

Essential but unaffordable: Poverty, social care and disability

Introduction

Disabled people are bearing the consequences of year on year cuts to vital public services. This has led to unequal access to education, volunteering and employment, transport and health services. As a result, many disabled people are worried about their future.¹

Our report sets out a troubling picture of potential waste and the impact this is having on the lives of disabled people. We have identified policy recommendations and the practical support needed to carry out daily tasks through social care, and how extra cost payments such as PIP can level the playing field. This ensures disabled people can live the lives they choose, with dignity and independence.

Poverty

Too many disabled people are living in poverty and are struggling to survive on low wages and reduced benefits. This is having a damaging effect on their mental and physical health.

More than one in four (27%) working age disabled adults in the UK report having less than £50 to spend each week after deducting income tax, council tax and housing costs.²

This view is echoed in the Equality and Human Rights Commission's report, which found disabled people are more likely than non-disabled people to be living in poverty.³ It found that just under a third (30%) of families with one disabled person are more likely to be living below the median income line after housing costs, compared to 18% of families with no disabled members.⁴

Barriers to economic inclusion and financial independence

There are many reasons why so many disabled people are living in poverty. Disabled people are more likely to be out of work than non-disabled people. The employment rate for disabled people is 49.2% compared to 80.6% for the rest of the population – a ‘disability employment gap’ of 31.3%.⁵

The situation is worse for young disabled people who are four times more likely than their non-disabled peers to be NEET (not in education, employment or training) at the age of 26.⁶

The barriers start at school where young disabled people often miss out on the support they need. This affects their ability to secure further training and education and, ultimately, to succeed in the labour market.

Of those who say they had a disability at school:⁷

- Four in ten (42%) disagreed with the statement, ‘I was supported to find suitable work experience related to my career’.
- Two in five (40%) say they were not able to take part in work experience while at school.
- This increased to two-thirds among those who say they needed support with personal care (67%). This indicates that the problem is even worse for those with higher support needs.

Last year we launched our Untapped Talent campaign which is calling on the government and employers to recognise the huge potential and benefits that disabled people bring to the workplace. We are calling for greater promotion and funding of schemes that can help, and more employers to use them.

Employment and benefits

For some disabled people, working is not an option. That may just be for a short time, or it may be more permanent if their condition makes work impossible. For example, someone who is in the later stages of Multiple Sclerosis (MS). When this is the case, disabled people need to know they can rely on the state to provide a safety net and help during times of need.

Disabled people in this situation should be able to receive Employment Support Allowance (ESA), a replacement income for those whose disability or health condition means they are unable to work. However, many are not receiving it because the current assessment process is not fit for purpose. Currently, 68% of decisions on ESA assessments are overturned on appeal. Those who have been found fit to work under the Work Capability Assessment (WCA) have appealed their case and won, highlighting the alarming rate at which the assessment gets it wrong.⁸

“I was too unwell to appeal [my PIP outcome], knowing that the extra stress would cause further relapse.”

PIP claimant with M.E

“I am too physically disabled to dress myself most days and have difficulty walking. Yet if you can pick up a pen or a pound coin, lift a small milk carton, push a button once, or turn a page in a book then you are fit to do a job”

ESA claimant with Raynaud’s Syndrome

Benefits such as the Personal Independence Payment (PIP) are intended to help disabled people meet the significant extra costs associated with their disability. However, many are failing to access these vital payments. Data from the Department of Work and Pensions (DWP) found almost half (48%) of those who were on Disability Living Allowance (DLA) and re-applied to PIP have either totally lost their award or received a reduced award.⁹ Not being able to access these payments can put a significant strain on disabled people’s ability to pay for the additional costs they incur because of their disability. Our research found 48% of disabled adults in the UK have incurred additional costs from managing their disability, including paying for taxis because they cannot use public transport or drive themselves (18%), paying for someone to help maintain their house (12%) and purchasing specialist equipment (8%).¹⁰

“I was too ill ever to appeal a wrong decision [for my ESA]. If I had been fitter I would have had the strength and willpower to appeal but I was too emotionally upset and my mental health was not good by the time I had been through the face to face interview.”

