

Disability Rights UK, Toynbee Hall, and Commission on Social Security:

Report on findings of our PIP survey

This is a critical time for Personal Independence Payment (PIP) a benefit that almost 4 million Disabled people rely on to maintain a level of dignity and independence. PIP can be – and is – used on anything that meets the needs of the individual from supporting with the cost of therapies, cost of living support to accessing transport.

Following the rejection of government proposals in July 2025, the Government launched a Review of PIP, this is now due to report this autumn. Whilst we have major concerns about the level, criteria and process, we are in no doubt that PIP is essential to working age Disabled people. The Minister for Social Security and Disability, Sir Stephen Timms, will be making a Statement to the House in the autumn on the findings of the PIP Review and it is vital that Disabled voices are heard clearly in advance of this. This briefing highlights key evidence and urges everyone to ensure that an improved PIP emerges from the Review.

About our survey

Disability Rights UK, Toynbee Hall, and the Commission on Social Security created a survey co-designed with Disabled people on state benefits. The survey ran for 3 months from late May till late August 2026 and was focused on whether PIP reflects the real costs and barriers Disabled people face, how people experience the assessment process and what changes are needed to make the system fairer, more accurate, and more supportive.

One of the key aspects of the survey was the co-design process with Disabled people in receipt of PIP. While the Timms Review claims a commitment to co-production, the limited engagement of DPOs and the admittance by one of its co-

chairs that the review is not “fully or true co-production”¹ makes this work more important. Disabled people decided what questions were important to ask, and how they should be asked without being shaped by government agenda.

This survey should be seen as a complementary source of evidence for the Timms Review, but one that is not constrained by the Review’s methodology or angle of questioning. Importantly our primary recruitment strategy was through MPs sharing the survey themselves. This technique has helped us reach areas of the UK that are less likely to engage with consultations, and has broaden participation, including from people who may not have engaged directly with the Review.

What is PIP?

Disabled people in the UK are over-represented in poverty statistics, with 33% of Disabled working-age adults living in poverty compared to 17% of non-disabled working-age adults², a number driven partially by the numerous additional costs they face to support health and wellbeing. PIP was set up to tackle this particular driver, with the aim that awards covering daily living and mobility would help mitigate these costs, putting Disabled people on even footing with the rest of the population. In practice the challenges of 1) applying for PIP, 2) getting an adequate award following assessment, and 3) the potential threat of awards being removed for engaging in activity mean that an essential need for Disabled people is transformed into another source of stress.

PIP is a non-means tested benefit for Disabled people aged 16 years to state pension age. It is not an out of work benefit, but instead open to all whose conditions affect their daily life. Individuals wanting to receive PIP have to complete a long paper-based form and sit through an assessment. Depending on the assessors judgment on the level of points to award in twelve separate categories, individuals on PIP may get higher or lower rates of daily living and/or mobility awards with different financial amounts tied to each level.

In practice however assessments frequently turn down those who should be eligible, shown by the fact that 65% of DWP decisions cleared at a tribunal hearing are overturned³. An average new PIP claim takes many months to process and be

¹ ‘PIP Review Update’, BBC In Touch: <https://www.bbc.co.uk/sounds/play/m0030cft>

² ‘Disability and Poverty’, Joseph Rowntree Foundation: <https://www.jrf.org.uk/uk-poverty-statistics/disability>

³ ‘Personal Independence Payment: Official Statistics to April 2026’, Department for Work and Pensions: <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-april-2026/personal-independence-payment-official-statistics-to-april-2026>

awarded, all while Disabled people continue to pay additional costs and drive deeper into poverty.

