

**Inclusion London’s response to the Commission on the Future of Health and Social Care, ‘A new settlement for health and social care’ interim report’s consultation**

May 2014

# 1. Introduction

Inclusion welcomes the opportunity to response to the consultation questions in Commission on the Future of Health and Social Care, ‘A new settlement for health and social care’ interim report which is available at: <http://www.kingsfund.org.uk/publications/new-settlement-health-and-social-care> funded by the Kings fund.

**Inclusion London**

Inclusion London is a London-wide organisation which promotes equality for London’s Deaf and disabled people and provides capacity-building support for Deaf and disabled people’s organisations in London.

**Disabled People**

There are:

* 11.5 million people in the UK who are covered by the disability provisions set out in the Equality Act. This is 19% of the population[[1]](#footnote-1).
* There are approximately 1.4 million deaf and disabled people in London[[2]](#footnote-2)

**Questions**

* *Do you agree with our conclusion that a new settlement in health and social care is needed?*

*If so, do you support our proposition for a single, ring-fenced budget**for health and social care that is singly commissioned, and within which entitlements to health and social care are more closely aligned?*

**Inclusion London’s response**

Inclusion London supports joint working and pooling of budgets rather than full integration of care and support with health services. This may improve gaps between hospital care and community care that occur and remove the artificial divisions between care and health. We also believe that it vital that the budget(s) for health and social care are ring-fenced.

However, it is vital to understand that there is an important difference in the culture between social care in the community and attitudes of staff in the NHS. This is due, in part, to the obligations place on Local Authorities under the Disability Discrimination Act’s Public Sector Equality Duties to produce disability equality schemes[[3]](#footnote-3) and act on them. This legal obligation has helped to raise the awareness of Local Authorities/social services of the need for reasonable adjustments and equality/discrimination issues. Also disabled people have fought long and hard to try and imbed the social model of disability[[4]](#footnote-4) and a culture of independent living, choice and control[[5]](#footnote-5) into the provision of care services. Unfortunately the best practice in social care and support has yet to be adopted by the NHS, where unfortunately discrimination by NHS staff is still experienced by disabled people as revealed by the ‘*Death by Indifference’* report,[[6]](#footnote-6) published in March 2013 following a confidential inquiry, commissioned by the Department of Health. The inquiry examined the deaths of 247 people with a learning disability under NHS care and found **that 37% of deaths were avoidable; exposing** unequal healthcare and institutional discrimination.[[7]](#footnote-7) Disabled people have also experienced abuse in NHS settings, such as Budock Hospital in Cornwall, as a report by Care Quality Commission showed.[[8]](#footnote-8)

Also disabled people can still find their power of decision taken away by NHS staff working under the medical model of disability; in 2013 a disabled person of working age wished to return home from hospital with domiciliary care in place, while the health professions in a hospital decided he should be placed in a residential home. The NHS staff showed no understanding or respect for either the disabled person’s wishes or the concept of choice and control. It took a considerable fight by the disabled person and their family to prevent him being put into the care home.

It is important that the concerns mentioned above are not dismissed in the race to put a major new strategy of integrating health and social in place.

**Questions**

* *Should the aim be to achieve more equal support for equal need, regardless of whether that support is currently considered as health or social care?*

*If so, should social care be more closely aligned with health care (that is, making more social care free at the point of use)? Or should health be aligned more closely with social care (that is, reducing the extent to which health care is free at the point of use)?*

* *Do you think that adequate funding for health and social care requires:*
	+ *increased charges in the NHS? If so, for what?*
	+ *increased charges for social care? If so, for what?*
	+ *cuts to funds from other areas of public spending, re-allocating it to health and social care? If so, from what?*
	+ *an increase in taxation? If so, which taxes would you favour increasing?*
	+ *none of the above? If you answer yes to this, is it because you think that funding for health and social care system is adequate, and that extra demands can be met by using existing resources more efficiently? Or is it for some other reason?*

**Inclusion London’s response**

Inclusion London agrees that there should be more equal support for equal need. We strongly believe that social care and support for independent living should free at the point of use, paid from general taxation/National Insurance contributions. We refer to independent living for disabled people in its widest sense as outlined in the [Article 19 - Living independently and being included in the community](http://www.un.org/disabilities/default.asp?id=279)[[9]](#footnote-9)and other rights under the UN Convention on the Rights of Persons with Disabilities,[[10]](#footnote-10) (UNCRDP). These rights include having the opportunity to get a job, build a career, have an education, and volunteer, also having the chance to have a family and a social and cultural life. If general taxation and/or National Insurance contributions need to rise to pay care and support that enables independent living as described briefly above, then so be it. We do not believe that existing health and care resources can used more efficiently.

We were concerned that the *Caring for our Future’* consultation seemed to presume that the public would be ‘Paying for care’ and needed to take responsibility for ‘planning and preparing for future care and support’.[[11]](#footnote-11) If a system is introduced whereby the public have to pay for their care it would severely disadvantage many disabled people between the ages of 25 and retirement age, because disabled people in this age group are twice as likely to being living in a low-income household, often because they are not working.[[12]](#footnote-12) Many disabled people in this age category will not be able to afford to pay for the level of care and support to maintain their rights as outlined in the Articles in the UNCRPD[[13]](#footnote-13) and will because isolated, cut off from the community, unable to live an active life. We are also concerned that if insurance schemes to pay for care and support become mandatory this will also disadvantage those that are disabled before pension age because it is likely that insurance companies will demand a much higher, unaffordable premium.