ESA claimant with arthritis

Social care

Like the NHS, social care is a vital public service, enabling over one million disabled and older people in the UK to live independently and contribute to society.¹¹ Currently, a third of social care users are working age disabled people.¹² Social care support can vary from assisting people to get out of bed and dressed, preparing hot drinks and meals to supporting them to go out and meet with friends. Social care can be crucial in giving disabled people the opportunity to secure and retain work and volunteering. For example, someone with limited mobility may need assistance with washing, but is able to work in an office with some minor adjustments in the workplace. Without social care, their skills are wasted because they are trapped in their homes.

Social care is separate to the NHS. Local councils are responsible for providing certain social care services using funding provided from government. However, depending on their financial circumstances people may be expected to pay for their social care.

Despite the high importance of this service many disabled people are not getting access to the social care they need.

“Everything escalates into a crescendo of total disarray of my life – I’m unable to function – it really is mentally exhausting”

Disabled person with partial paralysis

More than half (55%) of disabled adults in Britain say they don't receive the social care support they need.¹³

Research indicates that this is getting worse, with this figure significantly increasing from just under half (48%) in 2016.¹⁴

Over a third (37%) of disabled adults in Britain say they receive some social care support but not enough; a significant increase from the previous year (31% in 2016). Again, this shows that the problem is getting more severe.¹⁵

“[Bad care] puts a strain on everything...your life is all connected by your stress and wellbeing.”

Disabled person with a visual impairment and MS

The consequence of not receiving any, or enough, social care support cuts across all areas of disabled people's lives. Disabled adults in Britain have reported that it has a negative impact on their mental (53%) and physical (43%) health.¹⁶ This has significantly increased from 40% for both in 2016.¹⁷

“I have complained about the loss of social care, fighting this and responding to the local authority has made my health worse. I can't go outside and walk. This has caused contraction of my muscles which means my condition flares up.”

Disabled person with MS and mobility issues

Of those who say they don't receive enough or any of the paid support they need to maintain social and community links, two fifths (39%) of disabled adults in Britain say they are unable to leave their house when desired more than once a day. This figure has almost doubled from 21% in 2016.¹⁸ As result it is unsurprising that this same group reports a loss of confidence (60%) and feeling isolated or lonely (54%) from not receiving enough or any social care support.¹⁹

“I am isolated [without social care], dreading the future, it's stressful and I'm alone.”

Anonymous

Funding for social care

Rising unmet social care needs can be closely linked to significant cuts to funding for social care since 2010. At the end of the financial year 2017/18, it is estimated that over £6 billion will have been taken out of the system since 2010.²⁰ Various experts have estimated this has left councils responsible for funding social care, with a funding gap of approximately £2.5 billion by 2019/20.²¹ As councils are forced to ration further and further, disabled people are bearing the brunt and are not getting the services they need to maintain their dignity, well-being and independence.

“It does worry me that I need 24-hour care. I am unable to do anything independently, but I struggle to receive the funding from my local authority.”

Anonymous

In 2015 the government introduced new national eligibility criteria.²² This meant that all councils would only need to provide social care to those with a certain level of need.^{23,24} As a result, access to publicly-funded social care is now severely restricted to those with the highest needs. At least 400,000 fewer disabled and older people are now receiving care compared to 2009.²⁵ Those who continue to receive care are being forced to accept lower levels of support and a reduced quality of service. A survey of social workers found that nearly 7 in 10 (68%) of social workers said they felt expected to reduce care packages because of cost pressures.²⁶

“I have complained about the loss of social care, fighting this and responding to the local authority has made my health worse. I can’t go outside and walk. This has caused contraction of my muscles which means my condition flares up.”

Disabled person with MS and mobility issues

Anyone who needs social care should be able to access high quality care. The eligibility criterion therefore needs to reflect the actual needs of disabled people requiring a range of support. Any funding solution must reflect the increasing demand for social care.

Filling the funding gap

Recognising these challenges, the government has taken a number of steps to increase social care funding. In 2016, powers were given to local authorities to increase their council tax by 6% over three years to raise funding for social care, as well as a grant. In 2017, the chancellor announced an extra £2 billion for social care over the next three years. More recently local authorities were permitted to increase their council tax by another 1% and given an additional £150 million grant. These measures have helped councils to continue to provide social care to those with the highest needs. However, councils are still unable to provide care to many disabled people, leaving them in stranded and living in undignified circumstances. The measures also fail to take into account the fact that the number of people who need social care is only going up, with an ageing population and an increased incidence of disability amongst working age people. The impact of the funding cuts from previous years has resulted in the social care system being at tipping point, leaving many disabled people without the vital support and care they need.

