MPS Society

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UK MPS Society Response to the Timms Review of Personal Independence Payment (PIP)

Date: 26th May 2026

Introduction

The MPS Society welcomes the opportunity to contribute to the Timms Review of Personal Independence Payment (PIP).

We are the national charity supporting individuals and families affected by mucopolysaccharidoses (MPS), Fabry disease, and related lysosomal storage disorders. These are rare, progressive, multi-system and often life-limiting conditions which can result in highly complex physical, cognitive, behavioural and psychological needs across the lifespan.

As a voluntary sector organisation, we do not deliver statutory welfare services directly. Our response reflects the lived experiences of the individuals and families we support, many of whom rely on PIP to maintain independence, dignity and quality of life while managing progressive and fluctuating conditions.

Our response is informed by direct feedback gathered from MPS Society members with lived experience of the PIP system. All reposndant are either in receipt of PIP or are care for someone in receipt of PIP. 67% of respondents were awarded PIP initially, while 33% received an award only after mandatory reconsideration or appeal, highlighting the frequency with which decisions required challenge before appropriate support was secured.

The MPS Society recognises the importance of ensuring that PIP continues to support disabled people and people with long-term health conditions to live independently and participate fully in society. However, we strongly believe that any future reform must be grounded in a

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clear understanding of the realities faced by people living with rare, progressive and medically complex conditions.

For many individuals affected by MPS and related disorders, PIP plays a central role in meeting the additional costs of disability and supporting participation in daily life, including independence, family life and engagement in society.

Our members' experiences demonstrate significant concerns regarding the current assessment process, particularly around understanding of rare diseases, recognition of fluctuating symptoms, use of specialist evidence and the experience of claiming PIP.

Theme 1: Role and Purpose of PIP

The Review seeks to understand whether PIP is meeting its intended purpose, including enabling independent living, participation in society and supporting meaningful activity.

For our members, PIP is an essential support that enables day-to-day independence and helps manage the additional costs associated with progressive disability. These include mobility support, transport to specialist care, equipment, therapies, increased utility costs, and loss of income.

Among respondents:

- 92% reported using PIP to help cover travel to appointments
- 77% reported relying on PIP for mobility support
- 69% reported PIP helping to offset loss of income
- 77% reported additional heating and utility costs
- 62% reported caring-related costs
- 69% reported additional dietary costs
- 69% reported needing support for equipment or adaptations

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However, our evidence suggests that the intended purpose of PIP is not always consistently reflected in how the system operates in practice.

Independence and participation in society

Individuals living with MPS and related conditions often experience progressive deterioration, fatigue, pain and fluctuating capacity. These factors significantly affect independence and participation, even when not immediately visible.

Members report that support is essential to enable:

- participation in family and community life
- access to healthcare and treatment
- basic daily living activities
- maintaining dignity and autonomy

PIP therefore plays a crucial role in mitigating the additional costs of disability and supporting inclusion. However, the current assessment process does not always fully capture the impact of fluctuating and progressive conditions, which can limit access to appropriate support.

Meaningful activity and wider participation

Some members described how fluctuating health impacts their ability to work, study or participate socially. Rather than reflecting sustained capability, assessments may rely on isolated moments of functioning that do not represent overall lived experience.

Respondents noted:

"One day you can feel okay and do a few tasks and feel up to catching up with friends, then you could be out of action for a week - crippled with pain, so fatigued and unable to get dressed or showered."

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"I'm unable to work full time so I've created a self-employed role to work the days and hours I am able to. Some weeks I can do three days, others I struggle to function. We've sold our home, downsized and moved next to my parents because I need help and support."

These experiences highlight the importance of ensuring that PIP reflects real-world functioning over time, rather than snapshot assessments.

Theme 2: Eligibility, Fairness and Equity in the Award of PIP

The Review seeks to understand whether the assessment criteria fairly capture the impact of disability and long-term conditions.

Our evidence suggests that the current assessment framework does not consistently reflect the complexity of rare, progressive and fluctuating conditions.

Fluctuating and progressive conditions

69% of respondents felt the assessment process did not properly recognise fluctuating symptoms, and 77% felt there was insufficient understanding of rare or progressive conditions.

Respondents identified fluctuating symptoms (73%), mental health impacts (55%), fatigue (46%), cognitive difficulties (36%) and pain (36%) as aspects of their condition that were frequently ignored or misunderstood during assessment.

Members consistently described difficulty in ensuring that day-to-day variation, fatigue, pain and deterioration were properly understood within the assessment process.

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One parent described how limited functional observations failed to reflect their daughter's true abilities:

"There was a physical assessment that involved quickly squeezing the assessor's fingers. Because she could do that, my daughter was told she wouldn't qualify. The fact that she couldn't maintain the squeeze more than a nanosecond wasn't relevant."

Another member stated:

"They focus on a few moments where you manage something, rather than the days afterwards when you cannot function."

Use of evidence in decision-making

Families reported mixed experiences regarding the use of specialist clinical evidence. While some felt it was considered appropriately, others reported that detailed evidence from specialist centres was not fully reflected in decision-making.

One family described submitting extensive supporting evidence from Manchester Children's Hospital, including specialist consultant reports, only for the application to initially be refused before being overturned following MP intervention.

This raises concerns about consistency and the weight given to specialist input in complex cases.

Barriers to fairness and equity

83% of respondents reported being repeatedly required to explain or justify their condition, contributing to distress and perceived inequity in the process.

Members also highlighted that people with rare diseases may face additional barriers due to limited assessor familiarity with their condition.

