

SUPPORTING THOSE WHO NEED IT MOST?

Evaluating Personal Independence Payment

A report by the Disability Benefits Consortium

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Supporting those who need it most?

Executive summary

About the Disability Benefits Consortium

The Disability Benefits Consortium (DBC) is a national coalition of more than 80 different charities and organisations committed to working towards a fair benefits system. Using our combined knowledge, experience and direct contact with millions of disabled individuals and carers, we seek to ensure that Government policy reflects and meets the needs of all disabled people.

About the research

Personal Independence Payment (PIP) is a source of financial support designed to help disabled people and those with long-term conditions manage the extra costs of their condition. It was introduced in 2013 to replace Disability Living Allowance (DLA) with a view to “focus support on those with the greatest need”¹.

The Department for Work and Pensions (DWP) has commissioned two independent reviews into the implementation of PIP over the last five years. However, there has never been a detailed examination of how effectively PIP is working overall and, crucially, whether it is meeting its policy objectives. With no further reviews to come, this report is the first detailed opportunity to evaluate PIP as a whole.

In order to examine how well PIP is operating for disabled people and those with long-term conditions, the DBC and its members conducted a survey of 1,730 PIP claimants. We have also pooled DWP statistics and DBC member organisations’ own research and insights to contextualise these findings.

It’s clear that extra-cost benefits can make a huge difference to the lives of disabled people and those with long-term conditions. However, there are significant problems with how PIP works and is operating. These problems are increasing stress and anxiety among claimants and are often preventing people from getting the support they need.

For many people, PIP simply isn’t working.

Research findings

Submitting a claim for PIP is extremely difficult and providing supporting evidence is a struggle.

- Over 70% of respondents found the PIP application form ‘hard’ or ‘very hard’ and 11% of respondents were unable to complete it at all.
- Almost 60% of respondents found providing supporting evidence ‘hard’ or ‘very hard’.

The stress and anxiety of undergoing PIP assessments is making people’s conditions worse.

- Almost two-thirds of respondents to our survey disagreed when asked if assessors understood their condition.
- Almost 90% of respondents described their assessment as ‘stressful’.
- Over three-quarters of respondents agreed that the stress and anxiety associated with their PIP assessment had made their condition worse.

The PIP assessment criteria are preventing people from getting the support they need

- Evidence from DBC organisations has consistently shown that the assessment criteria continue to fail to account for fluctuation, and changes to the mobility criteria have seen many people with significant need lose out on support.
- Restrictions to the criteria have been proposed by the Government in a haphazard fashion since 2013 without clear evidence, an underlying strategy or significant input from disability charities.

Disabled people aren’t receiving the right level of financial support under PIP to manage the extra costs they face.

- Over half of respondents disagreed when asked if they thought they were awarded the right level of financial support. Of those respondents who had seen a copy of the PIP report completed by their assessor, 64% felt it ‘badly’ reflected the answers given during their assessment.

- DWP data shows that almost half (48%) of those who have already been reassessed from DLA to PIP have either totally lost their award or received a reduced award to date.



- DWP figures² show that of those in receipt of the higher rate of DLA mobility who have been reassessed, 25% have had their benefit reduced to the standard PIP mobility rate and 25% have lost their mobility rate altogether.

Gaining access to PIP benefits people significantly, but losing access to extra-costs support has damaging consequences.

- 58% of people who had gained support under PIP explained that it enabled them to buy the extra things necessary to carry out daily activities independently, while 32% of respondents reported an improved relationship with family members, their spouse or carer.

- 40% of people who told us they had lost access to their Motability car explained that they could no longer get around independently. 44% were forced to buy their own car and 31% were forced to pay for taxis, with consequences for their ability to get out and about.

The numbers of PIP claimants seeking to appeal their decisions are increasing exponentially and the majority of these appeals are successful.

- PIP appeals now comprise 45% of the Social Security and Child Support (SSCS's) 228,000 total tribunal receipts in 2016/17.
- In 2013/14 the proportion of successful PIP appeals stood at 26%. In the fourth quarter of 2016/17 this increased to 64%.

Recommendations

PIP is not fit for purpose in its current form. It requires significant, urgent improvement to restore fairness and disabled people's confidence in the system. The DBC recommends the following changes:

Application process

1. The DWP should immediately introduce simplified claim forms that are readily available in Jobcentres, downloadable online and in accessible formats (such as audio described and easy read), without the need to return them within four weeks.

Evidence gathering

2. The DWP should commission an independent review of the evidence gathering processes, to explore ways to:
 - educate health and social care professionals on how to provide relevant supporting evidence
 - ensure duties and responsibility of the assessor, the DWP and claimant are clear and observed
 - make sure the DWP has a strategy to articulate to claimants what evidence will be most useful for their claim
 - ensure evidence supplied by friends and family members is given due consideration
3. In order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant, with penalties if they do not.

Assessments

4. A thorough review of the PIP assessment criteria should be urgently conducted, with meaningful involvement from disabled people and those with long-term conditions to ensure criteria are fair and truly reflect the extra costs that people face. In particular, this should focus on examining rules setting out how fluctuation is considered.
5. Restore the '20-metre rule' for enhanced mobility support to 50 metres.
6. The DWP must re-establish direct responsibility for assessment quality and publish an urgent quality improvement plan to ensure assessment companies are conducting assessments consistently and to a high standard.
7. Reverse the changes made earlier this year to the mobility criteria, which restrict the ability of an individual who experiences overwhelming psychological distress when planning and executing a journey to qualify for PIP.

Appeals and awards

8. Pay PIP claimants an 'assessment rate' during the lengthy appeals processes, as is the case with Employment and Support Allowance, to enable them to maintain their independence.
9. Regularly publish data on the average length of time Mandatory Reconsiderations are taking and detailed information on how people are qualifying for PIP.
10. Introduce indefinite PIP awards for people with severe, complex conditions that have no prospect of improvement or are progressive. If reassessments absolutely must be undertaken because additional support may be available, these should happen without the need for a face-to-face assessment.

To find out more, please visit parkinsons.org.uk/pipreport



What is PIP and how does it work?

Personal Independence Payment (PIP) was introduced in 2013 to replace Disability Living Allowance (DLA). PIP is a disability benefit that can be claimed regardless of capital, assets or income, by people aged between 16 and 65. It is designed to cover the extra costs that working-aged disabled people and those with long-term conditions face.

Like PIP, DLA was also a non-means tested benefit designed to cover the extra costs of being disabled. DLA was introduced in 1992 for working age disabled people and provided equivalent support in relation to mobility and care needs.

Once received, PIP, like DLA, can continue after the age of 65 as long as someone continues to fulfil the conditions. DLA continues for children under the age of 16.

Rationale for replacing DLA with PIP

Part of the Government's rationale for introducing PIP in 2013 was that DLA "no longer provides the framework for supporting disabled people that is needed in the 21st century"³. In contrast, PIP would be "simpler to administer and easier to understand [...] fair, and support disabled people who face the greatest challenges to remaining independent and leading full, active lives"⁴.

The then Government was also explicit that the cost of DLA was unsustainable and that PIP was being introduced partly to reduce these costs. The impact assessment for DLA to PIP reassessments estimated that 510,000 people on DLA would receive a lower award under PIP, and 450,000 on DLA would receive no award under PIP⁵. This was expected to save around £2billion⁶.

How PIP and DLA differ

Under DLA many people were assessed 'on paper' – on the basis of their application form and the supporting evidence they had provided.

In contrast, PIP is designed around the basis of a face-to-face assessment. Eligibility for PIP is assessed against a set of criteria which examine ability to carry out a number of daily living activities, such as washing, dressing, cooking a meal and interacting in social situations. It ascribes points depending on the extent to which a person is able to undertake these activities.



Independent Assessment Services (previously Atos Healthcare) and Capita are contracted by the Department for Work and Pensions (DWP) to carry out these assessments across the UK. In most cases, these are conducted face-to-face. However, the final decision about whether PIP is awarded lies with the DWP.

One of the most significant differences in the assessment criteria is the reduction in the minimum walking distance a person must be unable to travel in order to qualify for the highest rates of the mobility component. Under DLA, a person had to be unable to walk 50 metres to qualify. Under PIP this has been reduced to just 20 metres. This means it is now much more difficult to qualify under this element of PIP.

It is noteworthy that the original consultation on PIP did not include mention of the change in walking distance and it was reduced without an opportunity for disabled people or charities to comment. After a Judicial Review of the walking distance change was issued, the Government consulted retrospectively on the '20-metre rule' in June 2013 – a month after PIP began to roll out⁷.

3. Department for Work and Pensions, Public consultation. Disability Living Allowance reform, December 2010, www.gov.uk/government/uploads/system/uploads/attachment_data/file/181637/dla-reform-response.pdf

4. Department for Work and Pensions, Public consultation. Disability Living Allowance reform, December 2010, www.gov.uk/government/uploads/system/uploads/attachment_data/file/181633/dla-reform-consultation.pdf

5. Department for Work and Pensions, PIP: Reassessments and Impacts, December 2012, www.gov.uk/government/uploads/system/uploads/attachment_data/file/180964/PIP-reassessments-and-impacts.pdf

6. Department for Work and Pensions, Disability Living Allowance Reform: Impact Assessment, May 2012, www.gov.uk/government/uploads/system/uploads/attachment_data/file/220176/dla-reform-wr2011-ia.pdf

7. Department for Work and Pensions, Consultation on the PIP assessment Moving around activity, June 2013, www.gov.uk/government/uploads/system/uploads/attachment_data/file/208334/PIP-mobility-consultation.pdf

Another big difference is that there were three rates for care needs within DLA, but there are only two rates of the PIP daily living component as set out below.

