



## About Merton Centre for Independent Living (Merton CIL)

Merton CIL is a user-led Deaf and Disabled People's Organisation (DDPO). We are based in the London Borough of Merton and work with Disabled adults (18+). 87% of our trustees, 69% of our staff, 81% of our members, and 100% of our service users are Disabled people with lived experience of the issues that we aim to address.

We all deserve to live free from discrimination, poverty and exclusion. However, many Deaf and Disabled people experience structural inequities that impact our ability to live independently and have choice and control over our lives.

Our **Vision**: A society where Disabled people can live as full and equal citizens in all aspects of life and lead systemic change.

Our **Mission**: Disabled people in Merton face marginalisation and disadvantage. We navigate barriers and work to create a borough that is truly inclusive.

We believe that people with impairments and health conditions are disabled by societal barriers. Therefore, our work to influence policies and practices which affect our lives is underpinned by the Social Model of Disability and an Independence Charter co-designed with Disabled people.

We work hard to provide free services and conduct work that challenges the barriers that we face:

- We run an accredited Information and Advice Service supporting with welfare benefits, social care, housing, grants, concessionary travel, and aids and adaptations issues.
- We run a person-centred Speaking Up Service that supports Disabled people to navigate barriers to healthcare and other services.
- We work as a community to achieve change locally by pushing for better access in Merton and building leadership skills in Disabled people.
- We host Craftivism and Chat sessions creating spaces for connection and joy, and encourage the utilisation of lived experience as a tool for social change.
- We bring Disabled people and supporters of the disability justice movement together to mobilise, connect, speak up and co-produce solutions to the barriers that we face.
- We provide accessible trainee and development roles.
- We conduct policy and campaigns work pushing for systemic change.

## **Merton CIL and PIP**

Over the past decade, our Information and Advice Service has taken on 1118 PIP cases, supporting service users with first-time applications, reviews, the reporting of a change of circumstances, functional assessments, mandatory reconsiderations, and appeals.

Our submission to the Timms Review's Call for Evidence is informed by a focus group run by our Policy and Campaigns Team, and attended by our staff, our Chair of Trustees, and our Vice Chair of Trustees.

## **Theme 1 – Role and Purpose of PIP**

### **How effectively is PIP delivering on its intended role and purpose?**

According to the Terms of Reference for the Timms Review, the intended role of PIP is to 'enabl[e] disabled people and those with long-term [health] conditions to live independently and fully participate in society.' However, our work shows us that in its current form and because of the way that successive governments and certain media outlets have framed discussions of it, PIP falls short of fulfilling this function in four main ways.

Firstly, whilst we are pleased that this government ditched the previous government's proposal to replace cash payments with vouchers, access to a shop/catalogue, access to certain types of treatment/support, or a receipt-based system, many claimants find that the amount of money that they receive is insufficient.

According to [Scope's Disability Price Tag 2025 report](#), households need, on average, an extra £1095 a month, just to have the same standard of living as non-Disabled households. This is because of the need for things like specialist equipment, accessible transport, higher energy consumption, adapted clothing, and assistance with personal care. PIP should close the gap, but the average payment across households is only £465 a month, leaving a £630 monthly shortfall, and since the extra cost of disability is estimated to reach £1224 a month by the 2029/2030 financial year, the shortfall looks set to increase.

The situation is exacerbated by the [high cost of living in UK](#) and ongoing problems with the Access to Work scheme.

Secondly, as detailed under Themes 2 and 3, the nature of the assessment process is such that it fails to engender independence. Our Information and Advice Service provides help with every stage – first-time applications, reviews, the reporting of a change of circumstances, functional assessments, mandatory reconsiderations, and appeals – but we feel strongly that the fact that many applicants are unable to negotiate the assessment process independently demonstrates a clear need for an overhaul of the system.

Thirdly, by repeatedly deploying rhetoric which intimates that money spent on PIP is an unsustainable drain on the economy – using phrases like ‘economically inactive’, ‘languishing on benefits’, and ‘dependent upon the state’ – both the previous government and the current government have stigmatised claimants and thereby undermined PIP’s importance as a form of social support for disabled people and people with long-term health conditions.

