PIP Review Regional Stakeholder Group Views By Consultation Themes

PIP Review Regional Stakeholder Group Views by Consultation Themes

Theme 1 - Role and purpose of PIP

The stated aim was a benefit that was fairer, more consistent, and more sustainable, assessed against objective criteria developed with disabled people, health professionals and social care specialists PIP was never designed as an employment benefit. It is not connected to whether someone works or not, and is payable to people in and out of work equally. As several MPs have recently argued in Parliament, it was conceived closest to the social model of disability — **compensating for a society that is not yet fully accessible, rather than incentivising or gating employment. It is this foundational principle that many disabled people's organisations argue is now under threat from proposals to reform PIP eligibility.**

From "Personalised Support" to "Guilty Until Proven Innocent"

The original promise of a personalised, fair and consistent assessment has been widely experienced as the opposite. DWP-commissioned research — suppressed by the previous government and only made public in 2024 — found that disabled people described the PIP system as "**degrading," leaving them feeling "broken," "numb," and "fuming"**. Claimants who had received zero points described **assessors as "unsympathetic and intimidating,"** and multiple interviewees felt that medical evidence they had submitted was simply ignored. The sentiment that "**the system is set up to refuse people" **recurs consistently across claimant testimony.

The Sustainability Narrative vs. the Lived Reality

Public discourse has increasingly been framed — by politicians and some media — around fiscal sustainability rather than independent living. Even under the previous Conservative government, Secretary of State Mel Stride cited PIP spending growing from £21.6bn to a projected £35.3bn by 2028-29 as the primary driver of reform, a framing that positioned **disabled people as a fiscal

problem **rather than as citizens exercising a right to independence. Mainstream media outlets have run headlines about “record millions claiming disability handouts”, a framing that directly contradicts the founding principle of PIP as a contribution to extra costs — not welfare dependency.

Claimant Anxiety and the Erosion of Trust

PIP’s original intent as a non-means-tested, regularly reviewed benefit to reflect current need has, in practice, **generated intense anxiety around reassessments. **Sam Brown, a woman with severe sight loss, described losing sleep over reform proposals, saying: “It frightens me because this is my way of life, and I would be lost without PIP”. The Timms Review’s own Call for Evidence acknowledges that customer trust in the process and equity and inclusion in the process are live concerns requiring evidence — a tacit admission that trust has broken down.

Stigmatising media framing affects not just public attitudes but also the behaviour of assessors, local authority staff, and employers across the capital.

PIP’s Role in Independent Living — London’s Extra-Cost Premium

Nationally, Scope’s Disability Price Tag research found disabled households face extra costs of £975 per month on average, equivalent to 63% of a disabled household’s income after housing costs. In London, these extra costs are structurally higher due to:

Housing costs: London’s private rented sector is the most expensive in England, and accessible/adapted housing is acutely scarce, meaning disabled Londoners face higher housing-related extra costs than the national average

Transport: 62% of disabled people nationally cut down or stopped using their car or public transport due to rising costs; in London, where many disabled people depend on Dial-a-Ride, Taxicard, or inaccessible tube and bus networks, PIP’s mobility component is frequently the only income that makes any travel viable

Energy: 52% of disabled people nationally reported they can no longer afford everything needed for their impairment or access needs, a figure compounded in London by high utility costs and overcrowded housing

Therapies and specialist services: Private therapy costs are higher in London, and NHS waiting times for ADHD, autism, mental health and physiotherapy assessments are among the longest nationally.

Last year I was diagnosed with Bipolar Disorder but no talking therapy was made available to me on the NHS. Low-cost counselling services in my borough were recommended but were further away than I would have been able to travel for face to face therapy on a regular basis. I found a local (one bus journey away) private therapist who I trust but I cannot afford to see them weekly at £60 an hour. When this therapist had to unexpectedly go overseas for a couple of months, I had to find an alternative counsellor whose office was more complicated for me to reach and whose hourly rate was £10 more per session.

