

Disabled people left without the care they need, in breach of the law

80 charities urge the Government to deliver at least £2.5bn in this Autumn Budget for care

A new survey by the Care and Support Alliance (CSA) has found that more than a quarter (29%) of disabled 18 – 64-year-olds who rely on council funding have had their care cut over the last year.¹

Yet respondents to this online survey often reported that there had been no change in their needs, or even a worsening of their condition, so it seems disabled people's legal rights to care are widely being breached. In the most worrying cases, the health, safety and wellbeing of these people was being jeopardised as a result.

The Care Act is absolutely clear that the amount of care people receive should be based on an objective assessment of their needs, and that councils have a duty to ensure that anyone whose needs fit the 'substantial' criterion are met. However, an estimated £6.3bn has been taken out of adult social care in real terms since 2010² and overall council budgets were cut by 49% in real terms over the same period because of the Government's policy of austerity.³ Meanwhile, need has steadily increased because of a rise in the numbers of older people and disabled people, creating an ever bigger gap between the demand for and supply of care. It would not be surprising therefore if cash strapped councils had been forced down a path of restricting the care they provide - but any such move would be in clear breach of the law and in defiance of disabled people's rights.

People who are entitled to receive council funded care have very considerable needs and require help with everyday basics the rest of us take for granted like getting dressed, eating and getting out of the house. Those whose care is funded by the council will have been assessed as not being able to pay for all or some of their care, so will also be living on a very low income. Failure to receive all the care you need in this situation can have a devastating impact.

The CSA research undertaken this year also revealed that regardless of how their care is funded, too many are going without even the most basic care. Nearly half of respondents to the survey told us that because of a lack of care they have experienced not being able to get out of the house (48%) and not being able to work (46%), or have seen their health deteriorate (49%). In addition, nearly a quarter (24%) told us they are unable to move around their homes safely because of not having the social care they need.

The alliance of over 80 organisations and charities is urging the Government to address the chronic underfunding of social care in the Budget on October 29th. Experts say that at least £2.5bn is needed to protect the social care system from the risk of further catastrophic decline in the next financial year (2019/2020)⁴, and to resource councils to deliver their duties under the Care Act.⁵

The Government recently pledged £240m to ensure that people who need care do not stay longer than necessary in hospital this winter. While this investment is welcome, it is only a stop-gap that does not address the chronic and systemic shortage of funding for care in local areas.

¹ CSA, "Big Social Care Survey", 2018 – see notes to editor for how this was calculated.

² National Audit Office, "Financial sustainability of local authorities", 2018

³ National Audit Office, "Financial sustainability of local authorities", 2018

⁴ Kings Fund, 2017 <https://www.kingsfund.org.uk/publications/autumn-budget-2017>

⁵ Social Care Institute for Excellence, <https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/definition.asp>

Social care user Rachel Looby, 31, from Harrogate, needed medical help after the amount of social care she received was cut (further details below). She said:

“When my hours were cut it was a stressful time for me. I took the wrong medication and ended up in hospital, and this made me feel like my health had not been considered at all. Being in hospital left me feeling anxious and upset and I worried if something else might happen once I got home.”

Julie Sharp, 32, from Rotherham, has Triple X syndrome, a genetic condition which affects her neurological and endocrine systems, impacting her balance and coordination (further details below).

“Last year, I had my care cut from 42hrs to 0. I had been using the care, for amongst other things, to help with meals. Without any care I tried cooking for myself but couldn’t follow the recipe and ended up with such bad food poisoning I was in hospital for five days. Severe dehydration, with my conditions could have been fatal.

“I have continued to fight this year for my care, and many consultants have written to social services on my behalf, only now it seems I might be getting funding again but through direct payments where I have to be an employer, which is more than I can understand. No one listens, I can’t cope with this.”

Respondents (in a free text options explained):

“Money is short in the area ... my social worker said if I get support then others don’t.”

“Care package hasn't changed, my income hasn't changed, but council now only fund 1/4 of costs for carer as they don't count mortgage or costs of running a car as living expenses.”

“It's complicated as I care for my wife and I also have MS as well. The hours that my wife had for carers to come in and help was cut last year. Which had put more of a strain on me, and some days I really really struggle.”

“Without telling me verbally or writing to me after my last assessment various services were cut including my laundry service, my free telephone rental service and my home bound library service is currently under threat. Meanwhile, I have been financially assessed without my being asked any questions or showing any bank statements or evidence and my contribution to the help that I get has been increased.”

Mark Lever, Chief Executive of the National Autistic Society and co-Chair of the Care and Support Alliance, said:

“It is scandalous that the rights of disabled people are being denied and that they are going without the care they need. As a result, some are being placed at risk and, more generally, disabled people’s opportunities to live full and productive lives are being seriously undermined. This is a false economy for our society and disastrous for the individuals concerned.

