

Barely Surviving: The Impact of the Cost-of-Living Crisis on Disabled People in Wales

This report is dedicated to the memory of the disabled people who have lost their lives during the cost-of-living crisis





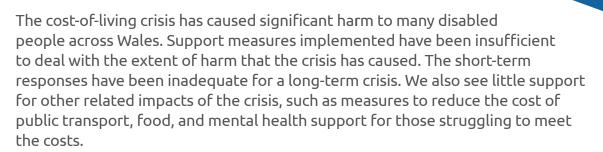


Introduction

It has been difficult to escape the cost-of-living crisis, but the reality of it for many disabled people across Wales has been devastating. This report may be a tough read for some, but we are unapologetic for it as we believe it is a necessary one. Our research indicates that disabled people in Wales and across the UK have been systemically let down by their governments and our findings show that trust in Government is at an understandable extreme low.

This report is split into sections to mirror the survey that was circulated. Starting with the impact of increased energy bills where we found that most respondents had experienced large bill increases and many found themselves unable to meet

their costs as a result. We next move to the impact of increasing costs in other areas, focusing mostly on transport and food, where we see disabled people being unable to afford three meals a day or their impairment-related diets and experiencing everincreasing social isolation due to lack of access to transport. We then consider the impact on physical health, mental health and well-being, this section sees some of our most concerning findings regarding an ongoing crisis in mental health among disabled people that remains unaddressed.







Methodology

In accordance with the social model of disability and the philosophy of our organisation, this report is primarily informed by the direct experiences of disabled people living in Wales. We ran a self-selecting survey available in English language, English language Easy Read, English language plain text, Welsh language, and Welsh language plain text. We received 74 responses to our survey across all formats; however, we did not receive any responses to our Easy Read survey.

71 respondents identified as a disabled person, one respondent identified as non-disabled but answering on behalf of a disabled person and one person identified as non-disabled and answered for themselves. Not all respondents answered every question, so not all figures will add up to 74. The highest response rate by local authority was from among residents in Cardiff City Council, the second largest number of respondents were based in Gwynedd. All respondents were based in Wales.

We also ran two self-selecting online focus groups aimed at disabled people. 25 individuals attended the focus groups overall, it is likely that some individuals both attended a focus group and completed the survey. We also ran a network meeting of disabled people's organisations and have incorporated some of that feedback into this report. This report also uses findings from a previous Disability Wales survey on the cost-of-living crisis conducted in Spring 2022, this survey received 39 responses. Our primary data is supplemented by secondary research of other key sources.

Context

Wales has a higher proportion of disabled people within their population than the rest of the UK, 28% of the Welsh population is disabled, compared to 22% in both England and Northern Ireland, and 21% in Scotland. Disabled people throughout the UK are also more likely to be economically inactive and have a higher rate of living in poverty.¹²³

The Locked-Out Report about the impact of Covid-19 on disabled people also demonstrated a clear link between outcomes and poverty, social deprivation, state benefits, housing and experiences of work and employment.⁴

Disabled people are particularly more likely to experience fuel poverty, in 2021 900,000 disabled people lived in fuel poverty, Scope and National Energy Action estimates raised that to 2.1 million people if bills reached £3,000 a year.⁵

What is referred to in this report as the "additional cost of disability" refers to unique costs experienced by disabled people or costs that are more essential for disabled people. Heat and electricity are also two costs that disabled people may need to meet to manage their impairments.

Some impairments can be triggered by extreme temperatures or require the use of equipment that uses a significant amount of electricity. These impairment-related expenses are essential for the disabled person, therefore in some cases, the basic payments they must make are increased in comparison to a non-disabled person or they would have to reduce expenditure in other essential areas, notably food and transport, to meet these costs.

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Section One: Impact of Rising Energy, Electricity and Water Bills

A significant majority of disabled people who responded to our survey experienced increased costs to their heating, electricity and water. Of the 74 respondents, 89% experienced increased costs, this is a slight reduction from the previous year in which 92% of the respondents experienced increased costs, however it is relevant that the 2022 survey had significantly less participants.

