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

Final report

Authors: Malen Davies, Lauren Porter, Hayley Lepps, Rossella Icardi and Aude Bicquelet
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Prepared for: Thomas Pocklington Trust, Royal National Institute of Blind People and Sense

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1 Executive summary

1.1 Overview of research

Thomas Pocklington Trust, Royal National Institute of Blind People (RNIB) and Sense commissioned NatCen Social Research (NatCen) and the University of Birmingham (UoB) to explore experiences of the transition from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) for people with sensory impairments. Recommendations for change are presented in section 1.5.

1.2 Methodology

The research was conducted over two phases[1]. This report includes findings from phase two of the study. Phase two involved 65 qualitative in-depth interviews with 53 individuals who had a visual impairment or dual sensory loss. It also includes secondary analysis of Department for Work and Pensions (DWP) administrative data which outlines the number of people with sensory impairments moving from DLA to PIP.

1.2.1 Amendments to the methodology

For phase two of the study, the intention was to follow participants longitudinally through the PIP application process. Interviews were to be conducted at three stages: stage one, before the application process began; stage two, when the initial PIP outcome had been received; and stage three, up to three months after the PIP outcome was awarded.

However, because of unexpected high volumes of applicants, the DWP was delayed in transitioning people over to PIP. This meant the longitudinal element of the research design had to be adapted. In total, 26 individuals completed a stage one interview. Three stage one participants were followed up at stage two. Twenty new individuals also completed a stage two interview. At stage three, 16 of the 23 stage two participants were followed up (additional

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[1] Phase 1 of the study can be found here: http://www.birmingham.ac.uk/research/activity/education/victar/research/experiences-of-personal-independence-payment-on-people-with-sensory-loss.aspx

information on adaptations to the methodology can be found in the Appendix C of this report).

The secondary analysis element of phase two was also amended. The aim was to use DWP administrative data to review the number of PIP applicants with sensory impairments and the outcomes of their PIP application. However, data released by the DWP between February 2013 and January 2016 does not enable analysis of the transition from DLA to PIP for three reasons. First, individuals are not observed longitudinally. Second, the DWP uses a different terminology to categorise DLA and PIP recipients with a visual impairment, and does not routinely report data on PIP recipients who have dual sensory loss as their main disabling condition. Third, DLA data presents the amount of award recipients received, where PIP data only presents the number of people in receipt of the benefit and does not provide information about the amount of award received.

1.3 Background

PIP is a non-means-tested benefit for people who are aged between 16 and 64 years old. The purpose of PIP is to contribute to the extra living costs for people who have a disability or a long-term health condition[2].

As part of the Coalition Government's Welfare Reform Act 2012, DLA was replaced by PIP. The introduction of PIP was set within the context of the Coalition Government's aim to create a "simpler system"[3] which is "fairer [and] protects those in greatest need"[4]. More specifically, according to an independent review of PIP undertaken by Gray (2012)[5] an overhaul of DLA was needed to ensure: "a stronger emphasis on assessment of the functional impact of claimants' underlying disabling and medical conditions, not the conditions themselves".

Alongside this refocus of the disability benefit, the PIP application process is different to the DLA application in two ways. First, a face-

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[2] DWP (2016) PIP overview: https://www.gov.uk/pip/overview

[3] Ibid

[4] Department for Work and Pensions (2010) 21st Century Welfare: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181139%20%20/21st-century-welfare_1_.pdf

[5] Gray (2012) An Independent Review of the Personal Independence Payment Assessment, Page 4.

to-face consultation was introduced (previously, decisions on eligibility were made on the basis of a DLA application form). Second, PIP involves regular reviews of eligibility. The aim is to capture any changes to recipient’s disability or health condition over time. The phased roll-out of PIP began in October 2013, although new claimants could claim PIP from April 2013. The transition from DLA to PIP is due to be completed in autumn 2017.

1.4 Key findings

1.4.1 Experience of the application process

Overall, participants in this study eventually received ‘positive’ financial outcomes (i.e. their PIP award was either the same as or higher than their DLA award) from the PIP application process. However, the journey through the application process was largely negative. Negative experiences were mainly caused by the application process not being tailored to the needs of people with sensory impairments.

Particular aspects of the PIP application journey that contributed to a negative experience included:

- **Necessity for support to navigate the PIP application process.** Participants who lived with family often relied upon them for help, whereas those who lived alone were more likely to access support from advocacy and support organisations or charities.
- **Inaccessible initial correspondence from DWP to participants.** Part 1 of the application process happens by phone, where claimants should be asked if they want any further correspondence in large print, braille or audio format. However, the research found that for many participants the on-going correspondence was largely sent via letter using standard print, resulting in participants having to rely on support from friends, family or support workers to explain the contents of any correspondence from the DWP. While one group of participants was accepting of this need for support, another group was frustrated that they were not given the choice to access correspondence from the DWP independently.
- **Inaccessible PIP2 form.** Participants reported that they found the PIP2 form (that most claimants complete as part of the application process), was inaccessible because it was neither

provided in the font size needed nor made available online. Again, it was necessary for participants to rely on family, friends, or advocacy and support organisations to complete the form. A frustration among participants was that they had no choice but to access support. This was felt particularly by participants who did not want to share how their impairment limited their ability to do day-to-day activities.

An emerging theme from the research indicates **there were two distinct approaches participants took when navigating the PIP application journey:**

- **The first and most common approach involved participants employing a strategy to 'prove' their eligibility for PIP.** Participants discussed using 'worst case scenarios' in their PIP2 form such as examples of bad experiences or accidents resulting from their sensory impairment. Participants felt that showcasing themselves in this way was the only option to ensure they were awarded PIP. Previous negative experiences of claiming other disability benefits, and advice from other PIP applicants or support from advice or advocacy organisations underpinned this particular strategy.
- **The second approach, in contrast to the first, was for participants to highlight their ability to 'cope' with their sensory impairment.** Participants who took this approach received an initial 'negative' financial outcome. 'Negative' financial outcomes are defined as being found ineligible for PIP, or receiving a lower PIP award compared to DLA. These negative financial outcomes were eventually overturned at a mandatory reconsideration or tribunal (a formal challenge of a PIP award).

Perceived poor quality assessors also underpinned the negative experiences of the face-to-face consultation. Aspects of perceived poor quality included: assessors who were insensitive and unresponsive to participants' needs, were dismissive of the experience of living with sensory impairments, or had poor knowledge and understanding of visual impairments.

1.4.2 PIP outcome

Findings show that participants who received a 'positive' financial outcome when first assessed were broadly satisfied with the level of PIP awarded.

Participants who initially received a ‘negative’ financial outcome were, unsurprisingly, upset with their outcome. All those who received less PIP than DLA chose to request a mandatory reconsideration and where that was not successful in some circumstances they appealed their decision (for some, this involved attendance at a tribunal which is independent of the DWP). Continued scrutiny of these participants’ sensory impairment caused additional stress.

1.4.3 The importance of PIP

Across all stages of the research, participants reported that both DLA and PIP helped with living costs incurred due to their sensory impairment – this was the case both for participants who were in work and those who were not working. Participants described using DLA for care or daily living needs, for mobility needs, to purchase assistive technology and to contribute to their household income.

Participants who received a higher PIP award compared to DLA explained this increase in monthly income reduced the worry of living on a tight budget. In some cases participants anticipated that the higher award would mean they might be able to set aside some PIP to build up savings which would eventually be used to purchase expensive adaptations or appliances to help them live more independently.

The length of time PIP was awarded to participants varied, from 2 to 10 years or more. All PIP recipients will have their eligibility reviewed once their award period comes to an end[6]. Views on the review process varied, some did not want to dwell on or worry about future reviews and would think about it in more depth when the time came. Others reported it was an ongoing concern that was always at the back of their mind.

1.5 Recommendations

A set of practical recommendations have been developed to provide clear and practicable suggestions for the DWP, the assessment providers (currently Atos and Capita) and external advocacy and support organisations to improve the PIP application process for people with a sensory impairment.

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[6] DWP (2016) PIP Guidance: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519147/pip-assessment-guide.pdf

1.5.1 Accessibility

For the application process to be accessible for people with a sensory impairment the DWP, both directly and through its contractual specifications for assessment providers, should:

- Ensure that all applicants are asked about their accessibility requirements at the start of the process (which is usually carried out over the telephone).
- Ensure that the PIP2 form is provided in an accessible format for people with a sensory impairment.
- Ensure that all on-going correspondence (e.g. letters inviting people to make a claim to PIP and the application outcome letter) is provided in the PIP applicant's chosen format.
- Increase the length of time people with a sensory impairment have to complete the PIP2 form.
- Raise awareness among applicants about the requirements for assessment providers that all people with a sensory impairment are given the choice of location for the face-to-face consultation (e.g. at their own home or at the provider's assessment centre provided that it is fully accessible).

1.5.2 Support

While adaptations should be made to increase choice and the ability to complete the PIP2 form independently, people may still require both practical and emotional support throughout the application process. Some key adaptations to improve the provision of support are suggested below:

- The DWP should provide a list of the existing resources for applicants to access, if needed, to support them at any point of the application process.
- Sensory impairment charities and local and national advocacy organisations should ensure that those who request support are supported until the point of their PIP outcome. This will ensure PIP applicants are followed through the process to identify any points they might need help with.
- Sensory impairment charities need to provide information on the resources and guidance available for those embarking on an appeals process.
- Appropriate help and support should be available to people with a sensory impairment that require it. This could be achieved by providing additional funding to third sector organisations to

provide this support. Study participants who used third sector support during the application process used it for its accuracy, reliability and trustworthiness.

1.5.3 Training

A key factor driving negative experiences was the perceived poor quality of the assessors (this is based on assessors' apparent lack of knowledge of visual impairment and insensitive actions and comments made by assessors to participants regarding their sensory impairment).

- As a minimum, the DWP and assessment providers should ensure that all staff receive sensory impairment training as part of wider disability awareness training.

1.5.4 DWP administrative data

DWP does not include dual sensory loss as a main disabling condition category when presenting information on PIP recipients. This makes it impossible to compare total figures of PIP recipients with dual sensory loss with total figures of DLA recipients with dual sensory loss.

- DWP should include dual sensory loss as a main disabling condition category when collecting and presenting PIP data as part of the evaluation process for this benefit.

2 Introduction

2.1 Personal Independence Payment

Personal Independence Payment (PIP) is a non-means-tested benefit for people who are aged between 16 and 64 on 8th April 2013 (although there are some exceptions to the upper age limit). People can receive between £21.80 and £139.75 a week[7]. The amount of PIP a person is eligible to receive depends on the extent of their mobility and daily living needs[8].

According to the Department of Work and Pensions (DWP), the purpose of PIP is to contribute towards the extra costs of living that people with a long-term health condition or disability might have[9]. PIP has two components which have been separated out to ensure that people with varying needs can access the benefit. These are:

- **Mobility component** – to help towards the cost of getting out of the house or moving around.
- **Daily Living component** – to help towards the cost of assistance someone might need with, for example: preparing or eating food; washing, bathing or using the toilet; dressing and undressing; reading or communicating; managing medicines or treatments; making decisions about money; or engaging with other people.

In April 2013, PIP replaced Disability Living Allowance (DLA). For more details on what PIP includes and how it differs to DLA, please see Appendix A.

