

# **Reforming Personal Independence Payment (PIP)**

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### **Recommendations for the UK Government**

There are many long-standing issues with PIP and Turn2us believe that it can be improved if the government:

- Include Disabled people in the design of PIP. Disabled people's insights are essential to making sure that this support meets their needs.
- **Recognises that disability is complex**. The social security system should support those who need it with compassion and trust, addressing challenges rather than punishing people. This means improving assessments and focusing on the social model of disability, recognising the barrier Disabled people face, as well as retaining cash payments to allow Disabled people to live with dignity.
- Introduce protected minimum amount of social security. Through an Essentials Guarantee, so that the basic rate of social security always covers life's essentials, and ensure support is never pulled below that level and that PIP is not used to subsidise household budgets. PIP cash payments should help Disabled people with the extra cost of disability as it was designed to do.

### What is PIP?

Personal Independence Payment (PIP) is a benefit for working age people who need help with daily activities and getting around, because of a long term illness or disability.

PIP has two parts: a daily living component and a mobility component. How much PIP claimants can get depends on how difficult it is to do certain things – such as preparing food and drink, dressing and undressing, or getting around.

### How is eligibility for PIP determined?

The PIP assessment is used to decide entitlement to PIP. There are two sections in the assessment for each component of PIP: daily living and mobility.

Each section consists of activities and points are awarded based on ability and how much help is needed to undertake an activity. Scoring between eight and 11 points for daily living entitles claimants to the standard rate and those who score 12 points or more can receive the enhanced rate. The same scoring system applies to the mobility component.

### Problems with the assessment for PIP

At Turn2us we seek to put people at the centre of our work. To understand the problems with PIP, we asked people with lived experience, our co-production partners, what they felt about the process to get PIP. These partners were involved in building our <u>Turn2us PIP Helper</u> and are in receipt of PIP or support other people to access the benefit. They come from a wide range of backgrounds and have different experiences of claiming PIP.

Partners said that the assessment was one of the more challenging parts of claiming PIP. The assessment is arguably the most important part of the PIP process as it determines whether



someone receives PIP or not, but since PIP was introduced, the assessment has been beset by problem.

So, the current assessment...from my experience, it's not really good, you know, like I have to go two or three times now for, you know, for review and everything. Even though we know people with long term disabilities, I don't agree that these people should go, you know, should have to go in and, because it's very stressful. -Co-production partner

### Impact of complex disabilities of functionality

The PIP assessment was supposed to be a 'new, fairer, objective assessment of individual need'<sup>1</sup> and was designed to be functional, meaning that it does not consider medical conditions, only people's ability to undertake daily living and mobility activities. However, as medical conditions can lead to loss of functionality, many claimants feel that the impact of their medical conditions are misunderstood or inaccurately assessed.

There is concern that assessors, who are often not specialists in the relevant medical conditions, are not equipped to make sound decisions about the impact of complex disabilities on functionality. A significant number of PIP decisions are overturned at appeal, suggesting systemic inaccuracies in the assessment process. Since PIP was introduced in 2013 there has been a consistently high rate of decisions overturned at tribunal. The latest figures from 2024 show that 7 in 10 PIP appeals succeeded.<sup>2</sup>

## Impact of mental health conditions

The PIP assessment doesn't always fully capture the impact of mental health conditions. Claimants with fluctuating conditions, such as anxiety or depression, often struggle to receive adequate recognition of how their disability affects their daily lives. Moreover, fluctuating conditions (where claimants functionality can increase or decrease) are not always captured by the assessment.

# Inconsistencies in decision-making

There is a lack of clarity in how assessment criteria are applied, leading to inconsistencies in decision-making. The DWP makes decisions based on a report produced by the assessors. The variability of the assessments means that claimants with similar conditions and loss of functionality have often received very different outcomes. Claimants can provide additional evidence, such as diary entries speaking to their functionality, but evidence from medical professionals is often dismissed or given insufficient weight during the assessment process, with decisions sometimes based solely on brief assessments.