Social care and support for independent living is woefully underfunded as research from Scope and Age UK indicates: there is a £1.2 billion funding gap in state funded support for disabled people under age of 65[[14]](#footnote-14) and England is £500 million a year short of ‘even maintaining the inadequate levels of provision’ for older people[[15]](#footnote-15). Central government has made significant cuts to local government funding; Local Authorities (LAs) have responded in turn with equally significant cuts in to social care and independent living support: In March 2014 there will have been £2.68 billion cut in the spending on adult social care over 3 years, a 20% cut of net spending.[[16]](#footnote-16) In response to pressure regarding the funding crisis the Government intended to provide £3.8 billion in funding for care and support, saying it would ‘help older and vulnerable people to stay healthy and remain at home…’[[17]](#footnote-17) . However, this funding has been delayed, casting doubt that they will be any increase in funding for care and support at all.[[18]](#footnote-18) Yet the President of ADASS[[19]](#footnote-19) said, “… without additional investment from that already planned, an already bleak outlook becomes even bleaker."[[20]](#footnote-20)

**Impact of the cuts and changes**:As a result of the funding cuts mentioned above disabled people’s support is being cut to a minimum ‘clean and feed’ model of care, which completely undermines disabled people’s rights under [Article 19 - Living independently and being included in the community](http://www.un.org/disabilities/default.asp?id=279)and other rights under the UN Convention on the Rights of Persons with Disabilities[[21]](#footnote-21): removing all choice, control, dignity and independence and making work, volunteering and participation in the community and in cultural, social or political activities increasingly impossible. Independent living as a right and as a way of life, is being systematically dismantled. Research findings illustrate this: nearly half (47%) in a survey said say they are withdrawing from society because the services they receive do not enable them to take part in community life[[22]](#footnote-22), over one third (34%) being unable to work or take part in volunteering or training activities after losing support services[[23]](#footnote-23), over half (53%) saying they felt anxious, isolated, or experienced declining mental health because they had lost support services[[24]](#footnote-24).

The Government’s response to the Dilnot Commission’s[[25]](#footnote-25) recommendations are inadequate as the measures proposed only benefit those with substantial savings or those who own their own home with only 100,000 benefiting[[26]](#footnote-26) leaving 1,400000 not benefiting at all. The Shadow Care Minister, Liz Kendall, has rightly raised concerns about the costs of implementing these reforms, which are contained in the Care Bill currently going through Parliament, saying that, “*Money is being taken off existing users to fund a new system*”.[[27]](#footnote-27) A County Council’s Network survey strongly suggested that ‘resource allocations’ to implement the reforms in the care Bill are ‘unrealistic’ and’ also speak of a ‘potential funding black hole’ if the Government does not ‘reassess funding allocations’.[[28]](#footnote-28)

# In addition the Independent Living Fund (ILF) closed to new claimants in 2010 and In March 2014 government decided to close the ILF in June 2015 and transfer responsibility for meeting the care and support needs of current ILF users to LAs.[[29]](#footnote-29) The ILF provides financial support which enables disabled people with high support needs to choose to live an independent life in the community rather than in residential care. Funding will be devolved to each local authority and to the devolved administrations on the basis of the pattern of expenditure in 2014/15[[30]](#footnote-30). But LAs have not committed to ring-fencing the funding, so it may well be used for other purposes other than care and support, such as mending pot holes in roads. Without the ILF level of funding independent living will be lost, as recognised by the Court of Appeal, which said: *“..inevitable and considerable adverse effect which the closure of the fund will have, particularly on those who will as a consequence lose the ability to live independently”.[[31]](#footnote-31)* Yet the ILF is a cost effective model of funding[[32]](#footnote-32), which supports independent living and inclusion in the community, while LAs increasingly only provide funding for basic a ‘clean and feed’ model of care.

As can be seen from the evidence above it is not without reason that many organisations believe there is a crisis in care and support for independent living funding,[[33]](#footnote-33) at a time when the population is ageing and the need for care and support is likely to increase.[[34]](#footnote-34)

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1. Fulfilling Potential: Building Understanding report <http://odi.dwp.gov.uk/fulfilling-potential/index.php> [↑](#footnote-ref-1)
2. <http://www.inclusionlondon.co.uk/all-in-this-together> [↑](#footnote-ref-2)
3. <http://www.equalityhumanrights.com/advice-and-guidance/your-rights/disability/>

