

THE FINANCIAL WELLBEING OF DISABLED PEOPLE IN THE UK: THE EXTRA COSTS OF DISABILITY

Quick Read

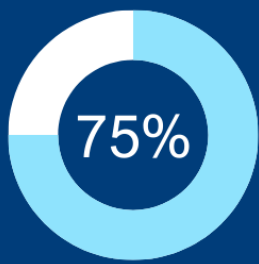
Most disabled people face extra costs because of their impairment and these costs are often unavoidable: Three-quarters (75%) of disabled people in our survey agreed that they have “particularly high costs” due to their impairment. Two-thirds (64%) agreed that there are things they need to buy because of their impairment that they could not afford. These costs may amount to more than £1,100 per month, according to research from Scope.

The ‘top three’ extra costs for disabled people are utility bills, transport costs and specialist equipment: The most common extra cost was energy or other utility bills (incurred by 78% of respondents), followed by transport costs – often as a result of getting a wheelchair accessible vehicle or paying for taxis (66%) – and paying for specialist equipment such as hoists or assistive technology (51%).

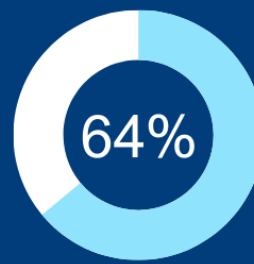
Many disabled people are borrowing money or relying on friends and family to cover their extra costs: While most survey respondents used money they had saved from their income to cover extra costs (61%), three-in-ten (29%) were paying for them using credit, a loan or other borrowings, and 21% relied on friends or family to support them. Others described how they could only afford these extra costs by cutting back on other forms of spending, including food and use of energy.

Targeted support to help with extra costs is patchy: While there are a range of targeted support schemes and social tariffs designed to help disabled people and others in vulnerable situations with extra costs, this help is patchy and relies on people being aware that it exists and able to apply for it. A major challenge for policy-makers is how to create some kind of joined-up approach from all the individual schemes to ensure that no one is left behind. Ensuring that people’s incomes are sufficient to meet their basic needs and extra costs is also paramount.

Most disabled people face unavoidable extra costs because of their impairment



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Utility bills



incurred by
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Transport costs



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Specialist equipment



incurred by
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Many disabled people are borrowing money or relying on friends and family to cover extra costs



3 in 10 (29%) were paying for extra costs using credit, a loan or other borrowings.

2 in 10 (21%) were relying on friends or family to support them to cover extra costs.

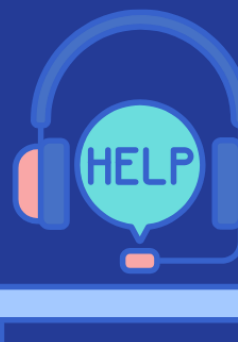


Others could only afford extra costs by cutting back on other spending, like food and energy use.

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We have produced four short briefings on the policy areas highlighted in the research. This briefing is on extra costs of disability. The others look at barriers to employment; the benefits system; and access to essential services. [You can download the full research report and four briefing papers in PDF format from our website.](#)

Most disabled people face extra costs because of their impairment and these costs are often unavoidable

A common theme that many disabled people spoke about in our research was the extra costs that they faced as a result of their impairment. These ranged from increased day-to-day costs – such as the need to follow a special diet, personal hygiene or use more energy to run medical equipment – to large one-off costs – such as making home adaptations or purchasing medical equipment or assistive technologies. Many of these costs were simply unavoidable:

“I’ve got to have hoists. I personally would choose not to have them, but you have to have them for carers to come in, for safety. So these are costs that you don’t even choose to have.”

“On any given day, it’s mandatory that I have power for: an electric bed (all night), an electric toilet (several times a day), an electric bath (once a day), an electric wheelchair (charged daily at nights), an electric hoist (used several times a day and permanently on charge), a lift (used frequently daily)... and that’s not including any ‘normal’ devices that folks use like kettle, internet, TV, heating and oven!”

