

# OUTLINES

A RESEARCH AND EVIDENCE SUMMARY SERIES

# Disability and extra living costs

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# Background

In the United Kingdom, more than 20% of the population live with a disability. The link between disability and poor financial circumstances has been well established by research. A household with a disabled member diverts resources to goods and services which are required because of disability, and experiences a lower standard of living than their non-disabled counterparts ([Morris & Zaidi, 2020](#); [Schuelke et al, 2022](#)).

These costs are diverse. Their type and extent depend on the person's functional capabilities, health conditions and support needs; the level of accessibility and inclusiveness of their environment; and their level of participation. There are direct costs - the extra expenditures required due to having a disability, including increased spending on regular goods and services and the purchase of disability specific devices and services. There are indirect costs - these include lower levels of earnings for people with disabilities caused by limited access to education, barriers to gain and retain employment, and the opportunity costs of lost income for family members giving up school and / or work to provide support ([Mont & Cote, 2020](#)).

The result is that disabled people are more likely to have higher living costs and a lower standard of living, even when they earn the same as those without disabilities.

# Evidence

There is consensus across the available research that disabled people face significant extra costs, though there is a wide range of estimates regarding these costs. But there are relatively few studies that break down costs by area of expenditure ([Joseph Rowntree Foundation, 2016](#); [Scope, 2016](#)). Most of the evidence available is quantitative - small-scale in-depth qualitative enquiry and survey-based quantitative methods - and while these approaches can be

important in raising issues, there are concerns about relying exclusively on individual interviews or focus groups to estimate extra costs ([Mitra et al, 2017](#)).

A complicating factor is that not all households with disabilities face the same extra costs. The variance in extra costs experienced by people with disabilities is quite large, not only in level but also type ([Mont & Cote, 2020](#)).

## Methodology

Measuring extra costs is not straightforward, with no single established methodological approach. Current research has focussed around standard of living approaches, which estimate the extra income required to close the gap between households with and without disabled members ([Anton et al, 2016](#); [Schuelke et al, 2020](#)).

Loughborough University ([2015](#)) built on Minimum Income Standard research - asking groups of members of the public to agree detailed lists of items that households need in order to reach a minimum acceptable standard of living) - using the same method to explore additional requirements for people with certain disabilities.

Joseph Rowntree Foundation ([2016](#)) analysed indicators of disability, income and material living standards from survey respondents, comparing a disabled individual with a matching non-disabled individual with the same living standard. Since the disabled person has higher living costs, the income needed to reach this common standard of living will be higher than the income needed by the comparable non-disabled person. This income difference shows the level of disability cost faced by the disabled individual.

Scope ([2019](#)) used a similar approach. After controlling for socio-economic variables, they assume differences in standards of living are due to the extra costs disabled people incur. A key feature of their approach is the addition of child health indicators to the model, which allow for a child's disability to be

considered in the calculation of standard of living, alongside that of the adults in the family.

## Difficulties

Differences in both the measurement and definition of disability costs mean estimates cover a very wide range making outcomes difficult to compare ([Anton et al, 2016](#)) therefore any estimate of disability cost should be treated with caution ([Joseph Rowntree Foundation, 2016](#)).

Direct comparisons of income levels between people with and without disabilities can mask many of the factors and dynamics that influence well-being, leading to an underestimate of the well-being gap ([Center For Inclusive Policy, 2021](#)).

## Poverty

Disability plays a huge part in poverty in the UK. Adults in households with one or more disabled people are more likely to have low incomes than other adults. Because people with disabilities have additional spending needs they are in reality living below the minimum level of well-being that that poverty line was meant to establish ([Center For Inclusive Policy, 2021](#)).

Disabled adults in working-age families are more likely to be in poverty than those who are not disabled (39% compared with 18%). Disability has also been linked with an increased risk of destitution, defined by the Joseph Rowntree Foundation ([2016](#)) as going without essentials such as a home, food, heating, lighting, clothing, shoes and basic toiletries ([Iriss, 2019](#)).

NPI ([2014](#)) estimate that the official poverty statistics cover up a missing million of people in poverty, in households with a disabled person. Findings from the Social Metrics Commission suggests these extra costs are likely to be responsible for measures of material deprivation being much higher for disabled families than for non-disabled families with the same level of

income. By adjusting poverty rates for working-age adults, these extra costs add 2-3 percentage points to the overall working-age adult poverty rate. This results in many disabled families incorrectly appearing to have resources sufficient to lift them above the poverty line. Someone with a disability and £100 extra income and £100 extra needs is as poor as someone without a disability ([Iriss, 2019](#)).