When asked to give further details, one disabled person told us that "Heating has increased to the extent that we don't turn it on, just wear more clothes." This is a common response throughout survey responses and within the focus groups, disabled people reported using coping strategies such as wearing more clothes,7 turning heating on for strategic times throughout the day, or resorting to having to try and bare the cold.

Respondents noted that they had already been struggling for money prior to the crisis, making it difficult to cut expenses in other areas to make up for bill increases. One key concern was the wages and benefits such as Universal Credit and Personal Independent Payments not rising in line with inflation⁸ was highlighted as a key issue "everything is getting more expensive. energy costs, household bills, food prices, travel costs and yet wages, and PIP remain the same I can't keep up."

Uncertainty about future bill increases was also highlighted. "What's worse is not knowing what to expect next, how much more costs will increase." ¹⁰ Some noted that even with cutting expenses, they are concerned about future financial issues or costs increasing further.

58 of the 74 respondents reported having to cut back on these costs. When asked to provide further details respondents reported having to sell their possessions to pay their bills, some had to significantly reduce their car usage. 11 One respondent reported that they had to change what they used their PIP for, switching from using it for certain therapies to using it for survival. Multiple respondents reported having to use outdated glasses prescriptions as they could not afford bills and to update their glasses. 12

Fuel poverty amongst disabled people is a problem that pre-exists this crisis, National Energy Action estimated that prior to the crisis, 900,000 disabled people lived in fuel poverty.¹³ Respondents to the survey and participants in the focus groups noted that the pre-existing problem with the price of fuel and financial insecurity has exacerbated the impact of the crisis. Many disabled people could barely afford to heat their homes previously, now it is an issue for an increased number of people.

There has been significant concern about people living on pre-payment meters. These meters are "a type of domestic energy meter that lets you pay for energy before you use it. This type of meter is also known as a pay-as-yougo meter."14 Customers using prepayment meters are disproportionately low income, but prepayment meters are often more expensive. National Energy Action found that people living with prepayment meters are far more at risk of disconnection than their counterparts. 15 Disability Wales is glad to see action from Ofgem on the forced installation of these prepayment meters, but more must be done to ensure that prepayment customers are not financially penalised for using this form of meter.¹⁶

Some action has been taken on energy bills and other household bills. We were pleased with the tariffs placed on energy companies and to see some support such as Winter Fuel Allowance and the one-off £150 cost of living payments. However, as will be discussed in further detail in section four, this is a long-term problem which cannot be fully addressed by measures designed to support people in the short term.

Section Two: Housing, Transport and Other Expenses

Disability Wales believes that this crisis is significantly more complex than just the rising cost of bills, this belief was reflected in the responses from disabled people living in Wales. This section addresses some of these other costs, such as the cost of transport, food, and leisure activities, and the impact on disabled people.

We found that disabled people in Wales are consistently spending more across Housing, Transport and Impairment related expenses. 61 disabled people told us that they had spent more on transport and 48 disabled people told us that they had to spend more on impairment-related expenses. Respondents noted the rise in prices of car fuel, and transport tickets as some of the main contributors towards rising travel costs. Some respondents noted that impairment-related expenses are essential costs for them so were had to sacrifice elsewhere to meet these costs. Housing costs was split evenly between those who had or had not spent more money on their housing costs. For those who had, many owned their own homes and attributed it to rising mortgages and the additional costs of having to make adaptations to their homes.

Disability Wales asked if respondents had cut back on a range of expenses. Transport was a typical area to make cuts with 53 respondents having reported to cut back on transport. This is a concern, especially considering that respondents reported that having to make these cuts had left them increasingly isolated and unable to see loved ones. They reported that they had found it difficult to afford to attend medical appointments and access important services that required transportation. Disability Wales is also concerned that these cuts have left other support measures less effective, when asked about if they had used a 'warm bank,' some respondents told us that they had been unable to use a warm bank due to the cost of transport to get there.