# Physical and mental health Impact

The PIP process is described as highly stressful and damaging to claimants' physical and mental well-being. The uncertainty of outcomes, combined with the arduous appeals process, exacerbates the stress experienced by claimants with long-term health conditions or

<sup>&</sup>lt;sup>1</sup> House of Commons Library (2015) Introduction of Personal Independence Payment p.5

<sup>&</sup>lt;sup>2</sup> <u>https://www.gov.uk/government/statistics/tribunals-statistics-quarterly-october-to-december-</u> 2023/tribunal-statistics-quarterly-october-to-december-2023#social-security-and-child-support



disabilities. For many claimants, attending assessments and undergoing stressful reviews can worsen their existing health conditions.

The design of the PIP system is overwhelming leaving many unable to access the benefit. The complex and often stressful nature of the application process and the need to challenge incorrect decisions or providing extensive evidence can be daunting and emotionally exhausting, particularly for individuals with health conditions or disabilities. This leaves many applicants feeling disheartened, with some abandoning their claims altogether due to the stress and frustration of navigating the system.

### What have successive governments done to improve PIP?

Changes to PIP have tended to focus on the change in process and the way PIP is delivered. The DWP have sought to address issues such as transparency by providing more detailed decision letters and explaining why decisions were made. They have also made it easier for PIP assessments to be recorded and for those with lifelong conditions they have reduced the need for frequent renewal.

Court rulings have also changed criteria in the assessment particularly regarding mental health conditions and mobility. A ruling in 2017 resulted in the government changing the mobility criteria for people with mental health conditions. This allowed more people with psychological distress to qualify for the enhanced mobility component of PIP. This had led to the PIP system better reflecting the needs of those with mental health conditions, including mental health being considered more holistically in both the daily living and mobility components of the PIP.

Despite efforts to improve the system, the administration and impact of the process continues to face significant criticism. Our partners highlighted the complexity of the application process, inaccurate assessments, frequent reassessments for lifelong conditions, and the stress of appealing decisions. Many partners felt that the system does not fully understand or accommodate the full range of disabilities, particularly mental health conditions.

'I believe that condition focused assessor might not be able to understand (the partners condition) fully because some people have multiple health conditions. So, what are you going to do when all those things overlap? So are you going to be able to understand that when there's a mixture of different elements from different health conditions, so it will be quite difficult for assessors who only get training to understand that.'- co-production partner

# Modernising support for independent living consultation

In the decade since PIP was introduced, the nature of health and disability has changed, and the caseload and costs of PIP have risen significantly. In April 2024, the government launched a consultation looking at better ways of supporting people to live independent and fulfilling lives.

The paper proposed removing cash as the main form of payment for PIP and replacing it with vouchers or a catalogue scheme. Our partners considered this to be stigmatising and an infringement on privacy, making individuals feel that they could not be trusted to manage their finances independently or make decisions with the money that were right for them.

Many of our partners use PIP to support their household budgets and cover extra costs that arise from disability such as 'home help' or having the heating on longer. While some of the



Disabled people we work with are employed, PIP is a vital contribution to their household income especially in light of the cost of living, allowing them to maintain a decent standard of living. There was concern that PIP should not be reduced to covering only the most basic needs but should also support a reasonable quality of life.

The consultation also proposed moving to a medicalised version of disability, focusing on conditions only instead of how medical conditions affect claimants and an overreliance on the NHS to provide support to people claiming PIP. If the proposals in the consultation are taken forward, it will be detrimental not only to the financial wellbeing of disabled people but also to their physical and mental health. The proposals don't address any of the long-standing challenges people are facing and risk making the PIP system more complicated, jeopardising disabled people's financial security.

### About Turn2us

Turn2us is a national charity offering practical information and support to people facing financial insecurity. We work alongside people who know what it's like not to have enough money to live on, and develop our tools, grants and information with them.

In 2023, over 2.7 million calculations were completed using the <u>Turn2us Benefits Calculator</u> and we provided over £3.1 million in grants to people in financial need, reaching almost 3,500 people. In July 2024, we launched the Turn2us PIP Helper, an accessible online information tool that people with disabilities, or long-term physical or mental health conditions, can use to confidently start their claim for Personal Independence Payment.

We deliver household grants by taking a cash-first and trust-based approach which has meant stripping back some of the evidence and documentation we asked of applicants, resulting in people being able to move away from crisis support and take steps towards thriving. Through our <u>Local Programmes</u> in Middlesbrough, Manchester and Barking and Dagenham, we understand the importance of building trust and sharing power within the community to tackle poverty and improve people financial security.