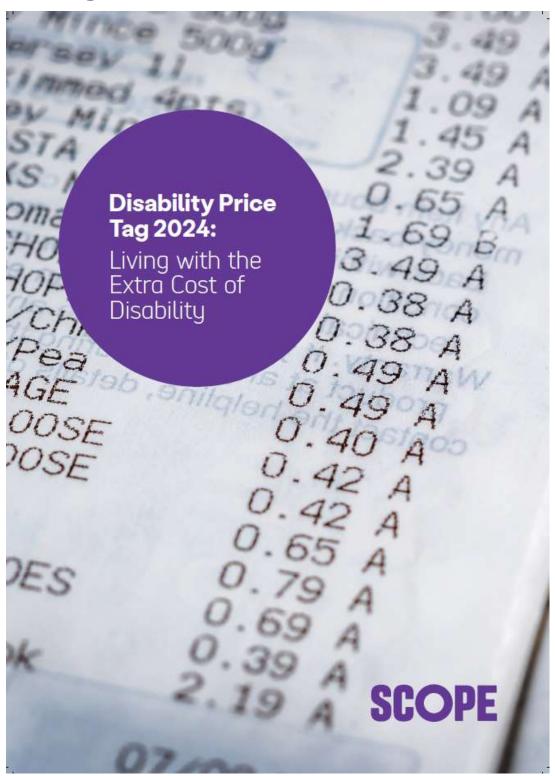
Disability Price Tag 2024:

Living with the extra cost of disability





Disability Price Tag 2024

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Foreword

James Taylor, Executive Director of Strategy, Impact and Social Change at Scope

At Scope, we know that life costs more if you are disabled. We know that these costs are down to many things. The high price of specialist products, as well as the need to use more of essentials like energy. These things add up.

Our latest Disability Price Tag calculation estimates that extra costs equate to a staggering £1,010 per month on average. For a disabled household to have the same standard of living as an equivalent non-disabled household.

These extra costs place an unequal burden on the disabled people and families who must meet them. These costs are a result of our society not doing enough. And failing to address the financial disadvantage of living as a disabled person in the UK.

Over the past few years, we have seen growing inflation and rising prices impact all of us. Impact our bills, impact our ability to enjoy our lives, and impact our ability to save for the future. For disabled households, the impact has been far more pronounced.

Making life harder than it already is.

Yet so often. In discussion about financial inequality and living standards. We hear about numbers and percentages. Winners and losers.

What we don't see, or hear from, are the people behind those numbers.

We worked with 31 disabled households to understand their lives and financial situations. We asked them about the decisions they have had to make to 'get by'. How far or not their income or their financial support goes. And the impact that these financial choices have on their lives.

This report tells their stories and tells their truths. These stories are the reality for many disabled people and families in the UK today.

At Scope we are unwavering in our determination to change this. To end the price tag associated with disability once and for all.

This report is a crucial step in making this goal a reality.



Executive summary

In 2024, disabled people and their families face a daily battle for financial and emotional survival.

Disabled households face a wide range of extra costs. These are inescapable costs associated with managing conditions and supporting accessibility.¹

Disabled households also spend more on household 'essentials' than non-disabled people.²

Our latest Disability Price Tag calculations show that extra costs for disabled households continued to increase in the 2022 to 2023 financial year.

We define extra costs as the additional money a disabled household needs to have the same standard of living as a non-disabled household.

Our analysis shows:

- On average, disabled households (with at least one disabled adult or child) need an additional £1,010 a month to have the same standard of living as non-disabled households.
- If this figure is adjusted for inflation over the current period of the 2023 to 2024 financial year, these extra costs rise to £1,067 per month.³
- On average, the extra cost of disability is equivalent to 67% of household income after housing costs.

These figures account for disability benefit payments. Such as the Personal Independence Payments (PIP), designed to help address these extra costs.

³ Consumer Price Index (CPI) inflation rate between the 2022 to 2023 and the 2023 to 2024 financial years was 5.7%. This was used to express the Disability Price Tag figure at prices of the current 2023 to 2024 financial year.



¹ Scope (2023) The Disability Price Tag 2023: Summary report.

² Scope (2024) <u>Life Costs More: The extra burden of essentials for disabled people.</u>

The pressure on disabled households to meet these extra costs makes it harder to have an acceptable standard of living. And it is very difficult for them to build savings, manage financial shocks and plan for the future.

Rising living costs have negatively impacted most people in recent years. We wanted to know more about how disabled households are managing existing extra costs within a cost of living crisis. As well as the physical and emotional impact this had on disabled people and their families.

Scope asked disabled UK households about their lived experience of managing the extra cost of disability. We found that disabled households experience significant extra costs.

Disability-specific benefit payments rarely cover these in full. This contributes to poor financial security for disabled households. Other challenging factors contributed to this difficult situation:

- Rising living costs
- Existing barriers to employment
- A drain on savings and the presence of existing and new debt

Disabled households had cut costs wherever possible. But reducing spending was particularly difficult for them. Some disabled people need to spend more on essentials, like energy, water, specific food, or transport.

- These essentials are needed to effectively manage their conditions or to provide support for accessibility.
- Costs that might be categorised as 'optional' spending are often essential for disabled people.

Disabled people are forced into making very difficult decisions about their household spending. This includes sometimes going without things that they need. With significant negative consequences for mental health. And the emotional wellbeing of them and their families, including:

- Stress, anxiety and uncertainty
- Shame and social isolation
- Hopelessness, and even suicidal ideation



There are also negative consequences for physical wellbeing. Disabled people often miss out on or avoid medical treatment or support due to concerns over costs.

The constant financial struggle with extra costs is ongoing for disabled households. This has a detrimental impact on the health and wellbeing of disabled people and their families. At the very worst, this can be lifethreatening.

Policy recommendations

Immediate policy changes are required to tackle the extra costs disabled people face. Our findings show that improving the benefits system and addressing essential utility costs are important factors for disabled households.

We recommend 6 solutions:

- Fix the broken benefits system so that it is fairer, more transparent, and better supports disabled people with their extra costs.
- Work Capability Assessment (WCA) must be replaced with an improved alternative. This must be based on input from disabled people and include fairer assessment criteria.
- Work alongside disabled people to design a new positive vision for Personal Independence Payment (PIP). At minimum, the benefit must be enhanced so it covers the essentials and assessments must be fairer.
- Make sure essential utilities are always affordable for disabled people.
 This must include introducing a discounted energy bills scheme. Disability benefits must also be included in the eligibility criteria for the Warm Home Discount.
- Introduce a government-funded 'help to repay' scheme. This will help disabled people to clear their debt on essential utilities.
- Government must make sure energy efficiency spending is better targeted towards disabled households.



Content warning

This report contains disabled households' experiences of financial, physical, and emotional distress.

If you are affected by any of the content in this report, and want to speak to someone about it, please contact Scope's helpline on:

- helpline@scope.org.uk
- 0808 800 3333.

If you need to contact someone urgently:

- Call Samaritans on 116 123
- Call Mind on 0300 123 3393
- Text Shout on 85258



To view this report on a mobile, first download Microsoft Word from the Apple Store or Google Store. Then, when you open the report in Word, view in print layout mode.



