DIGNIFIED, ACCESSIBLE SUPPORT FOR DISABLED PEOPLE AND PEOPLE WITH HEALTH CONDITIONS

October 2023
Summary

It’s not right that increasing numbers of disabled people, including people with mental health conditions and people experiencing long-term health conditions, need to use a food bank because they can’t afford to eat and pay the bills. 7 in 10 people referred to food banks in the Trussell Trust network are disabled.

Disabled people face significant additional costs and lower incomes that put them at greater risk of going without essentials. This is the result of the barriers disabled people face to work and the low paid and part time nature of work, combined with the very low levels of income from the social security system.

Disability benefits should help everyone participate fully in society - but flawed assessments, long waits and incorrect decisions are damaging people’s health and deepening exclusion. This, combined with a lack of meaningful person-centred support, is pushing people deeper into poverty and damaging people’s health and wellbeing. It’s time for a new approach.

The building blocks for a better future:

1. Everyone gets a decision on their disability benefit application which is right first time and as swift as possible.
2. Everyone who wants it can access meaningful and person-centred employment support, avoiding the use of punitive financial sanctions wherever possible and instead using other services to increase engagement.
3. Tackling financial hardship is always addressed as part of improving the health of individuals and society.
4. Everyone is aware of the benefits they are entitled to and are supported to apply through the widespread availability of quality accessible independent advice and support.
5. Much wider adoption of flexible employment practices and a significant increase in good quality jobs accessible to disabled people.

Everyone has a role to play in building a society with dignified, accessible support for disabled people and people with health conditions. These should be developed together with people with experience of disability and ill health, ensuring that their invaluable insight, knowledge, and experiences drive policy changes that address the specific challenges many face. Putting these five building blocks into place will help us to ensure that disabled people and people with health conditions can live fulfilling lives and are not forced to use a food bank.
What is the problem?

Increasing numbers of disabled people, including people with mental health conditions and people experiencing long-term health conditions, need to use a food bank because they can’t afford to eat and pay the bills.

The rate of disability among people referred to food banks in the Trussell Trust network is extremely high: 69% of people referred to Trussell Trust food banks are disabled, with even higher proportions (75%) saying that they, or a member of their household, is disabled.\(^1\) In comparison, 26% of the general population are disabled.\(^2\)

The most common disability reported by people referred to a food bank is a mental health condition (52%), followed by a long-term physical condition or illness (24%), a physical disability (18%) and learning disability or learning difficulty (7%).\(^3\)

More than a quarter of disabled people (26%) experience food insecurity, two and a half times the rate amongst non-disabled people (10%). Similarly, we see that 15% of working age disabled families are in deep poverty, compared to 9% of people in non-disabled families.\(^4\)

Our research has found what this means in practice for many disabled people, including parents who have gone without to allow their children to eat. Despite their best efforts, however, some parents felt that the food for their children was insufficient, reporting a lack of food in the fridge. This has serious consequences for the mental and physical health of families and households.\(^5\) This level of hardship holds people back from work, prevents them taking opportunities, and impacts on their health and wellbeing.\(^6\)

Disabled people face significant additional costs and lower incomes that put them at greater risk of going without essentials.

Disabled people, including people with mental health conditions, and people experiencing long-term physical health conditions, face additional costs and often have lower incomes than non-disabled people. Those additional costs are often associated with the nature of people’s health conditions - such as for prescriptions or maintaining equipment for their condition.

“I have a CPAP machine; because of sleep apnoea, I stop breathing if I don’t have my CPAP machine, and it takes the electricity. All these things are draining on the electric. Because of my blood condition I get so cold, so I need more heating, which is a big drain as well. Just last week

\(^2\) Ibid.
\(^3\) Ibid.
\(^4\) JRF (2023), From disability to destitution, From disability to destitution | JRF
\(^6\) Ibid.
we had to ask a charity for help with those... I never thought that I would have to go to food banks, but I have to go to food banks... because there’s only a certain amount of money from my PIP, my ESA, my husband’s Carers’, and then we’re paying off the mortgage. All those things, very, very tight, and that's stress.” (Disability and Financial Hardship participant, Northern Ireland).7

These costs too often cannot be met due to the very low levels of income people are living on. This is the result of the barriers disabled people face to work, the low paid and part time nature of work, and the very low level of income available from the social security system.

