding to local authorities for spending on social care was not financially sustainable, and much of this money never reached the front line.**
- **Health and Wellbeing Boards offer a practical and more sustainable approach to funding social care in the future. Through the Health and Wellbeing Boards, we believe the Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.**

The solution

Sustainably addressing the funding gap in social care will allow local authorities the breathing room to offer high quality preventative social care services that put disabled people at the centre of their care. With sufficient, allocated funding, authorities will not be forced to resorting to raising eligibility criteria in order to determine who is provided with social care. Placing a budget for preventative social care within Health and Wellbeing Boards offers this practical and sustainable approach to funding social care in the future, and encourages a new culture of integrated working that is able to flexibly offer the right care to disabled people at the right time.

Summary

The Care and Support Bill represents a profound opportunity for the Government to provide care and support for all those who need it. After decades of trying, this Government now has a chance to plug some of the historic gaps in the system. It can prevent rising demand for care and support from hitting wider services, drive forward the progress that has been made over the last 70 years and finally create a system that works for all those who need it.

Failing to implement a new concept of social care that places emphasis on preventative care would risk creating an escalation of crisis for thousands of disabled people, many of whom would risk re-entering the care system at a more serious level of need and at a higher resulting cost.

Addressing the eligibility criteria and the threshold for care would mean that more people are captured in the formal care system and that they continue to receive the care and support essential to ensuring that they are able to live fully independent lives.

We believe that the solution we set out in this report is clear, affordable and essential.

Social care must be about promoting independence and preventing crisis.

Recommendations

1. **In its statutory guidance of the Care and Support Bill, the Department of Health must practically describe the balancing of an individual's and carer's interests to make it explicitly clear that the needs of carers should not be used to obstruct disabled people's active participation in society.**
2. **The Government should extend the wellbeing principle in the Care and Support Bill to include a right to independent living (as described in articles 19, 20 and 21 of the CRPD).**
3. **The Government should acknowledge disabled people's concerns about the closure of the Independent Living Fund and work more closely with them to manage the closure for the 20,000 affected.**
4. **The Office for Disability Issues, as part of the implementation of the disability strategy, should urgently review (alongside TLAP) best practice in supporting disabled people, families, councils and providers to pursue independent living and ensure this is shared.**
5. **The Government should amend the duties under Clause 31 of the Care and Support Bill so that portability is based on a disabled person's 'firm intention' to move and that the received authority must have regard to the assessment and package given by the leaving authority to ensure the outcomes of support as 'equivalent' (or 'enhanced').**
6. **The Government must prioritise the design of a new framework of eligibility, actively engaging core stakeholders, and publish draft regulations relating to it before the Second Reading of the Care and Support Bill.**
7. **In establishing a national threshold for eligibility, the Government should commit to setting this at a lower level in the forthcoming Spending Review of 2013.**
8. **Regulations arising from the Care and Support Bill should contain transitional arrangements for councils who currently have set eligibility at the higher levels to ensure they can bring it down to a lower national threshold.**
9. **The Government should place Resource Allocation Systems (RAS) onto a statutory footing through the Care and Support Bill, supported by new duties on councils to be transparent about decisions relating to them and underpinned by a requirement on local authorities to take into account the true cost of care and support when setting RAS rates. This should have due regard for the contribution of disabled people to determining the nature of their care and support.**
10. **Healthwatch England should undertake an investigation into RAS and user-led purchasing to identify if care consumers are able to meet the true cost of care, identify the extent to which people have to subsidise care packages and suggest ways of strengthening the implementation of the market-shaping provisions contained in the Care and Support Bill.**
11. **Government should extend the definition of prevention in the Care and Support Bill to ensure the promotion of independent living and include duties to identify and support 'unmet need' and 'potential unmet need'.**

12. Health and Wellbeing Boards should be given, through the Care and Support Bill, a duty to identify, plan for and commission preventative services that maximise the independence of disabled people.
13. The Care and Support Bill should extend to the Right to Control regulations to pilot joint assessments and pooled budgets across health, social care, benefits, housing and employment support that can be directed by disabled people.
14. The Government must publish and consult on an evidenced rationale for the age at which care contributions should begin, and the level of the taper, for adults who acquire a disability in their adult life.
15. The Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.
16. Up to £2bn of NHS money should be made available for councils and the NHS to spend on preventative care, through Health and Wellbeing Boards at the Spending Review in June 2013.

Background to the inquiry

Below we aim to give a brief outline of the progression in decisions about legislation and funding that have led to the Draft Care and Support Bill, and our interest in how it could promote independence and prevent crises in disabled people's care and support in the future.

1. Adult social care law in England

In 1948, the National Assistance Act¹ established the National Health Service (NHS) and set out new duties on councils to provide accommodation and support to disabled people who needed assistance. But it was not until 22 years later that disabled people's rights to adult social care were strengthened under the Chronically Sick and Disabled Persons Act of 1970, introduced by the late Lord [Alf] Morris of Manchester.²

Since then, Government policy has sought to incrementally improve social care for disabled people, with a noticeable cultural shift since the late 1990s towards increasing people's choice and control over the care they receive. For example, in national Government strategies like Putting People First³ and Valuing People Now, and through the introduction of devolved payments for disabled people to commission and purchase their own support like Direct Payments,⁴ Individual Budgets⁵ and, increasingly, Personal Budgets.⁶

In 2008, the last Government asked the Law Commission to undertake a scoping review⁷ of the current state of social care law, with a view to providing an agenda for reform. This led to a wider discussion in Government about the purpose of social care in England.⁸ In 2010, the Law Commission built on this work, running a public consultation about their ideas for a new law.⁹ The Government published its own vision¹⁰ for adult social care on 16 November 2010.

The Law Commission published its final report¹¹ with insight from stakeholders and final recommendations were published in May 2011. They proposed a modernisation of adult social care law and the creation of one simplified statute that would supersede current legislation. To gain more clarity on the Law Commission proposals, the Department of Health launched an engagement exercise¹² to discuss the priorities for improving care and support with people who use care and support services, carers, local councils, care providers, and the voluntary sector.

1 National Assistance Act [1948]: <http://www.legislation.gov.uk/ukpga/Geo6/11-12/29/contents>

2 Lord Morris was also the first Minister for disabled people from 1974.

3 DH (2007) *Putting People First: A shared vision and commitment to the transformation of adult social care*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

4 Community Care (Direct Payments) Act [1996]: <http://www.legislation.gov.uk/ukpga/1996/30>

5 For more information see: <http://tiny.cc/ldrdvw>

6 DH (2007) Op. cit.

7 Law Commission (2008) *Adult Social Care: Scoping report*: http://www.justice.gov.uk/lawcommission/docs/Adult_Social_Care_Scoping_Paper.pdf

8 HM Government (2009) *Shaping the Future of Care Together*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102732.pdf

9 Law Commission (2010) *Adult Social Care: A consultation paper*: http://www.justice.gov.uk/lawcommission/docs/cp192_Adult_Social_Care_consultation.pdf

10 HM Government (2010) *A vision for adult social care: Capable communities and active citizens*: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_121508

11 Law Commission (2011) *Adult Social Care*: http://www.justice.gov.uk/lawcommission/docs/lc326_adult_social_care.pdf

12 DH (2011) *Caring for our Future: Shared ambitions for care and support*: <https://www.gov.uk/government/publications/caring-for-our-future-shared-ambitions-for-care-and-support--2>

This engagement resulted in the Government's response¹³ to the Law Commission's report in 2011 and in the Queen's Speech on 9 May 2012, the Government announced the draft Care and Support Bill. This was followed on 11 July 2012 by the publication of a White Paper¹⁴ setting out an ambitious vision for social care reform and the draft Care and Support Bill itself.¹⁵

After another consultation on the draft Bill and White Paper between 11 July and 19 October 2012, the draft Bill was considered in early 2013 by a Joint Committee¹⁶ of MPs and Peers in pre-legislative scrutiny, chaired by the former Care Minister, Paul Burstow MP. The committee invited stakeholders to submit written evidence and heard evidence from expert witnesses and Department of Health Ministers and officials. On 19 March 2013, the joint committee published their comprehensive report,¹⁷ making a number of substantive recommendations about how to improve the draft Care and Support Bill.

Our inquiry intends to build on the scrutiny by the Joint Committee by specifically considering how the draft Care and Support Bill could be improved to promote disabled people's independence. All references to the Care and Support Bill in this report refer to the draft Bill published for pre-legislative scrutiny.

2. The funding of adult social care in England

Whilst there has been concern about sustainable funding of health and care services for many decades, this came to a head when in 1997 the then Government established the Royal Commission on Long Term Care. The Commission's final report,¹⁸ published in 1999, recommended that the costs of long-term care should be split between living costs, housing costs and personal care. Personal care, they suggested, should be available after assessment, according to need and paid for from general taxation; the rest should be subject to a co-payment according to a means-test.

Specifically for working age disabled people, the Commission proposed that personal care should be provided free of charge at the point of use, and for a nationally consistent system of charges for publicly provided help with living costs (i.e. domestic help or help with tasks like shopping). It also recommended removing the means-test for applications to the Independent Living Fund (ILF).

The ILF was introduced in 1988 as a discretionary Government scheme to help fund care packages for disabled people with complex needs to enable them to stay in their local community, rather than residential care.¹⁹

The then Government, in its response to the commission's report,²⁰ stated that it did not believe that making personal care universally free was the best use of its resources and did not remove the means-testing on the ILF.

These debates were advanced when Derek Wanless was asked by the last Government to undertake an independent review of future health trends and the resources required over the two decades to 2022. The final reports of 2002²¹ and 2004²² recommended that a further review of social care be undertaken.

In 2005, the independent charitable foundation The King's Fund commissioned Wanless to produce a further report on the challenges facing adult social care over the following two decades, and options for funding and resourcing to meet the increasing levels of need. This review, however, focused primarily on demographic changes and cost drivers in older age. The final report²³ modelled future scenarios of funding and outlined three models that were most viable: a partnership model, a free personal care model and a limited liability model. Wanless's report suggests that the partnership model was the best, fairest and most cost-effective way of delivering a minimum level of care to people that they could top-up from their own resources.

The last Government followed this thinking by publishing a Green Paper²⁴ on the reform of care funding in 2009. It proposed the founding of a new National Care Service underpinned by national rights and entitlements to personalised services tailored to individual needs. The paper outlines a range of funding models; self-funding, partnership, insurance, comprehensive and tax-funded. The Green Paper also proposes pursuing a partnership model and explores topping this up through an insurance or contributory-based state insurance scheme. The subsequent White Paper²⁵ of 2010 continued the last Government's appetite for a partnership model.

After the General Election of 2010, the last Government's commitment to address the instability of social care funding was continued by the Coalition Government in their Programme for Government,²⁶ vision for adult social care²⁷ and a new strategy for supporting carers.²⁸ Delivering on this commitment, the Government established the Commission on Funding of Care and Support,²⁹ chaired by Andrew Dilnot, to consider a solution for the funding of adult social care in England. In recognition of the need to address the growing pressure on social care budgets, in the Spending Review³⁰ of 2010, the Chancellor transferred

13 HM Government (2012) *Reforming the law for adult care and support: the Government's response to Law Commission report on adult social care*: <https://www.gov.uk/government/publications/government-response-to-the-law-commission-report-on-adult-social-care>

14 HM Government (2012) *Caring for our future: reforming care and support*: <https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support>

15 Draft Care and Support Bill [2012]: <http://careandsupportbill.dh.gov.uk/home/download/>

16 For more information about the role of the committee see: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/draft-care-and-support-bill/role/>

17 Joint Committee on the Draft Care and Support Bill (2013) *Draft Care and Support Bill*: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/draft-care-and-support-bill/publications/>

18 The Royal Commission on Long Term Care (1999) *With Respect to Old Age: Long term care - rights and responsibilities*: <http://collections.europarchive.org/tna/20081023125241/http://www.archive.official-documents.co.uk/document/cm41/4192/4192.htm>

19 For more information about the ILF and eligibility see: <http://www.dwp.gov.uk/ilf> or <http://www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/IndependentLivingFund.aspx>

20 DH (2000) *The NHS Plan: The Government's response to the Royal Commission on Long Term Care*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4082154.pdf

21 Wanless, D. (2002) *Securing our Future Health: Taking a long-term view*: http://webarchive.nationalarchives.gov.uk/+http://www.hm-treasury.gov.uk/consult_wanless_final.htm

22 Wanless, D (2004) *Securing Good Health for the Whole Population*: http://webarchive.nationalarchives.gov.uk/+http://www.hm-treasury.gov.uk/consult_wanless04_final.htm

23 Wanless, D. et al (2006) *Securing Good Care for Older People: Taking a long-term view*: http://www.kingsfund.org.uk/publications/securing_good.html

24 HM Government (2009) *Shaping the Future of Care Together*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_102732.pdf

25 HM Government (2010) *Building the National Care Service*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_114923.pdf

26 HM Government (2010) *The Coalition: Our programme for government*: http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/documents/digitalasset/dg_187876.pdf

27 DH (2010) *A Vision for Adult Social Care: Capable Communities and active citizens*: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121508

28 DH (2011) *Recognised, Valued and Supported: Next steps for the Carers Strategy*: <http://www.dh.gov.uk/health/2011/07/carers-strategy/>

29 For more information on the commission see: <http://www.dilnotcommission.dh.gov.uk/>

30 HM Treasury (2010) *Spending Review 2010*: http://www.hm-treasury.gov.uk/spend_sr2010_documents.htm

£2bn of NHS expenditure to local authorities to be spent on social care.