Disability Price Tag 2024: living with the extra cost of disability

A wealth of data tells us that for disabled people, life costs more.4

Disabled people and the people they live with face a range of 'inescapable' extra costs. Costs which are needed for daily living. And costs which non-disabled households do not experience in the same way. Such extra costs include:

Specialist disability-related products and services

Certain items or services are necessary to meet disabled people's day-to-day needs. These are often expensive. For example, disabled people may need hearing or other sensory equipment. Or home adaptations. They may need manual or electric mobility aids. Or medicines or treatments.

Needing to spend more on everyday things

Some services for disabled people come with a price premium. This includes forms of insurance, particularly life and travel insurance. Disabled people and their families also pay more for accessible rooms and holidays.

Greater spending on 'essentials'

Disabled households must allocate a higher proportion of their income to essential goods and services. This is because they often require more electricity or hot water, or more expensive transport options (like taxis). Both to manage their condition effectively, or for reasons linked to accessibility.

⁵ According to the <u>Social Metrics Commission (2022)</u>, 'inescapable' costs are those that families cannot avoid paying. And which make them more likely than others to experience poverty. These include the extra costs of disability, costs of childcare and rental and mortgage costs.



⁴ Scope (2024) <u>Life Costs More: The extra burden of essentials for disabled people;</u> <u>Scope (2023) Disability Price Tag 2023: Summary report.</u> See also: WPI Economics (2024) <u>Disabled people's extra burden of essentials</u> and the Extra Costs Commission (2015) <u>Final report on driving down extra costs</u>.

Disability Price Tag

In 2024, disabled people continue to face unfair extra disability-related costs. And there are more disabled people than ever in the UK (16.1 million), representing almost quarter of the population (24%). Millions of disabled households are impacted by the soaring prices of essential goods and services.

Almost a third of disabled households are in poverty (31%).⁶ And many people claiming benefit support payments are financially insecure. More than 4 in 10 (42%) of Personal Independent Payment (PIP) claimants are in the poorest 20% of income distribution.⁷

Our latest Disability Price Tag calculations show that extra costs for disabled households continued to increase in the 2022 to 2023 financial year.

We define extra costs as the additional amount of money a disabled household would need to have the same standard of living of a non-disabled household.

Our latest Disability Price Tag analysis finds:

On average, disabled households (with at least 1 disabled adult or child) need an additional £1,010 a month to have the same standard of living as non-disabled households.

⁷ Resolution Foundation (2024) <u>Under Strain: Investigating trends in working-age disability and incapacity benefits</u>



⁶ Joseph Rowntree Foundation (2024) <u>JRF Poverty Report 2024</u>

If this figure is adjusted for inflation over the current period of the 2023 to 2024 financial year, these extra costs rise to £1,067 per month.⁸

On average, the extra cost of disability is equivalent to 67% of household income after housing costs.

These figures account for disability benefit payments. Such as the Personal Independence Payment (PIP), designed to help address these extra costs.

The pressure on disabled households to meet these extra costs makes it harder to have an acceptable standard of living. It is very difficult for disabled people and their families to build savings, manage financial shocks and plan for the future. Disabled households are also more likely than non-disabled households to be in 'deep' poverty. And have lower rates of employment, in part a consequence of social barriers to the job market and workplace.

Disability-specific benefit payments are available. Yet these do not cover all of the extra costs that disabled households face. And not all disabled people, including some of the most materially-deprived, are in receipt of them.⁹

⁹ Scope analysis estimates that a high proportion of disabled people may be entitled to disability benefits were not in receipt of them. We analysed the data of working age adults living in England and Wales for at least 2 years, who are not receiving benefits within the Family Resources Survey. We found that 23.5% of people who are disabled under the 2010 Equality Act claim PIP or DLA benefit payments. Furthermore, only 43.3% of people who are disabled, and report that this condition "impacts them a lot" claim PIP or DLA.



⁸ Consumer Price Index (CPI) inflation rate between the 2022 to 2023 and the 2023 to 2024 financial years was 5.7%. This was used to express the Disability Price Tag figure at prices of the current 2023 to 2024 financial year.

These statistics tell us a lot about the scale of the extra costs disabled households face. And they tell us about the bleak financial situation of disabled people and their families in the UK.

Yet they tell us little of the daily lived experience of extra costs for disabled households. Nor do they tell us about the physical and emotional impact of extra costs.

Disabled households shared their stories. Of the constant financial struggle of managing extra costs. And for those individuals and their families living with the extra cost of disability, the impact of these extra costs is significant.



About this research

Disability Price Tag 2024 (economic analysis)

To calculate the extra cost of disability, we follow a Standard of Living approach. This is consistent with academic work and our previous research.¹⁰

The extra cost of disability is measured by comparing the difference in the standard of living between disabled and non-disabled households. The standard of living of each household was calculated on whether important goods or services could be afforded. As well as on the ability of each household to conduct essential household tasks and manage finances.

To estimate the latest Disability Price Tag figure, important additions were made to the analysis:

- The model now accounts for ethnicity and employment situation of the head of household. And the employment situation of their partner (if applicable).
- The equivalised household income was calculated using the Department for Work and Pensions equivalence scales. This means we can account for the size and composition of different households.
- Organisation and cleaning of the dataset. Such as eliminating extreme values (top 1% percentile) in household income.

Taking into account these modifications, we are confident we have a better reflection of the extra cost of disability.

Living with the extra cost of disability (lived experience)

Scope sought to understand and share the reality of extra costs for disabled people and their families with their households. To explore the effect of managing household finances alongside extra costs. And to fully document the impact living with the extra cost of disability.

¹⁰ Scope (2023) The Disability Price Tag 2023: Summary report



To understand more about the daily and lifetime costs of being disabled we asked:

- What unique costs do disabled households experience?
- What are the extra costs of household essentials, such as food and utilities?
- What other 'essentials' are disabled households paying for?
- How has the cost of living crisis affected disabled households? 11,12
- What difficult decisions do higher costs force on them?
- What items or services are disabled people and their families going without?
- What is the physical and emotional impact of these experiences?

We spoke with 31 people from disabled households in the summer of 2023. These individuals came from households across the UK via the Scope lived experience Research Panel. We invited them to tell us about their experiences of extra costs, and to keep a weekly spending diary.

A co-production approach was adopted during the research, analysis, and report writing stages.¹³

Please see Appendix 1 (at the end of this report) for a full description of the research methods and participants.

¹³ Co-production is based on the principle of 'nothing about us without us'. For Scope, co-producing research with disabled people is essential. This makes sure that disabled people's experiences and priorities are at the heart of all of our work. To understand more, read Stephanie Coulshed's 2021 blog, 'Some reflections on co-production'.



¹¹ According to Crisis, the national charity for ending homelessness, the UK has been experiencing a cost-of-living crisis since late 2021. Where 'the cost of everyday essentials like food and bills increased more quickly than average household income' (Crisis, 'The cost of living crisis').

