



MS Society policy position statement – Personal Independence Payment (England, Scotland and Wales)

November 2019

Issue

MS is a neurological condition that affects more than 100,000 people in the UK. Due to the fluctuating and progressive nature of the condition, people are affected differently by symptoms that include fatigue, pain, loss of mobility, visual impairment and cognitive problems.

In 2013 Personal Independence Payment (PIP) started replacing Disability Living Allowance (DLA) with a view to supporting disabled people to live independently and to target support to those who need it most¹. At the same time, the government argued that the cost of DLA is unsustainable, and the move to PIP was estimated to save around £2 billion.

At the time of writing, 45,994 people with MS were in receipt of PIP², with a further estimated 17,000 waiting to be reassessed from DLA³.

People living with a neurological condition spend an average of £200 per week on costs related to their condition⁴. Personal Independence Payment (PIP) is a benefit that is designed to help disabled people manage these extra costs. It can help people pay for things that are essential to allow them to live independently, such as leasing adapted cars through the Motability scheme, paying for help around the home or for therapies to manage their condition. However, for many people with MS PIP will not cover all the costs associated with their condition⁵. The maximum weekly PIP award is currently £148.85.

While PIP works well for some, we continue to find evidence that it fails to adequately support many people with MS. A large number of people with MS who qualified for DLA are seeing a drop in the level of their awards as they are reassessed for PIP. Our research shows that changes to the rules in the way mobility is assessed - the 20 metre rule - is one of the main reasons for this.

We are also concerned about award lengths which are shorter under PIP, and leading to unnecessary reassessments, the quality of assessments, assessors' lack of knowledge and understanding of MS, and confusion over the collection and use of evidence by assessors.

We believe that people living with MS should be able to receive essential financial support they are entitled to. Having MS is hard enough. It shouldn't be made harder by a welfare system that doesn't make sense.

Devolved benefits in Scotland

The Social Security (Scotland) Act 2018 saw the creation of a new agency Social Security Scotland, which will be responsible for the administration of PIP in Scotland. The Scottish Government has already committed to making a number of changes to the benefit, including:

- The application process for Disability Assistance (the proposed new name for PIP) will be inclusive, accessible, provided in a range of formats, available through a range of routes (online, phone, post and in-person) and transparent.
- A holistic, person centred approach will be taken to decision making - consideration will be given as to how an individual's condition affects them, taking into account all of their circumstances.
- The system will be designed with the intention of significantly reducing the number of individuals required to attend a face-to-face assessment.
- All Social Security Scotland staff involved in decision making will undergo robust training reflective of the Agency's values of dignity, fairness and respect.

The Scottish Government has set out an indicative timetable for the transfer of the devolved benefits with new PIP claimants coming on-stream in 2021 and the full transfer of current PIP claimants by 2024.

Evidence/Findings

1. Applying for PIP

The application form is the first opportunity for people with MS to explain how their condition affects them. However, for many people with MS, it is also the first barrier to obtaining the right level of support.

Respondents to our 2019 survey about the PIP application process told us the form is too long and complex, yet it does not enable them to explain how fluctuation and hidden symptoms affect them. Two thirds (65%) of respondents said completing the form was either hard or very hard, and a majority (61%) of those respondents said the form was too long. Only 13% of people with MS said it allowed them to fully explain how their condition affects them and only 10% said the form allowed them to fully explain how the symptoms of their MS fluctuate.

Claimants are required to return the application to the DWP within 4 weeks. A third (32%) of respondents to our survey said this was not enough time to complete the form. The main reasons cited were that the form is too long, the effect of their symptoms make it difficult, and being unable to find help to fill the form in.

2. Evidence collection

People with MS said returning the form on time was difficult because of the time it took to get supporting medical evidence. Of all the respondents who said it was difficult to return the form within 4 weeks, the top reason given (at 59%) was 'I couldn't get evidence from my healthcare professional(s) in time'.