2.2 Background to the study

Thomas Pocklington Trust, Royal National Institute of Blind People (RNIB) and Sense commissioned NatCen Social Research and the University of Birmingham (UoB) to explore the experience of the transition from DLA to PIP for people with a visual impairment or dual sensory loss.

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[7] DWP (2016) PIP overview: https://www.gov.uk/pip/overview

[8] Ibid

[9] Ibid

The research is divided into two phases:

Phase 1: a case study approach to explore the experiences of people with sensory impairments transitioning from DLA to PIP. This was led by the University of Birmingham and took place between January and December 2014.

Phase 2 (findings included in this report): a large-scale longitudinal qualitative analysis of experiences of the transition from DLA to PIP for adults with sensory impairments, and analysis of DWP administrative data to explore the number of people moving from DLA to PIP.

2.3 Aim of the study and approach

2.3.1 Phase two – qualitative study

The study used a qualitative approach consisting of in-depth interviews (either face-to-face or by telephone). A longitudinal approach was taken, involving three stages of interviews:

- Stage 1 (May 2015 – October 2015): Interviews were conducted when DLA claimants with a sensory impairment received a letter inviting them to claim PIP.
- Stage 2 (January 2016 – April 2016): Interviews were conducted when the application process had been completed and the PIP outcome decided.
- Stage 3 (April 2016 – May 2016): Interviews were conducted four to six weeks after participants received their PIP outcome.

Sample
In total, 65 interviews were conducted with 53 individuals. People were eligible to take part in the study if they were claiming DLA and had a sensory impairment.

Table 1 shows a breakdown of the number of interviews at each stage.

Table 1: Number of interviews

Interview stage	Number of interviews
1	26
2	23
3	16

The sample included a range of people who were either Severely Sight Impaired (SSI), Sight Impaired (SI) or had dual sensory loss (the latter group was made up of people who had Usher Syndrome[10]). The sample also included participants who had a sensory impairment alongside another health condition or disability.

There was an even split between men and women participating in the study and a diversity of ages, ranging from 19 to 64 years. There was also a mixture of people in and out of work. To ensure we captured a diversity of experiences, specific quotas were set. Further detail and the numbers of participants within each characteristic group are provided in Appendix B.

Recruitment

Various recruitment approaches were used to involve participants in the study. An opt-in approach was taken during stages one and two. Information leaflets were disseminated via the funders' services/networks to notify members of the research and invite them to get in contact with the research team if they were interested in taking part in the study.

In addition, during stage one interviews, an opportunity arose to recruit from a sample of respondents who had previously taken part in another RNIB research project. An opt-out approach was taken with this sample. The implications of using this sample meant that only people with a visual impairment were targeted by this approach. To ensure we recruited participants who had dual sensory loss, we also continued to use the opt-in approach elsewhere, and specifically targeted organisations that supported people with dual sensory loss.

Adaptations to the methodology

The DWP was substantially delayed in transitioning DLA claimants over to PIP during 2014/15. This meant that in some cases, people had sent in their PIP2 form but were waiting up to six months for a face-to-face consultation or outcome. Delays had an impact on the research and the recruitment strategy had to be adapted. More detail on the adaptations can be found in Appendix C.

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[10] Usher Syndrome is a condition which causes both hearing loss and sight loss. The main cause of sight loss for people with Usher Syndrome is a condition called retinitis pigmentosa (RP). RP causes night blindness and tunnel vision

Interviews
Participants were given the choice to conduct interviews over the telephone or face-to-face. Each interview lasted up to an hour; please see Appendix D for detail on the topics covered.

2.3.2 Phase two – quantitative analysis

The analysis involved an exploration of DWP administrative data to capture the number of people with sensory impairments claiming DLA and PIP at certain points in time. An exploration of the amount of award was conducted but was limited to the level of information provided by data tools the DWP make publically available (please see chapter 3 for more information).

Limitations to the methodology

Two separate tools are used to present DLA and PIP data and within the tools data is categorised and presented differently. This meant it was not possible to directly compare figures across the different benefits (for more information on the limitations see chapter 3).

2.3.3 Report outline

Chapter 3 presents findings from the secondary analysis of DWP administrative data to capture the number of people with sensory impairments claiming DLA and PIP at certain points in time.

Chapter 4 provides detail of participants’ experiences of being invited to transition from DLA to PIP. It explores participants’ understanding and expectations of the PIP application process.

Chapter 5 provides an overview of participants’ experiences of the PIP application process. It includes participants’ experiences of and views about completing the PIP2 form and the face-to-face consultation.

Chapter 6 details the types of award participants received. It discusses participants’ experiences of and views on the different outcomes and the effect these may have on their independence and wellbeing. It also covers the views regarding the review process for once an award comes to an end.

3 Reviewing DWP administrative data of DLA and PIP recipients

3.1 Introduction

This chapter provides an overview of the number of people with a sensory impairment who claim DLA and PIP. It offers a snapshot of the number of DLA and PIP recipients at notable points during the PIP reassessment timetable[11].

3.2 DWP administrative data

Administrative data collected by the DWP offering information on both PIP and DLA benefits and claimants was analysed. The administrative data is publically available and was obtained using standard online tools provided by the DWP (for more information on the DWP's data tools please go to Appendix E).

3.2.1 Key findings

The key finding from reviewing DWP administrative data is that it is not possible to conduct comparable analysis of the number of DLA and PIP recipients or the amount of income received from each benefit due to the way the data is presented for each benefit. The analysis is restricted for two key reasons:

Firstly, the tool presenting DLA data includes the terms 'blindness' and 'dual sensory loss' as categories for main disabling condition whereas the PIP tool uses the term 'visual disease' and there is no separate category for dual sensory loss. This difference in categorisation hinders the direct comparison of results across each benefit.

Secondly, the tool which presents DLA data provides an average weekly income from DLA for each component (mobility and care) and each level of award (higher, middle (only for care) and lower). In comparison, the tool that presents PIP data only provides the number of PIP recipients by each component (enhanced and daily

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[11] DWP (2015) PIP reassessment timetable: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/478758/timetable-for-pip-replacing-dla.pdf (This timetable has been withdrawn, but is the latest timetable made publically available by the DWP)

living) and by the level of award (enhanced or standard rate), it does not provide figures on the average income provided to recipients by PIP.

We have done a simple calculation[12] to provide an estimate of the total spend of PIP for each component (mobility and daily living) and by level of award (enhanced and standard) in order to give some indication of PIP funding.

Limitation of the data

Comparable analysis is also hindered by the fact that the roll-out of PIP is still underway which means the PIP data presented provide only a partial a picture of PIP recipients and their awards. This means all data presented must be used with caution as they do not provide any definitive picture of information about PIP recipients as those who are already in receipt of PIP may differ from those yet to transition from DLA.

Taking the key findings and limitations into account, the following analysis is limited to providing comparisons between all disabilities and visual impairment and dual sensory loss for DLA and a separate comparison between all disabling conditions and visual impairments for PIP.

3.3 Number of DLA and PIP recipients

3.3.1 Total number of DLA and PIP recipients

Analysis of the number of people in receipt of DLA was conducted with data from February 2013, two months before the introduction of PIP. In order to provide the most relevant figures on PIP recipients, the most recent data (at the time analysis was conducted), published in January 2016, was used.

The **total** number of DLA recipients in February 2013 was **3.3 million**. As of January 2016 the total number of people in receipt of PIP was **692,104**. These numbers reflect the staged approach the DWP took to rolling out PIP by different postcodes[13].

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[12] Results have been calculated by looking at the total number in receipt of each payment (combination of mobility and daily living awards) and multiplying this by the set rates. The weekly rates have been taken from DWP's website: https://www.gov.uk/pip/what-youll-get

[13] Ibid

3.3.2 Number of DLA and PIP recipients with a sensory impairment

Data from the tool used to present DLA shows in February 2013 that there were **72,000** DLA recipients who had a visual impairment and **570**[14] who had dual sensory loss (representing 2.1% and 0.01% of the DLA population respectively).

Data from the tool used to present PIP shows in January 2016 that there were **8,334** PIP recipients with a visual impairment as their main disabling condition. But, as explained above the tool does not include a category for dual sensory loss. This is an important finding, as it will not be possible to access any information from DWP on how many PIP recipients are categorised as having dual sensory loss as their main disabling condition once all DLA recipients have had their eligibility for PIP assessed.

3.3.3 Amount of DLA and PIP received

As mentioned above there were variations between the tools used to present DLA and PIP data. The tool presenting DLA data provides **average weekly** DLA awards by each rate (higher, middle (only for care), and lower) by main disabling condition for both the care and mobility components. Whereas the tool presenting PIP data only provides total number of PIP awards by each rate (enhanced or standard) by main disabling condition for both daily living and mobility components.

Due to the variation in the way DWP present DLA and PIP data, it is not possible to directly compare the average level of award for the two DLA and PIP components.

Amount of DLA received for mobility component

This section compares the average income for the mobility component by each rate (higher and lower) across all DLA recipients of all main disabling conditions with the average weekly income for DLA recipients who have a visual impairment or dual sensory loss as their main disabling condition.

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[14] The figure of 570 DLA recipients with dual sensory loss is much lower than anticipated. It is possible that DLA recipients with dual sensory loss have chosen either their visual impairment or hearing loss as their main disabiling condition when making a claim for DLA.

The following figures are broken down first to show you the average amount DLA recipients received for mobility across **all disabling conditions** (see Table 4 in Appendix F):

- Higher Rate mobility: £96 per week
- Lower Rate mobility: £65 per week

DLA recipients with a visual impairment and dual sensory loss in receipt of a higher rate of the mobility component received **more** than the average weekly income compared to the average across all disabling conditions. Whereas DLA recipients with a visual impairment and dual sensory loss in receipt of the lower rate of the mobility component received less than the average weekly benefit compared to the average across all main disabling conditions**:**

- Visual Impairment - Higher rate mobility: £100 per week
- Visual Impairment - Lower rate mobility: £50.90 per week

- Dual sensory loss - Higher rate mobility:£106 per week
- Dual sensory loss - Lower rate mobility: £59.80 per week

Amount of PIP received for mobility component

This section shows an estimate[15] of the total spend (using data from January 2016[16]) for each rate (enhanced and standard) for the mobility component across all PIP recipients of all main disabling conditions. It compares an estimate of the total spend for both higher and lower rates for PIP recipients who have a visual impairment as their main disabling condition.

The overall estimated spending for the mobility component (equivalent to mobility component) across **all disabling conditions** was as follows: (see Table 5 in Appendix F):

- Enhanced rate: £12,540,013 total spend
- Standard rate: £4,849,758 total spend

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[15] Results have been calculated by looking at the total number in receipt of each payment (combination of mobility and daily living awards) and multiplying this by the set rates. The weekly rates have been taken from DWP's website: https://www.gov.uk/pip/what-youll-get

[15] Ibid

[16] This data presents total figures which are published on the Stat Xplore every quarter

Total estimated spending for the mobility component for PIP recipients with a **visual impairment** was as follows:

- Enhanced rate for mobility: £258,009 total spend
- Standard rate for mobility: £59,950 total spend

Amount of DLA received for care component

This section shows the average income for each rate (high, middle or lower) for the care component across all DLA recipients of all main disabling conditions. It compares this to the average weekly income again for higher, middle and lower rates for DLA recipients who have a visual impairment or dual sensory loss as their main disabling condition.