- Disabled people are almost twice as likely to be unemployed as non-disabled people.8
- 13% of disabled people, who are in work, have needed to use food aid in the previous 12 months.9
- The majority (74%) of disabled people referred to a food bank in the Trussell Trust network who are out of work, said that their health condition or caring responsibilities mean that they cannot work.10
- Amongst disabled people referred to food banks who said that they could and wanted to work, the most common reason cited for being out of work was that they found it difficult to find work that was compatible with their health condition (45%).11

In our research with the Scottish Centre for Social Research, Disability and Financial Hardship (2023), we identified multiple barriers disabled people face when looking for work including: inadequate support programmes, employers who are unsure how to accommodate disabled people’s needs, inaccessible transport options, and a gap in qualifications restricting the types of jobs disabled people can access.12

We also know that people are not getting the support they need for their condition, which is creating further barriers to taking up opportunities. The majority (65%) of people referred to food banks in the Trussell Trust network with a reported mental health condition had not received any

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7 Ibid.
11 Ibid.
support relating to their mental health in the three months before receiving support from a food bank.\textsuperscript{13}

This situation is compounded by a disability benefits system which provides inadequate support, is often experienced as being punitive by those who rely on it and which fails to provide dignity and the financial protection people need to participate fully in society.

“So carers for the night (a person who comes in to care for a sick or disabled person) is about £60, so it is expensive, and you have to still make ends meet. Gas prices are just horrendous and the electric prices, I have an electric wheelchair, I have all his other equipment that I have to run. I don’t get any help with that, you just have to put up with it. Am I worried? Extremely.” (Hunger in the UK research participant, England).

Disability benefits should help everyone participate fully in society - but flawed assessments, long waits and incorrect decisions are damaging people’s health and deepening exclusion.

Disabled people face a range of extra costs, above and beyond day-to-day living costs, in the treatment and management of their impairments and health conditions. Disability benefits should enable disabled people and people with health conditions to overcome the additional challenges and hardship they face by providing them with the security that they need to be able to participate in society.

These benefits include Disability Living Allowance, Personal Independence Payment, and Adult Disability Payment (Scotland) which are intended to pay for the extra costs associated with a disability. These benefits are not means tested, so people’s savings, or household earnings do not affect eligibility. Employment and Support Allowance and Universal Credit are income replacement benefits which long-term sick or disabled people can claim (some disabled people may also claim Jobseekers Allowance). For ESA and UC there are different rates depending on whether you are assessed as being fit for work, having limited capability for work, or limited capability for work and work related activity.

Our report, \textit{Disability and Financial Hardship} (2023), has gathered extensive evidence which suggests that the current approach to assessments and decisions on these disability benefits are deeply flawed.\textsuperscript{14} Claimants often wait several months between applying for benefits and receiving them. Research by Mind found that ‘people are left confused, angry and retraumatised when trying to navigate their assessment’ for financial support from the social security system that should be there to protect us all.\textsuperscript{15} The result is worsening mental health conditions, eroded


\textsuperscript{15} Mind (2023) ‘Reassessing Assessments’. See also MS Society (2023), PIP and MS: a decade of failure.
financial resilience and a severe lack of trust in the systems and institutions which people should feel they can rely on.

‘Having to explain over and over again to multiple, unqualified people why you think you are disabled and should qualify for financial help is degrading and exhausting.’ (Disability and Financial Hardship participant, Scotland).