Under DLA it was also possible to receive long-term or even indefinite awards. This was of great value to people with degenerative conditions, or conditions which do not fluctuate or change over time.

PIP ended the principle of lifetime awards, replacing them with fixed periods in order to “ensure awards remain correct” and “take a personalised approach to setting the length of awards, varying the frequency and format of awards and reviews depending on the individual’s needs and the likelihood of their health condition or impairment changing”⁸.

However, a legal judgement from March 2016 found that “if a fixed term award would be inappropriate, an indefinite award is to be made” and that “the First-tier Tribunal has jurisdiction to hear an appeal against a decision as to the duration of a fixed term award”⁹.

It is unclear how many disabled people who may benefit from this tribunal jurisdiction have done so: the DBC and our members continue to see the vast majority of our communities receiving fixed term, and often quite short, awards.

PIP also mirrors the requirement under DLA that a claimant must have “had difficulties with daily living or getting around (or both) for 3 months” and to “expect these difficulties to continue for at least 9 months”¹⁰.

This means that people who are suddenly incapacitated, for example people who are in an accident or have acute onset musculoskeletal condition issues, will face three months without additional support, with consequences for their ability to manage the extra costs they face.

How PIP works

Disabled people and those with long-term conditions who receive PIP can get access to two components, which help them to manage the additional costs associated with daily life and getting around, respectively.

These two components are each paid at two different rates, depending on need. Paid at the highest levels, disabled people can be awarded up to £141.10 per week¹¹. For many disabled people this a vital contribution towards the significant essential extra costs they incur.

	Standard	Enhanced
Mobility component	£22.00	£58.00
Daily Living component	£55.65	£83.10

People who receive the enhanced rate mobility component of PIP are eligible for the Motability scheme, which enables them to lease an adapted car for their needs in exchange for this element of their PIP award.

A number of DBC members have carried out research to examine the costs disabled people are facing. The Extra Costs Commission by Scope found that someone with a neurological condition will spend almost £200 a week on costs related to their condition. For someone with a physical impairment, these costs will be almost £300¹².

Condition-specific research into extra costs carried out by Demos on behalf of the Motor Neurone Disease (MND) Association found that people with MND and their families spend £609 in regular costs and £133 in enhanced costs every four weeks as a direct result of the condition¹³. Parkinson’s UK research shows that a household in the UK where someone has Parkinson’s loses an average of £16,582 a year due to higher health and social care costs and reduced income¹⁴.

For many people living with long-term health conditions and impairments, support from PIP will only go some of the way to covering this extra expenditure.

8. Department for Work and Pensions, Government’s response to the consultation on Disability Living Allowance reform, April 2011, www.gov.uk/government/uploads/system/uploads/attachment_data/file/181637/dla-reform-response.pdf

9. administrativeappeals.decisions.tribunals.gov.uk/Aspx/view.aspx?id=4789

10. www.gov.uk/pip/eligibility

11. www.gov.uk/pip/what-youll-get

12. Extra Costs Commission (2015). ‘Driving down the extra costs disabled people face – Interim report’, www.scope.org.uk/Scope/media/Interim-report/Interim-report.pdf?ext=.pdf

13. Demos (2017), ‘MND Costs: exploring the financial impact of motor neurone disease’.

14. parkinsons.org.uk/news/whats-cost-living-parkinsons

A history of the PIP roll-out

PIP was introduced in April 2013 and began rolling out in postcodes first for new claimants and then for previous DLA claimants. Those already aged 65 on 9 April 2013 are not being reassessed for PIP and can continue to receive DLA. The initial roll-out was mired by delays and administrative problems.

At the peak of these problems, disabled people were waiting significantly longer than expected both for an assessment to be conducted and to receive the DWP's decision. In July 2014, for new claims under normal rules, the average PIP claim took 42 weeks from the point of registration to a decision being made, including 35 weeks from the point of referral to the assessment providers¹⁵. The National Audit Office (NAO) reviewed the operation of the process in 2014 and concluded that "backlogs have developed in the assessment process, leading to delays and uncertainty for claimants"¹⁶. The DBC supported a judicial review into these delays. In June 2015, the judicial review was upheld and the High Court ruled that the delays were unlawful¹⁷.

The first Independent Review of PIP was conducted by Paul Gray in 2014, and focused particularly on underlying issues with the implementation of the benefit, but not the policy itself.

The review found that the PIP claim process "gives a disjointed experience for claimants"¹⁸.

Key recommendations included:

- reviewing claimant communications, particularly the letters, to ensure that claimants are aware of what is expected of them and their rights
- improving opportunities for proactive communications with claimants, including the use of text messages
- reviewing the PIP claims process to make greater use of digital technology, in particular an 'online portal' to help claimants track the status of their claim

- exploring opportunities to improve the collection of further evidence

Many of the recommendations were accepted by the Government in its two responses to the review^{19,20}. However, it is noteworthy that it did not accept in full a recommendation to "put in place and announce a rigorous quantitative and qualitative evaluation strategy" that included a "priority focus on the effectiveness of PIP assessments for people with a mental health condition or learning disability".

The Government's responses emphasised that, since the first review, it had undertaken a number of initiatives, such as launching a communication campaign to raise awareness of changes, reviewing PIP letters to claimants, introducing new text messages throughout the claimant journey, to keep claimants apprised of the status of their claim, and testing new approaches to maximise initial contact with claimants by asking additional questions to gather information about their needs.

From July 2015, the DWP announced that it would be inviting long-term and indefinite DLA recipients to claim PIP. Claimants were written to via a 'random selection process'²¹ and told that their DLA was ending and that they must make a new claim if they would like to receive continued financial support for their extra costs in future.

In December 2015, the DWP voiced concern at the number of people who qualify for the daily living component of PIP because they were unable to complete daily activities without the use of an aid or appliance. They launched a consultation, which sought to explore "how aids and appliances are taken into account when determining entitlement". It was based on a review of 105 cases and led to proposed changes to reduce the eligibility points people could score if they rely on aids and appliances²².

15 Department for Work and Pensions, Personal Independence Payment (PIP): Official Statistics, 14 December 2016, p.4

16 NAO 2014, 'Personal Independence Payment: early progress'.

17 www.irwinmitchell.com/newsandmedia/2015/june/government-must-urgently-rethink-national-pip-rollout-after-disability-as-delays-ruled-unlawful-jq-703862

18 Paul Gray, An Independent Review of the Personal Independence Payment Assessment, December 2014, www.gov.uk/government/uploads/system/uploads/attachment_data/file/387981/pip-assessment-first-independent-review.pdf

19 Department for Work and Pensions, Government's second response to the Independent Review of the Personal Independence Payment Assessment, November 2015, www.gov.uk/government/uploads/system/uploads/attachment_data/file/478224/pip-assessment-first-independent-review-second-response.pdf

20 Department for Work and Pensions, Government's response to the Independent Review of the Personal Independence Payment Assessment, February 2015, www.gov.uk/government/publications/personal-independence-payment-pip-assessments-first-independent-review-government-response

21 Department for Work and Pensions, Personal Independence Payment Toolkit, www.gov.uk/guidance/the-personal-independence-payment-pip-toolkit

22 Department for Work and Pensions, The Government response to the consultation on aids and appliances and the daily living component of Personal Independence Payment, March 2016, www.gov.uk/government/uploads/system/uploads/attachment_data/file/484217/pip-consultation-on-aids-and-appliances.pdf

The DBC strongly objected to these proposals on the grounds that aids and appliances are representative of the extra costs that people face and indicate an ongoing need for support. Despite near unanimous opposition, the DWP announced in March 2016²³ that it would proceed with plans to reduce the aids and appliances point scores in two areas – ‘dressing and undressing’ and ‘managing toilet needs’. These proposals were included in the March 2016 Budget, but were ultimately abandoned lacking sufficient parliamentary support²⁴.

Paul Gray’s second and final Independent Review reported in March 2017 – this was originally anticipated to take place once the full roll-out of PIP was complete. However, the DWP now expects the reassessment of DLA claimants for PIP to continue until 2018 and the Second Review therefore noted that “some conclusions can be drawn with less certainty than might have been anticipated”. The final Independent Review also focused on implementation issues, rather than whether PIP was meeting its original policy intention and effectively supporting disabled people.

The Review found that “public trust in the fairness and consistency of PIP decisions is not currently being achieved, with high levels of disputed award decisions, many of them overturned at appeal”. The Review called for the DWP to “build very considerably on current action to improve the way PIP is administered, continuing the direction of travel proposed in the first Review”²⁵.

The Second Independent Review also described the DWP’s progress to implement the first Independent Review recommendations as ‘mixed’, with the implementation of some recommendations “either incomplete or slower than had been hoped in many areas”.

It noted the “limited progress in delivering a digital claim”. It also voiced concern about “potential inconsistency of assessments” and strongly urged “the adoption of a more comprehensive and rigorous evaluation strategy”.

The Second Independent Review recommendations included:

- that evidence of carers is given sufficient weight in the assessment improving the transparency of assessments.
- for example by introducing audio recordings of assessments and providing claimants with a copy of their assessment report with their decision letter
- giving health professionals more time to consider the evidence provided with a claim before the assessment begins
- focussing audit, assurance and quality improvement activity on the quality of the assessment as well as the quality of the report

The DBC welcomed these recommendations, but the Government has not yet published its response to the review to state which recommendations it accepts and what activity is being undertaken to realise them.