Food was another typical area where respondents cut back. 50 respondents reported that they had cut back on their food expenses and this was also reflected in the focus groups. Respondents reported that the cost of food have left them only able to eat 1 or 2 meals a day and made it difficult to eat their required diet e.g., gluten free. Two of the most likely areas to cut spending was on clothing and leisure activities. 56 respondents had cut spending on clothing and 58 respondents had cut back on leisure activities. Although clothing was not mentioned specifically, many respondents reported that they had to cut back on leisure activities to afford their main expenses. Many disabled people have told us that they have been unable to do the activities which bring them joy or

fulfilment and as a result have experienced a significant reduction in their quality of life, one person noting that they are "just surviving" instead of living fully.¹⁷

Social isolation was a common theme throughout this section of research. The combination of a lack of access to transport, suitable housing and having to cut back on expenses not related to essentials needed to survive, left many disabled people becoming isolated from their communities and loved ones.

Although still the largest share of respondents, the least likely area to cut was impairment-related expenses. 32 respondents had cut back on impairmentrelated expenses, as mentioned in the previous paragraph, impairment-related expenses are often an additional essential expense for disabled people that often cannot be cut back on, or once cut back on has an extreme impact on their life. Examples of an impairment-related expense include costs of running equipment, particular diets and additional transport expenses. One respondent reported that they could no longer afford their support worker due to the crisis, one respondent couldn't afford to run their access equipment, and another respondent told us that they felt like they would be better off in a prison than in their current circumstances.

Disability Wales is alarmed at evidence that some disabled people are no longer able to afford the costs of their support workers due to the crisis. In Wales, he maximum weekly care charge is £100 for people in receipt of social care support from their local authority. Under the Welsh Government and Plaid Cymru agreement, a commitment was made to introduce a National Care Service which is free at the point of need. To date, there is no timetable for the implementation of free care and support.

Disability Wales is concerned about the long-term impact of these increased costs and the lack of targeted support addressing these concerns. This evidence does not exist in isolation and concerns over disabled people in Wales having to cut back on or live without in these areas have been repeated by organisations across Wales.²⁰ As costs continue to remain high, we must see swift and decisive action to tackle this.

Section Three: Impact on Wellbeing, Physical and Mental Health.

In this report there are references to suicide and self-harm, we have included this as we believe it is important to understand the severity of the impact of the crisis on disabled people, but this section may be triggering or distressing for some readers.

We have found that the cost-of-living crisis has had a profound impact on the wellbeing, physical and mental health of the disabled people we spoke to. This was highlighted as a concern in our previous research on this topic, of the 39 respondents to our 2022 survey 82% had reported that it had impacted their mental health. ²¹

It cannot be understated the extremity of the impact of this crisis on some of our respondents. Multiple respondents reported experiencing suicidal ideation and mentions thoughts of ending their lives. One respondent reported that a disabled friend had taken their own life after feeling like a financial burden on their family.²² Disabled respondents specifically talked about financial insecurity and feelings of hopelessness about the crisis as stressors for their mental health. This applied consistently to both disabled people with pre-existing mental health conditions and disabled people who developed mental health conditions, such as anxiety, due to the crisis.

Many respondents have reported worsening physical health. One respondent reported worsening asthma and anxiety attacks due to not being able to keep their home heated²³ Increased pain has been a common physical health concern from the crisis. This is mostly attributed to lack of being able to afford adequate heating for homes.

Well-being has also been hugely affected. Of our respondents, 80% reported it having a negative impact on their well-being. The main themes regarded the intersection of physical and mental health worsening and increased isolation. Many reported that having to sacrifice transport costs or others having to sacrifice their transport costs has isolated them from their loved ones and forced them to miss hospital appointments.²⁴

This is also a particular problem in residential homes where there is limited support for the disabled person to be able to financially support visitors.

