



## Collaborative briefing: Health and Care Bill Lord's Committee Stage

This briefing has been produced by ten leading charities who work with and support disabled adults under the age of 65 living with life-long conditions and impairments.

### Background on working-age disabled adults

The conversation around social care is often focused on older people and care homes, vulnerability and intimate care. However, over a quarter of a million adults under the age of 65 in England rely on social care to help them live independent, healthy and fulfilling lives, or recover from illness<sup>1</sup>.

A large percentage of this group are likely to access care and support for a significant period, some for the entirety of their adult life<sup>2</sup>. They are also unlikely to have had the opportunity to build up assets or savings:

- In the UK, more than a third (38%) of working-age disabled adults live in poverty<sup>3</sup>.
- On average, this group have £108,000 less in assets and savings than older people and this means they're more likely to rely on the publicly-funded social care system<sup>4</sup>.

### Impact of the current proposals

The Government's Impact Assessment shows the reform will benefit around 10% of working age care users. It also reveals the limited impact that the proposals will have on improving the funding being spent on working-aged disabled adults. The Impact Assessment also shows that an additional 20,000 self-funders will come in the lower capital limit (LCL), rising to 9,900 by 2031. Their contribution will be up to £23 per week less<sup>5</sup>. The rest of working age care users (86%) will not see any benefit and will have to pay contributions for many years before they reach the cap.

The assessment shows a projected additional cost of only £170m in 2023-24 rising to £690m in 2031-32. This limited additional funding will not address the increased demand for social care, with the National Audit Office predicting a 29% increase in adults aged 18-64 requiring care in 2028 compared to 2018.<sup>6</sup>

<sup>1</sup> NHS Digital, October 2021, Adult Social Care Activity and Finance Report, England - 2020/21

<sup>2</sup> Around 293,000 of adults aged 18-64 received long-term support from local authorities in England in 2018-19. This represented around 35% of all adults receiving support

<sup>3</sup> JRF, February 2020, UK Poverty 2019/20

<sup>4</sup> King's Fund, February 2018, Approaches to social care funding

<sup>5</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/1044903/adult-social-care-charging-reform-impact-assessment.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1044903/adult-social-care-charging-reform-impact-assessment.pdf)

<sup>6</sup> <https://www.nao.org.uk/wp-content/uploads/2021/03/The-adult-social-care-market-in-England.pdf>

We are therefore concerned about the impact of the Government's proposals on working-aged adults. Below are four areas key areas where further discussion and proposed amendments could be put forward to better protect those of working-age.

## 1. Government amendment of the cap on care costs

In September 2021, the Government announced an £86,000 cap on care costs. This also included raising the floor at which people begin to contribute to their care costs to £23,250 and the ceiling to £100,000.

On 22 November, a proposed amendment to the Care Act 2014 was approved, meaning that: "for individuals who receive financial support for their care costs from their local authority, it is the amount that the individual contributes towards these costs that will count towards the cap on care costs". This means that it will only be the 'out of pocket' expenditure on social care that will count towards the cap.

We are hugely concerned about the potential impact of this policy on working-age adults in the social care system. Those in the means-tested system, who contribute to part of their care costs but cannot afford to cover them in full, would not benefit from the cap until they have paid £86,000 out of their own pocket. These proposals will also mean that those with assets over £100,000 will also pay £86,000.

Working-age adults who are in the means tested system stand to be particularly disadvantaged by this amendment for a number of reasons:

- They are disproportionately likely to be asset and savings-poor.
- They are more likely to receive care and support for longer periods of time and therefore accrue care and support costs that are higher than some shorter-term care needs.
- Working-age adults are much more likely to access the kinds of support that are difficult to access in the local-authority social care system, for example, a personal assistant to support access to employment, leisure or social activities.<sup>7</sup> This means some adults face the prospect of paying additional costs privately towards social care support, which do not count towards the cap. Additionally, many social care charges for working-aged adults are taken out of their benefits such as Personal Independence Payments which we already know are insufficient to meet the extra costs associated with living with a disability.

We also welcome the two other amendments relating to Clause 155:

- Baroness Campbell's Notice to Remove Clause 155 will remove the unfairness of the Government's current proposals for all social care users, especially those over the age of 65 who have modest savings and assets
- Baroness Greengross' (235) amendment seeks to introduce the social care cap at the level the Dilnot Commission suggested updated with inflation to sit at £50,000.