As of April 2017 there are approximately 1 million DLA claimants left to be reassessed²⁶. DWP data shows that almost half (48%) of those who have already been reassessed from DLA to PIP have either totally lost their award or received a reduced award to date²⁷. Despite this significant, harmful impact on disabled people the final Independent Review noted that “PIP has not produced the benefits savings that that policy was originally designed to realise”.

While delays have been resolved and timelines for claims have significantly reduced, the whole process is longer and more complex for individuals than the DLA process was.

Furthermore, there are persisting issues with the quality of the assessments, the focus of the assessment criteria and the stressful and difficult nature of the process.

23 Department for Work and Pensions, The Government response to the consultation on aids and appliances and the daily living component of Personal Independence Payment, March 2016, www.gov.uk/government/uploads/system/uploads/attachment_data/file/507166/government-response-aids-and-appliances-and-the-daily-living-component-of-pip.pdf

24 Secretary of State for Work and Pensions, Statement on not going ahead with changes to Personal Independence Payment (PIP), March 2016, www.gov.uk/government/uploads/system/uploads/attachment_data/file/516954/secretary-of-state-for-work-and-pensions-statement-on-not-going-ahead-with-changes-to-pip-21-march-2016.pdf

25 Paul Gray, The Second Independent Review of the Personal Independence Payment Assessment, March 2017, www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/pip-assessment-second-independent-review.pdf

26 Department for Work and Pensions, Personal Independence Payment statistics. April 2017

27 Department for Work and Pensions, Table 8B: Summary of DLA to PIP Reassessment Outcomes, Personal Independence Payment: DLA to PIP reassessment outcomes, October 2016.

The importance of DLA and PIP to disabled people

We know first-hand the difference that appropriate financial support from disability benefits can make to members of our communities. The MS Society found that 74% of people with MS who were receiving disability benefits agreed that disability benefits have helped them manage the extra costs of their MS, while 83% said that without the support of disability benefits they would be unable to maintain their current level of independence²⁸.

More recent research by NatCen Social Research, commissioned jointly by Thomas Pocklington Trust, Sense and RNIB, saw participants report that DLA and PIP helped with costs associated with their impairment, including things like care, mobility needs and assistive technology²⁹.

For these reasons the DBC wholeheartedly supports the need for an extra-costs benefit that looks at the functional impact of people's impairment or health condition.

Indeed, there have been some disabled people who have received greater support under the new system. For those people who have accessed greater support under PIP, the DBC understands that this has had a positive impact – the NatCen research indicates that it has reduced the worry experienced by many disabled people of living on a tight budget, and in some cases claimants were planning to build up savings for bigger adaptations³⁰.

However, in too many cases the new process has made support difficult and stressful to access and assessments have failed to adequately understand the impact of a person's condition and the barriers disabled people face. Even where disabled people have received an increased award, the process of getting this has been needlessly difficult. Despite participants in NatCen's study into PIP and sensory loss eventually receiving 'positive outcomes', the research reported that the journey through the application for this group was 'largely negative'³¹.

This particular report highlights a number of the same issues that DBC members have been raising since the introduction of the benefit.

In 2015, the MS Society released the MS Enough report, which found that the system was stressful and confusing, that assessments were inaccurate and that people with MS were struggling to access the support they need³². DBC insight has consistently found similar problems with the PIP process, including difficulty initiating applications and the stressful and inaccurate nature of the assessment.

A number of our members have reported an increase in the calls they are receiving to their helplines about PIP throughout the roll-out. The Royal Mencap Society has told us that they have seen a significant increase in the number of calls and emails regarding problems or concerns with PIP decisions.

Similarly, Scope has reported that the number of disabled people seeking support with PIP through their helpline has increased by over 500% since 2015/16³³. For Age UK, Attendance Allowance is the main disability benefit that they deal with, but increasingly their local advisers are reporting concerns about PIP and seeing clients who need support with the process.



28 MS Society, MS Enough, September 2015, p. 6 www.mssociety.org.uk/sites/default/files/MS%20Enough%20report_1.pdf

29 Natcen et al., March 2017, p9 29. Natcen et al, Experiences of Personal Independence Payment (PIP) for people with sensory loss, http://natcen.ac.uk/media/1361395/per5onl-1nde6endence-pymtent_report.pdf

30 Ibid,

31 Natcen et al., March 2017, p7

32 MS Society, MS Enough, September 2015, p.6 www.mssociety.org.uk/sites/default/files/MS%20Enough%20report_1.pdf

33 Scope, PIP insecurity 'overwhelming' says Scope helpline, 3 March 2017, www.scope.org.uk/press-releases/PIP-insecurity-overwhelming-scope-helpline

Survey findings

Methodology

The DBC launched its annual Big Benefits Survey in February 2017. This was distributed by DBC members to their supporters. As of Thursday 27 July 2017 the survey had received 3,388 complete responses. Out of these, 2,614 respondents had applied for PIP or DLA. Of these, 1,730 claimants had either applied directly for PIP as a new claimant or were reassessed DLA claimants and had therefore been assessed for PIP. This was taken as the final eligible sample, as the remaining claimants had not undergone a PIP assessment.

It is noteworthy that 84% of claimants had applied for PIP relatively recently – in either 2015, 2016 or 2017. This shows that the issues with PIP highlighted by the research are a continuing problem.

DBC members were also invited to provide examples of their own research, statistics and case studies to contextualise the survey's findings. The recommendations derive from these sources.

Applying for PIP

Our communities have continued to see disabled people and those with long-term conditions struggling to navigate the initial claims process and finding the systems confusing and complicated, among both new claimants and those being reassessed.

Respondents applied for PIP as new claimants or had been previous DLA claimants and were subsequently invited for a PIP assessment almost equally. In all, 47% applied for DLA originally and 52% applied directly for PIP.

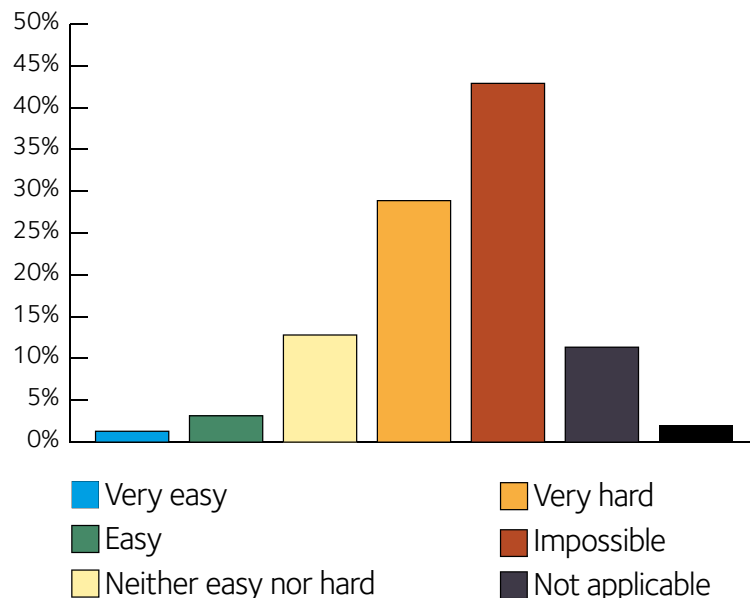
To apply for PIP, claimants must undergo a two-stage process. A person must make an initial telephone call, where they provide basic details about themselves. They are then posted an application form – known as the 'PIP2' form, which has their key details pre-populated and a unique barcode. They must complete the form, which asks detailed questions about a person's condition and how it affects their ability to undertake daily activities and get around, within four weeks.

This initial claim process can be extremely challenging for claimants who have problems using the telephone. For example, symptoms of Parkinson's can include swallowing problems, a quiet voice and slurred speech due to a loss of control of the facial muscles. This means that it is often extremely difficult for people with the condition to use the telephone.

PIP2 form

The majority of survey respondents found the PIP2 form difficult to complete. The graph below shows that over 71% of respondents found the form 'hard' or 'very hard' and 11% of respondents were unable to complete it at all.

How easy or hard did you find it to complete your PIP application form? (1501 respondents)



In free text responses, many people emphasised the complexity and difficulty of completing the form as a barrier to accessing PIP:

“My husband had to fill in forms on my behalf. No way I could have done that.”

– Respondent with hypermobility syndrome and Post Traumatic Stress Disorder.

“The whole process is worrying and stressful, and people need help to fill in the form correctly. I had to request extra time to fill it in due to my health problems, as it doesn’t take into account problems with concentration, energy availability, and cognition.”

– Respondent with spinal injuries.

“Completing the form reduced me to tears when completing virtually every section, as having been a highly effective person who had management responsibility for over 150 people over several offices prior to taking early retirement due to my deteriorating health, it was extremely distressing to see how little I can actually do just within my own home. It was very hard to bear.”

– Respondent with osteoarthritis and anxiety.

“Completing the PIP assessment form was a lengthy, stressful experience. It left me feeling depressed and anxious about the outcome. I have degree level qualifications, but found completion of the form an arduous process.”

– Respondent with rheumatoid arthritis.

Many people find the process so difficult that they need help, but with advice agencies under great pressure and time limits to respond, this can be hard to access.