There is some uncertainty around whether assessors will request evidence from healthcare professionals. This means that people with MS often prefer to obtain the evidence themselves. They are most likely to request evidence for PIP applications from their MS nurse. Of MS nurses who responded to our survey, 26% said it takes 3-4 weeks to provide evidence, demonstrating the difficulty of getting evidence in time⁶.

Having to pay for evidence can also be a barrier to obtaining evidence for people with MS⁷. The cost of paying for multiple pieces of evidence can place a huge financial strain on disabled people who are in the process of applying for vital financial support.

Even when claimants submit further evidence with their claim, they feel that often it is not considered – over half of the respondents to a DBC survey disagreed that the assessor took into account extra evidence about their condition that was sent with their application form⁸.

3. The face to face assessment

The Department for Work and Pensions (DWP) is the government department responsible for PIP, but face to face assessments are carried out by contracted companies.

The PIP assessment guide stipulates that all assessments should be conducted face to face, except in certain cases where the claimant has a severe condition, including neurological conditions. Despite this, the majority of people with MS who apply for PIP have a face to face assessment, either at home or in an assessment centre⁹.

Too often the face to face assessments fail to accurately and adequately capture the complex and fluctuating nature of MS and the impact this has on day to day life.

Assessors' lack of knowledge of MS is an issue people with MS have been telling us about since PIP was introduced. In a response to our survey, 55% disagreed that the assessor understood the impact of their MS, and the same proportion disagreed that the assessor had a good understanding of MS. Over half of respondents (54%) disagreed that the assessor considered their hidden symptoms such as pain, fatigue or cognitive difficulties¹⁰.

The fluctuating nature of MS is also overlooked in too many assessments. Of respondents to the survey, 44% disagreed that the assessor gave them the opportunity to explain how their MS affects them differently at different times.

According to PIP guidance, assessors must consider whether claimants are able to carry out each activity safely, to an acceptable standard, repeatedly and in a reasonable time. This is known as the reliability criteria. But too often, people with MS say that assessors overlook the reliability criteria, and only assess the ability of a claimant to do an activity on the day they are assessed. Many respondents to our survey told us the reliability criteria was not considered by their assessor¹¹.

The PIP assessment guidance is clear that informal observations - behaviours and actions that the assessor can see during the assessment - should be balanced against evidence. However, 67% of respondents to our survey who had informal observations included in their assessment report said the observations did not reflect how their MS affects them. 43% said they didn't reflect whether they could do the activity again¹².

Informal observations are also used to make assumptions about abilities. Nearly half (48%) of respondents to the survey who had informal observations included in their assessment report said they were incorrectly used to assume that they were able to do something else.

4. The 20 metre rule assessment criteria

The eligibility criteria for the higher rate of the mobility support was reduced from 50 metres under DLA to 20 metres under PIP. This means that anyone who is able to walk just one step over 20 metres no longer qualifies for the higher rate of mobility support.

Under DLA, 94% of people with MS were receiving the higher mobility rate, but today only 72% are receiving the higher mobility rate under PIP. In a 2018 survey of people with MS, 47% of people who were reassessed from DLA to PIP said their award reduced from higher to standard rate mobility following the transition¹³. This is by far the most common decrease for people with MS who have been reassessed from DLA, meaning that the 20m rule is the main reason that people with MS are losing vital support under PIP.

The changes to the assessment criteria for the higher rate mobility support result in people with MS losing their access to Motability cars, or to being trapped in their homes¹⁴. This rule doesn't reflect the real experiences of people with MS, who are still likely to have the same significant level of need for mobility support.

5. Decision making

Once an assessment has taken place, the assessor sends a report on to the DWP Case Manager, who reviews the report, the recommendations within it, and the evidence. They then tell the claimant what level and duration of award the claimant will receive in a decision letter.

Over half (54%) of the respondents to the survey who have had a decision on their PIP claim said they disagreed with the initial decision. 45% of respondents who had a decision said they did not think they were given enough information in the decision letter to explain how the decision was made¹⁵.

