Changing the world
of work for good

TUC response to Timms Review of Personal Independence Payment: Call for Evidence

May 2026

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Introduction

The TUC exists to make the working world a better place for everyone. We bring together more than 5.3 million working people who make up our 47 member unions. We believe all workers deserve respect, and the opportunity to make the most of their talents.

We have a long and proud history of promoting equality for all our members. We strive to end all forms of discrimination, bigotry and stereotyping. The TUC’s commitment to equality is written into our constitution and into that of our member unions.

The TUC takes a social model approach to disability, recognising that disabled people have impairments and are disabled by the environment, inaccessible workplaces, stigma and attitudes.

Social model of disability

The TUC has adopted the social model of disability. The social model of disability focuses on the ways in which society is organised, and the social and institutional barriers which restrict disabled people’s opportunities. The social model sees the person first and argues that the barriers people face, in combination with their impairments, are what disables them. Barriers can make it impossible or very difficult to access jobs, buildings or services, but the biggest barrier of all is the problem of people’s attitude towards disability. Removing the barriers is the best way to include millions of disabled people in our society.

Methodology

This report draws on detailed evidence gathered through a TUC survey of trade union members. It opened on 15 April 2026 and closed on 06 May 2026 in response to the Timms Review of Personal Independence Payment call for evidence. The survey comprised 15 questions, combining structured tick-box responses with open-ended questions, and was designed to align with the review's key themes: the role and purpose of PIP; eligibility, fairness and equity in awards; the experience of claiming PIP; and the changing context and its impact on the benefit.

In total, 93 responses were received.

Although the survey was intended to take approximately 15 minutes to complete, the average completion time was significantly longer at just over 53 minutes, reflecting the depth of engagement and the richness of evidence provided by respondents. The combination of structured and qualitative responses enables the identification of clear patterns alongside detailed accounts of lived experience, offering a grounded and practical insight into how PIP operates in practice for disabled workers.

Questions were designed to explore the practical realities of managing work and disability, impairment or health conditions, including the role of PIP in enabling employment, the extent to which assessments reflect the lived experience of being disabled, having an impairment or health condition and working, and the interaction between PIP, employers and wider support such as workplace adjustments and Access to Work. Specific attention was given to issues often underrepresented in formal assessment processes, including fluctuating conditions, the cumulative impact of work, and the additional costs associated with employment. Open responses were used throughout to allow respondents to expand on their experiences, providing insight into how policy is experienced on the ground.

Executive Summary

Personal Independence Payment (PIP) was introduced in 2013, replacing Disability Living Allowance (DLA), and was presented by the then government as a reform intended to better target support. A central feature of the new system was an increased emphasis on reassessment and review.

PIP plays a critical role in enabling disabled people to work. Responses to our survey[1] show that of 77 of the 78 respondents (98.7 per cent) who were currently working and receiving PIP said it positively affected their ability to work. Many reported that it helps them manage their condition while working, remain in their current role, or work at all. At the same time, nearly all respondents (93 per cent) said they face additional costs as a result of working, highlighting the importance of PIP in meeting both work-related and wider disability-related costs.

However, evidence suggests that PIP is not meeting its intended outcomes. Disabled workers report low levels of trust in the system, associated with repeated assessment, uncertainty, and perceptions of conditionality. This is despite evidence that reassessment rarely leads to change, with around 60 per cent of awards remaining the same following review. [2]

These issues are reflected not only in perceptions of the system, but in how it operates in practice. Our survey evidence shows that assessments frequently fail to reflect the realities of living and working with a disability, impairment or health condition. Eighty-one respondents (90 per cent) reported that their assessment did not fully reflect their experience. Key aspects commonly missed include fluctuating conditions, fatigue, recovery time, and the interaction between multiple conditions.

Structural and accessibility barriers were also a consistent feature of responses. The application and assessment process was described as complex, time-consuming and difficult to navigate, particularly for those experiencing fatigue, cognitive impairment or communication needs. Delays, poor communication and repeated reassessment were identified as key sources of stress.

There is also evidence that PIP is being used to cover costs that should be met elsewhere. Just under half of respondents (44.5 per cent) reported using PIP to cover

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[2] https://www.independent.co.uk/news/uk/home-news/dwp-pip-award-review-changes-conditions-list-b2966912.html

costs they believed should be provided by their employer or other support systems, including reasonable adjustments and work-related support. This highlights gaps in the interaction between PIP, employer responsibilities and wider provision.

These issues are reflected in the position adopted by the TUC Disabled Workers Conference, which has opposed proposed changes to PIP that were previously set out in the Universal Credit and Personal Independence Payment Bill 2024–25[3], highlighting concerns about the impact of reforms on stability, confidence and access to support for disabled workers.

Disabled people have higher costs than non-disabled people, and are likely to have lower incomes. TUC analysis released on 12 November 2025 found a substantial pay gap between the earning of disabled and non-disabled workers. It is equal to £2.24 an hour (a 15.5 per cent pay gap) and results in an annual gap of over £4,000. The same analysis also identified the pay gap was even wider for disabled women – as non-disabled men earn over a quarter (27.3 per cent) more than them.[4] This, coupled with Scope analysis which found disabled people have to pay out an additional £1,095 a month to secure the same standard of living as a non-disabled person[5] and the higher rates of unemployment for disabled workers, points to the reason why a disproportionate number of disabled people live in poverty[6].

The evidence also highlights that work does not reduce the need for support, but often increases it. Respondents to our survey reported that working brings additional financial costs and reduces capacity outside of work, yet the current PIP system does not adequately reflect these realities.

We need a social security system that supports disabled people and disabled workers. However, the evidence in our survey shows that the current PIP system is not working as intended. Assessments were widely described as stressful, adversarial and, in many cases, dehumanising, pointing to the need for a fundamental reform of the assessment process so that it better reflects fluctuating conditions, cumulative impact and the realities of work. A strong perception of distrust runs throughout responses, with claimants feeling they are not believed and that assessments are designed to catch them out. Many reported that the process itself worsens their condition, particularly for those with mental health conditions, energy-limiting impairments and Long Covid. Together, these findings point to a system that is misaligned with the realities of modern working life and is failing to deliver consistent, fair and accessible support.

Decision-making was frequently described as inconsistent and overly dependent on assessor judgement, highlighting the importance of improving assessor expertise and ensuring that medical evidence is properly understood and applied. Many respondents

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[3] See Appendix 1

[4] https://www.tuc.org.uk/news/tuc-disability-pay-gap-means-disabled-workers-effectively-stop-earning-today

[5] https://www.scope.org.uk/campaigns/disability-price-tag

[6] https://www.jrf.org.uk/uk-poverty-statistics/disability

only received the correct outcome after appeal, most often at tribunal, while others were deterred from challenging decisions due to fear, exhaustion or the risk of losing existing support.

