

# Personal Independence Payment (PIP) and Disability Living Allowance (DLA): report based upon fourteen case studies of people with sensory impairments engaged in application for PIP

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# **Personal Independence Payment (PIP) and Disability Living Allowance (DLA): report based upon fourteen case studies of people with sensory impairments engaged in application for PIP**

**February 2015**

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## **Executive summary**

As part of the UK government's welfare reforms, Personal Independence Payment (PIP) replaced Disability Living Allowance (DLA) for people aged 16 to 64 on 8<sup>th</sup> April 2013. This was initially for new claims in pilot areas. Over the coming few years there will be a staggered introduction of PIP, and it will eventually completely replace DLA for this age group.

PIP (and DLA) is not means tested or taxed, and is designed to help towards some of the extra costs arising from a long-term health condition or disability.

This research report forms the conclusion of Phase 1 of a larger scale piece of research, and had the following objectives:

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

## **Method**

Fourteen people took part in semi-structured interviews which explored people's experiences of PIP. The interviews discussed the different stages of the application process. Characteristics of the 14 participants included:

- Seven participants had a visual impairment, and seven participants had a dual sensory impairment;
- Six of the participants were between the age of 16 and 25; eight of the participants ranged in age from 33 to 57;
- Nine of the participants could be broadly described as having additional disabilities and/or health conditions beyond their visual impairment or dual sensory loss;
- Three of the case studies were in relation to people who had appointees who applied for PIP on their behalf because of the complexity of their situation (all of whom were under the age of 25 years);
- Participants were at different stages of the PIP application process: seven having received their decision letter at time of interview, four awaiting assessments/decisions, and three had not yet started the process;

- The majority of participants had prior experience and receipt of DLA – only two participants were not previously in receipt of DLA before applying for PIP (both were new applicants to this kind of benefit).

The transcribed interviews were subjected to a thematic analysis drawing out case summaries and vignettes, accounts of experiences of applying for PIP, and general emerging themes of relevance to the aims of the study.

## **Key findings in relation to PIP outcomes**

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

- All seven participants who received an award letter had a successful outcome (in that they were awarded PIP at some level).
- Four out of five participants who were previously in receipt of DLA appeared to have matched (two) or improved (two) the monetary value of the benefit they received following the award of PIP. One participant appeared to have a lower award (although this seemed ambiguous).
- At time of interview, all participants appeared satisfied with the final outcome of the PIP application process.
- One participant was not satisfied with the points score from the assessment. She asked for a mandatory reconsideration and the points were adjusted which led to a successful change in the award.

PIP (or the equivalent, DLA) provides an important financial contribution to the additional costs associated with disability and health conditions. Some of the costs associated with visual and dual sensory impairment were identified by participants with relative ease and are familiar to those working in the sensory impairment sector (e.g. transport and equipment). Nevertheless, some additional costs were less obvious and often normalised by the participants such that they were sometimes not recognised by the individuals themselves (e.g. additional heating, washing and cleaning).

### **Implications:**

Although we must be extremely cautious at this early stage of PIP rollout, the following implications have been identified:

- The findings of this research imply that people with visual and dual sensory impairment (and/or their appointees) – whether a new applicant or in receipt of DLA – should apply for PIP confident in the

mind that others have been successful in securing a satisfactory award. Those already in receipt of DLA might consider choosing to apply for PIP before the required deadline as it may lead to an increased award (but given there is a risk involved, this would need to be done after careful analysis). The case studies in this report may help applicants and their advisors decide upon whether to apply or not.

- Specialist voluntary sector organisations (such as RNIB, Sense, Action for Blind People) might offer positive, albeit cautious, advice that application for PIP can lead to the successful entitlement award. Similarly, appealing against a perceived low PIP award can lead to a successful adjustment. This might challenge the belief in some that application for PIP should be avoided. Nevertheless, it should also be noted that applying for PIP can be a stressful and time-consuming process.
- Those advising people with visual and dual sensory impairment (whether organisations or professionals advising individuals) could usefully offer clear guidance on the additional costs of disability and how it can be effectively represented in the PIP assessment process. This requires careful analysis far beyond that presented in this report, and it could draw upon existing literature as well as ongoing research (e.g. work by Loughborough University in relation to disability and minimum living standards, with particular reference to sensory impairments).

## **Key findings in relation to PIP application process**

The experience of the PIP application process was generally a negative one for the participants involved in this study. Participants were often anxious in anticipation of the application process. The process itself was often slow and delayed, and inaccessible to many people with sensory impairments. Key findings and associated implications are summarised as follows.

### **1. Appointees**

An appointee is a person who will manage claims and benefits on behalf of a claimant, as well as act in the disabled person's best interest in spending/saving the income generated (e.g. from PIP). The process and associated assessment to become an appointee appears to be straightforward. The flexibility of the process experienced by the participants in this study was viewed positively, although greater clarity and information would have removed anxiety. The flipside of this apparent flexibility is that there is potential for some vulnerable claimants

to face the complex PIP application process without advocates (e.g. young people at the age of 16). It is important to note that decisions about appointeeship can be complex and emotionally charged. For example, parents who are considering acting as an appointee for their children also may be considering their children's general post-school transition plans and long-term care needs.

### **Implications:**

- It would be helpful for DWP to provide greater clarity about the appointee process. Similarly, supporting professionals and sector organisations could target information and guidance of this process to people with visual and dual sensory impairment (and/or their family and carers).

## **2. Accessibility and time**

Aspects of the application process proved inaccessible at every stage for people with visual or dual sensory impairments. In particular for this group was that the application process often relied upon, or defaulted to, printed text (difficult for many people with visual impairment) or telephone (difficult for many people with deafness/hearing impairment). This poor accessibility, combined with the complex lives disabled people may often lead (e.g. organising hospital appointments), can put additional time pressure upon claimants who are trying to keep to the prescribed application timetable.

### **Implications:**

- In line with recommendations made by others, DWP should promote and respond to claimant choice in methods of communication. Claimants, their advisors, and organisations advocating and campaigning on their behalf, should demand this choice of communication. Given the additional time pressure that poor accessibility and complex lives can place upon claimants, it is also important that they can easily be given extra time to navigate the application process (e.g. to complete application forms).

## **3. Support**

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

the points system which is central to the PIP assessment.

### **Implications**

- Leading sensory impairment sector organisations should develop and maintain clear and accessible written advice in relation to PIP application. For example, existing websites (e.g. those offered by Sense, RNIB and Action for Blind People) offer useful information and could be developed further. Such guidance should be far reaching, offering details on all aspects of the process (e.g. the non-means tested nature of the benefit and its philosophical principles, the role of an appointee, the points system, and application procedures). Guidance should also be written for multiple audiences (most notably people with visual and dual sensory impairments but also welfare advisors and advocates). The availability of knowledgeable advisors is extremely important for many claimants and an analysis and communication of their availability would be helpful.

## **4. Assessment**

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

### **Implications**

- Clearer and accessible information from DWP about the assessment, including the criteria for the likely format the assessment takes, would be extremely helpful.

## **5. Timescales**

DWP had originally proposed that 97% of assessments would take place within six weeks from the submission of the PIP application form. Of the seven participants who had received their decision letter (all of whom were awarded PIP) none of them appears to have received the letter within the original DWP timescale. Four of the participants appear to have received the decision letter within a 26 week target timescale (the times ranged from three to six months). Twenty six weeks (six months)



appears to be current DWP estimated timescale based upon PIP enquiry line. For three participants the process took longer than 26 weeks (between seven and eleven months). Another participant who is still awaiting the decision letter has already been in the system for eight months.

It is generally widely agreed that the DWP targets for the timescale of the PIP application process have not been met, and these are not acceptable. Clearly the DWP should improve on this performance.

### **Implications**

- In the short term the DWP might more clearly communicate timetable challenges to claimants. Importantly, the delays have particularly negative impacts upon new claimants (i.e. those who are applying for a disability-related benefit for the first time, as opposed to those switching from DLA), because they do not have existing benefits while their application is being processed. The DWP might consider fast-tracking these particularly vulnerable new claimants.

## **6. Discomfort about the assessment process**

Some of the participants had feelings of defensiveness and even guilt about applying for PIP. PIP is not means-tested or taxed, and is designed to help towards some of the extra costs arising from a health condition or disability.

### **Implications:**

- An important role of advisers and advocates for people with disabilities is to remind potential claimants of the legitimacy of their application.

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

### **Implications:**

- Future research might usefully explore this potential phenomenon further.

## **Recommendations for the next phase of the research**

One of the objectives of Phase 1 of the research was to make recommendations for future phases of this research project. Phase 2 of this project might consider the following points:

- Consider recruiting participants with characteristics which will add to the experiences gathered in Phase 1. The sample size in Phase 1 was very small, but particularly under-represented were participants with less severe visual impairment and less complex additional disabilities and health conditions. Also in Phase 1 we did not recruit any participants who were profoundly deaf and/or communicated through British Sign Language.
- Consider recruiting participants through Local Authority Rehabilitation Teams and local visual impairment charities. Given the very low numbers of claimants with sensory impairments at this stage of the PIP rollout (as reflected in the DWP figures), making personal contacts with professionals and advisors who can approach individuals on the research team's behalf may prove more useful than general flyers and adverts.
- Given Phase 2 involves tracking participants as they work through the phases of PIP application, it may be helpful to build upon some of the recruitment in Phase 1. Seven Phase 1 participants do not yet have a PIP outcome and it would seem sensible to ask their permission to be involved in the next phase of work.
- The themes identified in Phase 1 will hopefully prove useful areas for exploration and clarification in Phase 2.

## **Acknowledgements**

We would like to thank a number of people for their help in preparing this report: the 14 participants who willingly and generously shared their experiences of PIP; the many other people who helped in the recruitment process; those who helped to facilitate the interviews, in particular the participants' family members and associated professionals. Thank you also to Thomas Pocklington Trust, RNIB and Sense for funding this research.

## Introduction

The research brief prepared by the three funding organisations (RNIB, Sense and Pocklington) entitled “Experiences of Personal Independence Payment (PIP) on people with sensory loss” provided a clear rationale and policy context for the work. The research brief outlined the funder’s concern to understand the impact of this policy change, both in terms of numbers of claimants and the lived experience of the process of claiming (including the assessment procedure) and any changes in relation to the benefit received.

A joint research proposal was prepared by the University of Birmingham and NatCen. The proposal was split into three phases of work, the first of which was undertaken by the University of Birmingham. This report presents findings from this first phase of work (and is in addition to a report presented in March 2014 entitled “Disability Living Allowance (DLA) and Personal Independence Payment (PIP): preliminary report based upon the views and experiences of young people with visual impairment”, see Ellis et al, 2014).

The aim of phase 1 was the development of case studies linked to young people (16-25 years) with sensory loss (including a small number of case studies of older adults with Usher syndrome). As the project progressed, recruitment of people sufficiently engaged in the PIP application process proved difficult and the criteria for inclusion in the project was modified to include a broader age range following consultation with the funders. The result was the recruitment of the fourteen participants who form the case studies presented in the report (aged between 16 and 57 years old).

With reference to the research brief, this phase of work sought to contribute to the following objectives:

- To investigate differences in benefit receipt before and after PIP was introduced for people with sensory impairments;
- To find out about the financial status of people with sensory impairments before and after PIP was introduced;
- To explore experiences of making a claim and the impact of this on the wellbeing of people with sensory impairments;
- To establish whether there is need for further research.

## A short introduction to PIP

As part of the UK government’s welfare reforms, PIP replaced Disability

Living Allowance (DLA) for people aged 16 to 64 on 8<sup>th</sup> April 2013, initially for new claims only in pilot areas. Over the coming few years there will be a staggered introduction of PIP (and it will eventually completely replace DLA for people in this age group).