The assessment report, which details information gathered at the assessment and the recommendation to the Case Manager about the level and duration of the award. The report is not automatically sent to all claimants but can be requested from the DWP. Only 46% of respondents to our survey who had a decision on their PIP claim saw a copy of their report, and 39% of respondents said they would have liked to see it, indicating that 4 out of 10 people are either unaware they can request it, are unclear about how to request it, or what the benefits of seeing their report might be. Without seeing the report it may be difficult for people with MS to decide whether the decision they received is correct, and whether or how they should challenge it.

6. Assessment recordings

Currently the PIP assessment guidance stipulates that PIP assessments can only be audio recorded if the claimant brings their own equipment – a recording device that is able to produce two identical copies, either on audio cassette or CD. Such recording equipment is expensive and not readily available to the majority of people with MS.

The DWP has recognised that trust in PIP assessments is very low. One of the ways the Department is trying to rebuild trust is by looking at ways to record the assessments, including audio and video options, where the equipment will be provided by the assessment providers rather than the claimants.

People with MS want to have the option to record their assessment. Two thirds (66%) of respondents to our survey would be happy to have their assessment video recorded, but a much higher proportion (84%) would be

happy with audio recordings¹⁶. One stipulation however came up a number of times – that the claimant is provided with a copy of the recording.

7. Reassessments

Reassessments under PIP are far more common than under the predecessor benefit DLA. Under DLA, 78% of claimants with MS had awards of 5 years or more¹⁷. In contrast, since PIP was introduced only 48% of people with MS received an award of 5 years or more¹⁸. Reassessments are therefore taking place for far more people with MS, despite MS being a progressive condition which is unlikely to improve. This causes unnecessary stress and anxiety as people continually have to prove their eligibility for the benefit.

In 2018 the Government announced new PIP guidance that means people who are awarded the highest level of support under PIP, and whose condition is unlikely to improve, will get an ongoing award with a 'light touch' review every 10 years¹⁹. The light touch review is currently being designed by the DWP.

8. Mandatory reconsiderations

If a claimant disagrees with their PIP decision, they can ask the DWP to look at the decision again. This is called mandatory reconsideration and must be requested by the claimant within one month of the decision date.

Of respondents to our survey who did not agree with their initial decision, only 63% requested a mandatory reconsideration. There are a number of reasons why people with MS do not challenge a decision they disagree with.

Only 42% of respondents to our survey who received a PIP decision agreed they were provided with clear information about the right to a mandatory reconsideration. One in 10 of those who disagreed with their decision were unaware that they were able to request a mandatory reconsideration²⁰.

The stress of the application and challenge process, the fear of ending up with a lower award, and lack of trust in the assessment process are all reasons people with MS give as to why they choose not to challenge a decision. The restrictive one month deadline is also a barrier, as MS symptoms can make it difficult to launch a challenge within this timeframe.

The DWP has rolled out new guidance to all Case Managers dealing with mandatory reconsiderations, ensuring that they contact the claimant to discuss their case and find out if any further evidence can be obtained to help with the reconsideration. This is a necessary step in improving the mandatory reconsideration process, where normally 80% of cases are upheld, and there are already signs that the new guidance is leading to more decisions being changed at mandatory reconsideration²¹.

9. Appeals

Three in four disabled people who appeal their PIP decision at tribunal are successful²². People with MS who were reassessed from DLA to PIP and challenge their decision at tribunal win at a rate of 83%²³.

However, 49% of respondents to our survey who disagreed with their decision said they did not think they were provided with clear information about the right to appeal and how to go about it²⁴.

People with MS also find that the process of appealing is too stressful, so even when they do not agree with a mandatory reconsideration decision, they do not go on to challenge the decision in court. All this suggest that the number of appeals by people with MS is artificially low.

10. The extra cost of PIP

Since PIP began replacing DLA in 2013, one in three people with MS have lost support, compared to the level of support they could expect under DLA. Support is primarily lost because of the 20 metre rule.

