

Mencap policy paper: **PIP and the additional costs of living with a learning disability**

Accompanying Cordis Bright qualitative study of the extra costs of people with a learning disability (February – March 2025)



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ABOUT LEARNING DISABILITY

A learning disability is a reduced intellectual ability and difficulty with everyday activities which affects someone for their whole life, caused before, during or soon after birth. There are 1.5 million people with a learning disability in the UK, of whom 884,000 are working age.

A learning disability can be mild, moderate, severe or profound. Some people with a learning disability may have challenges with everyday activities like household tasks, navigating journeys, socialising, or managing money. Other people may need to be fully supported for their whole life and can have complex health and care needs. A learning disability is not the same as: a learning difficulty (like dyslexia or dyscalculia), a hyperkinetic disorder (like ADHD), Autism Spectrum Disorder or mental health conditions.

ABOUT MENCAP

There are 1.5 million people with a Learning Disability in the UK. Mencap’s vision is to make the UK the best place in the world for people with a learning disability to lead happy and healthy lives.

We’re here to support people with a learning disability, their families and their carers. We fight for a kinder, fairer and more inclusive society for people with a learning disability to live in.

From providing 650 services supporting 3,500 people each year, to campaigning for change and by providing our Information and Advice service, employment support, community services - we are committed to being led by people with a learning disability from all communities.



ABOUT THE RESEARCH

Whilst there is some research on pan-disability extra costs, Mencap identified a gap in studies which assessed the specific extra costs¹ of learning disability and PIP’s (Personal Independent Payment) role in contributing towards them.

Mencap commissioned Cordis Bright to undertake in-depth qualitative research by conducting interviews with 15 people with a learning disability and/or their family members or carers who support them with their finances (approximately half of these people had mild to moderate learning disabilities, and half had profound and multiple learning disabilities).

The first part of the research identified the range of specific costs experienced by people with a learning disability and how they manage these unavoidable expenses. The second part of the research aimed to explore participant’s experience of PIP.

¹ Scope, Disability Price Tag, 2023

INTRODUCTION

PIP plays a critical role in supporting people with learning disabilities to live with dignity and autonomy and to help manage the unavoidable extra costs of their learning disability. Yet, the structure and administration of PIP often fails to account for the unique and complex support needs of this group. Without urgent reform, thousands risk losing vital support due to inappropriate assessment processes and systemic barriers.

This paper highlights key findings from the Cordis Bright research alongside Mencap’s policy recommendations based on these findings.

LEARNING DISABILITY AND PIP

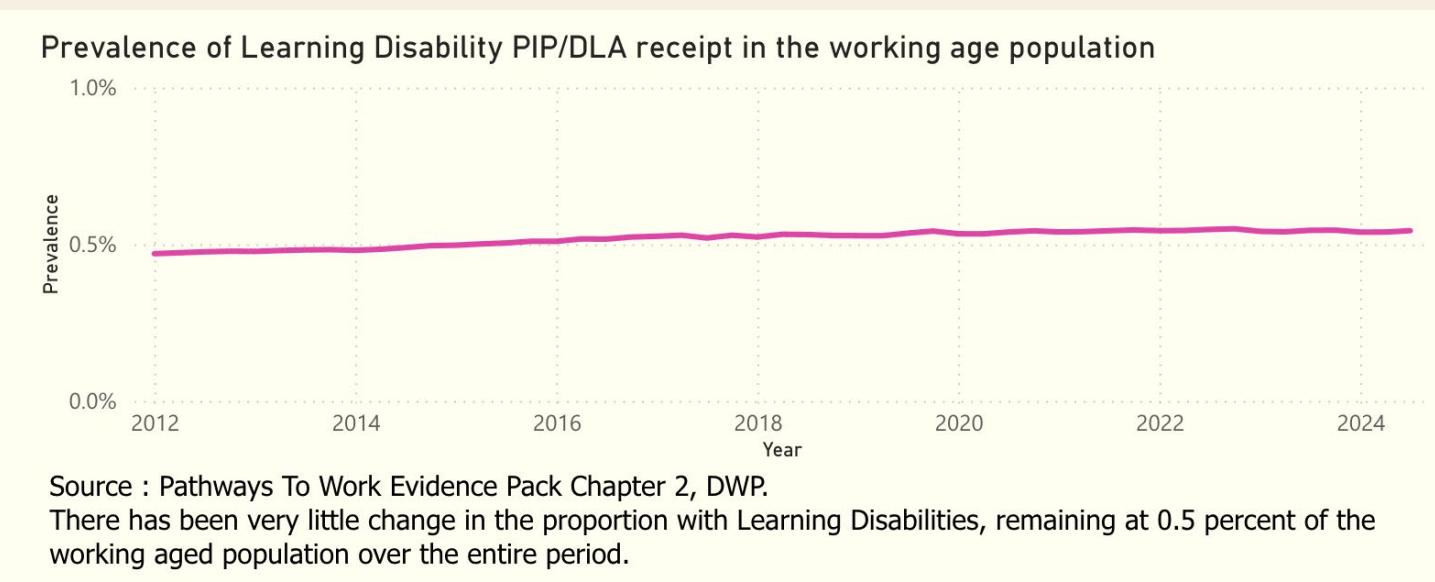
PIP is a disability benefit provided by the Department for Work and Pensions (DWP), that contributes towards the additional costs of being disabled (approx. £1,010 a month).² PIP is not means-tested and is paid regardless of whether someone is in work. There are 2 components to the benefit: the Mobility component and the Daily living component. Each component can be paid at a standard or enhanced rate.