The average amount of DLA recipients received for care across **all disabling conditions** was (see Table 4 in Appendix F):

- Higher rate for care: £119.1 per week
- Middle rate for care: £84.70 per week
- Lower rate for care: £50.80 per week

DLA recipients with **dual sensory loss** tended to receive **more** than the average higher, middle and lower rate for the care component compared to the average across all disabling conditions and visual impairment:

- Dual sensory loss higher rate for care: £131.1 per week
- Dual sensory loss middle rate for care: £103.3 per week
- Dual sensory loss lower rate for care: £72 per week

Whereas people with a **visual impairment** tended to receive less than, or similar to, the average amounts across the different rates:

- Visual Impairment higher rate for care: £117.2 per week
- Visual Impairment middle rate for care: £85.7 per week
- Visual Impairment lower rate for care: £46.1 per week

Amount of PIP received for daily living component

This section shows an estimate[17] of the total spend (using data from January 2016[18]) for each rate (enhanced and standard) for the daily living component across all PIP recipients of all main disabling conditions. It compares an estimate of the total spend for both higher and lower rates for PIP recipients who have a visual impairment as their main disabling condition (see Table 5 in Appendix F for more details).

- Enhanced rate for daily living: £26,380,853 total spend
- Standard rate for daily living: £17,614,974 total spend

The total estimated spending for the daily living component for PIP recipients with a **visual impairment** was as follows:

- Enhanced rate for daily living: £353,067 total spend
- Standard rate for daily living: £128,217 total spend

3.4 Summary of analysis

Overall the analysis has shown that DWP administrative data tools provide limited opportunity to undertake comparative analysis between DLA and PIP awards. Once the PIP roll-out is complete, it will be possible to provide a more robust comparison of total numbers of people in receipt of DLA and PIP. However at no point will a comparison of the average rates of DLA and PIP received by people with visual impairment or dual sensory loss be possible if publically available data remains as it is.

The qualitative data (presented in the rest of the report) goes some way to filling this gap and suggests that for those who are receiving PIP and have a visual impairment, many may be receiving a larger amount under PIP compared to what they were receiving from DLA.

While the qualitative data does not indicate prevalence of experience or indeed provide a representation of all experiences of the PIP application process, most of the 53 participants in this

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[17] Results have been calculated by looking at the total number in receipt of each payment (combination of mobility and daily living awards) and multiplying this by the set rates. The weekly rates have been taken from DWP's website: https://www.gov.uk/pip/what-youll-get

[18] This data presents total figures which are published on the Stat Xplore every quarter

research (eventually) experienced a ‘positive’ financial outcome (i.e. received the same or a higher award compared to DLA).

In conclusion our analysis suggests that further exploration and research is needed to investigate whether there are any differences between DLA and PIP receipt at the recipient population level. This could potentially form part of the DWP’s intention to put in place a rigorous quantitative and qualitative evaluation strategy to examine the claimant experience of PIP.

4 Being invited to claim for PIP

Chapter summary

- DLA was used to cover mobility needs, care needs, the purchase of assistive technology and appliances, and, in some cases, to supplement household income.

- Initial correspondence from the DWP about PIP was sent via an inaccessible standard print letter. This meant claimants had to rely on others to communicate information from the DWP.

- Participants who understood what was involved in the PIP application process had particular concerns about the face-to-face consultation. Their concerns were based on ‘bad news stories’ about the PIP application process. Concerns were also based on their own experiences of other benefit assessments, such as for Employment and Support Allowance (ESA).

- Participants were concerned that they would be awarded lower PIP rates compared to DLA. The level of concern regarding PIP appeared to be closely linked to how reliant participants were on DLA.

- Participants were worried that assessors may not have any knowledge about sensory impairments and how they affect people’s lives, and felt this might influence their PIP award. On a practical level, participants were concerned about the location of the face-to-face consultation.

- Generally, participants hoped that they would receive a PIP award that was the same as their DLA. However, there was concern that they would receive less money under PIP, especially among participants who viewed the introduction of PIP as a government cost-saving exercise.

4.1 Introduction

This chapter outlines the importance that DLA had for people with sensory impairments. It provides an overview of what people told us they used DLA for. It explores participants' experiences of being invited to claim PIP and their knowledge and expectations of the application process and of what the outcome might be.

The chapter draws primarily on findings from stage one interviews. At this point, participants had received a letter from the DWP informing them of the transition from DLA to PIP, and/or inviting them to claim PIP.

4.2 How people with sensory impairments used DLA

4.2.1 DLA for mobility needs

Some participants used DLA to cover costs relating to mobility needs resulting from their visual impairment or dual sensory loss – for example, for taxis to work or social events, or to purchase bus or rail discount cards.

Participants described how travelling independently was difficult, particularly when using unfamiliar routes. People gave examples of finding it difficult to find the right bus stop when using public transport or of trouble navigating an unfamiliar route on foot, for instance. Participants explained that they preferred to use taxis or rely upon their partner or family to provide lifts where a route was unfamiliar. For participants who lived alone, taxis tended to be more of a necessity to travel to unfamiliar places, whereas those who lived with family considered taxis a luxury, as they had support to travel.

4.2.2 DLA for care needs (daily living)

DLA was also used to cover a range of care needs or daily living needs. This included hiring people for cleaning and ironing, helping with post and paperwork, clothes management (helping to pick out outfits and mending clothes), and food management (checking use-by dates). For example, a participant discussed the ways in which support workers helped her with her care needs:

> “Sort of basic - everything in the house really, they're helping me go through paperwork so they go through the post. (…) I don’t know if I'd have an ironer or not if I was, if I was fully sighted, but the cleaner does the ironing as well.”
>
> (Female, Severely Sight Impaired)

4.2.3 DLA for assistive technology and appliances

Assistive technology and appliances were paid for using DLA payments. Examples of purchased items included technology that aided reading (e.g. smartphone applications and computer programs) and appliances that helped with cooking (e.g. talking scales and microwaves).

4.2.4 DLA added to household income

There was a group of participants who combined their DLA with their household income. This was particularly the case for participants who were out of work and/or had dependent children. In these instances, participants described DLA contributing towards day-to-day living expenses such as rent, council tax, utilities and food, before going towards their mobility and care needs. This is highlighted by a participant who was out of work:

> *“*I know you're not supposed to live on your disability living allowance really but if I didn't have that I wouldn't be able to cover the kind of, you know, general day-to-day living let alone think about getting a taxi somewhere*.*”
>
> (Female, Severely Sight Impaired)

These findings are consistent with other research commissioned by Thomas Pocklington Trust to understand the minimum living standards for people with a visual impairment and for people who are Deaf[19]. This research found that the additional costs of living for people who are sight impaired and for people who are Deaf related

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[19] Hill, K., Davis, A., Hirsch, D., Padley, M., & Smith, N. (2015) Disability and minimum living standards: the additional costs of living for people who are sight impaired and people who are Deaf. Loughborough: Centre for Research in Social Policy.

to paying for domestic help, assistive technology, additional costs for travel and to participate in social activities.

4.3 Awareness and understanding of PIP

Participants who took part in stage one interviews had varying degrees of awareness and understanding of PIP. By stage two, awareness of the PIP process had developed.

4.3.1 Awareness of PIP

Participants who took part in stage one and/or stage two interviews were asked to explain what they knew about the PIP policy and application process. Stage one interviews revealed there were varying levels of awareness of what the PIP application process would involve. On the one hand, there were participants who assumed that their eligibility and level of award may not be the same under PIP, even when they had received DLA for a long time, (including participants who had received ‘lifetime awards’). On the other hand, there were participants who thought that the only difference between DLA and PIP was the name, and assumed that there would be limited changes to the benefit. These participants had very limited awareness of what would be involved when applying for PIP (e.g. completing the PIP2 form or attending a face-to-face consultation).

4.3.2 Understanding of PIP

The group of participants who reported some awareness of the PIP policy believed there was one of two reasons for the policy change. One view was that it had been introduced to reduce the amount of people eligible for the benefit. Others held a view that PIP had been introduced to reduce the amount of money given to people receiving the benefit. One might expect these views to create feelings of concern or anxiety. However, there was no evidence at either stage one or two interviews that these views influenced how participants felt about PIP.

Those who were aware of the PIP policy received information from various sources, including the DWP letter detailing the transition from DLA to PIP (see section 2.4); national disability charities; local visual impairment charities; stories in the news; online; and friends and family that knew people who had already gone through the transition from DLA to PIP.

4.4 Inaccessible information about the DLA to PIP transition

Participants reported that consideration of their accessibility needs in relation to their sensory impairment throughout the PIP application process was limited. (For more information on accessibility see section 4.21).

4.4.1 Initial correspondence about the PIP application

According to participants, all correspondence about the transition to PIP from the DWP came in standard print, which was considered inappropriate because of its inaccessibility for people with a visual impairment. Some held the view that the DWP should know from their records that they have a sensory impairment, and that correspondence should always be sent in their preferred format.

Participants explained that they had to rely on family, friends or support workers to read the standard print letter to them. This frustrated those who would prefer to be able to access the information themselves independently, as highlighted by a participant who said:

> “Well, I, I think I'd prefer to read them myself. I think it's a bit; it's a bit intrusive to have to get people to read, you know, your correspondence, isn't it? (…) Yeah, too personal. It should be, it should be made in a format that one, one could access.”
>
> (Male, Severely Sight Impaired)

4.5 Expectations of the PIP application process

While the research found that it was common that participants were not well informed about PIP, those who were informed tended to have a good understanding of what it would involve.

4.5.1 Concerns about the PIP application process

Among participants who had a good understanding of the PIP application, there were concerns about the application process and the outcome.

Concerns about applying for PIP were influenced by a range of factors. These included ‘bad news stories’, from the media or peers, and experiences of other benefit assessments, such as the Work

Capability Assessment which forms part of the application for Employment and Support Allowance (ESA).

The level of concern appeared to be closely linked to how reliant participants were on DLA. Participants who were not in work were consequently more dependent on DLA to contribute to rent and household bills. For this group, particularly those in receipt of the higher DLA rate for either the mobility[20] or care[21] components, loss of DLA would mean a substantial loss of income.

Concerns about the face-to-face consultation

Participants were worried that assessors may not have any knowledge about sensory impairments and how they affect people's lives, and felt this might influence their PIP award. For example, a participant with Retinitis Pigmentosa (RP) was concerned about explaining the variability of his condition between day and night (people with RP experience tunnel vision and night blindness). The face-to-face consultation would be in the daytime, but he wanted to ensure assessors were aware of how his mobility and care needs changed at night-time.

On a practical level, participants were concerned about the location of the face-to-face consultation. If it was in a venue or location they were unfamiliar with, they would have to find someone to take them to the consultation. Participants who were concerned about the journey to the consultation venue were worried they would turn up flustered and would therefore not be able to answer the assessor's questions in the way they would like to.

Participants also felt that an hour-long consultation did not give sufficient time to assess how a disability or impairment affects an individual during their everyday life. The quotation below illustrates one participant's anger at the prospect of an assessor spending only one hour with them to assess their eligibility for PIP:

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[20] DLA highest rate for mobility equates to £57.45 per week.

[21] DLA highest rate for care equates to £82.30 per week.