PIP (and DLA) is not means tested or taxed, and is designed to help towards some of the extra costs arising from a long-term health condition or disability. The introduction of PIP is at a time of broader and fundamental welfare reform and the introduction of Universal Credit (which from October 2013 replaces working-age benefits and tax credits). It is in this context that this research is taking place. In addition, at time of writing this report an independent review of PIP assessment was published by the DWP (Paul Gray, December 2014). The review was required as part of the 2012 Welfare Reform Act, and presents important information about the general progress of the implementation of PIP (we draw upon this in our final discussion). It should also be noted that within the review Foreword, Paul Gray commented that, “with implementation being less advanced than originally planned, this is too soon to draw definitive conclusions on many aspects. The evidence is simply not yet available to do so reliably or robustly.” (p2).

## **Methods**

### **Overview**

Fourteen people took part in semi-structured interviews which explored people’s experiences of PIP. The majority of these interviews took place over the telephone, although three interviews took place in person in line with the wishes of the participants (the interviews with Matt, David, and Lyn). The telephone interviews lasted between 25 and 50 minutes, and the face-to-face interviews lasted for around an hour and a half. The interviews were recorded using a digital voice recorder, transcribed, and then analysed.

The research and recruitment procedures and research materials (interview schedules, participant information sheets, and consent forms) were approved by the University of Birmingham’s Ethics Committee (code: ERN\_14-0151).

### **Participants and recruitment**

The fourteen participants form a self-selecting convenience sample. Participants were recruited from a variety of sources and contacts,

including:

- Local Education Authorities;
- Advertisements in Talking Sense;
- Recruitment notices on Facebook groups, and other email distribution lists;
- Special School contacts;
- Word-of-mouth ('snowballed') from participants who had already taken part in the research;
- Local visual impairment charities (including through Visionary, the membership organisation for local sight loss charities);
- Requests to participants with a visual impairment or dual sensory loss who had previously taken part in research at the University of Birmingham.

The original proposal was to recruit younger participants (16-25 years) by advertising through Local Education Authorities and requesting participants (and potential 'case study' participants) completed a relatively short online questionnaire. This proved largely unsuccessful (although some case study participants were recruited through Local Education Authorities), and following consultation with the funders our recruitment strategy was modified to include a broader age range. The result was the recruitment of the fourteen participants aged between 16 and 57 years old. Some recommendations for recruitment in the next phase of the project are made (including through Local Authority Rehabilitation Teams, which was not possible in this phase of work because of timescales and the need to apply for ethical approval through the ADASS and Local Authority Research Governance Framework (RGF) committees).

An overview of the participant characteristics is presented in "Case summaries and vignettes" section. Nevertheless some general points are made below:

- **Dual Sensory Impairment.** Seven participants had a dual sensory impairment (and five of these had Usher syndrome). Although this might seem a high number from a relatively small sample, it reflects both the nature of dual sensory impairment and Usher syndrome. Usher is the most common form of acquired deafblindness in people who are under 65 years of age (the age category that PIP provides support for). In addition, the majority of those who have a congenital dual sensory impairment are likely to have profound needs and therefore be in receipt of an indefinite award under DLA, and so not

likely to be moving over to PIP until October 2015. Related, Usher syndrome is a progressive condition (the presence of retinitis pigmentosa as part of the condition means that eye sight tends to deteriorate from teenage years onwards), this makes it more likely that people with Usher syndrome would apply for PIP as their circumstances change.

- **Additional disabilities.** The presence and significance of additional disabilities and/or health conditions is difficult to summarise given the complexities of people's lives and the interactions and implications of some conditions. Nine of the participants could be broadly described as having additional disabilities and/or health conditions beyond their visual impairment or dual sensory loss. Three of the case studies were in relation to people who had appointees who applied for PIP on their behalf because of the complexity of their situation (all of whom were under the age of 25 years).
- **Age.** Six of the participants were between the age of 16 and 25 (categorised as 'younger people' in the original research proposal). The remaining eight participants ranged in age from 33 to 57.
- **Point in PIP application process.** Seven participants had received their decision letter at time of interview (i.e. completed all the stages of the PIP application process). Four participants were in the process of applying for PIP (including awaiting the outcome letter). The remaining three participants had not yet applied for PIP. The majority of participants had prior experience and receipt of DLA – only two participants were not previously in receipt of DLA before applying for PIP (both were new applicants to this kind of benefit).

## Interview schedules

Given our participants had varied circumstances and backgrounds (e.g. some were appointees and/or parents; some had not yet applied for PIP), the project used a range of interview schedules. Appendix 2 presents an example schedule which provides an overview of the approach which focussed the discussions upon the different stages of the application process.

## Analysis and reporting

The interviews were recorded using a digital voice recorder, transcribed, and then subjected to a thematic analysis using the software package

QSR NVivo. The analysis had three overlapping phases, which is reflected in the reporting approach.

1. The writing of short case study vignettes for each of the participants – see section “**Case summaries and vignettes**” and Appendix 1;
2. Draw out general experiences of applying for PIP in relation to the different stages of the application process (from application to outcome) – see section “**Analysis of the experiences of applying for PIP**”;
3. Identification of general themes which cut across the process as a whole and also reflected the research objectives which were not covered elsewhere – see section “**Further analysis and general themes**”.

Participants are identified with pseudonyms. Illustrative verbatim quotes are presented to illustrate the themes. The qualitative approach adopted in the research and the very small participant numbers do not warrant the aggregation of responses in particularly meaningful ways. Nevertheless, we do present some summary data in the form of tables to help the reader access information efficiently, and we also use some ‘quantifying’ language to aid reporting (e.g. ‘all’ meaning all participants; ‘some’ meaning more than two but less than half of the participants; ‘the majority’ meaning more than half of the participants).

In the main we use the term ‘in receipt of PIP’, ‘in receipt of DLA’, or similar expressions. Although we tend not to use the potentially emotive term ‘on PIP’ (or equivalent) we do occasionally use it for brevity and also because it reflected the language used by many participants.

## Case summaries and vignettes

The research involved 14 case studies, and a summary of the participants (all of whom had a visual or dual sensory impairment) is presented below. This information is listed in Table 3 in Appendix 1, and more detailed half page summaries also in Appendix 1. This information is important because it provides more details of lives and context of our participants which led them to engage with PIP. We encourage the interested reader to look at this carefully because it gives an important insight into the complexity of people's lives of which PIP is just a part, as well as demonstrating the generosity the participants showed in sharing this information with the research project.

**Owen** is 16 and has a dual sensory impairment. He has complex needs and profound learning difficulties. He used to get the higher rate for mobility and care for DLA, and now for PIP he is in receipt of an enhanced award for both mobility and daily living. **Elaine** is Owen's mother and appointee who told us her experiences of claiming PIP for Owen.

**Jim** is 57 years old. He is visually impaired as a result of complications from diabetes. He was not in receipt of DLA as he is newly registered as having a visual impairment (severely sight impaired – SSI). For PIP, Jim is in receipt of an enhanced award for both mobility and daily living.

**Lyn** is 54 years old. She has a visual impairment linked to a brain aneurism. Lyn has additional disabilities/ health problems including memory difficulties, poor circulation, walking difficulties, migraine and pain. For DLA Lyn was in receipt of the higher rates for mobility and care. For PIP, after a mandatory reconsideration, Lyn was awarded the enhanced rate for both mobility and daily living.

**Yazan** is 24 years old. He has a visual impairment (linked to retinitis pigmentosa) and also has well-managed epilepsy. He was not previously in receipt of DLA. In relation to PIP, Yazan was awarded the standard rate for both mobility and daily living.

**Tony** is 47 years old. He has Usher syndrome type 3 and has a dual sensory impairment. He has no additional health problems or disabilities. Currently he is receipt of DLA at the lowest rate for mobility and care, and his unhappiness with this award level has prompted him to apply for PIP. At present he has completed his application for PIP and is waiting to hear from DWP.



**Matt** is 35 years old and he has a dual sensory impairment as a result of Usher syndrome type 2. He has no additional health problems or disabilities. He was in receipt of DLA at the lowest level for care and mobility and this disappointment with the award level prompted him to apply for PIP. Matt has been awarded the enhanced rate for mobility and daily living.

**David** is 40 years old. He has a visual impairment linked to retinitis pigmentosa. He has not yet applied for PIP but is currently in receipt of DLA at the lowest level for care, and the higher level for mobility.

**Fiona** is 33 years old. She has a dual sensory impairment with her sight loss is linked to diabetes. Additionally Fiona is on the kidney and pancreas transplant list, and has anaemia. She is currently in receipt of DLA, having recently completed her PIP application form and is now waiting to hear from DWP.

**Dominic** is in his 50s. He has a dual sensory impairment as a result of Usher syndrome type 2. He is currently in receipt of DLA at the higher rate for mobility, and also care, although the level is unknown. Dominic has not yet applied for PIP although he is anxious about the potential reduction in award due to PIP.

**Alistair** is 57 years old. He has a dual sensory impairment as a result of Usher syndrome type 3. Alistair also has depression. He is currently in receipt of DLA at the higher rate for mobility and care. Alistair has not yet applied for PIP although he is anxious about the PIP application process.

**Alexander** is 16 years old. He has a visual impairment as well as complex medical needs and learning difficulties including autism and epilepsy. **Becky**, Alexander's mother and appointee was interviewed about her experiences of applying for PIP on behalf of her son. Currently Alexander receives the higher rates for DLA for both mobility and care. Becky has made no formal application for PIP as she was told that Alexander would automatically be transferred from DLA to PIP.

**Ryan** is 16 years old. He has a visual impairment and has to avoid knocks to the head in order to prevent complications which might cause his vision to deteriorate. Ryan receives PIP (at the enhanced level for both mobility and daily living) in his own name, however his father **Mike** tells us his experiences of supporting Ryan through his application.

Under DLA Ryan was in receipt of the lower rate for mobility and care.

**Sophie** is 18 years old. She has a visual impairment linked to albinism. She also has migraines due to eye strain. Sophie is currently in receipt of DLA, since she is still waiting to hear the outcome of her application and face-to-face assessment for PIP.

**Ricky** is 17 years old. He has a dual sensory impairment linked to Usher syndrome type 2. He has no other health problems or disabilities.

**Lindsay**, Ricky's mother, is his appointee and spoke of her experiences of applying for PIP for Ricky. Ricky was previously in receipt of DLA, and for PIP he is in receipt of the standard rate for mobility and the enhanced rate for daily living.

## **Analysis of the experiences of applying for PIP**

This section presents an analysis of participants' experiences of PIP at key points during the PIP application process. Reference is made to:

- applying for appointeeship;
- the application form (including comments on the points system);
- the assessment; and
- the award outcome.

The experiences of those who have not yet begun the formal application process for PIP are also discussed. As is shown, anticipatory experiences of PIP were significant for some of the participants long before application.

At this time, people are able to apply for PIP in five different circumstances:

- a young person who is already in receipt of DLA turns 16;
- a person who is in receipt of a fixed award DLA which has come to an end;
- a person who is already in receipt of DLA, has a change of circumstances;
- a person is applying for disability related benefit for the first time;
- a person who is already in receipt of DLA, chooses to apply for PIP.

At the time of writing (January 2015) the final option (a claimant of DLA chooses to apply for PIP) is only available to claimants living in certain geographical areas. From October 2015 all individuals who are in receipt of DLA will be called to apply for PIP.