Case study – Age UK

Age UK was contacted by a 59-year-old with short-term memory loss and many other physical problems, who was having trouble completing the PIP application form. She had not been responding to phone calls about PIP because she thought they were nuisance calls about Payment Protection Insurance and the deadline was approaching. She had tried several places for help but with no joy and was getting desperate as she was very worried about losing her DLA.

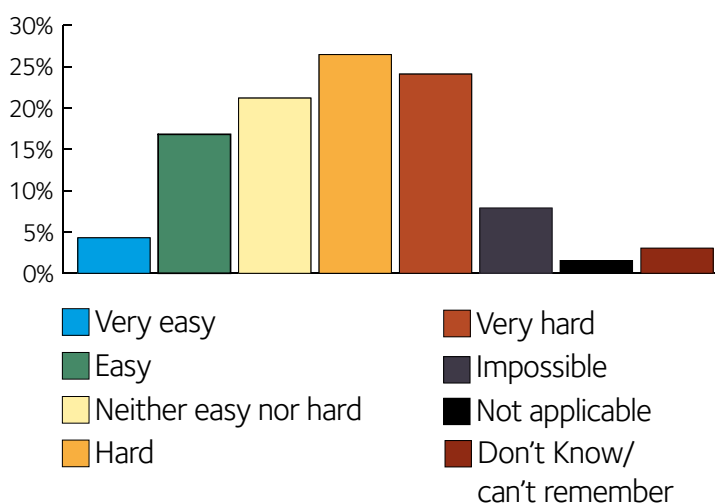
Recommendation

The DWP should immediately introduce simplified claim forms that are readily available in Jobcentres, downloadable online and in accessible formats (such as audio described and easy read), without the need to return them within four weeks.

The difficulties in claiming continue to be compounded by a lack of understanding around who is responsible for collecting further evidence, what healthcare professionals should provide and the short timescales available for gathering it.

The graph below shows that the majority of respondents found it difficult to provide supporting evidence for their claim. Collectively, almost 60% of respondents found providing supporting evidence ‘hard’, ‘very hard’ or ‘impossible’.

How easy or hard did you find it to complete your PIP application form? (1501 respondents)



When asked why, 54% of respondents reported that it was “unclear who would be able to provide the supporting evidence they sought”, 31% explained that “the person I asked did not understand what information they needed to provide” and a further 31% reported that they couldn’t provide supporting evidence in time.

Recommendation

The DWP should commission an independent review of the evidence gathering processes, to explore ways to:

- educate health and social care professionals on how to provide relevant supporting evidence
- ensure duties and responsibility of the assessor, the DWP and claimant are clear and observed

- make sure the DWP has a strategy to articulate to claimants what evidence will be most useful for their claim
- ensure evidence supplied by friends and family members is given due consideration

The Second Independent review in 2017 called for greater clarity around the responsibility to provide further evidence lying primarily with the claimant. It highlights that claimants “should not assume the department [DWP] will contact healthcare professionals”³⁴. The MS Society’s MS Enough report called for health and care professionals to be better supported to provide evidence for benefit claims³⁵. Similar issues were also explored by the National Aids Trust in their recent report on PIP, which found that “current approaches to gathering and weighing alternative sources of evidence are undermining trust in the assessment”³⁶.

Free text responses to our survey illustrate these difficulties further:

“It wasn’t explained to me where to get my evidence to support my claim and when I asked my doctor he had said he needs forms sent out to fill in and the reply was they didn’t need to do it as I should be getting the information even though he said he needed the forms from the DWP to complete.”

– Respondent with rheumatoid arthritis.

“They did not check with my GP, specialist, dental surgeon, doctors etc, despite giving them contact details etc. I tried to rely on copies of my hospital appointments instead of requesting specific letters from GP and specialists.”

– Respondent with liver disease.

“Had a lot of trouble getting evidence from GP, and trouble with Capita not sending the doctor a request for evidence when they said they had.”

– Respondent with dementia.

Recommendation

In order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant, with penalties if they do not.

PIP assessment experience

Assessment format and assessment centre accessibility

The majority of respondents to our survey had to attend a face-to-face assessment. Of those who answered the question “How were you assessed for PIP?”, 62% were invited for a face-to-face assessment, 28% were assessed (face-to-face) at home and only 7% were assessed on paper.

The DWP PIP Assessment Guide³⁷ emphasises that certain “types of cases should not normally require a face-to-face consultation” including:

- claimants with cardiorespiratory conditions such as severe Chronic Obstructive Pulmonary Disease (COPD) or those awaiting a transplant
- claimants with severe musculoskeletal conditions such as poorly controlled rheumatoid arthritis or severe osteoarthritis awaiting major joint surgery
- claimants with severe neurological conditions such as motor neurone disease, dementia and Parkinson’s

However, when the responses to this question are broken down by some of these conditions, it is clear that the overwhelming majority of PIP claimants are being invited for potentially unnecessary face-to-face interviews, as the graph overleaf shows.

In lots of cases people were unaware that they are able to request a home assessment: 79% of respondents were not told about the opportunity to request a home visit.

It is concerning that in a number of responses to our survey people highlighted being refused a home assessment, even where they had supporting evidence explaining why this was needed. Respondents expressed both frustration and disappointment with the assessment providers for failing to grant assessments in their preferred format.

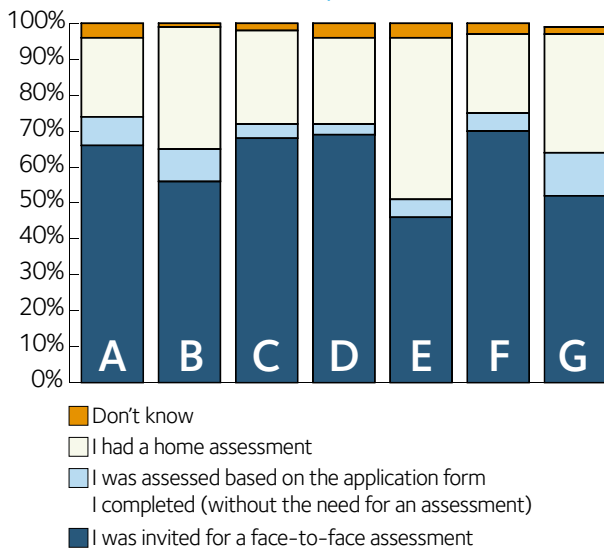
34 Paul Gray, The Second Independent Review of Personal Independence Payment, 2017, p. 12, www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/PIP-assessment-second-independent-review.pdf

35 MS Society, MS Enough, September 2015, p. 32, www.mssociety.org.uk/sites/default/files/MS%20Enough%20report_1.pdf

36 National Aids Trust, PIP and HIV: How Personal Independence Payment is working for people living with HIV, p. 21, www.nat.org.uk/sites/default/files/publications/PIP%20and%20HIV%20Report%20online%20v.3.pdf

37 Department for Work and Pensions, PIP Assessment Guide, September 2016, www.gov.uk/government/uploads/system/uploads/attachment_data/file/547146/PIP-assessment-guide.pdf

How were you assessed for PIP (1037 respondents)



- A**-Lung/breathing problems (COPD)
- B**-Multiple Sclerosis (MS)
- C**-Osteoarthritis
- D**-Other musculoskeletal condition
- E**-Parkinson's
- F**-Rheumatoid arthritis
- G**-Stroke

“Independent Assessment Services refused me a home visit and refused to allow me a paper-based assessment; despite being given two supporting letters advising this from health professionals – a doctor and an autism support worker.”

– Respondent on the autism spectrum.

“The gentleman who assessed my son (age 22) was puzzled as to why my son had been asked to come for assessment as it was obvious from the paperwork and evidence submitted prior to appointment that he has profound learning difficulties and autism. I sat and cried in the car afterwards – the assessor was very kind but it's so hard to have one's nose rubbed so hard into the difficulties one's child faces.”

– Respondent with a son on the autism spectrum.

“Assessor had seen my very thorough form and large amounts of supporting evidence so didn't know why she'd been sent to give me a home assessment, she thought my PIP requirement should be obvious from the paperwork alone.”

– Respondent with a neurological disorder.

Case study – Age UK

Age UK has heard of problems with the timing of home visits and assessments. A local adviser reported long delays in getting a home visit arranged, while a woman who rang the Age UK advice line had received a letter inviting her for interview the previous day. When she contacted the DWP she was initially told that this was not a good reason for non-attendance and both her DLA and the PIP application was stopped. After challenging this she got the PIP claim restarted but at the time of the call had not got her DLA reinstated.

It is also disappointing that only 67% of respondents reported being able to access assessment centres. A further 75% of respondents agreed that they were told someone could attend the assessment with them, such as a supporter or care worker.

Case study – Muscular dystrophy

“There was not enough Blue Badge parking, and all spaces were occupied. I waited a while, but had to park in the short-term parking further away and on gravel with kerbs to make the appointment. The distance to the building was too far from the parking and the building's entrance was at an elevated height, with many steps – it was only accessible through long, zigzagged sloped pathways, which was an even greater distance to cover.”



Assessment quality

A minority of respondents did report positive experiences of PIP assessments, while acknowledging that the rest of the assessment process was extremely stressful:

“I was pleasantly surprised by my home visit assessment during my PIP application. Though it made me extremely anxious and I feel it was unnecessary, the people who did it were kind, courteous and listened intently.”

– Respondent with a mental health condition.

“Assessor seemed very understanding and listened well. I received enhanced rate of both components but when looking at assessment write-up the assessor had given me less points than I was entitled to (and had clearly explained to her) in a few categories. It didn’t affect my overall result this time though.”