Our evidence shows there are numerous barriers people face when trying to access disability benefits, such as: low awareness of the benefit entitlements and eligibility, long delays, incorrect decisions, and an arduous and an oftentimes stressful application and assessment process.\(^{16}\) The Help through Hardship helpline, which is run in partnership by Citizens Advice and the Trussell Trust, handles thousands of calls each week from people seeking advice and support to help address the underlying causes of hardship. Between April and October 2022 more than four in ten people (43%) who had an issue identified that was associated with benefits or tax credits, had an issue specifically about PIP. Our separate research with the Scottish Centre for Social Research found that these issues often related to the stress and anxiety caused by the process, such as the lack of expertise of assessors, and the repetitive questioning which had serious impacts on people’s mental health, and suggested a correlation between barriers to support and causing conditions to worsen.\(^{17}\)

‘It’s dehumanising and it’s degrading, if I’m honest... they’re ticking boxes, or marking scores’ (Disability and Financial Hardship participant, Northern Ireland).

‘A lot of the people deciding for disabled people aren’t disabled, and have a very ableist outlook on life.’ (Disability and Financial Hardship participant, Scotland).

There is also concerning evidence that a significant number of disability benefit decisions are incorrect. The UK Government’s figures show that seven in ten (71%) PIP decisions taken to a tribunal are overturned, meaning that individuals who should have been eligible for the benefit had been denied it.\(^{18}\) Because the tribunal process takes 12 to 18 months, many people have had to wait a considerable length of time before receiving the income they are entitled to, often causing a great deal of stress and material hardship. There are many more who do not challenge the decision because they fear losing the small amount they have been awarded or cannot face the stress and upset of the appeals process.\(^{19}\)


\(^{17}\) Ibid.

\(^{18}\) DWP (2023), Personal Independence Payment: Official Statistics to July 2023 - GOV.UK (www.gov.uk)

'The six or eight weeks that it took for me to get the result felt like forever and it was so stressful but it's as if they knew straightaway if I didn't get accepted I wouldn't appeal it because it was just too stressful' (Disability and Financial Hardship participant, Wales).

The low level of uptake and the low value of disability benefits is pushing people deeper into poverty and damaging people’s health and wellbeing.

Financial hardship is a consequence of and a cause of ill health. When people cannot afford the essentials, their mental and physical health suffers. For this reason, protecting people from acute financial hardship is an essential part of building a healthier society.

The flaws in the disability benefits system, such as incorrect decisions and the ordeal of applying, are one key reason why the majority (62%) of disabled households referred to food banks in the Trussell Trust network are not receiving any benefits specifically related to their disability. Some of these people may not be eligible for disability benefits, but there are indications that design failures in the system play a key role in reducing uptake.20

This means that the higher costs associated with people’s disability and ill health are not being met, and the basic rate of Universal Credit remains far too low to offer an adequate financial buffer. Leading health bodies have set out the health risks posed by the extent to which Universal Credit falls short of essential costs.21 This was demonstrated in Trussell Trust research from August 2023, which found that disabled families receiving UC are nearly twice as likely to go without other essentials so they can afford food than non-disabled families (41% vs 25%) - with many in disabled families going without dental treatment (37%) and medication (16%) due to lack of income.22

The failure of social security to protect people from severe hardship is demonstrated in the fact that the majority (89%) of disabled people referred to food banks in the Trussell Trust network who receive means-tested benefits are experiencing destitution.23

The evidence shows that this kind of severe material hardship makes it even harder for people to take up opportunities for work or training, such as through worsening their mental and physical health.24 A new approach is needed.

22 YouGov surveyed 2,017 adults claiming Universal Credit on behalf of the Trussell Trust between 11th August - 5th September 2023. The survey was carried out online.
24 JRF (July 2023), Inadequate Universal Credit and barriers to work, available at: https://www.jrf.org.uk/report/inadequate-universal-credit-and-barriers-to-work#~:text=The%20recent%20two%20child%20limit,take%20advantage%20of%20other%20earning
“I don’t think the benefits reflect the extra cost, to be honest with you. [...] I do think the levels of the disability - the money that you’re paid should be increased.” (Hunger in the UK research participant, England).

The building blocks for a better future

The Trussell Trust envisions a future where disabled people and people with health conditions experience a life of dignity, equity, and empowerment. We aspire to see a society where disability does not equate to financial hardship, where every disabled individual can pursue their aspirations and contribute fully to their communities. In this transformed landscape, being disabled or living with long-term ill health should not mean financial struggle, marginalisation, and isolation. This future should be built in partnership with disabled people who are closely involved in the design and delivery of these new systems.