The DWP is responsible for PIP in England and Wales. Social security is a devolved matter in Northern Ireland, but by long-standing convention, Northern Ireland maintains ‘parity’ with the social security systems in England and Wales. PIP exists in Northern Ireland and has the same eligibility rules and rates as in England and Wales. Disability

benefits are a devolved matter in Scotland. Approximately 170,000 people with a learning disability receive PIP (main disabling condition). 97% of claimants with a learning disability as their primary health condition score at least 4 points on a Daily Living activity and claimants with a learning disability are far more likely to get an Enhanced award when compared to the caseload as a whole.³

People with a learning disability are coded in DWP PIP statistics as ‘learning disability global’ and are included in the broad ‘psychiatric disorders’ group, alongside conditions like anxiety, depression and substance disorders. However, a learning disability is not a psychiatric disorder. Whilst the ‘psychiatric disorders group’ caseload has increased considerably, the increase in the number of people in the ‘learning disability global’ category has been relatively stable over the past 5 years.

Under proposed government reforms, from November 2026 PIP claimants would need to score 4 points or more in at least one daily living activity. This would mean that many people with mild and moderate learning disabilities no longer receive PIP, even though they still require support in many aspects of their lives.



Recommendations for the government

Government must:

- Accelerate cross departmental work that can address the root cause of the extra costs of learning disability e.g by introducing an energy social tariff.
- Conduct or commission a review of the adequacy of PIP to ensure it provides a meaningful contribution to the extra costs that people with a learning disability face.
- In the upcoming PIP review the government must ensure the future system accurately captures the level of support needs that people with a learning disability have.
- Improve the accuracy of decision-making in PIP assessments and ensure people with a learning disability are well-supported to understand their right to appeal.
- Improve decision-makers awareness of learning disabilities through specialised training so people with a learning disability can trust that their specific support needs are understood.
- Exempt people with a learning disability from reassessment by including them in the Severe Disability group, as learning disability is a lifelong impairment that will not change or fluctuate.

² Scope, Disability Price Tag, 2023
³ Pathways to Work: Evidence pack; Chapter 2 reforming the structure’ GOV.UK

EXTRA COSTS FOR PEOPLE WITH A LEARNING DISABILITY

Cordis Bright’s research illustrates that people with learning disabilities and their families face a complex mix of additional and unavoidable costs. These expenses span across nearly every facet of daily life—from basic necessities like food, clothing, and bedding, to more specialised needs such as mobility equipment, sensory aids, therapeutic interventions, and personalised care, to activities that bring joy, fulfilment and social opportunities to enrich people’s lives.