Following a call for evidence³¹ the Dilnot Commission's final report³² made a suite of proposals. These included a £35,000 cap on an individual's lifetime contributions towards their social care costs and a higher means-tested threshold for self-payment in residential care of £100,000. The Commission also recommended that those who enter adulthood with a care and support need (or acquire a need before turning 40 years of age) should be eligible for free state support immediately, rather than being subjected to a means test. Echoing the Law Commission's recommendations, the commission also suggests the Government establish a national threshold of eligibility for adult social care.

The Government formally responded³³ to the commission's proposals in July 2012 and in the Budget 2013 the Chancellor announced³⁴ a cap on care costs of £72,000 and a higher means-tested threshold of £118,000 to be implemented in 2016. At the time of writing, we are still awaiting further detail of how the cap will apply to working age disabled people between the ages of 40 and retirement (64), representing a span of 18 years.

Additionally, the Minister for Care Services, Norman Lamb MP, in an answer to a written parliamentary question, confirmed³⁵ that the Government would be determining the level of the new national eligibility threshold, and the investment underpinning it, as part of the Spending Review in the summer of 2013.

It is in the context of these latter funding decisions that our inquiry investigated the solutions needed to resource a system which promotes disabled people's independence and prevents them from experiencing crises.

3. Remit of the inquiry

We decided to focus our inquiry on areas where we found a lack of evidence and insight into working age disabled people, as to not duplicate the consultation and scrutiny that has already been undertaken by Parliament. As such, the remit of this inquiry was to investigate four questions:

- 1. Does the current social care system support disabled people to live independently and in the accommodation of their choosing?**
- 2. What has been the impact of rising social care eligibility criteria on the ability of working age disabled people to live independently?**
- 3. What preventative social care services would most improve outcomes for working age disabled people?**
- 4. Would the introduction of the Dilnot Commission's proposals benefit working age disabled people? And if not, what other measures should be taken?**

In the writing of the inquiry report we have given prominence to those issues that were considered most urgent by those providing evidence to us.

³¹ Dilnot Commission (2010) *Call for Evidence on the Future of Care and Support*: <http://www.dilnotcommission.dh.gov.uk/files/2010/12/1.1-Call-for-Evidence-FINAL-pdf.pdf>

³² Dilnot Commission (2011) *Fairer Care Funding: The report of the Commission on funding of care and support*: <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

³³ HM Government (2012) *Caring for our future: Progress report on funding reform*: <https://www.gov.uk/government/publications/government-publishes-progress-report-on-social-care-funding-reform>

³⁴ HM Treasury (2013) *Budget 2013*: http://www.hm-treasury.gov.uk/budget2013_documents.htm

³⁵ Norman Lamb 26 Mar 2013, Hansard: Column 1101W: <http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130326/text/130326w0004.htm#13032680003417>

Chapter 1:

The right to independent living

Chapter summary:

- **Social care represents more than the basics of care and must enable disabled people to live fully independent lives, putting disabled people at the centre of their care. This is key to social care being able to achieve the wellbeing principles outlined in the draft Care and Support Bill.**
- **The list of wellbeing outcomes currently outlined in the draft Bill should be extended to include the right to participation in work, education, training or recreation, social and economic wellbeing, personal relationships and the contribution to society.**
- **Personalisation should represent more than simply tailoring social care to an individual and should be about breaking down the barriers between care, housing, transport, leisure and community involvement that currently face disabled people**
- **The Government must ensure the continuity of care packages when an individual moves from one local authority area to another.**

1. What disabled people want from social care

Disabled adults between the ages of 18 and 64 make up a third of all the people in England who use care and support services.³⁶ The evidence we received formed a clear picture about what they wanted from social care.

Many of the responses we received spoke about the importance of receiving personal care and the need for people to be assisted in getting out of bed in the morning, getting dressed and managing their condition on a day-to-day basis. Others highlighted the importance of receiving support in the home to assist with the cleaning or making a home-cooked meal.

Both Sense and the Royal National Institute for the Blind (RNIB) in their written evidence, and the National Autistic Society in their oral evidence, told us that communication and social interaction are frequently left out of discussions about social care and support, meaning that the needs of people with sensory impairments and autism are not always considered.

For example, deafblind people have told Sense³⁷ that councils ‘appear to be giving higher priority to support with personal care, such as dressing and bathing, than they do to support with communication’. Sense continues: ‘because most deafblind people do not need personal care, their needs go unmet and their independence is taken from them.’ They note that many are left unable to communicate with their family and friends, which leaves them isolated and withdrawn from their local community.

We heard evidence from Scope and Mind who also explained that some disabled people use care to help them manage their household budgets or make important decisions about their life. As Natasha, a young woman with Asperger Syndrome living in the West Midlands,

told us in her written evidence:

“When I decided to move out of the parental home and into my own home I needed some help and support to find out what options were available to me... I had never lived outside of the parental home until I decided to move into my own flat so I did not know how to run my own home which meant that I need some help and support to live as independently as possible in my own home. I have been living in my own flat for approximately 8 years now.”

But personal care, condition management, communication support and decision-making were not the only fundamentals that disabled people wanted from care and support. Liz Sayce, the Chief Executive of Disability Rights UK (DRUK),³⁸ asserted in her oral evidence that social care should:

“Enable you to live your life and participate fully in your community and your family, not just make sure you are fed, to put it, at a basic level.”

This sentiment was reflected in many of the written submissions we received. For example, Linkage Community Trust told us that the:

‘Support received is often only enough to meet basic needs rather than allow the person to obtain the support they need to enhance their lives on a wider basis in terms of education, employment and leisure.’

And the Joseph Rowntree Foundation, citing research for them by Peter Beresford,³⁹ suggested that:

‘Too often social care is seen as the nuts and bolts of physical provision – getting up, going to the toilet, going to bed, the occasional wash, meals on wheels and if you’re lucky, a trip to special day centres... we should be moving away from thinking about conventional social care and/or services, towards thinking about the assistance that people need and choose, and their experiences.’

They continue by citing a growing body of research showing people’s expectations and aspirations are increasingly focused on self-directed support that enables them to live independently and be actively involved in the local community and the wider economy. Similarly, a coalition of disability organisations⁴⁰ highlighted to us the experiences of one young woman, Amy, who said that social care should be about:

“...being able to have the same aspirations as others. I hold down a job, live independently and I am able to live life in the way I choose. I believe this is a fundamental right, but it has also given me an immense sense of freedom.”

Cllr Lynn Travis, the lead member for adult services, health and wellbeing in Tameside describes this freedom and independence as: “promoting and supporting wellbeing and enabling people to live fulfilling lives in the way that they wish to.”

³⁸ See the transcript of inquiry session one in the annex to this report

³⁹ Beresford, P: *Caring for our future: what service users say*, (JRF, York 2012) <http://www.jrf.org.uk/sites/files/jrf/caring-for-our-future-peter-beresford.pdf>

⁴⁰ Scope, Mencap, the National Autistic Society, Sense and Leonard Cheshire Disability who also submitted their joint report (2013) *Other Care Crisis*: <http://tiny.cc/qci8uw>

³⁶ See Scope analysis of Community Care Statistics, Social Services Activity - England from 2005/06 to 2011 / 2012: http://www.scope.org.uk/sites/default/files/The_Other_Care_Crisis.pdf

³⁷ Contained in Sense’s written evidence to the inquiry

We agree that the legal duties underpinning adult social care must reflect these wider expectations and aspirations that disabled people and organisations have described. In particular, the focus on maximising an individual's independence and using support to help them contribute to, and participate in, their local community. This is a vision that is shared by the Government in its social care White Paper.⁴¹

On this basis, we welcome the introduction, in the Government's draft Care and Support Bill, of a general duty on local authorities to promote the wellbeing of the individual.⁴² It builds on the recommendations of the Law Commission report into legislative reform⁴³ and sets out legal principles that disabled people can use to frame conversations about the support they receive.

In particular, we welcome the inclusion of outcomes contained in Clause 1 of the draft Bill, which are wider than those of personal care. These being subsection 2(c) control by the adult over day-to-day life; 2(d) participation in work, education, training or recreation; 2(e) social and economic wellbeing; 2(f) domestic, family and personal relationships; 2(g) the adult's contribution to society. Although we have concerns that subsection 3(e) could be used to limit the aspirations of the disabled person by suggesting that the disabled person's outcomes have to be balanced with those of carers.

We would ask the Government to give disabled people an explicit reassurance, during the passing of the Bill, that the anxieties or lack of aspiration of carers could not be used to undermine care and support that could enable them to achieve any of the wellbeing outcomes set out in subsection 2 of clause 1.

Furthermore, we expect the Department of Health in its statutory guidance to practically describe the balancing of interests to make it explicitly clear that care should put the voice of disabled adults at its heart, and the needs of carers should not be used to obstruct their active participation in society.

2. A right to independent living

We have identified that the Care and Support Bill could be improved to better promote the independence of disabled adults.

In their written evidence, the Social Care Institute for Excellence (SCIE) told us that social care should be seen to be:

'Part of a dynamic, integrated, cross-agency strategy that strengthens [disabled people's] position as citizens, secures their human and civil rights and removes sources of discrimination and other obstacles to full social participation.'

Tabitha Collingbourne, Neil Crowther, Inclusion London and Liz Sayce of DRUK in their evidence directed us to Article 19 of the UN Convention of Rights of Persons with Disabilities (CRPD).⁴⁴ Article 19 requires governments to recognise the equal right of all disabled people to live in the community of their choice, with support to ensure their full inclusion and participation in it. This includes the right to choose where you live on an equal basis to others, as to prevent isolation and segregation. The Government committed to the Articles of the Convention through its signature in 2006 and ratification in 2009.

41 HM Government (2012) *Caring For Our Future: Reforming care and support*: <https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support>

42 Clause 1 of the *Draft Care & Support Bill* [2012]: <http://careandsupportbill.dh.gov.uk/home/download>

43 Law Commission (2011) *Adult Social Care*: <http://lawcommission.justice.gov.uk/publications/1460.htm>

44 UN (2006) *Convention on the Rights of Persons with Disabilities*: <http://www.un.org/disabilities/default.asp?id=259>

In its new disability strategy, *Fulfilling Potential*,⁴⁵ the Government states that it supports Article 19 and 'fully subscribe[s] to the concept of independent living as defined by disabled people'; by which it means the definition set out in the former Disability Rights Commission's policy statement.⁴⁶

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

Neil Crowther refers in his written evidence to a previous parliamentary inquiry by the Joint Committee on Human Rights (JCHR) into the implementation of the right of disabled people to independent living in 2012.⁴⁷ In its concluding observations, the committee expressed regret that there was no specific legislation to protect and promote the right to independent living. It suggested that without a statutory footing disabled people's right to independent living would be under threat. This sentiment was reflected in written evidence to our own inquiry with, for example, Inclusion London telling us that:

'Isolation and exclusion from the community is not being prevented, on the contrary it is on the increase... The right for disabled people to choose where and with whom they live is also under attack. Article 19 of the UN Convention of the Rights of People with Disabilities (UNCRPD) is being breached'

Neil Crowther suggests that the approach taken in Section 2 of the Scottish Self Directed Support Act⁴⁸ 2013, which uses general principles informed by both human rights and Article 19 of the CPRD, could be adapted for the Care and Support Bill. Similarly, the JCHR recommended that the Care and Support Bill contain an explicit right to independent living (as defined by Article 19).

We agree with the JCHR's conclusion; however (given the evidence we have received) we would add that the Care and Support Bill should also incorporate Articles 20 and 21 of the Convention. These articles focus on the effective personal mobility of the individual and their freedom of expression. We think these would adequately cover the additional aspirations disabled people have about self-directing support and independently travelling around their community.

To ensure a right to independent living can practically work alongside the intended reform, we recommend that the Government extend the list of wellbeing outcomes in clause 1, sub-section 2 of the Care and Support Bill to include the additional independent living outcomes described in articles 19, 20 and 21 of the CRPD.