## Costs

Scope's research ([2018](#); [2019](#)) found on average, disabled people face extra costs of £570 a month related to their impairment or condition. This is on top of welfare payments designed to help meet these costs. For one in five disabled people, extra costs amount to over £1,000 per month. After housing costs, disabled people on average spend 49% of their income on disability-related costs. Extra costs mean that disabled people's money doesn't go as far: £100 for a non-disabled person is equivalent to just £67 for a disabled person.

Schuelke et al ([2020](#)) found the average household with disabled members saw their weekly extra costs continually increase from £293 in 2013 to £326 in 2016 [2020 prices].

Drivers of the additional costs of disability ([NPI, 2014](#)) include impairment type, severity of impairment, household composition, income, and other factors such as the suitability of accommodation, whether in employment or not, and issues around transport.

The Extra Costs Commission ([2016](#)) highlight the three main ways additional costs of disability are incurred:

- Paying for specialised goods and services. This may include one-off, but expensive, purchases, such as assistive technology or mobility aids.
- Greater use of non-specialised goods and services. For example, someone with limited mobility may have to spend more on energy to

keep warm, or a wheelchair user may have to use taxis more if public transport is inaccessible.

- Spending more on non-specialised goods and services. This may include things such as higher tariffs for accessible hotel rooms, or having to pay higher premiums on insurance products.

Research finds that disabled people experience additional costs in most areas of everyday life, from major expenditure on equipment essential for independence, to ongoing higher expenses for food, clothing, utilities and recreation.

## **Disabled adults**

Extra costs vary depending on the number of disabled adults in the family. The extra costs faced by a disabled adult living with a non-disabled adult are significantly lower than when a disabled adult lives with another disabled person. This may be due to the non-disabled partner providing informal care to their disabled partner ([Scope, 2019](#)).

In the long-term, extra costs have a damaging impact on disabled people's financial resilience. On average disabled people have savings and assets worth £108,000 fewer than non-disabled people. Households containing a disabled person are twice as likely as households without a disabled person to have unsecured debt totalling more than half their household income. This makes it harder for disabled people to do things like get a job, access education and training opportunities, socialise with friends and family, and participate fully in society ([Scope, 2018](#)).

## **Families with disabled children**

It's estimated to cost up to three times as much to raise a disabled child than to raise one without a disability ([CPRU, 2017](#)). Families with at least one disabled child experience greater deprivation than families with non-disabled children. On average, parents with disabled children face extra costs of £581 a month. For almost a quarter of parents with disabled children these costs

amount to over £1,000 a month. This is after taking into account welfare payments designed to help meet these costs. Disability benefits don't compensate for the majority of the extra costs faced by families with disabled children. On average, parents with disabled children face extra costs equivalent to almost half of their income ([Scope, 2019](#)).

Extra costs for families increase with the number of disabled children in the family. It also shows that extra costs don't increase proportionally with the number of disabled children, which suggests a diminishing marginal extra cost of a disabled child. This indicates that part of the extra costs that come with the second or third disabled child, is already captured by the costs that came with the first disabled child ([Scope, 2019](#)).

Solmi et al ([2018](#)) found families of children with mental health disabilities need to have higher income in order to achieve the same living standards of a family without a disabled child. These costs appear to be higher when there are co-occurring mental and physical disabilities.

The Joseph Rowntree Foundation ([2004](#)) emphasised disabled parents would need more personal assistance. Depending on need this could include, help with personal care, extra assistance with domestic tasks, and support with attending medical appointments. Additional costs can come from hospital stays, including: organising and paying for other children to be looked after, buying clothing and treats for the child in hospital, transport to and from home, and paying for food while in hospital ([NPI, 2014](#)).

Scope's report ([2019](#)) found families with disabled children compared to those without were less likely to be able to afford holidays, personal treats, replacement furniture, replace or repair major electrical items, household insurance, home decorations, and new clothing.

Parents ([Scope, 2019](#)) highlighted the key areas of extra costs:

- Transport - car travel and parking extenuated by frequent hospital visits, specialist equipment for travelling with a disabled child, and longer journeys to reach accessible recreation and leisure activities.



- Toys - purchase of more expensive specialist toys and play equipment for disabled children, such as sensory toys.
- Clothing - those suitable for disabled children are usually more expensive and need to be replaced more frequently due to wear and tear.
- Energy - increased heating in the home, and cleaning of bedding and clothes
- Therapies - privately purchased therapy for both children (physiotherapy, hydrotherapy, speech and language therapy) and their parents (parent counselling and emotional support).
- Home adaptations - changes to living spaces to make them safer and more accessible for disabled children.