At other times, people were left with near-impossible choices: should they pay for something more expensive that was more suitable for their needs and would potentially reach them more quickly, or wait for lower-cost or free support that might not be so suitable for them? This participant, for example, may have been able to receive crutches on the NHS but they would have been unsuitable:

“It’s more expensive being disabled. I couldn’t find the crutches I needed on the NHS. They wouldn’t fund it.

So I had to spend a considerable amount of money on my own crutches, which meant that I had to plan for it. It also meant I had to worry about it, and it means I can't relax into my disability. I can't just sit there. It means I'm always worrying that I can't change things."

In our survey of disabled people:

- 75% agreed that they have "particularly high costs" due to their impairment (comprised of 36% who 'strongly agreed' and 39% who 'agreed').
- 64% agreed that there are things they need to buy because of their impairment that they could not afford (comprised of 34% who 'strongly agreed' and 30% who 'agreed').
- 54% agreed that they needed to prioritise spending on their health over other types of spending (comprised of 19% who 'strongly agreed' and 35% who 'agreed').

Once we controlled for age and gender, people with the following impairments were more likely say they had 'particularly high costs' as a result of their condition:

- Physical mobility impairment (odds ratio = 5.15)
- Learning difficulty (2.31)
- Those with multiple health conditions (2.13)
- Impairment affects continence (2.01)
- Dexterity-related impairment (1.97)
- Impairment affects appearance (1.70)
- Hearing-related impairment (1.66)
- Disability acquired suddenly (1.50)
- Memory-related impairment (1.45)
- Fluctuating condition (1.39).

Utility bills, transport costs and specialist equipment are the 'top three' extra costs faced by disabled people

Figure 2 shows the kinds of extra costs that disabled people incurred. The most common was high energy or other utility bills (incurred by 78% of respondents), followed by transport costs – as a result of getting a wheelchair accessible vehicle or paying for taxis (66%) – and paying for specialist equipment (51%).

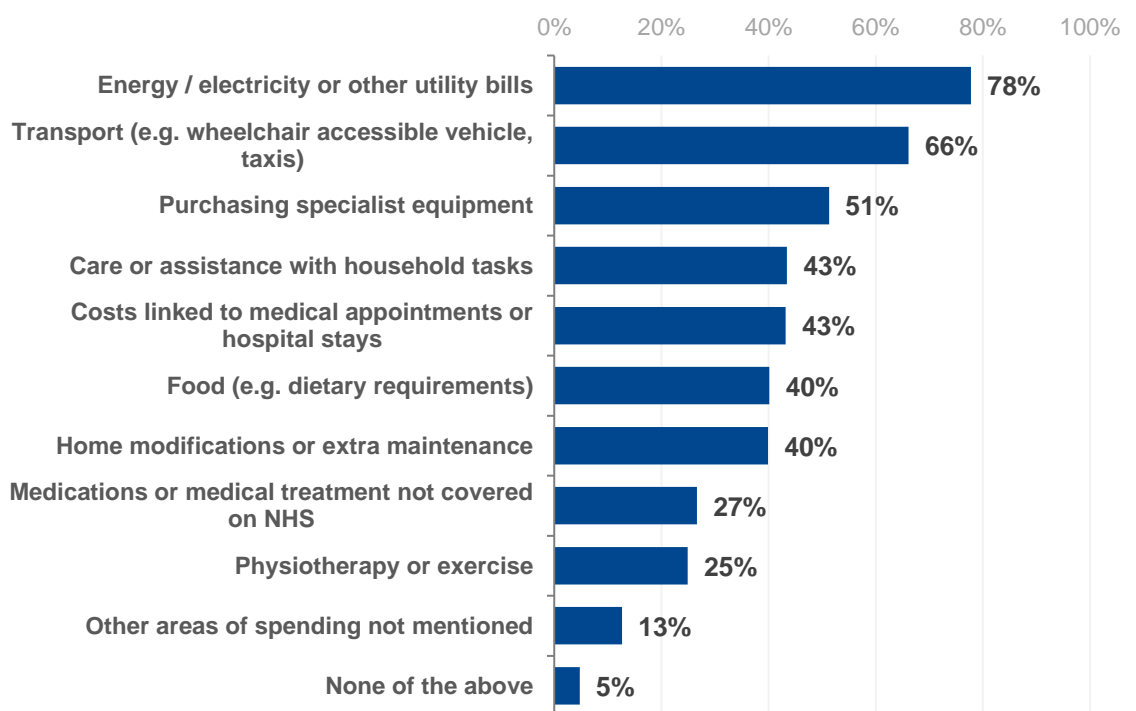
The cost of care or assistance with household tasks (43%), costs associated with medical appointments and hospital stays (43%), extra