Structural and administrative barriers were also widely reported, including delays, poor communication and inaccessible systems. The process was described as difficult to navigate for those with fatigue, cognitive impairment or communication needs, underlining the need to make the system more accessible and less burdensome through simpler processes, better communication and greater flexibility for claimants. Repeated reassessment, often within short timeframes, was a particular source of stress, despite evidence that most awards do not change, demonstrating the need to reduce unnecessary reassessment, particularly for those with lifelong or degenerative conditions.

Overall, the evidence points to a system that is difficult to access, unreliable in its initial decisions and misaligned with modern working life. Respondents were clear that change is needed not only in process but in tone and approach. This includes moving away from narratives that frame claimants as a problem to be managed, and towards one that recognises disabled people as workers, contributors and individuals with legitimate needs. Without addressing both the structural issues and the underlying narrative, the system will continue to act as a barrier rather than an enabler for disabled workers.

Recommendations

The government should:

1. Reform the assessment process: The current assessment model is not delivering accurate or fair outcomes. A fundamental redesign of the PIP assessment should be undertaken so that it reflects real-world experience.

- Moving away from a one-off, snapshot assessment to one that captures fluctuation, fatigue, recovery time and cumulative impact
- Embedding a clear consideration of work and its impact on health and daily living

2. Improve assessor expertise and decision-making: Outcomes are heavily shaped by assessor understanding.

- Ensure assessors have relevant medical knowledge and/or specialist training
- Ensure medical evidence is given appropriate weight in decision-making
- Introduce stronger quality assurance and accountability mechanisms

3. Reduce unnecessary reassessment: Reassessment is a major source of stress and is often unnecessary.

- Introduce longer or ongoing awards for lifelong or degenerative conditions
- Reduce repeat reassessments where conditions are unlikely to improve
- Use existing data to target reassessments more proportionately, recognising that most awards do not change

4. Make the system accessible and less burdensome: The process itself is acting as a barrier to access.

- Simplify application forms and allow multiple, accessible formats (online, email, supported completion)
- Provide more time and flexibility to submit applications and evidence
- Improve communication channels ensuing they are accessible

5. Improve first decision accuracy and reduce reliance on appeals: Too many correct decisions are only made at tribunal.

- Improve initial decision-making to reduce the need for challenge
- Maintain and strengthen access to independent tribunals and legal support

- Ensure claimants are not deterred from appealing due to fear of losing existing awards

6. Ensure PIP reflects the real cost of disability and work: PIP must keep pace with modern living and working conditions.

- Ensure payment levels reflect the true additional costs of disability
- Recognise the extra costs associated with working, including travel, energy and support
- Ensure eligibility criteria reflect modern work patterns, including hybrid and cognitively demanding roles

7. Better align PIP with employment support: PIP does not currently align well with the realities of work.

- Strengthen links between PIP and schemes such as Access to Work
- Ensure support is joined-up across the social security system
- Recognise PIP's role in enabling people to stay in work, not just supporting those out of work

8. Recognise fluctuating and less well-understood conditions: The system must better reflect the diversity of disability.

- Explicitly recognise fluctuating conditions, energy-limiting impairments and Long Covid
- Improve guidance on assessing mental health, neurodivergence and chronic pain
- Ensure assessments consider variability across a full week, not a single point in time

9. Shift the culture and narrative: Process reform alone will not be sufficient without a change in approach.

- Move away from narratives that frame claimants as fraudulent or undeserving
- Embed the social model of disability in policy and delivery
- Promote a system based on trust, dignity and support, recognising disabled people as workers and contributors

10. Invest in system capacity and infrastructure: Operational issues are undermining effectiveness.

- Reduce backlogs and delays through increased staffing and resourcing

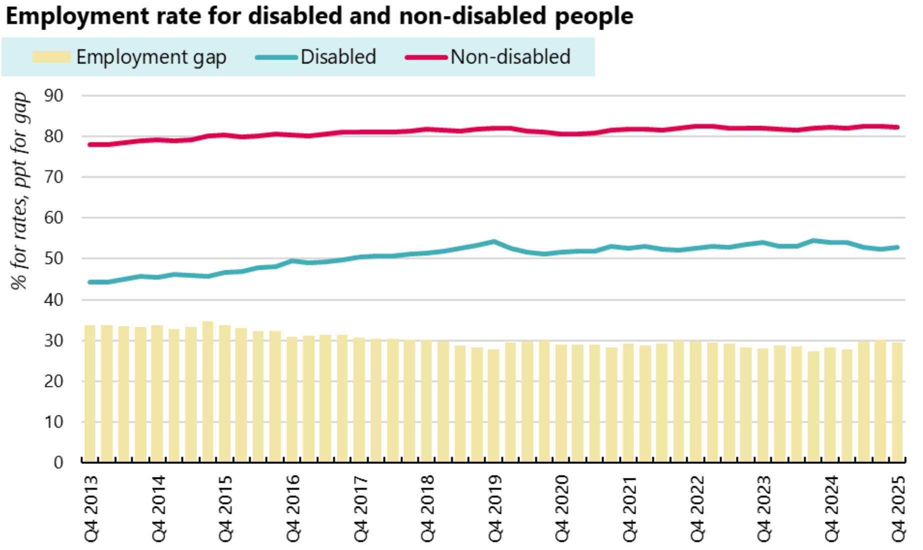
- Improve digital systems and infrastructure
- Ensure the system can respond to rising demand, including post-pandemic increases in disability

Disabled people face labour market inequalities

The latest data (Jan 2026) shows that there are 3.9 million people receiving PIP. The DWP does not routinely publish the percentage or number of people on PIP who are in employment. However, figures derived from DWP and HMRC administrative data show that between 2015 and 2023, the percentage of PIP claimants in employment ranged from 13 to 18 per cent[7]. If we apply this range to the latest data, between 510,400 and 706,700 people are estimated to be on PIP and in work.

As detailed below, we've heard from workers about how PIP payments have helped them to stay in work. Helping disabled people who want to work to stay in work is important due to the labour market inequalities already faced by disabled people.

The employment rate for disabled people is currently 52.8 per cent, an improvement from 44.2 per cent in 2013 but still far below what it is for non-disabled people (82.3 per cent)[8]. It's worth noting that progress on the employment rate for disabled people has stalled in recent years. The rate steadily climbed between 2013 and 2019, but has stuck around the same point since then. It's currently down on what it was a year ago (54.0 per cent).