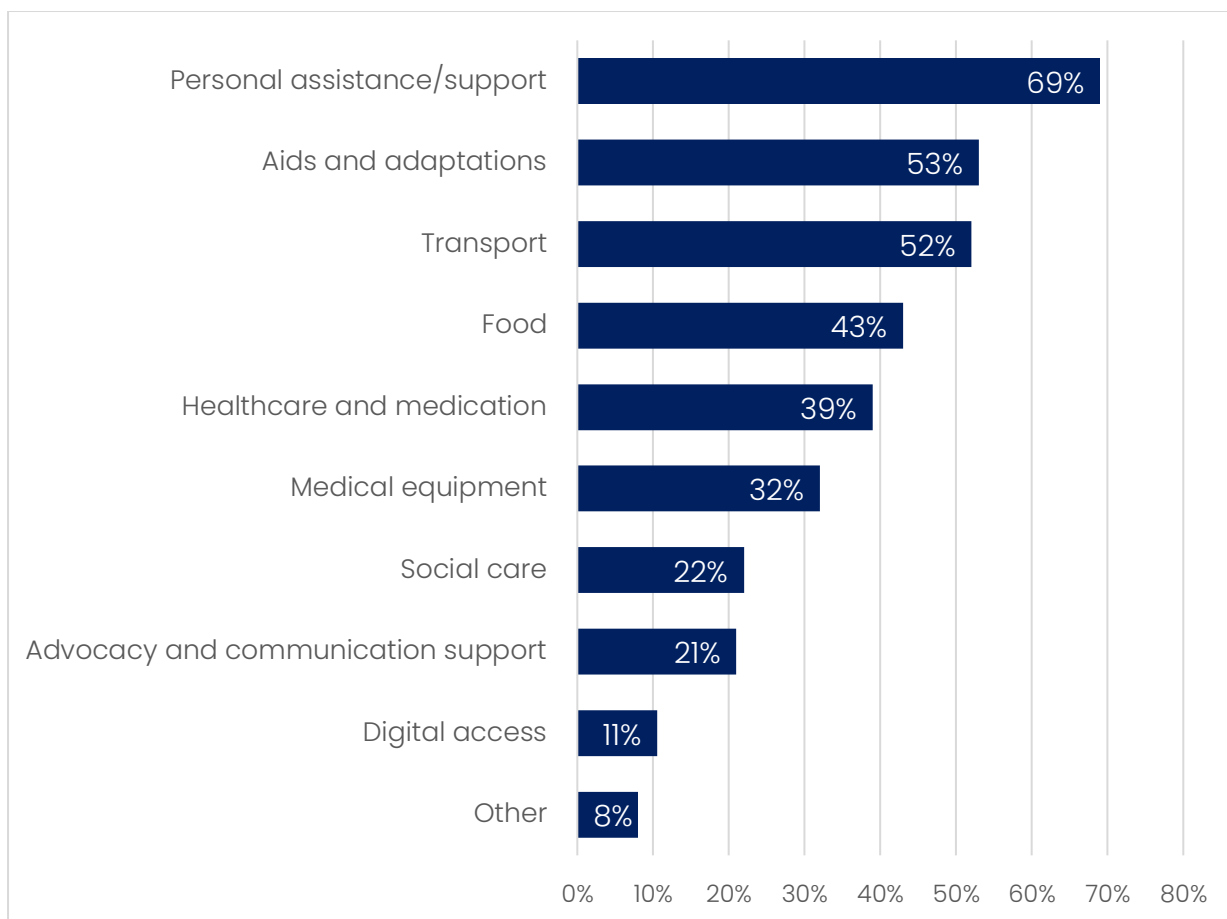
Key findings

Just over 2000 (2001) Disabled people from England, Wales, and Northern Ireland completed our survey. As Scotland has replaced PIP with the Adult Disability Payment (ADP) it was not included in the survey.

PIP awards are inadequate when it comes to covering the additional costs of disability. Only 16% of respondents stated the PIP covered all their additional costs. Just under a quarter (24%) saying it covers very little or basically none of their additional costs, rising to 35% for those who do not receive any higher rate award. As one respondent noted “Being alive is beyond my budget”.

Of those who stated that PIP did not cover all their additional expenses personal assistance/support (69%), aids and adaptations (53%), and transport (52%) were the most commonly cited disability related expenditure not fully covered by PIP. In open text responses people talked about the knock-on impacts of not meeting these costs, leading to being unable to cover standard bills, being unable to afford to leave the house, or having to stop private healthcare in areas where NHS waiting lists meant they were unable to access support.

“I am fortunate that I am able to live with family. If this were to change, PIP would not support me to live independently. I do not qualify for Universal Credit and had to leave my career due to ill health. I would therefore have to rely on my personal savings for rent, bills, food, personal care/support etc before receiving any additional financial support. In this scenario, PIP would not cover any of my additional costs and I would eventually run out of funds and food”



BAR CHART SHOWING THE TOP 10 RANKINGS FOR AREAS OF SHORTFALL, IN CASES WHERE RESPONDENTS INDICATED PIP DOES NOT COVER THEIR DISABILITY-RELATED COSTS.

The majority of respondents said that they were unable to fully explain how their condition affects their daily life in terms of barriers and costs during their assessment. On a 10 point scale where 10 was that the assessment process allowed them to 'completely explain' the impact of their condition, 54% of respondents gave a score of 4 or lower. This trend remained high even when the respondent was awarded both enhanced mobility and daily living, the maximum possible PIP award, with 48% of that group giving a score of 4 or lower.

This lack of ability to explain is shown in the fact that 10% of respondents who reported mobility problems did not receive any level of mobility award.

A key theme emerging from the open text responses on this topic was the lack of ability within the PIP assessment to talk about how multiple conditions might interact. This was especially pertinent for those who had fluctuating conditions, or less understood ones.