This is in line with the Government's own support of the JCHR inquiry recommendations in *Fulfilling Potential* and its aspiration that the transformation of the care and support system 'bring about the conditions for independent living' and 'promote independence and well-being'.⁴⁹

45 Office for Disability Issues / DWP (2012) *Fulfilling Potential – Next Steps*: <http://odi.dwp.gov.uk/docs/fulfilling-potential/fulfilling-potential-next-steps.pdf>

46 Disability Rights Commission (2002) *Policy Statement on Social Care and Independent Living*: London: DRC

47 JCHR (2012) *Implementation of the Right of Disabled People to Independent Living*: <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/independent-living-report>

48 Social Care (*Self-directed Support*) (*Scotland*) Act [2013]: <http://www.legislation.gov.uk/asp/2013/1/enacted>

49 Office for Disability Issues / DWP (2012) Op. cit.

We received written evidence and heard from Jane Young about the forthcoming closure of the £230m Independent Living Fund (ILF),⁵⁰ which currently provides overpayments to more than 19,000 disabled people. The Government closed the fund to new applications in December 2010 and from 2015 intends to devolve funding to local authorities under one 'cohesive' care system. Disabled people use the fund to help them stay independent, participate in their local communities and avoid reliance on more costly forms of care, such as going into residential homes.

Written evidence from the Independent Living Association and Inclusion London expressed concern that the closure of the fund would place additional financial pressure and caring responsibility onto disabled people and their families. Respondents to an Inclusion London survey said that the impact would be 'devastating'. The Merseyside Disability Federation added concerns from younger disabled people that they would be forced to live in inappropriate residential care as a consequence of the closure.

Inclusion London told us that disabled people will 'lose the independent support they need' because most local authorities 'are only providing very basic care'. This reflects a submission⁵¹ by the Association of Directors of Adult Social Services (ADASS) and the Local Government Association (LGA) to the consultation on the closure of the ILF who agreed that the value of local authority support would 'generally be at a lower level than the initial ILF' budget.

To illustrate the impact on its closure, Inclusion London quotes Jenny Hurst who says:

"Before I was referred for funding from the ILF I received a package of four hours a day, one hour for getting me up/showered and breakfasted, one hour for house work and lunch, one hour for supper and an hour to do the 'put to bed.'"

Inclusion London point out that support from the ILF subsequently enabled Jenny to go to university, get a full time job and become a trustee of a charity.

Since the announcement of the closure in December 2010, the Government's Office for Disability Issues and Department for Work and Pensions have been working with the ILF executive, statutory partners and local disability organisations to manage disabled people's transition from the fund. The Government suggests the 'transfer review programme' will enable people receiving ILF funding to have the necessary conversations with their council to look at how they can best be supported to retain their independence.⁵²

We note that, at the time of writing this report, a judicial review⁵³ has been launched by five disabled people against the Department for Work & Pensions (DWP) to challenge the consultation on closing the ILF. As an inquiry we do not seek to pre-judge the decision of the High Court, so have limited our comments to the relevance of disabled people's concerns about the closure on the wider reform of care and support.

We acknowledge disabled people's concerns that the current care and support system does not fully promote independent living and the impact that this has on their ability to participate

50 For more information about the Independent Living Fund see: <http://www.dwp.gov.uk/ilf>

51 ADASS / LGA (2012) *Response to the consultation on the Future of the Independent Living Fund*: www.dwp.gov.uk/docs/ilf-adass-lga.doc

52 ILF (2013) *ILF Transfer Review Programme: Supporting you with the transfer of your care and support*: <http://www.dwp.gov.uk/docs/transfer-review-booklet-england.pdf>

53 Stuart Bracking, Paris L'amour, Gabriel Pepper, Anne Pridmore, John Aspinall (by his mother and Litigation Friend Evonne Taylforth) (claimants) v SS for Work & Pensions (defendant) -and- Equality and Human Rights Commission (Intervener) [2013] HC AC <http://www.equalityhumanrights.com/news/2013/march/commission-intervenes-in-judicial-review-of-abolition-of-the-independent-living-fund/>

in, and contribute to, their local community. We believe that with the right level of resource (see Chapters two and four) it could be improved to ensure all disabled adults get the support they need to live independently and achieve the wellbeing outcomes we described previously.

We would encourage the Government to acknowledge disabled people's concerns about the closure of the Independent Living Fund and work more closely with them to manage the closure for the 20,000 affected.

3. The importance of personalisation

Social care has increasingly focused on maximising choice and control, with ideas of personalisation and independence coming to the forefront of policy and practice. Putting People First,⁵⁴ the Right to Control⁵⁵ pilots and Think Local, Act Personal⁵⁶ were all cited as cases in point. The Government's social care White Paper⁵⁷ builds on these ideas by describing personalisation as:

'giving people choice and control over their lives, and ensuring that care and support responds to people's needs and what they want to achieve. It is central to enabling people to lead active, independent and connected lives... [including] giving people control of their funding.'

We welcome this definition as it reflects the kind of care and support disabled people told us they wanted. However, we take note of the point made by the think tank Demos⁵⁸ who, in their report for Sue Ryder, tell us that practitioners and decision-makers sometimes conflate control over funding and commissioning your own care services, with tailoring support services to meet the needs and outcomes of an individual. They suggest that the two are used interchangeably, which risks, as Jane Young in her oral evidence described, "believing [that] a focus on personalisation would automatically create independent living."

The Joseph Rowntree Foundation agreed, suggesting that personalisation should not just focus on improving and tailoring personal care, but practically establishing the support that is needed to achieve the independent living outcomes described in the previous section. They suggest that personalisation, as an agenda, should practically break down barriers between care, 'housing, transport, leisure and community groups' to ensure support reflects the 'whole of people's lives.'

Along these lines, Liz Sayce suggests that social care should be characterised as a springboard for wider social inclusion, rather than a safety net for when people reach crisis point. This notion of person-centred care support focusing on independence was also advocated by the Equality & Human Rights Commission.⁵⁹

54 DH (2007) *Putting People First: A shared vision and commitment to the transformation of adult social care*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

55 C.f. DWP (2010) *Statutory guidance on the Disabled People's Right to Control (Pilot Scheme) (England) Regulations 2010*: <http://odi.dwp.gov.uk/docs/wor/rtc/rtc-stat-guide.pdf>

56 More information about the Think Local, Act Personal (TLAP) partnership can be found at <http://www.thinklocalactpersonal.org.uk>

57 HM Government (2012) *Caring For Our Future: Reforming care and support*: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136422/White-Paper-Caring-for-our-future-reforming-care-and-support-PDF-1580K.pdf

58 Demos (2011) *Tailor Made*: www.demos.co.uk/files/Tailor_made_-_web.pdf?1318945824

59 EHRC (2009) *From Safety Net to Springboard: A new approach to care and support for all based on equality and human rights*: <http://www.equalityhumanrights.com/key-projects/care-and-support/report-from-safety-net-to-springboard/>

It is clear from the evidence we received that disabled people, organisations providing social care and local authorities see personalisation as a powerful way of enabling disabled people to exercise choice and control over their support and funding to achieve independence.

However our inquiry also heard evidence that the pursuit of personalisation was hindered. Julie J Charles, the Chief Executive Director and National Ambassadors Lead of the Equalities National Council (ENC) told us about the experiences of disabled people from black and minority ethnic (BME) communities in attempting to get care and support.⁶⁰ She told us that:

“Many BME disabled people up and down the country felt that the social care system did not understand them, did not understand what their needs were, and they were having huge difficulty in accessing the system... there needs to be a holistic way of delivering personalisation, which cuts across health, social care and housing, because a lot of disabled people from our communities actually use community advocates.”

The Merseyside Disability Federation similarly raised concern that the compartmentalising of disabled people needs threatened the progress of personalisation. In their capacity as the lead partner for the North West Disability Infrastructure Partnership, they told us that personalisation is complicated by a lack of join up between different agencies creating a social care system that is ‘a myriad of systems that are complex, confusing and at times, contradictory.’

4. The transformation of care and support

We agree that personalisation should be at the heart of social care reform, enabling people to choose the level of control they want over determining their support. To do this, the Government need to instil a wider of culture of inclusion and independence in the social care system to avoid, what Jane Young called, a “poverty of aspiration.”

To do this the social care system needs to encourage forms of care that avoid unnecessary dependency and segregation. Dimensions and Helen Sanderson Associates suggest⁶¹ that the pursuit of personalisation should also address the detrimental effects of over-supporting disabled people, which can undermine their confidence in their own decision making powers and ability to maximise their resources. Similarly, Demos highlighted the importance of providing ‘just enough support’, a concept that recognises that:

“Too much support is as bad as not enough, and that developing community-based alternatives... is both more financially sustainable and better for the individual... Too much support, for example the idea that someone needs to be looked after by a qualified carer all of the time – can be a barrier to community participation, intrusive, even oppressive.”

Our inclusion of the concept of ‘just enough support’ should not mislead readers to think that either we or those providing evidence were suggesting that disabled people should be provided with inadequate or insufficient support. Rather, we are highlighting that the assets of individuals and communities should be considered in planning and purchasing support, ensuring they are maximised as a result. As Richard Humphries described to us:

“A lot of current assessment and interventions actually reinforce dependency. They create people’s dependency on services... I think there is a real opportunity to develop a new approach, which is produced based on assets, and on what people can do for themselves, as well as what they need.”

Similarly Laing and Buisson, in their written evidence, agree and suggest that the continuing culture of dependency in adult social care restricts their opportunity to become more independent. The Joseph Rowntree Foundation locates this dependency culture as stemming from financial pressures in local authorities, which:

‘prompts commissioners to become more risk averse and resort to tried and tested service models, rather than actually seeking the views of disabled people themselves or considering how to achieve the outcomes people want and value.’

Beyond these financial constraints, the Voluntary Organisations Disability Group (VODG), Jane Young and Mencap highlighted the importance of improvement in housing to fulfil personalisation and the transformation of care. Drawing on the evidence we received, we note that over the last two decades in particular there has been a transformation in the housing options available for disabled adults. Whereas previously the majority of disabled people were encouraged, or actively placed without consultation, into segregated residential care,⁶² more recently disabled people have been able to have greater choice in their accommodation including smaller supporting living arrangements and support in their own homes.

Mencap cited a recent study⁶³ that suggested two in five councils recognise that there is a housing shortage for adults with a learning disability in their areas, with nearly seven in ten stating this has worsened in the last 12 months. The report goes on to show that just one in three people with a learning disability lives independently in either supported accommodation (16%), as a tenant (15%), or as a home owner (2.5%).

They continue that nearly one in four people with a learning disability live in registered care homes and 22,000 people with a learning disability are living out-of-area. Worryingly, they warn that the underfunding of care and housing has resulted in people living in accommodation meant for older people or with elderly parents.

A report by Mencap and the Challenging Behaviour Foundation has shown that placing people in inappropriate services negatively affect their wellbeing, restricts their independence and can leave them vulnerable to abuse and neglect; Winterbourne View being a case in point.

Echoing these points, the Housing and Support Alliance suggests that good preventative care for people with learning difficulties is about ‘putting mechanisms and support in place to avoid institutional services and avoid over-dependency on care.’ Jane Young advises that more needs to be done to bring social care and housing closer together. She gives the example of a young disabled woman who is unable to take up an internship and pursue her career because of the lack of accessible housing in London. Nottinghamshire County Council, in their written evidence, agree suggesting that finding appropriate accommodation is a ‘limiting factor’ in the provision of care and they advocate for a more joined-up approach between housing and social care.

Reflecting on the importance of promoting independence, personalisation and a better

60 For more information see ENC / Scope (2012) *Over-looked Communities, Over-due Change: How services can better support BME disabled people*: <http://tiny.cc/nxzvbw>

61 Dimensions / Helen Sanderson Associates (2010) *Making It Personal: A provider’s journey from tradition to transformation*: <http://www.helensandersonassociates.co.uk/media/27410/makingitpersonalweb2.pdf>

62 Beadle-Brown, J. & Kozma, A. (2007) *Deinstitutionalisation and community living – outcomes and costs: report of a European Study (Volume 3: Country Reports)*: http://www.kent.ac.uk/tizard/research/DECL_network/documents/DECLOC_Country_Reports.pdf

63 Mencap (2012) *Housing for People with a Learning Disability*: http://www.mencap.org.uk/sites/default/files/documents/2012.108%20Housing%20report_V7.pdf

working relationship with housing, our inquiry led us to consider the work of the Office for Disability (ODI). We note that the former Independent Living Strategy⁶⁴ has been subsumed into the new Disability Strategy,⁶⁵ *Fulfilling Potential*. We note that independent living is embedded into the strategy, but are concerned that there isn't an associated work plan to help statutory bodies to promote independent living. We believe that the ODI, alongside the Department of Health and the Think Local, Act Personal partnership, could play an active role in identifying and sharing best practice in promoting and embedding cultures of personalisation and joint working with housing.