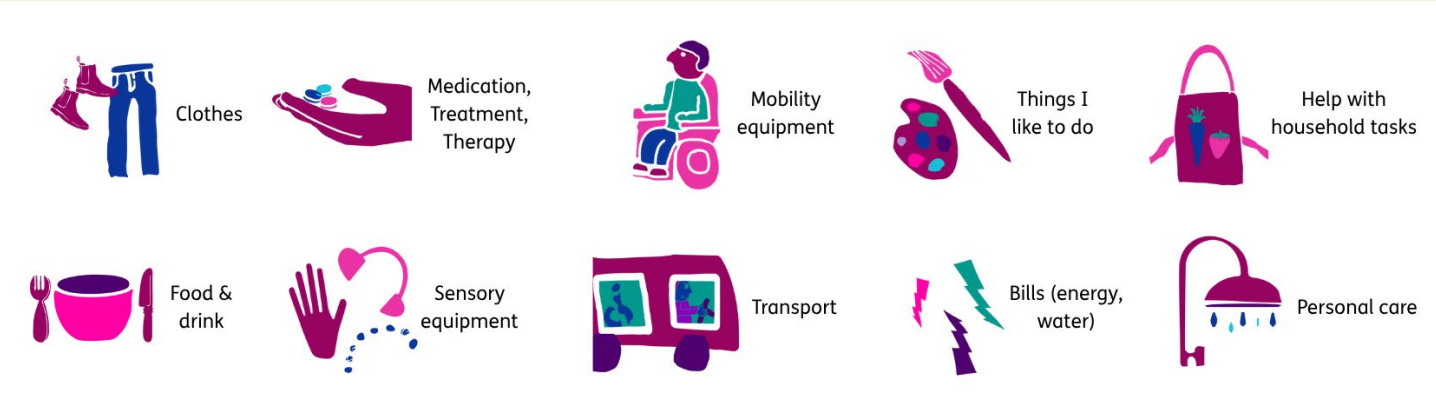
Costs can be further compounded by the need to replace some items more frequently due to sensory sensitivities, physical health conditions, or behaviour that challenges or by costly adaptations to vehicles and homes. These extra costs are variable and depend on the individual’s specific needs, environment, and the level of support they require. Research interviewees often highlighted that their extra costs were all equally necessary and represented significant monthly expenditure. Importantly, these costs are not optional or luxuries; they are essential for health, wellbeing, independence, and participation in society.

Frequent replacement of everyday items (e.g. clothing, bedding, furniture) was common amongst participants due to increased wear and tear or sensory sensitivities.

“We spend hundreds a month due to him tearing clothes. [He] has to wear cotton, his skin reacts to synthetic. Some months, about £300. Some days, it’s not just t-shirts, it’s his whole outfit.”

For some research participants, particular foods have to be bought in order to meet the sensory or physical health needs of the person with a learning disability. This sometimes means buying more expensive foods which are safer to consume.

“Everything has to be very specific and is therefore expensive, his dietary needs are very particular, he’s very skinny because he can’t chew foods, anything bobbly, because of his sensory issues in his mouth, the things he chooses to buy has to be specific to the cans or dish.”



DISPROPORTIONALLY HIGH ENERGY COSTS

Additionally, research participants cited their heightened use of essential services such as electricity and water as a major extra cost. Disabled people face disproportionately high energy costs: mobility and hygiene needs can require increased consumption of electricity, for example, to run electric wheelchairs, whilst some people with a learning disability have additional health barriers, requiring medical equipment like oxygen concentrators and ventilators. Many also have important non-medical sensory needs that might involve significantly increased use of electrical devices, or they may need their homes to be heated to a high temperature for longer because they have 24-hour carers.

“I don’t like asking my parents, it’s embarrassing, to ask for £10 to top up because we’ve got no gas in the house. It’s quite embarrassing and it’s very stressful, but I have no other choice, otherwise we have to sit in the cold. If I didn’t have the gas, in the winter months, we’re in the house most of the time, we don’t go far, just to supermarket so I have to have the heating on for most of the day, which is £5 a day, £35 a week.” Parent

“[Name] is incontinent a lot, so I need to strip the bed, put it in the washer, every day the washer is on once or twice – not just bed but clothes and everything, it takes so much more.” Parent

However, despite this increased energy need, Department of Energy Security and Net Zero data shows that nearly 50% of fuel-poor households have someone with a long-term illness or disability.⁴ This material hardship is particularly concerning, given the clear link between learning disability and health conditions that are exacerbated by living in a cold home and which make the supply of affordable heating vital.