Employment rate for disabled and non-disabled people

Source: TUC analysis of ONS A08 spreadsheet

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[7] *Evidence Pack: Modernising Support for Independent Living: The Health and Disability Green Paper: Section 6. Employment status of PIP claimants*, GOV.UK – DWP (2024), Available at: https://www.gov.uk/government/consultations/modernising-support-for-independent-living-the-health-and-disability-green-paper/evidence-pack-modernising-support-for-independent-living-the-health-and-disability-green-paper#employment-status-of-pip-claimants-1

[8] *A08: Labour market status of disabled people*, ONS. Available at: https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/labourmarketstatusofdisabledpeoplea08

Disabled people face other labour market inequalities. Disabled workers are more likely to be:

- Unemployed. The unemployment rate for disabled workers is 8.8 per cent, compared to 4.3 per cent for non-disabled workers. This particularly impacts young disabled workers, who face an unemployment rate of 24.2 per cent. This is double the non-disabled youth unemployment rate (12.2 per cent)[9].
- Employed on a zero-hours contract. 4.3 per cent of disabled workers are employed on a zero-hours contract, compared to 3.4 per cent of non-disabled workers[10].
- Paid less. Disabled employees face a significant pay gap. Median hourly pay for disabled employees is £2.24 less than it is for non-disabled employees[11]. On top of lower earnings, disabled people also face higher living costs. Analysis by the charity Scope shows that, on average, disabled households need an extra £1,095 each month to have the same standard of living as non-disabled households[12]

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[9] TUC analysis of Labour Force Survey Q4 2025

[10] Ibid.

[11] *TUC – Disability pay gap means disabled workers effectively stop earning from today*, TUC (2025). Available at: https://www.tuc.org.uk/news/tuc-disability-pay-gap-means-disabled-workers-effectively-stop-earning-today

[12] *Disability Price Tag 2025*, Scope (2025). Available at: https://www.scope.org.uk/campaigns/disability-price-tag

The role and purpose of PIP

PIP affects a disabled workers ability to work or stay in work

Respondents told us PIP was vital in enabling them to manage their condition while working and in making it possible for them to work at all.

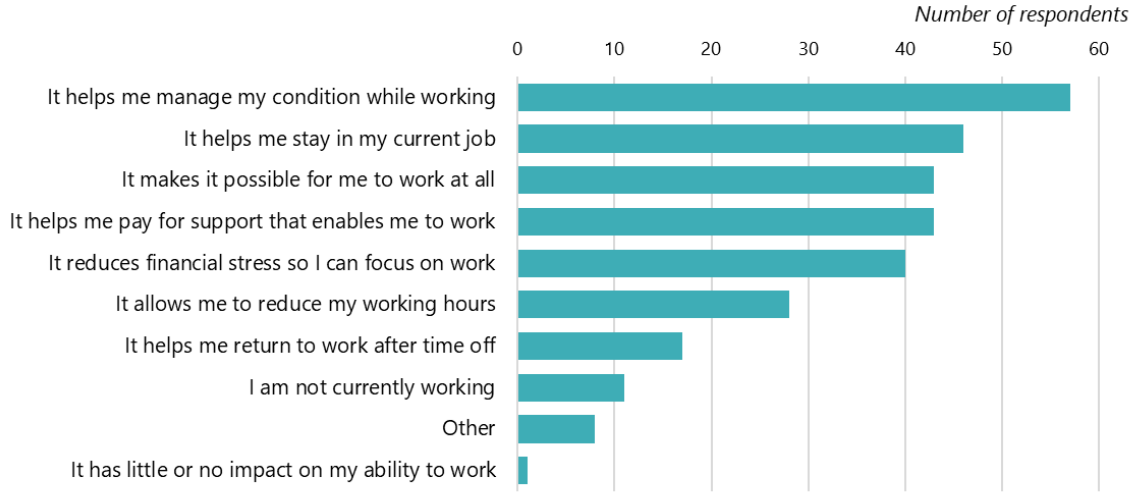
We asked survey respondents how PIP affects their ability to work or stay in work. The survey question had 10 options with respondents able to select all that applied to them.

90 people responded to this question, with 11 only saying they were not currently in work and a further one saying they were not currently receiving PIP.

Of the 78 responses from those who were currently working and receiving PIP, 77 (98.7 per cent) said PIP positively affected their ability to work. The remaining one person answered only "other".

Only one respondent out of the 90 that answered (1.1 per cent) said it had little or no impact on their ability to work. This respondent also answered that they were currently not working.

If you are in work and receive PIP (or have done recently), how does PIP affect your ability to work or stay in work?



There were 90 respondents in total. Respondents could choose all that apply.

57 of the 78 respondents who are currently working and receiving PIP (73 per cent) told us it helped them manage their condition while working, the most cited effect. 46 (59 per cent) said it helped them stay in their current job, 43 (55 per cent) told us it helped them to work at all, 43 (55 per cent) said it helped them pay for support that enabled them to work and 40 (51 per cent) said it reduced financial stress so they can focus on work.

Extra costs faced because of work

Respondents told us working creates extra costs for them and additional costs associated with being in work come in a wide range.

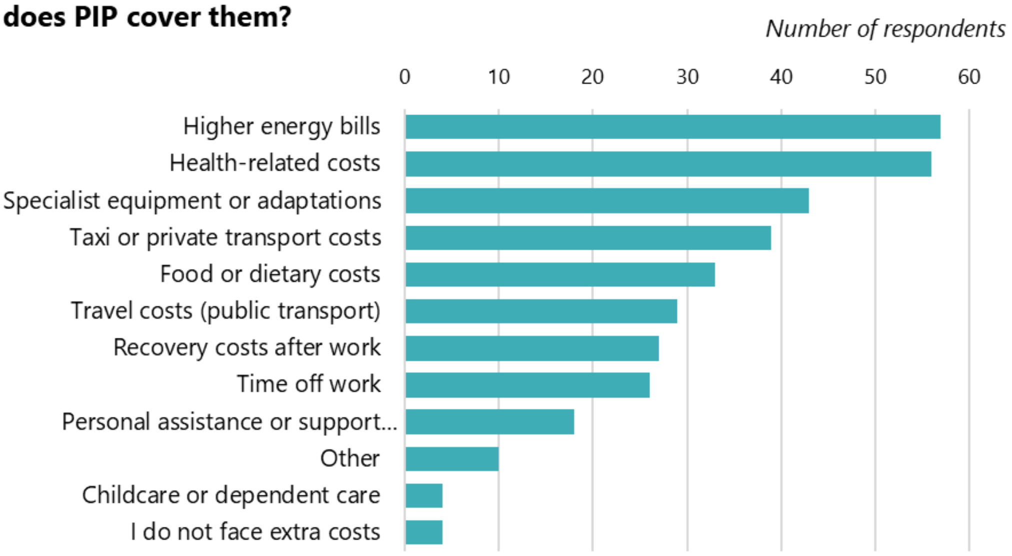
We asked respondents who were in work and receiving PIP (or have done recently), what extra costs they faced because of work, and how far PIP went in covering them. The survey question had 12 options with respondents able to select all that applied to them.

Nearly all respondents, 84 workers out of 90 (93 per cent), told us they faced extra costs because of work and used PIP to cover them. Only 4 disabled workers who completed our survey said they did not incur extra costs. Two respondents selected only "other".