We suggest that the Office for Disability Issues, as part of the implementation of the disability strategy, should urgently review (alongside the Think Local, Act Personal partnership) best practice in supporting disabled people, families, councils and providers to pursue independent living and ensure this is shared widely.

5. Ensuring continuity of care

Portability refers to the continuity of a care package when someone moves from one local authority area to another. Currently, when someone moves from one local area to another they have to be reassessed and renegotiate their care package, taking into account any differences in the levels of eligibility between the two authorities. As Jose-Luis Fernandez noted:

“The Bill is going to allow portability of your current package. But of course once you get to your destination you will be reassessed by local services. There is a democratic issue to be resolved there.”

This means that whilst someone's needs and desired outcomes may not have changed, the level of support they receive could substantially be reduced. Jane Young, in her written evidence to the inquiry, told us about a young woman who was an 'outstanding academic researcher' and lived and worked in one town. She wanted to apply for a prestigious academic post in a second town but was told that if she moved to the second town she would have no guarantee of care or support. Jane writes that it would have taken over six months for a new social care package to be put in place meaning the young lady was unable to apply for the position.

Reflecting the ideas in the Social Care Portability Bill⁶⁶ of 2012, Marc Bush suggests two additions to the Care and Support Bill, which would improve the continuity of care that people received and the portability of their support. The first was inserting under Clause 31 of the Care and Support Bill a duty on the receiving authority to guarantee an equivalency of outcomes through the provision of care, support and/or funding. He says:

“Currently, if you are in one area and you move to another area, you might have a new assessment. They might be co-operating well with that original authority you came from, but your new service does not have to be equivalent to that of the one you left. I am not saying that the Bill should specify you have exactly the same services... Each area needs the provision that works for that individual, but you want something that guarantees the person will have the same outcomes, and therefore the service being provided gives equivalent outcomes to the ones the person was getting, or improved outcomes.”

64 HM Government / ODI (2008) *Independent Living: A cross-government strategy about independent living for disabled people*: <http://odi.dwp.gov.uk/docs/wor/ind/ilr-executive-report.pdf>

65 Office for Disability Issues / DWP (2012) *Fulfilling Potential – Next Steps*: <http://odi.dwp.gov.uk/docs/fulfilling-potential/fulfilling-potential-next-steps.pdf>

66 Social Care Portability Bill [2012]: <http://services.parliament.uk/bills/2012-13/socialcareportability.html>

Jane Young agrees, noting that it does not have to be “exactly the same provision, because it might be that service configuration is very different in the area that you go to”, but the important element is ensuring there is a commitment from the receiving authority to achieving the outcomes the individual identifies. She adds that “if you want support to go to work... then that should be replicated in the new place, and you should have the resources to do it.”

Secondly, Marc Bush suggested (echoing the position of the Care and Support Alliance) an addition under Clause 31 that would put a duty on the receiving authority to have due regard to the care and support plan the individual formulated with the sending authority. As he describes:

“Care planning is quite a detailed process, hopefully and preferably. People go through and talk about the ambitions and outcomes they want, and think about the way that that could be met. As a starting block for thinking about how you are provided in a new area, you would want the old plan to be taken into account.”

Currently, 'ordinary residence' rules are used to establish which local authority is responsible for providing services and funding to an individual. Some local authority duties to provide care and support services depend upon the individual concerned being deemed ordinarily resident in their area.⁶⁷ If the person is deemed not 'ordinarily resident' in the area, then the local authority may have discretion⁶⁸ over whether or not it funds an individual's services.

Currently, there is not a legislative definition of 'ordinary residence' set out under the National Assistance Act of 1948, but rather it has been interpreted through seminal case law (such as *R v Barnet LBC ex p Shah [1983] 2 AC 309*) and interpretative guidance from the Department of Health.⁶⁹

This can lead to disabled people being trapped between two authorities over a dispute about who is responsible for funding their care package. This can occur when someone wants to leave a care home or when a service is deregistered and when an individual want to remain in an area that does not have the funding responsibility for the care package (i.e. when they have been given an out of authority placement). It is of particular concern to smaller authorities or those who house high numbers of out of authority placements, who cannot absorb the cost of provision, if they become responsible for funding and/or providing the care packages.⁷⁰

The concept of 'ordinary residence' is continued in the Care and Support Bill and evidence we received suggested that the Bill improves the current situation. However, we note the need for disabled people to be in control of choices and decisions about their care and support and place of residence. As such, we agree with suggestions from witnesses that it is the disabled person's own 'firm intention' to move to another authority that should trigger the process to begin.

67 For more information see DH (2011) *Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services*, England: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131705.pdf

68 Currently the rules apply to services provided under the Assistance Act [1948]: <http://www.legislation.gov.uk/ukpga/Geo6/11-12/29/contents> and Chronically Sick & Disabled Persons Act [1970]: <http://www.legislation.gov.uk/ukpga/1970/44>

69 C.f. DH (2011) *Ordinary Residence: Guidance on the identification of the ordinary residence of people in need of community care services (England)*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131705.pdf

70 For more information see VODG (2007) *No Place Like Home: Ordinary Residence, discrimination and disabled people*: <http://www.vodg.org.uk/uploads/VODG-no-place-like-home.pdf> and VODG (2010) *Not in My Back Yard: Ordinary residence, discrimination and disabled people*: http://www.vodg.org.uk/uploads/pdfs/VODG_report_final.pdf

We agree with the witness and recommend that the Government amend the duties under Clause 31 of the Care and Support Bill so that portability is based on a disabled person's 'firm intention' to move and that the receiving authority must have regard to the assessment and package given by the leaving authority to ensure the outcomes of support as 'equivalent' or 'enhanced'.

Recommendations:

1. In its statutory guidance of the Care and Support Bill, the Department of Health must practically describe the balancing of an individual's and carer's interests to make it explicitly clear that the needs of carers should not be used to obstruct disabled people's active participation in society.
2. The Government should extend the wellbeing principle in the Care and Support Bill to include a right to independent living (as described in articles 19, 20 and 21 of the CRPD).
3. The Government should acknowledge disabled people's concerns about the closure of the Independent Living Fund and work more closely with them to manage the closure for the 20,000 affected.
4. The Office for Disability Issues, as part of the implementation of the disability strategy, should urgently review (alongside TLAP) best practice in supporting disabled people, families, councils and providers to pursue independent living and ensure this is shared.
5. The Government should amend the duties under Clause 31 of the Care and Support Bill so that portability is based on a disabled person's 'firm intention' to move and that the receiving authority must have regard to the assessment and package given by the leaving authority to ensure the outcomes of support as 'equivalent' (or 'enhanced').

Chapter 2: The impact of changes to eligibility

Chapter summary:

- The current FACS criteria should be replaced by a system that is more objective and coherently implemented across the country.
- The current eligibility criteria has led to many thousands of disabled people falling out of the care system altogether and this must be rectified.
- The eligibility threshold for care must be set at a lower level to ensure that disabled people are able to receive the support needed in order to live independently.
- The use of Resource Allocation Systems should be reviewed to ensure fairness and consistency in reflecting the true cost of care for disabled people. To achieve this, Healthwatch England must take steps to assess the extent to which people are subsidising the cost of their care. Clause 25 of the Care and Support Bill must be strengthened to underline the duty of local authorities to be transparent about resource allocation decisions related to social care.

1. Becoming eligible for care and support

Unlike the NHS, council-funded social care is not free at the point of use. To receive funding and support, disabled adults have to be deemed to have a high enough level of need to warrant support. When a disabled person contacts a council they may have a number of 'presenting needs', however it is only those needs that meet an eligibility threshold that are factored into the support and funding an individual receives.

In England, local authorities use a policy framework called Prioritising Need and the Fair Access to Care Services (FACS)⁷¹ criteria to determine whether or not an individual's need is eligible for support. The FACS criteria are based on assessing the risk to the individual of not receiving support. The criteria are defined across four bands of eligibility: 'low', 'moderate', 'substantial' and 'critical.' The band at which a person's need is assessed determines whether or not they will be entitled to care and support.

RNIB, Scope, Sense, the National Autistic Society, Mencap, Leonard Cheshire Disability and ENC all told us that the primary concern for disabled people is whether or not they are supported by the formal care system. As a consequence the design and determination of eligibility is of paramount importance in ensuring disabled people's independent living.

Richard Humphries, Andrea Sutcliffe and Marc Bush in their oral evidence to the inquiry raised concerns about the focus of FACS criteria, explaining that it was underpinned by an assessment of risk, rather than the outcomes an individual wants to achieve. All of our witnesses, and written evidence we received, suggested that FACS should be replaced by a new eligibility framework, which moves away from the risk model of social care and instead

⁷¹ DH (2010) *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*: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113155.pdf which is based on, but supersedes DH (2003) *Fair access to care services – guidance on eligibility criteria for adult social care*: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4009653

focuses on an individual's independence, wellbeing and outcomes.

The evidence we have received reflects the conclusions of the Dilnot Commission who said that the FACS criteria should be replaced in the future with a 'more objective scale – one which can be the basis of a clearer, fairer and more coherent social care system'. Richard Humphries added that the current FACS criteria have been in operation for almost ten years with the aim of promoting consistency across local authorities. He agrees that in 'their current form they are largely irrelevant' and have had "very little impact on the actual care that people get, whether they get it, and how much is spent."

As outlined in their White Paper,⁷² the Government is proposing an interim solution, whereby they will make only minor amendments to the FACS criteria. They also commit to a longer-term project to redesign the framework of eligibility for social care.

We agree with both the Dilnot Commission and recommendations of the Joint Committee, that the Department of Health must prioritise the design of a new framework of eligibility, actively engaging core stakeholders like disabled people, their organisations, disability charities and social care professionals.

Furthermore, to give disabled people confidence in the new care and support system we expect the Government to publish draft regulations on new eligibility criteria before the Second Reading of the Care and Support Bill. We believe that this will ensure parliamentarians will be better informed when we undertake scrutiny of the Bill and allow us to assess whether the policy intentions of the new criteria meet the new focus on wellbeing and outcomes, and our inquiry's recommendations on promoting independence.

At present, councils have discretion to set eligibility for care and support at any one of these different FACS levels. Recent research⁷³ by José-Luis Fernández and Tom Snell at the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE) suggests that professionals working in local authorities use their discretion to massage the FACS criteria to ensure some needs are met even if the threshold is too high. Further, it demonstrates that councils are setting their own augmented thresholds of 'lower critical' or 'higher' or 'upper' 'substantial' and relying on alternative ways of controlling eligibility and related expenditure. This was echoed in the written evidence provided by the Social Care Institute for Excellence (SCIE).

We received evidence from Carers UK, Linkage Community Trust, Turning Point, ENC, RNIB, Scope, Mencap, Sense, the National Autistic Society and Leonard Cheshire Disability demonstrating how funding pressures on council budgets were affecting decisions about where eligibility thresholds should be set for adult social care. This is echoed in a recent report by the Audit Commission on adult social care in England.⁷⁴ In 2005, 50 per cent of the 152 local authorities in England provided care and support to those with 'moderate' needs and above, but by 2012, 84 per cent were only providing services at the higher threshold of 'substantial' needs.⁷⁵

⁷² Department of Health (2012) *Caring for Our Future: reforming care and support*: <http://www.dh.gov.uk/health/2012/07/careandsupportwhitepaper>

⁷³ Fernandez & Snell, T. (2012) *Survey of Fair Access to Care Services (FACS) Assessment Criteria Among Local Authorities in England*: <http://eprints.lse.ac.uk/44404/>

⁷⁴ Audit Commission (2011) *Improving Value for Money in Adult Social Care*: <http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/Downloads/20110602vfmadultsocialcare.pdf>

⁷⁵ Age UK (2012) *Care in Crisis 2012*: http://www.ageuk.org.uk/Documents/EN-GB/Campaigns/care_in_crisis_2012_report.pdf

This means that only three councils now provide social care to people who fall into all four eligibility bands and only 24 provide care to those with 'moderate' needs and above. Although we have been notified by witnesses, that one of the councils with a threshold of moderate eligibility, Bradford Metropolitan District Council, is consulting on increasing it due to financial pressures.⁷⁶ Richard Humphries told the inquiry that in this regard, the current FACS eligibility criteria had "outlived their usefulness" and had become a "zombie policy of adult social care, because it is kind of limping on, neither alive nor dead and it really now has very little impact on the kind of service that people get."