1. Everyone gets a decision on their disability benefit application as swiftly as possible which is right first time

It is unacceptable that people have to wait several months - sometimes longer - between applying for disability benefits and receiving them. The additional costs that accumulate over this period can push disabled people even further into poverty, particularly when the cost of living is already unaffordable, so processing capacity must be increased to ensure more timely decisions. This must go hand in hand with a compassionate, person-centred approach to assessments which gets decisions right, first time. Incorrect decisions not only cause significant levels of distress, they force disabled people to rely on tribunal appeals, which take 12-18 months and overturn 7 in 10 disability benefit decisions. Getting decisions right first time should include providing access to an assessor who is a specialist in the individual’s condition.

2. Everyone who wants it can access meaningful and person-centred employment support, avoiding the use of punitive financial sanctions wherever possible and instead using other services to increase engagement

While the disability benefits that help with extra costs, such as Personal Independence Payments, are not part of the conditionality regime, income replacement benefits through Universal Credit are subject to conditionality, sanctions and the benefit cap. In recent years, there has been a trend towards increasing both the harshness of financial sanctions and the groups exposed to them. This has led to some disabled people experiencing much greater material hardship and levels of stress which erode their health even further and reduce their ability to take up work and opportunities. 25

The social security system should be designed in collaboration with disabled people, with a strengths based and supportive approach. Putting dignified, accessible support in place can ensure that disabled people can live fulfilling lives, work where they can and contribute to their

communities, without needing to use a food bank. Approaches should prioritise pulling down barriers through evidence-based services which people want to engage with and which effectively train and support people into work, instead of relying on punitive approaches such as sanctions.

3. **Tackling financial hardship is always addressed as part of improving the health of individuals and society**

Protecting people from financial hardship is an essential part of building a healthier society. Whole person care means addressing the wider causes or ‘social determinants’ of ill health, such as financial crisis or housing insecurity. Recognising the role of hardship in local health systems means pooling resources and joint commissioning of services and support, while expanding and standardising social prescribing practices which address poverty and hardship. Improved information sharing is needed between health professionals and social security agencies, while doctors and health professionals should be supported to make people aware of their entitlements to disability benefits.

4. **Everyone is aware of the benefits they are entitled to, and are supported to apply through the widespread availability of quality accessible independent advice and support**

We know that specialist advice and support when making a benefits claim can be essential for many people, such as the availability of guidance on completing forms and interpreting questions correctly. However, the provision of advice and specialist support for people applying for disability benefits or looking for work is patchy, and too many are not aware of what is available. We need to see wider promotion of disability benefits, and disabled people able to access independent, expert advice to navigate the social security system effectively - something that has started to be delivered with promising results in Scotland.

5. **Improved and flexible employment practices and increased good quality jobs accessible to disabled people**

Concerted action is needed to increase the number of jobs, especially good quality jobs, advertised on a flexible basis accessible to disabled people, as well as effective support to clear the path to better paid jobs. This must include support for people with fluctuating or recurring conditions and people who may need to take time off for treatment or recovery. Diversity, inclusion and equal opportunities, encouraged through widespread reasonable adjustments and peer networks can help to create this future.

**Who needs to build this future?**

The UK Government

The UK Government holds key responsibilities in both the disability benefits system and reform of the labour market to increase number and access to high quality jobs. For example, the
Department of Work and Pensions must put in place a new framework to reform the disability benefits system so that it provides effective support and avoids punitive measures. This should include putting dignity and access at the core of the system, reducing waits, providing sufficient sick pay to help people into work, and increasing advice and support. The Treasury and Department for Business and Trade should lead labour market reform which encourages high quality, accessible jobs for disabled people. The Department of Health should work to reduce waiting times for treatment and support which make it harder for people to access good work and opportunities.