In this research project:

- four people were turning 16 (Alexander, Ricky, Ryan, and Owen);
- three people's fixed DLA awards were coming to an end (Lyn, Fiona, and Sophie);
- two people were applying for a disability related benefit for the first time (Yazan and Jim); and
- two people who were in receipt of DLA had chosen to apply for PIP (Tony and Matt).
- three participants were in receipt of DLA and expected to be required to apply for PIP after October 2015 (David, Alistair, Dominic)

## Appointeeship

For young people turning 16, before beginning the PIP application process, a decision has to be made by DWP as to whether the PIP payment will be made to the young person directly, or whether someone else (usually a parent or legal guardian) will act as an appointee. If someone is made an appointee, PIP will be paid to that person who will act in the individual's best interest in spending/saving the income generated from PIP. The appointee is also responsible for making the application for PIP on the young person's behalf. If a person indicates that they would like to be an appointee for a person who is applying for PIP, there will be an assessment by DWP, usually involving an interview at home.

Becky, Elaine, and Lindsay were appointees for their sons Alexander, Owen, and Ricky respectively. They spoke about their experiences of becoming an appointee. For Becky, the assessment was relatively straightforward and positive as the following quotation shows:

I didn't really know what to expect of it actually but it was fine. The lady was lovely. She was really understanding. I didn't feel scrutinised by her. It wasn't like that at all. She was really approachable and relaxed and the whole process was over in a couple of minutes. (Becky)

However the comment "I didn't feel scrutinised" suggests that Becky had had anxieties about the process. Feelings, and fears, of being scrutinised were repeated by participants throughout the interviews, in relation to completing the application form and the assessment process, and will be developed further in this report.

Becky's fears are perhaps also heightened by the fact that she did not have enough information regarding what would be involved in the process. As we shall also see as the report progresses, a lack of information, as well as difficulties in communicating with DWP is a recurrent theme for many participants throughout their application for PIP.

Elaine too faced difficulties in getting accurate information from DWP concerning the assessment for appointeeship, which caused distress for Elaine:

The first couple of conversations that I had on the phone in trying to set this up were quite stressful because they weren't able to tell me what time they were coming, they

were just going to give me a date, and it would be narrowed down on the morning of the visit, and they expected Owen to be there. They were expecting me to take Owen out of school, and out of routine, for something that he wasn't going to be able to contribute to anyway. I got quite hot under the collar about that. It was quite stressful. It was pointless. Owen misses enough school with appointments anyway. And it was just, as far as I was concerned a complete and utter waste of time and an unnecessary disruption. (Elaine)

Elaine goes on to mention the lack of understanding of the lives of people with disabilities and long-term health problems, evidenced by the fact that "we were sent random appointments, without consultation that they would fit with what we had already got in the calendar." This was particularly stressful for Elaine as she explains:

...there was so little information out there at the time, I felt that there was a risk that they would stop the DLA, before they got the PIP in place and we would be left without money for a period of time, simply because there had been a delay at the appointee stage, because they had sent us appointments that we couldn't keep. (Elaine)

Fortunately after her third telephone call to DWP Elaine discovered that Owen would not need to be present and that the assessment could take place without Owen being there. However Elaine felt that it was only after mentioning certain key phrases which triggered this response from DWP (i.e. because of his needs Owen did not need to be present at the assessment for appointeeship). The feeling of having to say the 'correct phrases' to trigger a certain positive response from DWP was also echoed by Lyn and Fiona in relation to their conversations to DWP when applying for PIP.

Linked to this, Mike was given the wrong information over the telephone from DWP when his son Ryan was turning 16 years old. As Ryan was going to be claiming PIP in his own name, Mike was wrongly told that he would lose his Carer's Allowance. When asked to make some suggestions as what could be changed to the PIP application process Mike commented:

I was a miffed with the first chap that we spoke to, when I phoned them up because he was a little bit confrontational. They can be a bit more sympathetic I think. And the advice he gave, some of it wasn't correct. And it put me under a

lot of stress. (Mike)

For Lindsay and Ricky the assessment itself “was fine” however Lindsay felt it was “a waste of time really” as all the assessor did was ask Ricky what he would do if given £50, and when he responded “err spend it” it was decided that Lindsay could be Ricky’s appointee. As Lindsay commented:

She went that’s it, that’s fine you can be his appointee. And I sort of looked at my husband and he looked at me, and both looked at Ricky and went “oh, ok.” It just seemed quite a roundabout way of going about things. (Lindsay).

The apparent lack of rigour, coupled with the needless necessity to have the meeting seemed inefficient and ‘hoop jumping’ to the participants. A perceived lack of rigour of the PIP assessments was also mentioned by two of participants and will also be examined more closely later in this report.

It is interesting to note that Lindsay opted to be the appointee for Ricky, who does not have any other disabilities or health problems apart from his dual sensory impairment. Whereas Ryan, who also does not have any other disabilities or health problems opted to be the claimant himself. Lindsay describes her son as “not that worldly” and that for him “money is a bottomless pit”: “He just doesn’t think about where it comes from or where it goes. Money is just a thing that happens. In his bank every week and that’s that.” Whereas Mike describes his son as “sensible”:

He’s 16. He’s a young lad. When you get money like that you tend to want to blow it. But he’s a sensible lad and he knows... We’ve sat down and had a chat. He knows in the future the same circumstances could affect his other eye. Which means that it will go back to how it was before. He’s a sensible lad, he will look after his money. (Mike)

Here we see the individual differences in personalities, and knowledge and understanding in relation to money and finances. At the age of 16 such differences may be more likely to exist from one individual to another, and in some case linked to relative maturity. To this extent we may view the appointeeship process for PIP as being flexible, nuanced and sensitive to an individual’s particular needs. For example, it was more appropriate for Lindsay to be the appointee for her son than Ricky to be the claimant, and this is recognised by DWP, rather than following an arbitrary age or disability/health problem cut off point. However,

speaking as a father Mike had some concerns about 16 being the starting point:

I'm glad Ryan's got it but at 16 maybe at the end they could have thought about upping the age by a year or two.

Possibly. He can't vote at 16, he can't go to the pub at 16, yet they are saying he's an adult and he should get his own money. It's a bit contradictory in a way but having said that I'm not begrudging him at all, and I would have fought tooth and nail for him to get it. (Mike)

A final observation is that applying for PIP often begins the process of dealing with adult services for the first time, and as Becky mentioned she had mixed feelings of the process of becoming an appointee "as the first time that we had had to sort of do something about him sort of going into adulthood."

## **Application**

This sub-section explores the participants' experiences, thoughts and opinions in relation to applying for PIP and the application form itself. The following aspects of the process are taken in turn:

- the initial telephone call;
- accessibility of the form;
- the questions on the form;
- confusion about accompanying documentation.

### **Initial telephone call**

The first stage in applying for PIP is to make an initial phone call to DWP to register basic details on a PIP1 form. If a participant's claim is viewed to be suitable they are sent a PIP2 form ('How your condition affects you'). Those whose fixed term DLA is coming to an end or those turning 16 receive a letter asking them to contact DWP, whereas those choosing to make a claim for PIP or whose circumstances have changed, must contact DWP via phone directly.

For many participants this initial phone call was not remembered clearly, as Elaine commented "It's all a bit hazy now!" It was generally only commented on by those who had a less than straightforward experience of completing the PIP1 form. As Lindsay commented, due to a lack of information she was unsure as to what the phone call was for:

After I was made Ricky's appointee, I was sent a letter and asked to call the PIP team to make the application. I was

given a telephone assessment to see if we would be eligible to make a full application for the PIP. Again, this was not explained, I thought the telephone call was to make the application but it was sort of an application for the application pack. (Lindsay)

Likewise Matt who is not able to use the telephone due to his deafness, had to rely on his support worker to make the phone call:

I don't use the telephone. My support worker does all my phoning for me. She helped me all the way. There was a situation "oh we need to speak to the actual person" so she just handed the phone to me and I went "yes". And I handed the phone back and that was it and she had permission to talk to the person on the phone. (Matt)

Matt was not too troubled by having to rely on his support worker to make the phone call to DWP, and seemed to accept that this was the way in which the system works. Paper copies of the PIP1 form are described as being made available in 'exceptional circumstances', to those who write and a request a paper version. For example the following guidance appears on the Citizens Advice website:

The DWP will only provide a paper claim form in exceptional circumstances, so you should tell them why you can't use the phone when you write to them. If you don't do this, they are likely to try to phone you.

Access to the assessment process (whether this is physical access of the format such as the telephone or paper, or whether this is something more profound in relation to understanding the questions) is also considered elsewhere in the report. Given the nature of the benefit and the client group it is relevant to, it is perhaps surprising that this has not been considered in more detail by the DWP.

Fiona had little confidence in the people that she was speaking to on the phone:

I felt that the person didn't really understand. I don't expect them to be a doctor but it was a bit awkward spelling out all of the words... ..they couldn't even spell retinopathy. I'm sure I'm not the only one that has applied with diabetic retinopathy. (Fiona)

This unnerved Fiona as "you don't know what they are documenting" and left her feeling vulnerable:



You can only hope that they are documenting exactly what you are saying to them. I mean they can put down whatever they want really, in the initial application so you really have to trust the person. That can really be quite difficult. (Fiona)

Alistair had similar unease surrounding confidence and trust in the comments that a DWP employee might make:

You don't know what they are writing on the form. You need somebody you can trust. They can write anything they like. I could say I'm blind and they could put partially sighted. This is very important. So that is my main concern. (Alistair)

## **Accessibility**

Accessibility of the PIP application form was an area that many participants struggled with, or anticipated that they would struggle with. Jim for example had to rely on his wife Sue to complete his application form as he is only able to read short documents using his electronic handheld magnifier:

I tried to use the [electronic magnifier] that I have got but you can't concentrate on what you are doing really there's that many pages and that many questions – it was unreal! Well we filled it in between us. Sue did all the writing and everything. There's no way in the format that it comes that you can actually understand it. If I were on my own I wouldn't have stood a chance to tell you the honest truth! So that's one of the problems obviously with these forms these days. (Jim)

Sophie commented “the little bits like my name and my date of birth, I do fill out myself” otherwise her mother had to support her in completing the form. For Alistair, who uses a reader/scribe to access written documents in daily life, described anxieties related to whether he would be able to trust another person to complete his application form accurately (as mentioned above). He was therefore anxious whether being “computer illiterate” would stand against him. Related, Alistair described the importance of the support offered by the voluntary sector organisation Sense (traditionally his first port of call when seeking support and advice in relation to being deafblind). He had been told Sense was “...very short of staff, [and] they've cut back on their legal section”. Alistair was anxious that Sense would not be able to help him at the application

stage when he needed help, and only later in relation to “tribunals, appeals, things like that.” He noted it might be more worthwhile for organisations such as Sense to provide support at an earlier stage, to not only avoid stress for the individual, but to prevent applications having to go to appeal in the first place:

I feel it’s in [Sense’s] best interests that we have people helping from the start, rather than going through stressful periods not knowing what’s happening, and then perhaps having to go to an appeal or tribunal, because the forms were incorrectly filled out or something connected with the process. One to one personal support is very important.  
(Alistair)

Fiona, Jim, Mike and Lyn also identified that the organisations for visually impaired people that they did go to, or might go to, to receive support and advice in relation to PIP, were also often stretched in terms of capacity:

They’re overworked themselves! (Jim)

[Local disability information service] tend to be quite good, although they are very, very short staffed. (Fiona)

For Jim, Fiona, Yazan, and David an electronic version of the application form would be useful. However, this does not appear to be available. Ironically for Yazan, who was dealing with sudden and significant changes in his vision, needed the money generated by PIP to purchase the necessary equipment to enable him to access the forms. For example when asked what he would do with the income generated by being in receipt of PIP, he described one potential use as:

...maybe I can say special software for my computer. Or even I have to save some money so I can read my letters on my own, and the problem is that these equipments are really expensive. (Yazan)

Lyn however was pleased that the application form sent to her was in large print, having requested it in the initial application.