¹² The cost-of-living crisis has had a bigger financial impact on disabled people than non-disabled people (WPI Economics, 2024, <u>Disabled people's extra burden of essentials</u>). <u>But we know less about the emotional impact of the crisis.</u>

Living with the extra cost of disability

These findings look at 5 important areas of the extra cost of disability:

- 1. Why disabled households spend more on basic essentials
- Spending beyond the basics: Additional 'essentials' in disabled households
- 3. Affording and managing extra costs
- 4. Living with financial insecurity
- 5. Impact on physical and mental health, emotional wellbeing, and quality of life

Why disabled households spend more on basic essentials

Disabled households are spending more of their overall income on 'essentials'. This is when compared to non-disabled households. 14 'Essentials' are products or services needed for good health or to have a decent quality of life. Items we must all buy regardless the price and income pressures. They are basic staples for living, such as food, utility payments and transport costs:

- Food basics and non-alcoholic beverages. Food basics such as milk, bread, cheese, rice, eggs, vegetables, fruit and meat or fish.
- Utilities and other household costs. Energy and water, rent or mortgage interest payments, furnishings, appliances, and household maintenance.
- **Transport.** Public transport, private vehicle fuel and maintenance or repair, taxis.
- **Health.** Appliances and equipment, dental services, opticians, private care, medicines, and medical goods.
- Other. Personal care and hygiene products, insurance, pet costs.

¹⁴ As a proportion of their total household income (Scope, 2024, <u>Life Costs More: The</u> extra burden of essentials for disabled people).



In the current research, we look in more detail at why disabled households are spending more on these everyday basics.

Food basics and non-alcoholic beverages

This represents the biggest cost area for disabled households. They spend more of their household income on food and drink than non-disabled households.¹⁵

On average, disabled households we spoke with are spending more than £50 per week on food, just to support their condition. This includes dietary food items, as well as particular types of food, or food brands. In some cases, these costs are so high that disabled people are spending more than £100 a week. Some rely on food banks to survive.

Certain foods are sometimes needed to manage conditions. This means disabled households struggle to use money-saving tips recommending simply 'buy less'. 16 Disabled households often have no choice but to pay these costs:



I can't just choose cheaper food or cheaper brands. I have to eat what I've got to eat, because of my [conditions] - I can't just eat whatever I want. If that goes up in price, there's nothing I can do about it."

Nathaniel

¹⁶ For example, the British Nutrition Foundation's <u>advice for 'eating healthily on a budget'</u>.



¹⁵ Scope (2024) Life Costs More: The extra burden of essentials for disabled people.

Utilities (electricity, gas, other fuels and water)

Disabled households also spend more of their overall income on utilities, such as fuel and water. ¹⁷ Again, higher usage of these essentials is necessary to manage conditions.

As with food costs, disabled people often cannot 'use less' gas, water and electricity. Doing so presents significant risks to their physical and mental health. These include:

- significantly increased pain
- an inability to maintain essential hygiene
- loss of social connectivity and reduced quality of life



In winter, I have to have the heating on all the time. I can't just have it on at set times. The temperature needs to be at a constant temperature for me, otherwise my pain increases and I'm cold. Then I'm in agony."

Heidi



Without my communication aid, I am locked off from world - I just lie in bed."

Krishnan



Because of [my son's conditions], or him being incontinent, the water bill is a lot higher. There is a lot more washing. Every time he soils himself, you know, I have to wash him constantly."

Ayesha

¹⁷ This is compared to non-disabled households (Scope, 2024, <u>Life Costs More: The extra burden of essentials for disabled people</u>).



Transport and travel

Basic travel costs more for disabled people. In part, this is a result of the mode of transport. Public transport is often inaccessible, unreliable, and sometimes unsafe. This fact pushes disabled people and their families into relying on taxis or cars. Which can be more accessible, but also more expensive:



I'm still reliant quite heavily on taxis, because I find the bus routes and the buses are just really quite inaccessible. And a lot of drivers ... pull away before you even get a chance to sit down. That causes me a lot of anxiety, which then pushes me towards using taxis."

Jack



[My son's autism] means he doesn't do public transport. ... So I have to spend more on car travel when I'm with him."

Ayesha

In addition to the mode of transport, there are other accessibility considerations which increase the cost of travel for disabled households. Particularly for travel away from home, including holidays. For example, needing to pay for overnight stops, to rest or decompress. Or needing to hire a personal assistant for the duration of a trip.

Accessible transport and accommodation increase the cost of holidays in other ways. This includes requiring suitable locations close to transport and facilities. Or a larger space to accommodate equipment. Companies charge more for these facilities. And holidays marketed as 'accessible' often cost more.



These costs lead to some disabled households paying more. Or putting themselves in potentially harmful situations:



For our anniversary, we saved up - for years - to go to [a UK holiday resort]. ... [But] they charge more for accessible lodges. Like, a lot more. So, we had to make do with a regular lodge, that we had to struggle to get my wheelchair in and out the door archway every single time we wanted to go anywhere."

Vanessa

But most disabled households are simply priced out of such opportunities:



Have you ever tried to have a break with a disability? It costs double the amount. ... I've looked at the [accessible holidays], that are actually specifically for disabled people, and ... it's too expensive. I want to, you know, but I can't - it doesn't happen."

Patrice



One thing I backed out of a while ago was going on ... a little weekend trip for myself. I realised that - going to an area I hadn't been to before - I would need the help. ... The cost of having [a personal assistant] for the whole weekend would've been crazy amounts of money. ... about £600 for 48 hours."

Jack



Health (specialist equipment, medicine and treatments)

Disabled households spend disproportionately more on health essentials than non-disabled people.¹⁸ This includes mobility equipment, which is one of the areas of greatest cost. For example, Mick's wheelchair cost **more than £8,000.**

These are rarely one-off costs. Most items will need replacing at some point. Others need regular maintenance:



[The biggest costs are] equipment and upkeep of my mobility scooter. You know, it's the daily charging thing, but it's also that putting two new batteries in the scooter is nearly £400. And those batteries do need replacing, very regularly."

Suzanne

Other disability-related items also cost a lot. For example, Terry has spent thousands of pounds on hearing aids. Rose recently paid almost £500 for noise-cancelling headphones and earplugs. Disabled people feel that a lack of market competition is an issue. And leaves them vulnerable to overpricing:



With disability products, the prices are horrific. ... You're being ripped off. But you have to be ripped off, because there's hardly any competition, you know? So, you haven't got a lot of choice in [paying for] it."

Vanessa

¹⁸ Scope (2024) <u>Life Costs More: The extra burden of essentials for disabled people</u>.



Disabled households also pay significant amounts for personal care products. For example, Adriana pays almost £2,000 per year on incontinence products, bed pads, and body cleaning wipes. This is because she had found free NHS products were "not fit for purpose" for her or her son.

Health essentials are also ongoing extra costs for disabled people. This includes prescriptions and over-the-counter products. Rather than occasional spending to manage one-off illnesses. There are also extra costs for essential treatments and therapies to manage conditions. This includes oral supplements, injections, deep tissue massages, counselling, and experimental treatments.

Some disabled people feel that their needs are not met through the NHS. For these people, private healthcare becomes an essential cost. Either because people do not trust the NHS to treat them effectively, or because they cannot wait for treatment any longer:



The NHS waiting list would've been about 12 months to have [the operation I needed]. I spent every evening rolling around in pain. ... It was a case of, honestly, it was either pay for surgery or go to a bridge [to kill myself]."