To address these longstanding energy affordability issues and extra costs, the government must introduce an energy social tariff to provide targeted price support through either a fixed cash, formula-based or unit rate discount for low-income and disabled households. This policy has received widespread support from Ofgem, the energy industry and the Energy Security and Net Zero Committee.⁵

Recommendations for the government

- Accelerate cross departmental work that can address the root cause of the extra costs of learning disability e.g by introducing an energy social tariff.

⁴ Department of Energy Security and Net Zero, Fuel poverty detailed tables, 2023/4, <https://www.gov.uk/government/statistics/fuel-poverty-detailed-tables-2024-2023-data>
⁵ Ofgem, Jonathan Brearley speech at Institute for Government, January 2023, <https://www.ofgem.gov.uk/press-release/jonathan-brearleys-speech-institute-government#:~:text=Therefore%2C%20we%20think%20that%20there,defined%20set%20of%20vulnerable%20groups>
Energy UK, press release July 2023 <https://www.energy-uk.org.uk/news/government-must-switch-on-to-help-vulnerable-energy-customers-this-winter/>.
Scope, 95 charities sign letter calling for social tariff, May 2024, <https://www.scope.org.uk/media/press-releases/charities-and-non-profits-call-for-discounted-energy-bills-for-low-income-households>

ADEQUACY OF PIP PAYMENT AMOUNTS

Whilst PIP is a vital payment, most research participants also said PIP did not adequately contribute to their additional costs, requiring families to subsidise or forgo essentials.

PIP rates are discretionarily raised in proportion to inflation, not a real-terms calculation of the additional cost of disability. As a result, PIP is rarely commensurate with the extra costs people with a learning disability have. More than 4 in 10 PIP claimants are in the bottom fifth of the income

distribution⁶ and Joseph Rowntree Foundation analysis of low-income households with a person who has a learning disability showed that 85% were still going without essentials last year.⁷

To address this, the government must commit to, or commission, a review of the adequacy of PIP rates. This should use a ‘Standard of Living’ approach which assumes that disabled households are required to spend more on special equipment, home adaptations, medicines and therapies compared to non-disabled people with the same income level. The review must also set out how the government should reach this benchmark alongside annual uprating.



Recommendations for the government

- Government must conduct or commission a review of the adequacy of PIP to ensure it provides a meaningful contribution to the extra costs that people with a learning disability face.

Losing PIP would have a significant negative impact on people with learning disabilities, threatening their ability to cover essentials costs, maintain independence, access care and passported benefits and entitlements.

Costs could also be shunted to other essential services such as health and social care.

The research also highlights that without PIP, some people with a learning disability would have to face ongoing challenges to cover basic bills and would cut their expenditure on food.

“[If no longer able to receive PIP, what would you have to stop doing?] Breathing! - just write breathing. No, I’m serious. You write breathing with an exclamation mark and say it was insisted I write this. It would decimate his quality of life.”
Parent

Activities, equipment and support that provides improved quality of life and wellbeing would need to be cut for others, which could lead to increased social isolation and detrimental mental health impacts.

PIP is a gateway to other benefits and entitlements such as Carer’s Allowance, council tax relief and exemption from the benefit cap. The government’s planned PIP reforms also extends PIP’s passporting function to out of work disability benefits too, potentially setting up a devastating cascade of loss for people who do not meet the new 4-point threshold in the PIP assessment.

COST-SHUNTING

The research shows that some participants used PIP to meet support needs and extra costs related to health and social care. A parent of someone with a mild to moderate learning disability said they used PIP to cover health needs as they had to buy customised insoles at a cost of approximately £400 a year, along with specialised wide-fit shoes at a cost of approximately £150 every three months (£600 a year).

“We used to get these [insoles] on the NHS but they were not good enough quality – they only lasted a month. If his feet not supported, he gets back problems, so this is important.” Parent

Some research participants used PIP to pay for specialised diets or therapies too, whilst other participants use PIP to pay for care.