– Respondent with neurological condition.

“It would seem that I was very fortunate to have the nurse tutor I had doing my assessment. She was kind, attentive and very understanding – I think she is the exception.”

– Respondent with a spinal injury.

“I have not received my results yet, however, I feel the assessor was understanding towards to my condition and took the time to listen to me, so I am hopeful that I will not lose my benefits.”

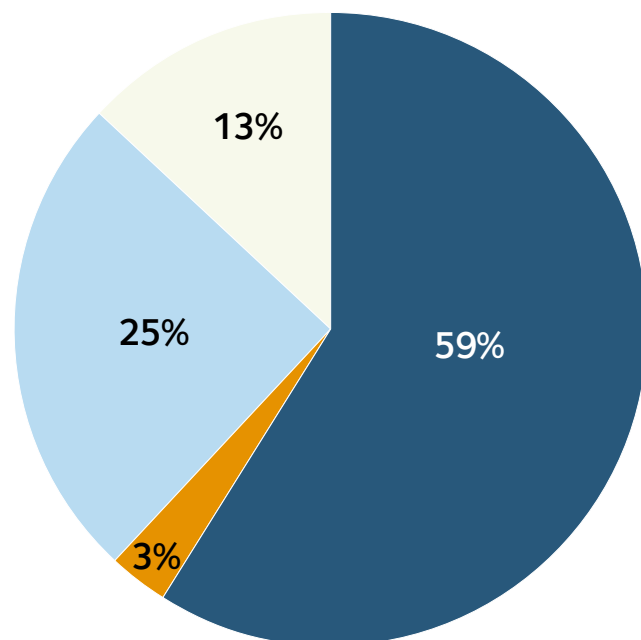
– Respondent with cystic fibrosis.

It is clear that well trained, empathetic assessors who have an understanding of conditions and disabilities can have a big impact on people’s experiences of assessment.

However, the vast majority of respondents to our PIP survey were strongly critical of the quality of their PIP assessment. Again, assessment quality has been a consistent and significant concern among DBC members since PIP was introduced.

When asked about assessors’ knowledge of their condition, as illustrated in the next pie chart, almost two-thirds of respondents to our survey disagreed when asked if assessors understood their condition.

The assessor understood my disability or health condition (1332 respondents)



■ Disagree
■ Agree
■ Not sure
■ Neither agree nor disagree

Free text responses show a range of concerns about assessors’ conduct during assessments. Key themes include:

Assessors’ knowledge of long-term conditions and impairments

“Not seen by qualified person who understood complexity of Lupus. Assessor answered questions for me.”

– Respondent with lupus.

“We didn’t feel that she had sufficient knowledge or insight into the spectrum to make any judgements on my behalf. She didn’t deviate from her script to ask any questions that may have given her more insight into my condition and how it affects my daily life.”

– Respondent on the autism spectrum.

“The questions asked were totally irrelevant to my condition, I was not asked about daily medication or to give detailed description of daily treatments. It was a very regimented interview and not personal to me.”

– Respondent with cystic fibrosis

“The assessor didn’t appear to know anything about special needs and their issues. Asked what medication he was on for Down’s syndrome and learning disability.”

– Parent of a person with a learning disability.

“I believe that fatigue and how it affects my cognitive function was not understood because (per the report) “there was no evidence of cognitive problems”. As a result of the assessment I now worry that I have to allow myself to become quite poorly to prove how I’m affected.”

– Respondent with MS.

Many DBC members have engaged individually with the DWP and assessment providers (Independent Assessment Services and Capita), to try and improve the quality of the training assessors receive about the most prevalent medical conditions. It is concerning that awareness of many conditions still appears to be low, particularly with complex, fluctuating and sometimes rare conditions.



For example, the National Aids Trust has expressed concern that people with HIV feel assessors are “trying to catch out claimants through informal observations” and question the accuracy of these observations³⁸.

“I was seen to have a glass of water several times, I can therefore drive a car – apparently. They claimed that I ‘have a strong pinch grip to open packaging’. These were very odd observations that have been made, that are weak to say the least.”

– Respondent with Parkinson’s.

“I felt totally and utterly invalidated. Health professional’s observations were used to say that I was not in pain or fatigued, and I was not asked. Fluctuations were ignored completely. On my medical report there were many inaccuracies, flaws and lies.”

– Respondent with fibromyalgia and depression.

It is also important that assessors receive sufficient disability-specific training to allow them to adapt their communication and assessment methods so that individuals are able to fully understand and take part in the assessment.

Assessors’ rude and unprofessional behaviour

Survey respondents and DBC members regularly report examples of rude and unprofessional behaviour from PIP assessors, including aggressiveness, insensitivity, indifference and not taking the time to listen to the person they are assessing:

“I’m worried for her actual patients and feel abusive treatment is being legitimised by association with the hospital, and through being encouraged by assessment process itself. In relation to my suicidal ideation I was asked ‘why haven’t you done it yet?’. I can’t understand why they’d ask someone with suicidal ideation why they haven’t killed themselves or what relevance it had to PIP, I can’t stop thinking about it, it has worsened suicidal ideation, I keep going over and over it and the response I tried to give.”

– Respondent with depression.

“The whole process has caused me a huge amount of stress. The assessment wasn’t long enough. The assessor barely touched the surface of the questions on the form but rather was delving into my past history for stuff I felt irrelevant to how my condition affects me day to day. She appeared to have already made her mind up. She showed no sensitivity to or knowledge of my health conditions. She was aggressive, rude and intimidating.”

– Respondent with fibromyalgia and migraines.

“The assessor was extremely rude with a terrible attitude. The assessor repeated questions several times within the space of five minutes as if to ‘catch me out’. The assessor completely ignored what we had to say and referred to situations from several years ago that are completely irrelevant now.”

– Respondent with depression and anxiety.

Consideration of supporting evidence

A further 58% disagreed that their assessor “took into account whether I could do activities reliably, repeatedly, safely and in a timely manner” and almost half disagreed that the assessor “took into account extra evidence about my condition that I sent in advance”. Respondents explained:

“The whole thing was horrendous. It was perfectly clear that the DWP did not even read, or pay any attention to, the letters of support from my various doctors.”

– Respondent with osteoarthritis, depression and anxiety.

“My specialists and doctors were 100% behind me but I had to pay for copies of all my medical reports, yet they were seemingly ignored as the assessor was unaware of many of my issues even though the detail had been sent in advance.”

– Respondent on the autism spectrum with epilepsy and anxiety.

“I sent my completed application form and 12 pages of supporting evidence to the DWP in one envelope, sent via Royal Mail Special Delivery. My papers arrived

the following day and were opened at a mail centre and signed for by a postie at 5.30am. However, when I got to the face-to-face assessment for PIP the nurse conducting the assessment very rudely told me that I’d not bothered to send my forms in, so if I forgot to mention anything that was on the forms then they wouldn’t be taken to account.”

– Respondent with ankylosing spondylitis.

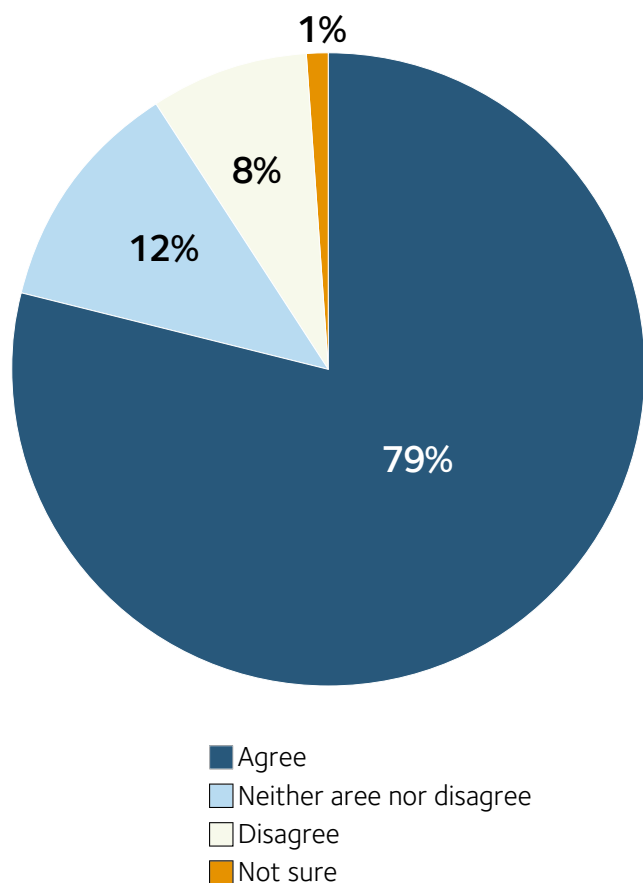
It is deeply worrying that the PIP assessment continues to be of low quality in many cases and a very difficult experience for many disabled people. Face-to-face assessments are too often being carried out needlessly, even where a significant amount of supporting evidence has been provided.

It is of particular concern that almost 90% of respondents described their assessment as ‘stressful’. As illustrated in the next pie chart, over three-quarters of respondents agreed that the stress and anxiety associated with their PIP assessment made their condition worse.

Again this echoes the findings of research carried out by DBC members previously. The MS Society’s research has found that over a third of people with MS who had a PIP assessment said it had caused their MS to deteriorate or relapse³⁹.