One suggestion made by Fiona was for applicants of PIP to request alternative formats in order to encourage DWP to provide documentation in the appropriate format:

Just to request an alternative format to begin with because the more people that request it, request things on audio, or braille or large print, the more people who ask for it the

more they are going to make it possible. (Fiona)

However as Fiona later went on to suggest it would be better if DWP asked applicants if they had any access needs, rather than waiting for individuals to request it:

...it would have been nice on the phone if they had said to me we can supply that in audio or braille would that be of any help? So that wasn't offered. Which would have been good. Offer it rather than waiting for someone to ask for it. (Fiona)

Lastly, participants required support from others to complete their PIP application, not only in terms of accessing the form due to their visual impairment but because of difficulties with reading and understanding English.

Matt described himself as finding reading difficult and this was exacerbated by his visual impairment. He described how he can only read a few words at a time before losing the meaning, so prefers to have assistance from his support worker to help him with forms and official documents. Sophie has support from her mother, "what I do is my mum reads the questions to me and I answer them and then my mum fills it in for me." This is because Sophie has difficulty understanding the questions and language used.

Yazan, whose first language is not English also described having difficulty accessing the questions on the application form:

I think it's hard. It's something tricky the questions. It's something because my first language is not English... so I was trying to concentrate and just asking a couple of times what is it about. I think for me it is hard. (Yazan)

Fortunately Yazan had the support of a 'friend of a friend' to help him complete his application form. Without such support Yazan believed he could not have applied for PIP, "I think if there was no one able to help I wouldn't apply. I wouldn't be able to apply."

This raises the question as to what support is available for PIP applicants who do not have the support of another person (whether professional or personal) in order to help them complete their application form. As is seen throughout this report, advice and support from others is a crucial element of participants' experiences of PIP.

## Time

For the majority of the participants the month given to applicants to complete their application form was adequate. However it still seemed to be an onerous task that needed careful managing as both Fiona and Jim explained:

I think it was ok for me because I tend to do things as soon as they arrive with me. I don't like bits of paper to be floating around the house. Soon as it comes, do it, deal with it, get rid of it. I'm sure some other people would struggle with it. Spending a couple of evenings, getting someone else to do it with them. It's 50 pages. It's not a 10 minute job really. (Fiona)

In total, in all fairness it took me about 3 days to do [...]. Sue works part time. When she came home she'd have a go at a few pages but she'd have to read every question out to me. It's a long process to tell you the honest truth. If I hadn't been with Sue and I had to go and find someone to fill it in it might have taken a month. (Jim)

Only one person (Elaine) had asked for an extension (which was granted). However she, like Fiona, was frustrated that DWP does not recognise the complex lives that many people who are applying for PIP will lead, "The very people it's meant to support are the very people who find it difficult to meet deadlines."

## Questions

The participants had many and varied opinions on the questions used in the application for PIP. For participants who had previous experience of DLA, inevitably comparisons were made between the two. Lindsay commented, "the form itself I found it a lot easier than the old DLA forms" and went on to say that she found the questions easy to understand and rather straightforward. This viewpoint was also shared by Mike who said, "No it was easy. It was ok. The form was alright." So, for some participants the wording of the form was felt to be relatively easy to access; although others, as noted above under 'Accessibility', still found the wording complex and confusing.

Also as we shall go on to discuss the questions themselves may be viewed as straightforward and easy to understand in terms of their structure or language, yet painful or difficult to answer in terms of their content (see section Further analysis and general themes: Concerns

about being assessed for PIP and definitions of disability, page 57).

For Matt, although it was a number of years since he had applied for DLA, he appreciated the fact that his hearing impairment was taken into consideration:

Because I had DLA quite a long time ago. I think it was 8 years ago. I don't know how that one worked, but this one had lots of questions and I answered lots of questions, of what I can do and what I can't do. And also it's better because they include deafness now. Which I think they should have done anyway because I do struggle with that. And sometimes I'm down the shop and I don't hear what they say. So I think that it is better. (Matt)

Tony (also a person with a dual sensory impairment) found the PIP application form more pertinent to his needs "...it's a bit better than DLA as it's more relevant." Elaine too felt that the PIP application form was more suited to her son's multiple needs than previous DLA application forms:

Because you've got much more scope to tell it how it is. You've got all that tell us why rather than yes to this question. I wrote reams for every question in actual fact. (Elaine)

On the other hand Fiona found that the questions were not particularly relevant to her visual impairment. The contrast between Elaine and Fiona is interesting: while Elaine appears liberated by the functional nature of the questions, Fiona found it much harder:

I don't think that it's any worse than doing DLA. The questions are not VI specific enough they're too can you get yourself into bed, can you walk, can you feed yourself, too specific to that, so you're not going to get any points are you because they are asking you questions and want specific answers to those questions. It's not allowing you to be free enough in what you are talking about. Some of the questions are a bit too closed. I don't think that it's any worse than DLA. (Fiona)

Lyn too also found some of the questions irrelevant or difficult to understand and that they could be interpreted in a variety of different ways:

Because there was one question on one form, can you place items in the top pocket of your jacket? And I said to

[support worker] the honest answer to that is no, the reason being is I've got no jackets with top pockets, I'm giving an honest answer but she didn't quite get that I was in a way I was joking but that was an honest answer, but we had to put yes, because yes I could. Cos I can. I said I wonder how many people have put that answer. (Lyn)

This was echoed by Elaine who commented:

The questions themselves at first seemed a bit difficult to fill in, they seemed a bit simplistic, but actually when I read it properly, and thought about it the new forms I felt were more appropriate for someone like Owen, than the old DLA forms. (Elaine)

Lyn also commented that she found it useful to refer to her previous applications for DLA and Employment Support Allowance (ESA) in helping her and her support worker complete her application for PIP. However for Jim, who had no previous experience of applying for disability related benefits the shock at the size of the task was clearly evident:

The thing is out of the 36, 37 years that we've been married I've never been out of work. So we've never had to do this sort of thing. The only thing that we've ever had to fill in was the Census form that we filled in a few years ago. We'd never ever experienced anything like this. It was 28, 30 pages long. It was unreal! (Jim)

Elaine, on the one hand had the experience of four previous DLA applications to help guide her application for PIP for her son Owen, yet at the same time displayed a sense of world weariness in that she had to take time out of her busy schedule of looking after a child with multiple disabilities to complete the application form, more so when a deafblind guidance review had recently been completed. Similarly Sophie, because she had been in receipt of DLA since she was six months old, expected DWP to have knowledge of her vision loss, including previous letters from doctors and consultants, so did not provide additional documentation (e.g. visual impairment registration status, GP and consultant letters, speech and language reports, physiotherapy reports) when applying for PIP:

No. No as far as I know. I don't think they require them. I don't think so because they've obviously got my statement from when I was a baby. (Sophie)

It is strongly recommended by DWP to send photocopies of documentation in order to supplement a claim and it may be found as her application is processed Sophie may need to provide more information. Jim commented, “It did say on the form to add any paperwork.” Other participants reported following this strategy, e.g. Fiona added:

I sent a letter from the diabetic consultant... ..I then became active on the [transplant] list so when I received the letter saying I was active on the list and receiving this treatment I sent this letter as well. I kind of feel that these sorts of letters help. It shouldn't be. They should take your word for it but that's what I did anyway. (Fiona)

Dominic was well aware that he would have to resend documentation when it was his time to apply for PIP, but for him, as a person registered both deaf and blind, it was frustrating and stressful, and not to mention time consuming and a waste of money:

Why don't they listen?... In my view they are wasting a lot of money. For a person who is registered deaf and blind, why can't they go through the change overs and say yeah right they are deaf and blind, it saves their time, saves our time. The amount of money they are spending on this I don't see them making any costings at all. It's just narrow minded. (Dominic)

## **Confusion about procedures**

Finally, it is worthwhile drawing attention to Becky's experiences of PIP. Becky, having been made the appointee for her son Alexander, was told by letter that she did not have to fill in a PIP application form and “they would be in touch with me when he was going to be transferred over.” These details were sensitively checked twice more by the researcher, and again Becky repeated, “I did get a letter saying you don't have to do anything. We'll get in touch with you.” According to the guidance available concerning PIP, **everyone**, even if they were previously in receipt of DLA will have to make a claim for PIP, so it is confusing as to why Becky is saying that she does not need to make a new claim for PIP for her son. It may be that DWP made an exception in this case. Alternatively, there may have been an error or misunderstanding on Becky's part, or an error by DWP. If either of these is the case it is likely to lead to further delays in the processing of the application.

At the end of her interview, it was suggested to Becky by the researcher that it might be a good idea to double check the situation either with DWP or a local charity which supports blind and visually impaired people, which Becky conceded would probably be a good idea.

## **Assessment**

Having returned the application form for PIP to DWP, there is an initial review of the case file (if necessary further evidence may be requested at this stage, e.g. clarification of details, or doctor's letters). At this initial review, on the evidence presented, it is decided if there should be either a) a paper-based review or b) a face-to-face consultation. (There is a separate process for those with a terminal illness).

It is expected that in the majority of cases that there will be a face-to-face assessment, however when there is sufficient evidence to advise DWP on the case there is no need for a face-to-face consultation. In this project:

- 4 participants had a face-to-face consultation (Matt, Lyn, Sophie, and Jim)
- 4 participants had a paper-based review (Ricky, Owen, Yazan, and Ryan)
- 1 participant had completed her application form four or five weeks earlier and had not yet received any further communication from DWP (Fiona)
- 1 participant had sent his application form to DWP and had received a text message stating that they would be in touch within 26 weeks (Tony)
- 3 participants were yet to apply for PIP (Dominic, Alistair, and David)

The section considers the following in turn:

- Face-to-face assessment;
- Points-based approach to assessment;
- Timing and communication from DWP.

### **Face-to-face assessment**

Face-to-face assessments are generally carried out at an assessment centre however a claimant or their GP can request a home assessment. They may also be conducted at home for business reasons or for patient choice. On reviewing the claimant's file the Health Professional conducting the assessment might also decide that a home consultation



is the best course of action for an individual (see DWP, 2014).

All four participants who had a face-to-face consultation had their assessment at home. None of the participants mentioned that they requested a home visit and seemed surprised to be having an assessment at home, however it was not specifically asked whether or not they or their GP had requested an assessment at home.

