



## Draft Care and Support Bill [Joint Committee on the draft Care and Support Bill]

### Written Submission

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#### **About Disability Rights UK**

1. Disability Rights UK is led, run and controlled by disabled people. We work to create a society where everyone with lived experience of disability or health conditions can participate equally as full citizens.
2. Disability Rights UK was formed through a merger of Disability Alliance, Radar and the National Centre for Independent Living on 1 January 2012.
3. Disability Rights UK's objectives are to: mobilise disabled people's leadership and control; achieve independent living in practice; break the link between disability and poverty; and put disability equality and human rights into practice across society.

#### **Introduction**

4. Our submission has been shaped by the combined expertise of our predecessor organisations and the evidence from our helpline and members, including people who responded to our survey on the draft Care and Support Bill. We are a member of the Care and Support Alliance (CSA) and have contributed to their submission. Our submission should be read alongside theirs.

#### **Question 1. About Part 1 of the Bill**

5. Disability Rights UK welcomes the draft Care and Support Bill ('the Bill') which should end some of the complexity of the current multiple care legislation. The simplification and harmonisation should clarify councils' duties and disabled people's entitlements to support. However we have particular concerns which we have

highlighted in response to the questions (alongside the CSA response). In particular we believe that:

- the direct payments provisions are a retrograde step as they change the duty to offer direct payments to a right to request direct payments, and restrict the flexibility and support for direct payments holders;
- the continuity of care provisions need to be strengthened in order to give disabled and older people and their families the confidence that, when they move to another area, they will continue to receive equivalence of care and support;
- if unchanged, the charging framework will undermine policy intentions to promote disabled people's independence and give them real choice and control over their lives.

6. In the context of this response we also want to stress the need to reach a sustainable and sufficient funding solution to the care crisis. We are concerned that the Government has decided to close the Independent Living Fund, which currently supports over 19,000 with the highest needs to live independently. With the current funding shortfall, estimated to be at least £2 billion<sup>1</sup>, this will add to the enormous pressure on local authorities, disabled people and carers. We fear that this will lead to increasing charges for essential services. The draft Bill needs to provide a vital protection against breach of the UN Convention on the Rights of Persons with Disabilities (the 'Convention'), including the right to live independently, participate in the community and the ability to make own decisions with support if needed.

#### **Q 4. Well-being principle**

7. We strongly welcome the duty to promote the adult's well-being. The well-being duty should usher in an approach to social care as a key enabler for disabled people to realise their full potential and to support their life choices (rather than the provision of social care as an end in itself).
8. However it needs to include the 'adult's full enjoyment of human rights and equality'. Respondents to our survey asked to include dignity, independence, self-determination. These are matters covered by (international) human rights law, including the Convention which requires the UK Government to ensure that local authorities are doing what is necessary to implement the obligations.

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<sup>1</sup> <http://www.dilnotcommission.dh.gov.uk/our-report/>

9. There will need to be strong guidance on the well-being duty. For example, 'relationships' need to include parental and caring responsibilities that a disabled person may have. We have anecdotal evidence of disabled parents who struggle to get basic parenting support, for example getting their children to school, and some have been threatened that their child will be removed instead of being offered appropriate support. We hope that the well-being duty strengthens the entitlement of disabled parents to support.

#### **Q 5. Co-operation and integration**

10. We welcome the co-operating duties outlined in Clauses 4 and 5. Disabled people often need support from different authorities and in order to join up the support and streamline it, these authorities must work together, and wherever possible this should be guided by the lived experience of disabled people themselves.

11. We believe that the range of authorities needs to be expanded to cover providers of further and higher education. The draft Children and Families Bill makes provision for an 'education, care and health plan' (ECHP) for young people up to the age of 25. Also absent are benefits and work authorities, for example it may be necessary to work with Jobcentre Plus to ensure that social care is geared towards enabling adults to get in and stay in a job (including work experience) or to avoid unintended consequences arising from charging and benefits policies (including sanctions).

12. We would welcome a provision on the enforcement of the co-operating duties in specific cases. Our members have told us that some local authorities tend to just give up if they do not get the co-operation they need. For the co-operative duties to be effective there needs to be a mechanism to ensure that disabled people aren't left without support or housing they need to live independently whilst authorities are resolving co-operation issues.

#### **Q 8. Views of service users, carers and prospective users of services**

13. The Bill needs to go beyond the duty to 'consult' the adult and to demand their active engagement, and to require local authorities to provide additional support if needed, including advocacy and independent brokerage services which help with the care and support planning.

14. We believe that it is right to consult the carer, as they often see things that others do not. However we are concerned that the duty is not qualified. Disability Rights UK has heard about disabled

people's frustrations with councils giving more weight to the views of the carer (especially if the disabled person is a young person who wants to move out of the parental home or is a person with a communication impairment or someone without an independent advocate when they need it to have their say).

