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House of Commons
Joint Committee on the Draft Care and Support Bill

Draft Care and Support Bill

Report

Session 2012–13

Report, together with formal minutes

Ordered by the House of Lords and House of Commons to be printed 6 March 2013
The Joint Committee on the Draft Care and Support Bill

The Joint Committee on the Draft Care and Support Bill was appointed by the House of Commons on 19 November 2012 and by the House of Lords on 22 November 2012 to examine the Draft Care and Support Bill and to report to both Houses by 7 March 2013.

Membership

HOUSE OF LORDS
Baroness Eaton (Conservative)
Baroness Greengross (Crossbench)
Baroness Jolly (Liberal Democrat)
Rt Hon Lord Mackay of Clashfern (Conservative)
Baroness Pitkeathley (Labour)
Rt Hon Lord Warner (Labour)

HOUSE OF COMMONS
Harriett Baldwin (Conservative)
Rt Hon Paul Burstow (Chair) (Liberal Democrat)
Margot James (Conservative)
Barbara Keeley (Labour)
Grahame Morris (Labour)
Dr Sarah Wollaston (Conservative)

Powers

The Committee had the power to require the submission of written evidence and documents, to examine witnesses, to meet at any time (except when Parliament is prorogued or dissolved), to adjourn from place to place, to appoint specialist advisers, and to make Reports to both Houses. The Lords Committee had power to agree with the Commons in the appointment of a Chairman.

Publications

The Report of the Committee was published by The Stationery Office by Order of both Houses. All publications of the Committee (including press notices) are on the Internet at http://www.parliament.uk/business/committees/committees-a-z/joint-select/draft-care-and-support-bill/contact-us/

Committee staff

The staff of the Committee are Michael Collon (Lords Clerk), Philip Aylett (Commons Clerk), Judith Goodall (Inquiry Manager) Tansy Hutchinson (Policy Analyst), Arianna Kelly (Policy Analyst), Michelle Edney (Senior Committee Assistant) and Rob Dinsdale (Committee Assistant).

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Summary

The draft Bill represents a major reform of the legal framework governing the provision of adult care and support in England. It goes further than just a consolidation by establishing in law, for the first time, that well-being is the guiding principle of decision-making in care and support. It significantly extends the rights of adult carers, and it places greater emphasis on prevention.

Less than a month before this report was agreed, the Government announced that the main recommendations of the Dilnot Commission’s report *Fairer Care Funding* would be implemented through amendments and additions to this draft Bill. They will come too late for us to be able to consider them. The likely implications of this announcement are discussed in Chapter 2 of this report.

The draft Bill has been widely welcomed. That does not mean that it cannot be improved. There are gaps, risks of unintended consequences and further opportunities to realise the Government’s White Paper vision.

Key among these is the need for the Government to work with interested parties to launch a campaign that raises awareness of what the national care and support offer is, how people can plan and prepare for their care needs, and what their rights to care and support are. The scope and limitations of care and support are very poorly understood, and it is clear that without such a national campaign the benefits of reform and of any capped cost system will be significantly diminished. We are concerned that the Government have not yet fully assessed the scale of the change the Bill will bring about.

The eligibility criteria will determine who obtains state funded care and support. Currently, every local authority operates its own interpretation of Government guidance on assessing what constitute eligible needs. To implement Dilnot, the Government intend for the first time to set a national minimum eligibility threshold. We heard evidence that for disabled working-age adults the restrictions placed on eligibility can make a huge difference to their quality of life and their independence. We recommend that, just as local authorities are bound by the Bill’s well-being principle when they make decisions, the Secretary of State should be bound to take this guiding principle into account when designing and setting a national eligibility threshold.

Care and support are not free; there has always been means testing and charging. It is therefore not surprising that the boundary marking the divide between free NHS services and means-tested care and support is contested. The draft Bill offers new language to describe this boundary. We believe the altered wording shifts the boundary, and may result in more people in residential care falling into the means tested system. This is a serious drafting issue that must be put right.

The introduction of a capped cost system will lead to a large influx of people with needs into the local authority assessment system. This will provide an opportunity for offering information, advice and assistance that can prevent and postpone the onset of greater care needs. The advice made available to those navigating their way through the system should include advice on housing options and on personal finances.
Evidence heard by the Committee has highlighted the crucial role that housing can play in relation to an individual’s well-being, leading to effective and successful hospital discharge arrangements, and safeguarding from abuse and neglect. We make recommendations to improve both the impact and the reach of the reform by recognising housing as a key partner of adult care and support.

A consistent message from our witnesses was that the key to successful integration is the relationships between different organisations, and their cultures. However, the rules should be made less onerous to make it easier for local authorities and the NHS to pool budgets and to commission together. We also believe that the draft Bill should be amended to allow the Secretary of State to mandate joint budgets and joint commissioning in certain circumstances.

The draft Bill marks a welcome extension of the rights of adult carers. However, the consequence is that young carers are left with their rights defined in “rump legislation” that sets a higher threshold for recognition and support. This is a serious omission which the Government must address.

While the draft Bill gives local authorities a new role in “market shaping” it does not directly address how services are commissioned. The Government in their White Paper criticise contracting care by the minute as an unacceptable commissioning practice. They should issue guidance to local authorities that explicitly rules out such practices.

The draft Bill for the first time places the safeguarding of adults on a statutory basis; however we believe there is a need to go further. The responsibilities of local authorities to prevent the abuse and neglect of those at risk must be made explicit, while steps must be taken to ensure that any provider of care and support services—whether from the private or voluntary sector—is subject to the same legal obligations as the local authority itself, including the Human Rights Act 1998. We also recommend that where abuses have taken place there must be corporate criminal responsibility, with organisations and key individuals held to account.

The draft Bill is predominantly about adult care and support, but also contains important provisions relating to the education and training of NHS workers, and health research. Mostly these have been welcomed by those giving evidence to our inquiry. We make a number of recommendations to improve the functions and objectives of Health Education England and of the Health Research Authority. In particular, we consider that the duties of HEE should be strengthened to facilitate integration of health and social care by ensuring more common training of care staff who switch between the two sectors. We also recommend making the promotion of research a key objective of the HRA, and we propose giving it the responsibility of protecting public safety by ensuring full disclosure of research data.

Finally, in much of the written and oral evidence we have received during the course of our inquiry we have heard a consistent message about the inadequacy of funding for adult care and support. As a result care and support have increasingly been rationed and restricted to those with the highest levels of need. This is ultimately self-defeating—shunting costs and reinforcing the dominance of crisis and acute care over approaches that prevent and postpone the need for formal care and support.
1 Introduction

Background

1. The current law relating to adult social care stretches back to the Beveridge reforms of the 1940s. The other major statutes implementing those reforms—the Education Act 1944, the National Health Act 1946, the National Insurance Act 1946 and the Children Act 1948—have long since been repealed, but many of the provisions of the National Assistance Act 1948 are still in force, including Part III relating to local authority services. In its time this Act was seen as ground-breaking: it swept away the Poor Law, abolished the Work House, the liable family rule, and the parish poor box in a system that dated back to 1531. It is now itself seen as out-dated and in need of repeal.

2. The provisions of Part III of the Act have of course been much amended over the last 60 years, and the law relating to adult social care was described by the Law Commission as “a confusing patchwork of conflicting statutes”. The Law Commission undertook between 2008 and 2011 a major project to reform the law on adult social care in England and Wales. This culminated in its report, published in May 2011. The Government accepted the majority of the recommendations, and a Bill to implement them was drafted, and was published in July 2012. It was decided that the draft Bill should receive pre-legislative scrutiny. This Committee was constituted on 22 November 2012 with the remit to consider the draft Care and Support Bill and to report on it by 7 March 2013. The membership of the Committee is set out in Appendix 1.

3. The draft Bill is divided into two parts. The reform of the care and support system is dealt with in Part 1 (clauses 1-53) and Schedules 1–4. Part 2 of the draft Bill—clauses 54–77 and Schedules 5–8—includes provisions on health education, health research, the Human Fertilisation and Embryology Authority (HFEA) and the Human Tissue Authority (HTA). The reason for this was that during the passage of the Health and Social Care Bill through the House of Lords a commitment had been given by the minister that draft legislation on establishing Health Education England and the Health Research Authority would be subject to pre-legislative scrutiny.

The Committee’s procedure

4. We held our first meeting on 29 November 2012, and have held a total of 16 meetings. On 14 December 2012 we issued a call for written evidence which is set out in Appendix 3, and received in response 143 items of written evidence from the persons and bodies listed in Appendix 2. After a meeting for informal discussion with officials from the Department of Health we took formal oral evidence from them on 13 December 2012. This was the first of 17 evidence sessions during which we took oral evidence from 61 persons, culminating

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1 Respectively by the Education Act 1996, the National Health Service Act 1977, the National Insurance Act 1965 and the Child Care Act 1980.
2 Scoping report, paragraph 2.1.
3 Law Com 236.
4 Cm 8386
5 Evidence of Shaun Gallagher, Q 9.
in evidence from the three ministers responsible for the different provisions of the draft Bill on 7 February 2013. To all our witnesses we are most grateful.

5. Between the appointment of the Committee on 22 November 2012 and the date by which we have had to agree our report, Parliament has been sitting for barely 11 weeks. The Government have previously made a commitment to allow “as much time as possible for pre-legislative scrutiny, with a minimum of twelve weeks as an objective.”6 In November 2009, in response to a complaint from the Joint Committee on the draft Bribery Bill that they had been given only ten weeks for their scrutiny, the Government replied: “The Government is grateful to the Committee for carrying out scrutiny of the draft Bill to a challenging ten week timetable. The Government agrees that 12 weeks should be regarded as the norm for pre-legislative scrutiny and will try to provide a minimum of 12 weeks wherever possible.”7

6. In 11 weeks it has been difficult to scrutinise and report on a draft Bill of this importance and complexity as thoroughly as we would have liked. Many persons and bodies asked to give oral evidence to us; we know that a number of them would have had interesting views to share with us; and we regret not having had time to hear more of them. We draw to the attention of both Houses the importance, when planning pre-legislative scrutiny of draft Bills, of agreeing a timetable which will give the Joint Committee an adequate opportunity to carry out its task, and the Department concerned sufficient time to consider and act on the Committee’s recommendations before the relevant Bill is introduced.

7. Some members of the Committee visited Torquay on 24 January to see for themselves how an attempt to integrate the working of the health and social care systems can work in practice. A note of that meeting is at Appendix 4. We also sought the views of carers through a web forum, and a note on this is at Appendix 5.

8. The great majority of the written evidence we received, and the oral evidence we took, related to the care and support provisions of the draft Bill. This is far from having been the first opportunity for those interested in these topics to give their views. The Law Commission conducted an extensive consultation between February and July 2010, and the views they received did much to influence the recommendations in their final report. Following the publication of the draft Bill, the Department of Health issued in July 2012 a consultation paper seeking views on the draft Bill.8 These were summarised in a paper published in December 2012.9 We have had the benefit of the views given in response to that consultation in addition to those replying to the specific questions in our call for evidence.

9. For our consideration of Part 1 of the draft Bill we have had the benefit of the advice of Professor Luke Clements, whose expertise in the law and practice of care and support has

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7 Government response to the conclusions and recommendation of the Joint Committee Report on the Draft Bribery Bill, Cm 7748.

8 Caring for our future: reforming care and support, Cm 8378

9 The draft Care and Support Bill: A summary of consultation responses.
been invaluable. We also had the assistance of Professor Bernard Crump for the provisions on Health Education England. We are most grateful to them both.

The structure of our report

10. This report considers first Part 1 of the draft Bill. Chapter 2 looks at the implications of the report of the Dilnot Commission, and of the Government’s announcement of their plans for its implementation. Chapter 3 considers Part 1 of the draft Bill overall and in its statutory context. In Chapter 4 we look at the general responsibilities of local authorities: the well-being principle, providing information and advice, promoting diversity and quality, promoting integration with health and other services, prevention and safeguarding. Chapter 5 deals with assessing and meeting needs, and paying for them. In Chapter 6 we consider the specific local authority responsibilities of portability—the continuity of care when an adult moves—and the transition of children to adult care. Chapter 7 suggests matters which might be dealt with in Part 1 of the draft Bill but currently are not.

11. We then turn to Part 2 of the draft Bill, and devote a chapter to each of its separate topics: health education, health research, and the future of the HFEA and the HTA. In the final chapter we summarise our recommendations for the changes which, in our view, should be made to the draft Bill before the Government introduce any legislation on these subjects.

The funding of adult social care

12. We have received a considerable volume of evidence, both written and oral, expressing concern about the overall level of funding of social care, and suggesting that the Bill should be amended in ways which would involve expenditure, some of it very considerable. In our sessions with provider organisations from both the private and voluntary sectors it was clear that funding questions were having a corrosive effect on working relationships with local authorities. Marc Bush from Scope told us “We have found that the under-funding has been going on for at least a couple of decades. The reason for that is that money has been going very much into the NHS, very much into crisis care, but not much into care and support. It is because social care is the poor sister of everything else.”

We also received evidence from a coalition of charities representing working age disabled people concerning the impact on access to services of setting the eligibility threshold for care and support at “substantial” or higher. Councillor David Rogers for the LGA told us “There is an ongoing gap; it is growing year-on-year and it is increasingly making the system unsustainable.”

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10 *Fairer Care Funding*, July 2011.
11 Q 174.
13 *The Other Care Crisis*, a report published on 17 January 2013. It contains research by the Personal Social Services Research Unit (PSSRU) at the London School of Economics, which shows that up to 105,000 disabled people are at risk of not receiving any social care if the Government were to set the national minimum eligibility threshold at the level of substantial or above (or its equivalent). The research also indicates a £1.2billion funding gap regarding social care support for disabled people under the age of 65.
14 Q104.
13. However, we were also told that the legislative framework proposed by the Government had been designed to be resource independent. Frances Patterson QC for the Law Commission summed this up when she told us: “In answer to the question about the cap at whatever level, our remit was to produce a legal framework. To do that, we produced recommendations, which we said in the report were resource neutral. What that means is that they are resource independent. So it does not matter whether there is a cap, or, if there is a cap, at what level it is. They provide a framework for the system to work effectively on a legal basis, independent of whatever the cap is.”

14. We have been sent the impact assessments on the draft Bill which make clear that not even the Government believe that the draft Bill is cost neutral. As an official from the Department of Health explained:

“It is not the case that we have said that no additional resources will be required from the draft Bill. The Law Commission when it did its work did an impact assessment and its view was that the legal framework was flexible and could be delivered in any resource envelope. There would be some transitional costs, but no ongoing costs. Our view when we have looked at the Bill and White Paper package as a whole is that there are measures which will increase costs. In the impact assessment for the White Paper, we set out a number of those and we have committed through the normal new burdens process on local authorities to fund those. Let me give you a sense of what some of those costs are and what they cover. The first is obviously if the Bill is for the first time giving carers an equal footing. We have assumed that that will lead to increased costs in terms of supporting carers. In the impact assessment, we have talked about figures getting up to £175 million a year in terms of additional support for carers. Improvements in information at a local level we have assumed will cost local authorities more. There, we have looked at both capital and revenue costs to support them in developing that. If your question is whether we think that it is realistic that it will not cost anything, our answer is that we do not, which is why have assumed that it will cost money and set those costs out in the White Paper. As we have mentioned before, eligibility would be one of the major things which would drive significant changes in the cost of a legal framework as a whole as opposed to the specific cost of the Bill. The primary legislation itself, as the Law Commission set out, is a flexible framework; it is designed to set out a framework that can work over multiple generations. It is the regulations partly that will help drive the costs.”

15. As we discuss in subsequent chapters, we are not convinced that the Government have fully assessed the implications of the reforms set out in the White Paper and the draft Bill. While some of the additional costs of implementing the Bill are accounted for in the impact assessment, for example the £175 million for carers, the impact assessment will need to be revised to reflect the full cost of, among other things, an increased number of assessments arising from the introduction of a capped cost system in 2017. Furthermore, the overall level of funding available for the care and support system will impact on how far the reforms envisaged in the draft Bill and the Government’s White Paper can be realised, particularly the stated goal of shifting the emphasis from crisis intervention to prevention and early intervention.

15 Q89.

16 Sally Warren, Director of Social Care Policy, Q 21.
2 Implications of the Dilnot Report and the Government’s proposals

16. In July 2010 the Government announced the establishment of an independent Commission on Funding Care and Support (the Dilnot Commission) to make recommendations on how to achieve an affordable and sustainable funding system or systems for care and support, for all adults in England, both in the home and other settings. The Commission reported in July 2011 making ten recommendations:17

- a cap on an adult’s lifetime contribution to their care costs set at between £25,000 and £50,000 with an improved national deferred payment scheme;
- increasing the upper means test threshold for state support from £23,250 to £100,000;
- those who enter adulthood already having a care and support need should immediately be eligible for free state support to meet their care needs;
- universal disability benefits for people of all ages should continue as now;
- people should contribute a standard, fixed, amount to their general living costs, such as food and accommodation, in residential care;
- eligibility criteria for service entitlement should be set on a standardised national basis to improve consistency and fairness across England, and there should be portability of assessments;
- encourage people to plan ahead for their later life with a Government awareness campaign to inform people of the new system;
- a statutory duty should be placed on local authorities to provide information, advice and assistance services in their areas;
- support the proposals set out by the Law Commission to give carers new legal rights to services and improve carers’ assessments;
- review the scope for improving the integration of adult social care with other services in the wider care and support system.

The Commission also said that, in the short term, they thought it was reasonable for a minimum eligibility threshold to be set nationally at “substantial” under the current system.

17. After a year of deliberation the Government published their progress report on funding reform in July 2012, accepting many of the Commission’s recommendations, but leaving open final decisions on the two key recommendations of a cap on lifetime care costs and an increased means test. In other chapters of this report we comment and make

recommendations on the provisions in the draft Bill covering information and advice, integration, eligibility, and carers' assessments.

18. When we began our work the Government had not announced how they intended to take forward the support in principle they had given to a cap on lifetime care costs and increased means test. This has hampered our ability to test the draft Bill’s compatibility with a capped cost system.

19. The Secretary of State for Health set out the Government’s plans in a statement to the House of Commons on 11 February. He told the House: “We propose to introduce a cap on an individual’s financial contributions towards the cost of care and a significant increase in the level of assets a person may hold and still receive some degree of support from the state.”\(^\text{18}\) The Government confirmed that a cap will introduced and set at £61,000 in 2010-11 prices, or £75,000 once it is introduced in April 2017. It was also confirmed that the amount of assets a person can hold and still receive financial support for their residential care costs will rise from £23,250 to £100,000 in 2010-11 prices, or £123,000 when introduced in 2017. The arrangements for young people who already have care needs when they turn 18 were also confirmed. They will now receive free adult care and support when they reach 18. People who develop a care need after 18 but before state pension age will be protected by a cap that is below the £75,000 threshold.

20. To help the Committee examine the implications of the Government’s decision to implement a capped cost scheme the Department of Health published a policy statement on care and support funding reform. Officials also briefed and took questions from the Committee.

**Capping care costs for working age adults**

21. We asked officials to set out how the Government intended to determine the level of the cap for working age adults. At the time we concluded our work the details were not available; however we note that the Government intend to take a power to enable the Secretary of State to be able to set this out in regulations. **Regulations determining the level of the cap for working age adults should be subject to affirmative resolution.**

**National eligibility rules**

22. Whether a person qualifies for state support towards their care costs hinges on having eligible needs. We comment in Chapter 5 on the need to redraft clause 13 to reflect fully the Government’s policy intention of setting a national eligibility threshold. The Dilnot Commission also said that “It is our view that there are problems with the current FACS\(^\text{19}\) scale, and we believe that it 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.”\(^\text{20}\) **We endorse the recommendation made by the Dilnot Commission that the Government**

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\(^{18}\) House of Commons Official Report, 11 February 2013, column 592.

\(^{19}\) The FACS guidance was replaced by Prioritising Need in the Context of Putting People First: a whole system approach to eligibility for social care – Guidance on Eligibility Criteria for Adult Social Care, England 2010, Department of Health. However the system is still commonly referred to as FACS, and we continue to use this term in our report.

should act quickly to devise a new assessment scale in conjunction with service users, carers and other interested parties. This work needs to proceed at pace. Draft regulations should be published before Second Reading to support Parliamentary scrutiny of the Bill during its passage through both Houses.

23. We are glad that during our oral evidence session with Ministers we were told by Sally Warren, the Director of Social Care Policy at the Department of Health, that “We are intending to publish draft regulations on eligibility so people can understand how we see eligibility working. We want to publish that as the Bill progresses through Parliament. The idea would be that, as Parliament was considering the primary legislation, they would understand how it would apply in secondary legislation, because it is so key to how the rest of the system works.”

Determining what costs count towards the cap

24. Under the Government’s plans those with eligible needs but who fail or decline the means test will have the value of their support metered, so that when they have been exposed to a certain amount of cost the State can step in. After considering the options the Dilnot Commission recommended using a notional amount that reflected the cost of meeting eligible needs. As we discuss in Chapter 4, it is essential that the way in which local authorities determine what they will pay reflects the actual cost of meeting eligible needs.

25. The way in which notional costs will be calculated has not yet been confirmed by the Government. However the policy statement says: “the local authority would be required to provide the person with a personal budget, which sets out the amount which is calculated to be the cost of meeting their eligible needs.” It goes on to say: “the personal budget would be ascertained by examining the individual’s eligible needs and assessing what the cost of meeting those needs would be, if the local authority were to do so—or “notional cost” of meeting the adult’s needs.”

26. When we asked officials how the notional costs might be calculated, they described to us the existing practice of many local authorities of using resource allocation systems (RAS) to help them to determine how much money a person should get in their personal budget to meet their needs. It seems likely that some form of RAS will become the means by which notional amounts are calculated.

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21 Q 326.
22 The Commission considered three options, metering actual spend, metering length of time and metering notional cost. It opted for notional cost. The reasoning is set out in Fairer Care Funding, Volume 2: Analysis and Evidence.
23 Paragraphs 111-113.
24 Paragraph 55.
25 Paragraph 57.
26 The Dilnot Commission explained that “A RAS works by assessing a person’s care needs using a questionnaire, which gives each person a numerical score. The scores for people entering the care system are compared with the scores of existing care recipients, and an estimated care package cost is assigned based on the cost of care for other people with similar scores. The local authority then designs a care package for that person, and aims to meet their needs for the same cost to ensure fairness with respect to other care recipients. Exceptions are made when it is not possible to fully meet the person’s needs at the same price.” Fairer Care Funding, Volume 2: Evidence and Analysis, pages 54-55.
27. Acting on a recommendation of the Law Commission, the Government are placing personal budgets on a statutory footing for the first time in clause 25 of the draft Bill. The clause requires the personal budget to include an assessment of the costs of meeting eligible needs. However the clause is silent about how that assessment is to be conducted. This is where RAS comes in.

28. Government policy on RAS can be found in a 2008 Local Authority Circular, which said: “In the future, all individuals eligible for publicly-funded adult social care will have a personal budget (other than in circumstances where people require emergency access to provision); a clear, upfront allocation of funding to enable them to make informed choices about how best to meet their needs, including their broader health and well-being.” This was then developed further in guidance issued in 2010. That guidance stated: “The aim of the RAS should be to provide a transparent system for the allocation of resources, linking money to outcomes while taking account of the different levels of support people need to achieve their goals. It allows people to know how much money they have available to spend so that they can make choices and direct the way their support is provided.” The guidance goes on to say that this “should not detract from a council’s duty to determine eligibility following assessment and to meet eligible needs”; and it is “a means of giving an approximate indication of what it may reasonably cost to meet a person’s particular needs according to their individual circumstances.” Critically the guidance concludes by stating that “However councils choose to develop systems for resource allocation, the first principle underpinning such systems should be transparency. Working towards greater transparency of resource allocation represents the first stage in a longer-term process to support the delivery of a more equitable system for all groups of service users based on need.”

29. The Law Commission made its recommendation that personal budgets should be placed on a statutory footing because of what it described as a “confusing structure, whereby social care practice is not founded in the legal framework.” It went on to express concern that some assessment procedures for personal budgets and the RAS were not compliant with the law. In responses to the consultation a number of consultees argued that RAS should be placed on a statutory footing to ensure greater oversight and transparency in the way they are set and operated. During our inquiry Richard Humphries of the Kings Fund told us: “we have begun to move in a way towards to a cash-based algorithm through personal budgets, but we are doing it through 152 different resource-allocation systems in local authorities. We actually have quite a muddled position at the moment.” We agree.

30. Both eligible needs and RAS are already highly contested areas of policy and practice (a matter we return to in paragraphs 202-204). With the extension of the duty to meet the needs of self-funders on their request, the introduction of national eligibility and portability of assessments and care accounts, there will be a clear need for transparency and predictability in determining notional costs. The introduction of a capped cost scheme,
which will result in many more people being assessed and entitled to a personal budget, is likely to lead to an increase in disputes and legal challenges. We are not confident that Ministers have yet fully thought through the implications for local authorities of these changes.

31. In particular we believe that the arrangements for redress and complaints resolution must be reviewed to ensure that they are fit for purpose. We discuss this further in Chapter 7.

32. Clarity and openness are essential to successful implementation of these reforms. The Government should place resource allocation systems for determining the notional costs recorded in a care account on a statutory footing, making it clear that they are subject to the well-being provisions in clause 1 of the draft Bill, and requiring local authorities to publicise their schemes and to include full details of how the amount included in the personal budget is calculated.

33. We also urge the Government to put beyond doubt that a resource allocation system cannot include a blanket policy of reducing a person’s personal budget or notional cost on the basis of the presence of a carer, without the carer’s knowledge or consent.  

**Measuring progress towards the cap: the care account**

34. In its policy paper explaining the change the Department of Health states: “People will need to have their care costs monitored over time, to record their total accumulated costs and demonstrate progress towards the cap. Where care costs change over time, for instance as a result of uprating for indexation, the total of their accumulated costs will need to be amended accordingly, so that they are not disadvantaged.” The Government intend to amend the Bill to create what will be known as a “care account”. This account will provide an annual update of a person’s accumulated notional care costs that count towards the cap.

35. The Department told us: “The price of care will change over time. To reflect this, the level of the cap and the amount in the Care Account that count towards people’s cap will increase in parallel every year.” The policy statement also explains that “this increase will be applied in a way that will ensure people with a Care Account would not be disadvantaged; a person who is 50% of the way towards the cap will remain 50% of the way towards the uprated cap. This will ensure that the real value of the cap remains constant and the partnership between the state and individual is stable.”

36. The Government intend to amend the Bill to uprate automatically both the cap and the care account annually based on a defined measure. The Department state that “it is expected that the level of the cap will be specified in regulations”. Officials told us that work on what factors should be included in the defined measure has not been completed. We note that the Dilnot Commission recommended that the cap should be uprated yearly on the same basis as the basic state pension.

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31 We consider this issue further in the context of clause 27 of the draft Bill, at paragraphs 205-208
32 Report, page 78.
37. The Bill must provide that regulations governing
   • the level and indexation of the cap,
   • any subsequent changes to the cap that fall outside the defined measure, and
   • arrangements for indexing the care account
are subject to affirmative resolution.

**Indexation of the means tests**

38. As well as the arrangements for uprating the cap and care account, there are the lower and upper means-test thresholds. In the Policy Statement the Department set out the Government’s intention that these will be uprated. However, the draft Bill does not provide for automatic indexation of these thresholds and the Government have indicated that the draft Bill does not require amendment to bring in the means-test change. However, one of the benefits claimed for these changes is the predictability that they bring to the system. The Bill must provide for automatic uprating of the lower and upper means test thresholds using a defined measure specified in regulations. The Bill must also provide that regulations that make
   • amendments to the defined measure,
   • changes to the lower and upper thresholds outside the defined measure, and
   • changes to the assumed tariff income
are subject to affirmative resolution.

**Ordinary residence rules**

39. We discuss in Chapter 6 the concern expressed to us by the Local Government Ombudsman that the draft Bill’s proposed arrangements for continuity of care when a person moves from one local authority to another could result in more cases of maladministration. In the case of people for whom there is no duty to meet needs (i.e. those who opt out before the financial assessment, or who do not meet the financial requirements and do not request the local authority to meet their needs) the Government should ensure that the ordinary residence rules and portability (continuity of care) provisions protect their care accounts and personal budgets.

40. We have not had time to take evidence on how the Government propose to operate the capped cost system in cases where people move from England to Scotland, Wales or Northern Ireland. However, the Government need to be clear how the accrued amount in a person’s care account is treated, whether it will it continue to be uprated, and whether the meter will have kept running in the event that the person returns to England. Answers to these questions will be critical to settling the rules for ordinary residence when people move from one nation of the United Kingdom to another.

**Implementation**

41. Enactment of the Care and Support Bill will constitute the biggest change in the law governing the operation of care and support in England since the National Assistance Act 1948. The Bill, when enacted, will not just consolidate and streamline into a single statute 60 years of piecemeal law making; it will also place on a statutory footing for the first time both the principles and the practice of self-directed personalised care. When
taken together with the introduction of a capped cost system and a national eligibility threshold the Bill presents a significant implementation challenge for everyone with a stake in the care and support system.

42. In response to our web forum concern was raised about the need for assessments to be “done by adequately trained and knowledgeable staff. If there aren’t enough people in social care to do this, why not use properly trained people from relevant voluntary organisations?” The volume and complexity of assessments, of carers, of people with care needs, the application of mean-testing, and the determination of notional costs all raise questions about the level of initial and ongoing training and support needed for local authority staff and social workers. These are matters we would expect to be fully analysed in the revised impact assessment that accompanies the final Bill.

43. As we discuss elsewhere in this report, we are concerned about the boundary that defines what constitutes free NHS care and what is means-tested care and support. Clarity is essential. Arrangements should be set in place either in statute, in regulations or in guidance to ensure that, where either the NHS or local authorities assess a person and determine that they are not eligible to have their needs met by them, they ensure that assessments are coordinated and information shared to minimise any delay in putting in place suitable arrangements to meet their needs, for example by provision of information and advice or by exercising the prevention duty in clause 7 of the draft Bill.

44. In its recommendations to the Government the Dilnot Commission highlighted the need for an awareness campaign on the costs of care and the new funding system. We agree with this recommendation, but we would go further. In the evidence we received in our web forum the need for clarity about who is responsible for what was a persistent theme. We believe that the Government must devise a campaign that raises awareness of what the national care and support offer is. This should make clear how people can plan and prepare, what their rights are and how to access the information, advice and assistance they need both to prevent and postpone the development of care needs and to support people to maintain their independence when they do have care needs.
3 The draft Bill in context

Part 1 of the draft Bill overall

45. Frances Patterson QC, the Law Commissioner who led the adult social care project, began her evidence to us by explaining:

“It is right to record that we are pleased with the Bill, which in fact adopts and takes forward the vast majority of our recommendations. The objective of our project was to simplify the very confused social care legal landscape to make it effective, accessible and fit for purpose for the 21st century. That was what we strove to do in our report, with its recommendations. We made 76 recommendations. When we counted up, 66 of those have been taken forward in the Bill… The differences are really of emphasis and detail, so far as we can see, and we think it does a good job.”

46. Almost without exception our witnesses, even though they had criticisms to make of the draft Bill, welcomed it just as enthusiastically. We share this view. We trust that our recommendations will be accepted to improve it further.

Adult social care: meaning

47. The words “care” and “support” are nowhere defined in the draft Bill—rightly in our view. However “care” is used in different ways. It is frequently used in legislation to mean “health care”; we point out in Chapter 8 how, in connection with Health Education England, the expression “care worker” is used to mean, in effect, “health worker”. In this Part of the draft Bill “care” means “social care”, and specifically excludes health care, as appears from clause 21, which we consider below. Some legislation—the Health and Social Care Act 2012 is an example—uses the expression “social care” when referring to that specifically. We agree that this would be clumsy in a Bill of this type, but we draw attention to this anomaly.

48. Although “care” is not defined, there is in clause 10(3) a definition of “carer”: an adult who provides or intends to provide care for another adult. Clause 52, the interpretation provision, points to this. It would help the reader if this definition could appear in clause 1, with a saving for clause 10(7) and (8).