Jack



Care contributions and personal assistance

Home and residential care are some of the greatest costs facing disabled households. Charges which Charlie described as a "tax for disabled people". These are essential extra costs that non-disabled people do not need to pay for.

Care charges are frequently a difficult financial obligation to meet. Particularly in the face of rising living costs:



Social care costs [are my biggest extra costs]. ... Non-disabled people don't have to pay this. ... Their bills are going up too, but they don't have to pay social care."

Kaden



One of my biggest costs ... is the rising care contributions. It's so high. I'm forking out £268 a month of money towards my care. ... It's not a manageable situation."

Robin

Many disabled households also rely on additional support for basic household tasks. For example, they may need to pay a personal assistant for support with cooking, cleaning, DIY and gardening. These are tasks that a non-disabled person could complete unaided. Disability benefits often do not cover the full extent of the cost of these support needs:



I have to pay people to do things that I can't do. [Things] that a non-disabled person wouldn't have to pay, like, you know? ... Now, I have to pay to get my garden tidied up and ... do basic DIY. Stuff that, before I was disabled, I would do myself."

Charlie



These costs did not include informal and unpaid personal care and assistance (which are discussed in detail later in this report).

Accessible accommodation

Disabled people often spend a significant amount of money to make sure that they live in an accessible home.

One reason for this is that basic accessibility requirements may include:

- Being close to public transport and local shops
- Having parking
- Having enough room to store large equipment.

Of course, these features also make a property more desirable, and therefore increase the cost of rent or sale. Having so many essential accessibility criteria for housing also limits disabled people's options. Usually this restricts them to a smaller number of more expensive properties:



I need extra space [for equipment storage] ... that tends to add onto extra costs. ... [So does] a downstairs toilet, [which I need] because I can't be up and down the stairs constantly. The house needs to be big enough that it can accommodate a wheelchair moving around. ... All that does make our rent higher. ... We probably could be in a small house or flat without those needs, you know? And that would then have a reduced price."

Alix



Disabled people also describe paying significant amounts for assistance in moving home. Since they are unable to reduce costs by packing and transporting their belongings themselves:



When I'd been moving house, I had to pay extra because I couldn't do anything myself, because of my disabilities."

Nathaniel

Spending beyond basics: additional 'essentials' in disabled households

We know that disabled households spend more on basic daily essentials than non-disabled households.¹⁹ We also know why these essentials cost disabled households more.

Yet these are not the only essential extra costs that disabled households face. In the current research, disabled households also describe spending significant amounts of money on:

- ready meals and takeaways
- clothing
- streaming services
- vehicle ownership

Disabled people and their families worried that this spending would be judged negatively. And misidentified as 'luxury' or non-essential spending.

¹⁹ Scope (2024) <u>Life Costs More: The extra burden of essentials for disabled people;</u> WPI Economics (2024) <u>Disabled people's extra burden of essentials.</u>



In this section, we explore the following 4 categories of 'optional' household cost.²⁰ And how these are essential in meeting disabled people's basic living needs:

- pre-prepared food and grocery delivery
- specific types of clothing
- online services and other technology
- purchasing a vehicle.²¹

Pre-prepared food and grocery delivery

High-price food items are not optional for some disabled households. This includes pre-prepared ready meals and takeaways. As some disabled people found it too tiring or painful to prepare meals. Quick and convenient food is therefore a significant and extra cost that is directly related to being disabled:



[We need] food we can just quickly grab and eat without having to stand preparing stuff, because we can't [physically] stand to prepare stuff. ... We need the easy stuff. But it's more expensive. ... And people go, 'Well, you can just do it yourself.' Well, we can't, you know? It's not that simple".

Heidi

²¹ This is not an exhaustive list. Instead, we have selected 4 spending categories which were discussed most commonly in our interviews with disabled households.



²⁰ These 'optional' household costs are defined by the 2020 Australian <u>'Consumer Price Index'</u>. (This formed the basis for Scope's recent extra costs analysis, Life Costs More: The extra burden of essentials for disabled people).



Cooking is a problem, so then I'm paying extra because I buy microwave foods. ... When I'm too sore, when I'm really in a lot of pain, I get takeaways. That's a lot of money ... but if I'm too sore, then I have to do that [to eat]."

Patrice

Disabled households also describe grocery delivery services as an essential cost. This increases the amount spent on the weekly food shop. While non-disabled people can and do pay for such services, disabled people have less choice:



What many people call 'convenience' is actually vital for me to be able to manage. Groceries and food shopping I get deliveries as well because going to the shops is [not possible]. ... I know many [non-disabled] people do it, but I've got no choice. ... It becomes a necessity rather than a disposable cost."

Nathaniel



Specific types of clothing

Some disabled people require specific types of clothing and shoes. This includes specialist and higher quality items. These are more expensive than standard and lower quality goods.



Everybody in our house needs sensory-friendly clothing. ... And what that effectively comes down to is you need high-quality clothing. So, there are extra costs there."

Jo

Extra costs also occur through wearing out these items. Certain conditions may speed up this process. For example, because falls cause wear and tear. Or because clothing needs to be washed more often.



I have a skin condition, so pretty much most things need to be washed once a day. ... It really aggravates my skin condition if things aren't washed regularly. I spend a lot on clothes. ... [because] I wear through them so quickly, [because] they get washed more often than usual."

Kaden



Online services and other technology

For disabled households, streaming services and audiobooks are essential. They are important for social connectivity and mental wellbeing. Disabled people feel that non-disabled people may not rely on internet access in the same way. ²² This is therefore an essential extra cost:



I think a lot of disabled people get judged a lot for having streaming services, because it's viewed as an unnecessary luxury. But when you are stuck in bed, ... you need it."

Hanna



Because you're trapped in the house quite a lot, so you need [online] entertainment. ... It becomes your social life."

Heidi



I know the internet is very much a requirement of modern life, but it is also a lifeline to us."

Jo

²² Subscription fees to internet and entertainment services are defined as 'optional' household costs (as defined by the <u>'Consumer Price Index' in Life Costs More: The extra burden of essentials for disabled people).</u>



Some disabled households described other ways in which technology makes life more accessible.²³ For example, Liane bought a camera doorbell with 2-way communication. This was because she could not always reach the front door before callers left. And this would often mean missing essential deliveries. Technology such as expensive doorbells then become essential costs for disabled people.

Purchasing a vehicle

Finally, vehicle ownership is also considered an 'optional' cost.²⁴ But disabled households who own a car feel it is essential. Often because public transport is inaccessible, and taxis are expensive. Car ownership was also a vital tool of independence for disabled people.

Owning a car is more expensive for disabled people. Accessible features increase prices. Including significant boot space, for storing disability-specific equipment. Jo explained, a "combination of factors" means owning a car "costs more than it would cost somebody [non-disabled]".

²³ Although an extra cost, technology can make life more accessible for disabled people. However, <u>research by Lloyds TSB bank</u> has found that disabled people are at significant risk of digital exclusion. And are over 50% more likely to face barriers to accessing digital and online services than non-disabled people.

