

Experiences of Personal Independence Payment (PIP) for People with Sensory Loss

Research Findings
No. 54 / Jan 2017

Published by
Thomas Pocklington Trust

This publication summarises research conducted by NatCen Social Research, exploring the experiences of 53 people with sensory impairments transitioning from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). It is the second phase of a larger study jointly supported by Thomas Pocklington Trust, RNIB and Sense.

This phase involved 65 in-depth qualitative interviews with 53 people who were either Sight Impaired (SI), Severely Sight Impaired (SSI) or who had dual sensory loss, with the latter group made up of people with Usher Syndrome. There was an even participation between men and women in the research, as well as a diversity of ages (ranging from 19-64) and a mixture of people in and out of work.

Additional information about the sample and methodology can be found in Appendices B and C of the full report, available at www.pocklington-trust.org.uk. The research findings document detailing the first phase of the study is also available at this site.

Key findings

The research found that the overall experience of the PIP claim process caused undue distress and anxiety to participants even though many eventually received positive financial outcomes (i.e. their PIP award was either the same or higher than their DLA award). This was the result of poor practice at numerous key stages of the process, including:

- Accessibility issues, such as initial contact from the DWP being inaccessible, failing to receive PIP communications in accessible formats, and inaccessible assessments;
- The 'PIP2' claim form not being tailored to people with sensory impairments, meaning participants struggled to know how to best fill in their application; and



- Negative experiences of face-to-face assessments due to a lack of perceived knowledge and sensitivity of healthcare professionals.

These negative experiences of the claim process are avoidable, and we set out recommendations to improve the process in this briefing.

Background

As part of the Coalition Government's Welfare Reform Act 2012, DLA was replaced by PIP. PIP is a non-means-tested benefit for people of working age (16-64 years old) and is designed to contribute to the extra living costs arising from having a disability or long-term health condition.

The PIP application process differs in two ways from the DLA process: firstly, by the addition of a face-to-face consultation and second, with the introduction of PIP award reviews.

The aims of this phase of the research were:

- To understand expectations and concerns about the transition process (after participants had been invited to claim PIP)
- To explore experiences of completing the PIP2 claim form and of the face-to-face consultation
- To capture the outcome awarded, and understand how participants felt four to six weeks after the decision had been made
- To determine the number of people with sensory impairments moving from DLA to PIP
- To produce recommendations for the DWP and other stakeholders where necessary

Summary of findings

The below summarises the key findings in more detail, by features in the PIP claim process that were most problematic for the research participants.

Overall accessibility of the PIP process

- A lack of accessible formats with DWP correspondence and the PIP2 claim form led to delays and distress

Initial correspondence from the DWP about the transition from DLA to PIP was inaccessible. This was sent to participants via an inaccessible standard print letter, resulting in many participants having to rely on friends and family or more formal support services to communicate the information to them. Formal support tended to be accessed by participants who had fewer support networks.



Regardless of the type of support, this was a frustrating experience for participants who would have preferred to read their own correspondence as it reduced choice and increased dependency on others.

Similarly, only some participants were given the option of receiving the PIP2 claim form in an accessible format. Current DWP guidance states that all PIP applicants should be asked in which format they would like to receive the PIP2 claim form. Whilst some participants recalled being asked and requesting the PIP2 claim form in their preferred format, others reported that they were not given the option; others could not remember either way. This resulted in some participants having to manage with inaccessible paperwork throughout the application process.

This lack of accessible communication resulted in additional stress and problems when completing the claim form.

Participants largely found completing the PIP2 claim form to be a negative process. The timeframe of one calendar month for completion and submission of the form, coupled with the need to access support to complete it, caused anxiety. This feeling was exacerbated for those participants who were forced to wait for support from friends, family or formal organisations to help them complete their form.

- Some participants needed support to attend assessments at the chosen location, and the assessment environment was often inaccessible

On a practical level, the extent or severity of a participant's sensory impairment did not seem to be a key factor in deciding the assessment location. For example, participants who had stated on their claim form that they found leaving the house alone difficult were still required to attend a face-to-face consultation at an assessment centre and would not have been able to travel there without support. They also required support at the assessment centre itself, as these locations were regularly ill-equipped to accommodate people with visual impairment or dual sensory loss. One participant commented:

'The waiting room, and the room that we [sat] in was so bright, which with RP [is] a huge problem....I sat and I cried in the waiting room.'