The impact on the lives of disabled people

As a result of limited access to financial support such as PIP and ESA, cuts to social care and many services which are inaccessible, disabled people have been further disadvantaged in their ability to live, learn and work. Financial support is essential to ensure disabled people can meet the additional costs they have to face every day. In many cases these additional costs are because many essential services are simply not accessible. For example, lack of access to public transport means disabled people need to pay for costly taxis for part or all of their journeys. Moreover, a lack of accessible public transport limits their ability to get to work. As a result, disabled people are unable to live full and independent lives.

The lack of access to social care can also compound the disadvantages disabled people face. For example, disabled adults in the UK who don't receive but need social care support are more likely to report having less disposable income than their counterparts who get the support they need (£116 vs. £153 per week respectively).²⁷

Living in poverty can have a severe impact on disabled people's quality of life. In some cases it could lead to a worsening of their disability. Almost one in four (23%) disabled adults in the UK report missing a meal in the past year because they couldn't afford it and one in five (20%) say they have not been able to keep their house warm.²⁸ This will undoubtedly affect their health and wellbeing.²⁹

The lack of social care provisions means disabled adults in Britain who want to access work and volunteering opportunities are unable to do so. Our research found that 80% of those who don't receive the social care support they need with working, volunteering or accessing education report feeling unable to apply for a job. Those who are already working find they have to give up employment when they cannot access social care. Our research found two-thirds (65%) of disabled adults who are not receiving enough or any paid support with volunteering or accessing educational opportunities have left their job as a result. Many disabled people are stuck in a poverty cycle and are unable to get the help they need. With too many barriers in place, they are unable to live an active and full life.

Often, just a small amount of support would make a huge difference to someone's life. Support with household tasks, mentoring and financial and emotional support could help disabled people to manage their disability. This would allow them to thrive and get more involved in community life, and take up employment and volunteering opportunities.

Conclusion and recommendations

Public services such as social care, and access to vital financial support such as ESA and PIP, are essential to ensure that disabled people can live, learn and work independently. Too often, disabled people are unable to access the same opportunities to education, training and employment as non-disabled people. As a result, too many are living in poverty and are unable to maintain their physical and mental wellbeing. This is not an issue that can continue to be ignored.

For disabled people to thrive there needs to be shift in how welfare benefits and social care is delivered so essential needs are met. The government needs to act without further delay to ensure that disabled people can access the care and services they need.

Access to financial support

Disabled people should be able to access the financial services they need to be able to live full and independent lives. Currently, the existing welfare system is not fit for purpose and leaving disabled people without the means to be able to financially support themselves.

The Work Capability Assessment (WCA), which was set up to identify whether a disabled person is fit for work and whether they are eligible for ESA, is flawed. It should focus on the impact of the individual's condition on the ability to complete real world tasks. It should assess their ability to find employment and the kind of functionality which is required at work.

In addition, an urgent thorough review of the PIP assessment criteria needs to be conducted without delay. This needs meaningful involvement from disabled people with long-term conditions to ensure the criteria is set fairly and truly reflects the extra costs that people face.

For both ESA and PIP, it is essential that assessors ask probing questions to accurately evaluate the impact of a fluctuating condition on an individual. Therefore, the rules on how those with fluctuating conditions are assessed need to be reviewed without delay.

Access to social care

The government is soon to release its plans for the future funding and delivery of social care for consultation. The green paper needs to deliver a long-term funding solution for the future of health and social care in England. It needs to work for both disabled and older people.

Disabled people cannot wait any longer. A new funding solution is needed by the end of this parliament.

We have proposed a set of principles which the government should use as a foundation when exploring the different funding options for social care. Disabled people should be at the centre of social care reforms. Any funding solution should be developed with disabled people to ensure their needs are being met and can work in practice.

Anyone who needs social care should be able to access high quality care. The eligibility criterion needs to reflect the actual and growing needs of disabled people. It should also be lowered from 'substantial' to 'moderate' to ensure all disabled people who need care receive it.