**Devolved governments in Scotland, Wales and Northern Ireland**

Responsibility for disability benefits such as ADP sits with the Scottish Government, who must continue to learn from the roll-out of these benefits and address many of the shared system failures which affect the wider disability benefits regime in the UK - such as long waits and incorrect decisions. Both the Welsh Government and a fully functioning Northern Ireland Executive should work on enhancing support and opportunities for disabled people, including improving access to disability benefits, advice services and employment. The Scottish and Welsh Governments, and a restored Northern Ireland Executive, should also work to reduce waiting times for healthcare treatment and support.

**Local government and health systems**

Local government and health systems, such as Integrated Care Systems (ICSs) in England or Health and Social Care Partnerships in Scotland, have powers to address social determinants of health and are well positioned to integrate health and financial support offers. For example, targeting deep poverty and hardship in their local strategies or when undertaking Joint Strategic Needs Assessments, or integrated cash-based local crisis support through health agencies. Awareness of disability benefits is low and can be increased through awareness raising campaigns.

**Employers**

Employers have a role in actively promoting diversity, inclusion, and accessibility within their workforce, offering equal opportunities for disabled individuals and people with mental health conditions to thrive. They should prioritise disability education and training, making reasonable adjustments, and using peer networks to foster workplaces that are supportive and respectful of disabled employees’ needs and aspirations. Employers should aim to make as many jobs as possible available on a flexible basis, with support from business organisations and government to help those employers who face challenges in redesigning jobs or putting reasonable adjustments in place.

**Civil society organisations**

Civil society organisations should work to tackle root causes of the problem, through raising public awareness of disability benefits in settings such as community centres or post offices, as well as seeking opportunities for co-location of services and support, and running anti-stigma
campaigns locally. There is an important role for civil society in developing support offers for people in need of financial support, as well as those seeking training, skills or employment.

**Conclusion**

These building blocks offer a clear direction of travel towards a society with dignified, accessible support for disabled people and people with health conditions. These should be developed together with people with experience of disability and ill health, ensuring that their invaluable insight, knowledge, and experiences drive policy changes that address the unique challenges.

Putting these blocks into place means will help us to ensure that disabled people and people with health conditions can live fulfilling lives without needing to use a food bank.

**Support for individuals**

Citizens Advice - network of charities offering confidential advice online, over the phone, and in person, for free via: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Adviceline (England): 03444 111 444  
Adviceline (Wales): 03444 77 20 20  
Adviceline (Scotland): 0800 028 1456

Advice NI (Northern Ireland) - free helpline providing advice on benefits, personal and business debt, EU Settlement Scheme, Tax Credits and HMRC services via: 0800 915 4604

Christians Against Poverty - free, expert debt help through local debt advice centres, via: [https://capuk.org/get-help/cap-debt-help](https://capuk.org/get-help/cap-debt-help)

Disability Information Scotland - free information for people living with a disability in Scotland  
[https://www.disabilityscot.org.uk](https://www.disabilityscot.org.uk) / 0300 323 9961

Mencap - free helpline service offering advice and support for people with a learning disability, and their families and carers via [www.mencap.org.uk](http://www.mencap.org.uk) / 0808808111

National Debtline - run by national charity the Money Advice Trust, National Debtline is a free and confidential debt advice service for people in England, Wales and Scotland via: [www.nationaldebtline.org](http://www.nationaldebtline.org) / 0808 808 4000

Scope - free, independent and impartial advice and support on issues that matter to disabled people and their families via: [www.scope.org.uk](http://www.scope.org.uk) / 0808 800 3333.

StepChange - help people with debt problems take back control of their finances and their lives via: [www.stepchange.org/Start.aspx](http://www.stepchange.org/Start.aspx) / 0800 138 1111
The Trussell Trust - free phone service delivered in partnership with Citizens Advice for people worried about money in England and Wales (can also transfer to Mind’s Infoline for mental health information and support) via: www.trusselltrust.org/get-help/help-through-hardship-helpline / 0808 2082138

Turn2us - helps people in financial need gain access to welfare benefits, charitable grants and other financial help - online, by phone and face to face through partner organisations via: www.turn2us.org.uk