> “Nobody in this world can tell me what I can and can't see. Nobody in this world can tell me how difficult it is for me to walk from here; I can't go out at night on my own because I can't see. So nobody really understands what it is to live my life. For one person to then judge me from an hour, that's wrong.”
>
> (Female, Severely Sight Impaired)

Overall, there was concern that the application process would be drawn out, and anxiety about the time it might take to receive a PIP award.

4.5.2 Concerns about the PIP outcome

Participants were asked what they were hoping their PIP outcome would be. Generally, it was hoped that they would receive a PIP award that was the same as their DLA. However, there was concern that they would receive less money under PIP, especially among participants who viewed the introduction of PIP as a government cost-saving exercise.

During stage one interviews, participants were asked if they would appeal a ‘negative’ financial outcome. A group of participants were certain they would appeal any ‘negative’ financial outcome under PIP.

> “I'd have to appeal. (…) I know it takes a long time to go through. That's what I've heard anyway. I know while you're waiting for the money, while you're waiting for the appeal to go through, they take your money away. You lose the money. (…) [But] I think I would, yeah. I don't see why they should blooming win.”
>
> *(Male, Severely Sight Impaired)*

This view was influenced by participants who had previous experiences of ‘positive’ financial outcomes from appeals for other benefits, such as ESA, or because participants believed that a ‘negative’ financial outcome would be unjustified as they had a certifiable disability. Participants did not want to have to undergo an appeal process, but felt they would do so if needed.

5 Experiences of the PIP2 form and face-to-face consultation

Chapter summary

- While participants' financial outcome were on the whole 'positive' (i.e. they received either the same or a higher award under PIP as compared to DLA), the journey of the PIP application process was largely negative.
- Support was essential to navigate the PIP application process (this includes both the PIP2 form and face-to-face consultation), and participants therefore reported having no choice to complete the process independently.
- During both the completion of the PIP2 form a group of participants developed a strategy of expressing their 'worst case scenario' of living with a sensory impairment to ensure they were awarded the PIP outcome to which they felt entitled. For example, focussing on bad experiences (such as accidents) resulting from their sensory impairment to ensure they could adequately demonstrate their eligibility.
- There were both positive and negative experiences of the face-to-face consultation. These were shaped by two factors: the perceived poor quality of the assessor conducting the face-to-face consultation, and the location of where the consultation would take place.
- 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 impairments or dual sensory loss and how they affect people's lives.
- The timeframe of one calendar month for completion and submission of the PIP2 form, coupled with the need to access support to complete the form, caused anxiety. This was particularly the case when participants had to wait for support from friends, family or formal organisations to complete the PIP2 form.

5.1 Introduction

This chapter outlines participants' experiences of completing the PIP2 form and attending a face-to-face consultation with an assessor. It draws on findings from stage two interviews, at which point participants had been through the application process and received their PIP outcome.

Two interrelated issues across both elements of the process (the PIP2 form and face-to-face consultation) influenced participants' experiences:

1. Support was essential to navigate the PIP application process, which took away any choice to conduct it independently.

2. The process was not tailored to meet the needs of people with visual impairment or dual sensory loss, causing frustration, concern and anxiety that participants would not be awarded the appropriate rate of PIP.

Participants adopted one of two approaches to completing the application process:

The first approach was to demonstrate their eligibility for PIP wherever possible. Participants felt they had to express the 'worst case scenario' of living with a visual impairment or dual sensory loss (this strategy is explained in more detail below).

The second approach, which was less common, involved participants highlighting the extent to which they 'coped' with a sensory impairment. Participants in this group limited the amount of information they shared about the difficulties they had day-to-day due to their sensory impairment. This approach was only used by participants when completing the PIP2 form.

5.2 Experiences of the PIP2 form

Participants largely found completing the PIP2 form to be a negative process. There were four aspects of completing the PIP2 form that shaped negative experiences:

- The inaccessibility of the PIP2 form (participants could not read it independently);
- Relying on support to complete the PIP2 form;
- The one calendar month timeframe to complete the form; and

- Addressing what it is like to live with a sensory impairment.

5.2.1 Inaccessibility of PIP2 form

Requesting an accessible PIP2 form

DWP guidance states that all PIP applicants should be asked which format they would like to receive the PIP2 form in. Some participants recalled being asked for and requesting their preferred format, others reported that they were not asked, and some could not remember whether or not they were given the option to request a preferred format.

Those who were asked about their preferred format requested large print, Braille, or an electronic version. Participants who requested large print or Braille received these formats and found them useful (i.e. they were able to read the form).

It was not possible for participants to receive the PIP2 form in an electronic version. The DWP explained that the PIP2 form could not be completed online for data security reasons. This was a source of frustration for those who relied upon assistive technology to access all of their paperwork. One participant requested the form to be sent in CD ROM format so that they could access the questions on the form, but this was never received. Participants could not understand why an electronic version of the PIP2 form was not available for PIP.

Requesting the PIP2 claim form via telephone was difficult for participants with dual sensory loss. Due to their hearing loss, they found it difficult to follow information given on the phone. One participant felt *"patronised"* when the DWP representative had to speak more slowly in order for them to understand the information given.

Having the form in an accessible format did not always mean participants could complete it independently. Those who received a large print form still needed support to write their responses.

There was one instance where someone accessed the form in their preferred format and did not need help completing it. This particular participant used Braille and was told that she would be able to type up her responses and send them back in this format.

Views on inaccessibility of the form

Participants were frustrated that they were not given the choice to complete the PIP2 form independently. This was particularly the case for those who were in work or who lived alone. These groups would have liked an electronic copy of the form so that they could use assistive technology to complete it independently. There were also participants who accepted that they would need support to complete the PIP2 form – particularly those who relied upon a family member or support worker to deal with all other correspondence.

5.2.2 Relying on support

Participants either received informal support from family or friends or accessed formal support from advocacy or support organisations (this included local and national charities specialising in supporting people with sensory impairments). Findings suggest that there were both benefits and difficulties with accessing support.

Benefits of support

According to participants who accessed support from family or friends, they felt ‘lucky’ and ‘grateful’ that they had someone available to help them. The case illustration below highlights how one participant benefitted from support.

Case illustration – Female, Severely Sight Impaired

Mary[22] is in her late 30s and lives alone. She was diagnosed with Retinitis Pigmentosa when she was 7 years old, and had gradually lost all peripheral vision. Mary described herself as very independent and does not like asking for support. Mary received her PIP2 form in standard print and realised that the only way she would be able to complete the first stage of the PIP application would be to ask for support from her mother.

> **“I don't like receiving any support but mum and I went through this, yeah, together, so it's my mum: that's good. I'm very fortunate I have a support network. If I didn't have her, I don't know how I'd feel about it.”**

Mary went on to express that she really felt for people with a visual impairment, who would have to complete the PIP2 form

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[22] Participant name has been changed to maintain anonymity

without any support. Without support, Mary felt she would have given up her PIP application:

> **“I probably would have given up long ago because it's been a long, long drawn-out thing.”**

‘Formal support’ (viz. support provided by advocacy or support organisations, including local and national sensory impairment charities) tended to be accessed by participants who lived alone and had less support/family networks. In these circumstances, participants felt that this type of support would be accurate, reliable and trustworthy. For instance, a participant who lived alone accessed support via RNIB as she felt their expertise would mean the form was completed correctly:

> “I preferred them to do it because you know they; they do it all the time. And I didn't want to miss out by you know putting something inappropriate, which I didn't think I would but it's better to have somebody to help you.”
>
> (Female, Severely Sight Impaired)

Another participant, who also lived alone, accessed support from a local sight loss charity and explained that he would not have been able to complete the [PIP2] form without their help: “if they didn’t exist [I] wouldn’t know where to start.” (Male, Partially Sighted).

Difficulties with support

While some participants were grateful for support that was provided, there were some who found it difficult to rely on others. This was particularly the case for those who were in work, lived alone and in their day-to-day life were independent without support. For example, one participant who worked full-time, found it difficult to rely on his partner to complete the form:

> “I've had to, for want of a better word, lean on my partner and say, “I'm sorry, I need you to do this. This application's important”.”
>
> (Male, Severely Sight Impaired)

Another participant, who lived alone and considered himself very independent, found the process of explaining to a family member how he lived his life with a visual impairment very difficult:

> “I'm quite a private person like that and obviously being, being totally blind, it was a case of it would have been nice to do all these matters myself but having to get somebody in the family [to complete the form] and opening yourself up in front of a member of your family to, how, how your home situation was and how it affected you [was difficult].”
>
> (Male, Severely Sight Impaired)

5.2.3 Timeframe to request and complete the form

If a participant did not request a PIP2 form within the 28 days of being invited to make a claim, they could risk having their DLA stopped. On receipt of the PIP2 form, participants had one calendar month to complete and submit the form. If they did not complete the PIP2 form in one calendar month, their DLA would not be stopped, but DWP’s guidance[23] states the application process would be delayed.

In one case, a participant who lived alone and was Severely Sight Impaired received the invitation to apply for PIP but had not read the letter as it was not sent in an accessible format. In this case, her DLA was stopped for a few months, which created severe financial hardship, resulting in her having to borrow money from family.

Even for those who did not have their DLA stopped, the timeframe, coupled with the need to access support to complete the PIP2 form, caused anxiety. This was particularly the case when there had been no choice but to wait for support from friends, family or formal organisations. Participants unable to access support within the calendar month allocated to completing the PIP2 form requested an extension, which in all cases was granted by the DWP.

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[23] DWP (2016) PIP guidance: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519147/pip-assessment-guide.pdf

5.2.4 Explaining what it is like to live with a sensory impairment

Reflecting negatively on identity

According to a group of participants, a key coping mechanism when living with a visual impairment or dual sensory loss is to focus on what they can do and try hard not to dwell on their disability day-to-day.

The PIP2 form, however, made them reflect on their disability in a different way, which people found difficult. One participant with dual sensory loss expressed how the form made them feel negative:

> “When you've got a long-term condition and you live with it day to day, if you dwell on all the negatives [you would] depress yourself and everybody else around you. So you tend to just sort of adapt and you're [not] necessarily always aware that you're making these adaptations. So it's not until somebody brings it to your attention that [it is] in the forefront of your mind.”
>
> (Female, Dual Sensory Loss)

Form not tailored to capture needs of sensory impairment

A group of participants reported that the PIP2 form was not tailored to capture the needs of people who live with a visual impairment or dual sensory loss. Rather, they felt it had been designed to capture the effects of living with mental health conditions or physical disabilities.

This is highlighted below by a participant who was Severely Sight Impaired and lived alone. She explained that a question about mobility did not allow her to explain that while she was physically mobile, she was not able to go somewhere independently if she did not know the route:

> “I don't need anyone to put me in and out of a shower for example, you know, support me with my personal needs, but if I don't know a route, I am literally trapped and stranded and there's nothing [I can do].”
>
> (Female, Severely Sight Impaired)

Consequently, participants felt that, to sufficiently reflect what it is like living with a sensory impairment, they had to ‘shoehorn’ experiences of living with a visual impairment or dual sensory loss into irrelevant questions.