My PIP assessment made my health worse because of stress or anxiety (1331 respondents)



Respondents explain:

“They cancelled on me twice at last minute making my condition worse. They ignored my availability and came when I said it was no good meaning more stress and anxiety as we had to quickly change things about. She only heard what she wanted and ignored everything else”

– Respondent with depression and anxiety.

“I am a 36-year-old woman who still works full time and this is causing me a great amount of stress. I was given the award through DLA as indefinite...now it lasts two years before this whole outrageous process starts again.”

– Respondent with rheumatoid arthritis.

“The assessment was straightforward but the process and the scrutiny and the threat of losing my award were incredibly stressful.”

– Respondent with M.E.

“Very stressful. I cried for an hour and a half but because I don’t actually see a mental health professional now I have seen them all in the past and the fact that I can suck on my inhaler is “managing my meds”! Wrong, wrong, wrong.”

– Respondent with depression.

“I’m scared I may see the same woman again this year (when I have to reapply) and am already stressed about it now.”

– Respondent with M.E.

Case study – Age UK

A local Age UK adviser highlighted the particular pressures for people with mental health conditions. One of his clients had a learning disability as well as mental and physical health conditions, and was living on a low income. The adviser helped complete the PIP form but when he rang a few weeks later the client said he had withdrawn the claim because he was too anxious about the assessment. He had been to one in the past which had left him feeling belittled, ill and depressed.

A small number of responses stated that the experience of claiming PIP was so distressing that it has caused new conditions to emerge, or even precipitated suicidal thoughts:

“By the time I got the decision which said I would lose my mobility car and drop to low rate I tried to commit suicide. It was reconsidered and it got changed back to high rate plus car but now I still have thoughts of suicide every day.”

– Respondent with Ehlers-Danos syndrome.

“I am sure if I hadn’t have been with my immensely supportive husband, I would have committed suicide. I still am in constant dread of going through this process again.”

– Respondent with epilepsy.

“Have found the whole PIP process to be a form of mental torture and felt suicidal for a while.”

– Respondent with depression.

“It was the [most] appalling and distressing thing I have ever gone through. I felt suicidal before, during and for some months after the assessment. It is because I have such a good GP that I did not kill myself.”

– Respondent with rheumatoid arthritis.



Assessment report accuracy

Of the respondents who had seen a copy of the PIP report completed by their assessor, 64% felt it ‘badly’ reflected the answers given during their assessment.

Free text responses show significant discrepancies between the assessment itself and the assessors’ report, with respondents noting that assessors had disregarded things they had been told, or wrote things that directly contradicted supporting evidence and answers given in the assessment:

“I have Bi-polar, depression and anxiety and submitted three expert supporting letters. The assessor claimed that I showed no signs of low mood, my bi-polar was controlled by medication on my own admission, (he asked a direct question about this and I had to say yes, not thinking he would say it fully controlled my illness.) I can’t believe anyone would believe that to be true. So, no points at all for mental health problems.”

– Respondent with mental health problems.

“I have to be supervised at work to keep me on task as I wander from my station and become distracted but this was disregarded. Lots of other discrepancies in the report.”

– Respondent on the autism spectrum.

“The report that came with the decision letter was so different from the answers we gave, [we] thought they had got us mixed up with someone else! So much about how my brain injury affects me was omitted in fact she said I had no memory problems at all, I am sure that will be news to the clinical psychologist and Neuro surgeon who saw me after my accident.”

– Respondent with acquired brain injury.

“Said I stated I catch the bus alone, I never leave the house alone. She said, I am able to take my medication on time, then said I forget so my children remind me. There are too many lies to mention.”

– Respondent with epilepsy, autoimmune condition, depression and anxiety.

Recommendation

The DWP must re-establish direct responsibility for assessment quality and publish an urgent quality improvement plan to ensure both assessment companies are conducting assessments consistently and to a high standard.

PIP outcomes

Continued issues with suitability of the assessment criteria as well as the accuracy and quality of assessments are reflected in the awards and outcomes disabled people are receiving. A majority of survey respondents did not agree with their PIP decision. In fact, over 54% of respondents did not agree that they were awarded the right level of support for their condition.

In total, 50% of respondents reported that they received a lower level of support under PIP than DLA, or lost their award completely.

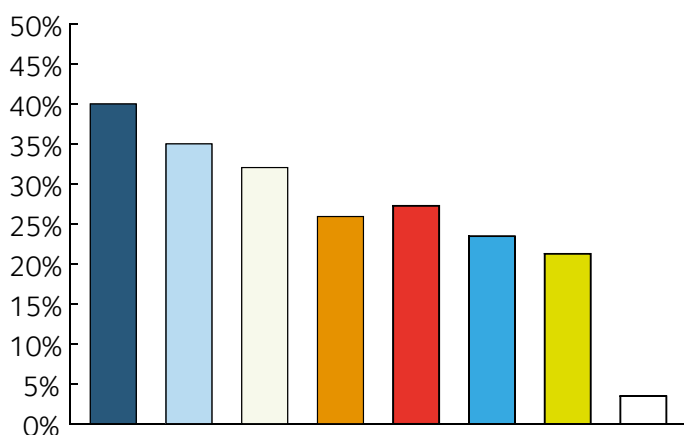
DWP data shows that as of October 2016, almost half of those who had been reassessed from DLA received a reduced or no award, while 12% received an equivalent award and 40% received an increased award⁴⁰.

As mentioned above, the Government initially estimated that 500,000 fewer people would be receiving PIP than DLA once the roll-out of the benefit was completed.

This demonstrates the significant impact that PIP is having on disabled people, and has the potential to have, before roll-out is complete.

For those who have had support reduced or taken away the impact has often been significant. As shown in the graph below, when asked what impact this has had on their independence, respondents highlighted the significant increase in isolation, difficulty paying for essentials and struggling to attend medical appointments. Only 4% of respondents said that losing some or all of their PIP award had not made much of a difference.

If you have received a lower rate of PIP than under DLA or lost your award completely, what has been the impact? (863 respondents)



- I am more isolated and less able to see friends and family
- I struggle to pay for basic things such as food, rent and bills
- I don't have enough money to live on
- It has negatively impacted my relationship with my family/spouse/partner
- I struggle to get to medical appointments
- It has had an impact on other benefits either myself or my partner is able to claim (eg. Carer's Allowance, Blue Badge)
- I can no longer get around independently
- It hasn't made that much difference

Impact of losing passported benefits

It is not just the loss of the cash amount of benefit that impacts disabled people claiming PIP. DLA and PIP also give access to a range of other benefits including Carer's Allowance and the Blue Badge Scheme.

Those receiving the highest rate of the mobility component also can access the Motability scheme, which provides them with a specially adapted vehicle. It is estimated that around 900 cars are being returned each week by disabled people who have lost access to the highest rate of mobility following reassessment from DLA to PIP⁴¹.

Motability vehicles

Of those who rely on the Motability scheme for their independence, we know it is a vital source of support and losing it could have a huge impact on them and their families.



Case study – Osteoarthritis

Debs, 45, has had osteoarthritis since she was born and was later diagnosed with fibromyalgia and chronic fatigue.

“When I wake up I am in pain instantly. My husband helps me get dressed, and shower. I try to stay active, but use walking stick all the time now and can’t bend down to put food in the oven. I also have trouble concentrating too which makes simple tasks really difficult.

“I got to stage where I couldn’t get low enough to get into my car, and became housebound for about 2 years. I applied for PIP in 2014 and qualified for a Motability car. Having the car gave me back my independence. It was ground breaking for me.

“I was told I wouldn’t be reassessed for three years, but after two years they asked to see me again.

“I scored fewer points on the reassessment, despite the fact my condition had got worse and I’d been involved in a car accident which had increased my pain. I was told I’d lose my Motability vehicle. It was awful. They said I could keep my car for 14 days, and then I either had to pay for it, or sign it back over. The letter said if I didn’t do either of these things, they would take me to court and send bailiffs to my house. If I gave my car away I didn’t know how I would be able to get anywhere.

In the assessment they’d concluded I could walk 20 metres but less than 50, but my nearest bus stop is over 400 metres away, which didn’t seem to be considered.

“It was incredibly distressing. I had hardly any time to make a decision. In the end, my dad stepped in and lent me the money to buy the car.”

Government figures give us a greater insight into the potential numbers losing access to this support as a result of PIP. A response to a Freedom of Information request by Disability Rights UK found that 254,200 people who were in receipt of DLA higher rate mobility have been reassessed safer. Of these 25% have had their benefit reduced to the standard PIP mobility rate and 25% have lost their mobility rate altogether⁴².

From our survey, 178 respondents revealed the impact of losing access to the Motability scheme. Of these, 40% explained that they could no longer get around independently, 44% were forced to buy their own car and 31% were forced to pay for taxis, with dire consequences for their ability to get out and about.

Respondents describe the significant, harmful impact of losing access to the Motability scheme:

“I have gone halves with my husband on a car that is just about possible for me to be driven in. I cannot afford a car that I would be truly comfortable in – my back problems mean I find sitting in most cars very painful.”

– Respondent with diverticular disease.

“I cannot get to doctors, hospital appointments or visit friends and family. I cannot use public transport or taxis as my neck condition worsens if jolted even slightly. I am housebound.”

– Respondent with cervical spondylosis.

“Got credit card to pay for car as need to keep my independence, nothing in the village I live in, 5 miles to the nearest shop, had agoraphobia few years ago now returning, very depressed.”

– Respondent with a thyroid condition.

“My father who is 81 has bought me a run around car. It hurts me and is not suitable for my needs. It’s a dreadful situation after being on DLA for 29 years during which time I have got a lot worse.”