15. In order to discourage this practice as well as to promote transparency, we strongly recommend a duty on local authorities to set out in writing how they have listened to the adult and the carer and resolved any conflicting views or interests.

#### **Q 9. Implications new care and support responsibilities**

16. We strongly welcome the general responsibilities which form the backdrop to the other provisions in the Bill. If implemented effectively, these duties should lead to a more responsive social care system that empowers individuals and their families. It should reduce waste of resources that currently exists because of lack of information and advice, mismatch between services and needs, authorities not working together and the delay in providing support until needs become more acute and more expensive to meet.
17. For the effective promotion of these duties, it is important that their implementation is monitored and that local authorities are held accountable (not just when disputes arise). This needs to be at local as well as national level.

#### **Q 10. Information and advice**

18. Disability Rights UK strongly welcomes the duty to provide information and advice. The White Paper rightly recognises their importance in accessing care and support and in supporting the exercise of choice and control. However there are fundamental omissions which are highlighted in the CSA submissions such as access to advocacy and the need to ensure that information and advice get to people who need it.
19. Without sufficient provision of independent information, advice and advocacy the full benefits of social care's preventative function cannot be reaped.
20. People with a care package who move into the new area often need information not just about care and support but also about housing, local benefits, health services and transport. They will also need to know who to notify about their intention to move. This needs to be included in the information duty.

#### **Q 11. Meeting local needs and diversity of providers**

21. Disability Rights UK strongly welcomes the new duty to promote diversity and quality in the provision of services. Disabled people often have to fit their lives around care provision rather than the other way around. We regard this as an infringement of their right to independent living (Article 19 UN Convention). Making the market far more responsive to local people's needs would be a significant step forwards.
22. Effective care and support needs to be aligned with people's expressed needs and aspirations, and this requires two-way communication. User-led organisations have been found instrumental in nurturing such support as a dialogue, which can also involve peer support.<sup>2</sup>
23. Any market-shaping activity must take account of the unique values and skills that individuals and families as well as user-led organisations bring to developing and providing support that maximise choice and control and use of resources, and the need to invest in them and to remove barriers. Our project on user-driven commissioning<sup>3</sup> (with Shaping Our Lives National Users Network) looked at giving individuals and families real power in shaping the social care system and has tested 'stepping stones' to make user-driven commissioning a reality. The report makes concrete recommendations to make the market more responsive to local needs, for instance by incorporating choices made by direct payments holders into the portfolio of care and support available to everyone.

### **Q 17. Charging**

24. Disability Rights UK wants a national charging system that is fair and easy to understand, and that reflects the true costs of disability-related expenditure. Disabled people and their families should be able to enjoy adequate standards of living as well as realise their aspirations.
25. Without the regulations we do not know what the new charging system will look like, however we would be very concerned if it retained the current charging system. We do not feel that the current system is fair as charges to use council care services already push thousands of disabled people into poverty – and figures show that charges rose £80m last year whilst overall spending fell £900 million.<sup>4</sup> We are also concerned that some

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<sup>2</sup> <http://odi.dwp.gov.uk/docs/ils/support-planning-and-brokerage-project-report.pdf>

<sup>3</sup> <http://www.disabilityrightsuk.org/userdrivencommissioning.htm>

<sup>4</sup> <http://www.localgov.co.uk/index.cfm?method=news.detail&id=105919>

authorities are consulting on policies that will leave people with no choice but to enter residential care which undermines their human rights (the 'maximum expenditure policy').<sup>5</sup> Longer-term evidence suggests support in the community represents the best deal for disabled people and the public purse.<sup>6</sup>

26. We support the recommendations by the Care and Support Alliance.

### **Q 18 Quality standards and market shaping studies**

27. There are a range of standards related to quality of care and support, including the NICE-produced quality standards, the Care Quality Commission's monitored legally binding standards, the Think Local Act Personal 'markers of progress', ratings on NHS Choices and the SCIE 'Find Me Good Care' website. This raises questions - How will consumers and commissioners know which is which and whether services meet a relevant quality standard? What measures will be taken to ensure that members of the public can use the standards and that the standards are enforced?

28. It will be important to ensure that quality, and market shaping duties, are driven by people's own ratings and choices which will become more substantial over time if people are sufficiently supported by information and peers' lived experience. See also our response to questions 3 and 11.

### **Q 19. Input from service users and carers in care and support planning**

29. We are concerned that the Bill does not do enough to ensure that support is genuinely self-directed. Currently guidance provides that personal budget holders write their support plan but through our helpline we often find that a social worker has written the support plan with minimum involvement of the service user or that the service user has not been given the assistance they need to choose and control their support. It is vital that adults are given stronger rights to design their own care and support package, including with the assistance of advocacy or independent brokerage services where needed. See also our reply to question 8 and the CSA submission.