49. There are arguments that care for children should have been included in the same draft Bill. Since it was not, there is an overlap between care for children and care for adults. We consider in Chapter 6 the relationship between this draft Bill and the Children and Families Bill, in particular in connection with young carers, and the care of children with special educational needs.

50. The Law Commission explained in its report what it understood by the expression “adult social care”.

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34 Q 83.
35 Paragraph 1.5.
Box: Meaning of “adult social care”

Adult social care means the care and support provided by local social services authorities pursuant to their responsibilities towards adults who need extra support. This includes older people, people with learning disabilities, physically disabled people, people with mental health problems, drug and alcohol misusers and carers. Adult social care services include the provision by local authorities and others of traditional services such as care homes, day centres, equipment and adaptations, meals and home care. It can also extend to a range of so-called non-traditional services – such as gym membership, art therapy, life coaching, personal assistants, emotional support, and classes or courses. Adult social care also includes services that are provided to carers – such as help with travel expenses, respite care, and career advice. Finally, adult social care also includes the mechanisms for delivering services, such as assessment, personal budgets and direct payments.

Clause 21: the boundary with NHS continuing care

51. As we have said, clause 21 sets out the boundary in law between the responsibilities of local authorities for care and support, and those of the NHS for health care. The current provisions are in sections 21(8) and 29(6) of the National Assistance Act 1948 and section 49 of the Health and Social Care Act 2001. Section 21(8) of the 1948 Act provides, in essence, that social services cannot provide care home accommodation if a power or a duty to provide the accommodation exists under the NHS Acts. In relation to services in the community, section 29(6)(b) of the 1948 Act limits the prohibition to situations where there is a duty (but not a power) to provide them under the NHS Acts; it prohibits a local authority from meeting care and support needs by providing services which are required to be provided under the National Health Service Act 2006. In the case of the provision of accommodation under section 21 of the 1948 Act, local authorities are prohibited from providing anything “authorised or required” to be provided under the NHS Acts; in other words, things which the NHS has the power to provide and things which it is under a duty to provide.

52. Since the earliest days the boundary between health care, which is free at point of use, and social care, which is not, has been highly problematic. Clarity over the boundary is of fundamental importance, and was described by Simon Medcalf, the Deputy Director for Social Care Policy and Legislation at the Department of Health, as “absolutely critical”. If the boundary is moved, it could result in either (a) a dilution of the NHS’s responsibilities, and as a consequence more people having to pay for their care (since it would no longer be deemed NHS care); or (b) more people becoming entitled to free NHS care (since it would

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36 Notes to the draft Bill, page 120, paragraph 43.
37 Section 21(8) provides ‘Nothing in this section shall authorise or require a local authority to make any provision authorised or required to be made (whether by that or by any other authority) by or under any enactment not contained in this Part of this Act or authorised or required to be provided under the National Health Service Act 2006 or the National Health Service (Wales) Act 2006.’
38 Section 29(6)(b) provides that ‘Nothing in the foregoing provisions of this section shall authorise or require … the provision of any accommodation or services required to be provided under the National Health Service Act 2006 or the National Health Service (Wales) Act 2006 or the National Health Service (Scotland) Act 1947.
39 Q 5.
no longer be deemed a social services responsibility), which would have substantial financial implications for the taxpayer. Parkinson’s UK believes that the move towards integration of health and social care could lead to a blurring of boundaries, and that it is crucial that this does not extend to the legal boundary between a means tested system and one which is free at the point of delivery.

53. In the *Coughlan* case the Court of Appeal interpreted section 21(8) of the 1948 Act. It explained that the prohibition would not stop social services providing a care package if a person’s nursing care needs were qualitatively and quantitatively low. In terms of *quantity*, it said that social services could be responsible if the nursing services were “… merely incidental or ancillary to the provision of the accommodation which a local authority is under a duty to provide to the category of persons to whom section 21 refers …”. In terms of *quality*, it said that social services could be responsible if the nursing services were “… of a nature which it can be expected that an authority whose primary responsibility is to provide social services can be expected to provide.”

54. The Law Commission advised that the new statute should retain the existing boundary. However the Law Commission also recommended that “the wording of the prohibitions should be reviewed and where appropriate simplified”. This is what the Government have attempted to do. However, clause 21, though it purports not to change the boundary, makes significant changes to the wording. It reads: “A local authority may not meet needs under sections 17 to 19 by providing or arranging for the provision of a service or facility that is required to be provided under the National Health Service Act 2006 … unless doing so would be incidental or ancillary to doing something else to meet needs under those sections.”

55. There is a significant difference between “anything authorised or required to be provided”—the current legislation—and “the provision of a service or facility that is required to be provided”—the wording of clause 21. It incorporates the “quantity” test—i.e. “incidental or ancillary”, but not the “quality” test. It only restricts social services provision to situations where there is a duty, rather than a power, under the NHS Acts. This would make no difference for community based services, but would constitute a material change for residential accommodation (which is generally the most expensive social care service). On the evidence we have received it is our view that this change would have the unintended effect of shifting the boundary so that fewer people would qualify for NHS continuing healthcare funding.

56. Nothing in the White Paper or the impact assessment suggests there is an intention to move this boundary. Simon Medcalf told us that there was “no overarching change in the policy here”. We put our concerns to the Department. In a note of 30 January 2013 they repeated that “it is not the intention to make any changes to what is the current boundary of what a local authority may do”, and they added: “We are satisfied the clause, which includes a regulation making power to enable provision to be made to clarify the limits of

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40  *R v North and East Devon Health Authority ex p Coughlan* [2001] QB 213, 232.

41  This does not do justice to the complexity of the legislation and its interpretation by the courts: see pages 147-152 of the Law Commission report.

42  Report, recommendation 51 at pages 151-152.

43  Q 9.
the local authority’s powers where necessary, enables us to ensure that the current policy on continuing healthcare can be maintained. … Regarding the “quality” prohibition, the Department does not consider it is necessary to incorporate the exact wording of the second limb of the case-law derived “quantity and quality” test. We consider that the formulation of the clause, combined with the regulation making power in the case of areas of uncertainty, incorporate the necessary elements of the “quantity and quality” test. However, as this point has also been raised in the consultation exercise, the Department will be giving further consideration to whether the existing drafting is sufficiently clear.”

57. **We are glad to know that the Department intends to look again at the drafting of clause 21. Whatever reassurance they may seek to give us, a court is likely to take the view that any change in wording which goes beyond bringing the drafting into the 21st century implies a change in the intended meaning of the provision. We therefore expect the Department to redraft the clause to put the question beyond doubt.**

58. Despite the apparently strict boundary between health services and social care, clause 21(2)(a) allows local authorities to provide, and by implication to charge for, types of services prescribed by regulations which would otherwise be provided under the National Health Service Acts, and hence free at point of use. The notes to the draft Bill explain that the regulations would clarify the boundary between local authority care and support and the NHS. If they are used only for this we have no concerns; but we would not wish to see them used to allow services to be charged for which should be free.

59. Regulations made under clause 21(2)(a) which allow local authorities to provide health services will not remove the obligation on the NHS to provide those services. We put this point to the Ministers. On their behalf Sally Warren replied: “This kind of proposal is about things like NHS continuing healthcare, where the local authority may well arrange for the provision of that because it might well be provided by a residential care provider. The local authority and the local CCG would need an arrangement to cross-charge each other for it, but it would not be that you would be charging the actual individual for that continuing healthcare, because it would be free.”

44 Clause 14(3) must be amended to make clear that, where a local authority provides services on behalf of a Clinical Commissioning Group, the authority may not recover the cost from the individual whose needs are being met.

60. It seems to us that there is a potential conflict between what may be done by regulations under clause 21(2)(a), and the qualified prohibition in subsections (3) and (4) on provision by a local authority of nursing care by a registered nurse. **We question whether subsections (3) and (4) of clause 21 are desirable. If they are retained, we are of the view that regulations made under clause 21(2)(a) should not be able to override the provisions of subsections (3) and (4), and consider that this should be made clear in the drafting.**

**The statutory framework and the hierarchy of rules**

61. In an area as large and complex as this, the primary legislation setting out the duties and powers of local authorities is only the first step. Most of the law is in secondary
legislation, where regulations set out these duties and powers in greater detail, and in
guidance and directions whose statutory status is often unclear. The Law Commission
recommended that the third tier of guidance should be a consolidated statutory code of
practice subject to Parliamentary control, following the model of the Mental Health Act
1983 and the Mental Capacity Act 2005. The Government have not followed this
recommendation. Clause 50 of the draft Bill instead follows the pattern of section 7 of the
Local Authority Social Services Act 1970, requiring local authorities to “act under the
general guidance of the Secretary of State in the exercise of functions” given to them by
Part 1 of the Bill or by regulations made under it.

62. In its response to the Law Commission the Department agreed that there was a
“plurality of documents, whose status can be unclear, and which can cause confusion on
the ground” but went on to reject the Commission’s recommendation of a code of practice.
It justified this view stating: “A code of practice, as distinct from other forms of statutory
guidance, is particularly inflexible. Codes of practice require a sizeable lead-in time for
amendment (being subject to Parliamentary timetabling), and so can quickly become out
of date. They are unable to respond to more urgent situations for the same reason.” The
Department argue that the goal can be achieved through a suite or bank of guidance that
would “look and feel the same” as a code of practice and point to this practice in children’s
services. In oral evidence Norman Lamb MP, the Minister of State for Care Services,
reiterated this point: “There is a risk that, if you have a statutory code, it makes it more
difficult to effect changes that everybody agrees might be sensible”. But he undertook to
look at the point again.

63. While we understand the attraction the Department has to flexibility and its
commitment to producing guidance that would “look and feel” the same as a code of
practice, we do not accept their approach. The guidance plays a crucial role. It is the means
by which the Secretary of State can guide the exercise of local authority functions under the
Bill, and it will carry substantial legal force. In our view, it is important that any changes are
given an appropriate degree of Parliamentary scrutiny. We think the approach of the Law
Commission is preferable. It is not the title of the document which matters—section 42 of
the Mental Capacity Act 2005 makes clear that the codes of practice issued by the Lord
Chancellor are “for the guidance” of those involved—but their statutory status, their
Parliamentary control, and the fact that courts may specifically take them into account.

64. The regulations will be made under powers in the Act, and will be subject to the Act
and other primary legislation. The draft Bill must make clear that the Code of Practice,
though also made under powers in the Act, is subject not only to the Act and other primary
legislation but also to the regulations and to any other law that may be applicable.

65. We recommend that the status of the third tier of the hierarchy of rules should be
clarified. Clause 50 should be replaced by provisions modelled on sections 42 and 43 of
the Mental Capacity Act 2005, allowing the Secretary of State to issue guidance
contained in a statutory Code of Practice.

45 Reforming the law for adult care and support: response to Law Commission report 326 on adult social care, July 2012.
46 Q 340.
66. The clause must make clear that the Code of Practice is subject not just to the Act and other primary legislation, but also to the regulations made under the Act and any other applicable law.
4 General responsibilities of local authorities

The well-being principle: Clause 1

67. In its consultation paper the Law Commission proposed that there should be tightly defined processes for determining the scope of adult social care. Replies to the consultation persuaded them instead to define the purpose of adult social care as promoting or contributing to the well-being of the individual. That recommendation was accepted by the Government and is central to the new policy on adult social care; clause 1(1) of the draft Bill provides that “the general duty of a local authority, in exercising a function under [Part 1 of the draft Bill] in the case of an adult, is to promote that adult’s well-being.”

68. The whole of the policy structure, and hence of the draft Bill, is shaped by this provision. All the evidence we have received which refers to this has done so in terms of approval; the general sense is that all those concerned regard this as a highly desirable development and one which leads to improved legislation.47 We agree. We also believe that when this legislation comes before the courts for interpretation, as inevitably it will, it will be easier for them to determine whether action taken, or not taken, complies with this principle, rather than to attempt to decide whether or not it falls within a definition of what constitutes adult social care.

69. The principle does not define the policy of a local authority, but applies to individual decisions taken within the context of that policy. “The well-being structure fits into the policy, rather than determines the policy. … if one local authority only met “critical” needs but another met “moderate” needs then the well-being principle would not determine that you could not have that policy, in terms of something equivalent to the FACS48 banding system. It would mean that within that FACS type structure, the well-being principle would apply to each individual decision that is made.”49

70. Clause 1(2) defines “well-being” as meaning, in relation to an adult, that adult’s well-being, so far as relating to any one of a list of seven factors. It was put to us that other factors should be included in the list. One of these, supported by Caroline Abrahams, the Director of External Affairs of Age UK,50 was “the dignity of the adult”. The Law Commission considered but rejected this: “We remain concerned that concepts such as dignity and independent living are too imprecise to be expressed as statutory principles. The notion of dignity has been used by the courts in judgments which are addressing texts which do not use the word dignity. This suggests that while a legal structure can be constructed in a way that is conducive to dignity—or even in a way which undermines it—

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47 By way only of example, Sue Bott (Disability Rights UK): “That principle of well-being is absolutely essential.”; Paul Farmer, Chief Executive of Mind: “We too would very much welcome this well-being principle.”; Sue Brown, Head of Public Policy, Sense: “We very much welcome the well-being principle and the checklist of what is included …” (Q 194).


49 Richard Percival, Q 92.

50 Q 168.
it is difficult to build a legal structure on the imprecise notion of dignity. 51 We respect that view, but believe that “dignity” is no less precise than some of the other factors listed, and we support its inclusion.

71. The list does not currently include any reference to housing, and a number of witnesses thought this was an omission that should be remedied. In their written evidence Midland Heart, one of the largest housing, care and regeneration groups in the country with over 33,000 homes, said: “We believe that the definition of well-being should include having access to safe and settled accommodation so that individuals are able to live independently in an accessible home which can be adapted to fit their needs.”52 We agree that the quality of housing is of such importance that a local authority should always have it in mind when considering the well-being of the individual, and that it merits a specific reference in the list.

72. There were other suggestions. One was a reference to parenting,53 but we believe this is already adequately covered by paragraph (f) which refers to “domestic, family and personal relationships”. Another was the insertion of a reference to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). On behalf of Disability Rights UK Sue Bott, the Director of Development, told us that the Convention “very much sees the disabled person as the whole person, not just a person who might be in need of particular support.”54 She was supported by Paul Farmer, the Chief Executive of Mind. The Law Society made the same point in their written evidence.55 The Law Commission, in considering a suggestion for the inclusion of “independent living” as a factor, rejected it on the ground that it was already adequately covered by Articles 8 and 19 of the Convention.56 It does not however seem to have been suggested to them that the Convention should itself be listed, and we do not think that it should be. It imposes numerous obligations on the States party, many of which have nothing to do with social care, and some of which are cast in very general terms. We are not convinced that it is realistic to suggest that local authorities, in exercising their duties under the draft Bill, should be obliged to have regard to such a document. The specific matters already listed in clause 1(2) will provide enough guidance.

73. Some of our witnesses also suggested that there should be an explicit reference to human rights legislation. When the Law Commission considered this question it concluded that statutory principles were not necessary to promote non-discrimination and human rights.57 In the Law Commission’s view it would simply repeat unnecessarily the provisions of the Equality Act 2010 and the European Convention on Human Rights. We share this view.

51 Report, paragraph 4.35.
52 Paragraph 3.2.
53 The Children’s Society, written evidence, paragraph 3.4.
54 Q 194.
55 Paragraph 6.
56 Report, paragraph 4.36.
57 Report, paragraph 326.
74. We recommend that the list in clause 1(2) of matters to which well-being relates should be enlarged to include the dignity of the adult, and the availability of safe and settled accommodation.

To whom does the principle apply?

75. As we have said, the well-being principle applies “in relation to an adult”. Clause 1(5) defines an adult as “a person aged 18 or over”, without further restriction. On this basis, the duty might be interpreted as including any adult in relation to whom a local authority exercises a function under Part 1 of the draft Bill. However there are provisions of the draft Bill where “adult” plainly does have a more restricted meaning, and in particular where it is contrasted with “carer”. Clauses 3(3), 3(5), 6(2) all contrast “an adult’s need for care and support” with “a carer’s need for support”. Clause 9(5) refers to “the adult” and “any carer that the adult has”. It is clear that in these and other provisions “adult”, without more, means “a person aged 18 or over who is or may be in need of care and support”. If “adult” was given this meaning in clause 1(1) to (3), it would follow that the well-being principle did not in terms apply to carers. 58 On the other hand, clause 10(3) defines “carer” as “an adult who provides or intends to provide care for another adult (an ‘adult needing care’)”.

76. That this is easily misunderstood is clear from the evidence of Emily Holzhausen, the Director of Policy of Carers UK, who said: “[Clause 1] just refers to adults and does not refer to carers, whereas in the rest of the Bill we refer to adults when they are adults who need care and carers separately. Just for completeness’ sake, starting with clause 1, we need to include carers. I honestly do not think for a minute that people would want to disentitle carers, but for the removal of doubt we would need to do that.” 59

77. The intention of the Law Commission is not entirely clear to us. Paragraph 4.29 of their report begins: “As a general rule the well-being principle relates to the subject of the decision. If there are competing interests, such as those of the carer, these would only be relevant insofar as they related to the well-being of the subject of the decision.” This suggests that the carer is not “the subject of the decision” to whom they intend the well-being principle to apply. But later they refer to “….. where two people are being assessed and their well-being is incompatible (such as a carer and a service user)”, and to “the carer’s well-being”.

78. Whatever their intention, the conclusion we draw is that it is at best not clear on the current wording of the draft Bill whether the principle will apply to carers. We believe that it should. We asked the Department of Health what the Government’s intention was, and they informed us that it is their intention that the principle should apply to carers as well as to adults needing care. 60 We believe the draft Bill should be clarified to put beyond doubt that the well-being principle applies as much to adult carers as to adults who are or may be in need of care and support—adults needing care, as they are described in clause 10(3). It would further clarify matters if our recommendation to place the definition of “carer” in clause 1 is adopted.

58 A point raised by Emily Holzhausen, the Director of Policy at Carers UK (Q 152).
59 Q 152.
60 Supplementary written evidence, 30 January 2013.
79. **Clause 1(5) should be amended to make clear that the well-being principle applies as much to an adult carer as to the adult needing care.**

80. The clause would still not apply in terms to a local authority’s functions in relation to children, even though the transition provisions in clauses 39-44 deal with assessment of a child’s needs for care and support, and a young carer’s needs for support. Such assessment are however made on the basis of the child’s or young carer’s needs when they reach the age of 18, and we believe that it is clear that the well-being principle must apply in such cases.

81. As drafted the Bill applies the well-being duty to decision-makers within the assessment and care planning framework set out in the Bill. However, many of the details that will shape the way in which local authorities discharge their functions under the Bill are subject to regulations and guidance issued by the Secretary of State. For example, clause 13 gives the Secretary of State very broad powers to set out in regulations the rules governing eligibility.

82. Section 1B(1) of the National Health Service Act 2006 provides that “in exercising functions in relation to the health service the Secretary of State must have regard to the NHS Constitution.” We suggested to the Secretary of State that he should be obliged to have regard to the requirements of clause 1 on well-being when exercising his functions under the draft Bill. He replied: “We absolutely want the well-being principle to apply comprehensively.”

83. **We welcome the importance that Ministers attach to the well-being principle. We recommend that the draft Bill should include a provision requiring the Secretary of State, when making regulations or issuing guidance, to have regard to the general duty of local authorities under clause 1.**

### Information and advice: Clause 2

#### Information and advice

84. Clause 2 has often, in evidence to us, been described as the local authority’s duty to provide information and advice to adults and carers on care and support. The obligation is in fact to “establish and maintain a service for providing people with information and advice…”. Sarah Pickup, the President of the Association of Directors of Adult Social Services (ADASS), explained the difference: “It does not have to be us that provides the advice. We need to make sure advice is available. In my signposting system in Hertfordshire, the HertsHelp system will get you to the place that can give you the best advice. The CAB is part of that network, for example, if you need advice in that territory. Our Money Advice Unit is part of that advice. We do a lot of welfare benefits advice.”

85. A number of witnesses reminded us that information is not the same as advice, and some thought local authorities were not always well placed to offer impartial advice, a point

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61 Inserted by section 3 of the Health and Social Services Act 2012.

62 Q 317.

63 Q 106.
made by Mears Group, one of the largest UK providers of domiciliary care, support services and social housing repair: “The key risks with the duty to provide advice are around impartiality, balance and quality. Our experience has shown that local authorities tend to be more reluctant to promote and even engage with private companies than third sector providers, even if it can be demonstrated that the private provider is delivering a higher quality service at better value for money. … Mears would like to see the Bill ensure that advice is given on the basis of the best quality of service and not whether the provider is a third sector or private business.” Mears of course have a particular interest in this, but we agree that this is another reason why advice services should be provided at arm’s length, and not by the local authority itself.

86. Clause 2(2) lists four particular matters on which the local authority’s service must provide information and advice: the system and how it operates; the choice of types of care and support, and of providers; how to access the care and support that is available; and how to raise concerns about the safety of an adult. These are illustrative only, but we received suggestions that other matters should specifically be added to the list. The National Housing Federation told us in their written evidence that a new paragraph should be added to clause 2(2) to make clear that information and advice should be provided on local housing options, including specialist housing, accessible housing and adaptations. They pointed out that local authorities already have a duty under the Housing Act 1996 to offer advice on housing options to those in housing need. Jake Eliot, the policy leader of the National Housing Federation, made the same point in oral evidence, as did other witnesses. For the same reasons that persuaded us to agree to the inclusion of housing in clause 1(2), we agree that it should receive a specific mention in clause 2(2). Another suggestion with which we sympathise was that a new paragraph should be added to make clear that information and advice should be provided on the ways in which people can contribute to the design of new services, where none are available to meet their needs.

87. Some of our witnesses were concerned that the Government had given the impression that digital was their preferred channel for information services. Given that there are over 5 million households without internet access, we would be concerned if digital or on-line sources were to be the sole means of obtaining information about the care and support system, a point echoed in the responses we received in our web forum. We were reassured to be told by the Secretary of State: “…we will make sure there is provision for people who are not IT literate, because they are some of the most vulnerable people whom we need to help.”

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64 Written evidence, paragraph 3.1
65 Paragraphs 6.2-6.3.
66 Jane Ashcroft, Chief Executive, Anchor Trust, and Domini Gunn, Director of Health and Well Being, Chartered Institute of Housing, Q 246.
67 Shared Lives Plus, written evidence, paragraph 2.8.
68 There were 5.2 million households in Great Britain without internet access in 2012: Office for National Statistics (ONS) Statistical Bulletin, 24 August 2012. The ONS quarterly update issued on 20 February 2013 showed that of the 7.42 million adults (15% of the adult population) who had never used the internet, 44% (3.23 million) were aged 75 and over.
69 Q 318.
Financial advice

88. The need for advice to be impartial is particularly acute in the case of financial advice. This does not currently appear in the list in clause 2(2), and several of our witnesses thought it should. Independent Age said: “We suggest that clause 2(2) … should include: “(e) any relevant charging arrangements for care and support in the local authority’s area;” and “(f) signposting to independent financial advice on the options for paying for care and support”.”70

89. The care and support framework extends to those who self-fund their care and support, giving rights to an assessment of care and support needs and the information and advice services the local authorities will be under a duty to provide. Clause 23(2)(c) gives those with care and support needs, but who are not entitled to local authority provided care and support, a right to information and advice. Partnership, the largest provider of long term care insurance in the United Kingdom, explained that advice would be particularly important for self-funders, who constitute 41% of those in the care system.71

90. Frances Patterson QC told us: “I suppose it might be argued—I am not saying that I am going to—that under clause 2(2)(a), which is so general about the system provided for by this Part and how the system operates in the authority’s area, it might include financial advice. That would then be taken up in guidance. For the avoidance of any doubt, if one wanted to go there, it could be included. You put the question rather more precisely by saying: does it have to be? I would say that it does not have to be but it could be.”72 We believe that it could be and should be.

91. The draft Bill should make clear that “information” and “advice” include financial information and advice, and that local authority services should recommend financial advisers only if they are regulated by the Financial Services Authority.

92. The following matters should be added to the list in clause 2(2) of matters on which the local authority’s service must provide information and advice:

- ways in which people can contribute to the design of services, where none are available to meet their needs;
- local housing options, including specialist housing, accessible housing and adaptations;
- any relevant charging arrangements for care and support in the local authority’s area;
- obtaining independent financial advice on the options for paying for care and support; and
- where such advice can be found.

93. We consider in Chapter 5 the particular need for financial advice when a person in need of care and support enters into a deferred payment agreement with a local authority, and in the case of third party top-ups.

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70 Written evidence, paragraph 32.
71 Written evidence, paragraph 1.2.2.
72 Q 96.
Advocacy

94. “Advocacy” is listed in clause 8(1) as an example of what a local authority may provide to meet an adult’s or carer’s needs, but it is not mentioned in clause 2 which, as we have said, deals only with a service providing information and advice. A number of our witnesses thought this a curious omission, and one which should be remedied. Action for Advocacy told us in their written evidence that it was important to provide independent advocacy at the right time: “This [clause 8] seems to be the wrong place to put advocacy. If it remains in this place, advocacy may only be provided following an assessment of needs for care and support. That would require the assessor to identify a person’s need for advocacy in order to have their voice heard and ensure choice and control ... the general duty to provide information and advice should be extended to include independent advocacy.” In his oral evidence Martin Coyle, the CEO, reiterated this point: “… that duty is implied through so much of the Bill so far that we may as well at least spell it out.”?

95. Action for Advocacy is a charity whose purpose is to promote advocacy services for vulnerable people and to support advocates, including paid advocates. But others were of the same view. Sarah Pickup thought it was “important that people have access to advocacy if they need it.” Andrea Sutcliffe, the Chief Executive of the Social Care Institute for Excellence, said: “… what we do not actually highlight in the Bill or make happen is the provision of what you might call either brokerage or advocacy to, as you suggest, fight the corner for an individual who might not be able to do that for themselves.” Richard Humphries agreed.?75

96. The Law Commission pointed out that “There is already a general right to advocacy in adult social care legislation, in the unimplemented provision of the Disabled Persons (Services, Consultation and Representation) Act 1986.” They recommended that this right should be recreated in the new statute, but thought they would be straying beyond their powers to recommend its immediate implementation.76 We are under no such constraints; we believe that the general right to advocacy should be included in clause 2.

97. “Information”, “advice” and “advocacy” are nowhere defined in the draft Bill. Action for Advocacy thought they should be defined in regulations, but did not offer suggestions for a definition.77 If “advocacy” is to be included in clause 2, we see no reason to attempt to define the boundaries between information, advice and advocacy.

98. When the Ministers gave evidence to us, Sally Warren told us she thought advocacy would be provided at two main stages: the point of assessment and care and support planning, to help the person articulate the outcomes they were trying to achieve, and the point of planning for their care and support needs, to help them to be clear about how they wanted to meet those needs. When asked whether the draft Bill should make clear that

73 Q 256
74 Q 122.
75 Q 46.
76 Report, paragraph 12.9.
77 Written evidence. In their Code of Practice they offer the following definition: “Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.”
advocacy could be provided at the first stage, she replied that the Bill already did this through the universal requirement for information and advice.\footnote{QQ 318-319.} 

99. We are glad that the Government intend that advocacy should be covered by clause 2, but we do not believe this is clear on the face of the draft Bill. \textbf{Clause 2 should be amended to make clear that independent advocacy is to be available before the assessment process has begun, and not only as one of the ways of meeting needs under clauses 17-19.} 

\section*{Promoting diversity and quality in provision of services: Clause 3} 

100. Clause 3(1) imposes on local authorities the duty to promote the efficient and effective operation in their area of a market in services for meeting care and support needs. In our call for evidence we asked how local authorities could satisfy that duty, and how they could encourage a diverse range of high quality providers. The Care and Support Alliance, while welcoming the duty placed on local authorities to promote diversity and quality in the provision of services, pointed out that local authorities have never had this market function before, so that regulations and guidance needed to be detailed and provide clarity as to how this function should be performed.\footnote{Written evidence paragraphs 25-26.} 

101. Many of our witnesses stressed the variety of services available in different local authority areas, and emphasised the importance of a range of care services and accommodation being available.\footnote{E.g. Dr José Luis Fernández, Deputy Director, Personal Social Services Research Unit, LSE, Richard Humphries, The King’s Fund, and Andrea Sutcliffe, Chief Executive, Social Care Institute for Excellence, QQ 56-58; Leonard Cheshire Disability, paragraphs 7-18; Standing Commission on Carers, response to Question 11.} Mears Group, while supporting the need to strengthen diversity, were concerned that many local authorities interpreted this as simply increasing the number of providers: more providers did not in their view equate to more choice.\footnote{Written evidence, paragraph 4.1.} 

102. To carry out this duty, a local authority needs detailed data on the availability of different services, and on the pricing and charging structures. There were suggestions that some local authorities do not have adequate data to support their strategic plans. Mencap told us that at a consultation event, service providers and Mencap local groups shared experiences of poor planning by local authorities which led to inadequate management of funding and a lack of choice of services for individuals. There was particularly a poor knowledge of people with a learning disability in local demographics. Mencap suggested that the duty to produce strategic plans should be supported by a duty on local authorities to keep accurate records of the number of people with a learning disability in their area.\footnote{Written evidence, paragraph 21.} 

103. This concern was summed up by Colin Angel of the National Home Care Association who told us that “What many councils have is a partial understanding of their local market based on the section that they transact with. Traditionally, authorities have had lists of approved providers; those are the organisations they will know. They will largely be providers delivering services to a council’s specification. There is much less intelligence, however, about what occurs outside of those arrangements. The risk is that people will
continue to be directed into the services that councils would traditionally have purchased and to miss out on knowledge, understanding and direction to more creative and flexible services that offer different options to people.”

104. A number of our witnesses expressed concern about the way in which local authorities exercised their existing commissioning responsibilities. For example, while welcoming the market shaping duty Des Kelly of the National Care Forum told us that “In a way, local authorities already had this responsibility. The market we have is a result of the way that local authorities have operated. We talk about commissioning, but actually, mostly, we mean contracting or procurement. It is not about commissioning. Too few of the discussions between local authorities as commissioners and providers are about commissioning rather than what price they are willing to pay. It is not really about what services they want in the future and how those services are best provided. That is part of the difficulty.”

105. This led some of our witnesses to call for the market shaping duty to be more explicit about the obligations on local authorities to gather intelligence and “talk to all of the players—be they not-for-profit or for-profit.” Others wanted to make sure that there was a clear link with the production of Joint Strategic Needs Assessments (JSNAs) to drive a full understanding of current and future population level needs for care and support. The Charity Sue Ryder in its written evidence said “In order to develop a diverse marketplace local authorities must complete an assessment of the local population’s needs.” However, they expressed concern that the current generation of JSNAs do not provide the data necessary to support the market shaping duty. In its report The Forgotten Millions it reports that only 5% of local authorities were able to provide detailed data on the number of people with any neurological condition that they provided care and support for.

106. Shaun Gallagher, the Department of Health’s Director for Social Care, Local Government and Care Partnerships, was clear that the market shaping duty is a broad one. He told us “First, you are missing a trick if you see this only as something that the social care bit of the authority is going to worry about. A really good market-shaping responsibility works with the local NHS and with housing authorities and other functions, because one of the best bits of innovation is where you can define new types of service that span those different areas. You actually achieve more by bringing those things together. Secondly, you need to work with the existing providers to say, ‘Okay, we think that our community needs a different type of service over the next five or 10 years. What are you going to do to try to develop that and where we might need to see some new developments, whether that is social enterprises or other sorts of innovative providers?’”

107. Many of these concerns are not directed at the market shaping duty itself. They reflect existing procurement practices, behaviours and relationships. The Department advised us that it is running a national support programme offering tailored assistance to local authorities to develop their capability to discharge this new duty. The Government should ensure that the Department of Health’s national support programme and guidance to

83 Q 138.
84 Ibid.
85 Ibid.
86 Q 11.
local authorities address these concerns; in particular they should make certain that Joint Strategic Needs Assessments provide a sufficiently detailed picture of the scale and character of current and future individual needs to support market shaping.