Transport costs are highlighted across the literature. Research found that a third of families with a severely disabled child had to seek grants to cover their transport related costs. There are clear cost implications for families required to travel extensively to access specialist services for their disabled children. In addition to this overnight stays are often required ([NPI, 2014](#)).

There is some concern that expenses associated with disabled children are underestimated, particularly due to intangible factors that affect living standards, such as limits to parents' work capacity, or the impact on the rest of the family ([CPRU, 2017](#)).

## Employment

People with disabilities and their families not only face disability related expenditures but also tend to earn less - described as an earnings handicap, where a disabled person may find it harder to get a job or to keep it, and may receive a lower wage ([Anton et al, 2016](#)). [Scope \(2019\)](#) highlight that 52% of working age disabled adults are out of work, and when in work, on average earn over £1 an hour less than non-disabled people ([Scope, 2016](#)).

It should be recognised that some disabled people will be unable to work as a result of the nature of their impairments, but disabled people make up 47% of those not employed but wanting to work. Those who can work are

disadvantaged in the labour market by employers' attitudes, discrimination, availability of suitable jobs, lack of promotion and training prospects, access to a potential workplace, lack of self-confidence, low pay and fear of losing benefits, and educational qualifications ([Joseph Rowntree Foundation, 2004](#)).

## Benefits

Lack of information about disabled people's living costs mean that levels of nationally provided financial benefits and local services are determined using limited evidence. Certain state benefits are meant to offset, at least partially, the additional costs associated with disability, but the extent to which they do is not clear ([Joseph Rowntree Foundation, 2014](#)).

Many disabled families are in receipt of extra-cost disability benefits like Personal Independence Payment, Disability Living Allowance and Attendance Allowance to offset the extra costs of disability. However, the Disability Benefits Consortium found that many disabled people aren't receiving the right level of financial support to manage the extra costs they face ([Iriss, 2019](#)). If the specific benefits designed to pay the extra costs of disability are not included as part of household income, half of all people in poverty either have a disability themselves or live with someone who does, compared with just a third of people in non-poor households ([Joseph Rowntree Foundation, 2021](#)).

The weekly income of disabled people who are solely dependent on benefits is approximately £200 below the amount required for them to ensure an acceptable, equitable quality of life ([Joseph Rowntree Foundation, 2014](#); [Joseph Rowntree Foundation, 2016](#)). Changes to the welfare system, and austerity measures have seen payments and recipients reduced, negatively impacting the incomes of disabled people and increasing the extra costs of disability ([Schuelke, 2020](#)).

According to the Joseph Rowntree Foundation ([2014](#)) benefits meet only 28% of the costs of people with low-medium needs, 30% of the costs of people with intermittent / fluctuating needs, 35% of the costs of deaf people and

people with visual impairments, and 50% of the costs of people with high-medium support needs.

## Savings

On average, disabled people are also less likely / able to save, holding £108,000 less in assets and savings than non-disabled people over their lifetime ([Scope, 2016](#)).

## Types of cost

Scope ([2016](#)) identified three types:

- Specialised goods - often with an added premium and includes disability-related equipment that can be a one off, but expensive, purchase, such as assistive technology, wheelchairs and other mobility aids, screen readers or adapted household items and furniture.
- Greater use of non-specialised goods and services - extra costs occur where disabled people consume more of certain non-specialised goods and services than non-disabled people. While the products themselves may be low-cost and would be recognisable to non-disabled people as necessary expenditure, needing to buy them more frequently results in disabled people spending more over time.
- Higher cost for non-specialised goods and services - includes anything that costs more to disabled people than non-disabled people for an equivalent product or service.

## Housing

Housing and household goods and services are more expensive when you're disabled, particularly if alterations and adaptations are required ([Scope, 2016](#)). It can also mean fewer choices and options.

Maintenance costs can be higher, with people often unable to carry out routine household repairs, decorating and general upkeep themselves and so would need to pay others to do this work ([Joseph Rowntree Foundation, 2004](#)).

In addition to conventional household items, a wide range of adaptations and equipment are required to support and enhance the independence of someone with high-medium needs.

## **Recreation**

People with high-medium needs are likely to spend more time in their home than their non-disabled counterparts, and therefore have higher costs for home entertainment including, hobbies, books, games and satellite television.

Holidays cost more for a person with medium-high needs than for a nondisabled person. Since a person with high-medium needs requires fully accessible facilities, they will have a relatively narrow selection of holiday options from specialist agents. These increased holiday costs would then be doubled if a PA is required ([Scope, 2016](#)).

