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Experiences of Personal Independence Payment (PIP) for people with sensory loss

Published by Thomas Pocklington Trust

June 2015

This publication summarises findings from research conducted by Dr Liz Ellis, Dr Graeme Douglas and Dr Harriet Clarke, University of Birmingham.

This research explored the experiences of 14 people with sensory impairments as they engaged in the PIP (Personal Independence Payment) application process. It is Phase 1 of a larger study jointly supported by Pocklington, RNIB and Sense.

Summary

The PIP **application process** was generally viewed as negative by participants:

- Participants were often anxious in advance of, and throughout, the application process.
- Many aspects of the application process were inaccessible to people with sensory impairments, and information from the Department of Work and Pensions (DWP) was often lacking or inconsistent.
- The time taken by DWP to process claims (from initial claim to decision letter) was much longer than originally planned. The delays were compounded by poor and inconsistent communication to claimants.

In relation to **outcomes** it was found:

- Experiences were broadly positive: participants who had received a decision had been awarded PIP.
- All participants who received an award, including those previously in receipt of DLA, were satisfied with its level.
- PIP was felt to provide an important contribution to the additional costs associated with disability and/or long-term conditions.
- Most of the costs associated with their sensory impairment were easily identified by participants and those working on their behalf. Costs that were less obvious were not always recognised and included in applications.



Introduction

PIP replaced Disability Living Allowance (DLA) for people aged 16 to 64 on 8th April 2013 – initially for new claims in pilot areas. Since then there has been a staggered introduction of PIP (and it will replace DLA for people of that age group). PIP is not means-tested or taxed, and is designed to help towards some of the extra costs arising from a long-term health condition and/or disability.

This research formed Phase 1 of a larger study and included the following objectives:

- To investigate differences in benefit receipt before and after PIP was introduced for people with sensory impairments;
- To find out about the financial status of people with sensory impairments before and after PIP was introduced;
- To explore experiences of making a claim and the impact of this on the wellbeing of people with sensory impairments;
- To make recommendations for the second phase of the research study.

Method

Fourteen people took part in semi-structured interviews which explored people's experiences of PIP. Characteristics of the 14 participants included:

- Seven participants had a visual impairment; seven had dual sensory impairment;
- Six of the participants were aged between 16 and 25; eight ranged in age from 33 to 57;
- Nine of the participants could be broadly described as having additional disabilities and/or health conditions beyond their sensory impairments;
- Three participants had appointees;
- Participants were at different stages of the PIP application process: seven having received their decision letter at time of interview, four awaiting assessments/decisions, and three had not yet started the process;
- The majority of participants had prior experience and receipt of DLA – only two participants were not previously in receipt of DLA before applying for PIP.

Analysis

The transcribed interviews were analysed drawing out case summaries, accounts of experiences of applying for PIP, and general emerging themes of relevance to the aims of the study. In this short summary it is impossible to capture this analysis process and offer significant evidence. Nevertheless, we offer two illustrative quotes which capture some of the key findings from this research.

Ricky is 17 years old. He has dual sensory impairment linked to Usher syndrome. He has no other health problems or disabilities. Ricky was previously in receipt of DLA. Lindsay, Ricky's mother, is his appointee and spoke of her experiences of applying for PIP on his behalf. Lindsay sums up their experience:

"I think now that it's over we are better off on PIP, [...] but actually applying was a nightmare. It's just because there was no communication from them. You sometimes receive a letter "we've received your form, thank you very much, you'll hear from us in so many weeks" – there was absolutely nothing from them. Then we got the letter – 'you need to be assessed' – but with no further information. That really was very stressful and nerve wracking for us. There was no further communication saying that there has been a backlog, we'll be in touch we haven't forgotten you. Then we got the letter completely out of the blue saying you've got your award. And I was like 'ha' that has taken 11 months! But it's done."

"I think now that it's over, we are better off on PIP, but actually applying was a nightmare."

Key findings in relation to PIP application process

Appointees

An appointee manages claims and benefits on behalf of a claimant and acts in their best interests in using the income generated (e.g. from PIP). The process and associated assessment to become an appointee appears to be straightforward and the flexibility of the process was viewed positively, although greater clarity and information would have removed anxiety. Decisions about appointeeship can be complex and emotionally charged.

Jim is 57 years old. He is visually impaired as a result of complications from diabetes. He was not in receipt of DLA as he is newly registered as severely sight impaired. Jim was eventually awarded PIP after seven months and having contacted his MP in frustration and despair. Jim reflects:

“Now bear in mind at the time [of my sight loss] I was working, I was self-employed. So obviously I couldn’t claim sickness benefits or anything. So financially-wise it was very worrying. From wages to no wages. The savings that I had got were going and going. So it was June-time before [the assessor] came to see me. It was very very stressful and it caused a few arguments in the house because money was tight and we still had bills coming in.”

Accessibility and time

Aspects of the application process proved inaccessible at every stage for people with sensory impairments. The application process often relied upon printed text or the telephone. This poor accessibility, combined with the complex lives some disabled people may lead (e.g. organising hospital appointments), can put additional time pressures upon claimants.

Support

When available, support workers (ideally specialising in sensory impairment), written guidance, and support from those in similar situations proved extremely useful and reassuring to participants. However this support was not available to all participants (partly linked to the early stage of the PIP rollout). Support is particularly important in helping people understand the points system which is central to the PIP assessment.