PIP’s flat-rate, nationally uniform payments systematically under-compensate London’s disabled population, whose extra costs substantially exceed the national average used to calibrate benefit levels.

I was referred to a specialist with regard to a lifelong skin condition. To attend the outpatients appointment I had to travel by bus, train and Underground train to get from my London borough to the hospital in East London. I am now on a waiting list to see a Psychologist in this hospital's Psychodermatology department. However, I do worry that the cost of, and anxiety caused by, travelling could outweigh the benefit of attending these appointments.

A London Disconnect

The Review asks about the extent to which PIP’s purpose is understood. In London, the picture is **complicated by the diversity of the population**. London’s high proportion of people with English as a second language, its large communities of recently arrived refugees and migrants, and its neurodivergent population (who may struggle with complex bureaucratic processes) all face structural barriers to understanding, accessing, and successfully claiming PIP. Inclusion London and Transport for All have jointly produced a toolkit for London organisations responding to the Timms Review.

PIP enabling employment and meaningful activity is directly relevant to London’s labour market. Connect to Work — a DWP-funded supported employment programme — is currently operating in South London boroughs (Croydon, Kingston, Merton, Richmond and Sutton), but coverage is patchy across the 32 boroughs.

Since being awarded PIP I have been in a financial position to attend local groups where I have done things such as singing, drama and creative writing. As my PIP award is currently under review I am concerned that this may not be the case in the future. It is being able to travel to and engage in these kind of activities that helps to increase my confidence and gives my life some meaning.

PIP is often the financial floor that makes it possible for disabled Londoners to engage in work at all: covering transport, assistive technology, specialist food or medication, and the unpredictable costs of fluctuating health. **Fear of losing PIP through reassessment when attempting work is a well-documented disincentive to employment** that London’s evidence base can speak to directly.

My PIP award has enabled me to engage in some in-person volunteering when my health permits, and also to attend courses that keep my brain active and increase my confidence with a view to a possible return to some kind of paid employment given that I am in the "work preparation" category with Universal Credit.

PIP is structurally inadequate for London: the benefit’s flat national rate does not reflect the significantly higher extra costs of living and participating independently in the capital

Borough-level inequalities are stark: the variation in out-of-work benefits and health deprivation across London boroughs means **PIP’s effectiveness is geographically uneven within Greater London itself**

London’s diverse population faces compounding barriers: language, digital exclusion, neurodivergence, immigration status and NHS waiting list backlogs all affect whether PIP fulfils its enabling purpose

The mobility component is disproportionately vital in London: given the capital’s still-incomplete transport accessibility, PIP mobility payments are often the only route to social participation

PIP must be a gateway, not a gateway drug to poverty: the Review’s ambition to use the assessment to unlock wider support is exactly what London’s disabled communities need — but only if linked to the capital’s specific ecosystem of services, from Access to Work to the ULEZ support schemes and local authority care packages.

A member described how PIP's premise has fundamentally changed since introduction ~10 years ago, originally meant to replace DLA for adults and roll into Universal Credit to cut admin costs 67. She filled out her son's PIP form with Mencap's family liaison officer, submitting 160 pages of reports, and he received a 10-year award initially—now extended to "ongoing award" status with review pushed to January 2027 89. Jackie emphasised that the most vulnerable on higher rate PIP are paying the most for social care, having their benefits seized by local authorities, which contradicts the independence framing.

Another member found the language "Personal Independence Payment" and "Employment Support Allowance" "highly insulting" to her daughter who functions at less than 2 years developmental age 4. She questioned why severe disability isn't acknowledged in an era focused on identity politics, noting the contradiction that those who can't speak for themselves are treated as more able than they are 45. Her daughter was moved from Severe Disability Allowance to Employment Support Allowance, and her care budget was cut by £2,000/month without notification.