Demonstrating eligibility for PIP vs. demonstrating independence

As outlined in the introduction of this chapter there were two distinct approaches to completing the PIP2 form. One group highlighted ‘worst case scenario’ examples of living with a visual impairment or dual sensory loss. Participants did this by including bad experiences or past accidents resulting from their sensory impairment (e.g. accidents when cooking, or a fall outside the house), in their PIP2 form.

Those who chose to highlight examples of worst case scenarios explained they did so to ensure successful receipt of PIP. This is highlighted by a participant who is Severely Sight Impaired and lived alone:

> “You have to think of yourself in the worst scenario. And that is what you do. Because you do need the money to help you, so what could you do? Um, so that's what I did.”
>
> (Male, Severely Sight Impaired)

Other participants explained their conditions were often variable, so it was important to include the point at which their sensory impairment affected them the most. For instance, a participant with Usher Syndrome explained that one aspect of his condition is night blindness:

> “Like I said, you might be able to do something in the day, like, but you certainly couldn't do it in the darkness, 'cause I suffer, I suffer complete night blindness. So, it's, it's very difficult. You have to really judge it on your worst case scenario.”
>
> (Male, Dual Sensory Loss)

In some instances this approach had been influenced by friends, family, advice organisations or local or national sensory impairment charities. In others, participants’ previous experience of claiming DLA or ESA and receiving negative financial outcomes encouraged this approach.

Although it was more common for participants to emphasise what they could not do, another group chose to demonstrate how they coped with their disability and were independent. One participant described herself as someone who ‘copes’ and explained that she did not use examples of worst case scenarios:

> “I filled it out as a coper, I was penalised, you know. That, that's how I, I feel when really I should have filled it out on my worst day, you know. There are days when I just want to not do anything or give up or, you know.”
>
> (Female, Severely Sight Impaired)

Analysis of participants who identified as ‘copers’ when completing the PIP2 form showed that people in this group were not initially found eligible for PIP at their face-to-face consultation. This suggests that information included on the form might strongly influence both the face-to-face consultation and the PIP award.

5.3 Direct experiences of the face-to-face consultation

The next stage of the PIP application process was a face-to-face consultation[24]. It was common for participants in this research to have a face-to-face consultation. However, a small group of participants (all of whom had Usher Syndrome, a dual sensory loss condition) received their PIP award without being required to undergo this part of the process.

Experiences of the face-to-face consultation were mixed. Both positive and negative experiences were shaped by two factors: the reported quality of the assessor and the location of the consultation.

5.3.1 Perceived Quality of assessor

Interview data suggests that there was variability in the quality of assessors. The extent to which participants had a positive or negative experience largely related to this.

Participants reported a negative and difficult experience of the face-to-face consultation when assessors:

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[24] According to DWP guidance, this only takes place when one of the two assessment providers – Atos and Capita decide more evidence is necessary for a PIP outcome

- were insensitive about living with a visual impairment or dual sensory loss;
- were dismissive of the experience of living with a visual impairment or dual sensory loss; or
- had limited knowledge of visual impairments or dual sensory loss and how this affects individuals' lives.

Insensitive and unresponsive to participants' needs

Participants who had felt their assessor to be insensitive about their sensory impairment explained how this left them feeling upset and frustrated with the process. For example, one participant reported that before completing a face-to-face consultation at home, the assessor asked whether the guide dog could be locked in another room because they were afraid of dogs.

> *"*The [interviewer] who turned up was scared of dogs, so through the whole interview the [guide] dog had to stay in the kitchen, which I know is a kind of petty thing but I also think it's actually [emphasis] really, really wrong*."*
>
> (Female, Severely Sight Impaired)

This particular participant was asked to complete a second face-to-face consultation as the first did not collect sufficient information. During the second consultation, the assessor was surprised to hear that people with visual impairments were able to cook, which left her feeling shocked:

> *"*I was quite annoyed when I was talking to...the lady and I [discussed] cooking…and she said, 'I don't mean this rude or anything but blind people actually cook?' and I just thought I can't believe you*."*
>
> (Female, Severely Sight Impaired)

Another participant reported experiencing an insensitive assessor. 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.

Participants reported feeling that assessors were not listening to them throughout the face-to-face consultation and asked questions which were perceived to be irrelevant. For instance, a participant had told the assessor at the beginning of his consultation that his driving licence had been taken away due to his visual impairment. Later, during the consultation, the assessor asked him if he drove.

Dismissive of experience of living with a sensory impairment

Participants experienced some assessors to be dismissive and inflexible about responses to questions asked. As with the PIP2 form, participants felt that questions were asked in such a way that they would not accurately capture the experience of living with a visual impairment or dual sensory loss.

Participants reported that they had tried to explain why the question was not relevant and what their needs in relation to their sensory impairment actually were, but they felt assessors dismissed these responses, saying they were irrelevant and not needed. The case illustration below highlights a common experience of participants.

Illustration – Male, Severely Sight Impaired

Phillip[25] has been Severely Sight Impaired since his early 20s. He lives with his partner and her two children and has a guide dog that he uses for mobility.

Phillip had his face-to-face consultation at his home. His partner also attended. Throughout the consultation, Phillip felt that the assessor was dismissive of his guide dog and also of his responses to questions exploring his mobility. For instance, during the face-to-face consultation Philip was asked whether he needed support to use the toilet. He explained that physical support was not necessary, but that he does sometimes need support to find toilets. Phillip explained the assessor dismissed this response:

> **“The assessor said, 'Oh, that doesn't count'. And it just feels like, well, actually, it does, it sort of ... it does, but you're just poo-pooing it, so what do you want?”.**
>
> **(Male, Severely Sight Impaired)**

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[25] Participant name has been changed to maintain anonymity

Phillip felt frustrated and misunderstood by the assessor, as they had not tried to understand his mobility needs in relation to his visual impairment.

Participants reported that these experiences left them feeling that the face-to-face consultation was a waste of time and that the assessor had made their mind up before even attending. Findings suggest this was particularly the case for participants who received a ‘negative’ PIP award on their first application.

Limited experience of sensory impairment

As discussed in chapter four (see section 4.6.1), a key concern for participants who had yet to apply for PIP was that their assessor would have limited experience and understanding of sensory impairments. At stage two of the research, this concern became a reality for some during their face-to-face consultation.

During the in-depth interviews, participants were asked whether they were informed of the assessor’s experience and background. Some participants explained when introducing themselves their assessors’ occupations included: gynaecologist, mental health nursing and occupational healthcare therapist qualifications. This concerned some participants, who felt that their assessor did not have the relevant qualifications, vocation or knowledge to assess adequately the care or mobility needs relating to their sensory impairment. For instance, one participant’s assessor informed her she was a neo-natal intensive care nurse. This made her feel that the assessor was not suitably qualified to assess her eligibility for PIP:

> “How does that equip her for assessing somebody with severe visual impairment?”
>
> (Female, Severely Sight Impaired)

Another participant, who had dual sensory loss (the only example where a participant with dual sensory loss had a face-to-face consultation), requested that the assessor was someone who had an understanding of visual impairment in particular. She was reassured by the assessment provider that this would happen. However, when attending the face-to-face consultation, the assessor gave no indication of having any experience with visual impairments. For instance, the participant explained that when asking where they should leave their coat, the assessor said “down there”, presumably indicating a place. Someone who had had training in sensory impairments would have understood that further description and/or support in an unfamiliar setting would have been appropriate.

All of these interrelating factors left some participants feeling frustrated and angry about their experience. These types of experiences increased anxiety about the outcome of the consultation and the PIP award they would receive.

Positive experience of assessor

There were instances where participants considered their assessor to be of ‘good quality’. These participants explained that their assessor behaved professionally and spent time listening to their responses. In these instances, participants came away from the face-to-face consultation feeling positive about the experience.

5.3.2 Experience of locating the face-to-face consultation

It is not clear from the interviews how the location of a participant’s face-to-face consultation is decided. From participants’ experiences, the extent or severity of a participant’s visual impairment or dual sensory loss did not seem to be a key factor; nor did any detail of participants’ visual impairment included on their PIP2 form appear to have been considered. Participants who had stated on their PIP2 form that they found leaving the house alone difficult were still asked to attend a face-to-face consultation at an assessment centre.

Participants who were required to attend a face-to-face consultation at an assessment centre explained they would not have been able to get there without support. They also required support at the assessment centre, due to centres being ill-equipped to accommodate people with visual impairments or dual sensory loss.

Finding the assessment centre

Although current guidance states that claimants should be no more than 90 minutes of travel time away from an assessment centre, participants felt that they had to travel a considerable distance from their home to the centre. To travel independently by public transport participants would have to access routes with which they were unfamiliar. This created unease and added to the anxiety of having to attend a face-to-face consultation. In one instance a participant looked up the public transport route and found it required her to take three buses. Consequently, participants relied upon friends or family members to take them to the face-to-face consultation. In chapter 4 concerns from stage one interviews about finding the assessment centre were highlighted (see section 4.6.1). These concerns appeared to have become the lived experiences of those stage two interviewees who attended an assessment centre.

Some participants asked for their consultation to be completed at their home, because they had no support to accompany them to the assessment centre. In these instances, assessment providers accommodated a home visit.

Accessibility of the assessment centre

Along with the anxiety around finding the centre, a group of participants also reported that the centre itself was not accommodating of the needs of people with a sensory impairment. For instance, one participant who had Retinitis Pigmentosa (which can make coping with bright lights difficult) found the waiting room to be too bright. This made her feel uncomfortable and added to her anxiety about the face-to-face consultation.

> “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)

Another participant described how he was asked to navigate a very narrow and steep set of stairs to locate the consultation room. He found this difficult and it upset him that his mobility needs had not been considered by the assessment provider.

Face-to-face consultation at home

Participants who were able to have a face-to-face consultation at home were happy that they did not have to travel anywhere for a consultation. It is important to note, however, that this group did also experience poor quality assessors (as outlined in 5.3.1).

6 Outcome of the initial PIP application and views regarding the review of eligibility

Chapter summary

- Participants who received a ‘positive’ financial outcome were, on the whole, relieved. Others viewed this ‘positive’ financial outcome as ‘fair’ or what they ‘expected’.

- All participants who received a ‘negative’ financial outcome (in the form of less PIP compared to DLA) requested a mandatory reconsideration and/or attended a tribunal. Eventually they were successful in receiving a ‘positive’ financial outcome.

- In comparison to how participants spent their DLA, those who received a higher rate of PIP felt this provided them with more scope to afford things such as more expensive assistive technology, support within the home, and to participate in more social and leisure activities, further aiding their independence, both in and outside the home.

- PIP was awarded for varying lengths of time – some participants received extended awards of up to 10 years, while others had much shorter award periods (e.g. 2 years).

- Participants strongly felt that people with sensory impairments should **not** have their PIP award reviewed as their conditions would not improve with time.

6.1 Introduction

Participants can be categorised into receiving one of two outcomes from their PIP application:

- **A ‘positive’ financial outcome:** participants were awarded a higher rate of PIP compared to DLA, or the same rate as their DLA payments; or a

- **A ‘negative’ financial outcome:** participants were awarded a lower rate of PIP compared to DLA, or they were not found eligible for PIP and received no award.

This chapter first discusses participants who received a ‘positive’ financial outcome and their reflections of the transition from DLA to PIP. It goes on to explore experiences of participants who initially received a ‘negative’ financial outcome. It will then cover how participants planned on using their PIP. Finally, it addresses how participants felt about their PIP award and the prospect of it being reviewed in the future.