“Evidence of the law being breached is widespread and compelling, and the cuts to council budgets since 2010 have been of such a scale that it would be little surprise if care is now being ‘rationed’, even though this should be impossible according to the Care Act.

“The Government must ensure that at least £2.5bn goes into the social care system in 2019/20 and announce this in the Budget. In addition, the social care Green Paper to be published later this year must contain proposals that give disabled people real confidence that our care system will be placed on a much firmer financial foundation over the next few years.”

Kari Gerstheimer, Director of Information and Advice at Mencap, said:

“We have seen an upwards trend in calls about social care and safe guarding issues linked to the worsening cuts. When Mencap challenges decisions, they are frequently reversed. Local authorities are making unlawful decisions because there is not enough money in the system.

“There is no point having a duty to provide care in the law but for councils to be powerless to provide it for budget reasons. The Government must provide an urgent injection of cash, at least £2.5bn and push on with urgent and sustainable reforms to social care. Unless this happens we are bound to see a continuing increase of neglect and safeguarding cases.”

Last year, 2017, the Care and Support Alliance conducted research which showed that the majority of social workers, and other professionals who undertake care assessments, felt expected by their managers to reduce the help on offer to people in need of social care. Social workers also revealed their experiences one said *“We are being encouraged to write care plans that do not include any form of social interaction.”*, another said *“The view within the council is that only 20% of all those assessed should be receiving formalised care packages from the local authority and that 80% should only receive information and advice.”*

The Association of Directors of Adult Social Services (ADASS) warned this year that 75% of directors said that reducing the number of people in receipt of care is important or very important for them to achieve necessary savings.⁶ They warned: *“This approach risks falling the wrong side of a fine line: if a reduction of those in receipt of care is an outcome of a strategy to develop asset-based, preventive approaches, this is a positive aspiration, but if it is about gatekeeping resources then it risks people in need being left without services, which would be unlawful and financially risky.”*⁷

Since the survey was conducted, financial problems for councils have hit the headlines as several have come close to bankruptcy as a result of delivering the services they’ve been legally required to provide. Northamptonshire, East Sussex, Somerset are among a number of councils which have come close to financial collapse, which is even more worrying given that recent research by the County Council Network shows that Government imposed cuts will continue, with around a further £683 million estimated to hit local authorities in 2019/2020.⁸

Ends

Note to editors

The Care and Support Alliance (CSA) – is a coalition of more than 80 of the country’s leading charities (including Scope, MS Society, Mencap, National Autistic Society and Sense) - who are calling for a properly funded care system.

About social care

⁶ ADASS, “ADASS Budget Survey”, 2018

⁷ ADASS, “ADASS Budget Survey”, 2018

⁸ County Council Network, 2018

Social care is an essential life support system that people rely on for everyday tasks like washing, dressing, eating and managing in the home. It also enables people who can't work, volunteer and take part in society. It helps people get out and about and is meant to support them not just to live but to have a fulfilling life. Without social care, many people would be lonely and isolated, as well as at risk of crisis.

About the survey: CSA ran an online survey 24th January 18 to the 9th March 18. The survey was shared via CSA members and was completed by 3,915 self-selecting people who identified as having experience of adult social care in England.

Case examples:

Rachel's Story

Rachel, 31, from Harrogate is visually impaired, epileptic and has speech and processing difficulties.

For a long time, Rachel received 17 hours of social care a week. This involved help with basic tasks such as cleaning and cooking, as well as support with managing her money, medication and personal care.

However, although her needs had not become any less pronounced her support was reduced to just five hours per week. This meant she only had help with basic tasks. With no one to help her manage her medication Rachel missed doses and had a seizure. To make things worse, while recovering Rachel mistook her dog's medication for her own and became very ill and had to be hospitalised.

These two incidents understandably knocked her confidence and she became demotivated and stopped taking her anti-depressant medication. This led to her becoming depressed and socially isolated, threatening to compound the difficulties she was facing. Social services stepped in again and returned her hours and now Rachel now has the care she needs to stay safe and well.

Julie Sharp's story

Julie has needed social care since 2008, aged 22, when she was hospitalised with a collapsed lung.

Julie studied music at Huddersfield University and wants to use her skills and experience with the care system to become an activities coordinator in a care home focusing on music therapy.

Her care has been cut several times over the years once when she left Huddersfield and returned to her birth town Rotherham, and also when she got married - despite her husband having high needs of care himself. Something that social services only recognised when Julie was rushed to hospital and they had to put in a care package for her husband. Despite still recovering and being in a wheelchair, the care package for her husband was immediately stopped on the day Julie returned home from hospital as the council presumed she could resume her caring role despite having high care needs herself.

Cuts of data

*Cut 1: working-age adults (18 – 64) (445 people) whose care was fully funded, or partially funded by their local council - A third (29%) said over the last year their care had been cut despite their needs remaining the same or getting worse.