Theme 2 - Eligibility, fairness and equity in the award of PIP

London’s Assessment Postcode Lottery

The PIP assessment system has been described by Inclusion London as fundamentally distorted by the biopsychosocial model rather than the social model of disability — meaning assessors are trained to explore what people can do, not the structural barriers they face. In London, this creates a particular injustice: a Londoner’s inability to plan a journey is assessed against an abstract standard, not against the reality of a tube network where only 42% of London stations are step-free, compared to 54% nationally. A Londoner with anxiety, autism or a visual impairment who genuinely cannot navigate this “accessibility lottery” may nonetheless receive zero mobility points because the assessment fails to account for London’s specific infrastructure failures.

Hidden and Fluctuating Conditions

The PIP assessment criteria are particularly poorly designed for the large and growing London population with hidden disabilities — including autism, ADHD, mental health conditions and ME/CFS

— where the impact of a condition varies day to day.

The assessment’s snapshot model of scoring fails to capture fluctuating capacity. Inclusion London has called for assessors to have demonstrably good knowledge of conditions including autism, fluctuating and episodic impairments, and mental health support needs, and for a minimum five-year gap between reassessments and the granting of lifetime awards where a condition will not improve.

I have been very fortunate to be supported by the benefits team at a local branch of Mind in completing my PIP award review form. This form arrived all too quickly after Mind finished assisting me to prepare a Mandatory Reconsideration request of the decision reached by my Universal Credit Work Capabilty Assessment. I find myself on constant high alert as I wait for a response to the MR request from UC, alongside preparing to send off my PIP review form. I will then have to wait to see if I will be required to attend an in person assessment for PIP. I understand from Mind that I may be required to travel up to 2 hours from my home to attend this. As a 53 year old who worked full time for about 25 years at the expense and detriment of my health I find it degrading to constantly have to explain and justify why I can no longer live at the pace I did previously to keep a roof over my head. I wish I could prepare a totally truthful CV so that the powers that be could see just how many times I have attempted to start over in the world of paid employment and, subsequently, volunteering. Will I have to spend the rest of my life trying to fit into the right box and tick the right criteria just to be able to survive?

Race, Culture and Structural Inequality

London’s uniquely diverse population means that cultural and language barriers to accessing PIP are far more pronounced here than nationally. Research shows that stigma around disability within South Asian and African communities creates significant barriers to accessing benefits and care, meaning PIP systematically under-serves some of London’s most deprived communities. The evidence used in assessments must be expanded to include community health worker testimony, third-sector advocacy evidence, and interpreters as standard — particularly across East and South London boroughs with large diaspora communities.

One member spent a year filling out her PIP change-of-circumstances form due to changing health and mental blocks from fear 1415. The assessment company (Igneous) scheduled her interview before her paperwork was due, and the young assessor told her "we don't look at the paperwork" 1516. After an hour-and-a-half phone call during which she had two meltdowns, she received a call days later (without security checks) demanding she do the assessment again 1718. When she refused, DWP immediately followed with 24-hour notice for their own assessment, threatening loss of Universal Credit—she believes this cannot be coincidence.

Another member reported similar harassment: after updating Universal Credit with her bipolar diagnosis (age 53), DWP offered an assessment "next week" but said she couldn't record it—only later dates allowed recording 2122. The young assessor left her waiting nearly 30 minutes, refused her request to voice record (despite being told she could ask), then behaved like "a petulant child," slouching and smirking throughout 2223. The report didn't reflect her conditions; when she requested mandatory reconsideration through Mind, DWP made 3 missed calls over Easter

weekend and demanded reasons immediately 24. Her PIP review forms then arrived (due November) with 26 April deadline—running parallel to Universal Credit assessment with year-long tribunal wait. She called this "intimidation" and "bullying" designed to overwhelm people into giving up.

Deliberate wording of PiP form/questions to confuse and create subjective answers that don't fulfill the SQL/algorythm criteria and automatically generate nil/minimum points. Also register (tone) of written word now suggests that 'incorrect' (failure to correctly describe disabilities etc) answers are a sign of attempts to defraud the system. The burden of having to provide evidence of appointments, diagnosis and explanation of disability can be overwhelming, time consuming and difficult to fulfill due to uncooperative medical professionals sending letters/notes etc to patients. NHS records/resources should be centralised so medics can be contacted for confirmation of diagnosis plus accountability of how it affects people.