²⁴ According to the classification system of household spending used in our recent report, <u>Life Costs More: The extra burden of essentials for disabled people.</u>



Affording and managing extra costs

Disabled households try to mitigate extra costs in 3 main ways. First, through accessing benefits, grants and awards to fund disability-specific costs. Second, by relying on friends and family to support personal care and assistance. And third, by simply going without the things that they need.

Disability-specific benefits and other income

30 of the 31 disabled households received at least one of the following disability benefits:

- Personal Independence Payment (England and Wales only)
- Adult Disability Payment (Scotland only)
- Employment and Support Allowance
- Disability Living Allowance
- Carer's Allowance
- Attendance Allowance

See Appendix 2 for details of these and other benefits that the households received.

Disabled households struggle to cover essential costs with benefit payments alone: ²⁵



[Benefits] just don't [cover my essential costs]. It's a joke. Because benefits haven't gone up with inflation. ... So people on benefits and disability payments are scrimping and saving ... just to survive."

Heidi

²⁵ Scope (2024) Life Costs More: The extra burden of essentials for disabled people.



Disabled households often have to use their disability-specific benefits to pay for their basic costs. So this money is being spent on rent and utility bills, for example. Instead of direct disability-related costs, such as equipment:



My [PIP] [is] going into having to pay for the gas and the electricity bill. ... And you're always having to take [disability-related costs] from other money. Which that in itself is wrong. ... That shouldn't be happening."

Emma

Using disability benefits for household bills leaves people struggling to pay for other extra costs. Particularly in relation to equipment and travel. These are the type of extra costs PIP was designed to cover.

Disabled people and their families describe life on benefits as "survival". Even where benefit payments have increased, it does not meet the rising costs for disabled households. As Ayesha explained:



This year, the increase through our child benefit, Universal Credit, Carer's Allowance and PIP is £187 [a month]. But my monthly rent has gone up £200. So that £187 goes into the rent. ... It's not really leaving us with much."

Ayesha



Most people told us they had cut everything they possibly could from their spending. And yet were still regularly close to being in debt.



[PIP] is not cutting it for me. ... There's a very big shortfall. There are so many things that you give up. And you think, 'I can't give up any more.' And still ... at the end of the month, you're like, 'I've only got a pound left'."

Emma

There is little or no contingency available for large or unexpected costs. As Bo explained, "there's no room at all for emergencies".



Disabled households with some employment income said they "just about" meet essential costs. Yet the majority of disability related extra costs were paid by their wages, rather than disability benefits. Some fear their condition worsening and having to rely on benefits alone. As this would create a situation where you "would still be alive, but you wouldn't ... be living"."

Arun

Grants and other awards

Extra costs would be even higher without disability grants and awards. Or simply unaffordable.

Many disabled households rely on such grants to improve accessibility and independence. Disabled people spoke about the importance of financial support with:

- travel and parking
- access to leisure activities
- disability related equipment



Yet there is often limited access to this type of financial support. The barriers to access include:

- eligibility restrictions
- awareness of funding opportunities
- ease of application processes



I had to spend £2,000 two months ago to buy a wheelchair that I should never have had to pay for. ... Because I'm an adult, and I have the wrong type of disability, and the wrong types of illnesses, and I live in the wrong area for this thing, and the wrong area for that thing."

Vanessa

Also, the amount of money given did not always reflect the actual cost of what was needed:



I need a new manual wheelchair really but can't afford it. ... The hospital have vouchers ... but I'd get about £450 towards a £5,000 wheelchair."

Ana

Grants and awards could be taken away at any time, without warning. This creates financial and emotional uncertainty for disabled households. There was a fear of not meeting extra costs.

Informal personal care and assistance

Most disabled people are unable to afford formal care support or personal help. Instead, they rely on informal support from family and friends to act as personal aides. Even people with funded care packages still rely on family members for support.



The value of this support is difficult to measure in economic terms. But its value for quality of life is significant:



I can't really quantify [the support my parents provide], but without that, my quality of life would suffer."

Arun

Informal care and support can still result in financial costs. For example, paying extra travel and refreshments ("It doubles the cost of everything", Alix). Or in lost household wages:



[My wife] has a day off every other week. Because we can't cope with ... the cleaning and the washing and things. ... So we lose out on that money."

Ella

There are also emotional costs of relying on informal care. Including guilt and anxiety:



When I'm really ill, ... [my eldest child] will sometimes step in, and she will cook. ... She will help me, she will wash my hair for me. But she's 18 - she shouldn't need to be doing any of this. ... It makes me feel bad that she has to do it."

Heidi



My parents provide a lot [of my care]. But they're getting older and wanting to do less. ... What happens in the future? I do worry about it."

Arun



Disabled people are angry about how little support there is for loved ones who care for and help them. And how much money informal care saves the government:



That informal care - from children to parents, or parents to children - saves the government millions. But [my children] don't get any support."

Heidi

'Going without'



There are so many things that we've restricted, and stopped doing, and stopped having."

Emma

Extra costs and insufficient benefits force disabled households to cut back on spending. But higher living costs now mean that disabled households manage finances by rationing or going without. And most have already cut everything they possibly can:



Over three years, the cost of living has risen enough to go from, 'Oh, that's quite expensive, can we afford it?' to 'What are we going to cut now?' and 'How are we going to do that?' We've cut everything that can be cut."

Jo



To reduce costs, disabled households cut back on or go without in every area of life, including:

- **Food**: missing meals, buying cheaper food, reducing spending on groceries, using food banks.
- **Utilities**: use of heating, electricity, hot water, kitchen appliances.
- Medication and health: prescriptions, over the counter medicines, transport to health appointments.
- Disability equipment: new wheelchairs, mobility scooters, batteries for electric mobility aids.
- Condition-specific treatments and therapies: deep tissue massages, injections, supplements, experimental treatments, or counselling.
- Everyday care and family items: suncream, shoes for school.

Tight budgets for essentials also mean sacrificing social events. As well as days out and holidays:



I haven't had a holiday now for, I don't know how many years. [My partner] keeps saying to me, 'We really must get away somewhere.' I said, 'Well, you haven't got any money, I haven't got any money'."

Mick



I can forget holidays for the next few years - holidays aren't going to happen."

Heidi



Living with financial insecurity



It's like if they could only see or if they could only experience what I experience for a day, the people that are making these decisions are putting us in, you know, unimaginable poverty. I wish they could."

Charlie

Many disabled households live with financial insecurity. As a result of extra costs, combined with low income and insufficient benefits. Many are living in debt, or in fear of getting into debt. And most have little or no money in savings which could help with unexpected costs.

Living with debt, and the fear of debt

Many disabled households in the UK are in debt.²⁶ People we spoke with reported an average debt of almost £8,000, with individual household debts of up to £30,000.²⁷

These debts are a consequence of several factors, including:

- ongoing (and sometimes lifelong) extra costs
- insufficient benefit payments
- · barriers to long-term and well-paid employment



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²⁶ Scope (2023). Disabled people hit doubly hard by cost-of-living crisis.

²⁷ Estimated figures of total household debt from 22 of 31 participating households.

Credit cards and personal loans are being used more often than before. Without them, households are struggling to meet their disability-related costs:



I have noticed the squeeze, and I have noticed that I'm having to use my credit card a lot. ... Because those [disability-related] extras are a bit too much."

