PIP Review: Regional Stakeholder Network Greater London Headline Views

NOTE: This represents views of the RSN Greater London Network structured by the strength of member views. It was assembled and summarised by the Chair (chair@rsngreaterlondon.org.uk), and adds direct quotes of experience.

1. Assessors, Knowledge, and Process Failures

- Commercial providers (Capita, Maximus) have **financial incentives misaligned with accurate assessments**
- Chair emphasised assessors are **target-driven with financial incentives misaligned** with accurate assessments, working for commercial providers like Capita and Maximus with no investment in claimant outcomes
- **Target-driven sanctions culture** at DWP pressures assessors to deny claims
- **5 assessments per day** leaves no time for relationship-building or psychological safety 151719
- Assessment reports frequently contain **inaccuracies claimants must appeal**, proven by high appeal success rates demonstrating initial assessment failures
- **Member** noted workplace autism assessments at the National Autistic Society took **a full day per person plus additional write-up time,** contrasting sharply with PIP's model
- **Member** shared a job description for PIP assessors requiring **5 assessments per day** through Maven Consulting Group, with minimal specialist training requirements
- **Member** questioned whether assessors receive **Oliver McGowan statutory training** for neurodiversity or have any meaningful autism/dementia interaction training, drawing parallels to undertrained care home staff
- Assessors lack **specialist knowledge of neurodiversity, fluctuating conditions, and cultural competency**
- Marc noted assessors lack skills to evaluate less visible conditions, particularly neurodivergence, and current assessment methods don't accommodate **fluctuating needs**
- 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.
- Many people highlighted the lack of understanding, context and inclusiveness of the contact, putting additional stress on them.

- **Member's brother** was required to physically remove socks and shoes to prove 8 toe amputations in an **office setting rather than medical facility**
- Other 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.

2. London's Cost Premium and Living Crisis

- PIP's **flat-rate structure doesn't reflect London's distorted costs** for housing, transport, and support services
- Cost of living crisis has made inadequate PIP amounts even less effective at enabling independence
- **Chair** emphasised London's **cost premium and deprivation** create magnified barriers compared to other regions, discussed in his monthly disability unit chair meetings
- Chair noted **PIP is being used to top up other inadequate benefits** including carer's allowance and cost of living gaps, creating dependencies beyond its original scope
- The flat-rate PIP structure fails to reflect London's distorted cost of living, leaving claimants unable to cover actual support needs and services in London.
- **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

3. Diversity and Structural Barriers

- **Language and cultural barriers** are magnified in London's diverse communities
- **Intersectionality** (race, language, deprivation, disability type) compounds needs and access difficulties
- 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.

- **Member** described **intersectionality barriers in Tower Hamlets**, noting Sileti language has no word for autism and untrained interpreters create fundamental communication failures
- **Systemic Changes Since 2013**
  - Chair documented that **autism and ADHD diagnoses have increased dramatically** since PIP's 2013 design, with current NHS waiting lists at **4.5 years for ADHD and 2.5 years for autism in Greenwich**
  - The system wasn't configured for the volume of neurodevelopmental conditions now prevalent
- **Uneven access across London boroughs** creates disproportionate burden for some claimants based purely on geography
- Chair noted the **postcode lottery across London boroughs** creates disproportionate experiences based on geography, compounded by diversity factors

4. Modern Work Patterns

- PIP wasn't designed for **self-employment and gig economy**, now prevalent work models
- For many disabled workers, **PIP is the last support enabling employment**, making reassessment anxiety acute
- Concern that government is attempting to repurpose PIP as **work capability gateway** despite original design excluding employment assessment
- **Self-employment and gig economy work** has expanded significantly, but PIP wasn't designed for these employment patterns
- For many self-employed disabled people, **PIP is the only financial support** enabling them to continue working, creating acute anxiety around reassessments
- The concern is government may be attempting to transform PIP into a **work capability assessment gateway** despite it never being designed for employment screening

Original PIP Intent vs. Current Reality

We reviewed PIP's 2013 aims to contrast with implementation drift

Original Purpose (2013)

- Enable disabled people to **exercise right to independence** through financial support for extra costs
- **Not designed as employment benefit** or work capability assessment
- Reduce **anxiety and distrust** in the assessment process
- Provide support based on impact of condition, not diagnosis alone

Current Problems

- Creates **dependence rather than independence** through inadequate amounts and assessment trauma
- PIP’s original intent as a non-means-tested, regularly reviewed benefit to reflect current need has, in practice, **generated intense anxiety around reassessments.**
- **Reassessments for lifelong conditions** waste resources and cause ongoing anxiety
- **Media framing treats claimants as fraudsters**, reinforcing distrust
- System hasn't adapted to **dramatic increase in autism/ADHD diagnoses and mental health conditions** since 2013
- Being repurposed as **work capability screening** against original intent
- **Commercial assessment model** prioritizes speed and cost over accuracy
- **Member** highlighted that the shift from **diagnosis-led DLA to functional-assessment-based PIP** paradoxically increased costs by requiring continuous reassessments of lifelong conditions rather than accepting medical diagnosis as baseline. She argued the burden of proof shifted to claimants, similar to how health and safety responsibility shifted from employers to employees in construction.

Proposed Improvements

Assessment Reform

- Require **specialist training in neurodiversity, fluctuating conditions, and cultural competency** for all assessors
- Remove **financial incentives from commercial providers** that reward claim denials
- Establish **lifelong condition registry** to eliminate unnecessary reassessments for permanent disabilities
- Allow **multiple evidence pathways** including video documentation, recorded GP consultations, or other formats matching individual preferences
- Ensure assessments are **psychologically safe with adequate time** for relationship-building (not 5 per day)

London-Specific Adjustments

- Implement **London cost-of-living premium** in PIP rates to reflect actual support costs
- Provide **trained specialist interpreters** for diverse communities with cultural and linguistic competency
- Address **postcode lottery through standardized borough support** and equitable access

Digital Accessibility

- Create **exception processes for biometric ID requirements** that exclude blind and other disabled people from Gov.UK access
- Ensure alternative verification methods available without requiring physical post office travel

Scope Clarity

- Maintain PIP as **disability cost support**, not work capability assessment
- Recognize modern **self-employment and gig economy** work patterns in eligibility criteria
- Acknowledge PIP's role in **topping up inadequate carer's allowance and other benefits** rather than treating as separate issue

Alternative Assessment Methods

- Chair suggested exploring **multiple evidence pathways** including video documentation of daily life, recorded GP consultations, or other formats matching individual preferences rather than one-size-fits-all forms
- **Member** expressed concern that recording personal daily life is overwhelming for neurodivergent individuals who value privacy, advocating for recorded GP consultations as alternative evidence
- Chair emphasised any alternative methods must be **preference-driven and accommodate individual needs** for inclusivity

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