– Respondent on the autism spectrum, with a spinal injury.

“My parents had to buy the mobility car with a bank loan.”

– Respondent with juvenile arthritis.

Case study – Muscular dystrophy

Connor was diagnosed with Duchenne muscular dystrophy at the age of 3 and he is now 16 years of age. This is both a severely disabling and life limiting condition. Many individuals affected do not live past their 30th birthday. He was receiving the full rates of DLA and had a Motability vehicle. When he switched over to PIP, he received the enhanced rate of daily living and nothing for the mobility component.

The family then went through to Mandatory Reconsideration process and the decision did not change. Then at appeal it changed to the standard rate of mobility.

Carer's Allowance

For those who have lost access to the daily living component of PIP, this also means that their carers can no longer receive Carer's Allowance – an additional reduction of £62.70 a week.

Research by Carers' UK highlights that it was estimated 24,457 fewer carers would be entitled to Carer's Allowance as a result of reduced eligibility for PIP⁴³ and that many carers are facing difficulty covering essential costs, including almost half who were cutting back on essentials like food (45%) and heating (44%),⁴⁴

Impact of gaining support to manage extra costs

Conversely, 19% of respondents explained that they had received a higher rate under PIP than they did under DLA. Of these people, 58% explained that having greater access to PIP enabled them to buy the extra things necessary to carry out daily activities independently, while 32% of respondents reported an improved relationship with family members, their spouse or carer.

Respondents explained:

"It has made me feel safer in the knowledge I can buy food, pay my rent and be able to look after myself. I have been self-employed for a number of years due to my disabilities but as they get worse I've had to reduce the time and that has reduced my income,"

– Respondent with migraine.

"It has made a huge difference to my previous existence where I was living week to week, and not able to afford replacement for broken down household items. The peace of mind this has given to me, has improved my mental health quite a bit."

– Respondent with spinal injury.

"It has enabled me to budget better and I can put extra into gas and electricity as I use pre-payment and ensure I have adequate food, which I could not do on ESA alone."

– Respondent with a mental health condition.

"I can also afford to pay for the extra electricity from being home a lot of the time and having the heater on and for the extra washing invoked too. It has meant that I have been able to order a wheelchair accessible vehicle through the Motability scheme."

– Respondent with ankylosing spondylitis.

Appeals and reconsiderations

Reconsiderations

When a claimant disagrees with their PIP decision, they must first request that the decision is reconsidered by another DWP decision-maker, a process known as Mandatory Reconsideration (MR).

Of the respondents who did not agree with their decision, 57% asked for the decision to be reconsidered. However, 63% of those explained that their MR request resulted in the decision being upheld, rather than overturned.

We note that the most recent quarterly DWP data shows that 84% of new PIP claim reconsiderations and 79% of reassessed DLA reconsiderations for normal rules resulted in no change to the award⁴⁵.

A recent Freedom of Information request also revealed a DWP 'measure' that "80% of the original decisions are to be upheld"⁴⁶. Ministers say that it does not constitute a "target", but it could certainly be construed as one, including by staff undertaking the reconsiderations. It is consistent with the high number of poor quality

43 Carer's UK, Caring and Family Finances Inquiry: Executive Summary, p.5, www.carersuk.org/for-professionals/policy/policy-library/caring-family-finances-inquiry

44 Ibid, p. 2

45 Department for Work and Pensions, PIP Statistics: April 2013- April 2017, June 2017, www.gov.uk/government/statistics/personal-independence-payment-april-2013-to-april-2017

46 DWP, Freedom of Information request 1740, May 2017, www.whatdotheyknow.com/request/402400/response/978248/attach/html/2/FOI%201740%20response.pdf.html

decisions that pass through the MR stage, only to be overturned at appeal. We are extremely concerned at the existence of this measure and what it means for the reconsideration process.

Nationally, the latest statistics show that 64% of PIP appeals were found in favour of the claimants⁴⁷. This indicates that where decisions are challenged they are often found to be incorrect, suggesting the assessment is failing to make accurate decisions first time around. This is both stressful for the claimant and extremely wasteful.

We are extremely concerned that there is no data on how long the MR process is taking for PIP claimants, or across the benefits system more widely. We have made continued calls for this to be made available to better understand how the process is working. When MR was first introduced, it was claimed that it should take a maximum of two weeks for claimants to receive decisions. However, since 2014 we have heard of cases where MR has taken more than a month to complete. Without data we cannot know how isolated these cases are.

In some cases, far from allowing disabled people quicker access to appropriate redress via MR, it may be discouraging claimants from seeking redress or progressing to appeal, even where this might be justified. Members of the DBC have reported claimants being discouraged from pursuing an appeal during the MR decision notification telephone call.

“A Jobcentre Plus call centre member initially refused to take my client’s mandatory reconsideration request. I argued that it was their right, whether she agreed to it or not. I also told her I was calling from Parkinson’s UK and pointed out it stated she could ask for a reconsideration in the letter. The member of staff apologised and took the reconsideration after putting me on hold and checking with a supervisor.”

– **Parkinson’s UK Benefits and Employment Adviser.**

Recommendation: Regularly publish data on the average length of time Mandatory Reconsiderations are taking and detailed information on how people are qualifying for PIP.

Appeals

Of the 157 respondents who reported that their appeal was successful, almost half (47%) felt this was because the appeal panel understood their condition better than their original assessor.

Case study – National Deaf Children’s Society

The National Deaf Children’s Society supports deaf young people aged 16–25 with PIP appeals and has had an even higher success rate, with around 85% of appeals overturning the original decision.

Joshua, aged 16, is profoundly deaf in his left ear and severely deaf in his right ear. Only two points were awarded at reconsideration stage for ‘activity seven’ (assessing verbal communication).

However, 18 points were awarded at tribunal and the tribunal hearing lasted around five minutes.

Free text responses from our survey show that respondents consistently report they overwhelmingly believe their appeal was successful because tribunal panels took full consideration of the original supporting evidence they supplied:

“I wrote a letter stating all the lies the assessor had told and why each part of the report was incorrect.”

– **Respondent with mobility problems.**

“The judge agreed, without me saying a word that the DWP had enough information to know that I was unfit to be assessed. The DWP had even admitted in writing that they knew a medical would be detrimental to my health but they wanted me to have one anyway. I think I was successful because my case was heard by someone impartial who had nothing to gain from turning me down and nothing to lose in making the award to me.”

– **Respondent with post traumatic stress disorder.**

⁴⁷ Ministry of Justice, Tribunal Statistics, June 2017, www.gov.uk/government/statistics/tribunals-and-gender-recognition-certificates-statistics-quarterly-january-to-march-2017-and-2016-to-2017

“The judge on the appeal panel said that in the panel’s opinion based on all the medical evidence in front of them my case should never had to go that far and awarded me the enhanced rate daily living and enhanced rate mobility backdated to the date when DWP switched me from DLA to PIP.”

– Respondent with ankylosing spondylitis and osteoarthritis.

Research from DBC members shows that the appeals process is extremely stressful. It is estimated that claimants face a 20-week wait for their appeal to be heard, during which time they are not entitled to any financial support.

Free text responses emphasise the difficulty that undergoing an appeal poses for disabled people:

“I had my higher-level mobility and care stopped, (unexpectedly and backdated by two weeks). I then lost a stone in weight over 3.5 months whilst going through the appeal and tribunal system. Only because I had support from the Citizens Advice/ Macmillan adviser did I continue with the appeal and tribunal.”

– Respondent with cancer.

“I waited months for an appeal which incidentally was the same length of time I waited for DLA appeal is ridiculous and continues to add more stress and anxiety to people already suffering. If you are suffering from progressive diseases and you are only going to get worse the awards should be indefinite as they were for DLA.”

– Respondent with rheumatoid arthritis.

“It took 10 months from beginning to actually going to the appeals tribunal. Who overturned the DWP decision to disallow my PIP claim. They had to backdate all my claim from 10 months. My asthma is a lot worse and causes me no end of hospital stays.”

– Respondent with asthma.



“I had to go to appeal and won. It caused me lots of emotional stress couldn’t pay rent, in-laws had to sort. It caused me to be quite ill with stress and had my first chest infection as got so stressed out. Put a huge strain on my marriage, thankfully I have a brilliant understanding husband.”

– Respondent with autism, depression and anxiety.

In many cases, people felt dissuaded from appealing because of the significant, harmful degree of stress this would cause them:

“I decided not to appeal because of the level of stress.”

– Respondent with mental health conditions and a spinal injury.

“The whole episode was a total farce and made me extremely ill, so much so, that I wasn’t well enough in time, mentally or physically, to get an appeal in against the decision.”

– Respondent with depression, anxiety and fibromyalgia.

“I was too unwell to appeal, knowing that the extra stress would cause further relapse.”

– Respondent with M.E.

“I did not have the mental energy to appeal so am struggling financially now which gets me down.”

– Respondent with depression and anxiety.

PIP appeals now comprise 45% of the SSCS’s 228,000 total tribunal receipts in 2016/17.

The proportion of successful PIP appeals has also significantly increased over the lifetime of the benefit. In 2013/14 the proportion of successful appeals stood at 26%. In the fourth quarter of 2016/17 this now stands at 64%.

Recommendation

Pay PIP claimants an ‘assessment rate’ during the lengthy appeals processes, as is the case with Employment and Support Allowance, to enable them to maintain their independence.