108. **We also believe clause 3 should be amended to put beyond doubt that local authorities must involve service providers, service users and carers in market shaping activity.**

109. Clause 3(2) sets out four matters to which local authorities must have regard in promoting efficient and effective operation of the market in services. The Standing Commission on Carers suggested adding to this list a duty to monitor the match between local supply and demand, and thereby to seek continuous improvement in quality and availability.\(^87\) They drew to our attention the relevant provisions of the Childcare Act 2006; they said these provisions appeared to have worked well and could be a model for provisions in the draft Bill. We agree.

110. **Clause 3(2) should be amended by the addition of a paragraph to provide for a duty analogous to that set out in section 6 of the Childcare Act 2006, which would require local authorities not only to develop a local market but also to monitor the match between supply and demand in their areas to and report publicly on the sufficiency of care and support services.**

111. The draft Bill does not directly refer to how the commissioning function of local authorities is to be discharged, except to state in clause 3(3) that in meeting an adult’s needs for care and support or a carer’s needs for support, a local authority must have regard to its duty to promote diversity and quality in the provision of services. However, in promoting a diverse market of services both to meet the needs of those local authorities support and those who make their own arrangements there is no obligation on local authorities to have regard for the actual costs of providing a service when setting the price they will pay. As we acknowledged in Chapter 1 this is ultimately a question of funding; nonetheless, the market shaping duty could be rendered worthless if local authorities undermine the diversity of the market through their pricing decisions. As John Adams from the Voluntary Organisations Disability Group told us, “We have seen a series of judicial reviews recently which have pretty much said that you have to take into account the provider’s real costs of providing that care.”\(^88\)

112. In evidence on 7 February Sally Warren, in response to a question concerning the need for the actual cost / usual cost requirement to be transposed into the new legislation, pointed out that there might be a number of reasons why the local authorities might pay a different price from what self-funders might pay, including the bulk buying power of local authorities and the fact that self-funders often choose a higher quality home or a better room. She said: “Our current intention is that we would not be replicating [provisions about the price of care] in guidance, but I am very happy to look at the evidence that has been provided to the Committee over the course of your hearings and reconsider that.”\(^89\)

\(^{87}\) Written evidence, response to Question 11.

\(^{88}\) Q 140.

\(^{89}\) QQ 320-321.
113. The draft Bill should include a requirement that local authorities properly take into account the actual cost of care when setting the rates they are prepared to pay providers.

114. We note that the Government have recently legislated to provide a mechanism for resolving disputes in the groceries market, establishing a Groceries Code Adjudicator. We have not had the opportunity to take detailed evidence on how such a model could be applied to the care and support sector. However, from the evidence we have received it is clear to us that a mechanism that enabled disputes over costs of care to be resolved would support the objectives of the draft Bill. The Government should examine the scope for introducing an independent adjudicator to settle disputes between local authorities and providers over the cost of care.

115. The announcement by the Government that they will be introducing a capped cost system raises further questions about disputes, redress and complaints which we discuss in Chapter 7.

116. Clause 3 provides that in exercising the market shaping duty local authorities must have regard to the “importance of fostering continuous improvement in the quality” of services. This reflects similar duties on the NHS. However, in the Health and Social Care Act there are clear references to quality standards. Gary Fitzgerald, the Chief Executive of Action on Elder Abuse told us: “I was quite surprised that the Bill does not link in with the essential standards that CQC measures against or the proposed NICE standards. There does need to be a link in commissioning between understanding what is taking place.”90 If local authorities are to be accountable for discharging their market shaping duty there need to be standards against which the public can judge them, a point Lord Adebowale made to us in his evidence.91 We agree. The Government should amend the market shaping duty in clause 3 by making an explicit link to both the essential standards of quality and safety and to NICE quality standards. This could be achieved by adding to clause 3(2) a requirement to have regard to regulations made under section 20 of the Health and Social Care Act 2008, and to the quality standards prepared by NICE under section 234 of the Health and Social Care Act 2012.

117. In the White Paper the Government refer to “particular tasks that are unrealistic to be carried out in a 10- to 15-minute home care appointment” and say that they “risk stripping people of their dignity and jeopardising their human rights.” This concern was highlighted by the Equality and Human Rights Commission’s inquiry into home care.92 These concerns were repeated in evidence to our inquiry; in particular, Leonard Cheshire was concerned by what it said was an increasing tendency to commission ever-shorter home care visits. “This can mean care workers are asked to provide person-centred personal care to an individual in a timeframe that does not allow for them to be supported with dignity or for any meaningful personal contact. We do not believe that such short visits are suitable for personal care, except in very limited circumstances.” The Government should ensure that they have the necessary statutory authority to make regulations or issue guidance

90 Q 200.
91 Q 140.
concerning what they call “unacceptable” commissioning practices, and amend the draft Bill if necessary.

**Cooperation: Clauses 4-5**

118. Clauses 4 and 5 deal with cooperation between local authorities and their partners generally and in specific cases. Clause 4(5) contains a list of relevant partners: other local authorities, NHS bodies in the authority’s area, the local police, prison and probation services, and other persons prescribed by regulations. Nothing is said there about housing providers, and we think they should be specifically mentioned, as one of our witnesses suggested.93

119. The list of relevant partners in clause 4(5) should be extended to cover registered housing providers, including housing associations and registered social landlords.

**Promoting integration of care and support with health services: Clause 6**

120. All adults in need of care and support, and probably all carers, will need health services. Clause 6 requires local authorities in exercising their social care functions to ensure the integration of care and support provision with health and health-related provision. This is the mirror-image of the duty under the Health and Social Care Act 2012 which confers similar duties on the NHS Commissioning Board and clinical commissioning groups. The benefits that such integration can bring are demonstrated in Torbay, which has taken the lead in integrating services. Members of the Committee visited Torquay on 24 January to see this in action, and to talk to those providing the services and to those receiving them. Although participants from both the NHS and local authorities stressed the importance of culture and relationships in creating the right conditions for successful coordinated care, they did point out the value of the use of section 256 of the National Health Service Act 2006 to transfer resources and as a catalyst for integration. A note of that visit is at Appendix 4.

121. Integration can mean many things, as Sarah Pickup told us: “You could integrate commissioning and you could do that for one service, all, or many. When people talk about integration they often mean integrated delivery, so there is one person going in to see people and you have generic teams. … Then in between that you have things like integrated access, where you want to have one front door where people can access therapeutic services, nursing or social care. Or you can have integrated assessment, where you look once at what people’s needs are and then you holistically get a care plan to meet them. The problem with having a firmer legislative requirement to integrate is that, in fact, you cannot really do that until you get to the regulation and the guidance.”94

122. The importance of integrated care, and in particular the financial context in which it operates, was emphasised to us by the Department of Health: “… if we want to see the overall shift in the pattern of services that we all talk about all the time, which is that we need to move health and care services to a more community focus, to support earlier

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93 Imogen Parry, independent safeguarding adults trainer for the housing sector, written evidence.

94 Q 102.
intervention and preventive services, which will in its totality involve a better use of resources across the entire system, if we are to achieve that big picture, which unquestionably will be a better use of resources and more efficient, the integrated working between health and social care and indeed other partners is an absolutely essential component." \(^{95}\)

123. There have been a number of proposals for adding to the face of the Bill a general requirement for local authorities to ensure the integration with particular services which have an impact on care and support. Many witnesses sought to include a requirement to integrate housing services with care and support. The BMA wrote: "Clause 6 on integration deals with integration between care and support provision and health provision but does not refer specifically to housing arrangement. Without explicit reference to integration of these elements of wellbeing, it is not specifically promoted within the draft Bill." \(^{96}\) Mark Goldring, the Chief Executive of Mencap, made the same point. \(^{97}\) Leonard Cheshire Disability asked that the integration duty should apply equally to employment and housing. \(^{98}\)

124. \textit{In clause 6(1) a reference to “housing provision” should be added to the reference to “health provision and health-related provision”}.\(^{99}\)

125. The wording of clause 6(1) requires a local authority to exercise its duty to ensure integration “where it considers that this would” promote well-being, contribute to prevention or delay of the need for care and support, or improve the quality of care. We agree with Leonard Cheshire Disability that this subjective requirement leaves too much latitude to local authorities, and could be strengthened. \textbf{We recommend that the words “it considers that” should be deleted from clause 6(1)}.\(^{100}\)

126. We asked why there could not be a provision in the Bill giving a power to direct the proportion of budgets being used for joint commissioning of health and social care. The reply we received from the Department was that “… all the evidence of where integrated care makes a difference tells you that it is locally led and locally owned and that there is a real resistance to something that is prescribed from the centre.” \(^{99}\) We are not persuaded by this answer.

127. There is moreover a good argument that joint commissioning and joint budgets will minimise funding disputes which are damaging to those who receive care and support, and which have been seen as part of the problems that led to the scandal at Winterbourne View. The Government have accepted this for children with special educational needs in the Children and Families Bill. That Bill states that local authorities and partner clinical commissioning groups must make joint commissioning arrangements in respect of children with special educational needs.\(^{100}\) Currently, the powers to pool budgets and undertake joint or lead commissioning are set out in section 75 of the National Health

\(^{95}\) Sally Warren, Q 15.  
\(^{96}\) British Medical Association (BMA), written evidence, paragraph 22.  
\(^{97}\) Q 181.  
\(^{98}\) Written evidence, paragraph 19.  
\(^{99}\) Shaun Gallagher, Q 16.  
\(^{100}\) Clause 6 of the Children and Families Bill.
Service Act 2006. This should provide NHS and local authority commissioners with a toolkit to support the discharge of the integration duties that the Health and Social Care Act 2012 and the draft Care and Support Bill impose. However, section 75 is not designed to enable such arrangements; it stipulates a complex set of requirements that amount to a “pre-nuptial agreement” that is cumbersome to put in place.

128. **Clause 6 should be amended to reflect the approach taken in the Children and Families Bill by giving the Secretary of State a power to prescribe groups of people or services that should be subject to joint commissioning and joint budgets.**

129. **The Government should take the opportunity to review section 75 of the National Health Service Act 2006 to make the requirements less onerous.**

130. We add a word of caution. It is clear from the Torbay experience that there is much that can be done without legislation, and the converse is also true: there is a limit to what can be done by legislation. Sally Warren told us: “…. what is going to drive integration is leadership, culture and a shifting at a local level.”\(^{101}\) And Richard Humphries took the same view: “… thinking back on my career and the various initiatives I have been involved with in trying to draw these different services together, I cannot think of a single one where it was made possible by new legislation. … The best that legislation can do is create the right framework that makes it easier for people to do it locally.”\(^{102}\)

131. A number of our witnesses expressed concern that the draft Bill did nothing to support information sharing between agencies. The Department acknowledged the problem in the information strategy it published in May 2012 when it said: “Concerns over security and privacy issues—and a lack of clarity for professionals in understanding what level of information sharing is permitted—can lead to a culture that is overly risk adverse and reluctant to share information at all, even where it would improve care.” The strategy goes on to set out a number of actions including the aspiration that the NHS number be used to provide a common identifier across health and social care.\(^{103}\) We suggested that the NHS number could form the basis of a shared record across different health-related services, and the Minister of State replied: “The idea of the NHS number applying across the system is enormously attractive. Having two different identities is crazy…”\(^{104}\) **The Government should review before the introduction of the Bill whether they have the necessary powers to support the implementation of information sharing using a common identifier such as the NHS number across different services.**

**Discharge from hospital**

132. Caroline Abrahams told us that 6% of hospital beds are occupied by people readmitted within a week of discharge, often because their care arrangements have not worked out properly.\(^{105}\) “This must be hugely distressing for those involved, and also a considerable waste of resources. Proper management of hospital discharge was seen as one

\(^{101}\) Q 14.

\(^{102}\) Q 39.

\(^{103}\) The power of information: Putting all of us in control of the health and care information we need.

\(^{104}\) Q 322.

\(^{105}\) Q 190.
of the most important areas for enhanced integration between services, and we received evidence, some of it anecdotal, on the problems that can be caused by inadequate preparation for and coordination of discharge. Hospitals owe it to their patients to consider their needs on discharge, and how they will be met, as part of the admission process. This point was further reinforced in the recommendations of the Francis Inquiry Report which said that “it should never be acceptable for patients to be discharged in the middle of the night, still less so at any time without absolute assurance that a patient in need of care will receive it on arrival at the planned destination.” We agree.

133. Jake Eliot said that the Bill needed tightening by requiring, where patients had needs for care and support, that an assessment of the need for home adaptations and housing related support should be undertaken before discharge. The same point was made by Domini Gunn for the Chartered Institute of Housing, and by Midland Heart in their written evidence. This concern was not restricted to patients with acute physical care needs. A number of respondents in their evidence expressed concern that patients from psychiatric hospitals are frequently being discharged without adequate support in place or facing delayed discharges in high-cost secure units because of inadequate arrangements for step-down and community support.

134. Clause 6(1) should be amended to require local authorities to ensure the integration of care and support provision with health provision on discharge from hospital, with particular emphasis on the adequacy of housing provision on discharge.

135. A number of respondents made the point that Schedule 2 applies only to those in acute care. This excludes people receiving psychiatric treatment or re-ablement services, an omission which in their view undermines the Government’s efforts to create parity of esteem between physical and mental health. They are concerned that patients from psychiatric hospitals are frequently discharged without adequate support in place or facing delayed discharges in high-cost secure units because of inadequate arrangements for step-down and community support. We agree with these witnesses that the Bill should not only introduce a clear duty on local authorities to carry out assessments for everyone leaving hospital with care and support needs, but should be extended to cover people using mental health services. We recognise however that the delayed discharge provisions in Schedule 2 simply replicate earlier provisions that put in place a system of reimbursement or fines and seek to apportion responsibility for delays in discharge.

136. We would be concerned that any extension of Schedule 2, as presently drafted, to other groups or settings could have unintended consequences. The Government should consider redrafting Schedule 2 to reflect its ambitions for integration and parity of esteem between physical and mental health. Any redrafting should seek to codify best

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106 E.g. written evidence from the National Housing Federation (Appendix), Age UK, and Arthritis Care.
108 Q 241.
109 Ibid.
110 Mind, Rethink Mental Illness, the Mental Health Foundation, the Centre for Mental Health and the Royal College of Psychiatrists.
111 Ibid.
practice in the coordination of the care of a person before, during and after their discharge.

137. We are aware of past controversy over the scope of section 117 of the Mental Health Act 1983. The Law Commission made a number of proposals concerning this provision. Paul Farmer told us: “We see concern around the way that this Bill is drafted and we certainly would encourage you to remove sub-section (5)(a) of clause 48 in that regard, because we think that would have a very detrimental effect on the application of [section] 117 care.” Paul Farmer expanded on his concern in written evidence: “Under the draft Bill as it stands, the definition is extended to state that these services must also meet a need ‘arising from the mental disorder of the person concerned’. In practice, it can be very difficult to establish which needs arise directly from an individual’s mental health problem and which don’t. We are concerned that narrowing the criteria for aftercare in this way will lead to disputes over what constitutes section 117 care, causing delays in the provision of services, distress for the people concerned and leaving them eligible to be charged for care that is essential to prevent their readmission to hospital. For example, under this new definition it seems likely that many local authorities will begin to charge for accommodation or residential care needed to prevent readmission to hospital, as it could be argued that the need for accommodation does not arise directly from a person’s mental health problem. People would have to go through difficult financial assessments while being discharged from hospital, with some likely to refuse crucial elements of their care that they worry they will be charged for.”

138. The Law Commission came to its recommendation in part to reflect the judgment in R (Mwanza) v London Borough of Greenwich. The court held that a local authority’s responsibility to provide after-care services under section 117 is restricted to those services necessary to meet a need arising from the former patient’s mental disorder and aimed at reducing that person’s chance of being readmitted to hospital for treatment for that disorder. The Law Commission concluded, “Consequently, the section 117 duty does not extend to providing normal accommodation simply on the basis that there is an increased risk to the person if accommodation is not provided, rather than because of their mental disorder. If the person is in need of care and attention then section 21 of the National Assistance Act 1948 is the more appropriate provision for seeking assistance.”

139. The Government have sought to translate the Law Commission’s recommendation on section 117 of the Mental Health Act 1983 into the draft Bill. Insofar as this simply reflects the court’s interpretation of the current legal framework for after care, we do not recommend any change. However, ministers should ensure that in the guidance to local authorities the risks are recognised and the well-being principle upheld.

Preventing needs for care and support: Clause 7

140. Anything that can prevent or delay the development of needs for care and support is obviously good for the adult concerned, good for any potential carer, and incidentally also good for the finances of local authorities and others who would have to pay for that care and support. The duty imposed on local authorities by clause 7 to take steps to prevent,
delay or reduce needs for care and support is very welcome, and was welcomed by a number of our witnesses.114

141. The term “prevention” is not well understood. Alex Fox, the Chief Executive of Shared Lives Plus, told us that “things labelled preventative often had no clear idea of what they were preventing, for whom and how they knew whether they prevented it ... Actually, all social-care interventions should be future-focussed as well as reactive. Things that are genuinely preventative leave people better informed, better connected and more able to live with dignity themselves. ... The more that we can help people connect and embed into a community, the more empowered and resilient, and the less dependent, they are. That to me is a much more helpful idea of what prevention is that applies at an early stage and is relevant at end-of-life care. There is no stage of life at which we want to be dependent and isolated.”115 We share Mr Fox’s desire for clarity.

142. **Ministers should ensure that the explanatory notes to the Bill and the guidance both provide clarity about the prevention duty and how it should be seen as an integral part of the care and support system at every stage.**

143. The financial benefits of prevention can appear relatively quickly. Sally Warren explained: “People always assume that prevention takes a long time to get returns. Actually, some prevention and early intervention can [produce] returns very quickly. What we need to get better and smarter at is sharing the evidence of where that works. Re-ablement, which is more on the early intervention than on the prevention side, has been proven to pay back very quickly within the financial year for local authorities, so that is definitely worth investing in.”116

144. Clause 7(2)(b) requires local authorities to have regard to “the importance of identifying adults … with needs for care and support which are not being met”. This reference to those who already have unmet needs does not include those who do not yet have needs, but may be at risk of developing such needs; nor does it include those who already have needs, but for whom prevention of deterioration might delay an increase in their needs. This is particularly true of people with a learning disability. Mark Goldring explained that “for people with a learning disability prevention has a rather different meaning … a modest level of support to people to live an everyday life can prevent not learning disability but a massive deterioration in their well-being”.117

145. **Clause 7(2) should be amended to state that, additionally, local authorities must have regard to the importance of identifying adults at risk of developing care and support needs, or increasing such needs, who may benefit from support to prevent deterioration in their well-being.**

146. Clause 7(1) requires local authorities to provide or arrange for the provision of services, facilities or resources to prevent or delay the development of needs. When asked if the market shaping duty in clause 3 included preventative services officials from the

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114 E.g. Laura Robinson, Policy and Communications Adviser, National Voices, Q 178.
115 Q178.
116 Q 17.
117 Q 178.
Department told us it did not. A similar point was made about the contribution that information and advice can make to preventing and postponing the onset of need by Laura Robinson, the Policy and Communications Adviser of National Voices, and also by Sarah Pickup who told us “Our line in ADASS, and indeed in my own authority, is that our priority must be to prevent, inform and advise.” The draft Bill should be amended to make clear that both clause 2 and clause 3 are linked to the duty of prevention.

147. During our oral evidence session with Ministers, Norman Lamb MP told us that the Government were looking at how implementing a capped cost system would impact on existing clauses in the draft Bill. He expressed the hope that a cap, “encourages people to come forward early to have the assessment as to whether their care needs meet the threshold for the clock to start. The more the local authority can do to have the early conversation with people to help them build their own resilience and to give advice and support about what the family can do—and the more the community can do to maintain independence and slow down any deterioration of condition—the better. I think that proactive conversation as early as possible is really important. Dilnot would help facilitate that earlier conversation, so we are looking both at the new clauses and any impact that they would have on existing clauses.” We agree with the Minister. Realising the “public health” benefit from introducing a capped cost system could result in significant quality of life gains by helping to engage more people in maintaining their health and well-being, with a positive impact on demand for long term care.

Safeguarding: Clauses 34-38

148. The fact that the draft Bill places adult safeguarding on a statutory footing for the first time was widely welcomed by our witnesses. However, we were told by a number of witnesses that “We are concerned that the first reference to safeguarding in the draft Bill is in relation to an enquiry … this does not recognise the need for local authorities to take steps to prevent abuse occurring in the first place.” The need clearly to link the safeguarding duties in the Bill to the other general responsibilities of local authorities set out in clauses 1 to 7 was suggested as an improvement to the drafting of the Bill. We agree that prevention should be an explicit part of the safeguarding responsibilities of local authorities.

149. The safeguarding provisions of the draft Bill should be moved to the General Responsibilities section.

150. Local authorities should be placed under a statutory duty to take steps to empower individuals to understand what abuse is, and how to protect themselves from it, whether by seeking help or otherwise.

151. What the draft Bill describes as “safeguarding” is in fact two different matters. Clause 34(1)(b) gives the local authority the duty to make enquiries where it has reasonable cause to suspect that the adult needing care “is at risk of abuse or neglect”—what the Law

118 Q 46.
119 Q178.
120 Q103.
121 Mencap, Care and Support Alliance, The British Red Cross, Action on Elder Abuse.
Commission describes in Part 9 of its report\(^2\) as safeguarding. But that paragraph also deals with the similar duty of local authorities where it suspects that the adult needing care “is experiencing” abuse or neglect—what the Law Commission describes as adult protection, which is in fact the heading of that part of its report. The first is a duty of prevention, the second a duty of investigation. In neither case is there currently a statutory framework giving local authorities the powers they require. It seems to us that by putting the two together the draft Bill may have caused some confusion about the separate powers.

152. We put this to the Law Commission who told us: “We are concerned that this duty may not extend to adult protection cases where abuse or neglect has or may have occurred in the past. This is because the duty appears to require that the abuse is occurring at the present time or is likely to occur in the future. However, there may be cases where the local authority is aware that abuse or neglect has occurred in the past but still needs to investigate. For example, enquiries may be necessary in a situation similar to that which occurred at Winterbourne View where procedures had been put in place to address the past episode of abuse but the local authority still needed to investigate to ensure that the residents were not at risk.”\(^3\) The Law Commission concluded: “we remain concerned that the duty will not cover a small but significant number of cases where the local authority has no reason to suspect that abuse is ongoing but still needs to investigate to ensure that the arrangements put in place are sufficient. We therefore think that the Bill should be amended to ensure that the duty to investigate covers such cases.”\(^4\) We agree.

153. Clause 34(1) should be amended to put beyond doubt that the duty of local authorities to make enquiries extends to cases where abuse or neglect has occurred in the past but still needs to be investigated. A similar amendment should be made to clause 4(4)(c).

154. In its written evidence ADASS expressed concern that the clause as drafted does not make clear what “cause to be made” means in practice, a point also made by the Practitioners Alliance for Safeguarding Adults. They suggest that the guidance on this point needs to be robust to ensure that action occurs and accountability is clear. We agree. The Government should ensure that both the explanatory notes to the Bill and the guidance make clear what obligations the words “cause to be made” place on local authorities and other agencies.

155. Clause 34(2) does not define “abuse”, but states that it includes having money or property stolen or misused, being defrauded, and being put under pressure in relation to money or property – what might be termed financial abuse. The lack of a definition was criticised by some witnesses.\(^5\) The Independent Living Association wrote: “… while we appreciate that clause 34(2) is not an exhaustive list, it erroneously suggests that financial abuse is the only type of abuse individuals are subjected to.”\(^6\) We do not agree with this criticism. Abuse is an ordinary English word, capable of being understood without being defined. It might not however normally be thought of as including financial abuse, and it is right that clause 34(2) should put this beyond doubt. But to attempt an exhaustive

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\(^2\) Paragraph 9.2.

\(^3\) Letter from Frances Patterson QC to the Chairman of 5 February 2013.

\(^4\) E.g. Action on Elder Abuse.

\(^5\) Written evidence, paragraph 30.
definition always has the danger of omitting something which, as subsequent events make clear, should have been included.

**A power of entry**

156. The Equality and Human Rights Commission (EHRC) suggested that “there should be an additional power of entry for local authority representatives, where a third party is refusing access to a person who may be at risk of abuse and neglect.”\(^{126}\) Several other witnesses took the same view.\(^{127}\) In subsequent evidence the EHRC suggested that the local authority representatives should be experienced in adult safeguarding and should where appropriate use independent advocates to establish effective contact with the person about whom they have concerns, to advise whether that person is in fact being subjected to abuse or neglect. They added that the relevant regulatory and inspection organisations should undertake a regular assessment to ensure the powers were used proportionately.

157. A provision on powers of entry already exists in the Adult Support and Protection (Scotland) Act 2007 and is proposed in the Social Services and Well-being (Wales) Bill. Sections 37 to 41 of the Scottish Act set out the necessary procedures for applying to a sheriff or, in urgent cases, to a justice of the peace, for a warrant for entry. It seems to us that these or similar provisions which require court authorisation and application of the Human Rights Act to a power of entry would provide an adequate protection against the powers being abused.

158. The Minister of State told us that the Department of Health had carried out a consultation. The results of the consultation had not yet been published but, not surprisingly, those who wanted to use the power were in favour, while those who believed that they might be subject to it were opposed to it.\(^ {128}\)

159. There are obvious dangers in according such powers to new categories of persons, but on balance we believe that the safeguarding provisions should include a power of entry for local authority representatives where a third party is refusing access to a person who may be at risk of abuse or neglect.

**Safeguarding Adults Boards**

160. Clause 35 requires each local authority to establish a Safeguarding Adults Board (SAB), and Schedule 1 sets out detailed provisions about the membership and strategy of SABs. The membership list does not include the relevant Health and Well-being Board; although it could be added by regulation, we think that, in order to identify relevant areas of concern and to ensure that strategies and planning arrangements fully reflect local needs, the local Health and Well-being Board should specifically feature in the list of members of the SAB.

161. The Care and Support Alliance suggested that the CQC should be required to identify a person within the regulator who should act as a link with each of the SABs. That person

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126 Written evidence, paragraph 19.
127 E.g. Action on Elder Abuse paragraph 2.34, College of Social Workers paragraph 22.
128 Q 331.
would be responsible for sharing information, advice and guidance with the board. We can see that this might have advantages, but we believe it would be unduly onerous to ask the CQC to name people to act as a link with 152 local authorities (fewer if two or more authorities established a joint SAB). We do however believe that the CQC should be added to the list in paragraph 3(2) of Schedule 1 of those who receive copies of the annual report of all SABs.

162. **The local Health and Well-being Board should be added to the list of members in paragraph 1(1) of Schedule 1 to the draft Bill. The Care Quality Commission should be added to the list of recipients of reports in paragraph 3(2).**

163. The contribution of housing providers to safeguarding has been raised by a number of witnesses. In written evidence Imogen Parry told us “that the role of housing in preventing and addressing adult abuse is neglected in legislation, policy, practice and research.” Graham Carey pointed out that the current guidance on adult safeguarding, No Secrets, sought to include housing in safeguarding boards but this had not happened in practice. We agree that housing has a place in adult safeguarding arrangements. **The Government should consider amending paragraph 1(1) of Schedule 1 to include appropriate housing representation in the membership of Safeguarding Adults Boards.**

164. A local authority is, rightly, a member of the SAB which it establishes. However there will be occasions when an SAB will be carrying out case reviews under clause 36 which might well be investigating alleged failures by the local authority in adequately carrying out the enquiries required by clause 34. Participation by a local authority in an investigation of its own shortcomings would be undesirable. **Paragraph 1 of Schedule 1 should be amended to specify the circumstances in which a local authority should not take part in the proceedings of the Safeguarding Adults Board.**

165. Adult serious case reviews, which become safeguarding adults reviews under the draft Bill, would not have the same statutory authority to obtain information as serious case reviews involving children. The current powers are set out in section 8 of the Children, Schools and Families Act 2010, which amended the Children Act 2004 to give Children’s Safeguarding Boards an express power to require a person or body to comply with a request for information from the Board where the information relates to the Board’s duties. The absence of any express power in safeguarding adults reviews leaves a gap which could undermine the ability of such reviews to learn the lessons from serious cases of abuse and neglect. **The draft Bill should include an explicit power to obtain information relevant to the conduct of safeguarding adults reviews.**

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129 Section 8 of the Children, Schools and Families Act 2010.
5 Assessing and meeting needs, and payments

How to meet needs: Clause 8

166. The nearest the draft Bill gets to an explanation of what is meant by care and support is clause 8(1), which gives five examples of what may be provided by a local authority to meet the needs of an adult needing care and support, or a carer needing support:
   a) accommodation in a care home or in premises of some other type;
   b) care and support at home or in the community;
   c) counselling, advocacy and other types of social work;
   d) goods and facilities;
   e) information and advice.

167. This list is a radical departure from existing social care legislation since it is illustrative rather than exhaustive; the care and support can be provided to either the carer or the adult needing care; and support provided under this clause is subject to charging (a point we consider further below).

168. We put to the Department of Health that holidays, travel, assistance to take advantage of educational facilities, and home adaptations, are all specifically mentioned in the current legislation.\textsuperscript{130} The Department’s note of 30 January 2013 makes clear that the list is illustrative only, and that all of these are intended to be covered by clause 8. We have been urged to recommend additions to the list, in particular transport,\textsuperscript{131} employment support services\textsuperscript{132} and equipment.\textsuperscript{133} We do not think this approach is likely to succeed. So long as the list is short, it is clear that it is illustrative only. The longer it is, the more likely it is to be interpreted as not including matters unconnected to those in the list, as indeed are many of those mentioned by the Law Commission.

169. The explanatory notes to the draft Bill on the one hand state that the list is intended to give some general examples, but then go on to say: “The examples provided are intended to be wide enough to cover all specific services which may be provided”. This is confusing.

170. The Department of Health should take the opportunity to review and revise the explanatory note for clause 8 and subsequent guidance to make clear that the list is not intended to limit the ways in which a local authority might meet any eligible needs or agreed outcomes, removing any possible ambiguity on that point.

Assessing needs: Clauses 9-12

171. The Law Commission took the approach of putting assessments at the centre of the legal framework for adult social care,\textsuperscript{134} suggesting that the focus of assessments should

\textsuperscript{130} Chronically Sick and Disabled Persons Act 1970, section 2.
\textsuperscript{131} Society of Later Life Advisers (SOLLA), written evidence.
\textsuperscript{132} National Autistic Society, written evidence, paragraph 35.
\textsuperscript{133} College of Occupational Therapists, written evidence, paragraphs 13-15.
\textsuperscript{134} Report, paragraph 5.3.
“not be on rating a person’s needs but rather how to assist the individual to achieve well-being within their own resources”. This approach has not been followed in the drafting of the clauses that cover a person’s journey through the formal care and support system.

172. Some of our witnesses felt that the draft Bill had not fully captured the Law Commission’s intention that well-being should become the organising principle around which adult social care is built. In their written evidence to the Committee Shared Lives Plus described people’s first contact with the care and support system as “often stigmatising, confusing and requires people to prove their vulnerability and dependence.” They echo the Law Commission’s ambition that the process of assessment should explore “resilience, coping skills and potential informal support networks”. This leads them to recommend reframing the entitlement to a needs assessment as an entitlement to access to planning support. The Government in their White Paper talk about adopting “asset based approaches” that consider the strengths that people and communities have to meet and manage their needs.

173. In their written evidence to us the Joseph Rowntree Foundation applaud the Government for adopting well-being but go on to say: “At some points, old-fashioned and narrow language creeps back in”. We agree that the Bill fails fully to follow the logic of adopting well-being as the overarching principle, and defaults to a more traditional model of needs assessment. The Department should amend the draft Bill to support people planning to achieve well-being within their own resources. The aim should be to frame assessment as a discussion about the additional support people may need to maintain or achieve well-being.

174. Clause 9 consolidates, in large measure, the assessment duty currently found in section 47 of the National Health Service and Community Care Act 1990. Section 47(3) provides that if it appears to a local authority when undertaking an assessment that the person being assessed has a health or housing need, then it is obliged to bring this need to the attention of the relevant health or housing authority, invite them to assist in the assessment, and take into account any services likely to be made available by that authority. However it appears that the obligations in section 47(3) have not been transposed into the draft Bill.

