

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

February 2024

INTRODUCTION

It's not right that increasing numbers of people in the UK today need to use a food bank because they can't afford to eat and pay the bills. People need to use food banks because they don't have enough money for the essentials. But all of this can change. We know what's pushing people to food banks, so we know the building blocks needed to end hunger for good.

We know the factors that make it more likely people will need a food bank. We know most people at food banks will face more than one of these factors, and we know the way these issues combine and interact can make someone's life even harder. So, while this briefing focuses on work, the recommendations will have most impact when combined with the recommendations in our other building blocks briefings.

We need every part of our society to drive this change. Together, we need to make sure that we have a supportive social security system, along with decent, secure, and rewarding work, and safe, secure and affordable housing.

In addition, we need dignified support for disabled people and people with health conditions, and support and recognition for everyone who provides care.

Finally, easy access to advice and support on money matters, readily available mental health and trauma-informed support, and strong and inclusive communities are also essential building blocks to a future where no one needs a food bank.

Further information about all of these building blocks can be found on our website trusselltrust.org/building-blocks

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. The majority (69%) of people referred to food banks in the Trussell Trust network are disabled.¹

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 finding and sustaining work, and the low-paid and part-time nature of work that they are often employed in, 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.

We will build dignified, accessible support for disabled people and people with health conditions by ensuring:

- 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 social security support they are entitled to, and is 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.

WHAT IS THE PROBLEM?

"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."

(Disability and Financial Hardship research participant, England)

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. The majority (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.² In comparison, 26% of the general population are disabled.³

The most common health condition 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%).⁴

More than a quarter of disabled people (26%) experience food insecurity, nearly three times higher than the rate among non-disabled people (10%).⁵ Similarly, we see that, for working age people, 15% of disabled families are in deep poverty, compared to 9% of people in non-disabled families.⁶

Research has found what this means for the day to day lives of 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. This level of hardship causes worry and holds people back from work.

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 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 research participant, Northern Ireland)

Too often these costs 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 may also experience periods where their disability payments are incorrectly withdrawn.

- The disability unemployment rate is over double the unemployment rate for nondisabled 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

Disabled people face multiple barriers 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 conditions, 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 support relating to their mental health in the three months before receiving support from a food bank.¹³

This situation is compounded by a system which provides inadequate disability 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.

Disability payments should help everyone participate fully in society - but flawed assessments, long waits and incorrect decisions in the social security system are damaging people's health and deepening exclusion.

Disability payments 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 payments include Disability Living Allowance, Personal Independence Payment, and Adult Disability Payment (Scotland), all of which are intended to pay for the extra costs associated with a disability. These payments are not means tested, so people's savings, or household earnings, do not affect eligibility. Employment and Support Allowance (ESA) and Universal Credit (UC) are income replacement payments that 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.

Research has gathered extensive evidence suggesting that the current approach to assessments and decisions on these payments are deeply flawed.¹⁴ People often wait several months between applying and receiving payments. Research by Mind found that "people are left confused, angry and re-traumatised when trying to navigate their assessment" for financial support from the social security system that should be there to protect us all.¹⁵ The result is worsening mental health conditions, eroded 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 research participant, Scotland)

This evidence shows there are numerous barriers people face when trying to access disability support, 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 in England and Wales, handles thousands of calls each week from people seeking advice and support to help address the underlying causes of hardship. Between April 2021 and March 2023, more than four in 10 people (45%) who had an issue identified as being associated with social security or tax credits had an issue specifically about PIP.¹⁷

Research has 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 - suggesting a correlation between barriers to support and worsening conditions.¹⁸

"It's dehumanising and it's degrading, if I'm honest... they're ticking boxes, or marking scores"

(Disability and Financial Hardship research participant, Northern Ireland)

There is also concerning evidence that a significant number of disability support decisions are incorrect. The UK Government's figures show that seven in 10 (71%) PIP decisions taken to a tribunal are overturned, meaning that individuals who should have been eligible for support had been denied it.¹⁹ 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 who do not challenge the decision because they fear being reassessed and losing all their payments, or cannot face the stress and upset of the appeals process.²⁰