6.2 Reflections on ‘positive’ financial outcomes

In some instances, participants who received a higher rate of PIP, compared to their DLA, expressed feeling surprised and relieved, as highlighted below.

> “It's been a pleasant surprise, to be fair, and it's a big weight to be lifted, worry to be lifted.”
>
> (Male, Severely Sight Impaired)

Alternatively, participants viewed this ‘positive’ financial outcome as ‘fair’ or what they ‘expected’.

Those participants who felt the process was ‘smoother’ than anticipated had negative experiences of previous benefit assessments. As highlighted by the case illustration below, previous experiences tended to shape participants’ preconceptions about what the PIP process would entail:

Case illustration (Male, dual sensory loss)

Ted[26] is 38 years old and has Usher Syndrome, a form of dual sensory loss. He first became aware of his visual impairment in his early twenties. Ted got an official diagnosis of Usher Syndrome seven years ago. As his condition deteriorated, he requested to be moved to a higher rate of DLA. Ted found this process very difficult and his application was unsuccessful. In the run-up to his PIP application, Ted described being ‘ready for another battle’.

Ted’s experience of the PIP application process, however, was generally positive. He was not asked to attend a face-to-face consultation and was awarded the enhanced rate for daily living and mobility components. Ted was really impressed with the application process and felt that the assessment provider had ‘taken on board’ the implications of his condition.

Upon reflection, another group of participants, though happy in principle with their ‘positive’ financial outcome were unsure whether the additional amount of PIP they were awarded was worth the difficult application process they had experienced.

For example, one participant said:

> “It's just… [Exasperated] I know it sounds awful; is £100 a month worth all the stress and hassle? I don't know if it is.”
>
> (Female, Severely Sight Impaired)

6.3 Receiving a ‘negative’ PIP outcome

A small group of participants initially received a ‘negative’ financial outcome from their PIP application. Participants reported feeling ‘shocked’ and concerned about how they would manage without this income.

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[26] Participant name has been changed to maintain anonymity

6.3.1 Considerations as to why ‘negative’ financial outcomes were received

Participants wondered if they had received a ‘negative’ financial outcome because they had highlighted their independence, rather than sharing their limitations, throughout the process.

For instance, one participant described feeling that they had been penalised for being a ‘coper’ (please see section 5.2.4 for more details). Following a mandatory reconsideration which was also turned down, a ‘positive’ financial outcome (of the standard rate of PIP) was eventually awarded after the case was then taken to tribunal. Interestingly, at the tribunal, the Presenting Officer (or tribunal member) explained that if the participant had answered the form differently (i.e. placing **less** emphasis on her coping strategies), she would have received an enhanced award for both components. The participant said:

> “…through me explaining all - going through all my coping mechanisms, she said really if I'd answered differently, in three years' time, I should reapply and I should get the top for everything.(...) I remember it, yeah, she said, “You undersold yourself really.””
>
> (Female, Severely Sight Impaired)

6.3.2 Implications of a ‘negative’ financial outcome

Participants who received a ‘negative’ financial outcome and who were in work felt that they needed to be more cautious with their spending. In one instance, a participant made up for the loss in monthly income by selling items online.

For those who were not working, the financial implications were felt to be more severe. Participants in this situation commonly described having to borrow money from family or friends and some stopped social activities because they could not afford the cost of taxis anymore.

Actions taken – disputing their PIP award

The dispute process is a staged process which involves first a mandatory reconsideration stage and appeal process (for more information on what this involves see Appendix A). Participants who received a ‘negative’ financial outcome requested a mandatory reconsideration. In some circumstances, participants made this decision themselves, whereas others were encouraged either by advocacy or support organisations (including local and national sensory impairment charities) to take action.

Some participants were awarded a ‘positive’ financial outcome at the point of the mandatory reconsideration. In other cases where a ‘negative’ financial outcome was again awarded, participants took their case to appeal. In cases where a tribunal took place, participants eventually received a ‘positive’ financial outcome.

Experiences of the dispute process

Participants who had requested a mandatory reconsideration or who had been to a tribunal anticipated that the process would be ‘tough’. However, findings suggest that the process was a more difficult and stressful experience than anticipated.

In one instance, following the appeals process a participant was awarded the enhanced rate for both the daily living and mobility components of PIP. However, this was after being told on two separate occasions (in his initial decision letter and after requesting a mandatory reconsideration) that he was not eligible for PIP. He described the experience as extremely stressful and draining, affecting not only his own, but his family’s emotional wellbeing.

Support during the dispute process

Participants explained that they received support from advocacy and advice organisations (including national and local sensory impairment charities). Support included help to complete a second PIP2 form, develop statements and letters when requesting a mandatory reconsideration, and, in some cases, having someone attend their PIP tribunal with them. Participants who had received less PIP, explained that they had been advised by organisations supporting them that they had to be ‘strong’ emotionally to undergo the mandatory reconsideration and subsequent appeal process, as they could receive less PIP than initially awarded.

Support from advocacy and advice organisations (including local or national sensory impairment charities) also provided participants with both practical support navigating the process and moral support helping them through the difficult experience. The case illustration below highlights the impact support had for one participant on her experience of the appeal process.

Case illustration (Female, Dual Sensory Loss)

Kerry[27] has dual sensory loss, which means she is Severely Sight Impaired and also has some hearing loss. She is in her sixties and lives with her partner and children. During her first PIP application, Kerry accessed support from her partner to complete the PIP2 form, and he attended the face-to-face consultation with her. Kerry received a standard rate for daily living and an enhanced rate for mobility, but this was lower than her DLA award, where she received higher rates for both the care and mobility components. Kerry was unhappy with her award and did not feel it reflected her needs. She decided to put in a mandatory reconsideration and her PIP award came back with the same result. At this point, Kerry decided to enlist the help of RNIB's legal team, who put her in touch with her local welfare rights team. Once she accessed this support, she explained that:

> **"… now that I've got help, and I feel that I'm not on my own anymore, I feel it's quite a big weight has been lifted off my shoulders, because when I was trying to deal with the claim and the mandatory reconsideration on my own, I felt as if I was wading through treacle…".**

Kerry was very happy that she had accessed support. At the point of her stage 3 interview she had not attended her tribunal, but felt confident she would receive a 'positive' financial award before it reached the tribunal date.

6.4 How people with sensory impairments used PIP

This section explores the impact of PIP payments and how they were used by participants. Participants were interviewed between four and six weeks after their stage two interview (having received one or two PIP payments in this time).

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[27] Participant name has been changed to maintain anonymity

6.4.1 Effect of PIP payments

For those who received a ‘positive’ financial outcome, PIP award, it reduced the worry of living on a tight budget which they had experienced under DLA.

A ‘positive’ financial outcome meant they were able to afford extra aids, adaptations and appliances. According to participants, this enabled them to consider purchasing more expensive and complicated equipment which would further aid their independence, both in and outside the home.

6.4.2 How PIP was being used

PIP was used for similar purposes to DLA, such as assistive technology, social and leisure activities and support within the home. However, where awards had increased, participants felt they had scope to do more and could afford more expensive equipment and appliances.

Assistive technology

Among participants whose income increased on receipt of PIP, there was a group of people who reported they were able to save money each month in order to buy assistive technology they ordinarily would not have been able to afford.

> “…you can perhaps can plan a bit more, if I need to make a real big purchase or something like, say, a new computer, something that is going to be like a £1,000 or more, whatever, you've - we've got more flexibility that we can do it, or - without having to really struggle and take a long time. We can plan, I suppose, a little bit more.”
>
> (Male, Severely Sight Impaired)

Another example is a participant who planned to purchase a text-to-speech magnifier to convert text documents into audio speech. Someone else purchased equipment which alerted them to bus stops on the street and their destination. This particular participant explained how this equipment increased her independence:

> “...it's this thing that kind of, as you're walking along the road (…) it kind of identifies what stops are near, and where those buses go. So (…) that's brilliant, because it kind of increases my independence.”

> (Female, Severely Sight Impaired)

Social life and leisure activities

Participants who received a higher PIP award compared to their DLA reported that they could afford extra things, such as taxis, which contributed to them being able to participate in more social activities.

This had positive implications for their independence. Participants reported that they could socialise in the way that they wanted. They did not have to rely as much on taking public transport, or on friends or partners providing lifts to social occasions or helping them with daily activities:

> "…it's better really in terms of social inclusion because, I mean, you know, at the end of the day, buses are okay up to a point but, I mean, there's places that buses, you can't get to, or you can't get back from and, and, you know, so your choices are very limited. So it does give you more options for that."
>
> (Female, Dual Sensory Loss)

Higher PIP payments enabled participants to do things such as meeting up with friends spontaneously, but also more regularly.

> "I know I've got money for taxis for that sort of thing and, you know, that, that just makes - you can do spur-of-the-moment things rather than planned things, which I think is a big - you know? (…) that makes people more, more willing to do that stuff."
>
> (Male, Severely Sight Impaired)

Support within the home

Participants explained that a higher income under PIP meant they could afford to employ someone to help them with housework. For instance, a participant whose PIP award was higher than her DLA award planned to employ someone to help in the house, which she felt would relieve some of the pressure on her partner:

> "I'm quite looking forward to [having support in the house], actually. Just, you know, I was making a list on my phone yesterday of what things I'd be, be getting them to do. And I

> just feel like it's going to relieve a bit of pressure off my partner (…) if he's a little bit happier then it will make our relationship a bit happier. (…) So it will help him as much as me, I think."
>
> (Female, Severely Sight Impaired)

Aside from the three main categories of spending, participants also described that a higher PIP award meant they could undertake much-needed household repairs or renovations. This would mean they could adapt their homes to ensure that they were more 'VI' friendly (e.g. by installing new artificial lights or more appropriate kitchen appliances). In some limited cases, participants explained that the extra money from PIP would enable them to pay off debts that they had accumulated while on DLA, which reduced financial pressures.

6.5 Views on PIP award periods and future reviews

Two elements of PIP that differ from DLA are that PIP includes:

- A fixed award period; and
- A review of eligibility for PIP takes place at the end of the award period.

This section addresses participants' understanding of and views on their award length and how they felt about being having their PIP award reviewed.

6.5.1 Understanding of and views of PIP award periods

Some participants received 'fixed awards' and others received 'ongoing awards'. Among those who received fixed awards, there appeared to be a wide variation in the length of award.

There were participants who were unaware of how long their award would last. In these cases, participants did not feel they had been given sufficient information about their PIP award. For instance, a participant explained that because her decision letter was sent in standard print format, she was not able to digest all the information on it.

> "It probably says on one of the letters but I can't read the letter…"

> (Female, Severely Sight Impaired)

6.5.2 Understanding and views on PIP review

Some participants were aware that their PIP eligibility would be reviewed. A common view among this group was that they should not have to reapply. Participants explained that their visual impairment or dual sensory loss was not going to improve with time, so they could not understand why they needed their eligibility tested again.

> “I've got a condition that's not going to get any better and then for them to say that was quite ludicrous. I mean I've known people in the same boat and they've been awarded it for two years and you think how on earth can you - who the hell makes that decision? They've obviously taken on board what you've got but they think you're going to get better. You're not.”
>
> (Male, Dual Sensory Loss)

While no participants in this study saw the possibility of their PIP award being reviewed as positive, it is important to note that reviews may provide some PIP claimants whose sensory impairments deteriorate with the opportunity to receive a greater award.