175. We put this point to the Department of Health, who replied: “It is our intention that the duty on local authorities to co-operate generally and in specific cases will ensure that they work with partners such as the NHS and housing authorities. The draft Bill also promotes integration between local authorities and the NHS. These provisions will underpin existing practice where local authorities already contact the NHS or housing authority if they believe a person has health or housing needs. We would welcome the Committee’s views on this approach.” While we welcome the intention, we believe that a specific provision on the lines of section 47(3) of the 1990 Act would be more appropriate.

176. The draft Bill should be amended to provide that if it appears to a local authority, when undertaking a needs assessment under clause 9 or a carer’s assessment under clause 10, that the person being assessed has a health or housing need or other relevant need, it should be obliged to bring this need to the attention of the relevant authority.

135 Report, paragraph 5.6.
177. Clause 10 for the first time imposes on local authorities a requirement to assess, not just the adult’s needs for care and support, but also the carer’s needs for support. This development was described by Dr Moira Fraser, Director of Policy and Research, Carers Trust, as “a huge step forward”.\(^\text{136}\) We agree. **We welcome the fact that for the first time local authorities will be required to assess whether a carer has, or is likely to have in the future, needs for support.**

178. A consortium of organisations with an interest in mental health\(^\text{137}\) suggested that where the person having a care and support needs assessment lacks capacity, the draft Bill currently contains no requirement to consider the involvement of “those concerned for the person’s care and well-being”, as would be expected under the Mental Capacity Act 2005. They said: “The Bill should explicitly state that these interested parties should be involved in the needs assessment process where it relates to an individual who lacks capacity.” We agree.

179. **Clause 9(5) lists those who must if possible be consulted by a local authority carrying out a needs assessment. In the case of a person lacking capacity, this should include those concerned for the person’s care and well-being in accordance with section 4(7)(b) of the Mental Capacity Act 2005.**

180. A number of our witnesses had concerns about assessments for those who were terminally ill. Marie Curie Cancer Care sent us a short submission confined to the issue of whether a statutory duty on local authorities to fast-track people with a terminal illness through assessment of care needs and financial resources could be included in the draft Bill. They quoted the Palliative Care Funding Review: “At this time [the end of life], the last thing individuals and families should be facing are arguments over funding of the care they need and delays in the provision of care due to complex systems and procedures”. At present, people who are terminally ill with less than six months to live can receive instant access to the highest level of welfare benefit through a DS1500 form, which is issued by the patient’s diagnosing physician, and Marie Curie Cancer Care suggested that “a completed DS1500 could also be used to trigger a fast-track through assessment of care needs and financial resources for terminally ill people.” Help the Hospices also made this point.

181. While a system based on form DS1500 was thus favoured by a number of our witnesses, we were told by the Motor Neurone Disease (MND) Association that this proposal “might not work for people with MND”. The Association suggest that end of life care locality registers or the Electronic Palliative Care Coordination System (EPaCCS) would be better. However they acknowledge that EPaCCS is not used universally.\(^\text{138}\) On balance we believe that there is a benefit to be gained from fast-tracking people through the care and support system. We think that there should be a statutory duty on local authorities to fast-track assessments for terminally ill people, other than those for whom the NHS has continuing healthcare responsibilities. **Clause 12(1), which lists the matters relating to needs or carer’s assessments for which regulations must make further**

\(^{136}\) Q 153.

\(^{137}\) Mind, Rethink Mental Illness, the Mental Health Foundation, the Centre for Mental Health and the Royal College of Psychiatrists.

\(^{138}\) Letter from the Motor Neurone Disease Association to the Chairman of 6 March 2013.
provision, should include provision for fast-tracking needs assessments for terminally ill people.

182. It is not clear to us whether the reference in subsection (1)(a) to the “needs of the family” gives sufficient prominence to the need to prevent any children from undertaking inappropriate caring responsibilities. We must ensure that, when carrying out needs assessments under clause 9, local authorities have regard to the needs of any children who may provide or be about to provide care for an adult. **Clause 12(1) should be amended to make clear that local authorities, when carrying out a needs or carer’s assessment, must have regard to the need to prevent any children from undertaking inappropriate caring responsibilities.**

183. Some witnesses did not believe that local authorities should have the power to combine the needs assessments of an adult needing care with their carer’s needs assessment. Self Direct thought “this would have the potential in some instances for the person who needs support to lose their individual identity and to lose control of the support they need”. But other witnesses, particularly carers’ organisations, welcomed the power to combine the assessments. Dame Philippa Russell, the Chair of the Standing Commission on Carers, said: “I warmly welcome the whole-family assessment. It will help us resolve some of the issues that have arisen around young carers, parent carers and, also, the quite natural disagreements or differences of opinion that can arise between the person needing care and support and the carer.”

184. **We support the possibility of combining a needs and carer’s assessment under clause 12(3), particularly to underpin whole-family assessment, and we believe that the requirement for agreement of the adult needing care and of the carer provide sufficient protection for the adult.**

**Eligibility: Clause 13**

185. In their written evidence Scope told us that eligibility is “the most critical aspect to the whole Bill since it determines who will and will not get vital support, both to carry out essential day-to-day tasks like washing, dressing and eating, and to work, study and contribute to the local community.” Quite simply, the eligibility threshold determines whether a person is able to seek state-funded support or have a care account to meter their care costs up to the cap.

186. Marc Bush, the Head of Research and Public Policy at Scope, told us that “the recent modelling that the PSSRU has done has shown that, if we take moderate level needs, there are 36,000 people within the system of working age who, if the reforms go through as they are currently set, would fall out of the care system. There are 69,000 working-age disabled adults in England who have already fallen out of the care system because of the changes to eligibility …” He thought that “if you do not meet need early, people’s needs escalate and the costs escalate. We know that there is a direct correlation between councils

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139 Q 152.
140 The London School of Economics Personal Social Services Research Unit.
141 Q 185.
having to ration their resources and therefore heighten the eligibility so that it is further towards substantial and critical, and that having a direct effect on the escalation of need.”

187. Sue Brown, the Head of Public Policy at Sense, said: “The Care and Support Alliance, and pretty much the entire sector, would like to see a threshold that is probably roughly equivalent to the current moderate band. The important thing to remember is “moderate” means moderate; “moderate” does not mean low. If you have a need that is moderate and is not being met, that is having a significant impact on your life.” Alex Fox saw the draft Bill as “an opportunity to describe more clearly what an acceptable level of well-being is, and to base eligibility on whether or not the impact of a long-term condition or impairment takes somebody below that level of well-being…”

188. Clause 13(1) of the draft Bill reads: “(1) Where a local authority is satisfied on the basis of a needs or carer’s assessment that an adult has needs for care and support or a carer has needs for support, it must (a) determine whether any of the needs meet the eligibility criteria, and (b) if any of them do, consider what could be done to meet those that do.” This does not of course say anything about what the eligibility criteria should be. The clause is currently drafted to require the Secretary of State to make regulations about the local authorities’ exercise of that duty, but gives him a very broad exercise of his discretion. We have already recommended that, in making regulations, the Secretary of State should have regard to the duty of local authorities to promote individual well-being. We recommend that clause 13(2) should be amended to make it a specific requirement for the Secretary of State, when making regulations concerning eligibility, to have regard to this duty. We are glad to note that these regulations will be subject to affirmative resolution.

The national minimum eligibility threshold

189. There is nothing in clause 13, or in the notes to it, to suggest that the regulations will be used to introduce a new national minimum threshold; on the contrary, the regulations can provide that the levels of need are to be set either by individual local authorities for their areas, or by reference to levels of need specified in the regulations. However in the White Paper the Government made the following commitment: “From 2015 we will introduce a national minimum eligibility threshold. Once implemented, local authorities will be free to set their eligibility threshold at a more generous level, but will not be able to tighten beyond the new national minimum threshold”. Such a threshold is desirable in any event; without it, implementation of the Dilnot recommendations would not be possible.

190. In reply to a question whether it was the Government’s intention, having regard to resources, to have a national threshold as the minimum people could expect across the country, the Secretary of State replied unequivocally “Yes”; though he was, understandably,
not prepared to commit himself to what that threshold would be. The Dilnot Commission recommended that, as a minimum, it should be “substantial” under the FACS system, but the evidence we have quoted above shows that many of those most closely involved believe this would be too high a threshold.

191. We are glad that the Secretary of State confirmed the Government’s intention to set a national minimum eligibility threshold. The Government should put this beyond doubt by redrafting clause 13 to make this policy explicit. We also suggest that the Government should consider whether the regulation-making power in clause 13 provides an opportunity to establish criteria that would clarify the boundary between eligibility for local authority funded care and support and NHS funded continuing care.

Charging: Clause 14

192. When meeting an adult’s needs for care and support under clauses 17-18, or a carer’s needs for support under clause 19, local authorities are given by clause 14 a power to impose charges. Sue Bott expressed her concern: “We have seen charges go up enormously over the last few years. Inflation does not enter into it. We have seen a situation of hyper-inflation with regard to the setting of charges”.

193. At present primary legislation stipulates (in relation to non-residential services) that a local authority cannot charge for a service more than it appears to them to be “reasonably practicable” for the person to pay. This statutory protection is not present in clause 14. We put this to the Department of Health. They replied that what it was “reasonable” to charge was never defined, but said that in future, to ensure that charges for care and support are reasonable, regulations must specify an amount below which an adult’s income must not fall after charges have been deducted. We note however that the courts and the Local Government Ombudsman have found the requirement in primary legislation of “reasonableness” to be of value in cases concerning the level of such charges.

194. As we have explained in paragraph 166, support under clause 8 can include not just care and support as this is usually understood, but information, advice, advocacy, and other matters. The Department told us that they did not intend to require local authorities to charge for types of support which had previously been provided free. Local authorities would retain a discretion to charge or not to charge for a wide range of types of care support, but would not be able to impose charges for any types specified in regulations under clause 14(4). These regulations would require that types of support which are currently provided free—for example, equipment and minor adaptations—should continue to be provided without charge. It was not clear to us whether local authorities

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148 Q 326.
150 Q 210.
151 Section 17 of the Health and Social Services and Social Security Adjudications Act 1983.
152 Note of 30 January 2013.
would be able to charge for needs assessments. They are currently not able to, and the Department of Health assured us that the draft Bill would not change this.\textsuperscript{154} They undertook to consider whether more could be done to make this clear on the face of the draft Bill.

195. Our final concern was that there was now the potential for carers to be charged for a wide range of local authority interventions. At present most local authorities do not charge carers for carers’ services. We wondered whether it was the intention that carers should now be charged for support that gave them respite from their unpaid caring roles. The Department explained that although local authorities do at present have a power to charge carers for the support they receive, most do not charge for most types of support, reflecting the critical contribution which carers make to the well-being of those they care for. The draft Bill did not set out to change this position. It consolidated the existing discretion to charge, but did not presume or intend that charging for carers’ support would become usual practice. The Department added: “In particular, the draft Bill makes clear that meeting a carer’s needs may involve providing a service direct to the person they care for, rather than direct to the carer (for instance, replacement care, in order to allow the carer to have a break). In these cases, the local authority must assess the resources of the person cared for, on the principle that the person directly receiving the service would pay any charge—even if provided in order to meet the carer’s needs. The person to whom the service is provided must agree—and where this is not the case, the draft Bill requires the local authority to consider alternative arrangements.”

196. We remain concerned that the combination of a general discretionary power and an open ended regulation making power could have unintended consequences and lead to charging creeping into more areas. The Department of Health’s reassurances are welcome, but we believe that for the avoidance of doubt it should be made clear in clause 14 that where charges are imposed they should be limited to what it is “reasonably practicable” for the person to pay. Clause 14 should also be amended to make clear that local authorities cannot simply charge the carer for services provided to the person cared for.

**Deferred payments: Clause 16**

197. A deferred payment agreement between an adult needing care and the local authority providing the care allows the adult to defer payment, the payment being secured on the adult’s home. It is thus potentially a complex agreement, and is likely to be seen as such by adults in a vulnerable position. They should not enter into such an agreement without financial advice. Just Retirement, a specialist provider of financial services for people in retirement, argued in their written evidence: “For the same authority which has a duty of care to a vulnerable adult to be providing financial advice and information about a financial product which it is offering (in the form of an interest-bearing loan secured against the individual’s home) to pay for care services represents a potential conflict of interest. This conflict is exacerbated if the care for which the loan is made is directly provided by the LA and the level of charges are also determined by the LA.” A similar argument was put forward by the Society of Later Life Advisers (SOLLA).
198. Our recommendation\textsuperscript{155} that clause 2(2) should be amended to ensure that the adult is informed of the importance of independent financial advice from an adviser regulated by the Financial Services Authority, and is advised how to obtain it, is of particular importance in the case of deferred payment agreements.

**Charging interest**

199. Care and Repair England highlighted a general concern about proposals to add to the deferred payment interest, plus administrative charges, plus interest on those charges, thereby resulting in what they called a ‘snowballing’ level of debt accruing on the value of the home owned by the adult needing care. We think it reasonable that interest at a rate governed by regulations under clause 16(4) should be charged on the amount of the adult’s payment which is deferred, since this otherwise becomes an interest-free loan. We also think it right that a charge should be imposed to cover the local authority’s administrative costs (limited to what is allowed by regulations under clause 16(6)(a)). But we think it excessive that the adult should pay interest on administrative costs, some of which may have been incurred many years previously. \textbf{We recommend that clause 16(4)(c) should be deleted.}

**Self-funders: Clause 17**

200. Clause 17(3) entitles self-funding adults who have the requisite mental capacity to require their local authority to meet their needs (subject to paying for this). Given that a substantial proportion of adults with care and support needs are currently self-funding, the extension of local authority responsibility to such persons is likely to have significant resource implications. The likelihood of such persons seeking local authority involvement will be increased as a result to the Government’s plans to implement the Dilnot proposals—for the reasons we outline in Chapter 2.

201. In contrast to clause 17(3) (which concerns the rights of self-funding adults who have the requisite mental capacity), clause 17(4) creates a substantial additional hurdle for a self-funder who lacks the requisite mental capacity. Such a person would not in general have the right to require their local authority to meet their needs (subject to paying for this) if they had (for example) a Lasting Power of Attorney (LPA)—even if the attorney is unwilling or unable to make the care arrangements. Even if there is no attorney or equivalent, the clause 17(4) duty would not arise if the local authority decided that someone (for example a family “carer”) was “in a position” to provide support on the person’s behalf. We consider that it is wrong in principle to place a person with impaired mental capacity in such a disadvantaged position, and we put our concern to the Department of Health. In a note of 30 January the Department responded, stating that it “takes on board these comments, and will consider whether any changes are necessary. It is not the Government’s intention to create a disparity.” We welcome this undertaking to look again at the drafting of this clause.

\textsuperscript{155} Paragraph 91.
Personal budgets and resource allocation systems

202. Beyond the question of reasonable cost we did not receive much evidence during our inquiry on the introduction of a statutory footing for personal budgets. In Chapter 2 we discussed the implications of introducing a capped cost scheme and the use of notional costs to meter a person’s progress towards the cap. We anticipate that resource allocation systems (RAS) will be used to determine what the notional cost should be, and recommend that these arrangements should be governed by regulations made under the new statute. However, this still leaves the question of those in receipt of local authority support and what role, if any, RAS should play.

203. In response to our web forum a number of people raised concerns about how eligible needs are met. One said: “After an assessment is done [it is] referred to a panel who have no knowledge of the persons involved and report back on their findings. This is where finance rules supreme and goal posts are moved to make it easier for the panel to refuse to give more care help. There should be national standards to adhere to as the duty of care is the thing that is lost in the decision making.”

204. The draft Bill confirms the pre-eminence of the duty to meet eligible needs, and clause 25(1)(a) requires the local authority to record in the personal budget the amount it assesses as the cost of meeting those needs. It is how those costs might be calculated that is left unclear. That is where RAS comes in. We note that some of the proponents of RAS have begun to question the secretive way in which they are developed and applied and expressed concern about their growing complexity156. As we say in Chapter 2, some of these issues were raised during the Law Commission’s work; however the Department in its summary of the responses to the draft Bill157 report only welcome for personal budgets and make no reference to how the costs are calculated. We therefore recommend that the Government should review the efficacy of RAS and ensure that the code of practice or guidance makes clear that the development and application of any methodology for calculating the cost of meeting eligible needs is transparent, has regard for the well-being principle, and is subject to the duty to meet eligible needs.

Additional cost under Clause 27

205. Clause 27 deals with the additional charge—the “top-up”—which a local authority may levy for providing an adult’s preferred accommodation where the cost exceeds the amount of the person’s personal budget. The cost may be paid by a third party, usually the family—“third party top-ups”. As with deferred payment agreements, some of our witnesses had concerns about the need for and availability of independent financial advice. Independent Age said: “[W]e received over 200 calls to our Advice Service in the past year on this subject. It is vital that the new legislation ensures that families only agree to pay a third party top-up when they have made a genuine choice to pay for more expensive accommodation. We believe that the draft Bill must ensure that the rights of these individuals and their families are protected more effectively than at present.”158

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158 Written evidence, paragraph 7.
206. Independent financial advice from an adviser regulated by the Financial Services Authority is as important in the case of additional cost under clause 27 as it is in the case of deferred payments.

207. We are not satisfied that clause 27, as currently drafted, provides sufficient protection from improper practices of the type highlighted by Independent Age (among others). The amount of a person’s personal budget is specified by clause 25(1)(a) as “the amount that the local authority assesses as the cost of meeting those of the adult’s needs which it is required or decides to meet …”. We were concerned that the wording of clause 25(1)(a) might enable a local authority to come up with a relatively arbitrary figure (produced, for example by a computerised resource allocation system) and then require a top-up for all care costs above this figure. Such a figure, being an amount assessed by the local authority, would appear to satisfy the requirements of the clause. We were in particular concerned that this clause differs from the current requirement (in relation to direct payments) that the amount be that which the “authority estimate to be equivalent to the reasonable cost of securing the provision of the service concerned”, the difference being the absence of the word “reasonable” which has been considered of importance by the courts when considering amounts generated by resource allocation systems. We put our concerns to the Department of Health. In response they advised us that the “personal budget represents the amount which the local authority assesses as the cost of meeting the adult’s needs. It is therefore an amount which is sufficient to meet those needs.” We do not find this response reassuring. Clause 25 contains neither the word “reasonable” (which appears in the current legislation) nor the word “sufficient”. We believe that this omission creates an opportunity for the current malpractice in relation to top-ups to continue under the new legal regime.

208. Clause 25(1)(a) should be amended to make clear that the amount of a personal budget should be equivalent to the reasonable cost of securing the provision of the service concerned in that local area.

**Direct payments: Clauses 28-30**

209. Direct payments to persons in need, allowing them to have more control over the services they buy and the priorities they accord to them, are likely to become a much bigger feature of social care in the future. We welcome the opportunity taken in the draft Bill to clarify important aspects of the policy, and to ensure that the expansion is in the right direction.

210. The Standing Commission on Carers was one of several witnesses who sought clarification on whether the person receiving a direct payment will be able to use it as the equivalent of a personal budget either for “whole family” purposes or to compensate another family member for loss of earnings. They told us that this was commonplace in some European countries. Shared Lives Plus argued that there should be a presumption that individuals can spend their direct payments how they like to achieve the desired

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160 “Reasonableness” was central to the judgment of the Supreme Court in R (KM) v. Cambridgeshire County Council [2012] UKSC 23 – eg paragraphs 9, 21, 38 and 40 – and see also R (Sava) v Royal Borough of Kensington and Chelsea [2010] EWCA Civ 1209.

161 Written evidence, paragraph 7.
outcomes. We agree that the purposes for which direct payments can be used should be clarified, and the presumption should be that individuals can spend their direct payments as they like to achieve the agreed outcomes. We would prefer to see this in the draft Bill itself. If it has to be included in regulations under clause 30, they should be subject to affirmative resolution.

211. Since the introduction of direct payments there has been a requirement that they are spent on services provided in the independent sector. Whatever the reasons for this policy we question whether it is consistent with the well-being principle established in the draft Bill. People in receipt of a direct payment should be in control and able to exercise choice. With the draft Bill introducing a duty on local authorities to promote diversity and quality in the provision of services there is no longer a need to restrict how direct payments may be used. The Department of Health should lift the ban on direct payments being used to pay for local authority direct services if the individual so chooses.

212. Direct payments are another area where independent financial advice will be essential both when the payments are first arranged, and subsequently.
6 Other responsibilities of local authorities

Portability: Clauses 31-32

213. Portability or, as the draft Bill describes it, continuity of care when an adult moves, refers to the ability of service users to ensure continuity of support when they move from one local authority area to another.

Language

214. The first matter to address is the language used in the Bill. The local authority from which the adult is moving is referred to as the “sending authority”, and the authority to which the adult moves as the “receiving authority”. We share the view of some of our witnesses\footnote{Self Direct and Shared Lives Plus} that this language reinforces a paternalistic culture in which some local authorities behave as if they have some sort of control over where people in need of support should live. In principle, people have a right to live where they choose – or, if they lack capacity, where those with their best interests decide. It is not for the local authority to “send” them anywhere. The language of the Bill should make clear that decisions about where to live are separate from decisions about which body funds a care package. We would prefer neutral language; the authority from which the adult is moving could be referred to as the “first” or “original” authority, the authority to which he or she is moving as the “second” or “new” authority.\footnote{As in the Social Care Portability Bill, currently before the House of Lords.} This language should be used in the Regulations, Code of Practice and Guidance as well as in the draft Bill.

215. \textbf{We agree with those of our witnesses who object to the language of “sending” and “receiving” individuals. We prefer neutral language which emphasises that people control their own decisions, and recommend that clause 31 should refer to the “first” and “second” authority, or to the “original” and “new” authority—the wording we use in this report.}

Ordinary residence

216. Where an adult is ordinarily resident generally influences, and often determines, which authority has a duty to provide for the adult’s needs. Clause 32 defines where an adult is to be treated as ordinarily resident, and clause 33 sets out the machinery for resolving disputes about ordinary residence, which are all too frequent. We have no problems with these provisions.

217. It was suggested to us that not only should people be in control of where they reside—which, as we have said, we fully support—but that individuals should have “the option of deciding their own ordinary residence status and therefore which authority continues to fund their care package.”\footnote{Shared Lives Plus.} This, we were told would prevent local authorities from...
“manipulating the system”. We do not accept this suggestion. The choice of where to reside is not the same as the choice of where to be treated as residing for particular purposes. A person residing in an area where treatment of those with particular needs is ungenerous should not be entitled to more generous treatment solely on the ground that in the past—perhaps a long way in the past—he or she resided in a different area where treatment was more generous.

218. **We do not accept the suggestion that individuals should have the option of deciding their own ordinary residence status and therefore which authority continues to fund their care package. Funding must be for the local authority where the person is ordinarily resident or is treated as being ordinarily resident.**

### Continuity of care

219. The principle of portability is that an adult who moves to a different local authority area should continue to receive from the local authority the same level of care and support that was being provided by the authority where he or she was ordinarily resident, or treated as being ordinarily resident, before the move. This is easy to state and, like our witnesses, we wholly support this.

220. The more difficult question is for how long the first authority should continue to be under a duty to provide that level of care and support. The draft Bill provides that the responsibility to do so continues until the new authority has carried out its own assessment of the need for care and support. Some of our witnesses thought this responsibility should continue indefinitely. VODG recommended “that the original (sending) local authority should remain responsible for funding a person’s care and support for as long as they are eligible for it.”165 Other of our witnesses voiced their concerns. The Alzheimers Society were “concerned that there is no guarantee that the individual will receive the same level of care once the receiving authority carries out an assessment of need. It is quite common for individuals with dementia to move closer to family members as their illness develops. Concerns that a person may no longer receive the same level of social care may deter people from making moves that would otherwise improve their wellbeing and support the family to care for the individual. We believe it is unreasonable for the level of support a person receives to depend on where they live.”166 Disability Rights UK told us: “Many disabled and older people can’t consider moving to another area because they can’t be sure that they will get equivalent levels of care and support in the new area. Disability Rights UK considers this to be a significant breach of basic human rights, depriving people of choice and control over their lives, denying them job and education opportunities or the chance to live closer to family or friends.”167

221. We believe such views fail to distinguish between the assessment of a need and the local response to the need. The point was well put by Sarah Pickup: “Say you had acquired a disability and lived in a two-storey house or block of flats and moved to another area, to more suitable accommodation, then some of your needs will have been met, by definition, by moving. Of course we do not dispute the fundamental disability, need, frailty or

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165 Supplementary written evidence, paragraph 6.1.
166 Written evidence, part 1.
167 Written evidence, paragraph 35.
diagnosis of dementia; those things do not change. However, the fullness of a needs assessment, even just to the point of assessment—before agreeing with your line about the support plan being a different thing—is that needs incorporate circumstantial issues. You may have a bigger need if you move from a rural area to a town, or vice versa. That is part of the needs assessments. Fundamental needs absolutely do not change, but circumstantial impact on needs does change.”

222. Councillor David Rogers told us: “… communities are very different and very diverse around the country. … the range of providers is very different in different parts of the country, as are the local circumstances: whether they are urban, rural or any other factor you might choose to bring into account. That balance between portable assessment but local decisions on how those needs are met is something we have always said is extremely important. We strongly believe that the decision-making about how those needs are met for those who are receiving taxpayer-funded services should be a local decision.”

223. We accept this view. As Richard Humphries said: “As long as you have got 152 different funding settlements and levels of resources, there will always be variation in the sorts of packages that people can expect…”

224. We are glad that after a move to a new local authority area there will be continuity of care until a re-assessment. We think it inevitable that the level of care may change after a move; indeed, that may have been the purpose of the move.

225. We do not accept the suggestion that the original authority should continue to fund the care so long as the person is eligible for it. Funding must be for the local authority where the person is ordinarily resident. However the Government may wish to consider whether there should be guidance on the minimum period during which an original assessment should be protected.

A possible failure of care

226. We were concerned that clause 31 does not address the possibility of what might happen if a new authority fails to act in the way it is required to—for example, if it fails to comply with its duty under clause 31(6) to meet the newly arrived adult’s needs. For such an adult there would be no safety net—unless the original authority retained residual responsibility in such cases (as, for example, provided for in clause 4 of the Social Care Portability Bill, now before the House of Lords).

227. We put this point to the Department of Health. In a note of 30 January the Department stated: “The Department does not envisage local authorities refusing to comply with their legal obligations”. Nor do we. But a failure to comply with their obligations is all too possible. We put this to the Local Government Ombudsman, Dr Jane Martin, and in her letter to the Committee of 31 January 2013 she told us that the provision had the potential to cause difficulties. In her opinion: “Maladministration may occur by

168 Q 111.
169 Q 109.
170 Q 57.
171 HL Bill 78.
failure of the sending authority to notify the receiving authority of a user’s intention to move, failure of the receiving authority to assess a user’s needs or if a receiving authority fails to implement or deliver programmes as outlined in section 31(6). All these areas could have a major impact on the provision of care and impact on service users’ experience. Local authority delay in providing the services mentioned above, may further dramatically affect users experience.”

228. We share this view. We believe that clause 31(8) should be amended so that the original authority is absolved from meeting the adult’s or carer’s needs only once the new authority has itself begun to meet their needs, as it is required to do by clause 31(6).

229. The Social Care Portability Bill, noted above, in clauses 4(2) and 6(2) provides for the new authority to be reimbursed its costs when an original authority fails to comply with its obligation to support a person who has moved. It appears to us that this provision is sensible and addresses the potential problem of a perverse incentive in such cases—namely, that a new authority might benefit financially from its delay (something that is happening under the existing regime).

Transition of children to adult social care: Clauses 39-44

230. The draft Bill relates to adult social care, but provides a power for local authorities to assess the needs of children, young carers and the parent or carer of a child if requested to, for the purposes of planning transition to adult social care when the child turns 18. The assessment covers both the child’s and young carer’s or child’s carer’s care and support needs, and what those needs are likely to be when the child or young carer reaches the age of 18. The local authority is not required to undertake the assessment, and this has been criticised.172 The clauses also provide that, where a child is in receipt of services under the Children Act 1989, those services will be continued after their 18th birthday until the assessments and care planning required by the draft Bill have been completed and any care and support required is in place.

231. In parallel to the draft Care and Support Bill, the Government have put forward the Children and Families Bill. Certain clauses of this, relating to special educational needs (SEN) provision, have been examined by the House of Commons Education Committee.173 That Committee has recommended that the application of these clauses, which create a right to an Education, Health and Care Plan for children with SEN, should be extended to cover disabled children without SEN.174

232. We have heard a range of evidence on the application of the draft Bill to children and young people. Much of the evidence welcomes the transition clauses. The National Autistic Society cited evidence that that only 53% of young people with autism who have statements of SEN were issued with transition plans during the course of their education, falling to just

172 For example by National Autistic Society, written evidence, paragraphs 26-29.
174 Ibid paragraph 78.
34% of students in mainstream schools. Adult social services were only involved in planning in 17% of cases.  

233. We agree that the transition clauses are a welcome development and meet a real need for improved transition planning. We also welcome the requirements that a local authority must continue to provide services under section 17 of the Children Act 1989 until it has met its duties under the draft Care and Support Bill for that person.

234. However, we have heard much evidence on how the clauses could be improved. The Papworth Trust expressed disappointment that the draft Bill did not extend to all ages, while Lorraine Butcher, the Strategic Director for Children, Families & Adults, Cheshire East, who spoke for the Association of Directors of Children's Services (ADCS), highlighted the complexity of support for learning disabled people and told us that she would prefer to see a support service through all the age range. Most witnesses, however, appeared to accept the current scope of application, but made a convincing case for improvements. These relate to three main areas: the children and carers to which the transition provisions apply; the relationship with Education, Health and Care Plans under the Children and Families Bill; and the situation of young carers.

**The children and carers to whom the transition provisions apply**

235. We do not agree with the requirement in clauses 39–44 that not only must there be a “child in need”, as provided for in section 17 of the Children Act 1989, but also that the child (or the child’s family) must be receiving services under that section. This is a higher threshold than is set for adults in need of care and adult carers, where it only needs to appear to a local authority that the adult may have needs for care and support (or support in the case of a carer). This seems incongruous, and will undermine the goal of smoothing transition into adult social care, in that it leaves out of the scope of these provisions a potentially significant number of children who are likely to need care and support under adult services. As to where these gaps are, Mencap highlighted that “young people with a learning disability may also receive services under the Chronically Sick and Disabled Persons Act 1970, or through other means, including educational settings, and as a result they would not be eligible for the transitional arrangements under this Bill.” Evidence from local authorities highlighted similar gaps relating to those whose care and support needs do not emerge, or are not identified, until adulthood: “One of the biggest challenges of transition is that people who get children’s services, for a range of reasons, are not always entitled to adult services, and vice versa. So people who have made it through the education system without any social care support sometimes become vulnerable adults and need support. So they are not identified for transition because they were just in the education system.”

236. The same is true for young carers. Barnardos cited the example of their Indigo service in Essex, which works with young carers. They reported that only 20% were in receipt of

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177 Q 126.
178 Mencap, written evidence, paragraph 38.
179 Sarah Pickup, President of ADASS, Q 126.
Children in Need Plans or more intensive statutory support. This suggests that 80% are outside the scope of the transition clauses.180 This concern is echoed by the Standing Commission on Carers, who highlight that “Many young carers will not be receiving services under section 17 of the Children Act but will be supporting parents whose care and support, if any, will be provided under current adult social care legislation, eg the Chronically Sick and Disabled Persons Act.”181 The Children’s Society,182 the Care and Support Alliance183 and the Carers Trust184 made similar points.

237. We accept that there is a strong case for extending the application of the transition clauses beyond “children in need” as defined by clause 39(3), and beyond a “young carer” as defined by clause 41(3). If the purpose of the transition clauses is to enable a smooth transition to adult social care, then it is essential that local authorities have the power to assess all those who, on turning 18, will come within the remit of adult social care regardless of whether they or a family member are currently receiving services under the Children Act.

238. We recommend that the transition clauses (39–44) be amended, in line with the threshold set in clauses 9(1) and 10(1), to apply where it appears to a local authority that a child or young carer may have needs for care and support at the time of the request for the assessment or on reaching 18 years. This should apply regardless of whether or not support is currently being provided, but there should be a presumption that any child in receipt of an Education, Health and Care Plan under the Children and Families Bill, and any child receiving care and support, or who has family members receiving care and support, under other legislation, comes within this definition.