[Making Real Change Happen: Getting **Disability Equality** **...**](http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0CCwQFjAA&url=http%3A%2F%2Fwww.equalityhumanrights.com%2Fuploaded_files%2FPSD%2Fusing_your_revised_des_new.doc&ei=WCN2U-iRD-SL7Aab74GYDw&usg=AFQjCNG-lBL8esMLWUj4MlW_ekMWWzlsTg&bvm=bv.66699033,d.ZGU) [↑](#footnote-ref-3)
4. <http://odi.dwp.gov.uk/about-the-odi/the-social-model.php> [↑](#footnote-ref-4)
5. <http://odi.dwp.gov.uk/odi-projects/independent-living-strategy.php> [↑](#footnote-ref-5)
6. <http://www.mencap.org.uk/campaigns/take-action/death-indifference>

<http://www.bristol.ac.uk/cipold/finalreportexecsum.pdf> [↑](#footnote-ref-6)
7. <http://www.mencap.org.uk/campaigns/take-action/death-indifference>

<http://www.bristol.ac.uk/cipold/finalreportexecsum.pdf> [↑](#footnote-ref-7)
8. <http://news.bbc.co.uk/1/hi/england/5148154.stm> [↑](#footnote-ref-8)
9. <http://www.un.org/disabilities/default.asp?id=279> [↑](#footnote-ref-9)
10. <http://www.un.org/disabilities/convention/conventionfull.shtml> [↑](#footnote-ref-10)
11. <http://consultations.dh.gov.uk/social-care-funding/funding_reform/consult_view> [↑](#footnote-ref-11)
12. <http://www.poverty.org.uk/40/index.shtml?2>

<http://odi.dwp.gov.uk/disability-statistics-and-research/disability-facts-and-figures.php#ls> [↑](#footnote-ref-12)
13. <http://www.un.org/disabilities/convention/conventionfull.shtml> [↑](#footnote-ref-13)
14. <http://www.scope.org.uk/news/other-care-crisis> [↑](#footnote-ref-14)
15. <http://www.ageuk.org.uk/latest-news/500m-funding-gap-for-older-peoples-social-care-revealed> [↑](#footnote-ref-15)
16. <http://www.adass.org.uk/Content/Article.aspx?id=1034> [↑](#footnote-ref-16)
17. <https://www.gov.uk/government/news/eric-pickles-hails-council-tax-5-year-freeze-and-38-billion-for-social-care> [↑](#footnote-ref-17)
18. <http://www.government-online.net/3-8bn-nhs-better-care-fund-policy-delayed-damning-whitehall-review/> [↑](#footnote-ref-18)
19. ADASS = Association of Directors of Adults Social Services: <http://www.adass.org.uk/home/> [↑](#footnote-ref-19)
20. <http://www.adass.org.uk/Content/Article.aspx?id=1034> [↑](#footnote-ref-20)
21. <http://www.un.org/disabilities/convention/conventionfull.shtml> [↑](#footnote-ref-21)
22. <http://www.scope.org.uk/campaigns/other-care-crisis> [↑](#footnote-ref-22)
23. <http://www.scope.org.uk/campaigns/other-care-crisis> [↑](#footnote-ref-23)
24. <http://www.scope.org.uk/campaigns/other-care-crisis> [↑](#footnote-ref-24)
25. The Dilnot Commission was tasked with reviewing the funding system for care and support in England: [http://webarchive.nationalarchives.gov.uk/20130221130239/http://dilnotcommission.dh.gov.uk/](http://webarchive.nationalarchives.gov.uk/20130221130239/http%3A//dilnotcommission.dh.gov.uk/) [↑](#footnote-ref-25)
26. <http://consultations.dh.gov.uk/social-care-funding/funding_reform/consult_view> [↑](#footnote-ref-26)
27. http://www.publications.parliam ent.uk/pa/cm201314/cmpublic/care/140114/pm/140114s01.htm [↑](#footnote-ref-27)
28. http://www.countycouncilsnetwork.org.uk%2Flibrary%2Fjuly-2013%2Ffile63%2F&ei=95xrU4ngBMzY7AbHh4C4Cw&usg=AFQjCNFAHLWy4Whioaj4wWjA8ZCT6gkj8w&bvm=bv.66330100,d.ZGU [↑](#footnote-ref-28)
29. <http://www.dwp.gov.uk/ilf/news/> [↑](#footnote-ref-29)
30. <http://www.parliament.uk/documents/commons-vote-office/December_2012/18-12-12/22.DWP-Independent-Living-Support.pdf>

<https://www.gov.uk/government/speeches/statement-on-the-future-of-the-independent-living-fund> [↑](#footnote-ref-30)
31. <http://www.bailii.org/cgi-bin/markup.cgi?doc=/ew/cases/EWCA/Civ/2013/1345.html&query=bracking&method=boolean> [↑](#footnote-ref-31)
32. According to the ILF it only has about 2% overhead costs compared 16% on average for Local Authorities. The ILF provides on average £337 per week per person– compared to Winterbourne View private hospital where, on average, it costs £3,500 per week. [↑](#footnote-ref-32)
33. <http://careandsupportalliance.com/about/>

<http://www.ageuk.org.uk/home-and-care/campaign-for-better-care/what-is-care-in-crisis/> [↑](#footnote-ref-33)
34. <http://www.parliament.uk/business/publications/research/key-issues-for-the-new-parliament/value-for-money-in-public-services/the-ageing-population/> [↑](#footnote-ref-34)