These changes in eligibility have led to more disabled people falling outside of the formal care system, left ineligible for care and support. RNIB told us that blind and partially sighted people have been disproportionately affected by these changes. The total number of adults recorded as 'visually impaired' in receipt of social care services has reduced by 36 per cent since 2005/06 and the total number of adults in receipt of social care services has reduced by 16 per cent over the same period. The Independent Living Association told us that in West Sussex 4,500 people have lost their social care funding, leaving many who previously 'had support to work or to engage actively in independent lives or community life no longer able to pay for the support to help them to do this.'

Giving the broader picture, recent modelling by José-Luis Fernández and colleagues at the PSSRU at the LSE found that 69,000 disabled adults (18 to 64 years) with moderate level needs and 8,000 with substantial level needs had already fallen out of the system. They note that if all councils were to raise their eligibility to a substantial level a further 36,000 disabled adults would lose the support they receive, or 105,000 disabled adults in total. When asked to describe the kinds of disabled people that have been affected, Marc Bush told the inquiry that these 69,000 people have a range of conditions, capturing a breadth of different needs, including "personal, social and communication needs, but also some people who need it for [managing their] finance and socialisation."

There was a consensus in the evidence we received that local authorities having discretion to set local eligibility thresholds at different levels was unhelpful and undermined the fairness of the care system and people's continuity of care. Reflecting on this in her oral evidence, Sue Brown from Sense said:

"It has always interested me why in the NHS it is called a postcode lottery and it is a bad thing, and in social care it is called local democracy and it is a good thing. The bottom line is if you can get support with maintaining your social networks in local authority A, and you cannot in local authority B, it has to be a bad thing for the people who live in local authority B. In my opinion, there have to be – for all disabled people, particularly those of working age – bottom lines. We need to say: this is a minimum standard of living and quality of life below which we will not let disabled people fall. That has got to be the minimum across the board."

The Linkage Community Trust agreed, noting that people with lower levels of need 'slip through the net' and that they had seen increasing number of people reaching crisis as a consequence. Demos added that in this context 'it is hardly surprising that support for independent living seems out of reach.' Marc Bush gave the inquiry a striking example of a man who used to receive low-level support to get dressed in the morning, who lost his support because the local authority raised their eligibility threshold. He recounts that it resulted in a situation where the man was going out in the street and asking strangers to help him tie up his

⁷⁶ For more information see: http://www.bradford.gov.uk/bmdd/government_politics_and_public_administration/news/fair_access_to_care

shoelaces, which he felt compromised his dignity and his quality of life.

We heard evidence from an individual with Asperger Syndrome who told us that:

“The impact of the recent changes to the eligibility criteria has meant that although I have support needs, they would be unlikely to be considered ‘substantial’ or ‘critical’ and therefore I would not be eligible for any support.”

Similarly, Mind quoted someone with a mental health condition who lost their support and found that:

‘Without support it is incredibly difficult to leave the house and I do not speak to anyone, and the more weeks that this happens consecutively then the harder it is to do so again. Before there was any support, it could be anything up to seven or eight weeks in a row of not going out at all. Whilst with support I actually get to engage with people, it’s possible to buy fresh food...and get various odd tasks done which can’t be achieved online.’

We were told about someone who spoke to Action for Blind People and suggest that:

‘Usually, we [blind and partially sighted people] do not fit into the critical or substantial categories, unless the blind person has the support of a good advocate who can emphasise the significance of the issues we face. Local authorities must recognise that there is more to social care than dressing, bathing and feeding’.

The written and oral evidence we received from ENC, Scope, Mind, SCIE, VODG and RNIB in particular, suggested there was a consensus that in the future the social care system should ensure those with moderate level needs, as currently described under FACS, are eligible for care and support. RNIB told us that raising the eligibility threshold represented a ‘false economy’, and that providing services to people who currently had lower levels of need would ultimately prevent their needs becoming greater and more expensive in the future.

This was substantiated in a joint report⁷⁷ submitted to us by Mencap, Scope, the National Autistic Society, Leonard Cheshire Disability and Sense entitled *The Other Care Crisis*. Similarly, VODG wrote that setting the national eligibility threshold at substantial or above would curtail the ‘independence, wellbeing and quality of life of many disabled people’ and claimed that it would conflict with the ethos of the Government’s White Paper and the wellbeing principle contained in the Care and Support Bill. The Joseph Rowntree Foundation added that if the local discretion over eligibility was not addressed the ‘concepts of independent living, choice and empowerment could soon become expensive luxuries.’

In terms of the knock-on cost of losing care and support, Carers UK told us that over two million people have given up work in order to care for a disabled relative⁷⁸ at a cost of £1.3bn a year in additional expenditure on carers’ benefits and lost tax revenues.⁷⁹ They suggest that if lost earnings are also taken into account this figure rises to £5.3bn.

77 Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability (2013) *The Other Care Crisis*: <http://tiny.cc/qci8uw>

78 For more information see: <http://www.carersuk.org/newsroom/item/3033-research-reveals-over-2-million-quit-work-to-care>

79 For more information see: <http://blogs.lse.ac.uk/healthandsocialcare/2012/04/25/dr-linda-pickard-public-expenditure-costs-of-carers-leaving-employment> and <http://www.carersuk.org/newsroom/item/2617-care-in-crisis-more-than-53-billion-wiped-from-the-economy>

To address this disparity, the Law Commission⁸⁰ proposed the introduction of a national threshold for eligibility that all local authorities would have to adhere to. The Dilnot Commission⁸¹ agreed and recommended that this national minimum threshold for eligibility should be set at a FACS ‘substantial’ or equivalent level. The Government’s adult social care White Paper⁸² follows the Law Commission’s recommendations and commits to a national threshold of eligibility. The Minister for Care Services, Norman Lamb MP, in an answer to a written parliamentary question, has confirmed⁸³ that the Government will be determining the level of the threshold, and the investment underpinning it, as part of the Spending Review in the summer of 2013.

We acknowledge the concerns raised during this inquiry about setting the national threshold of eligibility too high. As such, the Government, in establishing a new national threshold for eligibility, should commit to setting this at a lower level in the forthcoming Spending Review of 2013.

To support this, we also suggest that regulations arising from the Care and Support Bill should contain transitional arrangements for councils who currently have set eligibility at the higher levels to ensure they can bring it down to a lower national threshold.

2. Determining the value of care and support

Once someone is deemed eligible for support, the local authority assesses their needs to determine the value of their Personal Budget. The Personal Budget is the money that is allocated to a disabled adult to pay for or purchase their care and support.⁸⁴ The value of the Personal Budget is determined by authorities through the use of a Resource Allocation System (RAS). Through the RAS, local authority ascribes a number of points to each eligible need that has been identified. The authority then calculates the total number of points and refers to a table setting out the annual financial value of different bands of points. Sometimes, a person’s eligible need is higher than the maximum number of points the RAS sets and so local authorities apply a further calculation. For example, Cambridgeshire County Council uses an Upper Banding Calculator to determine the value of this additional need.⁸⁵

The calculated value of the Personal Budget is meant to be a ‘ballpark figure for the majority of users which can be adjusted up or down, depending upon those individual circumstances’, as the Association of Directors of Adult Social Services (ADASS) explain in their guidance⁸⁶ for the use of the RAS. Disabled people are meant to be able to use this indicative budget to develop a support plan, which sets out the support they want and will purchase to achieve their identified independent living outcomes. The final decision about the value of the Personal

80 Law Commission (2011) *Adult Social Care*: http://www.justice.gov.uk/lawcommission/docs/lc326_adult_social_care.pdf

81 Dilnot Commission (2011) *Fairer Care Funding: The report of the commission on funding of care and support*: <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

82 HM Government (2012) *Caring for our future: reforming care and support*: <https://www.gov.uk/government/publications/caring-for-our-future-reforming-care-and-support>

83 Norman Lamb 26 Mar 2013, Hansard: Column 1101W: <http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130326/text/130326w0004.htm#13032680003417>

84 DH (2007) *Putting People First: A shared vision and commitment to the transformation of adult social care*: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_081119.pdf

85 A detailed description of this can be found in R (on the application of KM) (by his mother and litigation friend JM) (FC) (Appellant) v Cambridgeshire County Council (Respondent) [2012] UKSC 23: http://www.supremecourt.gov.uk/decided-cases/docs/UKSC_2011_0145_Judgment.pdf

86 ADASS (2009) *Common Resource Allocation Framework*: <http://www.adass.org.uk/images/stories/Common%20resource%20allocation%20framework%20final%202.pdf>

Budget is made by a panel of social care professionals at the local authority based on the information provided by the disabled person and the RAS calculation.

The evidence we received raised a number of concerns about the use of RAS. In their survey of 131 local authorities in England, Sue Ryder⁸⁷ found a lack of uniformity in the approach taken by local authorities to allocate resources and calculate care packages for individuals. Sue Brown highlighted the lack of transparency of the decision made by panels suggesting that disabled people are forced to:

“Go through a tick box RAS that gives then an indicative budget that turns out not to be enough. Then another budget gets sent to a panel who have never met the person before, who attempt to randomly chop 25 per cent off the budget in the hope that they can get away with it. Sometimes they do get away with it, and sometimes you then go through the very expensive process of legal challenge to that decision. None of that is helping anybody, and it is not helping the local authority budget.”

Jane Young in her written evidence cites the case of a woman from the Wirral who says of social care panels: ‘not only am I forbidden from knowing anything about the panel who make decisions, I am not allowed to make representation to them and neither is the advocate who’s been appointed to me.’ Jane Young suggests that there should be an ‘obligation of transparency’ and that ‘a representative or the individual themselves should be present and their opinion valued as the expert in their own lives’ and that the panel should have due regard to this in any decisions they make.

To date Personal Budgets have only been contained in policy, rather than having a legislative basis. Given the extent to which they are used in practice and the importance they hold in determining the value of care packages, we welcome the Government’s move to put them onto a statutory footing in Clause 25 of the Care and Support Bill.

Building on the recommendations of the Joint Committee, we believe that the duties in Clause 25 of the Bill should be strengthened to ensure local authorities are transparent about decisions relating to the allocation of resources. We also recommend that there be a requirement on local authorities to take into account the true cost of care and support when setting RAS rates, having due regard for the contribution of disabled people to determining the nature of their care and support.

Sue Ryder, in their report, and Jane Young in her oral evidence suggest that there be greater consistency across local authorities about the formulae they use to calculate the true value of care and support. We agree and hope that the Government will encourage ADASS and the Think Local, Act Personal partnership to update their guidance⁸⁸ on the RAS and in particular look towards standardising the formulas used to calculate the value of Personal Budgets.

Finally, we note that in the new health and social care system, Healthwatch England acts as the independent consumer champion for social care in England. Given significant consumer concern about the calculation of the value of the care package and the restriction this can place on disabled adults in purchasing adequate care, we recommend that **Healthwatch England undertake an investigation into RAS and user-led purchasing to identify if care consumers are able to meet the true cost of care, identify the extent to which**

people have to subsidise care packages and suggest ways of strengthening the implementation of the market-shaping provisions contained in the Care and Support Bill to promote consumer rights.

⁸⁷ Sue Ryder (2012) *The Forgotten Millions: Social care for people living with neurological conditions (a blueprint for reform)*: http://www.sueryder.org/About-us/Policies-and-campaigns/Our-campaigns/~/_media/Files/About-us/The%20Forgotten%20Millions%20-%20Nov%202012.ashx

⁸⁸ For the current guidance see: <http://www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets/Resourceallocationsystems>

Recommendations:

1. The Government must prioritise the design of a new framework of eligibility, actively engaging core stakeholders, and publish draft regulations relating to it before the Second Reading of the Care and Support Bill.
2. In establishing a national threshold for eligibility, the Government should commit to setting this at a lower level in the forthcoming Spending Review of 2013.
3. Regulations arising from the Care and Support Bill should contain transitional arrangements for councils who currently have set eligibility at the higher levels to ensure they can bring it down to a lower national threshold.
4. The Government should place Resource Allocation Systems (RAS) onto a statutory footing through the Care and Support Bill, supported by new duties on councils to be transparent about decisions relating to them and underpinned by a requirement on local authorities to take into account the true cost of care and support when setting RAS rates. This should have due regard for the contribution of disabled people to determining the nature of their care and support.
5. Healthwatch England should undertake an investigation into RAS and user-led purchasing to identify if care consumers are able to meet the true cost of care, identify the extent to which people have to subsidise care packages and suggest ways of strengthening the implementation of the market-shaping provisions contained in the Care and Support Bill.