239. A further consequence of reliance on section 17 of the Children Act 1989 is that the provision on continuity of services, which only relates to services provided under section 17, is likely to leave important gaps. The Carers Trust argue that it appears to omit continuity of services provided to young carers under the Carers and Disabled Children Act 2000.185 The same issue arises for continuity of services under the Chronically Sick and Disabled Persons Act 1970 and for continuity of services in the Education, Health and Care Plans under the Children and Families Bill.

240. We recommend that clause 43 be extended to include services provided under the Carers and Disabled Children Act 2000, the Chronically Sick and Disabled Persons Act 1970 and in Education, Health and Care Plans under the Children and Families Bill.

Relationship with Education, Health and Care Plans under the Children and Families Bill

241. There is potential cross-over with the provisions on SEN currently being put forward through the Children and Families Bill. A local authority could be assessing the care and
support needs of a child with SEN for the purposes of transition or the needs of an 18-24 year old with SEN, while at the same time it or another authority is assessing them for an Education, Health and Care Plan. Clause 12(4) of the draft Care and Support Bill deals with contemporaneous assessments for those over 18. It is not however clear whether “another assessment” in that subsection refers only to another needs or carer’s assessment, or whether it is wide enough to include assessment for an EHCP. Similarly, clause 42(4) and (5) make provision for contemporaneous assessments for a child or child’s carer and a young carer respectively. These are worded in the same way as clause 12(4) and present the same difficulties.

242. The relationship between the draft Care and Support Bill, and Care and Support Plans in particular, is not yet clear. This lack of clarity undermines the aim of the legislation to smooth the transition to adult care services. If further adds a layer of complexity to provision for 18–24 year olds that, if allowed to continue unaddressed, will undermine the aim of simplifying the legislation on social care.

243. The Every Disabled Child Matters Campaign argue that “If a young person is eligible for both an EHC plan and a Care and Support Plan, these plans should be brought together to create a consistent approach from 18 to 25. Social care needs identified in an EHC plan should be met through a Care and Support Plan post-18. Outcomes identified in a young person’s EHC plan should also feed directly into adult assessments for Care and Support Plans.” We agree with this assessment. Our recommendation that the application of the transition clauses should not be restricted to “children in need” will be needed to meet this aim, as will amendment of the clauses on contemporaneous assessments.

244. Clauses 12(4), 42(4) and 42(5) should be amended to make clear that “another assessment” includes assessments carried out under other legislation, and specifically Education, Health and Care Plans.
7 Other care and support matters

Young carers and parent carers

245. The draft Bill does not make direct provision for young carers, other than in relation to transition planning. Contact a Family raised concerns about the approach being taken, telling us that “the retention of three amended Carers Acts means that although parent carers’ theoretical rights will be protected this is only by virtue of obscure and muddled rump legislation.” Similar criticisms apply to the legislation covering young carers. Other evidence argued that the requirement to provide a substantial amount of care on a regular basis, removed for adult carers of adults, should also be removed for young carers and parent carers.187

246. Explaining their reasons for this, the Department of Health told us that “Provisions are not the same, and never will be the same, because, when you are talking about young carers, you are talking about a child, so it is not just about identifying a young carer and saying, ‘Okay, what does that person need to support them in their caring role?’ Actually, there is a question of, ‘Is that an appropriate caring role and is this in fact a child in need who needs support in different ways?’”188

247. We agree with the Department on the importance of preventing children from undertaking inappropriate caring responsibilities. In paragraph 182 we recommended an amendment to clause 12 which would help to achieve this. However we share the concern of a number of our witnesses that an unintended consequence of the draft Bill applying only to adults will be to leave young carers with lesser rights than adults.

248. Dr Moira Fraser made the point to us that “We have to have two pieces of legislation that talk to each other.” While many of our witnesses told us that young carers should be treated differently, echoing the view of the Department, they did not want to see young carers relegated to a lesser status. Dr Fraser summed it up when she said: “What we need to be doing is this: the adult legislation needs to ensure that children who are in a household with a person who is being assessed for care and support are recognised as being part of that household and may have a caring role so that a referral can be made, so they can have an assessment. Hopefully, under adult services, the adult services can look at the needs of the adult and meet those needs so that the child does not need to take on a caring role.”189

249. Frances Patterson QC made plain the unintended consequence: “When there is an assessment it is still done under the old regime so there is still a requirement to show that a young carer is delivering substantial and regular care. The threshold is different; it is not the low threshold we have recommended in the adult social care statute. That is where we think there is an area for improvement.” She also told us that “we made various recommendations in relation to young carers. Those have been taken forward in part but not in whole, and our view is that they are much better taken as a whole.”190

187 For example, the Children’s Society.

188 Q 20.

189 Q 157.

190 Q 83.
250. Critically for the Law Commission, “The bit missing is the provision of services. The Bill, as currently drafted, makes provision for assessment in relation to young carers but our recommendation is that there should be assessment and there should be the provision of services in certain circumstances. To enable that to be delivered we were recommending that the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 were both amended to bring them into line with our recommendations in relation to the adult social care statute as it then was. Either they would then be brought together so there would be a freestanding young carers’ statute or they would be transported into what has become the Care and Support Bill.”

251. The Department of Health accepted that it is important to ensure that the provisions work together well. However, we believe a confused picture has emerged of the provision available to young carers, and how it relates to adult social care. If young carers are to be properly supported children’s services need to have the responsibility to assess the needs of the child and, where it becomes apparent that there are needs the adult has, refer back to adult services so that the adult’s needs can be met. It needs to work in both directions. In supplementary evidence the Department assured us that it “is in discussions with the Department for Education about how best to address the concerns that have been expressed, including the implications for existing and planned children’s legislation.”

252. In response to points raised by Committee members on the need for amendments to the draft Bill the Minister of State, Norman Lamb MP, said: “I would just say we have to be prepared to look at this. We have noted your concerns and we will have further discussions both within the Department but also across the divide between us and Education.”

253. We welcome the Minister’s commitment to discussions on young carers, and expect the Departments of Health and Education to work together to ensure that young carers do not fall between the cracks or face a higher threshold for receiving any support. The most straightforward solution would be for the draft Bill to be amended in line with the Law Commission preference to bring updated legislation for young carers into the draft Care and Support Bill.

254. Guidance on the application of the assessment and transition clauses should provide local authorities with clear information on the support available to carers and young carers. This guidance should aim to ensure that there is easy access to provision for carers, regardless of which legislation the provision is made under.

255. The Law Commission originally proposed that local authorities should have the power to provide services to 16 and 17 year olds. This would include young carers. The Government rejected this, taking the view that this was better dealt with in legislation specifically dealing with children and young people for the reasons given above. In oral evidence, the Law Commission stood by its view that such provision was appropriate.

191 Q 84.
192 Q 20
193 Supplementary evidence, 30 January 2013.
194 Q 339.
195 Recommendations 58 and 59 at pages 162 and 164.
196 Q 99.
There is a real need to prevent inappropriate caring by young people. However, the Committee agrees that local authorities should have the flexibility to provide services under the draft Care and Support Bill in appropriate cases.

256. **We agree with the Law Commission’s view that local authorities should have the power to make provision for children aged 16 and 17, including young carers, where an assessment under clauses 39 to 44 identifies need. We further recommend that this should be done in a way that recognises that the aims of support to young carers will often be different from those for adult carers.**

**Redress and complaints**

257. When the Law Commission embarked on its review in 2008 it argued that it should consider the “efficacy of the legal structures in place for complaining about, and seeking redress for, failures in decision-making and service provision by local authorities.”

This would have included considering whether a tribunal should be set up to provide “independent merits review” of care and support decisions made by local authorities. However, the Government at the time took the view that this was outside the scope of the review, and the Law Commission did not pursue it.

258. Despite excluding redress and complaints from its consultation paper in February 2010, the Law Commission received a number of responses arguing for a tribunal. Amongst those responding was the Henry Spink Foundation. They suggested that there should be a tribunal for the resolution of disputes relating to social services assessments, including eligibility and the detail of support packages. They argued that “operating a tribunal to resolve disputes would save considerable amounts of money in place of each local authority resolving disputes in-house”.

259. This view has been echoed in evidence to our inquiry. In written evidence ADASS and the LGA told us: “... we are concerned that a bill so strongly focussed on personal entitlements does not provide for any means of redress other than through judicial review.” In their evidence Advice UK expressed concern about this omission from the draft Bill: “Specific complaints and appeals duties are notably missing from the Bill ... Duties regarding complaints and appeals about social care assessment and reviews are not adequately represented within the Bill, nor are specific requirements about the length of time any process should take.” Leonard Cheshire offered a solution: “We would also like to see an appeal route for people who are challenging decisions within the system, particularly decisions about eligibility. At present it can be incredibly difficult and time-consuming for an individual to challenge decisions that they consider to be unfair or unreasonable. Having the protection of judicial review is important, but, like the Law Commission, we would like to see a specific route of challenge through an independent tribunal for contested decisions within the system.” They concluded: “This additional route should help to limit the potential for costly and lengthy court proceedings.”

260. In its report the Law Commission said: “Notwithstanding the decision not to take this area forward in the substantive project, the issue of complaints and redress came up at the...
majority of consultation events we attended, and was raised in several submissions. In
particular, many consultees argued that a community care tribunal was needed to provide
a merits review of local authority decisions in this area. Although this issue is outside of our
remit, in our view both Governments\textsuperscript{199} should consider reviewing this area in the future.”

261. In their response to the Law Commission, the Government\textsuperscript{200} pointed out that
changes had been made to complaints handling in 2009, and that its White Paper had set
out further actions to improve and increase the opportunities to offer feedback. They
concluded: “… we do not believe that any more substantial legal reform in this area is
required at this time.” However, the response did not directly address disputes over
decisions made by local authorities.

262. Since the Government published their response they have announced plans to
implement a capped cost system. This will result in a large influx of people into the local
authority assessment system for the first time. As we explain in Chapter 2, we believe that
the arrangements for determining a person’s eligibility and then capping care costs by
setting a notional cost to be accumulated in a care account will be highly contested.
Although the draft Bill largely replicates the existing legal framework it does extend and
clarify entitlements, particularly for carers. It also incorporates into statute for the first time
Government policy on personalisation and self-directed care.

263. We believe that the significant extension of local authority responsibility for
assessment, and the introduction of the well-being principle into decision making,
warrant an urgent review of arrangements for providing redress and complaints
resolution. The Government should reconsider establishing a care and support tribunal
to provide independent merit reviews of decisions made by local authorities.

264. It also seems likely that the boundary between free NHS and means-tested local
authority services will continue to be contested. The draft Bill and the establishment of a
capped cost system are likely to make the boundary visible to more people. Clause 21(6)
provides a regulation making power to prescribe how to resolve disputes between local
authorities and NHS bodies over the boundary. However, it is not just about disputes
between public bodies. The Government should consider giving a care and support
tribunal the responsibility for resolving disputes over NHS Continuing Health Care.

**Corporate responsibility**

265. In our Call for Evidence we asked witnesses to address the specific question whether
the draft Bill strengthened corporate accountability for neglect and abuse, and what would
be the risks and benefits of creating a new offence of corporate neglect. This is not a new
issue, but was of course brought to the fore by the events at Winterbourne View.

266. In their written evidence VDOG wrote: “We strongly support the creation of a new
offence of corporate neglect within the draft Bill. The chief benefits include: bringing
accountability and underlining in law the seriousness of abuse of vulnerable people …”\textsuperscript{201}

\textsuperscript{199} The Law Commission report is addressed to Welsh ministers as well as to the Government.

\textsuperscript{200} http://www.dh.gov.uk/health/files/2012/07/2900021-Reforming-the-Law-for-Adult-Care_ACCESSIBLE.pdf

\textsuperscript{201} Written evidence, paragraph 48.
Mencap pointed out that “new offences of ill treatment and wilful neglect were brought in by the Mental Capacity Act 2005 … however it appears there may be a gap in the legislation ….” 202 The view of Action on Elder Abuse was that “individual and corporate bodies that take decisions that lead to the abuse of people in vulnerable situations should be accountable in law for their actions ….”203

267. There was a contrary view from Social Care and Institute for Excellence: “The offence of corporate neglect is covered in section 37 of the Health and Safety at Work etc Act 1974. The risks of creating a new offence in relation to social care is that it may promote a risk averse culture across partner agencies and discourage open and constructive dialogue between organisations, particularly when learning lessons from safeguarding adults reviews.” They prefer to rely on SABs. H&S at Work Act 1974 s.37(1) in fact applies only to “relevant statutory provisions”, none of which are relevant.

268. Our Chairman has recently introduced a ten-minute rule Bill. His motion was “That leave be given to bring in a Bill to hold corporations criminally accountable for abuse and neglect in care settings; to make provision to compel any person or organisation to supply information to Adult Safeguarding Boards; and to introduce a new offence of corporate neglect whereby a corporate body can be found guilty if the way in which its activities are managed or organised by its board or senior management is a substantial element in the existence or possible occurrence of abuse or neglect.” The first reading of the Corporate Responsibility and Safeguarding of Adults from Abuse and Neglect Bill was on 16 January 2013.

269. In supplementary written evidence Leonard Cheshire Disability said: “We believe that a criminal offence along the lines proposed in the Ten Minute Rule Bill will have an important declarative effect. It would affirm publicly the extreme concern of all right-minded people that no-one receiving social care services should be at risk of abuse or neglect and that providers must use all their skills and experience to this end—or face severe consequences.”

270. We asked the Department of Health for their views. They replied: “The Department is reviewing how corporate bodies are held to account for the provision of poor and harmful care. The horrific abuses that occurred at Winterbourne View emphasise the importance of corporate entities having robust processes in place for overseeing the quality of the services they provide. We aim to complete this review and to bring forward proposals to improve the arrangements for corporate accountability in the Spring. The review is considering both regulatory sanctions available to CQC and criminal sanctions. We are also assessing whether a fit person test should be introduced for Directors of providers of care services.”

271. During our inquiry Robert Francis QC published his report into the Mid Staffordshire NHS Foundation Trust. He made 290 recommendations, including proposals to strengthen arrangements in the NHS for corporate accountability, criminal liability, and proposals to transfer the Health and Safety Executive’s powers of criminal prosecution for

202 Written evidence, paragraph 35.
203 Written evidence, paragraph 2.38.
both individuals and organisations to the Care Quality Commission. The Secretary of State told us that he was “very sympathetic” to this proposal.204

272. We welcome this proposal to close the regulatory gap and to review the accountability of corporate bodies, though it is not clear whether proposals brought forward “in the Spring” would be in time for inclusion in the draft Bill. We would be concerned if the Government sought to close the regulatory gap for health but left it unaddressed in care and support. When we put this point to the Minister of State he replied: “I totally agree.”205 We recommend that where abuse or neglect of an adult has resulted in the commission of an offence by an employee of a body corporate acting as such, and this is proved to have been committed with the consent of, or to have been attributable to any neglect on the part of, a director, manager or similar officer of the body corporate acting as such, he as well as the body corporate should be guilty of an offence.

273. We put to the Secretary of State that a statutory duty of candour should not be considered for the NHS alone, but care and support too. In reply he told us that he could not “see why one would want to introduce something like a Duty of Candour—if that is what we decide to do, and I should add we are very sympathetic to the idea of doing it—that did not apply more broadly than just to the acute sector.”206 We share the Secretary of State’s view that the application of a statutory duty of candour should not be limited to health but should extend to all regulated care settings. The Care and Support Bill would provide an early opportunity for the Government to legislate on these matters.

Free end of life care

274. We have heard from a number of witnesses who want to see proposals for free end of life care implemented. Macmillan Cancer Support told us that 73% of people with cancer would prefer to die at home, but currently only 27% are able to do so.207 Marie Curie Cancer Care argue that “for people who are terminally ill, time is one of their most precious resources. It is important that they be able to spend their time with their family and loved ones in the place where they would most like to be.”

275. Significant improvements could be seen if our recommendation to fast track assessments for those on the end of life register is adopted. However, this would still leave many people paying for their care. Macmillan Cancer Support have told us that: “...there is anecdotal evidence from social care professionals that people are put off from applying for the care they need, or may even refuse care, as they are worried about the impact it will have on their families’ finances after they die.”208

276. A further danger of charging for end of life care is that it leads to “time-consuming debates [between health and social care providers] about who should pay for and deliver different aspects of a person’s end of life care.”209 A joint submission by Help the Hospices, 204 Q 315.
205 Q 315.
206 Q 332.
207 Written evidence, paragraph 1.3, 2.1.
208 Written evidence, paragraph 4.4.
209 Written evidence, paragraph 4.6.
Macmillan Cancer Support, Motor Neurone Disease Association, National Council for Palliative Care and Sue Ryder echoes these concerns and points to research by the Nuffield Trust showing that greater access to social care support has the potential to reduce the need for admissions to hospital at the end of life. They argue that “If we could reduce by just 10% the number of hospital admissions ending in death in England, the potential saving would be £52 million.”

277. We agree that “people approaching the end of life and their families should not have to face this financial or emotional burden, nor be forced to go without the care that they desperately require.” Witnesses have welcomed the Government view that “there is much merit in providing free health and social care in a fully integrated service at the end of life”. A decision on the final policy is not expected until 2014. Nevertheless, those who made submissions on this point argued strongly that it is critical that the draft Bill should allow free social care at the end of life to be delivered without the need for further primary legislation.

278. When questioned on this point the Department of Health confirmed that they “have not undertaken a policy decision that there should be a statutory right to free end-of-life care.” However in further written evidence they also clarified that “If a decision to introduce statutory free end of life care is taken, the powers in draft clause 14(4)(b) or (c) would enable regulations to provide for this.”

279. Form DS1500, to which we have referred in paragraphs 180-181 in connection with fast-track assessments for the terminally ill, prescribes special rules for those certified by their doctor as suffering from a progressive disease and not expected to live longer than 6 months. In the case of such people we agree with the Government and witnesses that free social care at end of life has “merit”, and strongly endorse the case for its introduction at the earliest opportunity. We welcome the clarification by the Government that the draft Care and Support Bill does not need to be amended to enable this.

**Human Rights Act 1998**

280. A number of witnesses have emphasised the importance of human rights to the provision of care and support. The Human Rights Act 1998 applies to public bodies and “any person certain of whose functions are functions of a public nature” and, therefore, to local authorities implementing the draft Care and Support Bill. This means that local authorities must observe the rights under the Human Rights Act 1998 and the provisions of the draft Bill must be interpreted, as far as possible, so as to be compatible with those rights.

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210 Written evidence, part 1.
211 Macmillan Cancer Care, written evidence, paragraph 4.5.
212 White Paper: Caring for our Future.
213 Gallagher Q9.
214 Department of Health supplementary evidence, 30 January 2013, Note 8.
215 For example, Disability Rights UK, Real Life Options, the NHS Confederation and the Equality and Human Rights Commission.
216 Human Rights Act 1998, section 6(2).
281. Care and support providers are often responsible for the care of some of the most vulnerable people in our society. We do not have to look far for documented evidence of abuse by providers. As one witness put it “Every week we are struck by another headline which reveals the neglect and ill treatment of older people either in their own home, a care home or hospital.”217 The report by the Care Quality Commission into Winterbourne View218 provides a stark example of what can happen when things go wrong.

282. As well as the risk of abuse, a not uncommon problem219 is of a self-funding resident whose family has made a legitimate complaint about their care being given 4 weeks’ notice to quit. A resident who has their care commissioned by a local authority has the right to challenge such a notice by reference to the Human Rights Act, but a self-funder who arranges their own care cannot—even if the trauma of moving would shorten their life, cause enormous distress and wrench them from a “home” in which they had lived for many years.

283. However, witnesses have pointed to two areas where there are concerns regarding the application of the Act. First, clause 51 enables a local authority to delegate certain of its functions under the draft Bill. The joint submission by Mind, Rethink Mental Illness, the Mental Health Foundation, the Centre for Mental Health and the Royal College of Psychiatrists argues that there must be a clear chain of accountability where functions are delegated. They go on to say that “It is also essential that the Bill states explicitly that the body with delegated authority to carry out a function on behalf of a local authority must be subject to the same obligations as the local authority itself. This includes obligations under the Equality Act 2010, Human Rights Act 1998 and Freedom of Information Act 2000.”220

284. We agree with this assessment. **Clause 51 should be amended to state that the person with delegated authority to carry out a function on behalf of a local authority is subject to the same legal obligations as the local authority itself.**

285. Secondly, the Equality and Human Rights Commission have told us that: “The Commission has received advice from Senior Counsel that, because of the case of YL v City of Birmingham Council,221 human rights protection does not extend to ... home care services. As a result approximately 500,000 older people may lack the protection of the Human Rights Act. Similarly, disabled adults receiving home care under these arrangements are unlikely to be covered by the Human Rights Act. This means many people may be denied direct legal redress against the care provider for human rights abuses.”

286. That such abuses occur is demonstrated by the findings of the Commission in their inquiry into home care.222 As a result of the YL case, legislation was required to ensure the

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217 National Pensioners Convention, written evidence, paragraph 4.1.
218 Care Quality Commission, Review of compliance: Winterbourne View (July 2011).
219 Joint Committee on Human Rights: The meaning of public authority under the Human Rights Act (9th Report, Session 2006-2007, HL Paper 77, HC 410, Written Evidence, Ev 11. 5, Memorandum from Age Concern at paragraph 5.2)
220 Written evidence, paragraph 30.
221 (2007) UKHL 27
application of the Human Rights Act 1998 to publicly funded residents of private care homes. This was done through section 145 of the Health and Social Care Act 2008. However, this did not address the gap in protection for those in receipt of publicly funded, but privately provided, home care services, and this gap remains. Nor did the Act extend protection to residential care other than that provided under the sections 21(1)(a) and 26 of the National Assistance Act 1948, such as services provided under section 117 of the Mental Health Act 1983.

287. The notes to the draft Bill state that “The Department’s view is that all providers of publicly funded or arranged health and social care services should consider themselves bound by section 6 of the Human Rights Act”.\footnote{At paragraph 134.} In her evidence on 7 February Sally Warren said: “You are absolutely right, we don’t want to create either duplication or a gap in the provision of human rights.”\footnote{Q 316.}

288. In a subsequent note the Department of Health told us that the Government considered that there were dangers in any amendment to the Human Rights Act which specified explicitly that third sector and private providers of care were subject to the section 6 duty; this in their view risked casting doubt on the interpretation of the Act in other sectors. But they added that it was the Government’s view that “all providers of publicly arranged care and support, including private and voluntary sector providers, should consider themselves to be bound by the duty imposed by section 6 of the Human Rights Act 1998”.\footnote{Note for the Joint Committee on the Human Rights Act, 21 February 2013.}

289. We do not think that, in light of the YL case, this view can be sustained without specific provision in the draft Bill to continue protection under section 145 of the Health and Social Care Act 2008 and to close the remaining gaps in protection. \textbf{While we agree that all providers of publicly arranged care and support should consider themselves to be bound by the obligations of the Human Rights Act, we are of the view that, as a result of the decision in the YL case, statutory provision is required to ensure this.}

290. Clearly, the risk of harm or abuse in care is not determined by who pays for or arranges the care. The Government’s view, as set out in the notes to the draft Bill, shows a belief that protection under the Human Rights Act extends to care arranged by a local authority, even if it is self-funded. As we say, we do not agree that this does not require explicit statutory provision. However, regardless of this view, it does not address the situation of self-funders who arrange their own care and support. The Government will need to consider whether it is right that, of all adults in need of care, only this group should lack the protection of the Human Rights Act, solely because there is no public sector involvement in arranging or paying for their care.

291. Many commentators have found it difficult to understand why a provider of care in such cases should not be subject to the law that protects patients whose care is commissioned by a local authority.\footnote{See for example comments of Baroness Howarth of Breckland (amongst others): House of Lords Official Report, 22 May 2008, column GC634.} This is particularly so, since it concerns some of the
most vulnerable people in society – and very severe shortcomings have been identified in some care providers, be they public hospitals or private care homes.

292. The draft Bill should be amended to ensure that private and third sector providers of care services regulated by public authorities are deemed to be performing public functions within the meaning of section 6(3)(b) of the Human Rights Act 1998. This would also bring such providers within the scope of the general public sector equality duty,227 which uses the same definition of “public functions” as the Human Rights Act.

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227 The public sector equality duty (PSED) is set out in section 149 of the Equality Act 2010, the broad purpose of which is to integrate consideration of equality and good relations into the day-to-day business of public authorities.
8 Health Education England

Background

293. Less than a year ago the Secretary of State used his powers under section 28 of the National Health Service Act 2006 to set up Health Education England (HEE) as a Special Health Authority. The Authority’s function was to exercise the Secretary of State’s duties relating to the planning and delivery of education and training to persons employed, or considering becoming employed, in the delivery of services as part of the health service in England.228 Chapter 1 of Part 2 of the draft Bill will now formally constitute HEE as a non-departmental public body with its constitution and functions set out in statute. This conversion of HEE from a Special Health Authority into an NDPB was welcomed by our witnesses.

294. Sir Keith Pearson, the Chair of HEE, told us that the NHS employs about 1.3 million people. “We underpin that with training, education and continuous professional development. At any one time there are about 160,000 people in undergraduate or postgraduate education, so there are a fair number of people who are being supported through education.”229

295. HEE, as its name implies, has responsibilities for England but not for other parts of the United Kingdom. At local level HEE establishes Local Education and Training Boards (LETBs), together covering the whole of England, as Committees of HEE, to help HEE in carrying out its planning, education and training functions in their respective areas.

Health care and social care

296. It would have been possible to give HEE responsibilities for social care, but Jamie Rentoul, the Director for Workforce Development at the Department of Health, told us: “The view of Ministers at that stage was that it should focus on health and public health, with a particular focus on essentially future-proofing the health and healthcare workforce in terms of the development of health professionals, …. the view that it should not have a primary social care focus has generally been supported by stakeholders.”230

297. This has led to a problem of terminology. The primary function of HEE is the education and training of “care workers”, an expression which, in a draft Bill whose main concern is social care, might be taken to include care workers other than health care workers. The expression “care worker” is defined in clause 55(9) by reference to a provision setting out the persons in relation to whom the Secretary of State has responsibilities for education and training, viz “persons who are employed, or who are considering becoming employed, in any activity which involves or is connected with the delivery of services as part of the health service in England.”231 Such persons embrace

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229 Q 264.
230 Q 27.
231 Section 1F(1) of the National Health Services Act 2006, inserted by section 1(7) of the Health and Social Care Act 2012.
medical students and senior hospital consultants, taking in nurses, healthcare assistants and hospital porters; “a chief executive and a finance director are healthcare workers.”

To describe all these as “care workers”, especially in this particular draft Bill, strikes us as misleading.

298. We are not alone in that view. Professor Cumming, the Chief Executive of HEE, told us: “I personally do not think the term “care worker” is the right one. I think what we refer to is “health and healthcare workers”, because, of course, we have the public-health people as well who are not healthcare. The way we describe the people we interact with is “health and healthcare”. It seems to us that a more accurate and less misleading way should be found to describe the group of persons for whose education and training HEE has responsibility.

299. We recommend that the persons for whom HEE has education and training responsibilities should not be described in this Part of the draft Bill as “care workers”, but that some other generic description should be found, such as “health and care sector staff”.

Medical training of managers

300. Only 5% of NHS chief executives are doctors, and only 15% are clinicians of any sort. This country used to have officials with the title of “medical superintendent” who had medical training and, sometimes, medical experience, but acted in a managerial capacity. We suggested to Dr Daniel Poulter MP, the Parliamentary Under-Secretary of State at the Department of Health, that it would be valuable if some senior managers, whatever their title, had some medical knowledge and experience. He described this as “an excellent suggestion”.

301. HEE should certainly encourage a greater proportion of future managers to have clinical experience. However the development of NHS leaders is the responsibility, not of HEE, but of the NHS Leadership Academy, which leads the process of commissioning leadership development. It is not clear to us how the two bodies will work together. It should be a statutory requirement for HEE to work in partnership with the NHS Leadership Academy to ensure that managers in their training learn alongside their clinical colleagues, with a specific objective of ensuring that a greater proportion of the managers of the future have clinical experience.

Integration

302. We suggested to Dr Poulter that it might be useful to insert in the draft Bill a duty for HEE to promote and support education and training of people so that they could work either in the health care or the social care sector. Dr Poulter conceded that we would needed an increasingly multidisciplinary workforce that worked across both health and

232 Professor Cumming, Q 266.
233 Q 66.
235 Q 347.
social care. He told us: “Unless that is embraced and made a priority for HEE, which we feel we are certainly doing through the mandate, then that will not become a reality. It is about breaking down silo working; it is about making sure that there is a clear recognition that, in an age where we want to provide more care in the community, we need a more mobile workforce that can work across different care settings. As you rightly highlight, that needs to be reflected in the clear instructions given to HEE.” He invited us to make recommendations to have something more explicit in the draft Bill.

303. Making HEE responsible for the education and training of social care staff may be a bridge too far for this legislation. However we consider that the draft Bill should be amended to reflect better the Minister’s evidence and the growing need to recognise that many care staff—especially those without degree-level qualifications—switch between and work across health and care and support settings. In doing so they are often doing similar jobs of looking after people at times of great vulnerability that require the same skills, training and compassion. This needs to be reflected in the education and training programmes and qualifications resulting from the work of HEE and LETBs.

304. Clause 59 lists seven matters to which HEE must have regard in setting priorities and outcomes for education and training. We recommend adding to that list (a) the promotion of integration (including between health and care and support) to align HEE with the duties placed on the NHS Commissioning Board and Clinical Commissioning Groups, and (b) the desirability of enabling people to switch between and work across a range of different health and care and support settings.

**Long-term planning**

305. Clause 56 requires HEE to ensure that a “sufficient number of persons with the skills and training to act as care workers for the purposes of the health service is available to do so throughout England”; the LETBs help in carrying out this function at a local level. Clause 58 in effect requires HEE to publish a forward plan, and to revise and re-publish it every year. There is nothing to say how far ahead this forward plan should look. Jamie Rentoul explained that in clause 58: “… we did not want to say it was three, five or 10 years in primary legislation, because we felt HEE should be considering it, and there is a further sub-clause that says, ‘And it can vary the period of time for different care workers.’ We are trying to say we do want HEE to take a strategic view, building off the mandate it will get from ministers. It needs to thinks about what is sensible. In moving to the new system now, we have said five-year plans from LETBs—to take a view about whether that feels helpful.”

306. We agree with Professor Cumming when he said: “I certainly would not want to see us producing one year workforce plans. They are not worth the paper they are written on for anybody. They have to be longer term.” Unlike Mr Rentoul, we believe that primary legislation should specify the minimum term for a long-term plan. Professor Jessica Corner, the Vice-Chair of the Council of Deans of Health, speaking about the plans of
LETBs, thought a five-year plan might be appropriate. When, as we were told, the training of a consultant neurosurgeon can take up to 20 years, we believe that five years should be a minimum for HEE’s own forward planning. Clause 58(3) should be amended to make clear that, in setting out its forward plans, HEE should include one plan looking at least five years ahead, and preferably longer, and that it should be updated annually. LETBs should have a similar requirement.

The wider picture

307. HEE, though its direct responsibilities are limited to England, cannot act without cooperating closely with the bodies with similar responsibilities for Wales, Scotland and Northern Ireland, given the flow of personnel across the borders. It also has to be aware of and act upon global developments. Professor Cumming told us that staff at the GMC had been very busy processing applications from Greek and Spanish nationals wanting to join the UK medical register because of economic conditions in Greece and Spain. “So as well as producing workforce plans, which have to look many years ahead into the future, we have to be able to respond to events and move fairly quickly if we see something happening. With Obamacare in the USA, I believe that there is a high risk we are going to lose well-trained nurses to the US, because they need to increase the number of nurses they have relatively quickly. We are going to have to respond very quickly if that becomes a problem, or we will end up with a shortage of nurses in our healthcare system in this country.”