The most commonly cited extra cost was higher energy bills (e.g. heating, electricity) with 57 (63 per cent) respondents selection the option, closely followed by 'health-related costs (e.g. medication, therapy) with 56 (62 per cent) people choosing it. These options were followed by 'Specialist equipment or adaptations' 43 (48 per cent) and 'Taxi or private costs' with 39 (43 per cent).

While some of these costs are not exclusively incurred as a result of work, respondents' evidence shows that employment can increase both the level and frequency of these expenses. For example, home working can increase energy use, while managing work alongside a health condition can increase reliance on medication, therapy, transport or equipment. This highlights that the costs associated for Disabled Workers are both direct and indirect, and that PIP is often used to meet a combination of work-related and wider disability-related costs.

If you are in work and receive PIP (or have done recently), what extra costs do you face because of work, and how far does PIP cover them?



There were 90 respondents in total. Respondents could choose all that apply.

PIP should support better people to stay in or return to work

Respondents said PIP could do more to help people stay in, or return to, work. A priority respondents identified was reducing delays and stress in the application and assessment process.

We asked survey respondents, what should PIP be doing to better support people to stay in or return to work. The survey question had 12 options with respondents able to select all that applied to them.

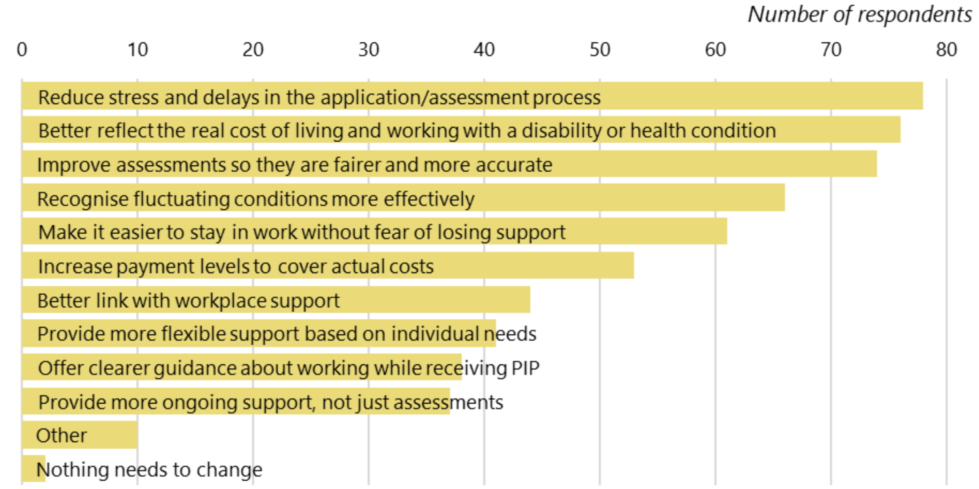
88 (98 per cent) identified ways the service could be improved. Only 2 respondents (2 per cent) said nothing needed to change.

The most commonly cited improvement was that PIP should 'reduce stress and delays in the application/assessment process' with 78 respondents (87 per cent) selecting that option.

The following four were the next most cited ways to improve PIP;

- better reflect the real cost of living and working with a disability or health condition with 76 responses (84.4 per cent),
- improve assessments so they are fairer and more accurate with 74 responses (82.2 per cent),
- recognise fluctuating conditions more effectively with 66 responses (73.3 per cent),
- make it easier to stay in work without fear of losing support 61 responses (67.8 per cent).

What should PIP be doing to better support people to stay in or return to work?



There were 90 respondents in total. Respondents could choose all that apply.

Experience of the PIP assessment process

To further understand respondents' reasoning, we asked them to tell us more about their experiences of the PIP assessment process. Respondents were able to enter free text into the survey. 75 respondents took the opportunity to share their experiences.

Their evidence shows that the current PIP assessment process is not working as intended for many disabled workers. Assessments are experienced as stressful, adversarial and unreliable, with decisions frequently corrected only at appeal. The evidence highlights assessment processes that fail to reflect the reality of being disabled, or having an impairment or health condition, and working. For some respondents, the process does not just fail to deliver support, it also acted as a barrier to assessment it in the first place.

Across responses, the process was widely described as stressful, intrusive and, in many cases, dehumanising. Respondents told us that completing forms, undergoing assessments and navigating reviews placed a significant emotional and psychological burden on claimants, often when their mental and physical health is already under considerable strain. Many reported that the process worsened their existing conditions, with stress and anxiety triggering deterioration. For some, the burden led to delaying or avoiding applications altogether. One respondent described "a million nudges to not apply, to not fill it in, to not give full information," while another said they "felt [they were] going through a police-style interview at a time when [they were] most vulnerable."

A core theme was a lack of trust in the process and an underling belief that claimants were not believed. Assessments were frequently described as adversarial, with questions experienced as misleading or designed in ways that undermine claims. As one respondent put it, "the assessment process is awful… it makes you feel like the assessor is trying to catch you out."

Respondents also raised concerns about the level of understanding demonstrated by assessors, particularly in relation to fluctuating conditions, mental health and Long Covid. The assessment framework was seen to inadequately account for variability and the cumulative impact of activity over time, with occasional capability often interpreted as full capability.

Many respondents reported being initially refused PIP or awarded no points, only to have decisions overturned at reconsideration or tribunal. This contributed to the belief that correct decisions were often only reached at or after appeal.

Structural and administrative barriers were also widely reported, including delays, poor communication and inaccessible systems. The process was described as difficult to navigate for those who have fatigue, cognitive impairment or communication needs. Frequently, respondents highlighted that communication formats did not adequately accommodate their needs.

Repeated reassessment, often within short timeframes, was a source of frustration, especially for those who had lifelong or degenerative conditions.

Overall, the evidence highlights a clear gap between the intended purpose of PIP and how the assessment process operates in practice.

Eligibility, fairness and equity in the award of PIP

PIP assessments and the realities of working life

Respondents told us the PIP assessment did not reflect what it was actually like to work if you are disabled or have an impairment or health condition.

We asked respondents if the PIP assessment reflect what it is actually like for them to work with their disability, impairment or health condition.

Respondents were able to select only one of the following five options;

- Yes, it reflected me experience well – 6 respondents (6.7 per cent)
- It partly reflected my experience – 23 respondents (25.6 per cent)
- It did not reflect my experience well – 31 respondents (34.4 per cent)
- It did not reflect my experience at all – 27 respondents (30 per cent)
- I have not had a PIP assessment – 3 respondents (3.3 per cent)

81 respondents out of 90 (90 per cent) told us the assessment did not fully reflect their experiences. Only 6 respondents (6.7 per cent) told us it reflected their experiences well, while 3 (3.3 per cent) said they had not had a PIP assessment.

Aspects of the experience not fully reflected in the assessment

Respondents told us there were areas where the assessment did not fully reflect their experiences.

To develop a fuller picture of respondents' experiences we asked what aspects of the PIP assessment were not reflected in the assessment. Respondents were able to select all the options that applied to their experiences.