“Losing money means you can’t afford the care; then how do we survive... The system is just going to kill me off, I’d just be in my flat, no PIP... no care, I’m just trying to survive.” Person with a learning disability

⁶ Resolution Foundation, Under Strain (2024), <https://www.resolutionfoundation.org/publications/under-strain/>
⁷ Joseph Rowntree Foundation analysis of Savanta survey. Savanta surveyed 4,092 UK adults aged 18+ in households in the bottom 40% of equivalised household incomes online between 26th April and 9th May 2024. Data were weighted to be representative by age, gender, region, ethnicity and housing tenure. A full method note can be found as part of the briefing The scale of the challenge: JRF’s pre-election cost of living tracker | Joseph Rowntree Foundation

Losing PIP would therefore have disastrous consequences for their ability to meet their health and social care needs, potentially leading newly ineligible people with a learning disability to seek alternative support from local health and care services. Cuts to PIP could be a false economy—displacing costs to the NHS and social care systems, while increasing distress for vulnerable individuals. Analysis from the Disability Policy Centre estimates that the green paper proposals would only deliver £100 million in savings – just 2% of the £5 billion the government has announced – largely because of these knock-on effects.

In the event of widespread losses of PIP, there should also be robust oversight and accountability. The Work and Pensions Committee should require the government to release quarterly reports on the number of disabled people losing PIP entitlement disaggregated by impairment group, the average change in income across claimant groups disaggregated by impairment group, appeals

Recommendations for the government

Government must:

- Review the planned introduction of the 4-point rule and release cumulative impact assessments to show the knock-on effect of loss of PIP on disabled households.
- If planned benefit cuts are introduced, the government must introduce comprehensive and robust transitional protection for disabled people who become ineligible for PIP.
- Increase transparency of the disaggregated data they release.



* Pen portrait

Maya

Person with a learning disability in part-time work losing the PIP daily living element



Maya has a mild learning disability and anxiety.

Benefits and employment status: Maya receives PIP. She has a part-time administrative role at a local recruitment office, working 16 hours at the National Living Wage.

Support needs: Maya often needs to be reminded to get dressed for work in the morning (2 points). She often needs support from her family to find the best value deals when she is shopping (2 points). Maya's mum has to remind her to take her medication and to attend her counselling sessions once a week (2 points). Maya can communicate verbally but when she meets new people, she needs support to engage with them (2 points). She prefers written information in Easy Read and needs cues to be able to understand complex written information (2 points). Sometimes Maya needs assistance to be able to get in or out of the bath and can also need prompting to go to the toilet (2 points).

Whereas previously Maya would have received 2 points for each of these daily living activity descriptors to qualify for the standard rate of PIP, under new proposals she will not be eligible, as she will not score 4 points for any category. When the WCA is abolished in 2028, and the UC health component is determined through PIP, she would not qualify for any benefit income beyond the standard UC allowance (which has been moderately increased.)

If Maya loses PIP, her monthly income would be £331 lower equating to **a loss of nearly £4,000 a year.**

Liam

Person with a learning disability losing the PIP daily living element who therefore loses the health-related element of Universal Credit



Liam has Down's Syndrome and lives at home with his parents.

Benefit and employment status: Liam receives PIP and is in the UC LCWRA group. He works 10 hours a week in his local library.

Support needs: Liam's family assist him in selecting appropriate clothing every day (2 points). Liam loves meeting new people but sometimes requires prompting to engage with them (2 points). Liam needs tasks broken down into small simple steps, and support to understand complex written information (2 points). Liam manages his own wages from the library but needs support from his family to make more complex budgeting decisions (2 points). Liam can't reliably cook a simple meal using an oven or use knives safely, but enjoys cooking microwave meals for his family (2 points). Due to his health needs, he needs to use his heating more often.

How he uses PIP: Liam uses PIP to pay for food he can cook, attend day services and his higher energy bills. Liam's support needs don't meet the threshold for social care so he also uses PIP to pay for a support worker who helps him a few hours a week to develop his skills.