Many participants were apprehensive and anxious about the face-to-face assessment, however all four participants who had a face-to-face assessment suggested that it was 'fine', and that the assessor was agreeable, and asked various questions which the participants answered, e.g. Matt explained:

She was just reading questions off the computer. Her laptop. And I was just answering them. (Matt)

However Lyn was made anxious by the assessor, as the assessor shared that the assessor's brother had also had an aneurysm. This shared information gave Lyn mixed feelings:

Well it could have gone either way. I think she was a nurse. And she let on that her brother had recently had an aneurism but he had recovered very well from it. So I thought that this could go either way; she obviously understands about aneurisms but because her brother had recovered well from it, she could be under the assumption that most people recover well from it. (Lyn)

As such, some participants were concerned that their outcome for PIP might be dependent upon the knowledge of the assessors rather than the procedure as whole. Participants were anxious as to what the person would be like, and the sorts of questions that they would ask. As Fiona, who was waiting for her assessment date, explained:

They said I would probably be asked to go and see some health professional. They could be dentists, they could be doctors, they could be nurses, they could be from a whole range of health care people. It wouldn't just be eye specialists it could be anyone. Which is a bit daunting really, trying to explain to a dentist how your sight affects you! (Fiona)

Participants were concerned that assessors would not know about the specific needs of people with a visual impairment or dual sensory loss. For example, Lindsay's speculation about what might happen in an

assessment reflects an example of this:

And if the assessor said can you walk from here to there he would have said yeah. It wouldn't have occurred to him to say let's turn the lights off and see how I do. Put me outside on my own and see what happens. He'd just say yeah I can. It's not registered with him at all. (Lindsay)

Although Ricky had been granted an award for PIP, his mother Lindsay was still anxious that the award was not 'complete' and that there could be changes to his award because Ricky had not had a face-to-face assessment. This lack of communication from DWP was mystifying for Lindsay:

It's just been totally bizarre from start to finish. There's been no communication from them and the assessment bit really wound me up, and there's been no communication and I still haven't been told if we are to have an assessment or not. Or why they've decided not to. I sort of want to assume that now we have the award we are not going to have the assessment. Cos I know that they had a massive backlog of assessment to get through. Maybe they re-looked at it and decided against it – I don't know. That's the thing – I don't know. (Lindsay)

Clear, accurate information surrounding the assessment process was also missing for others as well. Elaine explained how she got mixed messages about the likelihood of having a face-to-face assessment – first being told it would happen and then finding it would not happen:

I phoned to make sure that [the forms] had arrived and was told that they had. Somebody was able to give me that information and then I didn't hear anything for ages, I can't remember the time scale but it seemed like really a long time, so I phoned and chased it, I think I must have given it about 6 weeks or so. I was told that there was a backlog. I was also told that everybody would be called for interview as well. So I waited and waited and phoned again. And still heard nothing. And had that information repeated. Then a letter dropped through the box saying that Owen had been given PIP at the high rate for care and mobility! What they said was unless someone was terminally ill they were interviewing everybody but they decided that Owen didn't need interviewing. (Elaine)

Even Matt, who did not have any particular issues about the

assessment, mentioned that he was nervous beforehand. The following quote from Matt illustrates the mixed feelings he had – feeling that the assessment was inefficient, insensitive yet necessary all at the same time:

I think when it comes to people like with bad backs they want to see you walk. I didn't have to do any of those things because my condition was to do with my eyes and my ears. A little bit nervous I think. Couldn't wait to get it over and done with if you know what I mean. I've talked about it all of my life, all I want to do is move on. Anyway yeah so that's that. The thing is I want to move on and then there's people questioning that. You've got my doctor's note, I gave you permission to look at my doctor's note. These are the sorts of things that you can't... I understand why they do it. There's probably a lot of people that fake it but mine's not a fake condition, do you know what I mean. But it's ok, it's cool, once it was over and done with I couldn't wait. (Matt)

As mentioned above, none of the participants had had an assessment in a centre – all of them were assessed at home. However, Tony had experienced an assessment for ESA at his local Job Centre. The lack of openness and transparency with regard to the process was identified by him as being particularly worrying, and he was anxious that this would be replicated in the PIP assessment:

You hear these horrendous stories, you go for a medical at the Job Centre, the security guards there will monitor you and report back to the nurse. So I went in, there was two security guards there, I took my partner with me, he says do you want to go on the stairs, I said no I'll go in the lift if possible. He says the lift's over there. I couldn't even see where the bloody lift was. I'm saying where is the lift so he took me and put me in the lift. He took me up the stairs. The receptionist reported back to the nurse as well. (Tony)

Not all of the participants were anxious however. Sophie, in response to the question “Were you worried before the [assessor] came?” answered with a categorical “no”. Mike, commenting on his son Ryan's thoughts about the assessment process “[Ryan] said he would have preferred not to, but he wasn't worried about it.” These comments from Sophie, who is 18 years old, and Ryan who is 16 years old, fit closely with the findings from an earlier report presented to the funders which looked at young people's thoughts and opinions of applying for disability related benefits

(Ellis et al, 2014), in which few of the teenagers were anxious of impending changes.

Jim too was not worried about the assessment process, commenting:

I mean I've got nothing to hide and if they want to come along to assess me that's fine. I wasn't trying to fake anything. I suppose some people who are trying it on and saying ooh I've got a bad back. No, no I've got no worries about it. The only worries there was, was about how long it was taking to get done. But no I wasn't worried or anxious about anything like that, no. I was looking forward to somebody coming! (Jim)

As it was Jim's first experience of claiming a disability related benefit, it appears that he had fewer anxieties about the process than the participants who had previously applied for disability related benefits, especially Tony, Dominic and Alistair whose experiences went back 25-30 years. Indeed Jim found the assessment rather straight forward and was surprised at what he perceived as the lack of rigour in the process:

The lady came to the house. The assessment was very basic in a way. I was quite surprised that she didn't ask a lot of personal questions... ..I think if they do an assessment it should be done more thoroughly than that, you see because like certain problems cropped up, simple things like getting in the shower, she never even asked if you had a bath or a shower, or how you go on getting in that, she just didn't ask, she just didn't seem to relate to anything like that at all. I can't see what the point of all this assessment was when she didn't take notice of your personal welfare anyway. (Jim)

Here, as we shall see with regards to Lyn and Matt in the 'Award' section of this report, it is important for Jim's peace of mind that his disability, and his experiences of it, are recorded accurately.

## **Points**

The level of a person's award for PIP is calculated using a points-based system, where claimants receive a certain number of points in various categories if their disability and/or long-term health problem impacts upon their ability to complete a certain task. Gray (2014, Annex A) presents a more detailed description of the points-based system and how it fits within the PIP assessment process, but here we

present a summary. There are two parts to PIP – a daily living component and a mobility component. Each component has two rates – standard rate and enhanced rate. An individual can receive either or both components at either rate.

The daily living component:

- To get the **standard** rate of the daily living component of PIP, you must score **at least 8 points** for daily living activities.
- To get the **enhanced** rate of the daily living component, you must score **at least 12 points** for daily living activities.

The mobility component:

- To get the **standard** rate of the mobility component of PIP, you must score **at least 8 points** for mobility activities.
- To get the **enhanced** rate of the mobility component, you must score **at least 12 points** for mobility activities.

Within each component there are various activities identified. The daily living component identifies 10 activities:

- Preparing food
- Taking nutrition
- Managing therapy or monitoring a health condition
- Washing and bathing
- Managing toilet needs or incontinence
- Dressing or undressing
- Communicating verbally
- Reading and understanding signs, symbols and words
- Engaging with other people face to face
- Making budgeting decisions

The mobility component identifies two activities:

- Planning and following journeys
- Moving around

Within each activity there are a number of descriptors identified, each with a points score attached. An individual scores points when a person's disability or long-term health condition means that they match a particular descriptor for one of the activities. As an example, below we see the descriptors and points attached for the activity of 'planning and following journeys' within the mobility component:

- Can plan and follow the route of a journey unaided – 0 points
- Needs prompting to be able to undertake any journey to avoid

- overwhelming psychological distress to the claimant – 4 points
- Cannot plan the route of a journey – 8 points
- Cannot follow the route of an unfamiliar journey without another person, assistance dog or orientation aid – 10 points
- Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant – 10 points
- Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid – 12 points

Some participants such as Yazan had a basic awareness of this point-based approach:

Yes someone told me it's a points system but they didn't go further. They said something like it's 12, 8 points for this, 10 points for [that], something like this. Yes I didn't go further in the details but I heard of that. (Yazan)

Meanwhile Sophie had no awareness at all – when asked the question, “Have you heard about the points system?” she responded with a “no”. Likewise for Lindsay it was very confusing, made more difficult by the lack of information from DWP on the subject:

I had absolutely no idea how they worked that out. It didn't seem that straightforward to me. There wasn't a full explanation, there was sort of something oh you need to get a certain amount of points to get this rate, but I didn't quite follow how to get those points if you get what I mean. (Lindsay)

Other participants took it upon themselves to learn about the points system:

Before it all landed through my doormat no I didn't know about [the points system] and that's where the Sense website was unbelievably helpful. Cos it explained it all. (Elaine)

Elaine found the Sense website particularly useful in explaining the points system, and Lindsay also described having support from Sense in the form of a teacher specialising in multi-sensory impairment. However, there was evidence of organisations looking to individuals to tell them about the process, as at the time of application there was little information available:

At the [local voluntary organisation] they hadn't had anyone go through it – they'd had a couple of people ring up about it... ..So I was the first person that they were helping. (Lyn)

For Becky, it was reassuring to look at the points system because she held the belief that because of her son's multiple disabilities there was not that much to worry about with regard to PIP:

Yeah I think I must have done because I don't remember feeling worried about it. So I think he was all right on it.  
(Becky)

Tony and Matt believed that the points system gave them a 'better chance' of getting a higher award on PIP than DLA. While Tony's analysis of the points system below is not quite correct, the general points made by him and then Matt illustrate some of their logic and motivation for applying:

But what I've been told by the RNIB is please do not be afraid to go on PIP because it has been worded better, it's a lot better because it goes on a points system. You need 12 points. To get the top level DLA having a guide dog or a stick accumulates 8 points. And what they are saying is because you've got two hearing aids that's two points per hearing aid. That accumulates the 12 points. The majority of people now going on PIP are benefiting and are going on the equivalent of top DLA and middle care. (Tony)

I used to live with a deafblind guy, he was very clever and he was telling me Matt if you do this... cos I was on the low low before. I was getting not really nothing. I was getting the minimal. Because they never used to include deafness as a part of DLA, and PIP they did. He said the points should tally up. (Matt)

Fiona knew about the points system explaining, "Yeah I think that there are seven different categories. Seven different sections and you get awarded points for each different section and in some of them you might get none and in some you can get a certain amount." However she "didn't really want to think about it" as she did not wish it to influence the way that she completed the application form:

It should be you explain your condition, and it should be looked at that way, rather than, ooh if I put this down I can get a point. (Fiona)

David, would however prefer a medical-based approach to assessment, rather than one which takes account of the effect of disability or long-term health problem on a person's life as he believes that it is less

arbitrary and subjective:

Because if it's clear-cut, [it] makes me feel better. If they are saying 3/60 [visual acuity] or below you can have this, fine well that's me; if you need a long cane in familiar areas, that's me. Because I don't want to have to go somewhere and tell people how bad, make out how bad my life is. Which is what did have to happen for the DLA. On a very very long form. So if people can make a judgement on those straight facts that would make me feel better. (David)

In contrast, Elaine found the points based approach to assessment more appropriate:

With Owen actually it worked really well, because of his level of need in all sorts of different areas I was able to see, as far as I could tell, that he had got, the number of points that he needed for the highest level of award quite easily... ..It felt as though it gave a better chance of it being an objective assessment rather than landing on the desk of someone who hasn't got the experience and was more likely to use subjective judgements about the forms coming in. The fact that the points system made it quantifiable I felt was a better system. (Elaine)

## **Timing and communication from DWP**

The length of time to hear anything from the DWP after returning the completed application form was frustrating and anxiety inducing for participants. Fiona had chosen to pay extra to return her application form via recorded delivery to give her the peace of the mind that it had been received.

Lindsay did not receive any acknowledgement that her application form had been received and that her claim had moved on to the next stage 'waiting for assessment':

I heard absolutely nothing for a good 4 or 5 months. I wasn't sure if they had received it to be honest. There wasn't an acknowledgement. We just didn't hear a thing for many, many weeks. (Lindsay)

Lindsay tried to follow up her claim by telephone, "But all I got told was you'll hear in due course. Nobody actually checked and confirmed for me, all I got was you'll hear in due course." Lyn also tried to chase the



progress of her application by telephone and found that it was difficult to get accurate information from the call handlers.