Both ongoing and fixed award recipients were conscious that their PIP status could be reconsidered at any point. This view was held particularly by participants who had been granted a ‘lifetime’ DLA award but had to complete an application for PIP.

> “I just took it as in that's - it won't ever be assessed, reviewed or changed but we all know that's not true…so they shouldn't really put it. (…) a lot of people were awarded their DLA for life and they revoked that for this new PIP.”
>
> (Female, Severely Sight Impaired)

On the whole, participants reported that they did not want to dwell on or worry about future PIP award reviews. Some reported they would think about it in more depth when the time came. However, for others, the fact that they may be reviewed was an ongoing concern, always at the back of their mind.

> “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, got a rate, and you'd normally get it for life, near enough.”

(Male, Severely Sight Impaired)

7 Conclusions and recommendations

This chapter provides conclusions and reflections on the findings outlined in the report. It also sets out practical recommendations for key stakeholders involved in delivering the PIP application or supporting people through the process.

7.1 Conclusions

Overall we found that while study participants eventually received ‘positive’ financial outcomes (i.e. they received the same or a higher PIP award compared to DLA), the journey through the PIP application was negative. The PIP application process was experienced as a ‘**one size fits all**’ **approach** and therefore **not fit for purpose** for people with a sensory impairment based on the following findings from the study:

- **It was not accessible**. All stages of the application process were inaccessible for participants. This meant they could not complete the application process independently.
- **Support was necessary to navigate the application process**. Due to the inaccessibility of the process, participants had to rely on family, friends or external organisations to practically help them through the application process. Some participants felt less independent as a result. Moral support was also given to help participants through what they felt was a difficult process.
- **Some assessors lacked understanding of sensory impairments.** Some participants reported assessors were insensitive about their sensory impairment, dismissive of experiences of their living conditions, and overall had limited knowledge of sensory impairments and how they affected participants’ lives. This left people feeling concerned they were going to be found ineligible for PIP; and in some cases frustrated and angry at the way they had been treated.

On the whole, participants were not given the choice to engage with the PIP application in the way they wanted to. The inaccessibility of the PIP application process was the key driver in reducing choice and creating dependency on others to navigate the application process.

In some instances this lack of choice and limited independence led to participants feeling frustrated and sometimes to feel that they were a burden to those supporting them. In other cases participants were less concerned about the need to rely on friends, family or external support organisations, but found the application process practically more difficult to participate in because they had to rely on an intermediary to relay all information.

As outlined above the PIP application process was experienced as a ‘one size fits all’ approach to meet the needs of all PIP applicants. This study has shown that one size does not fit all; many participants with a sensory impairment experienced a lack of choice in the way they wanted to navigate the application process. This experience is at odds with the DWP standard of good practice in relation to accessibility[28]. For example, a number of participants said they were not asked about their preferred format for the PIP2 form and on-going correspondence, despite DWP policy stating that applicants should be offered PIP documentation in an accessible format. This is worthy of DWP’s on-going commitment to evaluate the PIP process and should be investigated further.

The study found that at all stages participants felt discomfort engaging with the PIP application process. Participants reported feeling ‘watched’ or ‘judged’ by assessors completing face-to-face consultations. This finding is perhaps unsurprising, given that the transition from DLA to PIP is taking place within a landscape of wider welfare reforms and these reforms have, unfortunately, given rise to a public narrative that benefit claimants are underserving or ‘cheating’ the system.

Unsurprisingly, some participants were concerned about presenting themselves as independent, worried that they may be found ineligible for PIP. One group of participants focused on demonstrating their eligibility by including ‘worst case scenarios’ and the negative effects of living with a sensory impairment. Conversely another group of participants opted for demonstrating independence. Those in the latter group initially received a ‘negative’ financial outcome, but eventually received a ‘positive’ financial outcome after appealing the initial decision. As this study is a piece of qualitative research, we cannot say whether this experience is typical of all PIP applicants who have a sensory impairment. It is, however, striking that applicants who chose to identify themselves as independent to begin with were initially found ineligible for PIP.

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[28] An example of this is inclusive communication published by DWP and ODI in 2014 https://www.gov.uk/government/publications/inclusive-communication

7.1 Recommendations

A set of practical recommendations have been developed to provide clear and practicable suggestions for the DWP, the assessment providers (currently Atos and Capita) and external advocacy and support organisations to improve the PIP application process for people with a sensory impairment.

7.1.1 Accessibility

For the application process to be accessible for people with a sensory impairment the DWP, both directly and through its contractual specifications for assessment providers, should:

- Ensure that all applicants are asked about their accessibility requirements at the start of the process (which is usually carried out over the telephone).
- Ensure that the PIP2 form is provided in an accessible format for people with a sensory impairment.
- Ensure that all on-going correspondence (e.g. letters inviting people to make a claim to PIP and the application outcome letter) is provided in the PIP applicant’s chosen format.
- Increase the length of time people with a sensory impairment have to complete the PIP2 form.
- Raise awareness among applicants about the requirements for assessment providers that all people with a sensory impairment are given the choice of location for the face-to-face consultation (e.g. at their own home or at the provider’s assessment centre provided that it is fully accessible).

7.1.2 Support

While adaptations should be made to increase choice and the ability to complete the PIP2 form independently, people may still require both practical and emotional support throughout the application process. Some key adaptations to improve the provision of support are suggested below:

- The DWP should provide a list of the existing resources for applicants to access, if needed, to support them at any point of the application process.
- Sensory impairment charities and local and national advocacy organisations should ensure that those who request support are supported until the point of their PIP outcome. This will ensure

PIP applicants are followed through the process to identify any points they might need help with.

- Sensory impairment charities need to provide information on the resources and guidance available for those embarking on an appeals process.
- Appropriate help and support should be available to the people with a sensory impairment that require it. This could be achieved by providing additional funding to third sector organisations to provide this support. Study participants who used third sector support during the application process used it for its accuracy, reliability and trustworthiness.

7.1.3 Training

A key factor driving negative experiences was the perceived poor quality of the assessors (this is based on assessors' apparent lack of knowledge of visual impairment and insensitive actions and comments made by assessors to participants regarding their sensory impairment).

- As a minimum, the DWP and assessment providers should ensure that all staff receive sensory impairment training as part of wider disability awareness training.

7.1.4 DWP administrative data

DWP does not include dual sensory loss as a main disabling condition category when presenting information on PIP recipients. This makes it impossible to compare total figures of PIP recipients with dual sensory loss with total figures of DLA recipients with dual sensory loss.

- DWP should include dual sensory loss as a main disabling condition category when collecting and presenting PIP data as part of the evaluation process for this benefit.

8 References

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Gray, P. (2014). An Independent Review of the Personal Independence Payment Assessment. Department for Work and Pensions: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/387981/pip-assessment-first-independent-review.pdf

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Appendix A. Overview of PIP

8.1 Introduction to PIP

As part of the Coalition Government's Welfare Reform Act 2012, DLA was replaced by PIP. According to the DWP, PIP was introduced to "better reflect disabled people's needs and extra costs they might incur in society today[29]". Eligibility for PIP is based on the extent to which a person's condition affects them, not the condition they have. A decision to replace DLA with PIP was based on four reasons:

1. DLA was introduced in 1992 and had not been reformed since,
2. The rising caseload and expenditure was unsustainable,
3. According to DWP[30] there was some internal and external confusion about its purpose, and
4. Under DLA there was no systematic way of checking that awards remained correct, i.e. no reassessment process.

The main rationale for change was based on the fact that DLA did not capture when a claimant had a fluctuating condition, or indeed recovered from ill-health. Therefore it was felt that an ongoing reassessment of eligibility was needed.

8.2 What is PIP?

PIP has two rates for both mobility and daily living components – 'enhanced' (which equates to £82.30 per week for the daily living component and £52.47 for the mobility component) and 'standard' (which equates to £55.10 per week for the daily living component and £21.80 for the mobility component). The level of benefit received for each component is meant to reflect the extent of support needed in both these areas.

From April 2013, DLA was closed for all new applicants and all prospective applicants had to make a claim for PIP. From October 2013 existing DLA claimants started their transition from DLA to PIP. A multi-staged approach was taken - the first group to transition from 2013 were children turning 16; people reporting a change in

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[29] DWP (2010) Welfare Reform: Disability Living Allowance for the 21st century
[30] DWP (2010) Public Consultation, Disability Living Allowance reform.

circumstance and those with a fixed-term award. From October 2015 all remaining DLA claimants were invited to make a claim for PIP. DWP took a random selection approach to inviting people to make a claim for PIP. It is anticipated that by September 2017[31] all DLA claimants will be moved over to PIP.

8.3 Applying for Personal Independence Payment

Being invited to claim for PIP

From April 2015 DLA recipients began being invited to apply for PIP. DLA recipients are not automatically eligible for PIP; if they do not request an application form within 28 days of receiving this invitation, their benefit will be stopped[32].

If someone is already receiving DLA, they will eventually be invited to claim PIP instead. To start the claim process for a new claim, they would first have to contact DWP by phone, or if they can’t start the claim by phone, they can request a paper copy form.

PIP2 form – ‘how your disability affects you’

The PIP application process first involves completing a PIP2 form named ‘how your disability affects you’. The form asks for details of any medical conditions and a number of questions which explore a person’s ability to carry out key everyday activities (i.e. preparing food, dressing and undressing or engaging with other people face-to-face). The form is paper-based and cannot be completed online.

The form must be completed within one calendar month of its receipt. As highlighted in the DWP guidance[33], if the PIP2 form is sent back later than one calendar month, this could cause delays to the application process.

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[31] DWP (2015) PIP role out timetable: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/478758/timetable-for-pip-replacing-dla.pdf

[32] DWP (2013) PIP handbook: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf

[33] Ibid https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf

Face-to-face consultation(s)

A key distinction between DLA and PIP is the introduction of the face-to-face consultation. This was introduced as part of the PIP application process to assess PIP applicants' eligibility for the benefit.

The Government contracted two private organisations (Atos and Capita) to undertake face-to-face consultations. This element of the application process is only required when more information about a person's health condition or disability is needed. In some instances, if the PIP2 form has sufficient information, a face-to-face consultation is not needed.

Face-to-face consultations are conducted by health professionals who consider the information provided by a PIP applicant; they either take place at contractor's assessment centre or in a claimant's home. It is not clear in DWP's guidance which factors influence the location of the face-to-face consultation.

Once the face-to-face consultation is completed, a health professional sends the information back to DWP where a Decision Maker (a member of staff at DWP whose role is to review PIP applications) uses the information on the PIP2 form, notes from the assessment provider, from the face-to-face consultation and any support evidence a claimant has given (e.g. a Certificate of Visual Impairment), to decide on an applicant's PIP award.

PIP disputes process

If a PIP applicant does not agree with the PIP award they are provided, they are told to contact DWP[34]. If after discussion with the Decision Maker they still do not agree with their award, they can request a mandatory reconsideration. At this point the applicant is asked to outline which particular points on the letter describing the reason for their outcome that they are unhappy with. They are consequently encouraged to provide any additional evidence they want DWP to assess at this point. At this stage a second DWP Decision Maker looks at the initial decision and any other additional evidence.