Liam gets 10 points in the current system and qualifies for PIP, however he does not get 4 points in 1 category so would miss out on PIP and will also lose the UC health element in 2028, totalling **a loss of £8,600 per year.**

Some people with a learning disability feel the PIP system lacks adequate understanding of learning disability, leading to negative assessment experiences, misjudged eligibility decisions, and distressing and unnecessary appeals.

NEGATIVE PIP ASSESSMENT EXPERIENCES

Research participants said they felt that the PIP application process was often inaccessible and stressful, with complex forms, poor communication, and assessments that fail to adequately account for learning disabilities – especially for those without advocacy or support. Some participants said that the PIP application form was too long and that they were unaware of an Easy Read version to help people with a learning disability to understand the assessment questions. The Work and Pensions Committee inquiry into health assessments for benefits (2023) similarly found that disabled claimants had difficulty completing forms.⁸

Several research interviewees described feeling that DWP was trying to catch them out which caused high levels of stress and anxiety. Communication with DWP staff was described as being challenging and impersonal. Several parent-carers felt that some of the standardised questions were irrelevant and displayed a lack of understanding about the type of impairment of the person they care for, particularly where their disabilities were profound and multiple.

“But there's no support with filling forms, you do it, hope you're putting the right thing, but if not they send it back, or you have to fight an appeal because they've not understood what things mean.

There's such a broad spectrum of learning disabilities and I don't think people reviewing applications understand that.” Parent

“I remember I had to do a face-to-face assessment [...] I was nervous and anxious – I didn't know what to expect. It was a concerning and anxious time. In the meeting, I was trying to say the right things. But I struggle in day-to-day life. I make sense as best as I can. My words get mixed up sometimes. Especially if I'm anxious. I know the words I want to say but can't always get them out.” Person with a learning disability

One interviewee explained that their personal assessment of what they can do independently might differ from how a parent or support worker would assess this.

“They asked stupid questions, I remember one, they said “can you cook”, I said “yes” but my support worker said, “but who cooks that for you?”. If I was on my own, I

⁸ Work and Pensions Committee, PIP and ESA assessments, HC 829 2017-19, 14 February 2018; Work and Pensions Committee, PIP and ESA assessments: claimant experiences, HC 355 2017-19, 9 February 2018

would have slipped up and I would not have got it [PIP], because the way they asked the question is not very disability friendly.” Person with a learning disability

This suggests that someone with a mild learning disability navigating the application system by themselves could be at risk of over-representing what they can do and under-representing the support they need, as PIP assessments

disproportionately rely on self-reporting and physical impairment metrics. As a result, their application could be wrongly declined or their PIP award might be at a lower rate than could be accurate. This concern was raised by the Work and Pensions Committee (2018)⁹ which concluded that ‘the activities and descriptors used in the WCA and in the PIP assessment were not fit for purpose, being weighted towards physical health conditions and disabilities.’

This indicates that understanding on learning disability needs to improve within the department and that comprehensive training is required. This could take the form of something similar to the Oliver McGowan Mandatory training on learning disability and Autism, which ensures staff have the right skills and knowledge to provide safe, compassionate and informed care to autistic people and people with a learning disability.

Recommendations for the government

Government must:

- Improve decision-makers awareness of learning disabilities, through rolling out comprehensive training on learning disability to all Case Managers, such as the Oliver McGowan Mandatory training on learning disability and Autism.
- DWP must also ensure people with a learning disability are well-supported to understand their rights of appeal.

Recommendations for the government

Government must:

- Ensure PIP activity descriptors and assessments accurately capture the level of support needs that people with a learning disability have

POOR DECISION-MAKING

Some research participants with mild and moderate learning disabilities had appealed PIP assessment decisions, including going to a tribunal.

“We got there having fought and fought to get there. And when we got there, they basically said “I don’t know why you’re here, it’s obvious what the problem is, yes [name] qualifies for this and it’s for life”. There was so much stress and strain, and then you finally see someone who knows and understands and they said, “I’m

sorry you’ve been put through this”. Parent

The Office for Budget Responsibility anticipate that the government’s reforms will increase the proportion of disabled people appealing PIP decisions, resulting in significant increases in administrative and tribunal costs for the DWP and distress and hardship for former recipients who have to fight to regain their awards. There is already a backlog of 80,000 social security cases in the tribunal service and an average wait time of 8 months, with PIP cases making up 61% of the total.¹⁰ 78% of appeals for people with a learning disability were lapsed or overturned in their favour 2023/24 at an estimated total cost of overturned appeals of £340,000.¹⁰

Reassessments for people with a learning disability can be anxiety-inducing and unnecessary, particularly as a learning disability is a lifelong condition that will not change.