Adriana

Yet some disabled households cannot afford the monthly repayments. And risk getting further into debt:



I'm slipping further and further into debt, and I worry about that. ... I'm putting things on PayPal credit all the time. ... I've got a loan as well. ... Everything I buy that's over £100, I have to put on a 'buy now, pay later'. And then I invariably can't pay the interest free credit off in time, so then I end up paying loads extra of credit."

Charlie

Trying to reduce costs and avoid debt is a common feature of the daily lives of disabled households. 'Going without' is the only way for some disabled households to avoid falling into debt:



If we were to spend all the money we actually needed to [on disability-related costs], we wouldn't have any money left every month. ... We would probably be in debt. So, you know, you go without stuff you actually desperately need all the time."

Vanessa



Living with little savings, and fearing the future

Disabled households described having a "savings mindset". Where every decision is made with a view to saving money or reducing costs. Within the specific context of being disabled:



Being able to save money as a disabled person [...] is so, so, so, so, so important. Because ... you can end up unemployed or need to leave your job. ... You need to save up a lot of money, just in case you're not able to work for a prolonged period. Then there's the whole unexpected costs of being disabled."

Dee



I've been very mindful of trying to save, trying to put a little bit away so that when the car or wheelchair finally reaches its last, I can buy a replacement."

Suzanne

Yet extra costs make saving money difficult for disabled households. Bo describes how being disabled means that you need to be "always saving more", to cover your extra costs. Yet, she added, "you can't save more, because those extra costs are continuous". Saving money has become even more challenging for disabled households. In the face of rising living costs:



My costs went up from being, 'I can afford to do this and still have a little bit of money go into a savings pot' to 'I have to stop doing those things or no money goes into that savings pot'. ... But that pot is the thing that covers things like the wheelchair."

Jo



The fear and anxiety arising from a lack of savings is not only a concern in the present. It also changes the way that disabled households feel about the future. Particularly those individuals who rely on benefits:



[Being on benefits] doesn't begin to provide the financial security that would be good if you're disabled, and you end up out of work for a long time, or never able to work. ... It doesn't give you that financial security when it comes to planning for the future."

Dee



There's a big black hole in retirement planning for disabled people. I know that somehow, depending on what our benefits are, we're getting National Insurance credits. I have no idea what that actually means. What happens when I'm older? ... I don't know. I have no idea how to plan for the future."

Hanna

Concerns about the financial future can also shaped by the nature of the disabled person's condition. For example, disabled people with progressive conditions. Those who put themselves under great pressure to earn and save as much money as possible in the present. When they could not be certain of working later in life:



[My disability-related costs now] impact my future planning, because every £50 extra towards those costs is £50 less that I've got as a buffer for when I can't work anymore."

Nathaniel



Impact on physical and mental health, emotional wellbeing, and quality of life



The extra cost of being disabled is not only financial; it's physical and it's emotional. You can't separate the emotional side of it from the financial side. It doesn't work, it's all interlinked."

Heidi



If we're financially secure and capable, then we can be mentally [the same]. Because when you are financially insecure, mentally, you are very insecure."

Ayesha

Impact of extra costs and financial insecurity

Extra costs add to existing financial stress and anxiety for disabled households. Money is a "daily worry" for most (Robin). With many disabled households fearful about "the next big thing" the need to pay out for (Suzanne). Being forced to cut costs to such extremes, or being in debt, also added to feelings of shame. And social isolation:



[All these extra costs], it makes you feel- like, 'very little', is the way I can describe it. It makes you feel, sort of, I don't know, hopeless. Helpless."

Nathaniel





When I was looking to upgrade my powerchair, I had nearly one of the worse bouts of depression I've ever had, because I knew I had to spend £2,000, and I was scared."

Vanessa



This winter that we've just gone through, I pared everything back. I knew that if I didn't, I was going to be faced with this humongous heating bill. ... [We went] back to really old-fashioned things. ... Like generating heat from a candle ... I made sure that nobody ever came here. I didn't want anybody in my home who would know that that's how it was. ... It's shameful, embarrassing."

Suzanne

Disabled people also describe the stress of relying on state benefits. And the impact of the constant fear of having these stripped away:



I can't work full time to get money, so essentially I'm relying on the government to be magnanimous with their support ... I've been lucky so far. But many people aren't. And it is a constant worry in the back of my head: 'What if they stop this [benefit], what if they stop that one?"

Kaden





I'm quite cautious that [my PIP] renewal is next year, and that causes me a lot of anxiety, like, 'The dreaded assessment again.' ... You think, 'What would happen if ... they made the decision that you weren't entitled?' ... If I was told I wasn't entitled any more, how would I get about? If I don't have PIP coming in, who pays for the taxis?"

Jack

These circumstances can lead to feelings of hopelessness. Some people withdraw from thinking too deeply about matters of debt and money. Others describe a sense that they cannot "go on" with things the way they are:



I actively avoid thinking about my actual situation because if I do, it's miserable. ... It's very, very hard to see a way out of the situation."

Suzanne



[My financial situation] is really affecting me, and it's made me feel suicidal at times. Because it's, like, 'I'm going under here, and no one is going to save me'. I feel completely helpless ... And I just cannot afford to live in this country as a disabled person, you know? ... It really does make me feel that I can't go on for much longer."

Charlie



For the most part, disabled people internalise these feelings. To the point that they feel guilty about spending money not directly related to "survival":



With hobbies, I think there is an additional [emotional] cost. ... There's always the element of guilt that you're buying [or doing] these things. Because they're not necessary to your survival. But they are necessary to your mental health."

Hanna

Yet there is also a clear sense of anger and injustice about government and businesses. Those who profit from disabled households:



I feel so angry with the government. ... They're robbing off the poor to give to the already rich. ... They don't understand what it costs to be a disabled person."

Charlie



I don't understand why we're having to pay so much [for utilities] when companies ... are billions of pounds in profit. ... That's unfair on everybody. But when you're really struggling, I just think it's a bit of a slap in the face."

Heidi



Impact of going without

The extra cost of disability is not only an issue of what money disabled households are spending. It is also about what they are not spending money on, and why. As well as what households are going without and how this affects them.

There is a twofold impact on disabled households of not spending when they need to. An emotional impact and a physical impact. 'Going without' diminishes health, wellbeing, dignity, and quality of life.

For example, some disabled households cannot afford school meals for their children. Others sacrifice meals themselves so that their children can have a rare treat. There is also the challenging experience of trying to manage energy costs in winter. By going without the heating and electricity they need:



I've learnt, over the last three years, that it's not just a case of saving any more - you have to sacrifice almost everything. ... [Last winter], I didn't go anywhere. I didn't eat as much. I just turned off all the lights. I didn't have a choice. [It felt] horrible."

Robin

The high cost of essentials means that disabled households must now miss out on hobbies, days out, and holidays. As this is the only way they can make ends meet. The negative emotional impact of this is clear:



It's sad, ... because we're having to cut down on going out. ... Before, I could afford to go bowling with the children, and 'You can go in the arcade', and 'We can have a burger there'. ... Stuff like that has gone out the window."

Adriana





I've definitely cut down on leisure things and activity stuff like books, games, art materials. It is frustrating because I use a lot of those things to try and manage my mental health."