Chapter 3:

The value of preventative care and support

Chapter summary:

- **Without access to social care, disabled adults' needs escalate, and many risk reaching crisis point. The impact of this on the everyday lives of disabled people can be devastating, leaving many at risk of social isolation.**
- **This escalation of need impacts financially on other bodies such as the health and criminal justice systems.**
- **Disabled people falling out of care often re-enter the system at a later stage and at a greater level of support need, leading to dependency on the care system.**
- **It is time for a new concept of preventative care to be developed that provides early and adequate support to disabled adults to ensure their needs do not unnecessarily escalate, and to make financial savings for local authorities.**
- **Health and social care bodies must be more closely integrated and pooled budgets utilised in order to provide a more effective route to promoting independence and preventing crisis.**
- **Health and Wellbeing Boards represent the appropriate vehicle through which Government can deliver effective preventative services.**

1. Escalating to crisis point

The Government's ambition for the reform of care and support is a system set up to support people to live independently, improve their wellbeing⁸⁹ and have their needs met early to avoid an unnecessary escalation of need. It rightly critiques the current system, noting that it 'only grinds into action in response to a crisis, rather than acting quickly to prevent one.'⁹⁰

The aspiration for a more preventative care system was written into the Department of Health's current Prioritising Need / Fair Access to Care Services (FACS)⁹¹ guidance. It states that early intervention and prevention are 'integral' to the implementation of the policy. However the written evidence we received from the Joseph Rowntree Foundation, Demos and others suggested that decades of chronic underfunding of social care has meant local authorities struggle to both meet increasing demand and invest in preventative support.

The evidence we received demonstrated that if disabled adults' needs are not met by the social care system they are left in crisis; frequently isolated and dependent on their friends and family for basic support. A report by Scope, Mencap, Sense, the National Autistic Society

89 In line with Clause on of the Care and Support Bill, also see Chapter 1 for our recommendations to strengthen this clause to promote independent living.

90 DH (2011) *Caring for our Future: Shared ambitions for care and support*: <https://www.gov.uk/government/publications/caring-for-our-future-shared-ambitions-for-care-and-support--2>

91 DH (2010) *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*: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113155.pdf which is based on, but supersedes DH (2003) *Fair access to care services – guidance on eligibility criteria for adult social care*: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_4009653

and Leonard Cheshire Disability⁹² draws on the experience of some of the 69,000 disabled adults who have already fallen out of the care system to predict that a further 36,000 disabled adults':

'Needs are likely to escalate without adequate and appropriate support. This will result in declining health, wellbeing and finances, and increasing cost to the state when they return to the system with a higher level of need and in crisis.'

Similarly John Lish suggested that without support, people's needs can:

"Develop into critical needs that place pressure on other services such as the NHS or the Police or other areas of local government. If local authorities just become fire-fighters for critical needs then societal costs will increase in other areas as [disabled people with lower levels of need] struggle to live independently without support. Other statutory requirements will be triggered as independence is lost."

2. Impact on other local services

Our evidence demonstrated that the current reduction or loss of care and support is having a profound effect on both disabled people's independence and their wellbeing. For example, a recent Scope survey⁹³ found that two in five disabled people are failing to have their basic needs met, with almost four out of ten unable to eat, wash, dress or get out of the house. This led, the survey claims, to nearly half withdrawing from community life and one third being unable to work or take part in volunteering or training activities after losing their care package.

This was reflected by the disabled people who submitted evidence and made it clear to the inquiry that they want to take an active part in society and contribute to the economy, but without the right support had withdrawn from community life, undermining the contributions they had been making.

The escalation of need within the social care system also places additional strain on other agencies, such as the local health services and the criminal justice system.

As the NHS Confederation substantiated in their written evidence to our inquiry:

'Given the massive financial challenge facing local authorities we are not surprised that many councils have had to cut some services and tighten eligibility criteria for social care. However, when people's needs are not met by the social care system, they turn to the NHS, which experiences the impact in the form of increased demand for emergency and unplanned work, and delays in discharging people from hospital.'

It is not only health services that are impacted when people drop out of the social care system. Sarah Lambert, of the National Autistic Society, told the inquiry that there was a whole range of 'low-intensity support' that could be put in place to: "prevent that group of people from developing further mental health problems, from being socially isolated and vulnerable to exploitation, and perhaps inadvertently entering the criminal justice system if they are vulnerable to exploitation." Sue Brown extended this, suggesting that the employment market and wider economy lost out on the contributions disabled people could make.

92 Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability (2013) *The Other Care Crisis*: <http://tiny.cc/qci8uw>

93 Scope survey of over 600 disabled adults aged between 18 and 64 cited in Scope, Mencap, the National Autistic Society, Sense, Leonard Cheshire Disability (2013) *The Other Care Crisis*: <http://tiny.cc/qci8uw>

3. Promoting dependence and creating crisis

In addition to the impact on other local services, our inquiry heard about the direct impact on the lives of disabled people. For example, Sarah Lambert told the inquiry that many people who are not eligible for social care are currently having their needs met in creative and low-cost ways, but are forced to “wait until their needs are higher and therefore more costly in order to move on.” She explained that this “does the individual and family no good and ultimately does not save the commissioner any money.” Relying on an escalation of need to re-enter the care system only increases disabled people’s dependency on the care system for support.

Mind, in their written evidence, raised a concern about the inequality that comes from a dependency driven system of care. They note that, ‘if people on low incomes only access care and support when their needs escalate [i.e. when their needs become eligible for support], then preventative services become the exclusive preserve of those who can afford to pay.’ They add that for those unable to access social care under the current eligibility threshold their ‘mental health condition may deteriorate, resulting in a crisis, requiring access to more costly health or social care interventions, and possibly use of compulsory powers of the Mental Health Act.’⁹⁴

We agree with our witnesses and submissions that suggested a dependency-driven approach to care was out of step with disabled people’s and the Government’s own aspirations for the care system. In this next section we consider what a preventative approach to care and support which promotes independence and reduces unnecessary escalation of need, should look like.

4. Focusing on prevention

Emerson, Hatton and Robertson,⁹⁵ in their review of social care for adults with learning disabilities, found that prevention is typically categorised into three levels:

- ‘Primary prevention which seeks to eliminate or reduce need by reducing the probability of it initially occurring.
- Secondary prevention which seeks to eliminate or reduce need by intervening in the early stages of the development of the need in order to reduce the probability of it escalating.
- Tertiary prevention which seeks to eliminate or reduce need by providing effective support to people who already experience such a need to prevent further disability or disadvantage and, as far as possible, to restore functioning.’

Our evidence suggests that this categorisation for prevention is not easily transferable to all disabled adults as it focuses on the prevention at the onset of an impairment and the ‘restoration of functioning.’ In line with our previous observations on the importance of independent living to disabled people’s lives (see Chapter 1), we believe the focus of prevention must be on providing early and adequate support to disabled adults to ensure their needs do not unnecessarily escalate, they can pursue independent living and improve their wellbeing.⁹⁶

94 Mental Health Act [2007]: <http://www.legislation.gov.uk/ukpga/2007/12/contents>

95 Emerson, E., Hatton, C and Robertson, J. (2011) *Prevention and Social Care for Adults with Learning Disabilities*: <http://eprints.lse.ac.uk/41200>

96 See also Windle, K., Francis, J. and Coomber, C. (2011) *Preventing Loneliness and Social Isolation: interventions and outcomes*: http://www.scie.org.uk/publications/briefings/briefing39/index.asp?dm_i=4O5,KIDG,T16AG,1NZNX,1

This sentiment was reflected in evidence we received from the Joseph Rowntree Foundation, Demos, Mind and RNIB. The British Red Cross argued that it was time for preventative care to be thought of differently. They suggested that ‘there must be a dramatic rethink to the way social care is organised in the future, with a focus on preventing crises before they occur and keeping people healthy and independent for as long as possible.’ Similarly, the president of ADASS, Sarah Pickup, reflected in her oral evidence:

“I do think you have to think about prevention in quite a different way. If you can move people to an environment where they are living somewhere they like living, doing things they like doing supported by people that they like, then you can actually prevent that escalation of needs, you can prevent the need for an independent hospital placement, and you can help people, again, to have better outcomes at lower cost. Prevention is one of the very few things where you can get both a better outcome and a reduced cost.”

Nottinghamshire County Council suggested that preventative services should target people ‘at risk of losing their independence’, rather than relying on a general universal offer to capture these needs. We received a number of examples illustrating the positive impact that prevention and the promotion of independence can have on disabled adults.

The British Red Cross told the inquiry that the evidence base on prevention is not as weak as is commonly supposed. Citing research⁹⁷ with Deloitte, they noted that preventative services achieved savings of £1.50 for every £1 invested. In addition, support at home services currently achieve savings of £8m for local authority and NHS commissioners through avoided acute costs. Giving a specific example, the British Red Cross highlighted:

‘The Camden Reablement scheme which British Red Cross were involved in provided £77,000 of total expected savings over a twelve month period, including savings to social care. This represents £246 per user. In addition to the financial benefits, 74 per cent of users rated the service as ‘excellent’ and 11 per cent rated it as ‘good’.

Cllr Lynn Travis agreed in her oral evidence, suggesting that there were benefits for both communities and public expenditure. She told us that:

“It is not about savings; it is about making sure that the right kind of care is targeted at the right people at the right time...For every pound spent in local government, the fruit falling in other gardens such as the NHS saves upwards of £1.40 in healthcare needs. So there’s a benefit in financial terms, but the real benefit is in community terms.”

Sarah Lambert, during her oral evidence, told us about the impact of local autism teams in Liverpool and Bristol:

“They are supported and funded by both health and social care. Most local authorities do not know how many people there are with autism in their area. What the teams do very well is to identify people with autism and Asperger Syndrome and then look at developing and supporting them, providing them with a lot of low-level types of support.”

97 Deloitte (2012) *The Economic Impact of Care in the Home Services: A report commissioned by the British Red Cross*: [http://www.redcross.org.uk/About-us/~media/BritishRedCross/Documents/What%20we%20do/UK%20services/Final%20report%20to%20BRC_with_marque_NO_APDIX%20\(1\).pdf](http://www.redcross.org.uk/About-us/~media/BritishRedCross/Documents/What%20we%20do/UK%20services/Final%20report%20to%20BRC_with_marque_NO_APDIX%20(1).pdf)

Sarah continued that the teams are not only effective in offering more specialised support, but are also cost-effective, citing research from the National Audit Office.⁹⁸ This research suggests that if local services identified and supported just four per cent of adults with high-functioning autism or Asperger Syndrome, the outlay would become cost neutral over time, and that if they identified eight per cent of adults in their local population then the Government could save £67 million a year.

Mind pointed to the Sunlight Development Trust in their written evidence. This social enterprise has seen the transformation of a local building to meet the needs of the community as opposed to providing prescribed services to segregated groups. The Trust⁹⁹ offers 'a range of services, including health, legal and debt advice, education, employment support and a café,' many of which are run by service users. Mind emphasised that low-level services such as Sunlight provided important support and cost savings:

'Sunlight is an excellent example of providing integrated social inclusion services focused on prevention. It also demonstrates the benefits of designing services based on a global cost-benefit analysis, as many of the people who use and work at Sunlight no longer need to access costly social care services from Medway Council, because their support comes from their employer, colleagues or other service users... Services aimed at people with lower level needs will make savings for the NHS, and for the state as a whole.'

In their evidence, VODG cited Sue Ryder's successful '5Rs' programme:

'Sue Ryder's 5Rs programme is a person centred 10 week programme designed to give practical help and assistance to meet the specific needs of people with MS. The programme includes therapeutic activities, educational classes and access to clinical specialists such as an MS nurse who is available to give advice and answer questions about individuals' conditions. The service aims to promote independence, choice and build participants' confidence. This valuable preventative service is recognised as best practice by the Department of Health, but does not receive statutory funding as most of the people attending fall below the eligibility criteria. The service is currently funded by the Big Lottery.'

We note that the Government is attempting to address the need for prevention in Clause 7 of the Care and Support Bill, which places a duty on local authorities to take steps to prevent, delay or reduce adults' needs for care and support.

We support the conclusions of the Joint Committee on the draft Care and Support Bill that Clause 7 should be extended to include those who do not yet have needs and may be at risk of developing such needs, or those for whom prevention of deterioration might delay an increase in their needs. However, we would urge the Government to go further to ensure that the provisions on prevention reflect the need to promote independence and prevent crises.

However, we note warnings from our submissions that investment in prevention is needed to ensure it promotes independent living.

The British Red Cross told us that preventative care had been 'historically underfunded by a

98 NAO (2009) *Supporting people with autism through adulthood: Model to assess the financial impacts of providing multi-disciplinary support services for adults with high-functioning autism/Asperger syndrome*: http://www.nao.org.uk/wp-content/uploads/2009/06/Autism_Tech_Paper.pdf

99 The Sunlight Development Trust, <http://www.sunlighttrust.org.uk/>

system which treats people only when they have already reached crisis point' and suggests that this approach is a 'false economy'. Similarly, Carers UK told us that 'underfunding of social care has led local authorities to disinvest[ing] in preventative services in order to fulfil duties to provide services to growing numbers of disabled and older people with higher-level needs.' Demos added that: 'creative solutions to independent living require vision and a commitment to the social model of disability which can be a big ask when commissioners face a daily battle to balance their books providing even the most basic of services.'