## **Transport**

Transport is highlighted across the literature as one of the highest extra costs across disabled groups.

If public transport is inaccessible, in short supply, or lacking altogether, disabled people will rely more on taxis and private hire vehicles or their own personal vehicles to get around ([Scope, 2016](#)). 2 in 3 wheelchair users say they have been overcharged for a taxi or private hire vehicle because of their wheelchair ([Extra Costs Commission, 2015](#)).

Vehicles would need to be of a type to accommodate a wheelchair, and may require adaptations such as ramps. The vehicle would need to be insured for use by carers or PAs ([Joseph Rowntree Foundation, 2004](#)).

Some disabled people require support from a personal assistant when travelling on public transport, but their discount or concessionary fare will not always cover both people.

The lack of public transport accessibility can have knock on effects, such as prohibitive costs of getting to work, limiting employment options ([Mont & Cote 2020](#)).

## **Food**

Some groups of disabled people face extra costs for food and drink because they require special diets or are unable to cook with the level of support they receive ([Scope, 2016](#)). Someone with high-medium needs would need a balanced diet of high-quality produce, low in fat, and rich in fruit and vegetables.

Problems with accessing restaurants and other venues could limit opportunities for meeting up with friends, colleagues and family, and thus increase the risk of social isolation. So a person with disabilities may be more likely to have to entertain at home ([Joseph Rowntree Foundation, 2004](#)).

## **Health and personal care**

Groups interviewed by the Joseph Rowntree Foundation ([2004](#)) stated that a person with high-medium needs would need the option of regular, therapeutic or health treatments in addition to those provided by the NHS. These could be for pain-management therapies or general health management, including hydrotherapy, acupuncture, massage, and vitamin supplements. The groups agreed that a person with high-medium needs would need a higher budget for toiletries and cosmetics, to include products to aid relaxation and self-image. A person with high-medium needs with incontinence would also incur the additional costs of incontinence pads and pants.

## **Personal Assistants**

People with disabilities may require and have to pay for personal assistants, which can include interpreters for deaf people and trainers for blind people, as well as support for personal care and other domiciliary services ([Joseph Rowntree Foundation, 2004](#); [Mont & Cote, 2020](#)).

Without them for example, deaf people can be routinely disadvantaged because of communication difficulties, restricted access to educational, social security, employment, health, recreational and commercial services ([Joseph Rowntree Foundation, 2004](#)).

On top of wages for PAs there are also additional indirect costs, including PAs' costs when participating in activities, employers' liability insurance, and laundering PAs' bed linen after sleep-in duties ([Joseph Rowntree Foundation, 2016](#)).

## **Equipment**

1 in 3 disabled people spend money on specialised equipment ([Extra Costs Commission, 2015](#)).

Specialised items cause high one-off costs for some groups, particularly those with a chronic or neurological condition, physical or sensory impairment. Mobility vehicles are regularly reported as an area of extra cost with some powered wheelchairs costing over £40,000, with additional costs for servicing and maintenance. On top of this wheelchair insurance (breakdown cover, third-party liability, and fire and theft cover) costs about £100 per year. Wheelchair use also causes increased wear on furniture and carpets.

Action on Hearing Loss reported a higher cost for flashing doorbells and amplified telephones / textphones compared to non-specialised items. Much specialised equipment is essential to support disabled people to live independently. The high price tag often associated with purchases of this sort can swallow up a large proportion of the income of disabled people and their families ([Scope, 2016](#)).

Sometimes, it may be about ordinary goods. People with albinism, for instance, may need good quality sunglasses and use significant quantities of quality sunscreen ([Mont & Cote, 2020](#)).

## **Clothing and bedding**

Over a third of disabled people spend additional money on clothing and bedding as a result of their impairment ([Extra Costs Commission, 2015](#)).

There are moderate extra costs for clothing, shoes and bedding, depending on the person's impairment, in particular people with autism, people with chronic conditions, children with a learning disability and those with physical impairments. This can be caused by wear and tear to garments, incontinence or other personal hygiene issues can lead to a need for extra items, frequent washing and changes of clothing and bedding. The additional cost of specialised items or tailored clothing to accommodate different body shapes or functional needs ([Joseph Rowntree Foundation, 2004](#); [Scope, 2016](#)).