Our research found that of the 74 respondents 52 reported that their physical health had been impacted by the crisis, 58 respondents reported that their mental health had been impacted by the crisis and 59 reported that their wellbeing had been impacted. We see that physical health may have been the least impacted, although levels are high for all three. We would like to stress that even if impact on mental health and wellbeing is more ubiquitous, the individual impact on the disabled respondents is extremely important.

There is a lack of joined up support between the health service, mental health, social care and other support providers. We are concerned that the evidence points to this resulting in disabled people slipping through the cracks and struggling on their own. These experiences of our respondents were completely avoidable, this must become a national priority for the Senedd.

Section Four: Support

One key takeaway from our research in 2022 was the lack of awareness of available support for the cost-of-living crisis. In 2023 this persists as an issue. Of the 74 survey respondents, 23 respondents felt informed of support options available. 11 disabled people were unsure and 30 did not feel informed with 8 people not knowing any support options available at all.²⁶²⁷

The raw number of disabled people who had received support had increased in the latest survey, from 9 of the 39 respondents to the first survey having received effective support increasing to 14 out of the 74 respondents in the most recent survey. The number of respondents who had received support in the most recent survey is a lower percentage of the total number of respondents than in the previous but given the smaller sample sizes we don't attribute too much significance to this.

When asked about some specific support options, we do see some improvement.

Comparing knowledge of Wales Fuel Support Scheme. In 2023 to 2022. In both years, we see a high level of knowledge compared to the other areas asked about. In 2023 91% of the 74 respondents had heard of Winter Fuel Allowance compared to 7% of people had not. In 2022 85% of respondents had heard of Winter Fuel Allowance compared to 6% who had not.

Responses to our question on Local Housing Allowance²⁹ is more interesting. Although the sample sizes remain small and are different in both groups, the changes are different enough that they may be of some significance. In 2023 we found that 46% of respondents had heard of Local Housing Allowance, compared to 53% who had not, while in 2022 30% of respondents

had heard of Local Housing Allowance in comparison to 69% who had not.

There is concern that across both years, the number of respondents who had heard of Local Housing Allowance was lower than those who had not, even if the gap is starting to close.

There seems to be less progress with Discretionary Assistance Fund. The number of respondents who had not heard of Discretionary Assistance Fund has remained high, in 2022 64% of respondents had not heard of Discretionary Assistance Fund and in 2023 58% of respondents had not heard of the fund. We do see that the percentage of those who had heard of the Discretionary Assistance Fund has increased, but less significantly than that of Local Housing Allowance. Of those who have heard of it, one respondent told us that even though they knew what it was they didn't understand it or how to get it.

In a focus group last year, we heard that a disabled person had received a £150 cost-of-living support payment³¹ without any communication regarding the payment.³²
Overall, 62 respondents had heard of the £150 payment making it the second most well-known following Winter Fuel Allowance. The impact of the payment however seems limited, one respondent reporting that it "helped make a dent for a month."³³

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In 2022 **85% of respondents** had heard of Winter Fuel Allowance compared to 6% who had not.

Section Four: Support (cont.)

We asked about respondents' usage of food and warm banks. Every respondent had heard of food banks, 10 respondents had been to a food bank, 9 respondents had considered going to a food bank and 51 respondents had reported never going or considering going to a food bank. Respondents who had not gone to or considered going to a food bank had a variety of reasons why, with not all respondents not needing them. The other responses focused on the accessibility of food banks, that they would go to a food bank if they had to means to access one, or shame surrounding food bank usage was key. Some reported living in 'gossipy' areas and being concerned about rumours, some reported that, despite needing one, their pride would not allow them to seek out a food bank. An attendee of the focus groups also reported that their pride had prevented them from going to a food bank. We see a key problem with the perception of food banks with shame around their usage preventing disabled people from accessing a key resource.