Indeed, reinforced by media coverage, particularly in the form of high-profile stories about claimants who are prosecuted or imprisoned for alleged misrepresentation, there is now a well-worn ‘workers versus shirkers’ narrative which separates people into those who claim PIP and those who work and pay taxes – wilfully misleading the public into believing that the former and the latter are mutually exclusive, and, in turn, not only generating anxiety for claimants, but also inevitably causing some people who would benefit from claiming PIP to hold back from trying to do so, for fear of being judged negatively.

We would like to see an end to this deception, demonisation, and division, and urge the government to, instead, educate the public about the intended role of PIP, as set out in the Terms of Reference, promoting it as a social good and publicising useful information about the assessment process accordingly. It could, for example, be fruitfully framed as essential for millions of disabled people and people with long-term health conditions who hold down jobs, or as an investment that creates demand for and, by extension, the supply of certain products or services, making it a driver of economic stability and growth.

Fourthly, whilst PIP is supposed to unlock wider benefits, such as access to the Motability Scheme, a Blue Badge, or a Disabled Person's Freedom Pass, the criteria for automatic eligibility is markedly narrow and our work reveals, at local authority level, an unwillingness and a lack of capacity to give fair consideration to applications from people whose awards do not meet this criteria. This needs to be addressed.

## **Theme 2 – Eligibility, Fairness and Equity in the Award of PIP**

**Does the PIP assessment, including the assessment criteria, effectively capture the impact of long-term health conditions and disability in the modern world, and provide fair access to the right support at the right level across the benefits system?**

Our work shows us that the assessment process discriminates against six particular cohorts and should be refined accordingly.

Firstly, whilst we are mindful that neurodivergence takes many forms, neurodivergent applicants are typically put at a disadvantage.

Out of a total of twelve activities, there are only two – 'engaging with other people face to face' and 'planning and following journeys' – for which they are likely to score points if they undertake the assessment process alone, minimising their chances of scoring enough points to equate to an award.

This is partly because the questions in the forms and the functional assessment are phrased in such a way that they lead black-and-white thinkers to fail to spell out their needs.

We know from the [DWP's guidance for assessment providers](#) that assessors are instructed to score activities according to: (a) whether an applicant 'cannot' complete an activity, or needs 'supervision',

'assistance', 'support' or 'prompting' to complete it; (b) how 'reliably' ('safely', 'to an acceptable standard', 'repeatedly', and 'in a reasonable time period') an applicant can complete an activity. However, the design of the form and the functional assessment are not transparent about this, meaning that unless an applicant is helped by a family member, friend or professional to understand how their capabilities are being judged, they will probably miss out on the opportunity to represent their needs sufficiently.

Secondly, applicants with long-term mental health issues too often miss out on an award because of an evident misconception about how people with long-term mental health issues present in face-to-face interactions. It is perfectly possible for someone with a long-term mental health issue to look as if they are not experiencing any problems, yet many reports written by the health professionals conducting the functional assessments draw inaccurate conclusions from superficial observations concerning an applicant's outwards appearance. Words and phrases like 'well-kempt', 'smart', 'clean', 'made good eye contact', and 'maintained eye contact' are used time and again in statements that attempt to justify the denial of an award, indicating an obvious training need that must be rolled out as soon as possible.

Thirdly, the nature of the assessment criteria and the way in which it is deployed by the health professionals carrying out the functional assessments frequently underplays the hardships faced by applicants with fluctuating health conditions. The lack of transparency detailed earlier in this section is once again pertinent, but it is the emphasis upon whether a health condition affects a person's ability to complete an activity, at some stage of the day, on more than 50% of days in a 12-month period, that is most problematic.

Attempting to quantify a dynamic disability in this way reveals a fundamental misunderstanding of the unpredictable but undeniably debilitating impact of it upon the shape of an applicant's life. The symptoms of, for example, endometriosis, fibromyalgia, and certain types of depression come and go. But, crucially, they are chronic conditions for which there are treatments but no cure, and flare-ups

tend to be so severe as to incapacitate someone for days, weeks or even months at a time, rendering insensitive and nonsensical the insistence of health professionals who try to pin down from an applicant how many days of the week they are affected by their fluctuating health condition.

Fourthly, applicants with impairments or health conditions that have not been officially diagnosed – usually due to a lack of capacity within the NHS, or not being able to afford to engage a private health professional in the absence of timely help from the NHS, or medical bias – are routinely dismissed by the various professionals involved in the assessment process. Although we understand that medical documentation can provide proof and, thus, reassurance that an applicant is not guilty of fabrication, we believe that its absence should not necessarily be read as an attempt to deceive.