5. Closer working between health and social care

We welcome the commitment contained in the Coalition Agreement to 'break down barriers between health and social care funding to incentivise preventative action,'¹⁰⁰ and note that the provisions in the Health and Social Care Act and the Care And Support Bill aim to support this ambition.

We found a significant appetite in the evidence we received from SCIE, ADASS, VODG, local authorities and disabled people, for a closer relationship between health and social care commissioning and delivery. As the NHS Confederation told us in their written evidence:

'There is widespread consensus that we need to make better use of resources and improve people's experiences by ensuring greater integration between health and social care. For sustainable, effective change, we must implement whole-system solutions across health and social care services.'

Building upon this, our evidence suggested pooled budgets between local authorities and health provided an effective route to promoting independence and preventing crisis. The RNIB suggested that 'joint commissioning and pooled budgeting should be the norm,' and that social care should be moving away from 'episodic disconnected care'. Sarah Pickup told the inquiry that:

"If you pool budgets then you can actually make flexible use of resources...In order to get the independent sector to build a new facility in Hertfordshire which replaced a hospital but which was on local authority land, we agreed to fund the intermediate care beds if health funded the therapy. But it is a pooled budget, and technically that is health spend. But at the end of the day we all got a better deal, as did the citizens, as a result of working together."

Similarly, Sarah Lambert told the inquiry that pooled budgets offered the best option when matching up the competing incentives of health and social care:

"You have got various different outcomes and frameworks that the health service has to deliver, and social care has to deliver. But if they do not match then they are going to be going in different directions. How we can join that up is a key issue."

Additionally, Sarah Pickup described the work of Torbay council, where health money is being spent on social care:

"Torbay is much quoted but the outcome there is that they are spending health money on social care, because by spending more money on social care they have been able to prevent hospital admissions."

In 2005, Torbay established a joint care trust to promote the integration of health and social care in the local areas. The care trust pooled the budget from health and social care, and was

100 HM Government (2013) *The Coalition: Our programme for Government*: http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/documents/digitalasset/dg_187876.pdf

run by a new post, which had the joint responsibility for adult social services and primary care. This pooling of budgets helped to facilitate the development of a wider range of intermediate care services including; the appointment of health and social care co-ordinators and joint working with general practices to capture need for community support early.¹⁰¹ The care trust resulted in evidenced benefits to both the social care and health system. There were significant reductions in the number of delayed transfers of care from acute hospitals to the community and the rating of social care services improved.¹⁰²

Although the example of Torbay focuses on older people, we feel it illustrates the impact of having a receptive culture to collaborative funding and strategic planning. Building on this, Sarah Pickup told the inquiry:

“The assumption that we are all working on – and the evidence so far suggests it is correct – is that we will have to spend more on social care. But the health service is recognising that and saying, ‘We recognise that if the impact of this is that we have to spend more on social care, we will pay, because it is worth our while spending that to prevent the acute beds.’”¹⁰³

6. Placing responsibility onto health and wellbeing boards

Drawing on the evidence we received from the British Red Cross, Sarah Pickup and others, we agree that the new Health and Wellbeing Boards could play an active part in ensuring disabled people can access preventative care and support.

Through the introduction of the Health and Social Care Act of 2012, the Government has strengthened the role that local government can play in shaping local health services.¹⁰⁴ Health and Wellbeing Boards are the Government’s primary vehicle for achieving this. The intention is that these boards will bring together the health commissioning of the new Clinical Commissioning Groups (CCGs) and the social care commissioning of local authorities to develop a shared understanding and prioritising of the health and wellbeing needs of the community. The boards have been operating in a shadow capacity since April 2012, but came into force in April 2013.

The boards have a strategic influence over commissioning decisions across health, public health and social care as their membership contains all decision makers with the power to commission both local health or care services. The board has a duty¹⁰⁵ to carry out a Joint Strategic Needs Assessment to inform the design of a Health and Wellbeing Strategy, within which all the commissioning plans are developed for health services, social care and public health. One of the responsibilities of the boards is to promote greater integration and partnerships across health and care, including joint commissioning, integrated provision and pooled budgets where appropriate.

101 For an overview of Torbay see the excellent report by The Kings Fund: Thistlethwaite, P. (2011) *Integrating Health and Social Care in Torbay: Improving care for Mrs Smith*: <http://www.kingsfund.org.uk/sites/files/kf/integrating-health-social-care-torbay-case-study-kings-fund-march-2011.pdf>

102 For further details see: Ham, C. and Smith, J. (2010) *Removing the policy barriers to integrated care in England*: http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/Removing_the_Policy_Barriers_Integrated_Care.pdf

103 Ibid.

104 For more information about the Government’s policy intentions see DH (2010) *Equity and Excellence: Liberating the NHS*: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/135875/dh_117794.pdf.pdf

105 DH (2013) *Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies*: <https://s3-eu-west-1.amazonaws.com/media.dh.gov.uk/network/18/files/2013/03/Statutory-Guidance-on-Joint-Strategic-Needs-Assessments-and-Joint-Health-and-Wellbeing-Strategies-March-20131.pdf>

Initial work by The Kings Fund¹⁰⁶ suggests optimism about the role of Health and Wellbeing Boards, with the members of the Shadow board thinking they will improve integration and increased pooling of budgets and joint commissioning.

Having reviewed a sample of Health and Wellbeing Strategies, the members of the inquiry are conscious that the Health and Wellbeing Boards will be focused on addressing priorities in public health and acute health. We would be concerned if the promotion of independence and prevention of care did not appear in these strategies and recommend that the Care and Support Bill be used as an opportunity to specify a priority focus for the Health and Wellbeing Boards.

Through the Care and Support Bill, we recommend that Health and Wellbeing Boards be given a duty to identify, plan for and commission preventative services that maximise the independence of disabled people.

7. Piloting a ‘whole-budget’ approach

In her oral evidence, Liz Sayce brought our attention to the Government’s ‘Right to Control Trailblazer’ programme.¹⁰⁷ This programme has been investigating the ways in which different funding sources could be brought together to maximise resources and enable disabled adults to be in control of the support they receive. The six funding streams included are the Access to Work fund,¹⁰⁸ Work Choice,¹⁰⁹ local adult social care, the Disabled Facilities Grant,¹¹⁰ the Supporting People¹¹¹ funds and the aforementioned Independent Living Fund. The Trailblazers are operating in six areas.¹¹²

We note that the independent evaluation report, due to be published in spring 2013, will inform future decisions about the Right to Control. We would not seek to make conclusions about this programme before the evaluation report is available, however we do acknowledge the importance of the policy intention behind the programme. As we have said previously, we agree with the need to address the lack of integration across local agencies and funding sources. Disabled people who gave evidence to this inquiry reminded us that their lives were not segmented in funding streams and that reform needs to recognise this.

Given the evidence we received and the aspiration for disabled people to be in full control of their care and support, we suggest that the Government explores extending the pilots to reflect the new policy context disabled people are navigating. In doing this we also suggest any future piloting incorporates funding streams available for welfare benefits, employment support and housing.

106 Kings Fund (2012) *Health and wellbeing boards: System leaders or talking shops?*: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/health-and-wellbeing-boards-the-kings-fund-april-12.pdf

107 ODI (2009) *Making Choice and Control a Reality for Disabled People: Consultation on the Right to Control*: <http://odi.dwp.gov.uk/docs/wor/rtrc/rtrc-consult-standard.pdf> ODI / DWP (2010) *Making Choice and Control a Reality for Disabled People: Government response to consultation on the Right to Control Trailblazers regulations*: <http://odi.dwp.gov.uk/docs/wor/rtrc/rtrc-reg-response.pdf>

108 For more information see: <https://www.gov.uk/access-to-work/overview>

109 For more information see: <https://www.gov.uk/work-choice/overview>

110 For more information see: <https://www.gov.uk/disabled-facilities-grants/overview>

111 For more information see: http://webarchive.nationalarchives.gov.uk/+www.direct.gov.uk/en/disabledpeople/homeandhousingoptions/supportedhousingoptions/dg_4000297

112 DWP (2013) *The Disabled People’s Right to Control (Pilot Scheme) (England) (Amendment) Regulations 2012*: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/183961/response-right-to-control.pdf

The Care and Support Bill should extend to the Right to Control regulations to pilot joint assessments and pooled budgets across health, social care, benefits, housing and employment support that can be directed by disabled people.

Recommendations:

1. Government should extend the definition of prevention in the Care and Support Bill to ensure the promotion of independent living and include duties to identify and support 'unmet need' and 'potential unmet need'.
2. Health and Wellbeing Boards should be given, through the Care and Support Bill, a duty to identify, plan for and commission preventative services that maximise the independence of disabled people.
3. The Care and Support Bill should extend to the Right to Control regulations to pilot joint assessments and pooled budgets across health, social care, benefits, housing and employment support that can be directed by disabled people.

Chapter 4:

Paying for care and relevance of the Dilnot funding proposals to disabled adults

Chapter summary:

- The Dilnot Commission suggestions will cap care costs and help to protect assets for older age people, but these reforms will not positively benefit working age disabled people.
- The majority of working age disabled people will not have had the chance to acquire assets, and many have faced the competing financial pressure of dealing with other care costs.
- The age at which an individual starts contributing to the cost of their social care has yet to be properly evidenced, and will be a key factor in determining the true value of the Dilnot proposals.
- The Government's 2010 Spending Review explicitly recognised the need for additional investment into social care services and re-allocated £2 billion a year of additional funding by 2014-15 to support social care from the NHS budget. However, this money did not reach frontline care services and the approach is not financially sustainable in the long-term.
- Health and Wellbeing Boards could offer a practical and more sustainable approach to funding social care in the future. Through the Health and Wellbeing Boards, we believe the Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.

1. Sharing the cost of care and protecting assets

The Government rightly recognised the difficulties that many older people faced in meeting the unpredictable and substantial costs of care in later life and set up the Commission on Funding of Care and Support, chaired by Andrew Dilnot. The Commission was tasked with reviewing the funding arrangements for social care and support in England. Its final report in 2011 suggests that:¹¹³

'The current funding system is in urgent need of reform: it is hard to understand, often unfair and unsustainable. People are left exposed to potentially catastrophic care costs with no way to protect themselves.'

The Commission recommended the introduction of a cap on an individual's lifetime contributions towards the cost of their care, to be set at £35,000; and an increase in the means-tested threshold above which people are liable for the full cost of care from £23,250 to £100,000.

¹¹³ Dilnot Commission (2011) *Fairer Care Funding: The report of the commission on funding of care and support*: <https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf>

The Government formally responded¹¹⁴ to the Commission's proposals in July 2012 and in the Budget 2013 the Chancellor announced¹¹⁵ a cap on care costs of £72,000 and a higher means-tested threshold of £118,000 to be implemented in 2016.

Echoing the evidence submitted to our inquiry, we welcome the introduction of a cap on care costs and the extension of the means testing threshold as it will contribute towards a fairer care system, however recognise that for working age disabled people the impact will not be as significant as for older people. Carers UK told us that 'the largest direct benefits of the Government's proposals on social care funding made in response to the Dilnot Commission's recommendations will be for older people who accrue high care residential care costs.'

Agreeing with this analysis, many of our witnesses described the cap on care costs as focusing on protecting the assets of older people and noted that disabled adults did not have the same opportunity to accumulate assets. The Dilnot Commission itself recognised this, recommending that disabled people who enter adulthood with an eligible need (or acquire one before the age of 40) should be considered to have met the cap as they will have not had an opportunity to reasonably plan or build the assets to contribute towards their care.

In response to a question about whether the cap on care costs would benefit working age disabled adults, Jonathan Carr-West told us that:

"The short answer to your question is 'little or not at all'. Dilnot had a mind to help people of working age, but I do not think that the cap was designed primarily to benefit them... disabled people of working age will not have had a chance to build up significant assets. Therefore an asset protection cap is of little value to them."

Similarly, the Joseph Rowntree Foundation, in their written evidence, suggested:

"The prospect of free care for those disabled in childhood or early life, combined with a taper regarding contributions from middle age, seems to JRF to be a promising dual funding model delivering inter-generational fairness, recognising that older people have more time to accumulate assets while many working age disabled people will have fewer opportunities to save for their care or pay for this through their incomes."

Sense agreed, adding that for working age disabled people, asset protection was 'not the most important issue'. VODG stated that working age disabled people with savings and assets were 'in a minority'. Furthermore, Mencap gave statistics to indicate that only 7% of people with a learning disability known to social services are in any form of paid employment: 'it is therefore rare for a person with a learning disability to have the assets and savings the cap will protect.'