It is a similar story with warm banks. These are less high profile than food banks with 8 respondents not knowing what a food bank was and a focus group participant not knowing what they are. As there are fewer warm banks than food banks, physical access to them was identified as a key issue from their use. Physical access in this case encompasses both travel to warm banks and the space used as a warm bank. "Cost of travel and uncomfortable seating are barriers." In the focus groups, some respondents did not access warm banks as the journey to get to the warm bank would still leave them extremely cold. 35

The cost and availability of public transport is a repeated barrier throughout this report. Even in parts of Wales which do have access to some of these services, or where support is set up and communities can work with each other, the transport system in Wales has meant that there are disabled people who still cannot access them. Public transport in Wales is a commonly discussed issue, but at the ground level the quality of transport in Wales is one of the largest barriers to being able to effectively support disabled people.

This research was conducted prior to the UK Government's announcement regarding introducing legislation to raise many benefits in line with inflation.³⁶ This is a welcome if long overdue step. We are however concerned that with inflation set to continue rising and that prior to the cost-of-living crisis, benefit levels still were not sufficient to meet basic let alone additional costs faced by many disabled people, this issue will reoccur.

'Cost of travel and uncomfortable seating are barriers'

Impact on Disabled People's Organisations

There are many disabled people's organisations the length of Wales delivering vital services and support to disabled people.

However, in a network meeting with disabled people's organisations, many stated that they do not have the funding they need to maintain the level of services they provide. Funding to combat the rising cost of bills and other expenses was highlighted as a key need. One notable example is **Aubergine Cardiff**, an autistic-led café and arts organisation which recently faced eviction due to their landlord drastically increasing their rent.³⁷

Disabled people's organisations are run and controlled by disabled people and are uniquely placed to deliver services and support to disabled people that more fully meet their needs. This has been recognised as vital to the implementation of the UNCRDP, but **funding for disabled people's organisations whether at national or local level is not adequate.**

Conclusion

The cost-of-living crisis has caused significant harm to many disabled people in Wales. For some it has meant cutting back on smaller costs, for some of the disabled people who responded to our survey it has completely changed their lives. The UK Government's response to the cost-of-living crisis also brings into sharp focus the inadequacy of the current welfare system and processes set up to deliver essential financial support.

The Welsh Government endeavoured to deliver timely yet short-term financial support to address the cost-of-living crisis which achieved some benefit for disabled people. To tackle the long-term, persistent inequalities faced by disabled people highlighted in the Locked-Out Report, **the First Minister set up the Disability Rights Taskforce in November 2021**. However, despite progress towards developing actions and objectives, the full Disability Rights Action Plan is not scheduled for publication until March 2024, leaving many disabled people feeling frustrated over the lack of urgency in tackling current issues.

Moreover, neither the UK nor the Welsh government provided assistance that was specifically targeted at addressing the unique circumstances experienced by disabled people, who face higher living costs on account of their impairments despite being more likely to live in poverty. Many disabled people report seeing their impairments and health conditions worsen as a result of the crisis, with mental health issues becoming a silent epidemic. Loneliness emerged as a strong theme in the research, indicating not only a lack of company, but also a sense of abandonment in having to make difficult choices with limited support.

With energy costs and the prices of essentials such as food and vital services such as public transport still high, both the Welsh and UK Governments **must act urgently** and meaningfully in response to the harrowing lived experiences of disabled people who found themselves **'barely surviving'**