However Dr Poulter was less concerned: “In terms of the Obamacare issue, we had the same discussion a few years ago when Australia and New Zealand were actively advertising and trying to recruit British nurses to go over to Australia and New Zealand. Some nurses, as doctors do now, may go over for two or three years to go and work there; it is something that young people tend to do—to go and spend part of their careers working overseas. But that did not have a particular impact on the NHS.”

An over-supply of staff

308. The problems caused by a shortage of staff are plain. Less plain are the difficulties, mainly of cost, if more staff are trained than are needed. “We cannot afford, and should not have, a large number of unemployed doctors, dentists, nurses, pharmacists or whatever it may be. …. It is absolutely critical that we get this right and I would not have a problem at all if the Bill were strengthened in that way.” But cost is not the only factor. Dr Poulter said: “I believe we have a moral duty to make sure that, when medical graduates leave medical school, they are fully signed up … There have been concerns that there may be a potential over-supply of doctors—newly qualified medical graduates—coming out of medical school compared with places on foundation programmes. That is not just this year; it has been for a number of years. …. in Wales there is an over-supply, and in

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239 Q 279.
240 Professor Cumming, Q 267.
241 Q 278.
242 Q 348.
243 The Royal College of Midwives report that there is currently a shortage of about 5,000 midwives: see the question from Baroness Cumberlege and the reply by Earl Howe, Parliamentary Under-Secretary of State at the Department of Health, House of Lords Official Report, 25 February 2013, columns 846-848.
244 Professor Cumming, Q 280.
Scotland a slight over-supply, of graduates compared with jobs. That is why we have to work across the UK to make this a reality.”

309. There also has to be a balance within the professions. Anecdotally, we were told that 60% of medical students on their first day at university aspire to be surgeons. Fewer than 10% will end up as surgeons; the great majority will become GPs. Sir John Tooke, the President of the Academy of Medical Sciences, explained that “All doctors are going to have to be able to cope with multiple co-morbidities rather than seeing themselves as a highly specific specialist, except in exceptional cases … true matching will take account of the balance between generalism and specialism.” And Professor Norman Williams, the President of the Royal College of Surgeons, told us that “surgery and the medical specialities are very exercised about the over-production of super-specialists.”

310. Clause 56 of the draft Bill is entitled “Ensuring sufficient skilled care workers for the health service” and, as we have said, requires HEE only to ensure that there are “a sufficient number of persons … to work as care workers”. Regulations under clause 56(2) may provide that this duty “is exercisable only, or is not exercisable, in relation to persons of a specified description”. That seems to us inadequate; it still will not deal with the question of over-supply. Professor Cumming expected that HEE would be “held to account on an annual basis for making sure that, as far as possible, supply and demand are in equilibrium.” We agree that this is essential. **Clause 56 must be amended to make clear that the duty of HEE is not merely to ensure a sufficiency of skilled workers, but to ensure that supply and demand are as far as possible matched, not just overall, but within each group of “persons of a specified description”**.

**Clause 57: the duty to promote research**

311. Clause 57(2) reads: “HEE must, in exercising its functions, have regard to—(a) the need to promote research into matters relating to the activities listed in section 63(2) of the Health Services and Public Health Act 1968 (social care services, primary care services and other health services); (b) the need to promote the use in those activities of evidence obtained from the research.”

312. A large number of our witnesses criticised the words “have regard to … the need to promote research” as being far too weak. They included some of the Royal Colleges, research organisations, and HEE itself. In oral evidence Sir John Tooke told us that “the key issue from the Academy of Medical Sciences’ perspective is that we need to strengthen the statement that HEE should ‘have regard to the need to promote research’ to actually ‘promote research’. I say that not simply as somebody who clearly has an interest in seeing research flourish in the UK. It is because of the requirement for the NHS to become far more research aware if it is going to develop the critical culture and transformative capacity it needs to respond to health challenges.”

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245 Q 348.
246 Q 307.
247 Q 308.
248 Q 280.
249 Q 305.
313. The Wellcome Trust was emphatic in its written evidence: “We consider the duty for HEE to ‘have regard to the need to promote’ research and the use of research evidence (clause 57(2)) to be far too weak. As drafted this duty is too ambiguous and fails to commit HEE to action, therefore this duty must be strengthened simply to ‘promote’. This change would recognise the important role that HEE must play in championing research. … In order to ensure that new technologies such as genomics and stratified medicines are deployed effectively in the NHS, it is essential that healthcare professionals are given the education, training, time and resources needed to support research and innovation. HEE must ensure that this is the case …”.

314. Sections 6, 23 and 26 of the Health and Social Services Act 2012 insert into the National Health Service Act 2006 provisions which impose on, respectively, the Secretary of State, the NHS Commissioning Board and Clinical Commissioning Groups a duty to “promote research on matters relevant to the health service”. Dr Poulter reminded us that the Bill for that Act had originally read “have regard to the need to promote research,” and that this had been changed in Committee to make the duty more explicit.250 The Wellcome Trust and the Royal College of Surgeons both told us in their written evidence that the duties of HEE should be brought into line. We agree.

315. Clause 57(2) should be amended so that HEE has, like the Secretary of State, the NHS Commissioning Board, and Clinical Commissioning Groups, a duty to promote research on matters relevant to the health service. In the case of HEE this duty should extend to the other matters listed in paragraph (a), which include social care services.

Commissioning research

316. Professor Cumming suggested to us that, in addition to promoting research, HEE should have the power to commission research into matters relating to its own activities of education and training.251 We see force in this, and are surprised that HEE does not already have this power. Clause 60 requires HEE to seek advice on the exercise of its functions from persons involved in or interested in education and training for care workers. We recommend that clause 60 should be broadened to allow HEE’s obligation to obtain advice to include the commissioning of research on the exercise of its functions.

Safeguarding

317. The Francis Inquiry report published during our inquiry makes a great many recommendations. In his letter to the Secretary of State, Robert Francis QC says that there is a need to “… enhance the recruitment, education, training and support of all the key contributors to the provision of healthcare, but in particular those in nursing and leadership positions, to integrate the essential shared values of the common culture into everything they do”. He goes on to makes 21 recommendations related to education and training. Most of these are directed towards the Government and the General Medical Council. During our evidence session with the Minister we raised with him the fact that neither in the draft clauses nor in Schedule 5 is there any explicit reference to HEE having duties relating to safeguarding. The Government should consider amending the draft

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250 Q 345.
251 Q 269.
Bill to give both HEE and LETBs a duty to ensure that the principles and practice of safeguarding are integral to education and training.
9 Health Research Authority

Background

318. The same powers that the Secretary of State used\textsuperscript{252} to set up Health Education England had already been used on 22 September 2011 to set up the Health Research Authority (HRA) as a Special Health Authority.\textsuperscript{253} Chapter 2 of Part 2 of the draft Bill will now formally constitute HRA as a non-departmental public body with its constitution and functions set out in statute, as Chapter 1 of Part 2 did for the HEE. This, the minister said, would ensure that it was independent of Government.\textsuperscript{254}

319. On behalf of the Wellcome Trust, one of the main global funders of medical research, Nicola Perrin, the Head of Policy, told us: “We have been very pleased to see the work it has done to establish itself. … it really has made an enormous difference as a research funder that they have come to us, engaged the research community and all their other stakeholders to ensure confidence and trust in what they are doing. We therefore welcome the alignment of responsibilities in the Bill; we think it is important that the HRA be established as an NDPB, which will give it both independence and stability to continue to do what it is doing already.”\textsuperscript{255} We agree; we too welcome the establishment of the HRA.

320. The main functions of the HRA are set out in clause 67 as the co-ordination and standardisation of practice relating to the regulation of health and social care research; functions relating to research ethics committees; and functions relating to approvals for processing confidential information relating to patients. Russell Hamilton, the Director of Research and Development at the Department of Health, explained that it would have two parts to its objective: “The first will be to protect participants and potential participants in research, and it will do that mainly through its oversight of the research ethics committee system. Equally important is the second part of its objective, which is to promote the interests of those participating in research, particularly by facilitating the high quality of research.”\textsuperscript{256}

Promotion and coordination of research

321. Among the functions of the current Special Health Authority are “such functions in connection with the facilitation and promotion of research … as the Secretary of State may direct”\textsuperscript{257} Since it is the intention that the HRA should take on the functions of the Special Health Authority,\textsuperscript{258} we would have expected to find the promotion of health and social care research listed in clause 67 as one of the primary functions and objectives of the HRA. The quality of such research in the United Kingdom is second to none, but if it is to thrive,
it needs all the support it can get from the Government and from NDPBs. The protection of participants and of the general public are certainly very important, but there is no single body with the primary responsibility for promoting health and social care research, and it seems to us that the HRA would be well placed to carry out this task. **Clause 67(2) should be amended to make the facilitation and promotion of health and social care research the first of the main objectives of the HRA.**

322. **Clause 68 requires the HRA, the Secretary of State and seven other bodies to “cooperate with each other in the exercise of their respective functions relating to health or social care research with a view to coordinating and standardising practice relating to the regulation of such research”. It seemed to us that there was considerable overlap between the responsibilities of some of these bodies. The field of embryo research is an obvious example. We asked officials from the Department of Health whether health research, which is defined by clause 67(3) as “research into matters relating to people’s physical or mental health”, included embryo research. They replied that this would be covered if it related to people’s physical or mental health, but that it would continue to be strictly controlled by the HFEA, which required embryo research proposals to be approved by a research ethics committee before a licence would be issued.**

259 We recommend in the following chapter that the HFEA should remain in being with its functions unaltered. It seems to us that the coordination of research will be easier if a single body has the responsibility for taking the lead, and that the HRA would be well placed for this. Where aspects of health and social care research are the responsibility of bodies other than the HRA, the duty of the HRA should include the coordination of that research with the research for which the HRA has responsibility.

323. **The Government should consider giving the HRA primary responsibility for coordinating and standardising the regulatory practice of all health and social care research carried out by the persons and bodies listed in clause 68(1) and by any others with similar responsibilities.**

**Research relating to social care**

324. Despite its title, the HRA is as much responsible for the coordination and standardisation of practice relating to social care research as relating to health research. Nearly all that we read and heard about the HRA related to its health research functions, and we asked Dr Wisely, the Chief Executive, why the providers of social care were not in the list in clause 68(1) of the groups of people who are required to co-operate with HRA “in the exercise of their respective functions relating to health or social care research …”.

Her reply was that “if a study sits across the NHS and social care it will go to one of our Ethics Committees. There is a social care REC that looks at total social care studies that we are not responsible for.”

260 Two bodies on this list appear to have responsibilities for social care research: the Health and Social Care Information Centre which, as its name implies, is in the business of providing information rather than advising on the regulation of research, and the Care Quality Commission, whose remit extends to regulation and improvement. It seems to us that the list of persons and bodies in clause 68(1) should specifically include the Social Care Research Ethics Committee.

259 Supplementary written evidence of 15 February 2013.

260 Q 304.
Consent for consent

325. One of the most intractable problems facing researchers who want to involve patients in clinical trials is the so-called consent for consent issue. As Nicola Perrin told us, “this is where in order to identify which patients are eligible to take part in a trial you may need access to identifiable information if you need to know their date of birth, post code, etc. Researchers do not have a legal basis on which to access that identifiable information, so you end up with a situation where either the clinical team has to identify the eligible participants—they do not have time; they understandably have a lot of other priorities—or alternatively to write to each person in the general practice and ask them if they would consent to their identifiable information being accessed by researchers. They would then be approached again if they were eligible for the trial to invite them to consent to take part.”261

326. The view of Sir John Tooke was that “patients by and large hugely benefit from involvement in clinical trials, whether they are in the active arm or not. … my experience in establishing registers of thousands of patients with diabetes, … is that I can count on the fingers of one hand the times patients, when adequately explained the purpose and controls, would not commit to that.”262

327. The HRA might well have a part to play in any solution to this problem. It has not however been suggested to us how these delicate issues of patient confidentiality might be resolved, nor whether this draft Bill would be an appropriate legislative vehicle. We understand that this an issue that the Caldicott Review263 is looking at, and we think it preferable to leave this to them, in the hope that an early solution will be found in time for any necessary legislative amendment to be included in the Bill.

Transparency

328. Much of the most valuable health research of course involves patients, and the problem has always been to ensure transparency in this research, and full publication of the results, while still adequately preserving patient confidentiality. Much of the evidence we received on this part of the draft Bill related to this, and some of it suggested that this draft Bill provides an opportunity for the HRA to be given responsibility for this issue, with the specific objective of ensuring the fullest possible publication of research results.

329. The Academy of Medical Sciences was one of those who thought that the HRA’s new responsibilities for patient data and its links with associated stakeholders would assist it in contributing to the wider debate around transparency in the publication of research results. “We welcome the fact that the HRA has already announced plans to take steps to follow up the commitments that researchers make to research ethics committees relating to the publication of summary trial data. We are supportive of mechanisms to make clinical trial data available to inform research for the benefit of patients. This is subject to appropriate safeguards of confidentiality of participants (many mechanisms already exist to ensure this) and of course assuming that the research is scientifically sound. There are a number of

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261 Q 293.
262 Ibid.
263 Review by Dame Fiona Caldicott of the balance between protecting patients’ confidential information against the need for sharing it to improve patient care.
issues around the publication of clinical trial data that need to be considered. These include the development of mechanisms to enable the release of data in a form that is both accessible and useful and avoids being misleading. We hope that the HRA will contribute to the debate about how these mechanisms should be developed.”

330. In their written evidence the Wellcome Trust said: “On the issue of transparency, we consider that transparency in the publication of research results is a vital part of the research pathway.” Somewhat to our surprise, they continued “… we do not envisage an immediate role for the HRA with regard to research transparency …”. However in her oral evidence Nicola Perrin told us: “We would add that although we certainly agree that transparency in research results is completely essential and we do see it as an intrinsic part of the HRA’s role, our only concern would be that putting it on the face of the Bill should not be seen as the only solution. We cannot put it in the legislation and tick the box that transparency is now sorted because there are so many other stakeholders involved.”

331. We asked the Department of Health for a written statement of the Government’s views. They sent us a note which said: “The Government is committed to transparency in the area of clinical trial data. From later this year, greater transparency and disclosure of trial results will be achieved by the work being carried out by the European Medicines Agency to make the summary results of interventional trials of medicinal products (other than phase 1 trials involving adults) in the European Union clinical trials register publicly available. There is also a strong focus on transparency in the proposed EU Clinical Trials Regulation being negotiated in the EU. In addition, the Government welcomes work being undertaken by the life sciences industry itself to develop schemes of voluntary publication of clinical trial data such as the initiative recently announced by GlaxoSmithKline (GSK). Issues of patient confidentiality must however be addressed appropriately to protect against the risks of releasing identifiable data. Under the Medicines for Human Use, (Clinical Trials) Regulations 2004 (Schedule 3, Part 1, paragraph (1)(o)), applications for an ethics committee opinion are required to include details of the arrangements for access to confidential data about the participants and the arrangements to protect their privacy, and any agreement on the policy for publication of the data produced by the trial. Ethics committees therefore consider the plans for both when giving their opinion in relation to clinical trials of medicinal products.”

332. Subsequently we put the question of transparency to the Minister, Dr Poulter. He did not agree in terms that there should be a duty to promote research transparency on the face of the draft Bill; he drew attention, as the Department had in its written evidence, to the voluntary participation of GlaxoSmithKline in the AllTrials campaign, and was concerned that a statutory duty of transparency might cause the big international pharmaceutical companies to take their research work overseas. We believe these fears are unjustified, and that better cooperation with the Medicines and Healthcare Products Regulatory Agency (MHRA), the European Medicines Agency (EMEA) and the US Food and Drug Agency (FDA), would help ensure similar approaches to transparency.

333. The view of the HRA itself was given by Dr Janet Wisley, its Chief Executive: “Currently applicants are asked when they apply to the Ethics Committee about their

264 Q 291.
265 QQ 353-354.
intention to register, publish, disseminate the findings of the research, make data available, make tissue available and how they would tell participants about the outcomes of the research. What we have not done before now is to look at compliance against those plans. .... From April we are going to start a simple check through the final report that we receive … to see whether or not people have published, made the data and the tissue available as they said they would to the Ethics Committee.”

When asked whether it would be helpful to have an obligation to promote transparency in research on the face of the Bill, she replied: “My personal view is that it is absolutely fundamental to protecting the patients and the public in health research. I see it as a very important part of our role, so therefore if we can give more confidence to people that it is mentioned specifically then we would support that.”

334. We continue to have concerns that, too often, researchers may be selective in the results they publish, giving more publicity to favourable results than to negative ones; that they publish summary results rather than full results; and that they use patient confidentiality as an excuse for any lack of transparency. We believe that the HRA and RECs have an important part to play in dealing with this situation.

335. Clause 67(2) of the draft Bill must be amended so that promoting transparency in research and ensuring full publication of the results of research, consistently with preservation of patient confidentiality, becomes a statutory objective of the HRA.

336. In its guidance to Research Ethics Committees, the HRA must place on them an obligation to include provisions on the publication of research when granting approval for the conduct of research, and an obligation to ensure that such provisions are complied with.
10 Human Fertilisation and Embryology Authority and Human Tissue Authority

337. Clause 75 of the draft Bill, innocuously entitled “Amendments to the Public Bodies Act 2011”, would in fact result in the abolition of the Human Fertilisation and Embryology Authority (HFEA) and Human Tissue Authority (HTA).

338. Section 1 of the Public Bodies Act 2011 gives ministers the power by order to abolish any of a large number of public bodies listed in Schedule 1 to the Act and to transfer their functions to another body. Section 5 allows ministers to modify the functions of the bodies listed in Schedule 5, or to transfer those functions, or some of them, to another body. Orders under section 1 or section 5 are subject to the super-affirmative procedure, which allows either House to refer the draft Order to a Committee of that House, and requires the Minister to have regard to any recommendations the Committee may make.\(^\text{268}\)

339. Currently both the HFEA and the HTA are listed in Schedule 5 to the Act, so that the minister may modify or transfer their functions, but may not abolish them. Clause 75 of the draft Bill would transfer both bodies from Schedule 5 to Schedule 1, so that the minister could abolish either or both of them and transfer their functions to other bodies (in which case he would of course have no need to modify their functions).

340. On 28 June 2012 the Department of Health issued a consultation paper entitled “Consultation on proposals to transfer functions from the Human Fertilisation and Embryology Authority and the Human Tissue Authority”. The paper noted that there was considerable overlap between the functions of both bodies and the Care Quality Commission (CQC). This point was repeated in oral evidence by Ted Webb, the Department’s Deputy Director for Health and Bioethics, who told us that “There is an apparent overlap of their role and that of the Care Quality Commission. Something like 300 places that the Care Quality Commission goes to are also regulated by the HFEA or the HTA, and something like 90% of the places that the HFEA regulates in England are also regulated by the CQC or are situated in places that the CQC already regulates.”\(^\text{269}\)

341. The Department’s preferred option was to abolish both bodies and transfer their functions to the CQC, with the exception of the HFEA research functions which would be transferred to the HRA. A second option was to abolish both bodies but with different provisions for the transfer of their functions. Option 3 was for both bodies to retain their functions but to deliver further efficiencies. Responses to the consultation were invited by 28 September 2012. 109 responses were received. They were placed on the Department’s website at the end of January 2013. The overwhelming majority of them favoured Option 3. Consultees were particularly afraid of losing the expertise which both bodies had built up.

342. In our Call for Evidence we also asked for views on these proposals. Those we received were from the major research organisations and their funders, and they unanimously

\(^{268}\) Section 11 of the Act.

\(^{269}\) Q 33.
opposed the abolition of either body or the transfer of their functions. The Academy of Medical Sciences replied: “There is a great deal of support among our community for the HFEA and the HTA; both are perceived as having developed the experience to respond in a balanced, practical way to the changing landscape that reflects the evolving risks and benefits of research. The relatively small savings to be made through disbanding the HFEA and the HTA need to be balanced against the inevitable period of disruption and uncertainty, and any potential risk of loss of expertise, efficiency, effectiveness and coherence that could hinder research and practice and result in the loss of public and professional confidence…. We therefore support retaining both the HFEA and the HTA, providing they work closely with the HRA and other regulators to further streamline the regulation, inspection and governance process for patient and public benefit.”

343. The Wellcome Trust reiterated much of the response they had given to the Department: “Transferring functions away from the HFEA and HTA would present a significant risk for loss of specialised expertise and specialist function within the HFEA and HTA, and potential corresponding impacts on researcher and public confidence in the regulatory system. Furthermore, we considered the proposal to split the HFEA’s functions by transferring its research functions to HRA, and the rest of its functions to the CQC, carried a risk of losing cohesion between the HFEA’s clinical and research functions and diminishing its ability to keep pace with emerging treatments and techniques. … In light of these concerns, we broadly supported Option 3 in which the HFEA and HTA would retain existing functions but deliver further efficiencies.”

344. Cancer Research UK supported the option of retaining the HTA and HFEA while streamlining their functions, but did believe that “the Department’s preferred model could potentially be an acceptable means to restructure the functions of the HTA and HFEA in the future once it has been established that the CQC is able to perform the functions to a standard that will support researchers in gaining approvals and also public confidence in the handling of human tissue and embryos.” But the Royal College of Surgeons did not believe that the CQC would be able to perform these functions: “The College is concerned that the safe and ethical use of human tissue is complicated and requires specialist expertise and appropriate regulation which is sufficiently different from the general regulation of health and social care currently undertaken by the Care Quality Commission (CQC).”

345. Dame Jo Williams, the outgoing Chair of the CQC, had said that the preference of the CQC was that the functions of the HFEA and the HTA should not be transferred to the CQC. At his pre-appointment hearing with the House of Commons Health Select Committee on 5 December 2012 David Prior, the newly appointed Chair of the CQC, was asked whether he agreed. He replied: “I think I probably do, without knowing enough about it to give you a considered answer. My basis of probably agreeing is simply that we have enough to do, I think, in CQC to get our existing shop in order without taking on a new responsibility. But I would have to take more advice on that. That would be my gut feeling.”

346. On 25 January, four months after the consultation had closed, the Department published their response to the consultation. They said: “In the light of the above, we have decided, on balance, that we will not pursue a transfer of functions at the present time.

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270 House of Commons Health Select Committee, 5th report, session 2012-2013, Evidence, Q 36.
However, retaining the HFEA and the HTA with further efficiencies must take account of the support for a review of the way in which the two bodies undertake their functions, with a view to reducing the regulatory burden. It must also include a programme of work on achieving efficiencies to deliver streamlining of their non-specialist functions.” Anna Soubry MP, the Parliamentary Under-Secretary of State, said in the course of a statement: “Taking all views into consideration, the department has decided, on balance, that it will not pursue a transfer of functions at this time.”

347. The words “at this time” caused us some anxiety, and when Dr Poulter gave oral evidence we asked him to confirm that it was his intention not to include the current clause 75. He replied: “… the clause as it stands will not be part of the Bill.”

348. Deletion of the whole of clause 75 would ensure that ministers could not now abolish either the HFEA or the HTA. It would however retain the current entry of both bodies in Schedule 5 to the Public Bodies Act 2011, allowing ministers to modify or transfer their functions, if not now, at some future date. We believe that ministers should retain this flexibility, which will in particular allow any changes to be made which are needed as the work of the HRA develops. We believe that ministers should not have the power to abolish the HFEA or the HTA, and we recommend that clause 75 should be deleted.
Summary of Conclusions and Recommendations

Introduction

1. We draw to the attention of both Houses the importance, when planning pre-legislative scrutiny of draft Bills, of agreeing a timetable which will give the Joint Committee an adequate opportunity to carry out its task, and the Department concerned sufficient time to consider and act on the Committee’s recommendations before the relevant Bill is introduced.

2. The overall level of funding available for the care and support system will impact on how far the reforms envisaged in the draft Bill and the Government’s White Paper can be realised, particularly the stated goal of shifting the emphasis from crisis intervention to prevention and early intervention.

Implications of the Dilnot Report and the Government’s proposals

Capping care costs for working age adults

3. Regulations determining the level of the cap for working age adults should be subject to affirmative resolution.

National eligibility rules

4. We endorse the recommendation made by the Dilnot Commission that the Government should act quickly to devise a new assessment scale in conjunction with service users, carers and other interested parties. This work needs to proceed at pace. Draft regulations should be published before Second Reading to support Parliamentary scrutiny of the Bill during its passage through both Houses.

5. The introduction of a capped cost scheme, which will result in many more people being assessed and entitled to a personal budget, is likely to lead to an increase in disputes and legal challenges. We are not confident that Ministers have yet fully thought through the implications for local authorities of these changes.

6. Clarity and openness are essential to successful implementation of these reforms. The Government should place resource allocation systems for determining the notional costs recorded in a care account on a statutory footing, making it clear that they are subject to the well-being provisions in clause 1 of the draft Bill, and requiring local authorities to publicise their schemes and to include full details of how the amount included in the personal budget is calculated.

7. We also urge the Government to put beyond doubt that a resource allocation system cannot include a blanket policy of reducing a person’s personal budget or notional cost on the basis of the presence of a carer, without the carer’s knowledge or consent.
Measuring progress towards the cap: the care account

8. The Bill must provide that regulations governing
   • the level and indexation of the cap,
   • any subsequent changes to the cap that fall outside the defined measure, and
   • arrangements for indexing the care account
are subject to affirmative resolution.

Indexation of the means tests

9. The Bill must provide for automatic uprating of the lower and upper means test thresholds using a defined measure specified in regulations. The Bill must also provide that regulations that make
   • amendments to the defined measure,
   • changes to the lower and upper thresholds outside the defined measure, and
   • changes to the assumed tariff income
are subject to affirmative resolution.

Ordinary residence rules

10. In the case of people for whom there is no duty to meet needs (i.e. those who opt out before the financial assessment, or who do not meet the financial requirements and do not request the local authority to meet their needs) the Government should ensure that the ordinary residence rules and portability (continuity of care) provisions protect their care accounts and personal budgets.

Implementation

11. Enactment of the Care and Support Bill will constitute the biggest change in the law governing the operation of care and support in England since the National Assistance Act 1948. The Bill, when enacted, will not just consolidate and streamline into a single statute 60 years of piecemeal law making; it will also place on a statutory footing for the first time both the principles and the practice of self-directed personalised care. When taken together with the introduction of a capped cost system and a national eligibility threshold the Bill presents a significant implementation challenge for everyone with a stake in the care and support system.

12. The volume and complexity of assessments, of carers, of people with care needs, the application of mean-testing, and the determination of notional costs all raise questions about the level of initial and ongoing training and support needed for local authority staff and social workers. These are matters we would expect to be fully analysed in the revised impact assessment that accompanies the final Bill.

13. Arrangements should be set in place either in statute, in regulations or in guidance to ensure that, where either the NHS or local authorities assess a person and determine that they are not eligible to have their needs met by them, they ensure that assessments are coordinated and information shared to minimise any delay in putting in place suitable arrangements to meet their needs, for example by provision of information and advice or by exercising the prevention duty in clause 7 of the draft Bill.
14. The Government must devise a campaign that raises awareness of what the national care and support offer is. This should make clear how people can plan and prepare, what their rights are and how to access the information, advice and assistance they need both to prevent and postpone the development of care needs and to support people to maintain their independence when they do have care needs.

**Part 1 of the draft Bill overall**

*Clause 21: the boundary with NHS continuing care*

15. We are glad to know that the Department intends to look again at the drafting of clause 21. Whatever reassurance they may seek to give us, a court is likely to take the view that any change in wording which goes beyond bringing the drafting into the 21st century implies a change in the intended meaning of the provision. We therefore expect the Department to redraft the clause to put the question beyond doubt.

16. Clause 14(3) must be amended to make clear that, where a local authority provides services on behalf of a Clinical Commissioning Group, the authority may not recover the cost from the individual whose needs are being met.

17. We question whether subsections (3) and (4) of clause 21 are desirable. If they are retained, we are of the view that regulations made under clause 21(2)(a) should not be able to override the provisions of subsections (3) and (4), and consider that this should be made clear in the drafting.

**The statutory framework and the hierarchy of rules**

18. We recommend that the status of the third tier of the hierarchy of rules should be clarified. Clause 50 should be replaced by provisions modelled on sections 42 and 43 of the Mental Capacity Act 2005, allowing the Secretary of State to issue guidance contained in a statutory Code of Practice.

19. The clause must make clear that the Code of Practice is subject not just to the Act and other primary legislation, but also to the regulations made under the Act and any other applicable law.

**General responsibilities of local authorities**

*The well-being principle: Clause 1*

20. We recommend that the list in clause 1(2) of matters to which well-being relates should be enlarged to include the dignity of the adult, and the availability of safe and settled accommodation.

21. Clause 1(5) should be amended to make clear that the well-being principle applies as much to an adult carer as to the adult needing care.

22. We welcome the importance that Ministers attach to the well-being principle. We recommend that the draft Bill should include a provision requiring the Secretary of State,
when making regulations or issuing guidance, to have regard to the general duty of local authorities under clause 1.

**Information and advice: Clause 2**

23. The draft Bill should make clear that “information” and “advice” include financial information and advice, and that local authority services should recommend financial advisers only if they are regulated by the Financial Services Authority.

24. The following matters should be added to the list in clause 2(2) of matters on which the local authority’s service must provide information and advice:

- ways in which people can contribute to the design of services, where none are available to meet their needs;
- local housing options, including specialist housing, accessible housing and adaptations;
- any relevant charging arrangements for care and support in the local authority’s area;
- obtaining independent financial advice on the options for paying for care and support; and
- where such advice can be found.

**Advocacy**

25. Clause 2 should be amended to make clear that independent advocacy is to be available before the assessment process has begun, and not only as one of the ways of meeting needs under clauses 17-19.

**Promoting diversity and quality in provision of services: Clause 3**

26. The Government should ensure that the Department of Health’s national support programme and guidance to local authorities address these concerns; in particular they should make certain that Joint Strategic Needs Assessments provide a sufficiently detailed picture of the scale and character of current and future individual needs to support market shaping.

27. We believe clause 3 should be amended to put beyond doubt that local authorities must involve service providers, service users and carers in market shaping activity.

28. Clause 3(2) should be amended by the addition of a paragraph to provide for a duty analogous to that set out in section 6 of the Childcare Act 2006, which would require local authorities not only to develop a local market but also to monitor the match between supply and demand in their areas and to report publicly on the sufficiency of care and support services.

29. The draft Bill should include a requirement that local authorities properly take into account the actual cost of care when setting the rates they are prepared to pay providers.
30. The Government should examine the scope for introducing an independent adjudicator to settle disputes between local authorities and providers over the cost of care.

31. The Government should amend the market shaping duty in clause 3 by making an explicit link to both the essential standards of quality and safety and to NICE quality standards. This could be achieved by adding to clause 3(2) a requirement to have regard to regulations made under section 20 of the Health and Social Care Act 2008, and to the quality standards prepared by NICE under section 234 of the Health and Social Care Act 2012.

32. The Government should ensure that they have the necessary statutory authority to make regulations or issue guidance concerning what they call “unacceptable” commissioning practices, and amend the draft Bill if necessary.

**Cooperation: Clauses 4-5**

33. The list of relevant partners in Clause 4(5) should be extended to cover registered housing providers, including housing associations and registered social landlords.

**Promoting Integration of care and support with health services etc: Clause 6**

34. In clause 6(1) a reference to “housing provision” should be added to the reference to “health provision and health-related provision”.

35. We recommend that the words “it considers that” should be deleted from clause 6(1).

36. Clause 6 should be amended to reflect the approach taken in the Children and Families Bill by giving the Secretary of State a power to prescribe groups of people or services that should be subject to joint commissioning and joint budgets.

37. The Government should take the opportunity to review section 75 of the National Health Service Act 2006 to make the requirements less onerous.

38. The Government should review before the introduction of the Bill whether they have the necessary powers to support the implementation of information sharing using a common identifier such as the NHS number across different services.

**Discharge from hospital**

39. Clause 6(1) should be amended to require local authorities to ensure the integration of care and support provision with health provision on discharge from hospital, with particular emphasis on the adequacy of housing provision on discharge.

40. The Government should consider redrafting Schedule 2 to reflect its ambitions for integration and parity of esteem between physical and mental health. Any redrafting should seek to codify best practice in the coordination of the care of a person before, during and after their discharge.