87 respondents out of 90 (96.7 per cent) selected options that indicated there were areas that were not fully reflected within the assessment. Only 3 (3.3 per cent) said that 'nothing was missed.'

There were 90 respondents in total. Respondents could choose all that apply.

The most commonly cited aspect missed were fluctuating symptoms (good days and bad days) with 69 respondents (76.7 per cent) selecting that option. The other most cited aspect were the impact outside of work (e.g. recovery time) with 64 respondents (71.1 per cent), fatigue or exhaustion from working with 63 respondents (70 per cent), the interaction between multiple conditions with 62 respondents (68.9 per cent) and mental health impacts with 61 respondents (67.8 per cent).

Factors that affect the outcome of a PIP assessment

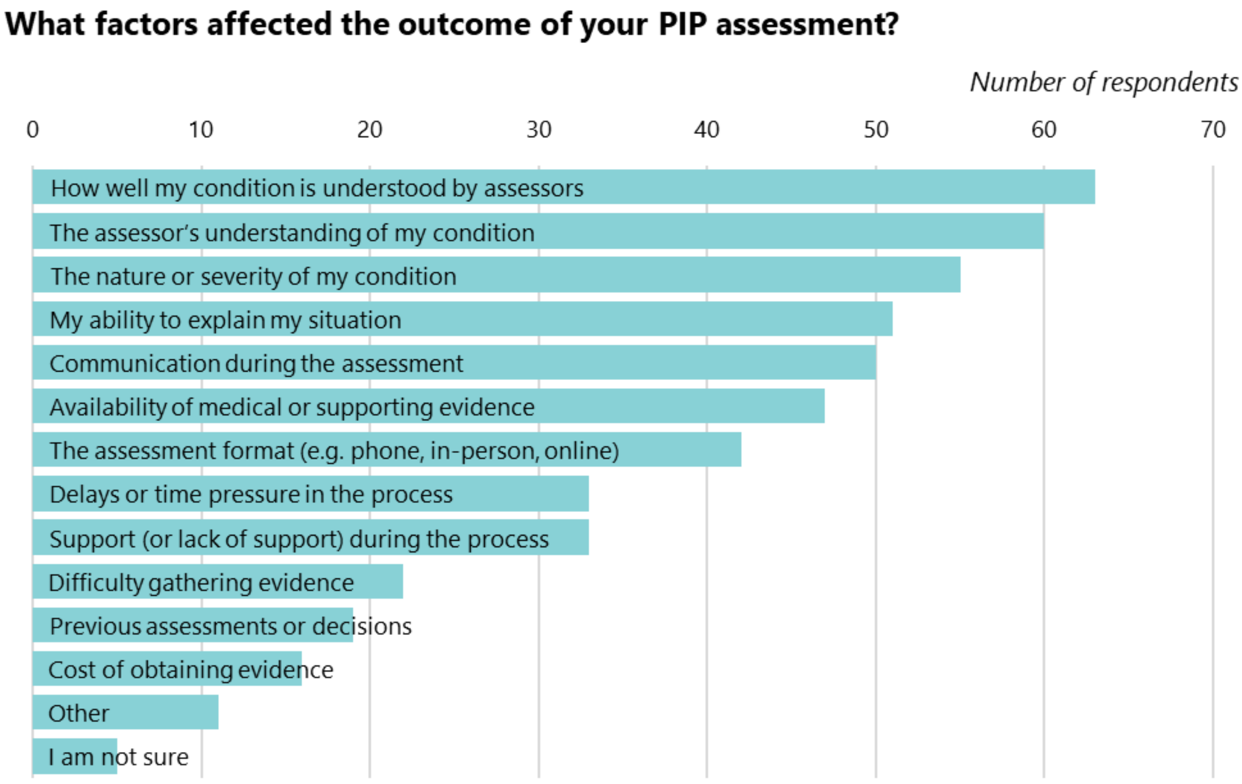
Respondents were clear the factors that impacted on their assessments the most were the assessors' understanding of their disability, impairment or health condition.

We asked respondents what factors affected the outcome of their PIP assessment. 90 respondents answered the question and were able to select any of the 12 options that applied to them.

The two most cited reasons were, 'how well my condition is understood by assessors' with 63 respondents (70 per cent) ticking that option and 'the assessor's understanding of my condition' with 60 respondents (66.7 per cent). This indicates the most important factor in an assessment is the assessors understanding of the applicants' condition, impairment or disability.

This was followed by 'the nature or severity of my condition' with 55 respondents (61.1 per cent) selecting the option and is linked to the assessors understanding.

The next most cited reasons were, ‘my ability to explain my situation’ with 51 respondents (56.7 per cent) and ‘communication during the assessment’ with 50 respondents (55.6 per cent).



There were 90 respondents in total. Respondents could choose all that apply.

PIP covering things the employer should

Just under half of respondents thought that PIP was covering costs that their employer should.

One of the ongoing issues reported to the TUC by affiliated unions disabled members is that their employers are not covering the costs of reasonable adjustments that they have a legal responsibility to provide. This creates additional strain for workers and their finances.

We asked respondents if they had to use PIP to cover things that they thought their employer or other forms of support should be covering, for example: the respondent’s condition, getting evidence, cost, communication, or the process itself.

90 respondents answered the question. Respondents were able to select one of four options including:

- Yes, regularly - 17 respondents (18.9 per cent)
- Yes, occasionally – 23 respondents (25.6 per cent)
- No – 32 respondents (35.6 per cent)

- Not Sure – 18 respondents (20 per cent)

44.5 per cent said either ‘yes, regularly’ or ‘yes, occasionally’, 35.6 per cent said no while 20 per cent said they were ‘not sure.’