Social care needs to go beyond meeting basic physical care needs. There needs to be greater support for measures that empower disabled people to live full and independent lives in their communities – whether through volunteering, learning or employment opportunities. This will ensure a more sustainable social care system for the future.

Want to know more?

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Endnotes

- ¹ EHRC (2017). Being disabled in Britain: a journey less equal. Available [here](#).
- ² ComRes interviewed 1,119 GB disabled adults aged 18-65, from 15th June to 10th July 2017. Data were weighted by gender and region to be nationally representative of disabled adults of working age in GB. Data were also weighted by the 2016 age distribution in order to make direct comparisons (in 2016 ComRes also interviewed 1,032 disabled adults in Great Britain, aged between 18 and 65, from 28th April to 10th May 2016). Full data can be found [here](#).
- ³ EHRC (2017). Being disabled in Britain: a journey less equal. Available [here](#).
- ⁴ EHRC (2017). Being disabled in Britain: a journey less equal. Available [here](#).
- ⁵ ONS Dataset: Labour market status of disabled people: A08, 16 August 2017 (our analysis)
- ⁶ Department for Work and Pensions, Fulfilling Potential: Building a deeper understanding of disability in the UK today, (2013).
- ⁷ ComRes data, 2017. Base: disabled adults aged 18-30 in the UK who say they had a disability at school (n=363)
- ⁸ MOJ, *Tribunals and Gender Recognition Quarterly Statistics*, 2017, Accessed 01/11/17
- ⁹ Disability Benefits Consortium (DBC), (2017). Supporting those who need it most? Evaluating Personal Independence Payments. Available [here](#).
- ¹⁰ ComRes, 2017 (n=1,609).
- ¹¹ NHS Digital, Community Care Statistics: Social Services Activity in England. Accessed [here](#).
- ¹² NHS Digital, (2016). Community Care Statistics: Social Services Activity, England - 2015 to 2016 Report. Available [here](#).
- ¹³ ComRes, 2017, (n=479).
- ¹⁴ ComRes, 2016 (n=428).
- ¹⁵ ComRes 2017 [Q2] Base: Disabled adults who need social care support in any area (n=479); 2016 (n=428)
- ¹⁶ ComRes, Base: Disabled adults who need social care support but don't receive enough or any paid support (n=337).
- ¹⁷ ComRes, 2016 [Q7] Base: all who do not receive enough social care support (n=299)
- ¹⁸ ComRes, 2017 [Q5] Base: Disabled adults who don't receive enough or any paid support with maintaining social and community links (n=154), 2016 (n=148)
- ¹⁹ ComRes, 2017 [Q4] Base: Disabled adults who need social care support but don't receive enough or any paid support (n=337).
- ²⁰ ADASS (2017). Budget survey 2017. Available [here](#).
- ²¹ The Kings Fund, Nuffield Trust and The Health Foundation, (2017). The Autumn Budget: Joint statement on health and social care, November 2017. Available [here](#).
- ²² Community Care, (2013). Nationwide care threshold 'will exclude hundreds of thousands in need'. Available [here](#).
- ²³ Department of Health and Social Care, (2013). Social care users will be guaranteed a minimum level of council help under new plans. Available [here](#).
- ²⁴ To be considered for social care the individual will need to have a physical or mental health problem which has a significant impact on them to carry out everyday tasks. For an individual to be eligible for care, they will be unable to do at least two outcomes out of a list of 10. Examples including unable to dress themselves, eating or drinking or accessing and engaging in work, training, education or volunteering. The main part of the assessment is the result of how much of an impact not meeting these outcomes has on the individual's wellbeing.
- ²⁵ NHS Digital, Community Care Statistics, 2013/14. The total number of people receiving services in 2013-14 was 1,273,000 (down 29 per cent from 1,782,000 in 2008-09).
- ²⁶ Carers Support Alliance, (2017). Social workers speak out about the state of care today. Available [here](#).
- ²⁷ ComRes, 2017. Base: Disabled adults who need social care support in any area (n=484); their counterparts who don't (n=371) * Disposable income is referred to in the research as money left to spend after deducting income tax, council tax and housing costs.
- ²⁸ ComRes, 2017. Base: All disabled adults (n=1,609).
- ²⁹ ComRes, 2017. Base: Disabled adults who don't receive enough or any paid support with working, volunteering or accessing education (n=142)