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[34] DWP (2013) PIP handbook: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/519119/personal-independence-payment-handbook.pdf

Applicants will then get a Mandatory Reconsideration Notice. This notice will respond to the issues that the applicant has noted and advises them of the outcome of the mandatory reconsideration. This notice will also provide an applicant with their right to appeal.

If the claimant still disputes the decision once DWP have reconsidered the decision, they can lodge an appeal directly with HM Court and Tribunal Service (HMCTS). Once a claimant lodges an appeal, they have one calendar month from the Mandatory Reconsideration Notice to appeal direct to HMCTS.

Once the process gets to this stage HMCTS will administer and process the appeal,and they will make all parties aware of the hearing dates if an oral hearing is to be held.

Appendix B. Achieved quotas by interview stage

Table 1.1 shows the demographics of the 26 participants who were interviewed at stage one of the study.

Table 1.1 – Demographics of participants interviewed at Stage One			
		Target	Overall interviews
Gender	Male	8-10	15
	Female	8-10	11
Age range	16-29	5-8	4
	30-49	5-8	13
	50+	5-8	9
Sensory Impairment	Severely Sight Impaired	4-8	16
	Sight Impaired	4-8	6
	Combined sight and hearing loss	4-6	4
Working status	In work	2+	10
	Out of work	2+	16
Physical or Mental Comorbidity	Present	2+	19
	Not present	2+	7

This table shows that 15 males and 11 females were interviewed at stage one. There were four participants in the 16-29 age bracket, 13 participants in the 30-49 age bracket and 9 participants in the 50+ age bracket. 16 of these participants were Severely Sight Impaired, 6 participants were Sight Impaired and 4 participants had combined hearing and visual impairment. There were 10 participants currently in work and 16 participants who were not in paid employment. 19 participants had either a mental or physical comorbidity alongside their sensory impairment and 7 participants did not have either mental or physical comorbidity.

Table 1.2 shows the demographics of the 23 participants who were interviewed at stage two of the study.

Table 1.2 – Demographics of participants interviewed at Stage Two

		Target	Overall interviews
Gender	Male	6	10
	Female	6	13
Age range	16-29	2-3	3
	30-49	2-3	12
	50+	2-3	8
Sensory Impairment	Severely Sight Impaired	2-3	16
	Sight Impaired	2-3	2
	Combined sight and hearing loss	3-4	5
Working status	In work	2+	6
	Out of work	2+	17
Physical or Mental Comorbidity	Present	2+	11
	Not present	2+	12

This table shows that 10 males and 13 females were interviewed at stage two. There were 3 participants in the 16-29 age bracket, 12 participants in the 30-49 age bracket and 8 participants in the 50+ age bracket. 16 of these participants were Severely Sight Impaired, 2 participants were Sight Impaired and 5 participants had combined hearing and sight loss. There were 6 participants currently in work and 17 participants who were not in paid employment. 11 participants had either a mental or physical comorbidity alongside their sensory impairment and 12 participants did not have either mental or physical comorbidity.

Table 1.3 shows the demographics of the 16 participants who were interviewed at stage three of the study.

Table 1.3 – Demographics of participants interviewed at Stage Three

		Target	Overall interviews
Gender	Male	4	7
	Female	4	9
Age range	16-29	1-2	2
	30-49	1-2	9
	50+	1-2	5
Sensory Impairment	Severely Sight Impaired	2-3	12
	Sight Impaired	2-3	1
	Combined sight and hearing loss	3-4	3
Working status	In work	2+	5
	Out of work	2+	11
Physical or Mental Comorbidity	Present	2+	10
	Not present	2+	6

This table shows that 7 males and 9 females were interviewed at stage three. There were 2 participants in the 16-29 age bracket, 9 participants in the 30-49 age bracket and 5 participants in the 50+ age bracket. 12 of these participants were Severely Sight Impaired, 1 participant was Sight Impaired and 3 participants had combined hearing and sight loss. There were 5 participants currently in work and 11 participants who were not in paid employment. 10 participants had either a mental or physical comorbidity alongside their sensory impairment and 6 participants did not have either mental or physical comorbidity.

Appendix C. Adaptations to the methodology

8.4 Adaptations to qualitative approach

During 2014/15 the DWP were substantially delayed in moving DLA claimants over to PIP. This meant that in some cases people had sent their application, but were waiting up to six months for a face-to-face consultation or outcome. These delays had an impact on the research, and thus the scope of the sampling strategy had to be adapted in two ways:

8.4.1 Change to the longitudinal approach to stage 1-3 interviews

Where possible, participants were included in all three stages of the research. Due to low numbers of participants being invited to apply for PIP when stage two interviews were scheduled (only 3 stage 1 participants), the sample had to be broadened to include new participants who had experienced the application process and received an outcome. This meant that most stage 2 participants had not taken part in a stage 1 interview.

The implication of this change meant it was not possible to compare participants’ expectations of and concerns about the PIP application process at stage one interviews, with the lived experience at stage two interviews.

The original methodological approach involved a three month gap between stage two and three interviews. Due to a short timeframe within which the research had to be completed, it was not possible to leave such a gap between interviews. Therefore, participants who agreed to a stage 3 interview were followed up between 4 to 6 weeks after their stage 2 interview.

The consequence of limited time between stage two and three interviews, meant participants had only been receiving PIP for a limited period of time (in some instances only one week). This meant participants had little experience of receiving PIP and therefore, in some instances, were unsure how their PIP award would affect them.

8.5 Adaptations to sampling approach

Initially two areas were chosen to conduct qualitative interviews – London and Birmingham. This purposive sampling strategy was taken because these locations were identified as areas were DLA claimants were being invited to apply for PIP during the fieldwork stage of the research. Using two case studies also eased scope of recruitment.

At stage two of the fieldwork, once the scope of eligibility had been broadened, it was still challenging to find participants in London and Birmingham who had transitioned from DLA to PIP. Therefore the sampling area was broadened out, so that anyone within the UK, who had a visual impairment or dual sensory loss, and had made the transition to PIP, was eligible. This adaptation to the sampling strategy did not impact the findings in any way, as location bore no influence on participants' experience of the PIP application process.

A second adaption centred on the point at which stage two interviews were conducted. Originally participants were recruited to participate in stage two interviews after recently receiving their PIP outcome. Again due to a limited number of opt-ins, this approach was adapted to include participants who may have undergone the PIP application process up to a year beforehand. The impact of this adaptation meant, that some participants conducted a stage two and three interview simultaneously, as they were able to reflect upon the impact PIP had on their life.

Appendix D. Overview of interview topics

Stage 1 (May 2015 – October 2015): Interviews were conducted when DLA claimants with a sensory impairment received a letter inviting them to claim PIP. Interviews at stage 1 explored:

- Claimants’ current financial situation (i.e. benefits being received, whether in or out of work);
- Their views on their current situation in relation to social and material wellbeing;
- Their understanding of the move to PIP; and
- Their expectations and concerns about the change (in relation to the process and to its perceived social and financial effects).

Stage 2 (January 2016 – April 2016): Interviews were conducted when the application process had been completed and the PIP outcome decided. Interviews at stage 2 explored:

- How claimants experienced the PIP application process (including the PIP2 form and face-to-face consultation);
- Challenges faced by claimants during the application process;
- An overview of the support they received; and
- The PIP outcome participants received and exploration of next steps e.g. appealing negative decisions.

Stage 3 (April 2016-May 2016): Interviews were conducted after there had been a period of time after the PIP outcome. Interviews explored:

- Any mandatory reconsideration or appeal experiences;
- How participants adapted to their PIP outcome; and
- How PIP affected participants’ financial status and emotional wellbeing.

Appendix E. Quantitative analysis data sources

8.6 DWP Administrative data

The DWP provides two useful tools to explore administrative data.

- The DWP Tabulation tool
- Stat-Xplore

The Tabulation Tool was used in this study because it offers information about DLA and allows running analysis on all DLA cases in payment. It provides data which includes information on people with dual sensory loss as well as on those with visual impairment

Stat-Xplore offers information about PIP and there is a function that allows for analysis of PIP claims in payment by subgroups - e.g. Disability, Disability category, Daily Living Award Status. Unlike the Tabulation Tool, data is available for each month of the year. Stat-Xplore provides data which includes information on people with visual impairment. It does not include information on people identifying as having dual sensory loss.

Appendix F. Administrative data tables

Table 1: Number of people in receipt of DLA by year and main disabling condition		
Base: DWP data tool	Month and Year of DLA award	
Main disabling condition	**Feb 2013**	**Nov 2015**
	N	**N**
All disabling conditions	3,300,000	2,967,000
Blindness	72,000	67,000
Deaf/Blind	570	550

Table 2: Number of people in receipt of PIP by year and main disabling condition	
Base: DWP stat Xplore tool	Month and Year of PIP award
Main disabling condition	**Jan 2016**
	N
All disabling conditions	692,104
Visual disease	8,334

Table 3: Percentage of PIP recipients, by year and type of visual disease	
Base: DWP stat Xplore tool	Year and month of PIP award
Main disabling condition	**Jan 2016**
	%
Diseases of conjunctiva, cornea, eyelids and lacrimal apparatus	5.7
Uveitis	1.7
Glaucoma	7.6
Injuries – Visual	2.1
Vitreous disease	0.6
Diseases of the retina and optic nerve	33
Cataract	3.3
Refractive errors	0.9
Disorders of eye movement	4
Visual field defects	20
Other diseases affecting vision	21
Total	100

	Table 4: DLA average weekly amount over time and by main disabling condition							
Base: DWP data tool	**Feb 2013**							
		Mobility component (£)				**Care component (£)**		
Main disabling conditions	**Average mobility and care**	Higher Rate	Lower Rate	Nil Rate[35]	Higher Rate	Lower Rate	Middle Rate	Nil Rate
All disabling conditions	78.3	96	65.5	35.6	119.1	50.8	84.7	46.1
Blindness	65.3	100	50.9	38.4	117.2	46.1	85.7	24.6
Deaf/Blind	104	106	59.8	51.9	131.1	72	103.3	53.1
	Nov 2015							
		Mobility component (£)				**Care component (£)**		

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[35] The nil payment columns show where recipients are in receipt of the care component and not the mobility component.

Main disabling conditions	**Average mobility and care**	Higher Rate	Lower Rate	Nil Rate	Higher Rate	Lower Rate	Middle Rate	Nil Rate
All disabling conditions	84.8	103.3	72.2	40.9	124.8	54.8	89.1	49.3
Blindness	71.9	107.6	54.9	43	125.1	49.3	92	26.5
Deaf/Blind	111.9	114	61.8	55.1	139.8	76	109.9	56.3

Table 5: PIP average weekly amount over time and by main disabling condition

Base: DWP data tool	**Jan 2016**			
	Mobility component (£)		**Daily living component (£)**	
	Enhanced rate	**Standard rate**	**Enhanced rate**	**Standard rate**
All disabling conditions	12,540,013	4,849,758	26,380,853	17,614,974
Visual disease	285,009	59,950	353,067	128,217

Note: Stat-Xplore does not offer information of amount in payment. To overcome this missing information, the amount in payment has been calculated by looking at the number of individuals in receipt of each payment type (combination of mobility and daily living awards) and multiplying this by the set rates

Appendix G. 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 won't 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.

End of report