Indeed Demos felt that the difference between the assets of older and working age disabled people was so significant that they proposed a 'dual funding system which recognises that disabled people have far fewer opportunities to accumulate assets and pay for their own care, compared to older people who have had a life in work to prepare for their care needs in later life.'

2. Applying a cap on care costs to disabled adults

In his Commission's recommendation for a cap on care costs as explained above, Professor Dilnot proposed that a 'taper' be introduced for working age disabled adults who acquire an

impairment during their working lives (above the age of 40 years). This was to acknowledge that these individuals could reasonably be expected to have acquired some savings or assets and could pay an incremental amount towards the full cap that applies to older people.

The Government has not yet confirmed the details of how such a 'taper' will work, nor the age at which it would commence, but we are told by witnesses that the Department of Health intends to launch a consultation in the summer of 2013. The Dilnot Commission suggested this should begin at 40, but didn't make explicit reference to any clinical or financial modelling to support this recommendation.

The evidence that we received expressed the need for further research to better ascertain the age at which care contributions should begin for adults who acquire a disability in their adult life. This was matched with concern about the details of the taper and the fact that the level and indexation it would be set at had yet to be fully established.

The Joseph Rowntree Foundation told us:

'The age at which someone is expected to start contributing and the amount they are expected to contribute will be central to the fairness of this model. We must bear in mind that if someone acquires an impairment in their twenties or thirties, or even forties, then the extent to which they will have been able to build up sufficient assets is questionable and will be highly variable.'

In their written evidence Demos also stated that:

'The entire plan will stand or fall on the detail – the rate of the taper for those disabled in middle age, and the levels of means and needs testing which will dictate how many people are eligible for free or subsidised social care.'

Nottinghamshire County Council agreed, stating that 'the determination of funding support for people based on age alone appears to be quite a basic tool which does not reflect levels of individual need or the ability of any individual to fund their care based on their income or asset base.'

In addition to concerns about how the detail of the 'cap' proposal would work for working age disabled people, we received evidence that detailed the significant impact that acquiring an impairment can have on the income, savings and job prospects of that individual.

A report¹¹⁶ from Scope, Mencap, the National Autistic Society, Sense and Leonard Cheshire Disability cited forthcoming Ipsos Mori research that shows that 85 per cent of working age disabled people have not saved any money in the last 12 months because of the extra costs they face, in turn placing strain on their resources. As a result of disabled people having fewer assets to protect, we believe the tapered amounts would have to be substantially lower than those currently being suggested for older people.

Evidence that we received also pointed out that the cap would also only apply to those individuals who were deemed eligible for social care support under the new national eligibility threshold. This would see those with care needs that were not above this threshold also ineligible for the cap and the amount they pay for their care and support would not contribute towards a cap on their care costs. The Joseph Rowntree Foundation told the inquiry that 'a funding regime promising free or highly subsidised care that is combined with a very high eligibility threshold will do little to improve the current situation.'

114 HM Government (2012) *Caring for our future: Progress report on funding reform*: <https://www.gov.uk/government/publications/government-publishes-progress-report-on-social-care-funding-reform>

115 HM Treasury (2013) *Budget 2013*: http://www.hm-treasury.gov.uk/budget2013_documents.htm

116 Scope, Mencap, National Autistic Society, Sense, Leonard Cheshire Disability (2013) *The Other Care Crisis*: <http://tiny.cc/qci8uw>

And John Lish, an individual with Asperger Syndrome, told us:

‘For those who haven’t qualified for social care support due to their not meeting the high bar set by the eligibility criteria, they have to bear the additional costs resulting from their disabilities throughout their working life.’

Carers UK agreed, adding ‘crucial to both working age disabled people and older people will be the level at which care needs are considered to be eligible for support whether paid for by the local authority, or by the individual.’ They went on to advise that the ‘the Government should set out more generous financial thresholds for care in the community and proposals on a lower care costs cap.’

To ensure disabled adults who acquire impairments later in the working life are not unduly disadvantaged by funding reforms, the Government must publish and consult on an evidenced rationale for the age at which care contributions should begin, and the level of the taper it will apply.

3. Sustainable funding for care and support

With the cap on care costs not being seen to improve the social care system for working age disabled people, our inquiry received evidence that drew attention to the significant funding gap in social care services for working age disabled people and argued that this was a priority area for investment.

Evidence carried out by the Personal Social Services Research Unit (PSSRU)¹¹⁷ calculated that social care for working age disabled adults is underfunded by at least £1.2 billion. At the same time, the number of disabled adults needing care and support is rising. We recognise that this is a significant challenge for local authorities as they face further budget pressures. The Joseph Rowntree Foundation suggested that:

‘There remains a serious problem of underfunding of the care system which leaves large numbers of working age disabled and older people without the support they need to live independently. It is vital to bear in mind that the Dilnot model was designed to answer a specific set of questions, and did not tackle the wider question of how to divert more resources into the social care system.’

The Government’s 2010 Spending Review¹¹⁸ explicitly recognised the need for additional investment into social care services and re-allocated £2 billion a year of additional funding by 2014-15 to support social care from the NHS budget. However, the evidence we received has raised concerns that this money did not reach frontline care services. As the NHS Confederation highlighted to us:

‘While the NHS Confederation has previously supported the transfer of some NHS funding to social care, in many areas this has been used to paper over the cracks in the social care system rather than supporting reablement...Research from the NHS Confederation found 18% of the funds transferred from the NHS to social care were used to maintain the current level of care provision, rather than to improve care in ways which help prevent the need for more intensive support.’

Despite this, there was a significant appetite from our witnesses for transferring money from health to social care budgets and that it must continue in order to make efficiency savings in

the long-term. Jonathan Carr-West told us that the Government should:

“Take money out of the NHS, put it in social care and give it to local authorities to spend sensibly and preventatively on keeping people out of acute need. That is where you make the saving... It is about taking the money that we are spending badly and spending it somewhere else, where it will be more effective. We talk about prevention as a way of saving money, but it is really important to remember that it is also better for people.”

VODG agreed, suggesting in their evidence that the Government should consider increasing the transfer of NHS budgets to social care to address the funding gap.

We agree with the concerns that continually transferring money from the NHS to local authorities cannot guarantee money will be spent on frontline social care and support. We further acknowledge that in the current climate of localism, proposing a ring fencing of this money would not gain political traction with either national or local government.

To avoid what the British Red Cross describe as ‘robbing Peter to pay Paul’, we build on our recommendations in Chapter 3 to suggest that Health and Wellbeing Boards could offer a practical and more sustainable approach to funding social care in the future. Through the Health and Wellbeing Boards, we believe **the Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.**

Reflecting this, the British Red Cross suggested that:

‘The prevention budget is allocated, in either indicatively or later in real budgets, to Health and Wellbeing Boards. The Boards have been presented as a transformational reform capable of delivering the integration of services and a shift to prevention across different budget silos. However they are currently regarded as relatively weak players as they have soft powers and no budget. Providing protected prevention budgets would shift the power relations...’

The NHS Confederation supported the idea of a more co-ordinated national approach to policy development between health and social care in any legislative reform, noting that ‘it is particularly important that new policies focus on enabling the NHS and local authorities to work together to use scarce resources effectively and coordinate care.’

Looking towards the forthcoming Spending Review in June, we agree with the evidence to our inquiry that suggests this Government and successive Governments need to invest in adult social care to ensure the ambitions of reform can be achieved.

On this basis we suggest that in the short term, **up to £2bn of NHS money should be made available for councils and the NHS to spend on care and support that promotes independence and prevents crisis, through Health and Wellbeing Boards at the Spending Review in June 2013.**

117 Personal Social Services Research Unit (2013) *Implications of setting eligibility criteria for adult social care at moderate needs level*: www.pssru.ac.uk/archive/pdf/dp2851.pdf

118 HM Treasury (2010) *Spending Review 2010*: http://www.hmtreasury.gov.uk/spend_sr2010_documents.htm

Recommendations:

1. **The Government must publish and consult on an evidenced rationale for the age at which care contributions should begin, and the level of the taper, for adults who acquire a disability in their adult life.**
2. **The Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.**
3. **Up to £2bn of NHS money should be made available for councils and the NHS to spend on preventative care, through Health and Wellbeing Boards at the Spending Review in June 2013.**

Full list of recommendations

1. In its statutory guidance of the Care and Support Bill, the Department of Health must practically describe the balancing of an individual's and carer's interests to make it explicitly clear that the needs of carers should not be used to obstruct disabled people's active participation in society.
2. The Government should extend the wellbeing principle in the Care and Support Bill to include a right to independent living (as described in articles 19, 20 and 21 of the CRPD).
3. The Government should acknowledge disabled people's concerns about the closure of the Independent Living Fund and work more closely with them to manage the closure for the 20,000 affected.
4. The Office for Disability Issues, as part of the implementation of the disability strategy, should urgently review (alongside TLAP) best practice in supporting disabled people, families, councils and providers to pursue independent living and ensure this is shared.
5. The Government should amend the duties under Clause 31 of the Care and Support Bill so that portability is based on a disabled person's 'firm intention' to move and that the receiving authority must have regard to the assessment and package given by the leaving authority to ensure the outcomes of support as 'equivalent' (or 'enhanced').
6. The Government must prioritise the design of a new framework of eligibility, actively engaging core stakeholders, and publish draft regulations relating to it before the Second Reading of the Care and Support Bill.
7. In establishing a national threshold for eligibility, the Government should commit to setting this at a lower level in the forthcoming Spending Review of 2013.
8. Regulations arising from the Care and Support Bill should contain transitional arrangements for councils who currently have set eligibility at the higher levels to ensure they can bring it down to a lower national threshold.
9. The Government should place Resource Allocation Systems (RAS) onto a statutory footing through the Care and Support Bill, supported by new duties on councils to be transparent about decisions relating to them and underpinned by a requirement on local authorities to take into account the true cost of care and support when setting RAS rates. This should have due regard for the contribution of disabled people to determining the nature of their care and support.
10. Healthwatch England should undertake an investigation into RAS and user-led purchasing to identify if care consumers are able to meet the true cost of care, identify the extent to which people have to subsidise care packages and suggest ways of strengthening the implementation of the market-shaping provisions contained in the Care and Support Bill.
11. Government should extend the definition of prevention in the Care and Support Bill to ensure the promotion of independent living and include duties to identify and support 'unmet need' and 'potential unmet need'.
12. Health and Wellbeing Boards should be given, through the Care and Support Bill, a duty to identify, plan for and commission preventative services that maximise the independence of disabled people.
13. The Care and Support Bill should extend to the Right to Control regulations to pilot joint assessments and pooled budgets across health, social care, benefits, housing and employment support that can be directed by disabled people.
14. The Government must publish and consult on an evidenced rationale for the age at which care contributions should begin, and the level of the taper, for adults who acquire a disability in their adult life.
15. The Government should encourage councils and the NHS to jointly invest in care and support that promotes independence and prevents crisis.
16. Up to £2bn of NHS money should be made available for councils and the NHS to spend on preventative care, through Health and Wellbeing Boards at the Spending Review in June 2013.

Oral witnesses

Wednesday March 13th 2013

Session 1: The right to independent living

Julie J. Charles - *Chief Executive Director and National Ambassadors Lead, Equalities National Council*

Liz Sayce - *Chief Executive, Disability Rights UK*

Jane Young - *Disability Consultant*

Session 2: The impact of changes to eligibility

Dr. Marc Bush - *Head of Policy and Research, Scope*

Richard Humphries - *Senior Fellow, The King's Fund*

Andrea Sutcliffe - *CEO, Social Care Institute for Excellence*

Tuesday March 19th 2013

Session 3: The value of preventative care

Sarah Lambert - *Head of Policy, National Autistic Society*

Sarah Pickup - *President, Association of Directors of Adult Social Services*

Cllr Lynn Travis - *Local Government Association*

Session 4: The Dilnot proposals and their implications on working age disabled people

Sue Brown - *Head of Policy, Sense*

Jonathan Carr-West - *CEO, Local Government Information Unit*

Dr. José-Luis Fernandez - *Principal Research Fellow Personal, Social Services Research Unit, London School of Economics (LSE)*

Written evidence submissions

British Red Cross

Carers UK

Demos

Disability Cornwall

Disability Rights UK

Housing & Support Alliance

Inclusion London

Independent Living Association

Jane Young

Jon Lish

Joseph Rowntree Foundation

Laing and Buisson

Linkage Community Trust

Mencap

Merseyside Disability Federation

Mind

Natasha Muirhead

Neil Crowther

NHS Confederation

Nottinghamshire County Council

Oxfordshire County Council

Roxanne Homayoun

RNIB

SCIE

Scope

Sense

Tabitha Collingbourne

Turning Point

VODG

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