food costs (40%) and the cost of home modifications or extra maintenance (40%) were all incurred by around two-in-five disabled people. A quarter mentioned the cost of medications or medical treatment not available on the NHS (27%) and costs associated with necessary physiotherapy or exercise (25%). One-in-eight (13%) mentioned other areas of additional spending.

It was beyond the scope of this research to calculate a monetary figure for the additional costs that disabled people face. However, disability charity [Scope](#) estimates that the ‘disability price tag’ in 2023 is £1,122 per month. This relates to both “money that has actually been spent, but also to purchases and services that disabled households have to go without because their available income has been used up on the basics. In other words, not every disabled household is able to meet the extra cost of disability.”

Other research for [Macmillan](#) in 2012 estimated that four-in-five people living with cancer were £570 per month worse-off on average, while research for the [Cystic Fibrosis Trust](#) in 2023 found that a typical family with CF will lose £560 per month – or £6,800 per year – as a result of additional costs and loss of income. Those with [motor neurone disease](#) (MND) typically incur extra costs of £742 every four weeks, while also facing one-off costs which amount to an average of £2,175 over the duration of the disease.

Figure 2 – Extra costs incurred by disabled people. Participants asked only to include extra costs that they consider meaningful and that had affected them in the last 12 months.



It's more difficult for disabled people to get a good deal

An additional way that disability could increase people's outgoings was by preventing them from getting a good deal or reducing their bargaining power when buying goods or services. This came in many forms, but there were similarities regardless of the nature of someone's impairment, as the following quotes demonstrate:

Finding bargains

“If you have a visual impairment it affects you in just simple ways... like, I can't see all the wonderful offers that they've got in the windows to tempt you in. In a shop, I go around with someone generally, but they don't necessarily show you the more affordable versions first.” (Visually impaired participant)

“Whatever type of impairment you've got, all these things that you've just discussed affect you. For example, for me, I know I'm going back to carers, but, say, for example, I want filtered milk, right? And I know that I can get a certain brand, two for £2.80. And then they'll go, oh, I couldn't find the one you wanted, so I bought you these, £2.25 each. And like you say, it's not just that.” (Mobility impaired participant)

Bargaining power

“I tend to get cabs here and there. I can tell that they've gone the longest way. So they ask you for more. You don't know what's on the clock when you're getting out.” (Visually impaired participant)

“Like, for taxis... [being unable to get a good deal] happens when you're in a wheelchair [too] because... you haven't got the same bargaining power somehow, because you needed that taxi. You had to get from A to B and you required that taxi in the way that you couldn't have taken the bus. So they're going to charge you anyway and they'll put up with an

argument if they have to.” (Mobility impaired participant)

Returning items bought online

“Even buying online, not realising that if you need to return... Because don’t forget, if you’re buying online, I can’t see that... and then having to pay to return it.” (Visually impaired participant)

“To return items, I’ve got to get a carer to parcel them up. I’ve got to take it to the post office. If a carer costs £24 an hour and it takes an hour to do that, then it’s cost £24 to send that thing back even if postage is free.” (Mobility impaired participant)

Issues faced by disabled people when returning items to retailers have been raised by [Which? in research conducted with the Research Institute of Disabled Consumers](#). They found that one in two disabled respondents who had to make a return in the past year had experienced an issue when doing so, with one in five feeling that the retailer had failed to make reasonable adjustments to accommodate their disability. Problems included a lack of access at returns drop-off points, retailers asking customers to get someone else to return it for them, and being charged more for accessible ways of returning items. In the twelve months to March 2023, Citizens Advice also reported providing advice to over 2,000 people related to issues with disability aids, often because of defective goods or poor customer service when trying to return items.¹

Many were cutting back, borrowing money or relying on friends and family to cover their extra costs

When asked how they cover the extra costs that they incur, the majority of our survey respondents were turning to money that they had saved from their income (61%). Three-in-ten (29%) were paying for them using credit, a loan or other borrowings, 21% were relying on friends or family to support them, 11% had received funding from a charitable organisation and 7% had received funding from a government organisation.