Key Recommendations

- Commitment to the proposed Disability Rights Action Plan, coproduced by the Disability Rights Taskforce, effecting radical change in maximising the social and economic potential of disabled people in Wales and minimising harms caused by national crises
- Incorporate the UN Convention on the Rights of Disabled People.
 Despite its inclusion in the Programme for Governance and the Cooperation Agreement with Plaid Cymru, there is still no timeline for incorporation of the United Nations Convention on the Rights of Disabled People. With limited time remaining in the legislative agenda, the Welsh Government must outline their plan for incorporation.
- Provision of resources and capacity building measures to ensure the
 establishment and sustainability of at least one Disabled People's
 Organisation in every local authority, to support coproduction of
 policies and services with public bodies, including peer support
 schemes for disabled people
- Commitment from the UK Government and the Welsh Government to prioritise tackling the extra cost of disability, involving disabled people and Disabled People's Organisations in the redesign of the benefits system.
- Devolution of the benefit Personal Independence Payment to Welsh Government, enabling a coproduced approach to the design and assessment process in line with the social model of disability.
- Action from regulators, such as Ofgem and Ofcom, to make sure that disabled people don't overpay for everyday essential services24. Exploitative higher standing charges for pre-payment meters should come to an end and social tariffs should be introduced. Government must intervene to ensure that energy bills are affordable for all and that customers are not being forced to move to pre-payment meters.
- Implementation of "One Ticket, One Route, One Service", with
 public transport, such as buses and trains, taken under public
 ownership to be delivered as a public service, including measures
 such as reduced ticket prices with the eventual goal to make public
 transport in Wales free.

- Food subsidies should be considered to reduce the cost of food in shops. To supplement this, the Welsh Government and Local Authorities should provide support to and nurture the creation of community food schemes. These schemes should include accommodation for dietary requirements and include options for access requirements.
- Utilising data collection and population needs assessments to inform a joined-up approach between Welsh Government, local authorities and health services to identify disabled people at risk from the impacts of the cost-of-living crisis on their health and wellbeing by ensuring better targeting of financial support and support services.
- The Welsh Government, health services and local authorities in Wales to provide specific support for the running and maintenance of disability related equipment, to ensure that all disabled people are not financially impacted by their need to use certain equipment.
- Welsh Government to urgently review its policy on social care charges, including whether the disregards for disability related expenditure are adequately protecting disabled people on low incomes with high costs.
- Urgent action to recognise and tackle mental health issues amongst disabled people, including pathways to accessing appropriate mental health support whether from social care, other areas of the health service and/or through peer support, such as from disabled people's organisations.

For more information and valuable resource www.disabilitywales.org/resources/

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- ⁷ Disability Wales survey respondent (2023)
- Since publication of survey, announcement made to raise these benefits in line with inflation.
- ⁹ Disability Wales survey respondent (2023)
- ¹⁰ Disability Wales survey respondent (2023)
- "The price of everything has shot up, but the money I live on all I have are disability benefits: PIP & ESA hasn't. Before the crises, when my oil in the tank got to half empty, I could afford to get it topped up straight away. For the last couple of years, the tank has been empty more than it's been filled. I'm sat here in a freezing home right now, because my oil ran out, & I didn't have the money to buy more. I also had to get an oil engineer in, to fix the boiler, because it'd run dry! I'm crippled with arthritis, and a host of other immune-based illnesses, & if I get cold, the pain

- intensifies my home is freezing, as I live in a 300 year old stone cottage." Disability Wales survey respondent (2023)
- ¹² Disability Wales survey respondent (2023)
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- ²¹ Disability Wales survey (2022)
- ²² "I have recently lost a close disabled friend due to suicide as she could no longer cope with the costs she was causing her family. She did not feel she was seen as an individual in her own right just because she was a mother and wife. Her husband and two young children are devastated." Disability Wales survey respondent, (2023).



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³² Disability Wales focus group (2022)

³³ Disability Wales survey respondent (2023)
³⁴ Disability Wales survey respondent (2023)

³⁷ Sanjana Idnani, BBC Wales, "Cardiff cafe

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 HM Treasury, "Spring Budget", (2023), https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1144441/Web_accessible_Budget_2023.pdf

staffed by autistic people fears closure", 23rd December (2022), https://www.bbc.com/news/uk-



If you are developing a project that can benefit from involvement or co-production with disabled people then get in touch to find out how we could work in partnership with you.

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Disability Wales receives funding from the Welsh Government



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