The DWP said there would not be 'any significant additional costs' to other government departments as a result of the 20 metre rule²⁵. However, MS Society research reveals that loss of support has serious implications for people with MS, as well as their family and friends, in terms of their health and employment. This in turn leads to significant extra costs to other Departments, as well as to the Exchequer and the DWP itself, which can be directly linked to the 20 metre rule.

The MS Society calculated that over the three year period from April 2020, the DWP would save £83.3 million from people with MS losing out due to the 20 metre rule, but the knock on costs to Government would be £92.7 million. These costs include increased use of GP and A&E services, increased spend on Carers' Allowance and Employment and Support Allowance, and loss of tax revenue as people with MS and their carers are forced to reduce their working hours or leave work altogether²⁶.

11. Quality assurance

The DWP uses a number of ways to assess how well it is doing in delivering benefits. The DWP's Customer Charter, Claimant Service and Experience Survey and the Single Departmental Plan all provide standards against which customer service delivery objectives are advertised and monitored.

However, a number of bodies such as the Equality and Human Rights Commission, the National Audit Office and the Social Security Advisory Committee argue that the Department's existing methods of monitoring and standards are inadequate and not fit for purpose. They recommend that the

DWP establishes suitable performance measures for delivery of working-age benefits. The Work and Pensions Committee also recommended that the DWP looks at whether there is a case for establishing an independent regulator for working age benefits and services.

Although assessments are conducted by contracted-out companies, the responsibility for ensuring assessments and decisions are of good quality rests with the DWP. In its contracts with the assessment providers Capita and IAS (Atos), the Department stipulates that no more than 3% of reports assessors submit should be deemed 'unacceptable'. According to information shared in 2018 by the then Minister for Disabled People with the Work and Pensions Select Committee neither company has met this target to that date²⁷.

The DWP's quality standards for PIP set a low bar for what is considered an acceptable standard²⁸. The DWP accepts flawed reports, with incomplete use of evidence and which contain serious errors but not ones that are deemed to affect the decision. The only unacceptable reports are those where a Case Manager would not be able to use to make a decision or it will cause them to make the wrong decision.

Recommendations for government

- The DWP, in consultation with disabled people and charities, should redesign the PIP application form to ensure that it allows people with progressive and fluctuating conditions to fully explain how their condition affects them.
- The DWP should extend the deadline to submit the PIP application form to 8 weeks as standard to allow claimants to obtain evidence and the support they need to fill in the form.
- The UK Government should ensure independent advice services are available to deliver help in filling in PIP application forms. Services should be available to all claimants in the UK free of charge and there should be clear signposting to this service in every communication from the DWP.
- The DWP should provide clear guidance to all claimants on the type of evidence they should provide, including evidence from informal sources such as friends, family and carers.
- The DWP should provide clear guidance to healthcare professionals, including specialists such as MS nurses and neurologists, on what evidence they should provide to support PIP claims.
- The DWP should strengthen PIP assessment guidance on evidence collection to ensure that evidence is always requested by assessors when assessing claims by

people with MS and other complex neurological conditions. Case Managers should return reports that do not comply with the guidance.

- The DWP should engage with the MS Society and MS specialist professionals including MS Specialist nurses, Occupational Therapists and Physiotherapists to review evidence collection mechanisms to ensure they are easy to use and well understood.
- People with MS should only be assessed by assessors who have some professional experience of neurological conditions and have received training developed in conjunction with relevant charities.
- Assessors' reports must consider the reliability criteria for each descriptor, proactively setting out evidence for why they consider that each activity can be carried out safely, to an acceptable standard, repeatedly and in a reasonable time. Case Managers should return reports that do not comply to the assessment providers, and no decision should be taken without fully considering the reliability criteria.
- All informal observations included in the assessment report must be backed up by evidence. Where this is not the case or where the assessor has chosen to 'override' evidence from healthcare professionals and the claimant, the assessor must explain this clearly in the report. Case Managers should return reports that contain unsubstantiated informal observations.
- The DWP should amend the PIP assessment descriptors to embed the reliably, repeatedly, safely criteria and their definitions within the wording of each descriptor.
- The DWP should ensure both audio and video recordings of PIP assessments are provided as an option to claimants.
- Assessors should ensure a copy of the audio or video recording is provided to the claimant at the end of the assessment
- The Government should scrap the 20 metre rule for the highest rate of PIP mobility support. A review and design exercise should be carried out with disabled people, charities and healthcare professionals to design an agreed appropriate alternative. In the meantime the 50 metre threshold should be reinstated.
- The DWP should carry out an evaluation of how the PIP assessment criteria consider hidden symptoms including pain, fatigue and cognitive symptoms.
- PIP guidance should require assessors to demonstrate that they have sought and considered further evidence from the professionals a person with MS lists on the PIP application form.