¹ Unpublished briefing. Citizens Advice (2023) Disability aids.

Others described how they often only afford these extra costs by cutting back on other forms of spending, including food and use of energy. Some disabled people were in very severe situations as a result:

“My house is 9 degrees because I am frightened to put the heating on. My sister is doing my washing because I am on a water meter and terrified my incontinence including night wetting will run my bills up too much. I don't let my family know but I also don't always eat. I have gone up to 7 days without eating.”

The costs of travelling to and from medical appointments can also add up. In [previous research](#), we found that adults with cystic fibrosis typically incur a cost of £22 per month – or £264 per year – in medical trip-related expenses. Similarly, the charity [Young Lives Vs Cancer](#) found that young cancer patients and their families were having to travel 350 miles per month to get to and from their treatment – with 71% of these families struggling to afford their travel costs.

This led us to ask survey respondents about any support that they receive with the cost of travelling to and from medical appointments. We found that:

- 73% of respondents received free parking at appointments because they have a Blue Badge.
- 15% had used public transport for free to get to appointments.
- 5% had received a refund of the cost of their travel, such as via the [Healthcare Travel Costs Scheme](#).
- 5% had used a form of voluntary community transport to receive free or discounted travel to appointments.
- 18% had not accessed any of the above support, with a further 2% who reported not needing any forms of support because they don't typically drive or use public transport to get to appointments.

The Healthcare Travel Costs Scheme is designed to help lower-income households with the costs of travelling to and from non-routine healthcare appointments (including the cost of parking). There are questions about the effectiveness of the scheme though; for example, regarding awareness of the scheme among patients and healthcare professionals and the bureaucracy involved in accessing refunds. Just 9% of *low-income* respondents to our survey had accessed the scheme, despite many more potentially being eligible.

In some cases, participants still needed to pay for parking at appointments, despite having a Blue Badge, because the car park that

they rely on is privately owned. Others described difficulties finding accessible parking spaces, sometimes as a result of other people using the spaces without having a Blue Badge.

What needs to happen to help disabled people with the extra costs they face because of their impairment?

Simply put, the extra costs linked to disability can be tackled in two ways: (1) by ensuring that disabled people have sufficient incomes to cover such costs and (2) by providing targeted support to reduce the cost of specific goods or services that a disabled person may need.

We discuss the issue of insufficient incomes in our briefing papers on barriers to employment and the benefits system. The Personal Independence Payment (PIP), for example, is designed to cover the extra costs of living with a disability, but – as we learned from participants – the process of applying can be very difficult and stressful, while benefit levels are often seen as insufficient to cover the full range of costs that disabled people may incur. Many disabled people also feel a sense of stigma about applying for benefits, which may lead to them not receiving the financial support they are entitled to. Indeed, as many as 71% of disabled benefit claimants in our survey described how they had been made to feel guilty about applying for such benefits.

Beyond the benefit system, there are several ways in which disabled people can access discounted or free goods or services. In the case of costs that are incurred by a small number of people or on an infrequent basis, such discounts, free provision or reimbursement can be a more effective way to support people than income-side measures – for example, the reimbursement of home dialysis costs described below.

Targeted support to reduce costs may also include social tariffs for utilities such as water, energy and telecoms, also described below. A drawback of these tariffs is that people may not be aware of such support or find that it is patchy – either with complex eligibility requirements or a ‘postcode lottery’, where people in some areas may receive more support than those in others.

What’s already happening: Reimbursement of home dialysis costs

Following a [campaign from Kidney Care UK](#), the NHS in England and Wales (and NHS Grampian in Scotland) have taken action to ensure that patients who need home dialysis are reimbursed for the extra costs they face as a result of this treatment. [Depending on the type of dialysis](#)

[required](#), patients may be able to receive reimbursement for extra electricity or water costs. Patients receive support regardless of whether they are in receipt of means-tested benefits or not.