The slowness and lack of information from DWP after he returned his application form caused a great deal of stress and upset for Jim. After returning his application form in January 2014, Jim had originally been told that he would be contacted for an assessment within 28 days. By April Jim had still not heard anything definitive from either DWP or Capita (the organisation subcontracted to carry out the assessment) as he explains:

I was just getting nowhere and hitting my head against a brick wall. Every time you spoke to someone from Capita they said the same thing that we are experiencing extreme delay due to the vast volume. (Jim)

At this point, and describing himself “at my wit’s end” and “not knowing what was going on; I was absolutely fuming”, Jim contacted his local Member of Parliament (MP) and asked him to intervene. The situation was particularly difficult because as a new claimant for a disability related benefit, Jim did not have the ongoing financial income from DLA as is the case for people moving over from DLA to PIP. Furthermore due to his employment arrangements he did not have any other support to fall back on:

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

After contacting his MP in April, Jim had a quick response via letter from him saying that he had contacted both the Minister for Health and Capita about his case. Capita then contacted his MP, again via letter, saying that “they were going to put [Jim] up higher on the rankings.” However it was not until June that the assessor came, and not until July that Jim received his award.

Once again it was the lack of information/communication from the agencies that made a difficult situation even more stressful than it ought to have been:

From when you fill that form in people should be told what

the stages are. They should have a letter, Mr Joe Bloggs or whatever we have now forwarded your form on to such and such a body and they will be in touch with you – if people were informed that would make a lot more difference. I think that it's lack of communication. People not knowing. That would be another main concern is communication. Without a doubt. (Jim)

## **Award**

Seven of the participants (Ricky, Owen, Jim, Matt, Yazan, Lyn and Ryan) were in receipt of an award for PIP. An examination as to whether people were 'better off' in receipt of PIP as opposed to DLA will be made in the next section of the report – "Discussion and General Themes: Differences in benefit receipt before and after PIP" (page 51). This section explores the processes related to an award for PIP by the participants in the project, including:

- Accessibility of the award letter;
- Timing and communication;
- An example of a Mandatory Reconsideration;
- Inconsistencies in the award letter;
- Fixed and indefinite awards.

## **Accessibility**

An individual's award is made known to them in a letter from DWP. Unfortunately Yazan and Matt were unable to know the contents of their award letter until it had been read to them due to the award letter not being provided in the appropriate format. Yazan commented, "[the award letter] was in print and I am not able to read anymore..." Indeed, Matt did not know the full details of his award until he saw the researcher because his support worker only visits every fortnight.

## **Timing and communication from DWP**

In summing up their experience of PIP, participants commented on the length of time that it took for them to receive their award, from the initial stages of the pre-application phone call, the application and the assessment, to finally receiving the decision letter.

The National Audit Office identifies that the 'expected average time to make a decision on a new claim' is 74 days (National Audit Office, 2014: 13). However, given our analysis focusses upon individual case studies, average target times are not very useful and it is better to consider the

threshold target times set by DWP to process most claims. DWP originally proposed that 97% of assessments would take place within six weeks from the submission of the PIP application form<sup>1</sup>. However at the time of writing (January 2015) it appears that this has been modified and there is now an automated message on the PIP enquiry line advising callers not to expect a decision within six months, and a text message confirming this once the PIP application form ('How your disability affects you' – PIP) has been returned. This is reinforced by Tony's comment that he received a text message saying that he would hear within 26 weeks.

Furthermore at present the frequently asked questions section on the website for Capita<sup>2</sup> suggests that it may take 12 to 16 weeks to arrange an assessment and the website for Atos<sup>3</sup> says that it can take 26 weeks to arrange an appointment. Once again there are inconsistencies and uncertainties related to the process of claiming PIP.

Table 1 presents the length of time for PIP application for the participants in this project.

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<sup>1</sup> See Child Poverty Action Group "PIP: process, problems and pragmatism", point 9 - [http://www.cpag.org.uk/content/pip-process-problems-and-pragmatism#footnote9\\_6huink6](http://www.cpag.org.uk/content/pip-process-problems-and-pragmatism#footnote9_6huink6)

<sup>2</sup> See Capita website, FAQs - <http://www.capita-pip.co.uk/faq.aspx#>

<sup>3</sup> See Atos website, FAQs - [http://www.atoshealthcare.com/pip/faq\\_view/How\\_long\\_will\\_it\\_be\\_until\\_I\\_get\\_a\\_consultation\\_appointment](http://www.atoshealthcare.com/pip/faq_view/How_long_will_it_be_until_I_get_a_consultation_appointment)

**Table 1 Length of time for the PIP application to be processed**

<b>Name (age)</b>	<b>VI / DSI</b>	<b>PIP outcome (yes / no) plus additional details</b>	<b>Length of time (including so far)</b>
Owen (16)	DSI	<b>Yes</b>	3 to 4 months
Jim (57)	VI	<b>Yes</b>	7 months
Lyn (54)	VI	<b>Yes</b>	6 months
Yazan (24)	VI	<b>Yes</b>	2 months
Matt (35)	DSI	<b>Yes</b>	8 months
Ryan (16)	VI	<b>Yes</b>	3 to 4 months
Ricky (17)	DSI	<b>Yes</b>	11 months
Tony (47)	DSI	<b>No</b> Completed application. Text message from DWP indicated he would hear within 26 weeks.	So far:
Fiona (33)	DSI	<b>No</b> Completed application.	So far: 4 to 5 weeks
Sophie (18)	VI	<b>No</b> Completed application and assessment.	So far: 8 months
Alexander (16)	VI	<b>Uncertain</b> Appointee reported she was told Alexander would automatically be transferred to PIP from DLA	Unknown
David (40)	VI	<b>Has not yet applied for PIP</b>	N/A
Alistair (57)	DSI	<b>Has not yet applied for PIP</b>	N/A
Dominic (50s)	DSI	<b>Has not yet applied for PIP</b>	N/A

When the participants in this report were discussing the length of time that it took to receive an award they were calculating it from the time when they sent off their application form.

Of those seven participants who had received their decision letter (all of whom were awarded PIP) none appears to have received the letter within the original DWP timescale (assuming this timescale refers to period from application submission to receipt of decision letter). Four of the participants (Owen, Lyn, Yazan, and Ryan) appear to have received the decision letter within a 26 week target timescale (the times ranged from three to six months). For three participants (Ricky, Matt, and Jim) the process took longer than 26 weeks (eleven, eight, and seven months

respectively). Another participant (Sophie) who is still awaiting the decision letter has already been in the system for eight months.

Sophie who had had completed her application for PIP in April 2014, then had her face-to-face assessment in August, and in mid-December was still waiting to receive her award and was feeling very frustrated with the process, calling it a “nightmare” and “ridiculous”. She found this particularly difficult to understand as her step-father who was applying for PIP for the first time, had heard back within a month, whereas she had previously had DLA and “they [have] got all my notes since I were 6 months old.”

Sophie had contacted DWP and had been told that “a manager was dealing with it”, yet she was unable to speak with this manager. Sophie had had a few missed calls on her mobile phone which may have been related to this, but because the number was withheld she was unable to return the call. Sophie was increasingly anxious that these missed calls may have been from DWP and because she was unable to reply felt “my money is going to be taken away.”

## **Mandatory reconsideration and errors**

Lyn was the only participant to formally disagree with the outcome of her PIP award. She had been awarded the enhanced rate for mobility, but only the standard rate for daily living. As she says, “I was one mark off getting into the highest” and when examining her scores more closely noticed that in the category ‘making budgeting decisions’ she was awarded zero points which meant that she could make ‘complex budgetary decisions’ independently. Lyn did not agree with this as although she does some things independently (e.g. checking her bank statements), there were other areas for which she did require support, as Lyn explains:

I’m always double checking with my husband and it’s something that we discuss between us. I don’t just go off and do things myself, especially if I am going off spending money. I have to double check with my husband to make sure that there is enough money there and what have you. And I said no we are not happy with your decision that I’m 100% OK to do all of that myself. (Lyn)

Lyn made this argument to someone at DWP over the phone, which initiated the pre-appeal stage of the dispute process – a ‘mandatory reconsideration’. A mandatory reconsideration must be requested less

than one month after the award. If a claimant requests a mandatory reconsideration, DWP will look again at the individual's claim (including application, accompanying documentation, and face-to-face assessment). In agreement with Lyn, the DWP decided to give her two points in the 'making budgetary decisions' category. This meant that she was then entitled to the enhanced rate for daily living. For Lyn this was very important as the award letter now accurately reported her disability and the way that it affected her life, as she said, "for my peace of mind it is there that I am not able to do those things." She was also positively surprised by how smooth this process was, "I couldn't believe how straight forward this was – that they would actually accept my dispute over the phone." Nevertheless Lyn was still slightly irritated that she had had to go through the process of a mandatory reconsideration as she felt that it was obvious that if she had got points in other areas, "why have they not realised that [I am] not able to make those sorts of decisions – if I need help with so many other things!"

Although Matt did not dispute his award, he was keen to point out that there were some errors within it, "Some of it is a bit wrong... one of them there says communication I don't struggle with it and I got zero which is not true. I do struggle with it." He then went on to discuss some of the difficulties that he faces with face-to-face communication particularly in noisy environments, and places with poor lighting (unsurprising given Matt has dual sensory impairment). Matt did not dispute his award because, "if you've got more than 12 [points] you can't get any higher, so I hit it any way. So I thought there's no real point saying about it, if I got it anyway." However, he suggested that if he had not already reached the qualifying level he would have appealed the decision.

### **Fixed or indefinite award?**

Participants were asked whether their award was for a fixed or indefinite time period. However many of the participants did not know, with only Lyn, Lindsay, Mike, and Elaine being able to provide this information. Lindsay commented, "We've got it to 2018, but I could be wrong." Elaine said that although Owen had an indefinite award of PIP, "we were told that we may well hear from them again in another 2 years because they are going to review everybody." However Elaine was hopeful that it would "be along the lines of has anything changed, rather than going through the whole process again, so I hope that's how it's going to be done."

Lyn knew that she would have a review in a few years' time, however

she was less confident that it would be a straightforward process:  
It's just going to be interesting when we have to reapply again how much notice they take of information that they've already got and the fact that it hasn't changed and never will change. That's the thing that makes my consultant and doctor quite cross – don't they realise some things are never going to get any better! (Lyn)

This links back to Dominic's earlier comments that if someone is registered deaf and/or blind that their condition is unlikely to change and they should not have the ongoing rigmarole of applying for disability related benefits.

### **Satisfaction and relief with the PIP award**

At time of interview, those participants who had been awarded PIP appeared generally satisfied with the outcome, and relieved the process was over. Lindsay summed up these general feelings:

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

## Further analysis and general themes

This section presents general themes which cut across the process as a whole and also reflect the research objectives which have not been covered elsewhere. The following themes are discussed in turn:

- Importance of PIP;
- Differences in benefit receipt before and after PIP;
- Support when applying for PIP;
- Concerns about being assessed for PIP and definitions of disability; and
- Beyond the application and the award.