Taken together, these amendments seek to both remove the potential negative effect of Clause 155 from those with lower levels of wealth and improve the current provisions in the cap by reducing the cap limit (which will benefit all care users) and eliminating the high costs of care for younger working-age adults who are least able to afford it and who would otherwise be expected to pay for their care for a significant portion of their life.

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<sup>7</sup> More than 8 in 10 (84%) people aged 18 to 64 who receive care are supported in their community (NHS Digital, December 2020, Personal Social Services Adult Social Care Survey (ASCS) England 2019-20)

## 2. A zero cap

In his report on the Funding of Care and Support, Sir Andrew Dilnot addressed this unfairness by proposing a 'zero cap' for younger adults:

"Anyone developing an eligible need up to the age of 40 should also face a zero cap, as we do not think that people younger than 40 can, in general, realistically be expected to have planned for having a care and support need, nor will they have accumulated significant assets."<sup>8</sup>

The Government has rejected this recommendation, but we believe it is now essential to mitigate the risk of catastrophic care costs on care users who can least be expected to shoulder them. To this end, Baroness Bull with the support of Lord Warner, Baroness Campbell and Lord Lansley, has tabled an amendment, number 143 which would address this and introduce a 'zero cap' for this group. These amendments are likely to be debated on **7th or 9th March**.

### **After Clause 155**

*Insert the following new Clause –  
"Social care cap for younger adults*

*In section 15 of the Care Act 2014 (cap on care costs), after subsection (4) insert –  
"(4A) The Secretary of State must ensure that regulations made under subsection (4) specify a zero amount for adults –*

*(a) who are under the age of 40 when they first receive care and support to meet their eligible needs, or*

*(b) who have eligible needs which first required care and support before they reached the age of 40."*

### **Member's explanatory statement**

*This new Clause would ensure that adults entering the care system under the age of 40, or who were under 40 when they first entered it, would have their care costs capped at zero, in line with the Dilnot report recommendation.*

## **Pen Portraits**

### **Emma (as set out in Dilnot's report)**

Emma was born with a learning disability. Her mother died when she was 35; she then had to move into supported housing. She inherited £150,000 from the sale of her mother's house. She died aged 52.

Under the current system, Emma received all her care and support free of charge up until the point at which she inherited £150,000. From then on, Emma had to use these assets, along with disability benefits, to pay for her supported housing and care and support costs. By her mid-40s, she had spent down her assets to £20,000, the means-tested threshold and received support from the state, without charge.

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<sup>8</sup> Fairer Care Funding: The Report of the Commission on Funding of Care and Support. July 2011

Under the Government's current proposals, she would see a significant amount of her wealth going towards her care costs (leaving only £65,000). This is notwithstanding the care and support that is not eligible for the cap such as her non-personal care costs. It is likely that a significant amount of her savings would then go towards the cost of her care.

By applying a zero cap, as Emma would have an eligible care need before the age of 40, she would be deemed to have met the cap and would receive all her care without charge for the whole of her lifetime. She would have contributed to her general living costs partly herself and partly through her disability benefits. She would spend half of the £150,000 on her general living costs, but could use the rest of the money throughout the rest of her life to improve her overall well-being.

### 3. A tapered cap

Dilnot's commission also advised a tapered cap for those with eligible needs after the age of 40, increasing every decade up to retirement age when the full cap would apply. A tapered cap for working-age adults does offer some protection to those who have less opportunity to accumulate savings and assets. **The levels would need to be set out in Regulations, but can be allowed for in s.15(4)(a) of the Care Act 2014.**

### 4. Workforce crisis

The care sector is currently facing a workforce crisis with over 110,000 vacancies and a turnover rate of 40%. The social care system cannot be stabilised without a long-term sustainable workforce plan. The National Care Forum has called for an immediate bonus and pay rise for staff, and for care workers to be added to the shortage occupation list.

As a long-term strategy to tackle historical shortages, **we supported all steps to improve the situation and in particular, the amendment to Clause 35 of the Health and Care Bill** in the name of Baroness Cumberlege, Lord Stevens of Birmingham, Lord Walmsley and Baroness Merron, which would require the Secretary of State to publish independently verified assessments of current and future workforce numbers every two years, and how this relates to projected health and care needs of the population.

#### **List of charities supporting these amendments**

Disability Rights UK  
Epilepsy Action  
Leonard Cheshire  
Inclusion London  
Mencap

Motor Neurone Disease Association  
MS Society  
National Autistic Society  
Neurological Alliance  
Sense