Fifthly, the difficulties experienced by applicants with impairments or health conditions that compromise their ability to stay on top of communications such as letters in the post and emails undermine massively their ability to be independent and participate fully in society, yet go unacknowledged in the assessment process. We suggest the introduction of a question that recognises this challenge in ways that go beyond the criteria for the activities 'reading and understanding signs, symbols and words' and 'making budgeting decisions'.

Sixthly, the various professionals involved in the assessment process should show greater awareness of the possibility that some applicants come from an ethnic background that discourages or forbids them from expressing discomfort and pain and/or asking for help. With the right line of questioning, applicants in this position could be helped to explain their situation effectively.

### **Theme 3 – Experience of Claiming PIP**

## **What is the experience of people claiming PIP and does this vary for different groups of people?**

Our work shows us that the overwhelming number of people who apply for PIP have a negative experience of the assessment process:

1. Whether calling to request an application form or for some other reason, the average waiting time on the PIP helpline is too long – often an hour in our experience – and sometimes one is inexplicably cut off mid-conversation.
2. Much more work needs to be done to ensure that plain English is used throughout the assessment process. For example, 'mandatory reconsideration' could be replaced with 'second opinion'.
3. Completion of the forms requires a lot of time and energy – the latter of which is often in short supply for disabled people and people with long-term health conditions. Hence, research which looks at whether it could be made more concise, and whether it is reasonable to expect an applicant to complete it within one month of the date on which it is posted to them, would be eminently worthwhile – especially when it often takes a week or two for a form to reach the applicant.
4. It is enormously frustrating that the questions asked in the functional assessment are a repeat of those asked in the forms. Such duplication is inefficient, both in terms of time and money, and it always seems as if the health professional who conducts the functional assessment has not read the applicant's written answers or taken the time to digest them, or is trying to catch the applicant out. Furthermore, no effort appears to be made to match the specialisms of the health professionals to the applicants that they assess, casting great doubt over the former's ability to make accurate and fair judgements about the latter. As stated in the Terms of Reference for the Timms Review, one of the aims is 'to ensure [that] public money is spent as effectively as possible in supporting disabled people to live independent and fulfilling lives'. A good starting place would be a robust debate about the choice

to pay external assessment providers to ask questions that have already been asked.

5. Many applicants find it difficult to gather medical documentation because of a lack of capacity in the NHS to deal with the demand for it. Moreover, since the form seeks the applicant's consent for the DWP to contact their GP and/or other relevant professionals, it is arguably illogical that those who have given their consent are also encouraged to submit evidence. We request that the DWP and the NHS collaborate on finding a way to streamline the sharing of information on a need-to-know basis and using secure methods.
6. When one takes into consideration the extremely high overturn rate of the DWP's decisions, with His Majesty's Courts and Tribunal Service (HMCTS) more often than not finding in favour of the appellant, there is a strong case for investigating why this pattern persists, and then using the findings to help to inform the design of a more effective assessment process. Fewer appeals would not only save the state time and money, but also reduce the stress and financial hardship caused for applicants. Indubitably, mounting a challenge and waiting several months for a hearing is traumatic and, more widely, erodes public trust in the DWP.

## **Theme 4 – Changing Context and the Impact on PIP**

### **What has changed in wider society and the workplace since 2013 (and might be expected to change in the future), how has this impacted PIP and does PIP need to change accordingly?**

Our work does not put us in a position to be able to answer with confidence this notably wide-ranging question, and we suspect that there are few individuals or organisations who could provide a well-informed response to it. However, we would like to take this opportunity

to make clear our opposition to the suggestion, in the Terms of Reference for the Timms Review, that PIP becomes 'the future single gateway to health-related and disability benefits'. As the DWP often states in its defence of its decisions, the Work Capability Assessment (WCA) and PIP assess different things. Hence, receipt of the former has no probative value when considering receipt of the latter, and vice versa. PIP has never been about one's ability to work, and it is hard to picture an assessment process that could amalgamate comprehensively and fairly its concerns and those of the WCA.

## **Contact**

If you have any questions, please contact our Policy and Campaigns Manager, Dr Pippa Maslin, at [pippa@mertoncil.org.uk](mailto:pippa@mertoncil.org.uk) or on 07884 232391.

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