“The assessment process did not give enough opportunity to explain how my conditions interact with each other and the cumulative impact they have on my daily life. Each condition was considered in isolation, whereas in reality they often worsen one another. For example, pain, mobility limitations, fatigue and respiratory issues combine to create greater difficulties than any single condition alone. I also felt there was limited opportunity to explain the additional costs and practical barriers arising from managing multiple long-term conditions”

“The assessment only covers a very limited number of tasks, in isolation. It fails to consider tasks in relation to each other nor within the context of someone's wider life. [...] It wasn't until Tribunal (2 years after my initial application was submitted) that I felt listened to and believed. I went from scoring 0 points across every element of the assessment to receiving the enhanced rate for both Daily Living and Mobility, without submitting any additional evidence.”

“The assessor didn't have the insight to understand how aspects of my hidden disabilities affect me. The assessor had preconceived ideas that, because I can do a "clever" desk job, I don't have the disabilities that I do.”

“The assessor was professional, but the process felt heavily focused on obtaining specific answers against set criteria. At times it felt as though there was already a preferred version of the answer that fitted the assessment framework, and my role was to provide information that could be placed into those categories. As a result, I found it difficult to explain the wider reality of living with multiple interacting health conditions and the cumulative impact they have on my daily life”

Almost half of Disabled people in the survey found the assessment process to be hostile. Approximately 48% of respondents said the process was somewhat or very

hostile and only 20% found the process to be supportive for them. This was true even for those who received higher rate awards for both daily living and mobility, with 47% saying the process was very or somewhat hostile.

"The most humiliating experience of my life. Ninety minutes of being made to feel like a fraud. Assessor repeatedly tried to trip me up at a time when I was feeling suicidal. I sobbed the entire time"

"...it was an extremely uncomfortable process because there's this background pressure to try and put you in boxes where you don't claim points rather than just listening to fully understand why you should have points"

"I felt intimidated and interrogated. Like every question was there to trip me up and trick me into saying I could do something."

A clear theme throughout the survey was that Disabled people are afraid of doing normal activities such as going to the shops or trying sports. This ties into the [Activity Trap research](#) from Durham University and Disability Rights UK, where Disabled people stop engaging in activities for fear of losing benefits. Respondents talked about having points deducted for engaging with activities like hydrotherapy, and in one instance attending their parent's funeral. This not only has immediate impacts in terms of keeping Disabled people away from activities that would support wellbeing but also added to the cumulative stress in day-to-day life. As one person put it "this added stress of the tiny amount of support I am getting possibly being taken away is horrific! I self-harm due to the paranoia, I attempted my life last year".

Our final section was an open text asking what respondents would do if they could change one thing about the PIP process. Five key suggestions arose:

1. Assessments should start from the perspective of helping uncover what additional costs a person may have, rather than working to a narrow

checklist. Many mentioned the Scottish Adult Disability Payment as a model that could be followed.

2. Assessors should be trained in the specific condition that the individual is being assessed for so that there is a baseline shared understanding, with the reliably, repeatedly, and safely criteria being emphasised.
3. Reduction in form complexity coupled with more guidance on how to do the application process. As one respondent put “My wife said she found writing her dissertation easier than the assessment forms for PIP”. Participants also wanted more ways to submit their form, such as online or in-person, rather than paper-based.
4. Longer award lengths, lifetime awards, and clearer understanding of what changes can trigger a review.
5. Award amounts should be increased to better reflect the actual additional costs faced by Disabled people.