Theme 3 - Experience of claiming PIP

A System Built on Distrust

Scope’s Making Benefits Work research found that disabled people consistently experience the claims process as intimidating, impersonal and disbelieving.

The use of **external commercial assessment providers** — Capita and Maximus — has been central to this breakdown in trust, as their **financial incentives are not aligned with accurate assessments**. DWP’s own suppressed research found assessors described as “**unsympathetic and intimidating”** and medical evidence routinely ignored. Inclusion London has called for financial penalties for every assessment cancelled at short notice and for tape recording as standard when requested.

I agree that recordings should be standard. It's an extra hurdle for us to navigate. It shouldn't be so difficult to request the bare minimum. If assessments more accurately reflected our lived experience then we wouldn't have to request recordings to rely on down the line.

London-Specific Accessibility Barriers

The assessment process itself creates access barriers that compound London’s geographic inequalities:

Transport to assessment centres: a Londoner with mobility impairment in Barking or Sutton may face 60-90 minute journeys to the nearest centre, an experience documented by Spinal Research’s 2026 transport challenge showing 80% of disabled participants experienced delays of 35–65 minutes due to inaccessible Tube infrastructure and broken lifts

Digital exclusion: London’s high population of digitally excluded older disabled people, and disabled people with learning difficulties, means online-first communication creates de facto barriers — yet the review is also considering AI in the process

I don't understand why the PIP award review form is sent by post. Knowing how much work has to go into completing this would it not make more sense to offer a digital version so that the applicant or those supporting them could more easily save their work as they go.

Reasonable adjustments: there is consistent evidence that requests for adjustments — home visits, British Sign Language interpreters, easy-read formats — are inconsistently applied across London's geographically dispersed assessment centres

Technology and AI: A Double-Edged Risk

The Review's interest in AI in the assessment process must be treated with significant caution by the RSN. While AI could improve consistency and reduce waiting times, the disability community's concern is that algorithmic decision-making will embed and scale existing biases — including the biopsychosocial model — rather than correct them. Any use of AI must be co-designed with Deaf and Disabled People's Organisations (DDPOs), with built-in human override and transparent explainability requirements.

A member raised fundamental question: "Is this a fair consultation?". She cited the SEND consultation where AI is being used to read responses and people finding their submissions "clipped" or "reviewed". Darren Lewis (private secretary to Keir Starmer) conducting ID card consultation told Nick Ferrari that **even if everyone opposes ID cards, "they're going ahead anyway"**—consultations only "add to policy," not change it 3536. Jackie's contacts among SENCOs believe "policy's already been decided" and consultation is just for legal cover 36. She questioned what guarantees exist that any consultation will have impact, given emphasis on defense over welfare and repeated welfare cuts tied to geopolitical crises 3637.

Another member agreed: "We should be campaigning to redefine the word consultation in the dictionary" because it now means "we'll let you say something, but we're going to ignore it" 38. At 59, with 30 years in disability field, she's been in marches, protests, Parliament consultations— **"we're still doing the same things, and we're actually now going backwards".**

If PiP is purported to fund therapies/PAs etc as a top up - why is this not supported by NHS services eg OT, SALT and yet daily living component taken by LAs for social care contributions?

A member stated, if professionals are named why are unqualified assessors used to corroborate diagnoses and the effect they have on people. Why are targets given to DWP for the amount of claimants they accept first time or per week??

Theme 4 - Changing context and the impact on PIP

The Explosion of Neurodivergence and Mental Health Diagnoses

Since 2013, the landscape of disability in London has changed fundamentally. NHS England waiting lists for ADHD and autism assessments are among the longest in the country — with waits in some

London boroughs exceeding 5 years — meaning many Londoners are living with undiagnosed conditions that affect their ability to claim or evidence PIP at all.