41. The Government have sought to translate the Law Commission’s recommendation on section 117 of the Mental Health Act 1983 into the draft Bill. Insofar as this simply reflects
the court’s interpretation of the current legal framework for after care, we do not recommend any change. However, ministers should ensure that in the guidance to local authorities the risks are recognised and the well-being principle upheld.

**Preventing needs for care and support: Clause 7**

42. Ministers should ensure that the explanatory notes to the Bill and the guidance both provide clarity about the prevention duty and how it should be seen as an integral part of the care and support system at every stage.

43. Clause 7(2) should be amended to state that, additionally, local authorities must have regard to the importance of identifying adults at risk of developing care and support needs, or increasing such needs, who may benefit from support to prevent deterioration in their well-being.

44. The draft Bill should be amended to make clear that both clause 2 and clause 3 are linked to the duty of prevention.

45. Realising the “public health” benefit from introducing a capped cost system could result in significant quality of life gains by helping to engage more people in maintaining their health and well-being, with a positive impact on demand for long term care.

**Safeguarding: Clauses 34-38**

46. The safeguarding provisions of the draft Bill should be moved to the General Responsibilities section.

47. Local authorities should be placed under a statutory duty to take steps to empower individuals to understand what abuse is, and how to protect themselves from it, whether by seeking help or otherwise.

48. Clause 34(1) should be amended to put beyond doubt that the duty of local authorities to make enquiries extends to cases where abuse or neglect has occurred in the past but still needs to be investigated. A similar amendment should be made to clause 4(4)(c).

49. The Government should ensure that both the explanatory notes to the Bill and the guidance make clear what obligations the words “cause to be made” place on local authorities and other agencies.

**A power of entry**

50. The safeguarding provisions should include a power of entry for local authority representatives where a third party is refusing access to a person who may be at risk of abuse or neglect.

**Safeguarding Adults Boards**

51. The local Health and Well-being Board should be added to the list of members in paragraph 1(1) of Schedule 1 to the draft Bill. The Care Quality Commission should be added to the list of recipients of reports in paragraph 3(2).
52. The Government should consider amending paragraph 1(1) of Schedule 1 to include appropriate housing representation in the membership of Safeguarding Adults Boards.

53. Paragraph 1 of Schedule 1 should be amended to specify the circumstances in which a local authority should not take part in the proceedings of the Safeguarding Adults Board.

54. The draft Bill should include an explicit power to obtain information relevant to the conduct of safeguarding adults reviews.

Assessing and meeting needs, and payments

How to meet needs: Clause 8

55. The Department of Health should take the opportunity to review and revise the explanatory note for clause 8 and subsequent guidance to make clear that the list is not intended to limit the ways in which a local authority might meet any eligible needs or agreed outcomes, removing any possible ambiguity on that point.

Assessing needs: Clauses 9-12

56. The Department should amend the draft Bill to support people planning to achieve well-being within their own resources. The aim should be to frame assessment as a discussion about the additional support people may need to maintain or achieve well-being.

57. The draft Bill should be amended to provide that if it appears to a local authority, when undertaking a needs assessment under clause 9 or a carer’s assessment under clause 10, that the person being assessed has a health or housing need or other relevant need, it should be obliged to bring this need to the attention of the relevant authority.

58. We welcome the fact that for the first time local authorities will be required to assess whether a carer has, or is likely to have in the future, needs for support.

59. Clause 9(5) lists those who must if possible be consulted by a local authority carrying out a needs assessment. In the case of a person lacking capacity, this should include those concerned for the person’s care and well-being in accordance with section 4(7)(b) of the Mental Capacity Act 2005.

60. Clause 12(1), which lists the matters relating to needs or carer’s assessments for which regulations must make further provision, should include provision for fast-tracking needs assessments for terminally ill people.

61. Clause 12(1) should be amended to make clear that local authorities, when carrying out a needs or carer’s assessment, must have regard to the need to prevent any children from undertaking inappropriate caring responsibilities.

62. We support the possibility of combining a needs and carer’s assessment under clause 12(3), particularly to underpin whole-family assessment, and we believe that the requirement for agreement of the adult needing care and of the carer provide sufficient protection for the adult.
Eligibility: Clause 13

63. We have already recommended that, in making regulations, the Secretary of State should have regard to the duty of local authorities to promote individual well-being. We recommend that clause 13(2) should be amended to make it a specific requirement for the Secretary of State, when making regulations concerning eligibility, to have regard to this duty.

The national minimum eligibility threshold

64. We are glad that the Secretary of State confirmed the Government’s intention to set a national minimum eligibility threshold. The Government should put this beyond doubt by redrafting clause 13 to make this policy explicit. We also suggest that the Government should consider whether the regulation-making power in clause 13 provides an opportunity to establish criteria that would clarify the boundary between eligibility for local authority funded care and support and NHS funded continuing care.

Charging: Clause 14

65. It should be made clear in clause 14 that where charges are imposed they should be limited to what it is “reasonably practicable” for the person to pay. Clause 14 should also be amended to make clear that local authorities cannot simply charge the carer for services provided to the person cared for.

Deferred payments: Clause 16

66. Our recommendation that clause 2(2) should be amended to ensure that the adult is informed of the importance of independent financial advice from an adviser regulated by the Financial Services Authority, and is advised how to obtain it, is of particular importance in the case of deferred payment agreements.

Charging interest

67. We recommend that clause 16(4)(c) should be deleted.

Personal budgets and resource allocation systems

68. The Government should review the efficacy of RAS and ensure that the code of practice or guidance makes clear that the development and application of any methodology for calculating the cost of meeting eligible needs is transparent, has regard for the well-being principle, and is subject to the duty to meet eligible needs.

Additional cost under clause 27

69. Independent financial advice from an adviser regulated by the Financial Services Authority is as important in the case of additional cost under clause 27 as it is in the case of deferred payments.
70. Clause 25(1)(a) should be amended to make clear that the amount of a personal budget should be equivalent to the reasonable cost of securing the provision of the service concerned in that local area.

Direct payments: Clauses 28-30

71. The purposes for which direct payments can be used should be clarified, and the presumption should be that individuals can spend their direct payments as they like to achieve the agreed outcomes. We would prefer to see this in the draft Bill itself. If it has to be included in regulations under clause 30, they should be subject to affirmative resolution.

72. The Department of Health should lift the ban on direct payments being used to pay for local authority direct services if the individual so chooses.

73. Direct payments are another area where independent financial advice will be essential both when the payments are first arranged, and subsequently.

Other responsibilities of local authorities

Portability: Clauses 31-32

74. We agree with those of our witnesses who object to the language of “sending” and “receiving” individuals. We prefer neutral language which emphasises that people control their own decisions, and recommend that clause 31 should refer to the “first” and “second” authority, or to the “original” and “new” authority – the wording we use in this report.

Ordinary residence

75. We do not accept the suggestion that individuals should have the option of deciding their own ordinary residence status and therefore which authority continues to fund their care package. Funding must be for the local authority where the person is ordinarily resident or is treated as being ordinarily resident.

Continuity of care

76. We are glad that after a move to a new local authority area there will be continuity of care until a re-assessment. We think it inevitable that the level of care may change after a move; indeed, that may have been the purpose of the move.

77. We do not accept the suggestion that the original authority should continue to fund the care so long as the person is eligible for it. Funding must be for the local authority where the person is ordinarily resident. However the Government may wish to consider whether there should be guidance on the minimum period during which an original assessment should be protected.
A possible failure of care

78. Clause 31(8) should be amended so that the original authority is absolved from meeting the adult’s or carer’s needs only once the new authority has itself begun to meet their needs, as it is required to do by clause 31(6).

Transition of children to adult social care: Clauses 39-44

79. We recommend that the transition clauses (39–44) be amended, in line with the threshold set in clauses 9(1) and 10(1), to apply where it appears to a local authority that a child or young carer may have needs for care and support at the time of the request for the assessment or on reaching 18 years. This should apply regardless of whether or not support is currently being provided, but there should be a presumption that any child in receipt of an Education, Health and Care Plan under the Children and Families Bill, and any child receiving care and support, or who has family members receiving care and support, under other legislation, comes within this definition.

80. We recommend that clause 43 be extended to include services provided under the Carers and Disabled Children Act 2000, the Chronically Sick and Disabled Persons Act 1970 and in Education, Health and Care Plans under the Children and Families Bill.

Relationship with Education, Health and Care Plans under the Children and Families Bill

81. Clauses 12(4), 42(4) and 42(5) should be amended to make clear that “another assessment” includes assessments carried out under other legislation, and specifically Education, Health and Care Plans.

Other care and support matters

Young carers and parent carers

82. We share the concern of a number of our witnesses that an unintended consequence of the draft Bill applying only to adults will be to leave young carers with lesser rights than adults.

83. We welcome the Minister’s commitment to discussions on young carers, and expect the Departments of Health and Education to work together to ensure that young carers do not fall between the cracks or face a higher threshold for receiving any support. The most straightforward solution would be for the draft Bill to be amended in line with the Law Commission preference to bring updated legislation for young carers into the draft Care and Support Bill.

84. Guidance on the application of the assessment and transition clauses should provide local authorities with clear information on the support available to carers and young carers. This guidance should aim to ensure that there is easy access to provision for carers, regardless of which legislation the provision is made under.
85. We agree with the Law Commission's view that local authorities should have the power to make provision for children aged 16 and 17, including young carers, where an assessment under clauses 39 to 44 identifies need. We further recommend that this should be done in a way that recognises that the aims of support to young carers will often be different from those for adult carers.

**Redress and complaints**

86. We believe that the significant extension of local authority responsibility for assessment, and the introduction of the well-being principle into decision making, warrant an urgent review of arrangements for providing redress and complaints resolution. The Government should reconsider establishing a care and support tribunal to provide independent merit reviews of decisions made by local authorities.

87. The Government should consider giving a care and support tribunal the responsibility for resolving disputes over NHS Continuing Health Care.

**Corporate responsibility**

88. We recommend that where abuse or neglect of an adult has resulted in the commission of an offence by an employee of a body corporate acting as such, and this is proved to have been committed with the consent of, or to have been attributable to any neglect on the part of, a director, manager or similar officer of the body corporate acting as such, he as well as the body corporate should be guilty of an offence.

89. We share the Secretary of State's view that the application of a statutory duty of candour should not be limited to health but should extend to all regulated care settings. The Care and Support Bill would provide an early opportunity for the Government to legislate on these matters.

**Free end of life care**

90. We agree with the Government and witnesses that free social care at end of life has “merit”, and strongly endorse the case for its introduction at the earliest opportunity. We welcome the clarification by the Government that the draft Care and Support Bill does not need to be amended to enable this.

**Human Rights Act 1998**

91. Clause 51 should be amended to state that the person with delegated authority to carry out a function on behalf of a local authority is subject to the same legal obligations as the local authority itself.

92. While we agree that all providers of publicly arranged care and support should consider themselves to be bound by the obligations of the Human Rights Act, we are of the view that, as a result of the decision in the YL case, statutory provision is required to ensure this.
93. The draft Bill should be amended to ensure that private and third sector providers of care services regulated by public authorities are deemed to be performing public functions within the meaning of section 6(3)(b) of the Human Rights Act 1998.

**Health Education England**

**Health care and social care**

94. We recommend that the persons for whom HEE has education and training responsibilities should not be described in this Part of the draft Bill as “care workers”, but that some other generic description should be found, such as “health and care sector staff”.

**Medical training of managers**

95. It should be a statutory requirement for HEE to work in partnership with the NHS Leadership Academy to ensure that managers in their training learn alongside their clinical colleagues, with a specific objective of ensuring that a greater proportion of the managers of the future have clinical experience.

**Integration**

96. Clause 59 lists seven matters to which HEE must have regard in setting priorities and outcomes for education and training. We recommend adding to that list (a) the promotion of integration (including between health and care and support) to align HEE with the duties placed on the NHS Commissioning Board and Clinical Commissioning Groups, and (b) the desirability of enabling people to switch between and work across a range of different health and care and support settings.

**Long-term planning**

97. Clause 58(3) should be amended to make clear that, in setting out its forward plans, HEE should include one plan looking at least five years ahead, and preferably longer, and that it should be updated annually. LETBs should have a similar requirement.

**An over-supply of staff**

98. Clause 56 must be amended to make clear that the duty of HEE is not merely to ensure a sufficiency of skilled workers, but to ensure that supply and demand are as far as possible matched, not just overall, but within each group of “persons of a specified description”.

**Clause 57: the duty to promote research**

99. Clause 57(2) should be amended so that HEE has, like the Secretary of State, the NHS Commissioning Board, and Clinical Commissioning Groups, a duty to promote research on matters relevant to the health service. In the case of HEE this duty should extend to the other matters listed in paragraph (a), which include social care services.
**Commissioning research**

100. We recommend that clause 60 should be broadened to allow HEE’s obligation to obtain advice to include the commissioning of research on the exercise of its functions.

**Safeguarding**

101. The Government should consider amending the draft Bill to give both HEE and LETBs a duty to ensure that the principles and practice of safeguarding are integral to education and training.

**Health Research Authority**

**Promotion and coordination of research**

102. Clause 67(2) should be amended to make the facilitation and promotion of health and social care research the first of the main objectives of the HRA.

103. The Government should consider giving the HRA primary responsibility for coordinating and standardising the regulatory practice of all health and social care research carried out by the persons and bodies listed in clause 68(1) and by any others with similar responsibilities.

**Research relating to social care**

104. The list of persons and bodies in clause 68(1) should specifically include the Social Care Research Ethics Committee.

**Transparency**

105. Clause 67(2) of the draft Bill must be amended so that promoting transparency in research and ensuring full publication of the results of research, consistently with preservation of patient confidentiality, becomes a statutory objective of the HRA.

106. In its guidance to Research Ethics Committees, the HRA must place on them an obligation to include provisions on the publication of research when granting approval for the conduct of research, and an obligation to ensure that such provisions are complied with.

**Human Fertilisation and Embryology Authority and Human Tissue Authority**

107. We believe that ministers should not have the power to abolish the HFEA or the HTA, and we recommend that clause 75 should be deleted.
Appendix 1: Members and interests

The Members of the Joint Committee that conducted this inquiry were:

Baroness Eaton (Conservative)  Harriett Baldwin (Conservative)  
Baroness Greengross (Crossbench)  Rt Hon Paul Burstow (Chair) (Liberal Democrat)  
Baroness Jolly (Liberal Democrat)  Margot James (Conservative)  
Rt Hon Lord Mackay of Clashfern (Conservative)  Barbara Keeley (Labour)  
Baroness Pitkeathley (Labour)  Grahame Morris (Labour)  
Rt Hon Lord Warner (Labour)  Dr Sarah Wollaston (Conservative)

Declaration of Interests

The following interests have been declared:

Paul Burstow: Until September 2012 I, the Minister responsible for care services in the Department of Health and as such had responsibility for the policy area covered by Part 1 of the draft Bill. Also a Trustee of Silverline, a charity providing a new helpline and befriending service.

Baroness Greengross: President and Chief Executive of the International Longevity Centre UK, Co- President of the International Longevity Centre Global Alliance, and has interests in various charities which are involved in the area.

Lord Mackay of Clashfern: Hon Fellow, Royal College of Surgeons of Edinburgh, Hon Fellow, Royal College of Physicians of Edinburgh and Hon Fellow, Royal College of Obstetricians and Gynaecologists. Vice-President of the Carers Trust.

Baroness Pitkeathley: Patron/Vice President of various charities which have an interest in the area.

Lord Warner: Member of Dilnot Commission; former Health Minister with responsibility for the subjects in Part 2 of the draft Bill.

Full lists of Members' interests are recorded in the Commons Register of Members' Interests:

http://www.publications.parliament.uk/pa/cm/cmregmem/contents.htm

and the Lords Register of Interests:

Appendix 2: Witnesses

Thursday 13 December 2012

Shaun Gallagher, Director General, Social Care, Local Government and Care Partnerships, Department of Health, Sally Warren, Director of Social Care Policy, Department of Health, Simon Medcalf, Deputy Director, Social Care Policy and Legislation, Department of Health and, Ed Moses, Deputy Director, Social Care Strategic Policy and Finance, Department of Health; Jamie Rentoul, Director of Workforce Development, Department of Health, and Russell Hamilton, Director of Research and Development, Department of Health

Wednesday 9 January 2013

Richard Humphries, Senior Fellow, Social Care and Local Government, The King's Fund, Dr José-Luis Fernández, Deputy Director of PSSRU, LSE, and Andrea Sutcliffe, Chief Executive, Social Care Institute for Excellence; Adrian Masters, Managing Director of Sector Development, Monitor, David Behan, Chief Executive, Care Quality Commission, NHS Commissioning Board, and Dr Martin McShane, Director Lead for Domain 2, NHS Commissioning Board

Thursday 10 January 2013

Frances Patterson QC, Commissioner responsible for Public Law, Law Commission, Tim Spencer-Lane, Lawyer, Law Commission, and Richard Percieval, Team Manager, Law Commission; Lorraine Butcher, Director of Children’s Services and Director of Adult Services in Cheshire East, Association of Directors of Children’s Services Ltd (ACDS), Cllr David Rogers OBE, Chair of Chair of Community and Wellbeing Board, Local Government Association, and Sarah Pickup, President, Association of Directors of Adult Social Services (ADASS)

Wednesday 16 January 2013

John Adams OBE, General Secretary, Voluntary Organisations Disability Group, Des Kelly, Executive Director, National Care Forum, Lord Victor Adebawale, Chief Executive, Turning Point, Colin Angel, Policy and Campaigns Director, United Kingdom Homecare Association Ltd (UKHCA), and Martin Green OBE, Chief Executive, The English Community Care Association (ECCA); Dame Philippa Russell OBE, Chair, Standing Commission on Carers, Emily Holzhausen, Director of Policy, Carers UK, and Dr Moira Fraser, Director of Policy and Research, Carers Trust
Thursday 17 January 2013

Laura Robinson, Policy and Communications Adviser, National Voices, Marc Bush, Head of Research and Public Policy, Scope, Caroline Abrahams, Director of External Affairs, Age UK, Alex Fox, Chief Executive, Shared Lives Plus, and Mark Goldring CBE, Chief Executive, Mencap; Paul Farmer, Chief Executive, Mind, Gary FitzGerald, Chief Executive, Action on Elder Abuse, Sue Bott, Director of Development, Disability Rights UK, and Sue Brown, Head of Public Policy, Care and Support Alliance

Wednesday 23 January 2013

Jo Webber, Interim Director of Policy, NHS Confederation, Dr Brian Fisher, Network Lead for Patient and Public Involvement, NHS Alliance, Professor Nigel Mathers, Vice Chair, Royal College of General Practitioners; Domini Gunn, Director of Health and Wellbeing, Chartered Institute of Housing, Jake Eliot, Care and Support Policy Leader, National Housing Federation, and Jane Ashcroft, Chief Executive, Anchor Trust

Wednesday 30 January 2013

Dr Yvonne Braun, Head of Savings Retirement and Social Care, ABI, Martin Coyle, Chief Executive, Action for Advocacy, and Chris Horlick, Managing Director of Care, Partnership; Professor Ian Cumming, Chief Executive, Health Education England, Sir Keith Pearson, Chair, Health Education England, Professor Jessica Corner, Vice Chair, Council of Deans of Health and Professor Sir Peter Rubin, Chair, General Medical Council

Thursday 31 January 2013

Janet Wisely, Chief Executive, Health Research Authority, Sir John Tooke, President, Academy of Medical Sciences, Sharmila Nebhrajani, Chief Executive, Association of Medical Research Charities, and Nicola Perrin, Head of Policy, Wellcome Trust; Sir John Tooke, President, Academy of Medical Sciences, Dr Mark Porter, Chair of Council, BMA, and Professor Norman Williams, President, Royal College of Surgeons

Thursday 7 February 2013

Rt Hon Jeremy Hunt MP, Secretary of State for Health, Norman Lamb MP, Minister of State for Care Services, Sally Warren, Director of Social Care Policy, Department of Health; Dr Daniel Poulter MP, Parliamentary Under-Secretary of State, Jamie Rentoul, Director of Workforce Development, Department of Health, and Russell Hamilton, Director of Research and Development, Department of Health
List of written evidence

1 Academy of Medical Sciences
2 Action for Advocacy
3 Action on Elder Abuse
4 Action on Hearing Loss (formerly RNID)
5 Adults with Learning Disabilities Services Forum
6 AdviceUK
7 Age UK
8 Alzheimer's Society
9 Ambitious about Autism
10 Angela Cavill-Burch
11 Arthritis Care
12 Associated Retirement Community Operators (ARCO)
13 Association of British Insurers
14 Association of Medical Research Charities (on behalf of a coalition of charities and organisations who fund and support health research in the UK)
15 Barnardo's
16 British Medical Association
17 British Red Cross
18 Bupa
19 Cancer Research UK
20 Care and Repair England
21 Care and Support Alliance
22 Carers Network Westminster
23 Carers Trust
24 Carers UK
25 Cats Protection
26 Centre for Mental Health, Mental Health Foundation, Mind, Rethink Mental Illness and the Royal College of Psychiatrists
27 Chartered Institute of Housing
28 Chartered Society of Physiotherapy
29 Chief Fire Officers Association (CFOA)
30 Christian Science Church in the UK
31 Community Matters, Race Equality Foundation and NAVCA
32 Contact a Family
33 Council of Deans for Health
34 David Hill
35 Department of Health
36 Devon County Council
37 Disability Law Service
38 Disability Rights UK
39 East Riding of Yorkshire Council
40 Epilepsy Action
41 Epilepsy Society
42 Equality and Human Rights
43 Equity Release Council
44 ETC Advice Ltd
45 Every Disabled Child Matters
46 Family and Parenting Institute and Daycare Trust
47 Family Carer Support Service (FCSS)
48 Gateshead Advocacy and Information Network (GAIN)
49 Genetic Alliance UK
50 Graham Carey
51 Health & Safety Executive
52 Help the Hospices
53 Help the Hospices, Macmillan Cancer Support, Motor Neurone Disease Association, National Council for Palliative Care and Sue Ryder
54 Hollybank Trust, Chailey Heritage Foundation and Prior’s Court Foundation
55 Human Tissue Authority
56 Ideal Care Homes
57 Imogen Parry, Independent Safeguarding Adults Trainer for the Housing Sector
58 In Control
59 Inclusion London
60 Independent Age
61 Independent Living Association
62 Jeremy Porteus
63 Jewish Care
64 Joseph Rowntree Foundation
65 Just Retirement
66 Law Commission
67 Leonard Cheshire Disability
68 LGA and ADASS
69 London Councils’
70 Macmillan Cancer Support
71 Margaret Flynn and Shirley Williams
72 Marie Curie Cancer Care
73 Mears Group PLC
74 Mencap
75 Michael Pollard
76 Midland Heart
77 Mind
78 Motor Neurone Disease Association
79 National AIDS Trust
80 National Autistic Society
81 National Care Forum
82 National Housing Federation
83 National Institute for Health and Care Excellence (NICE)
104 National Institute of Adult Continuing Education
105 National Pensioners Convention
106 National Voices
107 NHS Confederation
108 NHS Employers
109 Nick Kirwan
110 Optical Confederation
111 Papworth Trust
112 Parkinson’s UK
113 Partnership
114 POhWER
115 Practitioner Alliance for Safeguarding Adults
116 Real Life Options
117 Royal Colleague of Surgeons
118 Royal College of General Practitioners
119 Royal College of Nursing
120 Royal College of Physicians
121 Royal National Institute of Blind People
122 Sandhya Dass
123 Sapienter Wealth Management
124 Scope
125 Self Direct
126 Sense
127 Shared Lives Plus
128 Social Care Institute for Excellence
129 Socialist Health Association
130 St. James’s Place
131 Standing Commission on Carers
132 Sue Ryder
133 The Children’s Society
134 The College of Occupational Therapists (COT)
135 The College of Social Work
136 The English Community Care Association (ECCA)
137 The Law Society
138 The Older People’s Advocacy Alliance (OPAAL)
139 The Relatives & Residents Association
140 The Riverside Group
141 The Society of Later Life Advisers (SOLLA)
142 Tim Kendall, Independent Advocacy Consultant
143 Transition Taskforce
144 Turning Point
145 United Response
146 Voluntary Organisations Disabilities Group
147 Wellcome Trust
148 Worcestershire Safeguarding Adults Board
Written and oral evidence is published on the committee website
Appendix 3: Call for written evidence

The Joint Committee on the draft Care and Support Bill, chaired by Paul Burstow MP, is conducting pre-legislative scrutiny into the draft Bill and the policies it seeks to implement. The Joint Committee comprises 6 Members of the House of Commons and 6 Members of the House of Lords. It will take oral and written evidence and make recommendations in a report to both Houses. The Joint Committee invites interested organisations and individuals to send written submissions by 11 January 2013 as part of the inquiry.

The Joint Committee would appreciate any general views on the Government’s policies on care and support, and on whether the draft Bill is adequate to achieve them, but would in particular welcome any evidence you may wish to contribute on the specific issues listed below. It is not necessary for your submission to address every question. The Joint Committee will also welcome other comments related to the draft Bill, even if not directly addressing the questions below.

Care and Support

General

1. What is your view of Part 1 of the draft Bill (care and support)? In your view, are there omissions in this Part of the draft Bill?

2. Has the Government made it clear what it aims to achieve in the draft Bill’s provisions on care and support? In particular, will it be effective in clarifying the law on social care?

3. The Government states in its White Paper that “the quality of care is first and foremost the responsibility of the provider”. Does the draft Bill support this policy intention, and does it pay due attention to the responsibilities of commissioners and regulators for quality of care?

4. Are there other ways of framing the draft Bill’s underlying principle, that local authorities must promote an individual’s well-being? Are there other principles that might be substituted for it?

5. Does the draft Bill make sufficient provision to achieve the Government’s stated goal of greater integration within the NHS and with care and support and housing?

6. What benefits or problems may arise as a result of the draft Bill’s scope being restricted to adult care and support?

7. If it is found necessary to stage the implementation of the care and support provisions of the draft Bill, in what order should they be implemented?

8. Are the provisions of the draft Bill in relation to the views of service users, carers and prospective users of services sufficient? Would you suggest any improvements to these provisions?
Responsibilities of local authorities

9. What is your view of the financial and other implications for local authorities of the new care and support responsibilities set out in the draft Bill?

10. What are the risks and benefits of the duty on local authorities to provide advice on adult care and support? Are they the same for the duty to provide information?

11. How can local authorities ensure that the local care market provides enough care services to meet local needs? How can they encourage a diverse range of high-quality providers?

12. Are the draft Bill’s provisions adequate to ensure that service users are protected in the event of serious market failure among providers?

13. The White Paper talks about “approaches that promote support within communities” and calls for the adoption of “asset-based” approaches. Is the draft Bill successful in embedding this approach, or should other preventative approaches be adopted?

Assessment and Eligibility for Social Care

14. What are the risks and benefits associated with self-assessment for care and support as proposed in the draft Bill?

15. What are the best ways to increase the numbers of people identified as carers? What are the risks and benefits of placing a duty on public bodies to identify carers?

16. Do you consider that variable local charging regimes for services are compatible with national eligibility criteria, and any future funding changes involving capping individual financial liability?

17. The White Paper says that assistance with care and support needs will be subject to a reasonable charge. Do the charging provisions in the draft Bill reflect this policy intention, and is the policy intention clear?

18. Are the arrangements for setting and enforcing national minimum standards for care and support clear? What part should the new social care quality standards developed by NICE play in supporting local authorities in discharging their new market shaping duties?

Care Planning and personal budgets

19. Do the care and support plan provisions allow adequately for input from service users and carers?

20. Does the draft Bill make adequate provision to help people achieve personalised care and support and to manage the payment process?

21. The White Paper says that commissioning practices which put tight constraints on how care and support is provided - so-called ‘care by the minute’ - are unacceptable. Does the draft Bill have a part to play in addressing such practices, and if so how?
Adult safeguarding

22. To what extent do the safeguarding provisions ensure that all those at risk are adequately protected, and should these provisions be extended in any way?

23. Does the draft Bill strengthen corporate accountability for neglect and abuse? What would be the risks and benefits of creating a new offence of corporate neglect?

Transition from children’s care and support services

24. Will the draft Bill’s provisions smooth transition from child to adult services, and should they be extended in any way?

Discharge of hospital patients with care and support needs

25. Does the draft Bill promote greater integration between health, social care and housing around hospital discharge?

Health Provisions

General

26. What is your view of Part II of the draft Bill (health)? In your view, are there any omissions in this part of the Bill?

Health Education England

27. Are the powers envisaged in the draft Bill for Health Education England sufficient, especially in relation to long-term workforce planning? Does the draft Bill set out HEE’s powers clearly, along with its relationships with other bodies, especially the Local Education and Training Boards?

28. Are the proposed arrangements for the governance and accountability of HEE and the LETBs robust enough?

29. Is the Government’s goal of greater integration within the NHS and with care and support facilitated by the HEE provisions?

Health Research Authority

30. Will the powers envisaged for the Health Research Authority be effective, and is there a risk of conflict between transparency in the publication of research results and patient confidentiality?

Human Fertilisation and Embryology Authority and Human Tissue Authority

31. What are the risks and benefits of the provisions in the draft Bill on the Human Fertilisation and Embryology Authority and the Human Tissue Authority?
Appendix 4: Note of visit to Torbay

Summary Note of Visit to Torbay 24 January 2013

Meeting with representatives of NHS and local authorities

Sam Barrell, Chair, South Devon and Torbay Clinical Commissioning Group
Caroline Taylor, Interim Chief Operating Officer & DASS, Torbay Council
Councillor Stuart Barker, Devon County Council
Jennie Stephens, Strategic Director, People, Devon County Council
Tim Golby, Head of Social Care Commissioning, Devon County Council
Carolyn Elliot, Assistant Director, Health and Social Care (Southern), Torbay and Southern Devon Health and Care NHS Trust
Mandy Seymour, Chief Executive, Torbay and Southern Devon Health and Care NHS Trust
Dr Sonja Manton, Chief Operating Officer, Torbay and Southern Devon Health and Care NHS Trust
Julie Foster, Zone Manager, Brixham
James Drummond, Lead Officer for Integrated Carers’ Services, Torbay Trust
Paul Cooper, Deputy Chief Executive, South Devon Healthcare NHS Foundation Trust
Dr John Lowes, Medical Director, South Devon Healthcare NHS Foundation Trust

Torbay has a large elderly population which suffers from a high degree of co-morbidity. There is a large health inequality gap, with poorer people dying up to nine years earlier than others. To help tackle this, community healthcare and adult social care services were integrated in 2004 to create a Care Trust. Health and social care staff are co-located, with well established links with GPs.

There is also a joined-up Health and Care Cabinet for South Devon and Torbay. There is a long history of senior managers and clinicians working together on health and social care in Torbay, and not necessarily always within national policy guidelines. There are moves afoot which could lead to the integration—via acquisition—of the Health and Care Trust with the acute Foundation Trust to improve integration.

The Brixham Zone Team explained how health and social care workers are brought together to tackle complex care problems in Torbay. There are pooled budgets, integrated commissioning and shared HR and IT. Close working with GPs and acute hospitals to identify the problems of service users and their carers is a key part of the system. Care home placements have come down and there is a very low rate of hospital deaths, and one of the shortest average lengths of hospital stay. Financial constraints and the loss of some
“coterminosity” between local authority and NHS boundaries are making it more difficult to operate the Torbay system. It is getting harder to share risk.

Much of Devon is rural, while some areas have a very large population of elderly people. Investment in prevention services was increased some years ago, and the benefits are coming through now. Prevention measures can be innovative; singing groups were among the ideas that have been tried. They can be funded by pooling of personal budgets.

Under S 256 of the 2006 NHS Act, Primary Care Trusts have a power to make payments towards expenditure on community services, and this can be put to good use in investing for the future. The East Devon Hospital at Home scheme is a good example of S256 spending, which has helped to reduce admissions to both acute health care and long-term care. [One comment during this session was that S256 money was the single most important intervention to support and encourage joint working between health and social care, and needed to be maintained].

In Devon some care homes have been converted into dementia centres of excellence, offering both residential and homecare services. Better support for carers has reduced care costs to the local authority. Extra-care housing places will be provided for people with dementia and learning disabilities, but the Council is struggling to find enough providers and has had to shape the market with funding to encourage developers and providers to take up the idea.