Costs respondents are using PIP to cover

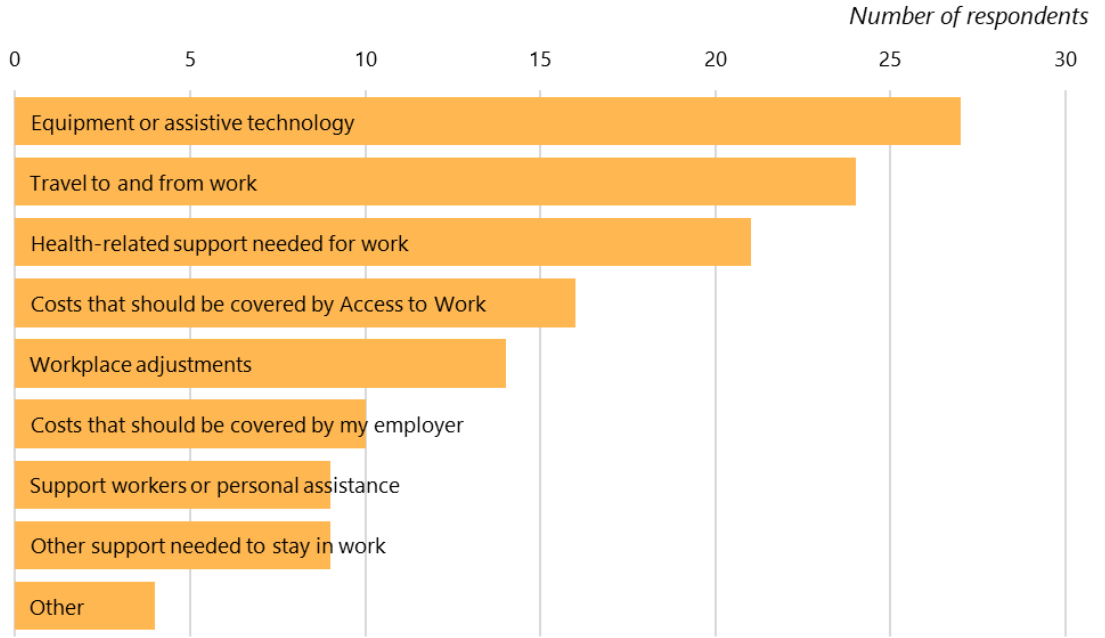
Respondents gave specific examples of where PIP was being used to cover expenses/costs that they thought their employer should be covering.

We asked respondents what costs they were using PIP to cover expenses that their employer should. 40 respondents answered the question and were able to select all/any of the 9 option that applied to them.

27 respondents (67.5 per cent) said they were using PIP to cover equipment or assistive technology, 24 (60 per cent) said travel to and from work and 21 (52.5 per cent) highlighted health-related support needed for work. 16 respondents (40 per cent) indicated they were using PIP to cover things that should be covered by Access to Work and, unsurprisingly, 14 (35 per cent) said they used PIP to cover reasonable adjustments.

Employers have a legal duty under the Equality Act 2010 to provide reasonable adjustments that remove barriers in the workplace. While Access to Work provides additional, specialist support where needs go beyond what it is reasonable for an employer to cover. Access to Work is intended to complement, not replace, employer responsibility.

Costs respondents are using PIP to cover



There were 40 respondents in total. Respondents could choose all that apply.

Experiences of the PIP assessment process

To further explore what respondents were using PIP to cover, we asked them to share additional details about their experiences of the process.

57 respondents answer the question in a free text box.

The evidence provided supports the findings set out above, particularly in relation to the extent to which PIP assessments fail to reflect the realities of living and working with a disability, impairment or health condition.

Respondents consistently described a disconnect between their lived experience and how this was captured through the assessment process showing that most respondents felt their assessment did not fully reflect their experience. Responses reinforce the importance of fluctuating conditions, fatigue, recovery time and the interaction between multiple conditions.

One respondent highlighted, “the focus felt heavily weighted toward what I could do at a single point in time, rather than what I can do reliably, repeatedly.”

Respondents also highlighted the central role of assessor understanding in shaping outcomes, reinforcing the survey findings that this is a significant factor affecting assessments. Many described experiences where assessors lacked sufficient understanding of their condition, particularly in relation to complex, fluctuating or less well-understood conditions such as Long Covid.

One said, “the knowledge of the assessor massively affects the outcome.”

Communication and the ability to explain their situation were also frequently identified as key factors influencing outcomes, particularly for those experiencing fatigue, cognitive impairment or communication difficulties. Respondents described the process as difficult to engage with, especially where assessments rely on formats that do not accommodate these needs.

The evidence provided highlighted how the structure and demands of the process itself can influence outcomes. Respondents described the process as lengthy, complex and difficult to navigate, with some reporting that they delayed or avoided applying altogether due to the anticipated burden. This reflects wider concerns about accessibility and fairness within the system.

One respondent said it was “too cumbersome and long… people… do not have the strength to apply.”

In addition, respondents reinforced concerns about how PIP interacts with work. Many highlighted that assessments do not adequately consider the realities of working with a disability, impairment, or health condition, despite the clear role PIP plays in enabling employment and managing work-related costs.

This reinforced our findings that outcomes are shaped not only by the nature of an individual’s condition, but by assessor understanding, communication, system design and the accessibility of the process itself. It also highlights a clear gap between the intended purpose of PIP and how the assessment operates in practice for disabled workers.

Experience of claiming PIP

Factors that affected the outcome of a respondent’s PIP assessment

We were interested in hearing from respondents in their own words about the factors that affected the outcome of their PIP assessment. To capture these factors, we asked respondents what factors affected the outcome of their assessment. The question was an open question, with 72 respondents sharing their experiences.

The evidence shows that outcomes are shaped both by the design and operation of the assessment process and by the impact of a person’s disability, impairment or health condition. Respondents identified consistent factors influencing outcomes, pointing to issues in how evidence is gathered, interpreted and applied.

A central theme was the role of the assessor in determining outcomes. Many respondents reported that decisions did not reflect the evidence they provided, with respondents believing assessments relied heavily on individual judgement. There was a strong perception that key aspects of respondents’ conditions were not fully explored, or were misunderstood, or actively discounted. One respondent explained that the assessor “excluded half of my needs as they did not even ask me about them,” while another described assessors “making their own decision despite [you] clearly telling them what you can’t do.”

Concerns were frequently raised about how medical evidence was used. Respondents reported that professional evidence was sometimes overlooked or contradicted, while barriers to obtaining evidence, including cost and limited support from healthcare providers, were frequently highlighted. One respondent noted that “the process didn’t seem to take account of any of the medical evidence.”

Another issue was the limited understanding of certain conditions, particularly fluctuating impairments. Respondents consistently described how variability in symptoms was not adequately reflected in assessment outcomes. One respondent stated that the process “doesn’t take into consideration fluctuating condition and conditions worse at night.”

The design of the assessment itself was also identified as a significant factor. Respondents described difficulties in accurately conveying their needs within the structure of the application. One respondent put it, “the design of the PIP assessment makes it difficult to describe chronic and/or fluctuating conditions.”

Barriers within the process were also evident, including time limits, complex forms and the effort required to gather evidence. For many, these issues acted as a deterrent to applying or challenging decisions. One respondent highlighted that they “cannot overstate how much of a barrier the forms and the 6-week deadline are.”

Communication and the ability to explain a respondent’s situation were also factors, particularly for those experiencing fatigue or cognitive impairment. As one respondent noted, “communication is a huge problem when you suffer with exhaustion and brain fog.”

There was evidence put to us that outcomes are shaped by an individual’s ability to navigate the system, with those having greater support or knowledge more likely to succeed.

The findings suggest that outcomes are influenced not only by an individual’s disability, impairment or health condition, but by assessor judgement, system design, access to evidence and support, and the ability to navigate the process.

Challenging PIP decisions

We asked respondents whether they had needed to challenge a PIP decision and, if so, what happened. 72 respondents answered the question within a free text box.