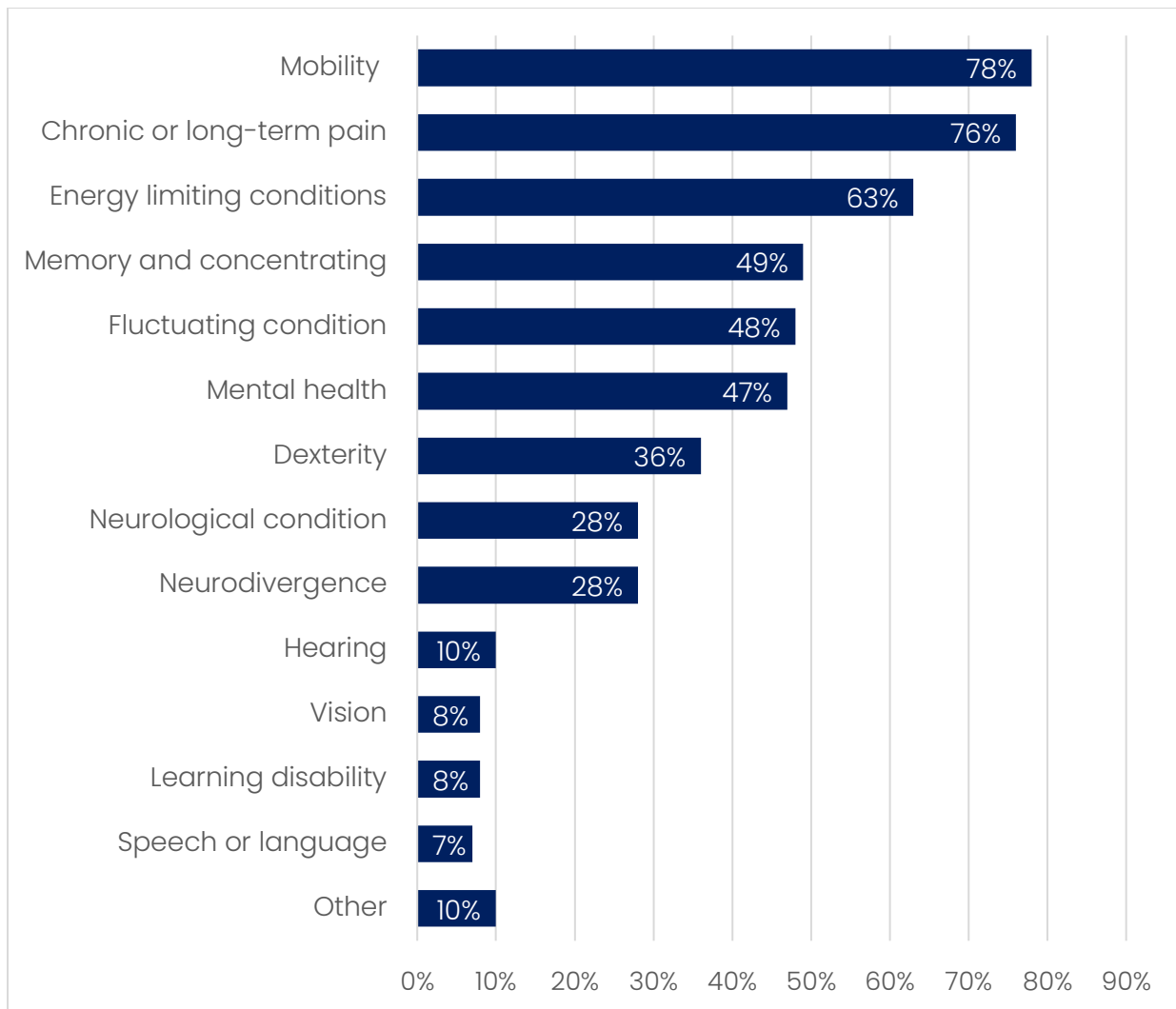
Participants

Our survey participants for these findings were 2001 people from England, Wales, and Northern Ireland. Of the respondents 83% received both daily living and mobility awards, with 47% of those who have two awards receiving both at enhanced rates.

		Daily Living Component		
		Higher Rate	Standard Rate	No award
Mobility Component	Higher Rate	39%	18%	1%
	Standard Rate	7%	18%	2%
	No award	3%	11%	–

TABLE SHOWING THE BREAKDOWN OF RESPONDENTS AWARDS BY COMPONENT AND RATE

The vast majority of respondents reported mobility problems (78%), followed by chronic or long-term pain (76%), and energy limited conditions (63%). Additionally 48% stated they had a fluctuating condition. Significantly of those who reported mobility issues due to their condition, 10% did not receive an award of any level for the mobility component of PIP.



BAR CHART SHOWING THE IMPACT OF RESPONDENTS CONDITIONS. NOTE THAT RESPONDENTS COULD SELECT MORE THAN ONE OPTION.

About our organisations

If you wish to speak to us about our work on social security, the Timms Review or to learn more please email:

- **Sophia Kleanthous** (Policy and Campaigns Officer, Disability Rights UK):
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- **Rushaa Louise Hamid** (Head of Research, Toynbee Hall):
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- **Commission on Social Security**:
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[Disability Rights UK](#) is the UK's leading Disabled People's Organisation (DPO), meaning we are led by, run by, and working for Disabled people. We work alongside other DPOs, as well as campaigning policy-makers and Government across the UK to influence regional and national change for better rights, benefits, quality of life and opportunities for Disabled people.

[Toynbee Hall](#) is a charity working alongside people facing poverty, injustice and inequality since 1884 to build a fairer future for all. Our research and policy work supports Toynbee Hall's mission by using a co-production approach to drive systemic change and ensure everyone has an equal chance to thrive. One of our current projects is [a participatory action research project with Disabled people receiving the health element of Universal Credit](#) looking at how the benefit system can be fairer for those excluded from work.

[Commission on Social Security](#) are a group of people with lived experience of the current social security system. In other words, they are experts in the social security system, what works, and what doesn't. They make proposals for a fairer social security system. Their most recent proposal is the [Additional Costs of Disability Payment](#), an alternative to PIP, co-produced by Experts by Experience.