The draft Care and Support Bill was welcomed, but there were criticisms, and the following main points were made by various people at the meeting:

- The draft Bill should contain explicit provision for resource flexibility between health and social care and should have more on joint commissioning
- The emphasis on prevention and the underlining of the need to identify carers are very valuable aspects of the draft Bill
- The practical implications of a ‘duty to co-operate’ need to be explained in more detail than they are in the draft Bill
- The Bill might make it easier to share information between health and social care providers; the multiplicity of providers envisaged under NHS reforms makes it harder to share.
- The duty to provide information is important, but not everyone can access information via the cheap routes, especially online.
- The Bill needs to address the needs of young carers, and not perpetuate age-related barriers in the system.
- Giving authorities a power to charge for services to carers is a “fundamental mistake”; carers should be seen as partners in caring, not recipients of services
- Regulations must make clear that identifying and keeping in contact with carers are the responsibility of all health and social care professionals, including GPs
• One gap in the draft Bill is something on carers’ physical and mental wellbeing

• Hospital discharge remains a fundamental problem, and the Bill does not encourage proactive approaches to it

**Outreach Event**

During the visit, members of the Committee held an outreach event in Torquay, at which they heard the views of around 60 care and support service users and carers on the key practical issues in the draft Care and Support Bill. We are very grateful to all those who took part, for giving up so much of their time to share their wide experience of the care and support system with the Committee, and for telling us what they believe the Bill can do to make it work better.

**Comments—a selection**

**Information and Advice**

• Information on care and support locally has been improving year by year since the early 2000s, but I fear that it is going backwards

• There is too much duplication of information and advice – it needs co-ordination

• There should be a national standard for information and advice

**Prevention**

• The voluntary services in Torbay fill the gaps and help to prevent care needs developing

• There is a need for drop-in centres to support prevention

**Discharge**

• There needs to be more aftercare following discharge, to stop people having to go back into hospital

• Discharge from hospital is terrible; there is no proper liaison. The family needs to know about discharge arrangements

**Carers**

• I cared for years without knowing I was a carer

• There is a stigma to being a carer

• Being a carer can be isolating

• Being a carer demeans you as a person
• Carers are reluctant to say “I’m a carer” – especially if the cared-for person has a mental health problem

• I want to live in a normal world – not to be a carer

• Services look at the cared-for person, not the carer. Once the cared-for person is over 18, the service providers listen to them, not their carer

• There needs to be a better link between the healthcare provider and the carer

• I was a young carer for a mother with mental illness. I thought that all young people looked after their parents

• In one school for youngsters with moderate learning difficulties, six out of 100 students are carers—aged about 14

• There are also 90 year old carers

• One carer did not get an assessment because his father didn’t want an assessment of his own

• Cutbacks to the physiotherapy service are making it harder for me to care for my wife

• Carers may not have the skills to be employers and the ground rules from the local authority seem to be lacking—no help to set up the care plan etc

• Carers may not want to say everything in front of the cared-for person, especially when there are differences of view

• If the Bill allows local authorities to charge carers for services, people will not take up the services

• There is a strong need for advocacy to support individuals and their carers – people are stumbling around in the dark

• What would make life better for carers?
  - Regular contact, someone to ask how I am doing
  - Advocacy
  - Stop patronising us—be sensitive in communication
  - Extra financial help in recognition of the careers we have given up
  - Training for local authority staff and carers

**Assessment and Charging**

• It was not clear where to go for an assessment. There was not enough information available. An old leaflet was sent to me
• Assessments are looked at by panels—the bar is moved depending on funding levels and diagnosis rates

• Care needs were assessed, then I was told amount was being halved and that if I appealed it might be taken away

• Assessors are too focussed on the financial implications of their assessments

• Assessments are done by people who don’t understand what they are assessing

**Care and Support Plans**

• People don’t know they have a care and support plan

• My care and support plan doesn’t work—the occupational therapist cut back on my care

• A care and support plan is good if it is kept up to date

• I had a good package of care, but once I got it I was left to get on with it. It hasn’t been reviewed for 2 years

**Personal budgets and direct payments**

• It would help me to have direct payments. At the moment, my careworker only gets £75 out of the £130 they are paid, with the agency taking the rest

• Personal budgets should be available but not imposed

• Not everyone would be better off with direct payments—for example my daughter with mental health problems

• Having choice and control is very good—but only if it is explained and supported

**Portability**

• There is a risk that under the portability provisions local money will be used to fund services for the many ‘incomers’

• There should be the same services wherever you live

**Safeguarding**

• Difficult to get information relevant to safeguarding issues from local authorities—they hide behind data protection

• You need independent Safeguarding Adults Boards, not ones set up by local authorities, which may be under scrutiny themselves

• Hate crime against people with disabilities is poorly recorded by the police
• You could have another Winterbourne View—people with learning disabilities are an easy target

• Concerns and complaints have to be reported to the provider, not the commissioner. Serial complaints therefore may go undetected

• People don’t know how to distinguish good care from bad care

• There is massive potential for exploitation, especially with direct payments

• There need to be better ways to whistleblow—the CQC is paper-based and under-resourced

**Transition**

• I am the mother of two disabled children. When they were in education all was fine, but after they became 19 I was just pointed towards the cheapest option.

**Local services**

• The Signposts service (run by the Torbay Care Trust) gives good information and support to carers in Torbay

• The integrated Torbay model is good—the benefit is the very local approach

• I have had a good experience of Torquay.

• Joined-up health and social care works brilliantly in Torbay

• The carers’ lead in Torbay gave great help when I became a carer

• Torbay’s joined-up services are OK once you know how to access them

• Not many people know the number to call in Torbay

• There is no single website about services in Torbay because there is no agreement on who pays and who would update it.

• There needs to be better communication between different services

• Many care agencies are ‘sprouting up’ but there is no choice

• GPs are not always linked in to the care and support system, although some practices and individual GPs are very good at liaison

• People on the ground don’t know about the Health and Well Being Board

• There are so many different workers involved with care and support. It is essential to have just one key worker.

• There is a risk with funding cuts that the NHS and local authorities will retreat into their silos and start ‘cost shunting’
Appendix 5: Note on the Committee’s web forum

Introduction

1. The Joint Committee on the draft Care and Support Bill set up a web forum to hear the views of carers. The Committee was keen to hear about the experiences of carers and what impact they thought the Government’s proposed legislation might have on their own situation, either positive or negative. The comments helped inform the recommendations the Committee made to the Government in the report.

2. Practicalities

- The forum opened on 21 January 2013 and was closed to new comments on 22 February 2013.

- The site was designed and created by the Parliamentary Web and Intranet Service. During the registration process, users agreed to a set of discussion rules. The forum was moderated by Joint Committee staff. Messages were checked to ensure that they adhered to the discussion rules before they were published on the forum.

Outreach

3. The forum was announced by the Committee via a press notice. The Web and Intranet Service publicised the forum via social media outlets including Facebook and Twitter. Parliamentary Outreach also promoted the forum to their contact base.

Forum questions

4. Participants in the forum were asked to address the following questions:

- Based upon your experiences as a carer what impact do you think the proposed changes will have on the role of local authorities? Will the proposed changes help carers?

- Based upon your experiences as a carer what impact do you think the proposed changes will have on the current assessment process?

- Based upon your experiences as a carer what impact do you think the proposed changes will have on the current measures in place to safeguard vulnerable adults?

Responsibilities of local authorities

A number of posts described the shortcomings of local authority performance in providing social care, often making suggestions for improvements.

The need for better information, and a clear idea of who was responsible for what, was a persistent theme:
“Another major issue is information and advice provided by local authorities. Many are moving over to web based solutions. Only around 58% of disabled people live in households with internet and of those many will not be able to access computers without support. Local authority care packages are increasingly being focused on basic personal care alone which means that even if a disabled person has a computer in their home they may well not have the support to use it. Web based solutions do not work for disabled people yet, in full knowledge of this, local authorities are opting to cut face to face and telephone advice and information services.”

“We need:

- One point of contact with the authority to make things happen.
- A first visit which will incorporate a risk assessment agreed with the prime carer as to what manual help, psychological support and provision is required, how often they are visited by the lead social worker as well as the service providers, and vision of any service providers’ contractual obligations.
- The telephone number you complain to to be answered by the person who can, there and then, issue an instruction to resolve the matter.”

“There needs to be a one-stop information place where the process of help is followed through. So many departments and agencies all blaming each other for what’s not being done.”

“During the last ten years that I cared for my late husband, I found local authorities to be less than transparent when it came to advice about availability of carers and equipment. One had to forage through websites and a plethora of information concerning the disease and effects surrounding my husband’s illness. Local social workers were less than ready to divulge information concerning funding and accessibility thereof. Social workers assigned to my husband’s case displayed apathy not empathy.”

One respondent called for

“full information on services and entitlements to those who are initially self-funding as well as those whose care the Local Authority pay for. At present there is not cohesive support for carers of those who are self-funding—you have to find out things for yourself and it can be difficult to find out what help is available now (whether or not you have to pay for it yourself) and what would be available in the future when self-funding money has run out.”

The pressures on carers came through in a number of contributions:

“Carer needs should be assessed on a personal level. We want/need a break, myself especially after 24/7 caring for nearly six years without a break. Having to deal with daily living and all it entails and look after hubby’s complex needs has left me, at times, suicidal.

“All we wanted a week together in a hotel where the strain of daily living (washing, ironing, cooking cleaning, finances etc) was taken off me for a while and where we could just enjoy being together. But no. We are not allowed a holiday together, we have to be separated and we do not want to be separated so we struggle on. Hubby’s life expectancy is very short, we’re talking a year or two, and after 43 years together time is so precious. Why cannot the
assessors see our individual needs? I have saved the country thousands for what? To spend the last few months/years struggling on the brink of suicide?”

“The case of carers caring for more than one person must also be sorted out; the cumulative effect is enormous and at present is not fully taken into account. Also the issue of carers who have been caring continuously for over 25 years must be recognised and the effect it has on your health taken into account. Training on how to promote carers’ assessments and how to do them properly should be mandatory and moderated to ensure equality.”

The role of carers should be better understood and explained by Government, one respondent told us:

“The government overall could do a great deal more to enlighten the general public about carers and the caring role - people still do have an outdated understanding of what caring means and still think caring is about people being paid to go into someone’s home to help them prepare a meal or do some cleaning for them.”

The quality and pay of social and care workers were seen as inadequate by some respondents:

“Care workers desperately need worthwhile training and better pay in order to provide a quality service.

“Social workers need more experience of the needs of the elderly. The generic nature of the social work degree does not equip them with the tools to deal with care for the elderly. Once you find out that the social worker is just a pen pusher, knows very little about the elderly or about local services you withdraw and help yourself.”

“You get what you pay for. Pay a better wage and a better quality of staff will be prompted to work in this industry. Currently ‘bank’ staff receive more than regular staff; what message does this send and what continuity of care does this provide?”

Some wondered whether local authorities would find it possible to shape the local care market (Clause 3):

“In terms of promoting diversity and quality of local services local authorities struggle to support the development of a range of providers. I have been involved in setting up a user-led disabled people’s organisation to provide peer support and advice for disabled people. We have faced many barriers with the local authority contracts and procurement processes that are designed to work with large organisations ... Working with a range of smaller services as opposed to a few big ones creates extra work for local authorities at a time when ... their funding is being cut and they are over-stretched. In my experience that have neither the capacity nor the will to change their practices to support the development of more options for service users. Who is going to measure whether they have done all they can to support the market to develop?”

Respondents often pointed to the problems involved in meeting the needs of those with specific conditions:
“Whilst I find Clause 3 laudable in promoting the quality of local services I am concerned that it will fail to allow access to specialist services where the local authority is of the opinion that it provides adequate services to meet the needs of the individual. In our case we had to battle to obtain funding for our daughter to attend a national Specialist College where she receives a full range of therapies and support to assist her continuing recovery from brain injuries sustained in a car accident nearly three years ago when she was nearly 18 ... My fear is that short-term penny pinching will reduce choice to the local provision even when it has no specialist knowledge, rather than recognising that every inch of gained or regained independence represents a long term cost saving.”

“It is important that whoever is responsible for assessing the needs of anyone on the autistic spectrum has had training in order to interpret responses around, for example, needs and aspirations. Support to prevent and provide early intervention is to be welcomed; however any reduction in presumed dependency should be done with caution to avoid crises.

“Simplifying support makes sense only if it does allow for flexibility in a new system as those requiring care are so diverse and one set of ‘rules’ may well not fit all needs.”

“I care for my brother who was diagnosed with psychosis 18 years ago. I can honestly say I have had no caring support of any use ever offered to me. Unfortunately all that was on offer was a leaflet & someone basically feeling sorry for me. This is not helpful to be able to look after the people we love. The people who are supposed to give you support have no or little knowledge of psychosis, so for me and I’m sure others the barrier starts there.”

“A social work degree does not equip social workers with what is needed for accurate and meaningful assessment of clients and their situations. Skills of knowing what is around for clients and how to access the provision are often limited. I found that in the end when I became a very substantive carer I did all the research / investigations, myself to get available services.”

There were questions about whether the duty on local authorities and others to co-operate (Clauses 4 and 5 of the draft Bill) would work in practice:

“Greater co-operation between councils and other local organisations is a very welcome move in my view. However I have little or no faith in local authorities using monies for the purpose it is intended; the carers’ grant is a prime example.”

“In my area of inner London I know that of ten professionals in the health field do not necessarily think highly of the local authority officers or its social workers, but use them as a necessary ‘pass on function’, in the hope that clients will be helped. Of course they never follow up to see what actually happens. In my case as a carer- very little and harmful actions due to failures to assess relevant information already held ... This Bill will change nothing as it is the same people and system.”

“If the proposed changes are implemented it will help enormously to have streamlined services with perhaps one point of contact to help guide one through the many and varied agencies and financial obstacles for the carer. Something akin to the Admiral Nurses used by Dementia UK should be adopted. These nurses are invaluable for those lucky enough to have them in their areas.”
“I am a carer for a mother who has dementia and who has not found the current system easy to navigate. The care and support access needed and the constant battle between local organisations has unduly created more stress for carers and their families. More needs to be done to reduce interfaces and blame culture between organisations ...”

“I approve of the theory of the new Bill but I have seen attempts in the past to generalise services and they have not worked. I think co-operation must be improved but if you ignore the needs of carers in special areas like mental health, young carers or physical disability you will be selling the carer down the river. We have managed to persuade our county council to reverse some decisions they wanted to make recently in these areas, when they were forced to really listen to the carers involved.”

“Clause 3 outlines a framework for providing service users with choice over their care providers. The insurance industry is not geared up for this, and in fact is several years behind in its response to the last government's increasing emphasis on choice in home care.”

“It may not be the place of the Bill to make provision for agreements with insurers, but it certainly does not in its current form. For any people who rely on these health cash plans to supplement the cost of their care, personal choice of care is a non-starter unless the government makes supportive agreements with the insurance industry.”

There was recognition of the important role of the voluntary sector, especially the Alzheimer’s Society, in filling gaps apparently left by local authorities and the NHS:

“Without the Alzheimer’s Society I would still be struggling to care for my mother. There is no proper support at all. The phrase “all words and no action” comes to mind. I didn’t need a lot of help but what I needed was essential to both our well beings. According to local authority we didn’t meet their criteria so they weren't interested in giving any help at all.”

“In our area so much of the support for Alzheimer sufferers and carers is initially actually organised and provided by the Alzheimer’s Society charity and not the local authority anyway, in many cases.”

There was a welcome for some of the provisions, including those for the support of carers, but also scepticism that local authorities would be able to fund the extra services:

“I think the proposed changes will help carers if implemented by Local Authorities - but will they be in practice? Doubtful whether the required funds will be there to do so. “

“These proposals are very fine on paper, but central government must provide adequate funding for local authorities to implement them.”

The role of prevention is prominent in the draft Bill, and one respondent saw this as a way in which local authorities could reduce dependency and so keep costs down:

“Let’s not kid ourselves - the main thrust of this Bill is a reduction in care costs. What is more legitimate is to try and provide more, better quality and adequately funded prevention and early intervention support services. If done properly (a big if!) this will reduce (but not eliminate) the need for very expensive high level support and care. There
will still be a need for this but if it's a reduced need, perhaps we can focus on making this better too?"

Assessing needs

A number of respondents said that financial pressures were preventing local authorities from meeting the assessed needs of service users. For example:

“After an assessment is done [it is] referred to a panel who have no knowledge of the persons involved and report back on their findings. This is where finance rules supreme and goal posts are moved to make it easier for the panel to refuse to give more care help. There should be national standards to adhere to as the duty of care is the thing that is lost in the decision making.”

“At the moment there are plans to close the Independent Living Fund from 2015, with no replacement ring-fenced funding being made available to local authorities, to provide the support needed for people with high support needs to continue to live independently in the community, nor any firm plans for how those with the highest support needs and their families will be able to get the support they need. This is in spite of the fact that only 2% of the ILF budget goes on administration, compared to as much as 24% in some local authorities.

“I do not think the proposals in this bill afford adequate ways in which those who have high support needs will be given the support they need. In particular, although there are some minor improvements being suggested in terms of portability of care and support, unless every local authority has to provide the same levels of support to meet the same needs there is still no guarantee that someone can move to another part of the country and have their needs met, as each council will still have its own eligibility criteria.”

There was concern that the requirements of those with complex needs should be assessed properly, especially where Continuing Health Care (CHC) is needed from the NHS:

“It is essential that the assessment process is made fit for purpose, and that those with profound disabilities that will require 24/7 support in everything they do for ever, are not forced to fit into an assessment process that does not fully cover the complexity of their needs. This is also essential for those funded by CHC from CCGs where the assessment process is very different and the two processes should be dovetailed so no one is made to suffer if they move between the two.

“As a carer it is also essential that I have the right to an assessment of my needs and that my input even if my daughter is in residential care is still recognised.”

Others had similar comments:

“I think the government has missed a vital opportunity to put national eligibility threshold in place now, rather than ‘in the future’. A national criterion which states whether those on low, moderate, substantial or critical needs are eligible would end the current postcode lottery of access to care and support services.”
“As a carer for an elderly parent it came as a shock to me that no provision is made for people of my age (59/60). The Carer’s Allowance goes no way to recompensing people for giving up full time work, and then, to add insult to injury, pension dates have been delayed to 2015 onwards. You cannot realistically claim Jobseeker’s Allowance because you are not available for full time work, and then if you do have part time work the system seems incapable of working out what you are entitled to.”

We heard that some carers who could make a contribution to wider society were not able to do so under present arrangements.

“The bill states that it aims to modernise care and support law so that the system is built around people’s needs and what they want to achieve in their lives. This could also be achieved with a system for paid leave for carers, so as to avoid them having to give up work and those skills lost to the company they work for.”

“As a carer of my husband, I agree with carers having all support they can and should get. But why are we not getting a proper allowance? And carer’s allowance is taxed. This is wrong. Many carers can’t go out & work. My husband is partially sighted in both eyes, also deaf and has chronic ongoing osteo-arthritis of the spine, hips & knees. I have been a carer since the early 1990s. Carers should also be entitled to regular yearly carer’s breaks; if needs be we should also be able to take our loved ones with us and not separated.”

One person who was a main carer for their 28 year old son, and a nurse, told us:

“I have had many assessments but very little action. I have had to give up the job I love because of the state or lack of care for my son. How can this be right? Now I am a main carer I want my needs met ... and would love to go and study and keep myself involved and up to date but cannot get the support to do this.”

The quality of assessments was criticised by a number of respondents, with some expressing the hope that the draft Bill will bring improvements:

“I have just spent ages composing a response which got lost. Nothing will ever compensate me for the loss of pay, promotion and pension for being the unpaid carer of my disabled child—there are not enough hours in the day. We assessed and assessed and assessed—when they are not short of assessors and we never fit the boxes ... all disabilities are different and costly and in different family environments and it is never that simple.....”

“As a substantive carer who was well aware of my rights to an assessment I requested my inner London authority adult services to provide this. This was a farce. It took 18 months for this to be done, although as a very substantive carer of two frail elders the stress on me was made very obvious. After it was done I received no services because of a complete failure of adult social services to be concerned by the fact or to take into account that I cared for two persons who needed assistance in my absence- both of whom had been assessed as in substantive need. What was the point of wasting everyone’s time?”

“As a carer for the past 30 years I welcome the move forward that the draft bill represents, although it could probably go further. I welcome that it states that the assessment will focus on the outcomes the person wishes to achieve—however, due to the economic reality of local authorities I wonder if this will be translated into practice or if assessment will
continue to focus on care needs alone as that is all that the local authority can afford to meet. I also welcome the emphasis on carers’ right to have a life and that there is some recognition that the life of the carer and the person being cared for is interwoven - so for many of us a joint assessment makes sense. At present the tick box type of assessments carried out by many local authorities are so rigid—there is little recognition of the symbiotic relationship that exists between carers and the cared for person—as that does not easily fit the tick boxes. Finally words are easy and unless there is some financial backing to this bill I will remain sceptical that things will change for either the carer or cared for person.”

“My carer’s assessment meant listening to the life story of an assessor, no help. And as my mother would have to pay for care they weren't interested in helping. What difference would this [Bill] make? Probably none. More wasted money.”

“A carer’s assessment should be done at the same time the caree is assessed. Many carers I support have not been offered or realise their needs should be assessed as they are not the one having that particular care needs.”

The chair of one carers’ organisation said that

“the assessment needs to be done more than once as the person’s moods change from day to day The feedback from carers is that the forms are too long and some have said they think that assessor does not appear to understand what a carer’s role is We need to look at ways for equal pay for elderly carers who only get a pension but are still caring so when assessing look at the income into the family and the needs of the carer. “

There was a call for local authorities to arrange;

“timely care assessments and ensure they are done by adequately trained and knowledgeable staff. If there aren’t enough people in social care to do this, why not use properly trained people from relevant voluntary organisations?”

And local authorities should, it was said, also:

“ensure all carers know as early as possible in their caring life that they are entitled to an assessment, even if they are likely to have to pay for any services. At least they would find out about advice and other help that they could buy in. So often, caring is a very lonely job.”

“The assessment cannot be a boxed set standard form, as many disabled people/children have very different needs.”

There was a call for clarification of one Clause in the draft Bill:

“Under Clause 10 (carers' assessments) it is not clear whether this would give local authorities a duty to assess more than one carer per adult. My sister and I share care for my mother, but when we were offered a carer’s assessment in 2009 (which consisted only of completing a questionnaire each) the local authority said they would disregard my assessment because they could only accept one carer assessment per service user.”

One carer called for a simpler assessment process, with:
“One form that I could complete with all relevant information that would then be centrally assessed and all relevant benefits paid e.g. attendance allowance, housing benefit, pension top-ups etc. rather than having to apply to several different bodies, often with very similar information, and at a time that is already extremely stressful;

Safeguarding adults at risk of abuse and neglect

Respondents were in no doubt about the scale of potential abuse and the need to tackle it:

“I have been staggered by the statistics of abuse ... there are 5000 incidents reported monthly in the UK and it is estimated that only 1:6 cases are actually reported. These statistics are an indictment of our society which is failing the most vulnerable people in our care homes. Mandatory training with proper screening, supervision and appraisals would address this scale of abuse as it would wheedle out the wheat from the chaff and ensure that only those who genuinely do care are employed for the demanding and rewarding role that they undertake. I also propose that all care staff, upon successful completion of the apprenticeship training programme, are then entered onto a national register similar to that of trained nurses.”

One linked the risk to changes in funding:

“These proposals do nothing to prevent abuse or neglect from taking place. Disabled and older people are at great risk of abuse and neglect within residential and institutional settings like Winterbourne View, which was far from an isolated incident as the follow up BBC Panorama programme showed, and which anyone who has spent much time in ‘care’ settings knows. Yet the closure of the Independent Living Fund is, as the government admitted in its response to the Future of the ILF consultation, going to mean a loss of support for existing claimants and likely to lead to some disabled people with higher support needs being forced into residential care against their will.”

One respondent referred to “the most worrying area of responsibility” for carers, and explained:

“People with learning disabilities are proven to be at greatest risk of abuse in the community

“The practice of housing people separately in social housing situations is unsuitable for many dependent people who are being given ‘independence training’ which makes them even more vulnerable. The inspection system leaves much to be desired. A safeguarding adults board seems like another talking shop where the members rarely if ever meet people who have problems with communication. As an elderly carer I have concerns about financial abuse after I have gone as my daughter has no family member to take care of her.”

Several respondents were sceptical that local authorities could effectively enquire into cases where there might be abuse or neglect of those with needs for care and support. One said:

“Social services / workers have been given this role in the assumption that their actions and omissions do not result in serious harm or even death.

“The experiences of many families suggest that this is far from the reality as social workers frequently ignore warnings from family carers / members and breach Mental Capacity Act
principles. Research shows that this is little taught and understood on social work courses. I have witnessed an approved mental health social worker walk into the room to interview client and without ascertaining mental capacity shout out ‘I am acting in your best interests’. This goes against the very principles of the MCA. This behaviour denies the rights of decision making by those who can and would wish to make their own decisions.”

“**The whole of safeguarding needs a rethink as it is done so badly by most local authorities. Removing a person from a presumed abusive family environment, where the relationship is long established, can precipitate fast decline and death if the vulnerable adult does not want to be separated- how can this be a good outcome from a safeguarding investigation? The human rights issues cut both ways- the right to freedom from harm and abuses, but also our own right to decide whether our family relations are so bad that we need to be ‘policed’ or removed as adults without our consent.”**

 Others said all relevant bodies needed to act quickly, and in particular to take action to **prevent harm** before it starts:

“**We need local authorities/ CCGs that act when things go wrong, we need the inspectors CQC to have teeth and to act when things go wrong. We need avenues of communication for carers and families to register concerns and for these to be looked into quickly.”**

“**In the area of assessing need of a person suffering from mental ill-health, early intervention cannot be stressed highly enough. It also follows that, on subsequent occasions, when the patient’s health deteriorates, speed is of the essence again. The delay in re-commencing or maintaining previously successful medication is detrimental to the long-term welfare of the patient.**

“**Informed opinion declares that the attained level of well-being is unlikely to be achieved again, leading to the need for higher levels of input, which may well have adverse financial consequences.”**

“**Preventative safeguarding work cannot be dissociated from other aspects of care and support provision.**

“**Carers (and the people they care for) should be able to benefit from social worker assessments that have the courage to identify when either party may be at risk of abuse/significant harm if their current situation continues and then help them to take steps to avoid (i.e. prevent) things getting that far. This, of course, may require services, which the given local authority has to fund. There is a real risk of nothing really changing for people if this doesn’t happen, and carers/cared for are left until something does actually happen and we get the same old reactive intervention.”**
### Appendix 6: Abbreviations and Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Name</th>
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<tbody>
<tr>
<td>ADASS</td>
<td>Association of Directors of Adult Social Services</td>
</tr>
<tr>
<td>ADCS</td>
<td>Association of Directors of Children's Services</td>
</tr>
<tr>
<td>AHSC</td>
<td>Academic Health Science Centre</td>
</tr>
<tr>
<td>AHSN</td>
<td>Academic Health Science Network</td>
</tr>
<tr>
<td>ALDS</td>
<td>Adults with Learning Disability Services</td>
</tr>
<tr>
<td>AMRC</td>
<td>Association of Medical Research Charities</td>
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<tr>
<td>AMS</td>
<td>Academy of Medical Sciences</td>
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<tr>
<td>BMA</td>
<td>British Medical Association</td>
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<tr>
<td>CCG</td>
<td>Clinical Commissioning Group (operative from April 2013)</td>
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<tr>
<td>CHCP</td>
<td>City Health Care Partnership</td>
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<tr>
<td>CPRD</td>
<td>Clinical Practice Research Datalink</td>
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<tr>
<td>CQC</td>
<td>Care Quality Commission</td>
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<tr>
<td>CSA</td>
<td>Care and Support Alliance</td>
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<tr>
<td>CSV</td>
<td>Community Service Volunteer</td>
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<tr>
<td>ECC</td>
<td>Ethics and Confidentiality Committee</td>
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<tr>
<td>ECCA</td>
<td>English Community Care Association</td>
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<tr>
<td>ECHR</td>
<td>European Convention on Human Rights</td>
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<tr>
<td>EHCP</td>
<td>Education, Health and Care Plan</td>
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<tr>
<td>EHRC</td>
<td>Equality and Human Rights Commission</td>
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<tr>
<td>EMEA</td>
<td>European Medicines Agency</td>
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<tr>
<td>EPaCCS</td>
<td>Electronic Palliative Care Coordination System</td>
</tr>
<tr>
<td>FACS</td>
<td>Fair Access to Care Services</td>
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<tr>
<td>FDA</td>
<td>Food and Drug Administration (United States)</td>
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<tr>
<td>FPH</td>
<td>Faculty of Public Health</td>
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<tr>
<td>GMC</td>
<td>General Medical Council</td>
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<tr>
<td>HEE</td>
<td>Health Education England</td>
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<tr>
<td>HFEA</td>
<td>Human Fertilisation and Embryology Authority</td>
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<tr>
<td>HRA</td>
<td>Health Research Authority, Human Rights Act</td>
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<tr>
<td>HSE</td>
<td>Health and Safety Executive</td>
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<tr>
<td>HTA</td>
<td>Human Tissue Authority</td>
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<tr>
<td>JSNA</td>
<td>Joint Strategic Needs Analysis</td>
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<tr>
<td>LASSA</td>
<td>Local Authority Social Services Act 1970</td>
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<tr>
<td>LGA</td>
<td>Local Government Association</td>
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<tr>
<td>LSE</td>
<td>London School of Economics and Political Science</td>
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<tr>
<td>LETB</td>
<td>Local Education and Training Board</td>
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<tr>
<td>MHRA</td>
<td>Medicines and Healthcare Products Regulatory Agency</td>
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<tr>
<td>Monitor</td>
<td>Independent Regulator of NHS Foundation Trusts</td>
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<tr>
<td>NAPC</td>
<td>National Association of Primary Care</td>
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<tr>
<td>NAVCA</td>
<td>National Association for Voluntary and Community Action</td>
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<tr>
<td>NDPB</td>
<td>Non-departmental public body</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
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<td>NHS Act 2006</td>
<td>The National Health Service Act 2006</td>
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</table>
NHS Acts 2006The National Health Service Act 2006 and the National Health Service (Wales) Act 2006

NHS CB NHS Commissioning Board
NIACE National Institute of Adult Continuing Education
NICE National Institute for Health and Care Excellence
NIGB National Information Governance Board for Health and Social Care
NIHR National Institute for Health Research
NRES National Research Ethics Service
NSPCC National Society for the Prevention of Cruelty to Children
PSSRU LSE Personal Social Services Research Unit
QIPP The NHS programme of Quality, Information, Productivity and Prevention
RAS Resource Allocation System
RCP Royal College of Physicians
RCGP Royal College of General Practitioners
RSL Registered social landlord
RNIB Royal National Institute for the Blind
REC Research Ethics Committee
SAB Safeguarding Adults Board
SCIE Social Care Institute for Excellence
SHA Strategic Health Authority
SpHA Special Health Authority
SSC Strategic Society Centre
UKECA UK Ethics Committee Authority
UKHCA United Kingdom Homecare Association Ltd
UNCRPD United Nations Convention on the Rights of Persons with Disabilities
VCS Voluntary Community Service, Voluntary Community Sector
WRVS Women’s Royal Voluntary Service
Appendix 7: Formal Minutes

Wednesday 6 March 2013

Members present:

Mr Paul Burstow, in the Chair

Baroness Eaton    Harriett Baldwin MP
Baroness Greengross Margot James MP
Baroness Jolly    Barbara Keeley MP
Lord Mackay of Clashfern    Dr Sarah Wollaston MP
Baroness Pitkeathley
Lord Warner

Draft Care and Support Bill

Draft Report (Draft Care and Support Bill), proposed by the Chair, brought up and read.

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

Paragraphs 1 to 348 read and agreed to.

Summary agreed to.

Appendices to the Report agreed to.

Resolved, That the Report be the Report of the Committee to both Houses.

Written evidence was ordered to be reported

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