Kaden



It has an impact on the mental health because, you know, I want to do things. ... Go and see Portugal, go and see Spain. ... It's not 'expensive' [for non-disabled people], but for me, it is. Because I've got to organise ... a wheelchair and I've got to try and pay for extra for my scooter. ... I don't like to think about that because it makes me very depressed. It puts me in a very low place."

Patrice

Needing to cut back and reduce costs in this way is also having a negative impact on physical wellbeing:



My physical health has been neglected for quite a long time with everything else, so I haven't prioritised that, because of the different costs and things."

Arun





[Utility bills] have been the main contributor to our debts, kind of, skyrocketing. Last winter, when we were really aware of it, and concerned, ... we tried to not heat the house. And then ended up with mould everywhere. And that, obviously, then impacted my health. We all ended up ill with chest infections, and flu, and everything. It affected my joints as well, being cold and damp all the time. It was tough."

Alix

In some instances, the physical impact of going without is life threatening for disabled people:



I'm freezing cold in winter - I need it warm, but I can't afford to heat it. I didn't heat it much last year - I dropped [the temperature] down. [As a result], I was so stiff and in so much pain. ... My asthma has got way worse since I've been living in a cold flat. ... Also, when I get too cold, it can trigger an adrenal crisis ... and I have to inject steroids. I had to do that twice last winter. ... That's [a] life-threatening situation."

Charlie



Tackling the extra cost of disability

We asked disabled people what needed to change to reduce their burden of extra costs. And the negative physical and mental effects this causes.

From a wide range of practical ideas, 4 important themes emerged:

Reduce some of the most significant extra costs for disabled households

- Reduce the cost of formal at-home or residential social care.
- Reduce the greater cost of utilities via discounted energy bills.²⁸
- Improve independent oversight of price setting for disability-specific products.
- Prevent companies from charging more for accessible hotel rooms, transport, and holidays.

Improve and secure additional financial support for extra costs

- Enhance Personal Independence Payment (PIP) to better reflect the extra costs which disabled households face.
- Make sure the revised PIP process offers a more compassionate and accessible assessment. And a more humanised appeals process.
- Suspicion and mistrust should not be the Government's default position. Disabled people are the experts in their own circumstances. Therefore, the starting point for assessments must be that they are trusted and believed.



²⁸ Scope have already set out such a scheme. You can read about their calls for a 'social tariff on energy' on the Scope website (Scope, 2023, <u>'The social tariff on energy explained'</u>).

- Make sure that well-trained, specialist assessors are used throughout the PIP assessment and appeals process. These assessors should make an informed decision based on expert knowledge of a disabled person's circumstances.
- Make sure that local grants and awards exist to help with extra costs.
 Provide greater support to help people identify and apply for these.
- More free activities for disabled children and children with disabled parents. Including during school holidays.

Improve financial security for disabled households

- Revise rules relating to saving limits disability benefit recipients.
- Develop accessible guidance and support around planning for retirement as a disabled person.

This allows for greater financial security. It would help to prepare disabled households for unexpected financial shocks. Such as unemployment or reduction in working hours, changes to benefits, or buying expensive equipment.

Improve awareness of extra costs and the impact for disabled households

Disabled households want to see disability awareness training for:

- Parliamentarians, civil servants and policymakers. Particularly those involved with the welfare system.
- All public sector staff and other service providers. For example, bus and taxi drivers, and train station staff. Or hotel, shop, and restaurant staff.
- The media and journalists.
- The general public.

These groups must pledge to make changes wherever they can. To reduce extra costs and embed accessibility.



We would also like to see the development of a new national dataset to better understand disabled households' spending in the context of extra costs. Current UK datasets on household spending ²⁹ underestimate disabled households in 2 important ways:

- They do not collect specific spending data on 'extra costs' for disabled households.
- They do not collect data on non-spending and unmet needs of disabled households.

These data are critical to understanding the extra cost of disability. Since many disabled households only survive financially by going without.

These measures should be included in UK datasets on household spending moving forward.



²⁹ For example, the UK Family Resource Survey.

Policy recommendations

Immediate policy changes are required to tackle the extra costs disabled people face. Our findings show that improving the benefits system and addressing essential utility costs are important factors for disabled households.

We recommend 6 solutions:

- Fix the broken benefits system so that it is fairer, more transparent, and better supports disabled people with their extra costs.
- Work Capability Assessment (WCA) must be replaced with an improved alternative. This must be based on input from disabled people and include fairer assessment criteria.
- Work alongside disabled people to design a new positive vision for Personal Independence Payment (PIP). At minimum, the benefit must be enhanced so it covers the essentials and assessments must be fairer.
- Make sure essential utilities are always affordable for disabled people.
 This must include introducing a discounted energy bills scheme. Disability benefits must also be included in the eligibility criteria for the Warm Home Discount.
- Introduce a government-funded 'help to repay' scheme. This will help disabled people to clear their debt on essential utilities.
- Government must make sure energy efficiency spending is better targeted towards disabled households.



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APPENDIX 1: Methods

Calculating the Disability Price Tag

To calculate the Disability Price Tag, our statistical modelling used a Standard of Living approach consistent with our previous research and academic work on extra costs.³⁰

The extra cost of disability is measured by comparing the difference in the standard of living between disabled and non-disabled households.

The standard of living of each household was calculated on whether important goods or services could be afforded. In addition to the ability of each household to conduct essential household tasks and manage finances. This included purchasing household contents insurance. Or repairing and replacing broken electrical goods. As well as having small amounts of money to spend each week and enough to save a little.

Our analysis accounts for factors such as location, ethnicity and the employment situation of members of the household, as well as household income level among other factors. This means we are confident that we can determine the disability-related costs accurately from information available in the Family Resources Survey (FRS) dataset.

We have also used equivalised household income, to compare a variety of household compositions in different settings, from single individuals to families made up of both adults and children. This means we can account for the size and composition of different households.



³⁰ Scope (2023) The Disability Price Tag 2023: Summary report

To estimate the latest Disability Price Tag figure, important additions were made to the analysis:

Inclusion of other relevant socioeconomic characteristics

The model now accounts for ethnicity³¹ and employment situation of the head of household, and the employment situation of their partner (if applicable).

2. Revised household income equivalence scales

The extra costs for disabled households are now estimated utilising the equivalised household income scales in line with Government and used by the Department for Work and Pensions. Our previous Disability Price Tag used the OECD equivalence scales in line with our existing analyses and academic approaches.

- 3. Organising and cleaning the Family Resources Survey (FRS) data
- a. Elimination of extreme values in household income (top 1% percentile)
- b. Focus on households with only 1 benefit unit within the FRS. This simplification streamlined the analysis by concentrating on households that have either a single adult or couples (with or without children)³².

Accounting for the above points in our calculations, we are confident that difference in standard of living, and the money needed to achieve the same standard of living is because of disability-related costs. And provide a more accurate estimation of the extra cost of disability.



³¹ It is important to account for differences in ethnicity. For example, ethnic minorities groups are more likely to experience higher poverty rates leading to health conditions according to <u>JRF Poverty Report 2024</u>. Potentially leading to additional extra costs.