The research highlights the significant anxiety and stress that people with a learning disability can face at the prospect of reassessment.

“I’m concerned about reassessments. Not just for me but for others with a learning disability too. When we hear on the news about frequent reassessments for people who have PIP it’s concerning. And I don’t know how the entitlement will be done, is it to do with money, is it to do with point scoring, what will it involve.

Thankfully, I have parents to help me for now. Without my parents I wouldn’t know where to go, I would absolutely struggle.” Person with a learning disability.

On average around 766 people with a learning disability are forced through stressful reassessments every month, even though their learning disability is lifelong and support needs are unlikely to change.¹¹

Following reassessment their award is unlikely to change: 88% of people with a learning disability who already received a Daily Living Award and who got reassessed did not have their award changed, the highest of all conditions.¹² Repeated reassessment of this group throughout their life, when their condition

⁹ <https://www.gov.uk/government/statistics/tribunals-statistics-quarterly-october-to-december-2024/tribunal-statistics-quarterly-october-to-december-2024#social-security-and-child-support>

¹⁰ Mencap analysis of tribunal data from FOI request and uses data from financial year 23/24. Estimated tribunal costs based on average figures in 21/22.

¹¹ Mencap analysis of DWP StatXplore

¹² Mencap analysis of Stat-Xplore data. Top 50 conditions by number of reassessments



will not change, is not an efficient use of government resources.

The green paper proposes to remove reassessments for people with severe disabilities. The Prime Minister and Minister Timms have indicated that eligibility for this group will be based on the existing WCA Severe Disability group criteria¹³ until the WCA is scrapped. Following this, a new criteria will need to be devised. Current rules stipulate that to be eligible for the Severe Disability group, a healthcare professional must advise that a claimant meets all 4 of the following criteria:

1. Level of function will always meet LCWRA e.g MND, severe autism, all chromosomal conditions
2. Lifelong condition (once diagnosed the condition will always be present)
3. No realistic prospect of recovery of function
4. Unambiguous condition

Even though a learning disability is a lifelong, unchanging impairment, some people with mild and moderate learning disabilities may not be included in this group and will still be subject to reassessment.

Recommendations for the government

- Government must exempt people with a learning disability from reassessment by including them in the Severe Disability group, as learning disability is a lifelong impairment that will not change or fluctuate.
- People with a learning disability should be able to ask for a reassessment should they develop a new condition or an existing one has worsened.



CONCLUSION

Cordis Bright's research highlights clearly that participants with learning disabilities and their families face significant, ongoing and unavoidable additional costs that span across all aspects of their life.

These include basic needs like food and clothing, as well as more specialized requirements such as mobility aids, sensory equipment, therapeutic interventions, and personalised care. These costs are highly variable, depending on the individual's specific needs, environment, and level of required support, and they often represent a substantial part of monthly expenditure for families.

The research also points out the crucial role of PIP in helping people with learning disabilities manage these extra costs while maintaining dignity and autonomy. However, the structure and administration of PIP often fails to address the

complex, unique support needs of this group. The research highlights concerns that the assessment process is inadequate, with systemic barriers potentially leading to the loss of essential support for thousands of people.

In light of these findings, Mencap offers several recommendations for government action. It urges cross-departmental efforts to address the root causes of extra costs, such as introducing an energy social tariff, and a review of PIP to ensure it adequately contributes to covering the extra expenses faced by people with learning disabilities. Mencap advocates for greater accuracy in PIP assessments, improved decision-making, and better support for understanding the appeals process. Specialised training for decision-makers is recommended to improve awareness of learning disabilities, as is the exemption of people with learning disabilities from reassessment.

¹³ The Prime Minister, Kier Starmer - House of Commons - Engagements
 Volume 765: debated on Wednesday 23 April 2025, in response to Question 903701 from Alison Hume MP



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