### Importance of PIP

All of the participants spoke about the importance of either DLA or PIP and the financial contribution that it provides to daily life, as well as the difficulties that would arise if it was not available. As would be expected the participants used the income available to them in a range of different ways as Elaine and Fiona explain:

On an everyday basis we go through wet wipes like it's going out of business. Musical toys he's very very hard on. And very often spills things, or dribbles on to them, so they don't last very long. And we go through batteries like nothing on earth as well. He's limited in the sort of exercise that he can access but horse riding is something, and we have to travel 45 minutes to the nearest appropriate stables for horse riding and horse riding itself is not a cheap activity. Special needs toys are expensive as well. So it doesn't go far by any stretch of the imagination. It also contributes to things like umpteen hospital appointments, clinic appointments. (Elaine)

It's used for equipment. Sight Village I go to every year. I will buy different pieces of equipment. It's for things like my iPhone. I've got an iPad. You know the talking SatNav. It's buying the Apps for that. It's buying the colour detectors. The Apps you can download. It's the money detector. All sorts of things... I have a cleaner that comes every week. I pay her £25 a week. I have a gardener. I live on my own. He doesn't come so often now. And the window cleaner. I would clean myself but I would miss things all the time. I just wouldn't see them. And I'm quite particular about the way that I look. And the way that my house is. It's a lot for



taxis as well now that it's getting dark. And I feel a bit vulnerable walking around with a cane especially late at night. (Fiona)

Overall however the most frequently mentioned uses of the income generated by DLA or PIP were transport, equipment (either high end communication equipment such as iPads and electronic screen reading software, or everyday equipment such as scales and vegetable choppers), and generic 'daily life'.

Participants were clear that the income was crucial for this use. For example, Dominic when speaking about his use of taxis and communicator guides commented, "This is purely essential – it's not luxuries". Becky also commented, "It's essential for your day-to-day life." In a third example, in response to the question, "How important is the money you receive through DLA?" Alistair replied, "Extremely important. It maintains your quality of lifestyle. I have to spend a lot of extra money on taxis, minicabs, because the council have had cut backs on door-to-door services."

Although all of the participants appreciated the income generated by either DLA or PIP, a small number of the participants argued that the income received does little to off-set the additional expenses related to disability/long-term health problems. For example Dominic commented:

So with any benefit you are actually paying out for the service – and that money just goes. That's just to have a normal, independent life. And that's another important point too – if you have a disability you seem to have to pay more to become equal. (Dominic)

Elaine found the income from PIP insufficient to care for son, particularly when compared to how much it would cost the Government if she did not take on board this caring role. This reduced income, coupled with her feeling that she constantly has to justify her situation, makes the whole process an unpleasant experience:

You're on the go 24 hours a day, there is no let up at all, you're supporting your son, if the Government were supporting him it would cost an awful lot more if he was in care somewhere, and you're being put through all of this in what in the scale of things is quite a small amount of money to support him, and you feel as if you are having to justify yourself and prove you're not being some sort of fraud or cheat and particular in the recent political climate

where the Government has been going on about workers not shirkers and so on and so forth. (Elaine)

Fiona and David were the only participants currently in employment, and they both raised the question of whether they should be in receipt of disability related benefits. Similarly Yazan raised the question of if he were in full time employment whether he would be eligible for disability related benefits. Despite acknowledging that such income was not as crucial for them as perhaps for other non-working claimants, Fiona and David provided a lengthy account to why this income was justified:

I mean I would be alright without my money, but I know a lot of people rely on it to pay bills, extra electricity and things.... And up to about an hour ago I had my lights on all downstairs because it was quite dark – well it was for me. And things like extra electricity for heating because I'm anaemic I'm always tired and cold. The heating goes on and my lights are on a lot. Even in the summer I'll have my lights on in the kitchen because my conservatory makes it quite dark. I've changed all my kitchen cupboards. The walls are light, the floor is white, but it still seems dark to me. It's all these little things, these extra things that you don't think about. (Fiona)

I do think sometimes ooh goodness I am sitting here in a university job and I'm claiming a benefit. And a lot of people might think you don't need to. And there is a part of me that feels guilty for that. It does make me feel guilty for that... The other side of things is that may be my visual impairment has taken opportunities away from me, opportunities that I don't want to rant on about, I don't want to be one of those people that says I can't do this I can't do that, I can't drive and da da da... I can't just go anywhere unfamiliar at a drop of the hat, I have to do an awful lot of things if I have to go to an unfamiliar place, planning and organising potential support. (David)

Importantly, the reason PIP is non-means tested is because the additional costs of disability exist irrespective of employment and/or other sources of income. To this extent David should not have any feelings of guilt that he has a job with financial security and receives DLA – but he still does feel this guilt.

Jim and Tony had previously been in full-time employment before

retiring on medical grounds. They explained how the associated drop in income from a full-time wage was felt particularly acutely:

We [Jim and his wife] use a lot of it for taxis for getting around. Different things like that. It goes to the household bills and everything now. We've got rid of a lot of stuff like Satellite TV, which enabled us to live. As you know it's five hundred and something pounds every month I get, I used to pick up £400 a week wages. So obviously it's affected our lives quite a bit. So we can't go out or anything like that. We have taxis when we go out shopping. Obviously before, when I had the van and I was driving, there was no problem. It's £12 just there and back. Food. Taxis. And generally just running the house. (Jim)

It's a case of living. I've been a manager in the past, and I've had my own business and that, so you're going from having a good income to virtually nothing. There's no other way I can possibly get my income put up. (Tony)

Dominic, who had also been in fulltime employment for 12 years, was grateful that his private pension was available to him in order to 'top up' the income generated by disability related benefits:

Well it's vital. For my living allowance. If I didn't have my small pension I think that I would be stuffed and that goes the same for everybody. The fact that I was working in local government for 12 years was a blessing. I had to take early retirement at the age of 30 in [1989]. Because of the disability. So basically I just have that to live on. It only just keeps our heads above water. (Dominic)

As was seen in the case of Jim, getting an award in a timely manner is crucial, particularly for those people who are applying for a disability related benefit for the first time because they are not receiving income while they await the application outcome. This will have serious implications for the individual and also the household generally.

Jim and Tony also spoke of contributing into the welfare system whilst in employment, feeling that it was only right that disability related benefits were available to them. There was also a sense of frustration when comparing their situation to others (including those with disabilities). For example:

What frustrates me is those people, and you see them getting in their brand new car, which means that they are

on top level DLA. Cos you can't get a mobility car unless you are on the top level DLA. ...there's many a week that I've worked 80 hours or more, instead of 40 and I've definitely paid my contribution and national insurance.  
(Tony)

The relative legitimacy of their claim to disability related benefits is a theme that runs through all the participants' stories, and will be discussed further below.

For teenagers Sophie and Ryan, the income generated by PIP is described as important as it gave them financial independence from their parents:

It does help because like at the age of 18 you can't survive off your parents. So to me it's money to be able to live.  
(Sophie)

He can buy things, which not having a job, he wouldn't be able to, unless we went and bought them for him. But to be honest my funds are extremely limited and so are my wife's... ..But yeah if it's going to help him get by, and of course he needs to have a certain amount of independence and there's certain things that he needs to have. (Mike)

As with some of the teenagers in the earlier March 2014 project report, Mike identifies that many non-disabled young people are likely to have (part-time) jobs which provide independence, whereas such employment may be difficult to obtain for those with a sensory impairment. Evidence from employment patterns amongst young people supports Mike's argument.

## **Differences in benefit receipt before and after PIP**

One of the aims of this research project was to explore any differences in benefit receipt before and after PIP for people who have sensory impairments. Overall, the experiences of the participants in terms of award outcome were positive – all seven participants who had received their decision letter at time of writing had been awarded PIP. This positive message should not be lost in the more mixed findings in relation to application process (which was often fraught, time consuming and stressful).

Also of specific interest to the funders was how PIP awards compared to previous DLA awards. Five participants who had previously been in receipt of DLA had received their decision letter for PIP at time of writing. Table 2 summarises the associated payments for each of the five participants, and a more detailed description is presented below. In summary, two participants appear to be better off, two receive the same payment, and one participant appears worse off.

**Table 2 Comparison of DLA and PIP payments**

Name (age)	Previous DLA	DLA payment (£/wk)	PIP outcome	PIP payment (£/wk)	Difference (£/wk)
Owen (16)	Higher rate for mobility and care	£138.05	Enhanced for mobility and daily living	£138.05	0
Lyn (54)	Higher rate for mobility and care	£138.05	Enhanced for mobility and daily living	£138.05	0
Matt (35)	Lowest rate for mobility and care	£43.10	Enhanced for mobility and daily living	£138.05	+£94.95
Ryan (16)	Lowest rate for mobility and care	£43.10	Enhanced for mobility and daily living	£138.05	+£94.95
Ricky (17)	High rate mobility and middle rate care	£111.20	Enhanced for daily living and standard for mobility	£102.85	-(£8.35)

Owen and Lyn were in receipt of PIP at the same rate as their previous award for DLA – the enhanced rate for both components, providing £138.05 per week. Matt and Ryan received a greater income as a result of PIP than in comparison with DLA. Previously Matt and Ryan were both in receipt of the lowest rate for care at £21.55 per week, and the lower rate for mobility at £21.55 per week, which provided them with a weekly income of £43.10. Under PIP they are in receipt of the enhanced rate for daily living which is £81.30 per week, and the enhanced rate of mobility at £56.75 per week. This provides Matt and Ryan with a weekly income of £138.05 which means that they are £94.95 a week better off on PIP than DLA. This considerable rise in income for them both is a very positive outcome and must be acknowledged against the fears and frustrations of the application processes, as mentioned by all the participants.

Nevertheless it may be that Matt and Ryan were in receipt of the ‘wrong’ rate of DLA, so were struggling on a reduced income on DLA when in fact they ought to have been on a higher rate anyway (and to this extent the move to PIP simply coincided with a re-calculation of the benefits they were entitled to). Furthermore Matt had been in receipt of DLA for eight years, so perhaps he should have (or could have) contacted DWP with details of changes to the way in which Usher syndrome was affecting him before this time. Ryan and his father Mike had no support when completing his application for DLA, and in Mike’s opinion the support they received from the RNIB Welfare Rights Officer was crucial in reaching the enhanced levels for his PIP application.

Ricky’s situation is slightly unclear. Ricky’s mother thought, although she was unsure, that Ricky was in receipt of the higher level for mobility under DLA (£56.75 per week) and the middle rate of care (£54.45 per week), giving a total of £111.20 per week. In comparison Ricky receives the enhanced rate for daily living (£81.30 per week), and the standard rate for mobility (£21.55 per week), which provides Ricky with £102.85 a week. If the rate that Lindsay recalled for Ricky’s DLA is correct, that means that Ricky is £8.35 worse off on PIP than DLA. However in the interview with Lindsay she said, “He’s got a much higher award with PIP than he had with DLA.” It is also interesting that Ricky went from being in receipt of the higher rate of mobility for DLA, to the standard rate for PIP. If this is the case, perhaps it would be worth further investigation by Lindsay – by the nature Ricky’s condition (Usher syndrome), it is highly unlikely that Ricky has fewer difficulties with his mobility than he did in the past.

Although the situation looks positive for participants, and claimants of PIP with a visual or dual sensory impairment, in terms of award outcome, is important to be cautious when using the insensitive phrase ‘better off on PIP’. Claimants are unlikely to feel better off than those who are not in receipt of PIP (and without a disability). David makes this point clearly:

Doesn’t make you feel good. I’d rather not have to go through any of it. And I’d rather not have sight impairment. It’s that thing that you have to go through these things, when you have got these impairments. (David)

## **Support when applying for PIP**

All of the participants suggested that they would want or need some sort of support in order for them to complete their application for PIP. Indeed

for Yazan it was the support of another person, a ‘friend of a friend’ who suggested to him that he ought to apply for PIP. Without this person, “I don’t think I even [would have] the idea to apply” commented Yazan.