The rise in mental health conditions, long COVID, and complex multi-system conditions (such as EDS and ME) represents a new majority of claimants whose needs the 2013 assessment criteria were simply not designed to capture.

Self-Employment, the Gig Economy and London's Labour Market

More disabled people are now self-employed, particularly those for whom the conventional workplace fails to accommodate their strengths. Nationally, over 600,000 disabled people are self-employed — a 30% rise over five years — with push factors including inaccessible workplaces, stigma and inflexibility, and pull factors including greater autonomy and flexibility.

In London, this trend is amplified by the capital's gig economy and creative industries. However, Access to Work delays of up to 19 months are actively undermining the viability of self-employment for disabled Londoners — **PIP is therefore often the only financial floor keeping self-employed disabled people afloat** while awaiting support.

The Lilac Centre evidence referenced is relevant here: the gap between those already running businesses and those who need initial support to begin self-employment — and that some Lilac Centre events have themselves not been fully inclusive, reflecting a wider challenge in the ecosystem.

The WCA Abolition and the Expanding Role of PIP

From November 2026, the proposed minimum score of 4 for PIP eligibility will take effect, and the Work Capability Assessment is being abolished — meaning PIP will become the primary gateway to both extra costs support and UC health elements. **This is a structural shift of enormous significance: **

PIP was never designed to be a work capability assessment, and loading it with this additional gatekeeping function without co-designing a new assessment framework with disabled people risks catastrophic harm to London's most vulnerable claimants.

My WCA outcome is currently at odds with my PIP award which I have previously viewed as problematic. Are government trying to stretch PIP too far by amalgamating the two? I agree that collocative working will be needed for this change to be achieved.

Far more people are self-employed or business owners, especially for those for whom the employment workplace fails to support or facilitate their strengths sufficiently.

The Lilac Centre and its review revealed much of this evidence. However, it tends to support mostly those already running businesses, as opposed to those who need to start somewhere. Also some of its events and venues have not lent themselves to inclusion.

As a parent/carer for over 27 years now PiP has served a purpose as a 'top up' towards parent/carer who cannot work due to caring responsibilities and inadequate recompense in form of Carers Allowance through the 0-18 years due to wage stagnation, austerity and cost of living. Even as adults carers are still penalised through UC, lack of part time work plus punitive tax if over earning limits (now £204).

Extra Factors Outside Prescribed Themes

1. Geographic Cost Weighting

PIP's flat national rate was not designed with London's cost premium in mind. A formal London weighting mechanism — or a costs index mechanism linked to regional extra costs data — should be explored. This mirrors the principle already accepted in public sector pay and London Living Wage policy.

2. Intersectionality and Cumulative Disadvantage

Disabled Londoners who are also from racialised communities, are women, are LGBTQ+, or are living in poverty face **compounding disadvantages** that the current single-axis assessment cannot capture. The Review should commission i**ntersectional analysis of award rates** by ethnicity, gender and borough.

3. The Rights Framework

The UN Committee on the Rights of Persons with Disabilities has already found the UK to be in **"grave and systematic violation" of the CRPD**. Any reform must be positioned explicitly within an international human rights framework — not merely a fiscal or administrative one — with an independent CRPD impact assessment of any changes proposed.

4. Co-Production as a Non-Negotiable

While the Timms Review has appointed a disabled people's steering group, genuine co-production means DDPOs having decision-making power — not merely advisory input.

A **co-production protocol** binding on DWP is needed, modelled on best practice in London boroughs such as Camden and Hammersmith & Fulham.

5. The Crisis of Advice and Advocacy

PIP appeal success rates are extremely high — over 60–70% of tribunal appeals succeed — **which indicates systemic inaccuracy in initial decisions.** In London, the specialist welfare rights and benefits advice sector has been decimated by legal aid cuts since 2013. The Review must address the advice infrastructure required to make PIP function fairly, not just the assessment itself.

Revision #4
Created 2026-05-27 16:52:31 UTC by Marc Goblot
Updated 2026-05-28 12:10:15 UTC by Marc Goblot