Female, Dual Sensory Loss

Filling in the PIP2 claim form

- The PIP2 claim form is not tailored to capture the needs of people with sensory impairments

'The waiting room, and the room that we [sat] in was so bright, which with RP [is] a huge problem....I sat and I cried in the waiting room.'

**Female,
Dual Sensory Loss**

Some participants felt the form had been designed to capture the effects of living with mental health conditions or physical disabilities and not the specific complexities of sensory impairments.

- Confusion around how best to fill in the PIP2 claim form led to varying approaches to completing the form, some with negative outcomes

Some participants felt that showcasing their 'worst case scenarios' was the only way to ensure that they were awarded PIP. Although a smaller group highlighted their ability to 'cope' and limited the amount of information they shared about their day-to-day difficulties, participants who took this approach received an initial 'negative' financial outcome, i.e. either receiving no PIP award or a lower PIP award as compared to DLA (all were eventually overturned at a mandatory reconsideration or tribunal).

Experiences of the face-to-face assessment

- A lack of knowledge and sensitivity from assessors resulted in negative experiences

Participants worried that the assessors did not have any knowledge of sensory impairment and that this might affect their PIP outcome. Participants felt that an hour-long consultation was insufficient time to assess how sensory impairments impacted their everyday lives.

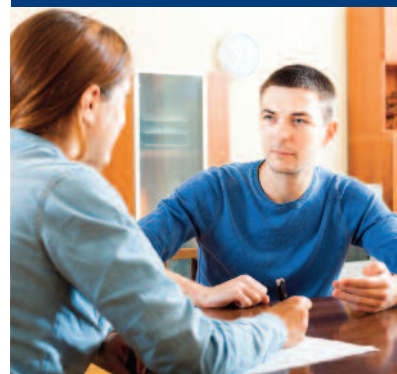
Negative experiences of the face-to-face consultation were largely influenced by assessors who participants felt were insensitive or dismissive about living with a sensory impairment, or had limited knowledge of visual impairment or dual sensory loss and how they affect people's lives. For example, one participant commented:

'I was quite annoyed when I was talking to the [assessor] and I [discussed] cooking and she said, "I don't mean [to be] rude or anything but [do] blind people actually cook?" And I just thought, "I can't believe you".'

Female, Severely Sight Impaired

Another participant shared that in response to a question regarding her employment, the assessor said, 'Well, you do seem to be very confident for a blind person'. The participant felt angry about this comment, and anxious that this view could result in them being found ineligible for PIP.

In instances where participants considered their assessor to be of 'good quality' it was because they felt that their assessor listened to them.



Additional key considerations

Reflections on a 'positive' financial PIP outcome

Participants who received a 'positive' financial outcome when first assessed were broadly satisfied with the level of PIP awarded. Researchers defined a 'positive' financial outcome as receiving either the same or higher PIP award as compared to DLA.

Those who received a higher PIP award as compared to DLA felt reduced worry about living on a tight budget. In some cases, participants anticipated that the higher award would mean they could save to purchase adaptations to help them live more independently. One participant commented:

*"It's been a pleasant surprise... and it's a big weight to be lifted."
Male, Severely Sight Impaired*

Receiving a 'negative' financial PIP outcome

Those who received a 'negative' financial PIP outcome reported feeling concerned about how they would manage. Some described having to borrow money from family and friends and some stopped their social activities because they could no longer afford the cost of taxis. All of these participants went on to be awarded a 'positive' financial outcome at the point of an appeal. Participants received support from advocacy and advice organisations during this process.

Views on PIP award periods and future reviews

Some participants received PIP 'fixed awards' and others were 'ongoing'. The length of 'fixed awards' varied greatly between participants, from two to ten years or more. There were participants who were unaware of the length of their award, which they felt was due to the DWP decision letter being in standard print and therefore inaccessible.