Respondents highlight a consistent pattern in how decisions were made and resolved.

Many reported that they were only able to secure a positive outcome through challenge, most commonly at tribunal. One respondent described having gone through “mandatory reconsideration and tribunal many many times… I always won.”

The evidence also showed that the ability to challenge a decision was often restricted by the impact of the process itself. Many respondents described being too unwell, stressed or overwhelmed to pursue an appeal, even where they believed the decision in their case was wrong. As one respondent explained, “I should have challenged the decision but… the stress was making my PTSD worse so I accepted it and focused on my recovery,” while another stated simply, “I’m too ill and tired to add that fight to all the others.”

For those who did appeal, the process was frequently lengthy and often worsened existing conditions. Respondents described long periods without support and the impact of stress, uncertainty and financial pressure. Some respondents highlighted that their case outcomes were revised only at a late stage, including shortly before tribunal. One respondent reported that after an unsuccessful reconsideration, they proceeded to appeal, but “just before the appeal… [the DWP] made me an offer which I accepted.”

There was also evidence that some respondents were deterred from challenging decisions due to fear of losing existing awards, even where elements of a decision were believed to be incorrect.

These findings suggest that while the appeals process can and does correct decisions, it is often not an accessible route to justice. Respondents’ evidence shows outcomes are often dependent on an individual’s ability to endure a long and difficult process. This raises serious concerns about fairness and accessibility within the system.

Changing context and key areas for PIP reform

Work and its impact on the need for PIP

We asked respondents how their work or working patterns had changed and how this interacted with their condition in an open-ended free text box. 73 respondents answered this question.

Responses show a clear pattern of work becoming harder to sustain, more costly and, in many cases, less secure for disabled workers.

Many respondents reported reducing their hours, moving to part-time work or leaving employment altogether due to their condition. Others described having to change roles to less physically demanding or lower-paid work, or being unable to progress in their careers.

At the same time, respondents highlighted that the nature of work has changed, with increased workloads, higher expectations and more mentally demanding roles. While hybrid and home working were often described as essential in enabling people to remain in work, these arrangements did not reduce workload intensity with respondents described blurred boundaries between work and recovery time, with fatigue and other symptoms extending beyond the working day.

Hybrid and home working also brought additional costs, including higher energy use and the need for specialist equipment or adapted workspaces. Many respondents reported using PIP to meet these costs, alongside transport costs where travel remained necessary.

Respondents also highlighted work-related demands, including travel, manual handling and workplace expectations, worsened existing conditions. Employers were often described as unwilling to provide appropriate adjustments.

The evidence shows that work does not reduce the need for support but in many cases it increases it. PIP clearly plays a critical role in enabling disabled workers to remain in employment but currently the system does not consistently recognise or respond to claimants lived experiences.

PIP and modern working

We asked respondents how well PIP reflects the realities of modern working life, including changing work patterns, rising costs and future pressures. This was an open question with a free text box. 72 respondents answered the question.

The evidence shows a clear and consistent view. For most respondents, PIP does not reflect the realities of being disabled, having an impairment or health condition while working in today’s labour market.

A dominant theme was the impact of rising costs. Respondents consistently reported that the financial support provided through PIP has not kept pace with the real cost of being disabled, having an impairment or health condition and working. This includes energy costs linked to home working, transport costs and the price of equipment and support. One respondent said that "rising costs needs to be addressed as a matter of urgency," while another explained that "costs have increased tremendously… there's no way I could afford to reduce my work even if it would help me manage my condition."

Respondents also highlighted that PIP does not take into account work. Many pointed out that the assessment process is disconnected from employment, despite the clear interaction between work, health and support needs. One respondent stated that "nothing on the claim form relates to work… it does not take into consideration anything to do with work nor the impact of work upon health," while another described the system as "discriminatory against people working."

There was also a strong view that the assessment framework is too simplistic and fails to reflect the realities of working in 2026. Respondents described a system focused on one-off tasks rather than the impact of work overtime, particularly fatigue and recovery. As one respondent put it, "the system looks at things in a simplistic way and not a realistic way," while another described it as "mechanical, rigid and clearly designed to reduce costs rather than actually help people."

Respondents also pointed to a lack of joined-up support across the system, particularly between PIP and Access to Work. One respondent noted that "PIP isn't a work-linked benefit… [and] Access to Work is totally unfit for purpose," highlighting gaps in how support is designed and delivered.

The evidence suggests that PIP has not kept pace with changes in the labour market, rising costs or the realities of managing health conditions alongside work.

Top changes respondents want to see to PIP

We asked respondents to tell us what they thought most important changes the government could make to PIP. This was an open question with a free text box. 72 respondents answered the question.

Respondents identified a clear set of reforms they believe would make the biggest difference to PIP. The strongest theme was the need to overhaul the assessment process so that it is fairer, more accessible and better able to reflect the realities of disabled people's lives. As one respondent put it, "the assessment process needs to be reconsidered as in its current format it doesn't work for anybody."

Many respondents called for longer awards and fewer reassessments, especially for lifelong, degenerative or irreversible conditions. One respondent said the DWP should "not bother to reassess stable unchanged conditions," while another called for "life assessment on people with irreversible diseases." This was linked to the stress, uncertainty and administrative burden created by repeated reviews.

Respondents also called for better assessor training and stronger use of medical evidence. There was clear support for assessors having proper knowledge of the conditions they are assessing, including fluctuating conditions, Long Covid, chronic pain, mental health, autism and energy-limiting impairments. Several respondents argued that expert medical evidence should carry greater weight, rather than being overridden by a short assessment.

Accessibility was another major theme. Respondents called for more time to complete forms, simpler forms, online and email submission options, better communication routes, and support to complete applications. One respondent said claimants should be given “more time to fill out forms and gather evidence,” while another called for applications to be available as “a simple document that can be emailed.”

Many respondents also wanted PIP to better reflect real costs and modern working life. This included higher rates, recognition of work-related costs, and explicit consideration of how work, fatigue, recovery time and fluctuating capacity interact. One respondent called for “a section of the assessment specifically that mentions working.”

Finally, respondents called for a change in culture. They wanted a system rooted in dignity, trust and the social model of disability, rather than one experienced as punitive or suspicious. As one respondent said, government should “quit feeding a narrative that people are scroungers or abusing the system.” Taken together, the evidence points to a need for reform that makes PIP more accurate, humane, accessible and focused on enabling disabled people to live and work with dignity.

Stigma, narrative and the impact on claimants

In this survey we asked respondents about their experiences of applying for and being assessed for PIP. Although the goal was to understand how the PIP process is functioning in practice, one consistent theme emerged that was linked more broadly to widespread narratives about and around disabled people and the social security system that it is important to note.

There is clear evidence that respondents feel a wider narrative, one that frames benefit claimants as undeserving or fraudulent, is shaping both the design and delivery of social security including PIP. With regard to PIP the narrative is experienced directly through the tone of assessments, the structure of the process and the way claimants feel they are treated.