³² 90% of the households have families that tend to have 1 or 2 adults (single or couples with or without children). There are other households that could have more than 1 benefit unit. For example, there could contain elderly disabled parents living with their non-disabled adult children. Or disabled adults who are still living in the household with their parents. These types of families are heterogenous and may have differently structured benefits with the household. However, in undertaking sensitivity tests and including them in the analysis, the difference in the extra costs estimations are negligible (1 % pt), so households with multiple benefit units were excluded from the analysis for simplicity.

Living with the Extra Cost of Disability

Between May and July 2023, Scope ran a mixed-methods study. This involved keeping a weekly spending diary and taking part in an interview. We used this data to look at the experience of living with extra costs for disabled households.

This research follows on from Scope's 2023 Disability Price Tag report.³³ Some of this data has already been presented in Scope's 'Life Costs More' report.³⁴

We recruited the people we spoke with from across the UK, through the Scope Research Panel.³⁵ At all stages of the research process, a coproducer worked with the Research team.

We used 2 methods of asking about lived experience of extra costs. The first was a weekly homework diary. We asked disabled people, and parents of disabled children, to record their spending for 3 weeks. This was across a range of weekly, monthly, and annual costs. We also asked for information on household income, including benefits.

People from 31 disabled households completed these diaries.³⁶ The Research Team then analysed the spending data from the diaries.

We then interviewed 30 individuals who had completed the 3 weekly cost diaries.³⁷ We set aside 90 minutes for each interview. Although some were shorter, and others were longer. We ran these either online, via Microsoft Teams, or via telephone.



³³ Scope's Disability Price Tag 2023.

³⁴ Scope (2024) Life Costs More: The extra burden of essentials for disabled people.

³⁵ Scope's Research Panel is a group of more than 3,000 disabled people. And parents and carers of disabled children. In April 2023, the Panel team asked for people to take part in this study through their online portal. Participation was incentivised.

³⁶ The research began with 35 Research Panelists. But 4 people withdrew at the homework diary stage.

³⁷ 1 Panellist completed 3 weekly diaries but did not attend 2 planned interviews. As such, they were withdrawn from the study.

Interviews were semi-structured but focused on:

- The 'inescapable' extra costs facing disabled households.
- The impact of rising living costs on financial decision-making.
- Whether benefits and other financial support cover extra costs.
- The impact of extra costs on security, hopes and goals.
- Impact of these experiences on emotional and physical wellbeing.

Interviews were then transcribed and analysed by the Research team.

Who took part in the research?

A total of 31 people took part in the research. Most (29 people) identified as disabled. Of these, 8 lived with at least 1 other disabled person. The remaining 2 people identified as non-disabled 'full-time care providers' for their disabled children.³⁸

The mean (average) age of people in the study was 41 years. The median age was 39 years old. Ages ranged from 22 years old to 71 years old.

Most people in the research lived across England's 9 regions (28). The other 3 lived in Scotland (1 person) and Wales (2 people).

We also sought to represent experiences of people with different gender identities. Like Scope's Research Panel, most (20) identified as female. 8 identified as male, and 3 as non-binary.

Most (23) people in the research were of White British ethnicity. We also made a deliberate choice to seek experiences outside of this ethnic group. Of the remaining 8 people, 3 identified as Asian (Indian, Bangladeshi and Pakistani). 2 identified as being of Mixed or Dual ethnicity (White and Asian and Mixed: Other). 2 identified as White: Other, and 1 person identified as 'any other ethnic group'.



³⁸ The concept of 'carer' is problematic. For example, <u>see a critique of this phrase here</u>. But we have used it here to stay faithful to people's own descriptions of their experience within the context of this study.

We asked the 29 disabled people in the research to tell us what type of impairments they had. Most people reported more than 1 impairment. The 3 most frequently reported impairment types were:

- Mobility impairment (26 people)
- Mental health impairment (17 people)
- Stamina or breathing or fatigue impairment (14 people)³⁹

The list that follows provides demographic information for each of the 31 participants, and includes: name, age grouping, gender, location in UK, and ethnicity. Please note that all names in this reported have been anonymised.

- Adriana, 40s, female, Yorkshire and Humber (England), White: Other
- Alix, 40s, non-binary, North West (England), White British
- Ana, 40s, female, South West (England), White British
- Arun, 30s, male, North East (England), White British
- Ayesha, 40s, female, South East (England), Asian: Bangladeshi
- Bo, 20s, female, Yorkshire and Humber (England), Mixed: White / Asian
- Charlie, 50s, female, South East (England), White British
- Clare, 30s, female, East Midlands (England), White British
- Dee, 20s, female, Scotland, White British
- Ella, 40s, female, East Midlands (England), White British
- Emma, 50s, female, East (England), White British
- Ethan, 30s, male, London (England), White British
- Hanna, 40s, female, Wales, White: Other



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³⁹ These numbers exceed the number of people in the study. This is because most people reported multiple impairment types.

- Heidi, 40s, female, East Midlands (England), White British
- Jack, 30s, male, North East (England), White British
- Jo, 40s, female, Yorkshire and Humber (England), White British
- Kaden, 30s, non-binary, West Midlands (England), White British
- Krishnan, 20s, male, West Midlands (England), Asian: Indian
- Liane, 30s, female, South West (England), White British
- Maddy, 20s, female, Greater London (England), White British
- Mick, 70s, male, South West (England), White British
- Mirha, 40s, female, Greater London (England), Asian: Pakistani
- Nathaniel, 20s, male, North West (England), White British
- Patrice, 60s, female, East (England), White British
- Rhys, 20s, male, Wales, White British
- Robin, 30s, non-binary, South East (England), White British
- Rose, 30s, female, North West (England), White British
- Suzanne, 40s, female, East Midlands (England), White British
- Terry, 60s, male, Yorkshire and Humber (England), White British
- Thandi, 60s, female, East Midlands (England), Other ethnic group
- Vanessa, 30s, female, East (England), White British



APPENDIX 2: Income data

Income levels and status varied across the 31 households. We asked individuals whether they worked. They responded as follows:

- **15** in part or full-time employment (mostly based at home)
- 10 were currently not working. Although many had previously worked and wanted to be in the labour market
- 3 were full-time care providers
- 2 were retired
- 1 was in full-time study

All except 1 of the 31 disabled households were in receipt of at least 1 form of state benefit. And the majority were in receipt of at least 1 disability-specific benefit.⁴⁰ These are as follows:

Personal Independence Payment (England and Wales) (23 households) ⁴¹ or Adult Disability Payment (Scotland) (1 household)

- Universal Credit (12 households)
- Housing benefit (10 households)
- Employment and Support Allowance (8 households)
- Disability Living Allowance (5 households)
- Carer's Allowance (3 households)
- Attendance Allowance (1 household)

Several households also receive direct payments or care contributions from their local authority. These are to help them manage their personal care and assistance requirements. Unfortunately, the exact number of households is unknown.



⁴⁰ Most households were in receipt of more than 1 form of benefit. These numbers therefore exceed the total number of households (31) participating in the study.

⁴¹ Of these 23 households, most received both PIP 'daily living' and 'mobility' parts. Others received only 1 part. There was a mix of awards at the higher and lower rates.



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