Assessment

The participants in this research were all anxious about the PIP assessment process. However, in practice all those who experienced it found it straightforward. Claimants’ anxiety is inevitable given the assessment is high stakes for those who apply. Nevertheless, some of the anxiety could be reduced by clearer communication about the assessment process. The main issue of confusion was linked to whether a paper-based or face-to-face assessment was to take place, and where this assessment would take place.

“It was very stressful and it caused a few arguments in the house because money was tight and we still had bills coming in.”

Timescales

DWP had originally proposed that 97% of assessments would take place within six weeks from the submission of the PIP application form. Of the seven participants who had received their decision letter (all of whom were awarded PIP) none of them appears to have received the letter within the original DWP timescale. Four of the participants appear to have received the decision letter within a 26 week target timescale (the times ranged from three to six months). Twenty six weeks appears to be current DWP estimated timescale based upon the PIP enquiry line. For three participants the process took longer than 26 weeks (between seven and eleven months). Another participant who is still awaiting the decision letter has been in the system for eight months.

Discomfort about the assessment process

Some of the participants had feelings of defensiveness and even guilt about claiming PIP. PIP is not means-tested or taxed, and is designed to help towards some of the extra costs arising from a long term health condition or disability. An important role of advisers and advocates is to remind claimants of the legitimacy of their application.

Some of the discomfort expressed by participants was in relation to the deficit nature of the application process (focussing upon what they cannot do) and it was dispiriting that independence that they worked hard to achieve (in themselves or the people who, as appointees, they represented) may work against them in relation to gaining a PIP award.

Key findings in relation to PIP outcomes

This research presents evidence which is broadly positive in terms of the successful outcomes of the PIP application process for the study participants:

- All seven participants who had received an award letter had a successful outcome (in that they were awarded PIP at some level).
- One participant asked for a mandatory reconsideration and the points were adjusted which led to a successful change in the eventual award.
- Four out of five participants who were previously in receipt of DLA appeared to have matched (two) or improved (two) the monetary value of the benefit they received following the award of PIP. One participant appeared to have a lower award (although this seemed ambiguous).

“There’s no way in the format that it comes that you can actually understand it. If I were on my own I wouldn’t have stood a chance to tell you the honest truth!”

- All participants appeared satisfied with the eventual outcome of the PIP application process.

PIP provides an important financial contribution to the additional costs associated with disability and long term health conditions. Some of the costs associated with sensory impairments were easily identified by participants (e.g. transport and equipment). Some additional costs were less obvious and often normalised by the participants and they were sometimes not recognised by the individuals themselves (e.g. additional heating, washing and cleaning).

Conclusions

Extreme caution needs to be applied when drawing implications from this exploratory and small-scale piece of research, particularly at this early stage of PIP rollout. The research was a time specific piece of research and was carried out between January and December 2014. To this extent Phase 1 provides a useful foundation for future phases of this research study (e.g. in terms of methods and themes to explore).

The findings of this research imply that people with sensory impairments should apply for PIP confident in the knowledge that others have been successful in securing a satisfactory award.

Clearly the PIP application process proved challenging for participants. Clearer and accessible guidance about the various aspects of PIP application would be very useful (e.g. the appointee, application and assessment processes), and the availability of knowledgeable advisors would prove especially helpful for many claimants. This is especially important in helping people with sensory impairments to understand the additional costs of disability and how it can be effectively represented in the PIP assessment process.

It is generally agreed that the DWP targets for the timescale of the PIP application process have not been met. Clearly the DWP should improve on this performance and in the short term they might more clearly communicate timetable challenges to claimants. The delays have particularly negative impacts upon those who are claiming a disability-related benefit for the first time. The DWP might consider fast-tracking these particularly vulnerable new claimants.



Next Steps

NatCen Social Research will conduct Phases 2 and 3 of the study between January 2015 and December 2016 and will focus on the period of change for both new PIP claimants and existing DLA claimants with sensory loss who will be moving to PIP.

Phase 2 will be a larger scale qualitative analysis of the experiences of PIP on adults with sensory loss and this research will take place between Spring 2015 and Summer 2016. Interviews will comprise of a mix of face-to-face depth and telephone interviews, or other more suitable formats, with claimants. Data will be collected from the same DLA-PIP claimants at three points in time. Firstly when they receive instructions from DWP on how to claim PIP, secondly after claimants have been informed of the decision of their PIP claim and finally at least three months after a transfer to PIP or after DLA payments have stopped.

Phase 3 will consist of a secondary analysis of specific datasets from two longitudinal surveys: Understanding Society and the Life Opportunities Survey, as well as an analysis of DWP administrative data. The research will take place in Spring 2015, late 2015 and Summer 2016. Analysis will be by type of impairment and will compare claimants with sensory impairments with those with other types of disability. This will enable the researchers to analyse changes in benefit receipt at different points in time.

NatCen Social Research will provide a final report, incorporating findings from all stages of the research, including making policy and research recommendations.

The full report from the University of Birmingham can be found at

<http://www.birmingham.ac.uk/research/activity/education/victar/research/experiences-of-personal-independence-payment-on-people-with-sensory-loss.aspx>



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