### **Q 20. Personalised care and support and payment process**

30. We welcome the requirement to specify in a personal budget how much the council pays and how much the individual through

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<sup>5</sup> <http://www.communitycare.co.uk/articles/02/01/2013/118798/legal-challenge-launched-against-council-care-spending-cap.htm?cmpid=NLC|SCSC|SCDDB-20130103-GLOB|news>

<sup>6</sup> <http://odi.dwp.gov.uk/docs/res/il/better-outcomes-report.pdf>

charges. However, we want to see this strengthened with a requirement to set out how the council has calculated the costs. Having the transparency would facilitate collaborative care planning and empower the disabled person to make decisions.

31. We believe it is helpful to include other funding streams in the personal budget as is proposed. We recommend that the scope is extended to include education (disabled student's allowance) and employment (Access to Work, Work Choice). Employment-related funding is also included in the Right to Control pilots.<sup>7</sup>

#### *Direct payments*

32. The 'right to request' direct payments is a retrograde step from the current law and we would like to see a duty to offer direct payments reinstated. The Bill threatens to restrict access to direct payments and to reduce the flexibility that direct payments holders currently enjoy and we urge the committee to take account of the CSA recommendations. For example, a woman contacted our Independent Living Adviser about her mother with dementia who was getting visits from up to 20 different care assistants a week and this was having an adverse impact on her well-being. They requested direct payments so that they could have more control over visitors to their house. However, the local authority denied them direct payments on the grounds of the mother's age and ill-health. As a result of our support, the mother now gets direct payments and uses the local Independent Living Association for support in employing Personal Assistants. We have more stories from people who have been denied direct payments for various reasons and people who were not allowed to use direct payments for support of their choice.

#### *Direct payments for carers*

33. Currently a partner or a relative can receive direct payments if the local authority is satisfied that this is necessary.<sup>8</sup> This is particularly helpful for families of Asian/Arab background and other minority ethnic backgrounds who are more likely to opt for the option of family member being the carer rather than employing

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<sup>7</sup> <http://odi.dwp.gov.uk/odi-projects/right-to-control-trailblazers.php>

<sup>8</sup> Community Care, Services for Carers and Children's Service (England) Regulations 2003 SI No 762 and Guidance on direct payments for community care, services for carers and children's services: England 2009, available at [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_104840](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_104840)

someone else especially in terms of personal care and rituals.<sup>9</sup> However the draft Bill excludes them from carers' rights to assessment and services, even though this is not the intention stated in Detailed Note 21. The current position must be maintained with clear guidance when circumstances may arise that require payment to partner or relatives.

#### *Managing support and payment processes*

34. It is vital that the local authority provides information and independent advice and advocacy to support people with managing their direct payments. For example, we are concerned that many people use self-employed personal assistants rather than becoming their employer. This is something we strongly advise against as the HM Revenue and Customs will still treat them as employers and thus be liable for tax and NI contributions. We urge the Committee to take note of the CSA recommendations.

#### *Portability*

35. 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.
36. We were therefore very pleased to see provisions to ensure continuity of care for people who move from one area to another. However whilst it ensures continuity of support until a new care package is in place it does not give disabled and older people and families the confidence that they will be able to continue to achieve the same outcomes in the new area. We have heard from people who have had their support cut by half or who have been told that they cannot employ a personal assistant but should go in a residential home instead – even when their needs have been assessed the same.
37. The Bill needs to make provision to ensure equivalence of care and support outcomes, for example by requiring the receiving authority to have regard to the care and support plan of the previous authority until they have put in place a new package. This

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<sup>9</sup> See also Equalities National Council and Scope (2012) Over-looked Communities, Overdue Change: how services can better support disabled people.  
<http://www.scope.org.uk/campaigns/publications/bme>



would mean that they have to meet assessed needs as well as take account of the outcomes and how the needs used to be met.

38. Furthermore the requirement to give a written explanation of the differences in assessed needs is so important that it must be placed on the face of the Bill (with regulations setting out the circumstances when this duty may arise); and the duty must be extended to cover (a) differences in how these needs and outcomes are met and (b) reasons for the differences.

### **Q 22. Safeguarding provisions**

39. Disabled people have a right to be safe, and free from violence and abuse (Article 16 of the UN Convention).
40. It is important to recognise that strong community networks and effective support will help reduce the risk of abuse and that is why it is vital that the Bill helps to ensure that disabled people have access to those assets.
41. In addition to a right to an independent advocate for an adult who is at risk of abuse or has been abused (see CSA submission), we recommend that regulations place a duty on local authorities to ensure that those carrying out investigations have received adequate training to carry out an investigation of alleged abuse against a disabled person – and this includes being able to listen and take note of the views of the disabled person concerned.
42. That is because we find that people who carry out investigations may not necessarily have received training which would help them understand specific issues that arise in relation to disabled people (for example, perceived incapacity, bias towards the carer, or lack of skills to communicate effectively with a disabled person, with the support of an independent advocate if so required). This hampers their ability to carry out an effective investigation and it may make a bad situation worse.