- Assessors should be legally bound to provide a copy of the assessment and any medical evidence they obtained at the decision stage in every case, so that claimants are fully aware how a decision was made, and provided with all the information they require should they decide to appeal.
- The DWP should work with GPs to establish a mechanism for GPs to charge the Department for letter-writing fees rather than these charges being placed on claimants.
- DWP Case Managers should contact claimants prior to making a decision on mandatory reconsideration, to discuss the case and obtain further evidence if necessary.
- The Government should explicitly include MS in the list of 'severe neurological conditions that should not require a face to face consultation' under para 2.5.10 of the PIP Assessment Guide.
- The DWP should review and establish suitable performance measures and targets for disability benefits, including PIP. These should be published regularly.
- Assessment providers' performance metrics should be monitored by an external, independent body that also has responsibility for direct observations of assessments, with a role analogous to that of the Care Quality Commission for the health and care system.

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- ¹ Department for Work and Pensions – Personal Independence Payment rolls out to existing claimants (2013)
- ² Department for Work and Pensions – data available on Stat-Xplore, figures for PIP from July 2019
- ³ Department for Work and Pensions – number of people with MS under the age of 70 receiving DLA. Figures for February 2019 obtained from the Stat-Xplore website
- ⁴ Extra Costs Commission – Driving down the extra costs disabled people face - final report (2016)
- ⁵ DBC – Supporting those who need it most? Evaluating Personal Independence Payment (2017)
- ⁶ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 16
- ⁷ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 16
- ⁸ Disability Benefits Consortium (DBC) – Supporting those who need it most? Evaluating Personal Independence Payment (2017), p. 17
- ⁹ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 20
- ¹⁰ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 20
- ¹¹ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 22
- ¹² MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 24
- ¹³ MS Society – PIP: A step too far (2018), p. 28-29
- ¹⁴ <https://www.mssociety.org.uk/get-involved/campaign-with-us/ms-enough/scrap-pip-20-metre-rule>
- ¹⁵ MS Society – PIP fails: how the PIP process is betraying people with MS (2019), p. 28
- ¹⁶ MS Society – PIP fails: how the PIP process is betraying people with MS (2019), p. 27
- ¹⁷ MS Society – MS Enough: Make welfare make sense (2016) p. 25
- ¹⁸ DWP response to Freedom of Information request by MS Society, July 2017
- ¹⁹ DWP – Government to end unnecessary PIP reviews for people with most severe health conditions (June 2018)
- ²⁰ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 31
- ²¹ DWP – Personal Independence Payment: official statistics (quarterly), September 2019, p. 6
- ²² Ministry of Justice – Tribunal statistics quarterly, April to June (provisional), September 2019
- ²³ DWP – response to parliamentary question 180081, October 2018
- ²⁴ MS Society – PIP fails: how the PIP process betrays people with MS (2019), p. 32
- ²⁵ DWP - The Government's response to the consultation on the PIP assessment Moving around activity, October 2013, pp. 25
- ²⁶ MS Society – The cost of the PIP 20 metre rule, April 2019
- ²⁷ Department for Work and Pensions – written evidence to the Work and Pensions Select Committee, PEA0449, 2018
- ²⁸ Work and Pensions Committee – Welfare safety net: twenty-eighth report of session 2017-19, July 2019