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One respondent stated:

"Medical reports should be enough to be believed."

Another wrote:

"We were born with these conditions and cannot change them. Learn a little about the illness and progression before speaking to the applicant."

Theme 3: Experience of Claiming PIP

The Review considers the experience of claiming PIP from application through to decision and appeal.

Our evidence highlights significant concerns regarding trust, communication and the overall experience of the assessment process.

Assessment experience and trust

100% of respondents reported that the process negatively affected their mental health or wellbeing, with 54% describing the impact as significant.

Members repeatedly described the process as stressful, repetitive, emotionally exhausting and degrading.

One respondent described the process as:

"lengthy, degrading and humiliating."

Another stated:

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"Completing the form felt like a depressing reminder of everything my condition prevents me from doing."

A further respondent summarised their experience in a single word:

"Traumatic."

Several respondents described assessments that appeared poorly adapted to rare or complex conditions.

One parent reported:

"My son is non-verbal yet they insisted on him being present for a telephone call where they had no idea if he was there or not… a total waste of time and stressful."

Another respondent described repeated questioning despite detailed paperwork already being provided:

"I felt like I was constantly repeating the same answers in most of the questions."

Communication and accessibility

Members highlighted concerns regarding accessibility and the appropriateness of assessment methods for people with communication difficulties, neurodevelopmental needs and progressive conditions.

Respondents also described confusion caused by repetitive forms and assessment questions that did not adequately reflect their lived experience.

Several members called for simplified forms and alternative processes for people living with lifelong rare diseases.

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Appeals and decision-making

33% of respondents required mandatory reconsideration or appeal before receiving an appropriate award.

Several reported that decisions were only corrected after escalation.

One respondent reported being denied support twice before succeeding at tribunal:

"The judge was disgusted that after providing all the evidence I had, it had even gone to court."

This suggests that greater consistency may be needed within initial decision-making to reduce reliance on reconsideration and appeal processes.

Professional understanding and training

69% of respondents felt assessors did not understand the condition involved.

Members frequently reported that assessors lacked understanding of rare and progressive diseases, contributing to perceptions of inconsistency and reduced trust in the system.

Respondents emphasised the need for greater education around rare diseases, progressive deterioration, fluctuating symptoms and hidden disabilities.

Theme 4: Changing Context and Impact on PIP

The Review considers how wider societal changes since 2013 have impacted PIP.

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Rising complexity of disability

Our members reflect a population living with rare, progressive and multi-system conditions that require complex, ongoing support. Advances in treatment and diagnosis mean more individuals are living longer with complex needs.

Changing patterns of participation

Fluctuating conditions mean that traditional assumptions about capacity for work or activity may not reflect lived experience. Individuals may experience significant variability in functioning over time.

System adaptation and future resilience

Members emphasised the importance of a system that is flexible and responsive to progression and fluctuation, rather than fixed assessments that may not reflect long-term change.

100% of respondents believed that people living with lifelong or progressive rare diseases should receive longer-term awards with fewer reassessments, reflecting the permanent and degenerative nature of these conditions.

One member stated:

"My condition is progressive and lifelong. I won't suddenly wake up one morning without Morquio."

Another wrote:

"If medical evidence clearly states it is a progressive degenerative condition that will not improve, it should be a mandatory lifelong award."

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Voices of Our Members

Throughout this consultation, members shared deeply personal experiences of navigating the PIP system while living with rare and progressive conditions.

These experiences reflect not only the practical challenges of claiming support, but also the emotional impact of repeatedly having to justify lifelong disability.

"It's difficult enough to accept that this is our lives forever with no cure, without having to prove it over and over again."

"Why are we making it harder and harder — who does this serve?"

"Nobody wants MPS. It is incredibly difficult to live with it, assuming you don't die from it first."

"The process made me feel like a fraud and a failure."

"People with rare diseases deserve to be treated with respect and dignity."

"We don't choose not to work, to miss celebrations or cancel plans. We are allowed a day or two to feel good without being judged as fully capable."

These testimonies demonstrate the importance of a system that is compassionate, informed and capable of recognising the realities of rare, progressive disease.

Recommendations and Conclusion

The UK MPS Society supports the ambition of ensuring that PIP remains fair, effective and sustainable in supporting disabled people and those with long-term health conditions.

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However, our evidence demonstrates that people living with rare, progressive and medically complex conditions continue to face significant challenges within the current system, particularly in relation to fluctuating symptoms, assessment consistency, communication and recognition of specialist evidence.

The Timms Review should consider:

- ensuring PIP fully reflects its role in enabling independent living and participation in society
- improving recognition of rare, progressive and fluctuating conditions within assessment criteria
- strengthening the role of specialist clinical evidence in decision-making, particularly evidence provided by nationally recognised specialist centres
- improving consistency, transparency and fairness within initial decision-making
- reducing unnecessary reassessment for lifelong progressive conditions
- improving communication, accessibility and person-centred assessment practice
- ensuring assessments reflect real-world functioning over time rather than isolated observations
- improving understanding of fatigue, pain, cognitive impacts, hidden disability and mental health impacts associated with rare disease
- considering simplified or specialist pathways for lifelong rare and degenerative conditions

Without explicit consideration of rare and progressive conditions, there is a risk that people with the most complex needs may continue to experience inequitable outcomes within the PIP system.

The UK MPS Society remains committed to working collaboratively with government and stakeholders to ensure that the voices and experiences of people living with rare diseases are fully reflected in the future development of PIP.