Respondents described assessments as adversarial, with questions framed in ways that feel designed to catch them out or disprove their needs. One described it as "cruel… you are treated as if you're a scrounger or are faking your disabilities." This reflects a broader perception that the starting point of the system is disbelief rather than support.

This narrative was also linked to feelings of shame, fear and self-censorship. Several respondents described holding back information, avoiding applications or not challenging decisions because of how they expected to be perceived. One respondent spoke about fear of losing existing awards if they challenged decisions, reinforcing a sense that engaging with the system carried risk.

Respondents reported feeling that working undermines their legitimacy as claimants, despite PIP's role in enabling them to remain in employment. One respondent stated that "there is a strong belief that if you can work, you shouldn't receive PIP." This contributes to anxiety about being judged and creates barriers to both claiming and staying in work.

The impact of these narratives extends beyond individual experiences. It shapes trust in the system, with some respondents describing long-term distrust of institutions following their assessment. It also reinforces barriers to access, as people delay or avoid applying altogether due to anticipated stigma or stress.

Respondents were clear that change is needed not only in process but in tone and approach. This includes moving away from narratives that frame claimants as a problem to be managed, and towards one that recognises disabled people as workers, contributors and individuals with legitimate needs. Without addressing this underlying narrative, there is a risk that reforms to process alone will not fully resolve the issues identified.

Conclusion

The evidence is clear and consistent. Personal Independence Payment (PIP) is essential but also not achieving its aims in its current form. For many disabled workers, PIP is the difference between staying in work and being forced out. Yet the system, designed to deliver this support, is often experienced as stressful, adversarial and unreliable. Respondents were clear, the assessments process does not consistently reflect the reality of living and working with a disability, impairment of health condition. This was particularly true for those with fluctuating conditions, energy-limiting impairments and Long Covid, where assessors lacked the necessary knowledge and understanding to make informed decisions. The evidence highlighted decisions are frequently inaccurate at first instance, and often only corrected through challenge, while others are left unchallenged due to fear, exhaustion or perceived risks.

The evidence points to deeper structural issues with the design and delivery of PIP. It shows the claimants experiences with assessors are shaped by suspicion rather than support, reinforced by a wider narrative that questions the legitimacy of claimants. These experiences deter people from applying, discourage challenge and undermine trust. For too many it also has the unfortunate outcome of worsening existing health conditions. At the same time, the system has not kept pace with modern working life or rising costs, leaving disabled workers to bridge the gap between what they need and what is provided.

It is clear reform of PIP is now both necessary and urgent. Reform is needed to create a system that is more accurate at first decision, less burdensome to navigate and grounded in the lived realities of disabled people. This reform would not only improve outcomes for individuals, but also strengthen the labour market by enabling more disabled people to remain in work. This requires changes to PIP process, practice and culture. Changes that ensure assessments are fair and informed, support reflects real costs, and claimants are treated with dignity and trust. Without this shift, PIP will continue to fall short of its purpose, acting as a barrier rather than the support system it was intended to be.

Appendix 1

Motion 38 Disabled workers oppose welfare reforms

Carried motion

Received from: TUC Disabled Workers Conference

This conference notes with anger the government's spring statement, published on 18 March 2025, which attacks disability benefits (proposed significant welfare changes to Personal Independence Payments (PIP) and Universal Credit (UC)) this will force disabled workers into unemployment.

This conference condemns the UK government's plans to cut £5bn from PIP, which represents an unacceptable attack on disabled people.

Disabled people use PIP to pay for extra disability-related costs, including therapies not available on the NHS, to help them continue working.

These proposals reduce disabled people's choice and autonomy and will create more poverty and isolation. The government has ignored disabled people's advocacy organisations' evidence on the damage this will cause and instead followed the same "blame" narrative as the Tories.

Conference recognises that:

i. PIP and UC are claimed by thousands of disabled workers
ii. PIP is not an out-of-work benefit but a lifeline that helps disabled people manage the additional costs of their conditions – in work or not
iii. attacking PIP will make it even harder for people to meet the extra costs of having a disability, including those already in work
iv. employers will lose experienced, loyal workers. The treasury will lose tax and NI contributions potentially worth more than a disabled worker's PIP, disabled workers will contribute less to the economy and unemployment benefits claims will increase
v. analysis by the New Economics Foundation on the impact of the proposed cuts shows £6.7bn would be taken directly out of the pockets of disabled people
vi. up to 1.2 million disabled people will lose between £4,200 and £6,300 a year by 2029–30. Plus, the carers who will lose carer's allowance
vii. £23bn in benefits and passported entitlements go unclaimed annually
viii. over half of the 16 million people living in poverty have a disability

ix. cutting support under the false pretence of boosting employment is unjust and economically incoherent
x. leading disability organisations have warned that the planned cuts will have catastrophic consequences for disabled people
xi. these changes include blocking under 22s from claiming.

The benefits system isn't perfect but reform cannot be used to fill the budget deficit left by the Tories. Disabled people must be involved in designing a welfare system that is fit for purpose now and in the future.

Conference believes:

a) it is unjust that disabled people are forced to bear the burden of government spending choices
b) PIP is an essential non-means-tested benefit recognising additional costs of living with a disability/ long-term health condition
c) the proposed reforms attack disabled people's rights and dignity, risking deepening discrimination/social exclusion.

Conference calls on TUC Disabled Workers Committee to work with the General Council, and other trade unions to:

1. lobby government to stop the proposed changes and work with disabled people and workers on any proposed welfare changes

2. campaign for a fully resourced, supportive social security system

3. demand that instead of these regressive changes government provides a fair social security system providing dignity/respect, genuine consultation on policy with disabled people and investment in independent living, inclusive employment and accessible services

4. publicly condemn proposed changes, demanding immediate withdrawal

5. oppose all cuts to PIP and disability benefits and campaign for the expansion of financial support for disabled people

6. challenge the government and demand immediate assurances that PIP will not be cut or frozen

7. launch coordinated campaign against the cuts, highlighting their impact on disabled people

8. mobilise trade union members to stand in solidarity with disabled people through public campaigning, lobbying, and direct action

9. organise a demonstration and lobby of parliament in support of disabled workers as a launchpad for sustained trade union action in defence of workers and young people

10. organise a weekend demonstration against Labour austerity as a launchpad for sustained trade union action in defence of workers and young people

11. organise an accessible static protest against the proposals in Parliament Square before changes are implemented

12. campaign against the proposals including lobbying individual MPs and the government

13. work with disability rights organisations to resist these attacks and push for policies that genuinely support disabled people's rights, independence, and inclusion in society

14. work closely with unions to challenge the implementation of this policy

15. collaborate with disabled people's organisations – amplifying opposition

16. reaffirm their commitment to the TUC Welfare Charter.

TUC Disabled Workers Conference