Some did not want to worry about their PIP eligibility being reviewed in the future whereas others reported that it was an ongoing concern. Participants felt strongly that people with sensory impairments should not have their PIP award reviewed, as their conditions would not improve with time. One participant commented:

*'In another couple of years I'm going to be filling the forms in again, and I'm thinking, "What's going to happen? Is it going to drop again, or is it going to go down, or, or what's going to happen?" . So it's nice at the moment, but all in the back of your mind you're thinking it's only for a very short time, really, which is one disadvantage of, of this new system compared to the old DLA, where you got a rate and you'd normally get it for life, near enough.'
Male, Severely Sight Impaired*

Some described having to borrow money from family and friends and some stopped their social activities because they could no longer afford the cost of taxis.

Current data limits comparable analysis between PIP and DLA

It is not currently possible to conduct comparable analysis of the number of DLA and PIP recipients or the amount of income received from each benefit due to differences in the way information is presented by the DWP.

Conclusions and recommendations

Overall, although many participants in the study eventually received a 'positive' financial outcome, in that their PIP award was equal to or more than the amount received on DLA, the journey through the PIP application process was overwhelmingly negative. The process was experienced as a 'one size fits all' approach, rather than being person-centred, which was seen in issues with accessibility, a confusing PIP2 claim form and stressful experiences in the face-to-face assessment.

Particularly in the face-to-face consultations, participants reported feeling 'judged' or 'watched' by assessors. These experiences are at odds with DWP standards of good practice and should be investigated further.

These research findings have led to the following recommendations:

• Accessibility

Both directly and through its contractual specifications for assessment providers, **DWP should promptly address the multiple accessibility issues identified** in this study, ranging from the inaccessibility of correspondence and the PIP2 claim form to the inaccessibility of centres where face-to-face consultations take place.

• Support

Support should be provided to PIP applicants with sensory impairments and to third sector organisations which support them, to ensure that applicants receive practical and emotional support throughout the PIP application process, as and when they need it.

• Training

A number of participants reported experiencing poor quality assessments and therefore **we call for the re-training of all assessors in relation to sensory impairment by DWP and assessment providers.**

'In another couple of years I'm going to be filling the forms in again, and I'm thinking, "What's going to happen?"'

• **DWP administrative data**

DWP should include dual sensory loss as a main disabling condition category when collecting and presenting PIP data to allow for comparable analysis with DLA data.

This Research Findings document has been edited by RNIB, Sense and Thomas Pocklington Trust.

Note on terminology

The terms 'people who are sight impaired' (SI) and 'people who are severely sight impaired' (SSI) are used to describe those who are eligible for certification as sight impaired (SI) or severely sight impaired (SSI). The terms 'sight loss' and 'visually impaired' cover both of the above categories.

The term 'dual sensory loss' refers to people who are considered deafblind. Deafblindness is a combination of sight and hearing impairments that affects someone's ability to communicate, access information and get around. A person who is deafblind will not usually be completely deaf and blind, but both senses will be sufficiently reduced to cause significant difficulties in everyday life.

Usher Syndrome is a rare and variable condition causing hearing loss and loss of vision.

How to obtain further information

The full research report sets out the methodology and findings in more detail. Authors: Malen Davies, Lauren Porter, Hayley Lepps, Rossella Icardi and Aude Bicquelet - NatCen Social Research.

The report, 'Experiences of Personal Independence Payment (PIP) for People with Sensory Loss' is available at www.pocklington-trust.org.uk.

Accessible formats are available on request from research@pocklington-trust.org.uk or 020 8996 1937.

To find out more about the work of NatCen, RNIB, Sense and Thomas Pocklington Trust, please visit:

naten.ac.uk/

www.rnib.org.uk/

www.sense.org.uk/

www.pocklington-trust.org.uk/





for people with sight loss

Pocklington Hub
Tavistock House South
Tavistock Square
London WC1H 9LG

Tel: 020 8995 0880

Email: research@pocklington-trust.org.uk

Published by Thomas Pocklington Trust

Registered Charity No. 1113729

Company Registered No. 5359336

ISBN 978-1-906464-82-0



www.pocklington-trust.org.uk