"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 research participant, Wales)

The low level of uptake and the low value of disability support 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 support available through the social security 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 support specifically related to their disability. Some of these people may not be eligible for disability payments, but there are indications that design failures in the system play a key role in reducing uptake.²¹

The basic rate of Universal Credit remains far too low to meet the higher costs associated with people's disability and ill health,²² and research has found that disabled families receiving UC are far more likely to go without other essentials so they can afford food than non-disabled families (41% vs 25%). Many in disabled families report going without dental treatment (37%) and medication (16%) due to lack of income. ²³

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 social security payments are experiencing destitution.²⁴

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.²⁵

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

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 support application as swiftly as possible, and that it is right first time.

It is unacceptable that people have to wait several months - sometimes longer - between applying for disability support and receiving payments. 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. Processing capacity must be increased to ensure more timely decisions. This must go hand in hand with a compassionate, person-centred approach to assessments that is co-designed with people with lived experience, which gets decisions right, first time. Incorrect decisions not only cause significant levels of distress, but they force disabled people to rely on tribunal appeals, which take 12 to 18 months and overturn seven in 10 of these decisions.²⁶ Getting

decisions right first time should include providing access to an assessor who is a specialist in the individual's condition.

 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 payments that help with extra costs, such as Personal Independence Payments, are not part of the conditionality regime, income replacement payments 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.²⁷

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, along with information and support to help people understand the social security they are entitled to, should be available in all healthcare settings.

4. Everyone is aware of the social security support they are eligible for, and is supported to apply through the widespread availability of quality accessible independent advice and support.

We know that specialist advice and support when applying for social security support - such as guidance on completing forms and interpreting questions correctly - can be essential for many people. However, the provision of such advice and specialist support is patchy, and too many are not aware of what is available. We need to see wider promotion of disability payments, and disabled people need access to independent, expert advice to

navigate the social security system effectively - something that has started to be delivered with promising results in Scotland.

5. Much wider adoption of flexible employment practices and a significant increase in 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 equity, 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 social security system and reform of the labour market to increase the number of - and access to - high quality jobs.

For example, the Department of Work and Pensions must put in place a new framework to reform the support available for disabled people through the social security 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.

Scottish Government, Welsh Government, and the Northern Ireland Executive

Responsibility for disability support such as Adult Disability Payment sits with the Scottish Government, which must continue to learn from the roll-out of this support and address many of the shared system failures which effect the wider social security system in the UK - such as long waits and incorrect decisions. Both the Welsh Government and the Northern Ireland Executive should work on enhancing support and opportunities for disabled people, including improving access to disability support, advice services and employment. The Scottish and Welsh Governments, and the Northern Ireland Executive, must also reduce waiting times for healthcare services.

To tackle poverty and reduce the need for emergency aid such as food banks, Welsh Government must deliver their Welsh Benefits Charter, which, underpinned by policies that reflect the social model of disability, intends to increase take-up of Welsh benefits.

The Northern Ireland Executive must implement a Disability Strategy in line with commitments made under New Decade, New Approach, based on the priority recommendations of the Disability Strategy Expert Advisory Panel: participation and leadership of disabled people (recognising their multiple identities and spanning the entire spectrum of disability), economic security of disabled people, autonomy of disabled people, and resources to achieve the Strategy's objectives.

Local government

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 heath 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 payments is low and can be increased through awareness raising campaigns.

Businesses and employers

Businesses and 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.

Charities and community organisations

Charities and community organisations should work to tackle root causes of the problem, through raising public awareness of disability support 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

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 recommendations into place will ensure that disabled people and people with health conditions can live fulfilling lives and are not forced to use a food bank.

Anna Hughes & Elizabeth Miller

Contact: <u>public.affairs@trusselltrust.org</u>

https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/10/Disability-Benefits-Research-Report.pdf

https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/10/Disability-Benefits-Research-Report.pdf

¹ The Trussell Trust (2023), *Hunger in the UK*, https://www.trusselltrust.org/wp-content/uploads/sites/2/2023/08/2023-The-Trussell-Trust-Hunger-in-the-UK-report-web-updated-10Aug23.pdf

² The Trussell Trust (2023), *Hunger in the UK* – see endnote 1.