## **Digital**

Advances in digital technology have had a huge impact on how consumers obtain information and access goods and services, and it is increasingly needed for consumers to access offers, price comparisons and review information. It's also a medium for easier transactions compared to telephone or by avoiding trips to purchase goods and services. However, there continues to be a significant digital divide between disabled and non-disabled people - 30% of disabled people have never used the internet, compared to 7% of non-disabled people. To have the best chance of driving down costs, disabled people need improved internet access ([Scope, 2016](#)).

## **Insurance**

Insurance, and most often travel insurance, can be unaffordable rather than an extra cost for most disabled people. At least half a million disabled people have been turned down for insurance ([Extra Costs Commission, 2015](#)).

Research conducted for Scope found that 22% of disabled people feel that they pay more for insurance, and a further 8% said they had been turned down for insurance, of whom the majority felt that this was due to their disability or pre-existing health condition ([Scope, 2016](#)).

## Energy

There are at least 833,000 fuel poor households in England with a disabled person ([Extra Costs Commission, 2015](#)), which is around 38% of the total fuel poor households ([Scope, 2018](#)).

Many disabled people experience moderate to high costs for gas and electricity, driven by a number of factors such as being home more, sensory sensitivities to temperature, and physical inactivity. This is alongside extra electricity to charge or power assistive technology, extra use of washing and drying machines, and extra power used by PAs ([Scope, 2016](#); [Scope, 2018](#)).

Groups in the Joseph Rowntree Foundation study ([2004](#)) estimated that electricity and gas costs for someone with high-medium needs would be double those for average households.

According to Scope ([2018](#)) the average UK household spends £1,214 a year on energy, while over a quarter of households with a disabled person spend more than £1,500 a year. Of these, 790,000 households spend over £2,500 a year on energy.

## Types of disability

Tibble's 2005 review found a variety of factors that influence the size of extra costs. Several studies found that type of activity limitation has at least a minor effect on the amount of extra costs; higher costs are associated with locomotion, eating, drinking and personal care limitations. Severity of an activity limitation or impairment might be more important than type ([DWP, 2008](#)).

For example, Kidney Care UK ([2022](#)) highlight the extra heating costs required due to anaemia, and increased water and electricity usage due to home haemodialysis. This is alongside the lower employment rate and incomes of people on dialysis.



Demos ([2017](#)) found that people with Motor Neurone Disease and their families face a significant financial burden, with 82% experiencing a negative financial impact following diagnosis. On average, the study found that people with MND and their families spent the equivalent of £9,645 per year in regular and enhanced costs and an additional £2,175 in one-off costs. Over two-thirds of the families surveyed reported using their savings to cope with extra costs during the illness, and only one in five consider the financial support they receive to be adequate.

## **Sensory impairments**

Costs can vary greatly from one situation to another. Depending on the amount of personal assistance or personal services required, paying regularly for an interpreter or cleaner can dwarf one-off costs such as purchasing equipment ([Loughborough University, 2015](#)). People who are vision impaired or profoundly deaf have significant extra day-to-day costs associated with how they live, including extra domestic help, different kinds of travel and additional costs of social participation ([Hirsch & Hill, 2016](#)).

Personal Independence Payments are based narrowly on what people can and cannot do, rather than the wider context of how people who are sight impaired live so there is a risk that people with significant additional costs will not be eligible ([Thomas Pocklington Trust, 2015](#)).

People who are sight impaired have additional travel costs, requiring more use of taxis because public transport can be harder to access. This is for practical reasons - for example, getting to appointments and support networks - but also related to confidence, such as making journeys in the evenings or on unfamiliar routes ([Hirsch & Hill, 2016](#)).

Higher additional technology costs relate to a need for higher or different specifications and more frequent replacement of computers, mobile devices and screens. Severe sight impairment requires more focus on computer speech software, and the heavier use of the telephone as a multi-use item. Some of these would be one-off purchases such as a larger laptop, scanner,

video magnifier, specialist software and IT training, whose cost would be spread across a long period ([Loughborough University, 2015](#)). For those with hearing impairments these are likely to be powered warning systems for doorbells, telephones and fire / smoke alarms ([Joseph Rowntree Foundation, 2004](#)).

Sight impaired people say they need more help in the home, including extra cleaning costs and help in undertaking household maintenance. Contractors need to be paid for major work such as decorating and repairs, but also for minor tasks such as changing fuses and window cleaning. Interviewed groups agreed that the household maintenance costs for a blind person would be almost three times as much as for an average household ([Joseph Rowntree Foundation, 2004](#); [Loughborough University, 2015](#)).

Deaf people face particularly high costs due to their need to arrange and pay for interpreter / communicator services. This comprises most of the additional costs for a profoundly deaf person ([Loughborough University, 2015](#)).

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