The patient still needs to be able to pay for the costs up-front first, however, and there are variations in what is and isn't covered across different geographical areas. [Evidence suggests that some NHS Trusts](#) are struggling to establish effective payment processes and calculating reimbursements, and have suggested that a national system may be preferable to ensure consistency.

The [Retail Energy Code Company \(RECCo\)](#) suggests that such reimbursement schemes are likely to continue to be an important way of providing assistance to consumers with high energy needs as a result of home medical treatment. They suggest that a new service should be established to administer a scheme covering a wider range of medical devices and reimbursing people proactively, rather than retrospectively based on meter readings.

The potential of social tariffs to help disabled people?

The issues of up-front payment and geographical variation have been raised in relation to the provision of (or potential provision of) social tariffs within the water, energy and telecoms sectors.

Currently, in the water industry, each company provides its own version of a social tariff, resulting in low-income customers facing very different charges depending on where they live. According to the [Consumer Council for Water](#), in some places those on low incomes will pay just 20% of their bill, while in other areas they face the full charge. And [three-in-four \(76%\) are not aware](#) if their water company provides help of this kind or not. This has led to the water industry aiming to establish a single social tariff – or 'water affordability scheme' – aligned across all English and Welsh water companies.

The water industry also currently runs the [WaterSure scheme](#), which caps the water bill for households in receipt of certain benefits who have high essential use of water because of a medical condition. Again though, support is patchy as some water companies offer the scheme to those in receipt of the Personal Independent Payment (PIP) or Disability Living Allowance (DLA), while others do not.

Social tariffs have been introduced within the telecoms industry to broadband and mobile phone customers. However, there are concerns that firms are ['burying cheaper deals'](#) on their websites and that awareness of discount schemes for vulnerable groups is low. Currently,

just 5.1% of eligible households are on such deals, leading both the Chancellor and Shadow Cabinet to call on firms to do more to promote the tariffs.

There have also been calls from leading charities, including disability charity Scope, for the [introduction of social tariffs in the energy sector](#). This would primarily help to reduce the energy bills of those in receipt of benefits (including disability benefits). In addition, campaigners want to see the Government use data-matching between income data held by HMRC and energy company data to ensure that customers are automatically identified for support, with struggling customers *not* in receipt of benefits also being targeted for help. There is debate about certain elements of this proposal, with [Policy in Practice](#), for example, arguing instead that “the best way to support low income households is through the welfare system” because incomes are insufficient to meet basic needs. In the absence of improved social security, however, a social tariff may be the next best option. Social tariffs are also more responsive to changes in price, given it takes a number of months for inflation data to be compiled and for benefits to then be updated in line with this.

Given the risk of patchy coverage or low awareness of support schemes, a major challenge for policy-makers is how to create some kind of joined-up approach from all the individual schemes to ensure that no one is left behind. Projects such as The Children’s Society’s [Coordinated Community Support](#) programme, which ran from 2020 to 2022 to provide emergency support to people facing financial crisis, offer potential models to consider, as they aim to improve the way that local partners (including local authorities and the voluntary and community sector) can work together to ensure that individuals in vulnerable situations access all of the support available to them. Advanced data-sharing arrangements may also be helpful in identifying people eligible for support. In addition, a variety of organisations – such as Pocket Power, described below – offer consumers help with accessing discounts. These may have particular relevance to disabled people.

What's already happening: Help to access discounts

A range of organisations offer consumers help with accessing discounts or reduced rates on their household bills. Pocket Power is an example of an organisation that does this, focusing particularly on people who may be digitally excluded and who find it harder to access the best deals. It helps people to access discounted water rates, the Warm Home Discount and broadband social tariffs, as well as helping with things like switching energy provider. In 2021, [half of the households](#) that it supported had someone disabled or living with a long-term illness.



About this research

This research was a collaboration between the University of Bristol's [Personal Finance Research Centre](#) (PFRC) and the [Research Institute for Disabled Consumers](#) (RiDC). It was funded by [abrdn Financial Fairness Trust](#).

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