Reassessments

In all, 18% of PIP respondents have already undergone reassessment since their original PIP award, despite the fact that the majority of survey respondents only applied for PIP in the last three years. Of those that had been reassessed, 64% have only received one reassessment, although a third of respondents to this question have been reassessed two or three times.

When asked what the outcome was of their first reassessment, 29% of respondents received more support, 25% received less support and 30% received the same level of award as previously. It is gravely concerning that 23% of respondents explained that they had lost their PIP award entirely.



Case study – Parkinson’s UK

Parkinson’s UK has received a number of examples of people with the condition who have been awarded PIP, then requested a reassessment because their condition had deteriorated and subsequently received fewer points.

A Parkinson’s UK Benefits and Employment Adviser explains:

“I have had six recent referrals of people who were in receipt of PIP (in particular daily living) and either asked for a supersession on the grounds that they had got worse, or were reviewed by the DWP (in one case a year early) and their whole award has been removed so they are now having to go through the reconsideration and appeal process to try and get PIP back into payment. I have two people who went from eight points to zero despite having supporting medical evidence about their Parkinson’s, and one who went from 10 points to two.”

Recommendation

Introduce indefinite PIP awards for people with severe, complex conditions that have no prospect of improvement or are progressive. If reassessments absolutely must be undertaken because additional support may be available, these should happen without the need for a face-to-face assessment.

PIP assessment criteria

In addition to the PIP assessment process, DBC members are extremely concerned about the appropriateness of the assessment criteria that claimants are examined against.

The criteria were designed around “key everyday activities which are essential to enabling participation and independence”⁴⁸. However, the experiences of disabled people and those with long-term conditions shows that the criteria are not sufficiently sensitive to recognise the impact that many conditions have on a person’s ability to undertake daily living activities. They also often fail to take into account hidden and fluctuating symptoms, including cognitive difficulties, or account for the holistic impact of a person’s condition on daily life.

Mobility criteria

The DBC opposed changes to the distance a person must be unable to walk in order to qualify for the highest rates of mobility under the ‘moving around’ criteria. The distance was reduced from 50 metres under DLA to 20 metres under PIP. This means that people who are able to walk only very short distances of over 20 metres will no longer receive as much support, in contrast to DLA.



In response to the original consultation (which was undertaken retrospectively following the decision to reduce the walking distance) the DBC warned that “50 metres is a realistic measure to gauge whether a person is ‘virtually unable to walk’. The distance of 20 metres is an arbitrary figure that lacks an evidence base and automatically discounts thousands of disabled people who really do need the benefit the most.”

The experiences of thousands of disabled people and patient organisations over recent years support this.

Case study – Muscular dystrophy

Jane is a manifesting carrier of Duchenne muscular dystrophy. Not having been given clear guidance on questions regarding her mobility, Jane confirmed that she could walk 65 metres. In reality, if Jane were to attempt to walk this distance, she would need to take several breaks, and would therefore be unable to complete this in a timely manner. She would be greatly fatigued, highly prone to falls, and would be unable to repeat this or any other activity for the rest of the day. Owing to the paucity of information and lack of prompting for these key criteria, Jane was awarded the incorrect level mobility component and lost access to her Motability vehicle.

Case study – Parkinson’s UK

A Parkinson’s UK Benefits and Employment Adviser explains: “I currently have seven people who I am helping with reconsiderations or appeals following a poor PIP assessment, and I get more every week. Of these four have been moved from DLA to PIP and kept their daily living award the same but completely lost their mobility award. They all had high rate mobility, two had a Motability car (which they have had to return), three of them had the higher-rate mobility for over 10 years.”

Research by the National Aids Trust also examined the impact of the walking distance change on people with HIV. The research found that “HIV specialist welfare rights advisers and support services told us that the approach to mobility taken by the PIP assessment is a barrier to appropriate support for people living with HIV who have previously accessed Motability support.”

Recommendation

A thorough review of the PIP assessment criteria should be urgently conducted, with meaningful involvement from disabled people and people with long-term conditions to ensure criteria are set fairly and truly reflect the extra costs that people face. In particular, this should focus on examining rules setting out how fluctuation is considered.

Recommendation

Restore the '20-metre rule' for enhanced mobility support to 50 metres.

Planning and following a journey

The 'planning and following a journey' descriptor fails to capture the significant psychological impact many people with long-term physical conditions also experience when trying to navigate a journey.

The poor design of this descriptor will be exacerbated by the recent regulations change, which undermined a potentially helpful judgement that better recognised the psychological impact of many disabilities and long-term conditions.

Mind and the National Autistic Society have specifically voiced concern that recent changes to the PIP regulations mean that people who cannot plan or follow journeys because of psychological distress will be prohibited from scoring points under several of the mobility descriptors⁴⁹.

Committees responsible for scrutinising the regulations have expressed concern about the longer-term impact of the changes, and emphasised the need for a review of the assessment criteria to ensure they meet the policy objectives upon which PIP is based as well as calling for a clearer understanding of the impact before implementation.

The Lords Secondary Legislation Committee⁵⁰ has warned that "while this change may not result in an immediate cut for people currently receiving PIP, they may lose out in future (despite no change to their condition), if they are reassessed under the new criteria". The committee calls on the Government to clarify the long-term impact of these changes and to "review all the descriptors and the guidance to ensure that they are delivering the

policy intention and being correctly interpreted". The Social Security Advisory Committee also voiced concern⁵¹ over potential "unintended operational and legal consequences" arising from the changes. In a letter to the Minister for Disabled People, Health and Work, the committee also suggested that the Government review the PIP descriptors to ensure they are "clearly defined and remove ambiguity".

Recommendation

Reverse the changes made earlier this year to the mobility criteria, which restrict the ability of an individual who experiences overwhelming psychological distress when planning and executing a journey to qualify for PIP.



⁴⁹ Mind, Written evidence from Mind, April 2017, <http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/work-and-pensions-committee/personal-independence-payment/written/69189.html>
⁵⁰ Secondary Legislation Scrutiny Committee, Twenty Seventh Report: Social Security (Personal Independence Payment) (Amendment) Regulations 2017 (SI 2017/194), February 2017, www.publications.parliament.uk/pa/ld201617/ldselect/ldseclcg/126/12604.htm

⁵¹ Social Security Advisory Committee, The Personal Independence Payment (Amendment) Regulations 2017: SSAC correspondence, March 2017, www.gov.uk/government/publications/the-personal-independence-payment-amendment-regulations-2017-ssac-correspondence

Conclusions and recommendations



Disability charities strongly agree with the principle of a source of financial support to help people manage the extra costs associated with their condition or impairment.

The value of extra-costs benefits like PIP to disabled people is made clear in our research findings. The positive impact it has on their ability to pay for essentials and maintain their independence cannot be overstated. It is clear that when PIP works, it works well.

However, DWP data, the two PIP Independent Reviews, DBC survey findings and the experiences of disability charities and thousands of disabled people themselves have consistently shown that these cases are the exception, rather than the rule. In too many cases, PIP isn't supporting "those who need it most" – it is failing the very people it was designed to support.

The system is complex and consistently denies people the support they desperately need, with devastating consequences for their ability to remain in work, manage their extra costs and maintain their health and wellbeing.

PIP is being poorly implemented due to the extremely variable quality of assessments and difficulties providing supporting evidence for claims

There are also a number of significant problems inherent in the design of PIP, including a complex two-stage claim process and an unwieldy application form. The current strict assessment criteria do not truly examine the extent of a person's extra costs and the difficulties they face, while the reconsideration and appeal processes are stressful, time consuming and onerous for claimants.

In all, the DBC does not believe PIP is fit for purpose in its current form, and requires significant, urgent improvement to restore fairness and equality and people's confidence in the system. The DBC recommends the following changes:

Assessment process

1. The DWP should immediately introduce simplified claim forms that are readily available in Jobcentres, downloadable online and in accessible formats (such as audio described and easy read), without the need to return them within four weeks.

Evidence gathering

2. The DWP should commission an independent review of the evidence gathering processes, to explore ways to:

- educate health and social care professionals on how to provide relevant supporting evidence
- ensure duties and responsibility of the assessor, the DWP and claimant are clear and observed
- make sure the DWP has a strategy to articulate to claimants what evidence will be most useful for their claim
- ensure evidence supplied by friends and family members is given due consideration

3. In order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant, with penalties if they do not.

Assessments

4. A thorough review of the PIP assessment criteria should be urgently conducted, with meaningful involvement from disabled people and those with long-term conditions to ensure criteria are fair and truly reflect the extra costs that people face. In particular, this should focus on examining rules setting out how fluctuation is considered.

5. Restore the '20-metre rule' for enhanced mobility support to 50 metres.

6. The DWP must re-establish direct responsibility for assessment quality and publish an urgent quality improvement plan to ensure assessment companies are conducting assessments consistently and to a high standard.

7. Reverse the changes made earlier this year to the mobility criteria, which restrict the ability of an individual who experiences overwhelming psychological distress when planning and executing a journey to qualify for PIP.

Appeals and awards

8. Pay PIP claimants an 'assessment rate' during the lengthy appeals processes, as is the case with Employment and Support Allowance, to enable them to maintain their independence.

9. Regularly publish data on the average length of time Mandatory Reconsiderations are taking and detailed information on how people are qualifying for PIP.

10. Introduce indefinite PIP awards for people with severe, complex conditions that have no prospect of improvement or are progressive. If reassessments absolutely must be undertaken because additional support may be available, these should happen without the need for a face-to-face assessment.

Notes