**Cut 2: working- age adults (18 -64) (1,247 people) who had experienced any of the following because of a lack of care...:

Basics

- Nearly half, 48%, haven't been able to leave their home.
- Nearly a third, 31% have been unable to maintain basics like washing, getting dressed or visiting the toilet.
- A quarter, 25%, have gone without meals.
- More than half, 53%, have felt lonely or isolated.
- Nearly a quarter, 24%, told us they are unable to move around their homes safely

Health

- Because of not getting the care they need 50% said their health has deteriorated.
- More than a quarter, 27%, have needed hospital treatment because of not getting the care they need.
- A quarter, 25%, have missed medical appointments because of not getting the care they need.
- Nearly one in 10, 8%, have had to stay in hospital longer because care was not in place.

Working and development

- Nearly half, 46%, haven't been able to work because of not getting the care they need.
- More than a quarter, 28%, have been unable to volunteer/access training or education.
- 60% of people said they couldn't do the things important to them.

Why are we describing the situation as 'unlawful'?

As described by the Social Care Institute for Excellence (SCIE), the “*national eligibility criteria set a minimum threshold for adult care and support and carer support. All local authorities must at a minimum meet needs at this level. The threshold is based on identifying how an individual's needs affect their ability to achieve relevant desired outcomes, and whether as a consequence this has a significant impact on their wellbeing. The overall aim of adult care and support is to help meet their needs to achieve the outcomes that matter to them in their lives, which in turn promote their wellbeing*”.⁹

Under the national eligibility criteria (Care Act 2014) local authorities have a legal responsibility to assess people who appear to have a need for social care and then apply the eligibility criteria to determine whether the local authority is required to meet those social care needs. Local authorities have some discretion over “how” to meet eligible needs, but not whether to meet such needs.¹⁰

The charging criteria determines how much a person must contribute towards the cost of meeting their care needs. Meanwhile, the needs eligibility criteria set out in the Care Act require local authorities to consider whether a person is unable to achieve two or more of the specified outcomes and whether failure to meet those outcomes has an impact on the person's wellbeing. These are as follows:

- Managing and maintaining nutrition
- Maintaining personal hygiene

⁹ Social Care Institute for Excellence, <https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/definition.asp>

¹⁰ Care Act, “Care and support statutory guidance”, 2014

- Managing toilet needs
- Being appropriately clothed
- Being able to make use of the adult's home safely
- Maintaining a habitable home environment
- Developing and maintaining family or other personal relationships
- Accessing and engaging in work, training, education or volunteering
- Making use of necessary facilities or services in the local community, including public transport, and recreational facilities or services
- Carrying out any caring responsibilities the adult has for a child

If the inability to meet the outcome means that there is a significant impact on the person's personal dignity; on their mental or physical health; or on their control over day to day life; then there is deemed to be an impact on a person's wellbeing. As the Care and Support Alliance's research shows, over a quarter of working-age disabled adults (29%) who responded to the survey and rely on local authority-funded or part-funded support have had their care packages cut even though their needs have stayed the same or have increased.¹¹ This indicates unlawful behaviour, as local authorities should continue to provide care to those who have two or more of the specified outcomes outlined above.

Supportive statistics

- Disabled people are more than twice as likely to be unemployed as non-disabled people and over 3.4 million disabled people are in employment.¹²
- A 10 percentage point rise in the employment rate amongst disabled adults would contribute an extra £12 billion to the Exchequer by 2030.¹³
- Life costs you £570 more on average a month if you're disabled.¹⁴
- After housing costs, the proportion of working age disabled people living in poverty (28 per cent) is higher than the proportion of working age non-disabled people (18 per cent).¹⁵
- As of 2016, there were 63 million people between the ages of 18 and 64 in the UK.¹⁶ Meanwhile, 19% of working-age adults in the UK have a disability.¹⁷ An estimated 12million people.
- When asked about which groups they were most concerned about in terms of financial pressures on adult social care budgets (relating to increasing need, complexity and demand), 32% Directors of Adult Social Services (48) were most concerned about the financial pressures relating to working-age adults.¹⁸
- There are 252,850 people aged 18-64 receiving long-term support in England.¹⁹

¹¹ CSA, "Big Social Care Survey", 2018

¹² Office for National Statistics, "Labour Force Survey", April to June 2017

¹³ Scope, "Enabling Work", 2015

¹⁴ Scope, "The disability price tag", 2018

¹⁵ "Households Below Average Income", 2015/16

¹⁶ ONS,

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/july2017>

¹⁷ Scope, "Disability facts and figures", <https://www.scope.org.uk/media/disability-facts-figures>

¹⁸ ADASS Budget Survey, 2018

¹⁹ NHS Digital, "Personal Social Services Adult Social Care Survey (ASCS) Survey", 2017/2018