³ The Trussell Trust (2023), *Hunger in the UK* – see endnote 1.

⁴ The Trussell Trust (2023), *Hunger in the UK* – see endnote 1.

⁵ The Trussell Trust (2023), Hunger in the UK – see endnote 1.

⁶ Joseph Rowntree Foundation (2023), From disability to destitution https://www.jrf.org.uk/blog/disability-destitution

⁷ Biggs H, Wildman J, Hamid A and MacGregor A (Scottish Centre for Social Research) The Trussell Trust (2023), *Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK*

⁸ Department for Work and Pensions (2023), Employment of disabled people 2022,

⁹ The Trussell Trust. (2023), Hunger in the UK, 2022. [data collection]. UK Data Service. SN: 9110, DOI: http://doi.org/10.5255/UKDA-SN-9110-1

 $^{^{\}rm 10}$ The Trussell Trust (2023), Hunger in the UK – see endnote 1.

¹¹ The Trussell Trust (2023), Hunger in the UK – see endnote 1.

¹² The Trussell Trust (2023), *Hunger in the UK* – see endnote 1; and Scottish Centre for Social Research & The Trussell Trust (2023), *Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK* – see endnote 7.

¹³ The Trussell Trust (2023), Hunger in the UK – see endnote 1.

¹⁴ Biggs H, Wildman J, Hamid A and MacGregor A (Scottish Centre for Social Research) The Trussell Trust (2023), *Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK*

¹⁵ Mind (2023), Reassessing Assessments https://www.mind.org.uk/media/sjbptudq/reassessing-assessments-report.pdf
See also MS Society (2023), PIP and MS: a decade of failure https://www.mind.org.uk/media/sjbptudq/reassessing-assessments-report.pdf
See also MS Society (2023), PIP and MS: a decade of failure https://www.mssociety.org.uk/sites/default/files/2023-09/PIP%20and%20MS%20a%20decade%20of%20failure%20FINAL%20REPORT.PDF

¹⁶ Scottish Centre for Social Research & The Trussell Trust (2023), *Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK* – see endnote 7.

¹⁷ Help through Hardship data, Citizens Advice, Casebook.

¹⁸ Scottish Centre for Social Research & The Trussell Trust (2023) *Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK* – see endnote 7.

¹⁹ Department of Work and Pensions (2023), *Personal Independence Payment: Official Statistics to July 2023* <a href="https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-july-2023/personal-independence-payment-statistics-payment-statistics-payment-statistics-payment-statistics-payment-statistics-payment-statistics-payment-statistics-pa

independence-payment-official-statistics-to-july-

 $\underline{2023\#:^{\sim}:text=Latest\%20 quarterly\%20 figures\%20 to\%20 July,17\%2C000\%20 clearances\%20 for\%20 DLA\%20 reassessments}$

- ²⁰ Scottish Centre for Social Research & The Trussell Trust (2023) Disability and financial hardship: How disability benefits contribute to the need for food banks in the UK see endnote 7.
- ²¹ The Trussell Trust (2023), *Hunger in the UK –* see endnote 1.
- ²² Joseph Rowntree Foundation (2023) *Universal Credit falling so far short of the cost of essentials is putting the health of millions at risk say health bodies and charities*
- ²³ YouGov survey 11th August 5th September 2023 See endnote 8.
- ²⁴ The Trussell Trust. (2023). Hunger in the UK, 2022. [data collection]. UK Data Service. see endnote 9.
- ²⁵ JRF (July 2023), *Inadequate Universal Credit and barriers to work* https://www.jrf.org.uk/report/inadequate-universal-credit-and-barriers-work#:~:text=The%20recent%20two%2Dchild%20limit,take%20advantage%20of%20other%20earning
- ²⁶ Department of Work and Pensions (2023), *Personal Independence Payment: Official Statistics to July 2023* see endnote 19.
- ²⁷ Economic and Social Research Council (2018), *Final Findings report: welfare conditionality project 2013-2018* 40475 Welfare-Conditionality Report complete-v3.pdf (welfareconditionality.ac.uk)