As described in the previous sections, friends, partners, and relatives supported many of the participants in accessing the PIP application form. Elaine and Lindsay also obtained support and advice from the Sense website. There was a further, more abstract form of support from the medical practitioners, in particular GPs who provided supporting documentation as Lyn explained:

I’m really lucky that [my GP] is on my side. I’m not the only patient that he’s been supporting. He said it’s just unbelievable what they are putting people through! (Lyn)

There was also specialist support in making claims for disability related benefit from people trained in advising people with a visual impairment or a dual sensory impairment. For example, Mike and Lyn were pleased to have support from an advisor specialising in visual impairment. Unfortunately not all the support workers specialised in sensory impairment. Matt described how he had requested a Social Worker specialising in deafblindness to support him. However this was not possible. Consequently, the support worker that was assisting him was not specialised in deafblindness, which could have potential repercussions for the application:

I did have a proper one back in [different city], a proper deafblind social worker. She was trained. She used to help me do all my forms. The trouble is when I moved up here and I asked for a social worker, they said that you can’t have one. They said no you can’t have one in [current city]. [Current city] is not a big enough place. So I had to get a support worker, and they’re not... you know what I mean. They’ve not had the training in it. (Matt)

A number of participants got support from a range of different sources. The support from different individuals and organisations provides both practical advice and emotional support – often the two were intertwined. For example, Lindsay described receiving:

- moral support from her husband in completing the application form;
- specialist advice from the Sense Usher team and a specialist MSI teacher in terms of understanding the questions and the points system;

- support from medical professionals in terms of consultant's reports; and
- practical and emotional support from the mother of another child with Usher syndrome.

Keeping with the example of Lindsay above, the support from the mother of another child with Usher syndrome was particularly important as it helped Lindsay to understand on a practical level how to complete the PIP application form and the sort of information that is required. Additionally, it also helped her emotionally with the difficulties of saying how her son's dual sensory loss affects him:

[The mother of another young person with Usher] has been amazing. She's taught me to look at the forms in a different way. Like can they walk unaided I would have put yes, but then it was [she] who taught me, can he? Think about it. Stop and think...I found it really upsetting because you work everyday to improve their confidence and then you have to think back to everything that they can't do. Even questions like can they walk unaided. Well he can walk around the house absolutely fine, he can walk down to the shop absolutely fine, as long as it is daylight, so I had to answer no he can't, because at night he needs support. And you don't want to think about that, because he can in the day and he is fine. I find it upsetting to have to focus on the negative. It's what you have to do to get them to see and understand what you're living with daily. (Lindsay)

As will be discussed in the sub-section 'Concerns about being assessed for PIP and definitions of disability' (page 57), explaining the worst possible scenario was particularly difficult for participants. However, it was recognised as crucial to getting the appropriate level of award. Related, Mike credited the support provided by a Welfare Rights Advisor from RNIB for his son Ryan being awarded the higher rates for both mobility and care:

[The Welfare Rights Advisor] came to our house, sat down with us, went through the questions with us. It was about how it affects Ryan the worst. The thing that they tell you to do is to give the worst possible scenario. Which we hadn't done in the past, and the first time that we claimed disability for Ryan, we never got it. We should have done really. (Mike)

It is the emotional support to encourage a person to do this which is



invaluable, as well as the knowledge and understanding that this is the appropriate way to complete an application for PIP. Similarly Elaine used the Sense website, and advised others to do the same, to learn how to complete the PIP application form 'correctly':

I would refer [applicants] to the Sense website because as I said those guidelines were really helpful. And take the time to put in as much relevant information as you can. Don't just answer yes to the questions, you have to take the time to go into the detail of explaining exactly whatever affects them. For example the feeding, Owen is a choking risk so what we have to do, and how we support Owen in eating safely for example. Don't just say he has a choking risk go into the detail of how that affects. (Elaine)

Fiona and Lyn both drew attention to the fact it is important to have someone supporting you that you feel comfortable with. Fiona was supported by her grandmother to complete her application form for PIP, stating, "She's brilliant but if it had been anyone else I am sure that I would have struggled to get any benefits at all." As with Elaine in the example above, Fiona's grandmother encouraged and supported her to detail all the examples of the way in which her visual impairment and health problems affect her daily life:

And for someone to help you with the things that you have not thought about. For example who checks your 'sell by dates'? [...] These are the little things that people don't think about. (Fiona)

Fiona was clear that her grandmother was the best person to help her complete her application form as she felt comfortable and at ease in discussing all her difficulties with her. Yet at the same time Fiona wanted to avoid her boyfriend from having to hear all the difficulties that she faces:

Or somebody who knows you quite well, I wouldn't say a partner, to help you fill the form in. If I got my boyfriend to fill the form in, although he knows me really, really well and he's the nicest person in the world I don't really want for him to know, or for me to talk in front of him about all the things that I find really difficult. The other week I went to a toilet, a public toilet, and when I bent down to go to the toilet there was a massive massive knob to lock the door, a big chunky knob it was, and I banged my head when I went down and the next night and we were having dinner and was sat next to me and said "what's that on your head?"

And he'd noticed it. And I don't want him to know how much I bang myself or fall over because I don't want him to see me like that. So I'd say think carefully about the people they choose to fill these forms in. (Fiona)

Lyn had a mixed experience with the support that she received from the local organisation which supports people who have visual impairments, highlighting both the discrepancies in the skills and training of support workers, as well as the personalities involved, which can have a significant effect on the experiences of claiming PIP:

...sometimes sitting there I felt awkward when I was giving her an answer I could sort of see that she was hesitating in she wouldn't quite of put it that way but I think that I got it through to her in the end. (Lyn)

## **Concerns about being assessed for PIP and definitions of disability**

Applying and being assessed for disability-related benefits (in this case PIP) encouraged participants to think about what it means to have a disability / being disabled. Some participants spoke of their situation, and implicit in this was a belief in the unique status of visual and dual sensory impairments, as a 'real disability' compared with other disabilities and claimants:

I do have people in my own family and I do call them scroungers. The reason being they are just bone idle. Never done a day's work in their lives. Got two kids. Says she's got a problem with her legs but I know for a fact, and I keep saying this to people, there's nowt wrong with her. I don't scrounge and I think that people round here, I've lived here for 37 years, know what hours I used to work. I don't think any of them would ever call me a scrounger! (Jim)

I think that genuinely people see that I have a need for it and don't spend it on stupid things. It makes some people mad if you mention benefits. They go oooh he's pretending to have a back problem or depression or this or this or this. So I think in terms of the media at the moment it does anger a lot of people. (Fiona)

This was also linked to a worry felt by a number of the participants that assessors would not understand the specific nature of visual impairment or dual sensory impairment, which was compounded by the way that the

questions were formulated:

And what annoys me with all this news stuff is this sort of thing is exactly happening again. They seem to think that if you can walk that's fine – it's not a question of that. If you've got a deafblindness condition you are not able to hear and see things in the same way that a blind person does. And that double sensory impairment is a big issue – and that's what they don't seem to realise. (Dominic)

And they ask if you can walk 10 metres or 20 metres. I need a white stick! And I don't think that's a fair question. If you are blind and with a white stick we can't walk and that is not applicable! We can't walk and that's not fair. It just isn't fair. (Alistair)

Tony however identified that people with all kinds of disabilities may have similar experiences:

I was having a great discussion the other day with a disabled man. And he was feeling the same as I was. You feel anxiety, you feel depressed. Even things like going down the street to the pub you think everyone's watching you. Everything I said he said, because he's got one leg shorter than the other. And you sort of analyse it and break it down and there's a girl who's obese and she must be feeling the same way, there's somebody with a prosthetic limb they must be feeling the way. So it's not just you. Then you analyse it again and well what is perfection? There is nobody perfect. You should just fit and get on with your life. (Tony)

It is interesting to note that he speaks of talking to a 'disabled man', Tony does not say 'another disabled man' – maybe he does not identify himself as a person with a disability. Perhaps this is then linked to the difficulties for participants in explaining on their application form the struggles that they face in undertaking various activities because practices become everyday and normalised to them. Matt and Fiona illustrate this clearly in relation to everyday washing strategies they have that are so normalised they can be forgotten and trivialised:

...if I wear a top one day or a pair of trousers I'll just wash it. I won't think I can probably wear those trousers in a few days time again because I won't risk that I've not got mud up the back of them. (Fiona)

Just talking about my daily life really. Just about my clothes. The thing is... you know how we get on with life, you know if you see one stain on your shirt, there's probably about 100 more. So I look on that. There's things that I do struggle with. I just get on with it but actually you've got to say these things. Because we just get on with it, say I'm fine, but we're not. (Matt)

Furthermore, participants did not live their lives with the things that they (or their children) **cannot do** at the forefront of their mind. Consequently, when participants were asked to relay 'their worst possible scenario', it was often extremely upsetting to think of themselves in such a negative way. Participants described this negative and deficit experience eloquently:

I suppose because we have done the DLA forms four times we have almost got used to that aspect of it. I hate it because you live your daily life thinking positively, doing your best, looking at the good things, what he can do, and suddenly you're asked to sit down and talk about the things that he can't do. And that's very difficult and that's emotionally very draining and I think that's one of the things that makes the form particularly difficult. But that was the same as the DLA as well. (Elaine)

Even when I was doing it for DLA, and with PIP, I found it really upsetting because you work everyday to improve their confidence and then you have to think back to everything that they can't do. Even questions like can they walk unaided. Well he can walk around the house absolutely fine, he can walk down to the shop absolutely fine, as long as it is daylight, so I had to answer no he can't, because at night he needs support. And you don't want to think about that, because he can in the day and he is fine. I find it upsetting to have to focus on the negative. It's what you have to do to get them to see and understand what you're living with daily. (Lindsay)

...you need to think about your worst day when you're filling in these forms, but I am very aware that I have good days and those are the days I am very self conscious about because if people see you having a good day they're going to think ooh she's alright and they don't realise that you can never judge when you are going to have a bad day. (Lyn)

For David, thinking about himself in this way also brought up the question of independence and returned to the definition of what it means to have a disability:

I can use buses and trains. My eyesight, because of the nature of field loss, I'm a different person to understand during the hours of darkness than daylight. Although my eyesight is deteriorating and is not so good in daylight hours. So people might look at me and go your mobility is quite good, compared to... do I have to be going in stumbling on the steps? Do you know what I mean? You're almost the blind stereotype. If I'm too confident do I not fit the bill? And I'm not in need? This is the worry. I do think that I would be nervous and almost trying to fit the stereotype at the assessment I must admit. (David)

Similarly, Tony had thought twice about getting a guide dog as he was worried that he would be seen as too independent and denied disability related benefits. However ultimately for him a guide dog was the only option in supporting him with his mobility:

There were a lot of rumours in the beginning that they were going to penalise you for having the likes of the dog or the cane. And that was going to be a major problem because people were going to turn around and say I don't want a dog because I'm gonna lose money which is ludicrous. But I took that decision anyway – the dog is going to be my best aid. (Tony)

Both Tony's and David's experiences and analysis have similarities to arguments made in relation to employment and some aspects of the so called 'benefits trap' (a situation where the loss of money from withdrawn benefits when securing employment is greater than the money gained from the job itself). Understandably, both participants feel frustrated, anxious and dispirited that the independence that they work so hard to achieve may go against them in relation to gaining the PIP award that they are entitled to and need. In fact, the PIP assessment appears to count canes and/or guide dog use as examples of descriptors with associated points (see the description of Points, page 35). This may be another example where clear communication of information about the PIP process would reassure claimants and reduce anxiety about the process.

## Beyond the application and the award

People's experiences of PIP stretched far beyond the processes of applying for an award and linked to wider discussions in relation to benefits and media representations of people who are in receipt of benefits. For example Sophie spoke of the television programme "Benefits Street", and was quick to point out that the income generated by PIP was invaluable to her to lead an independent life. As mentioned above, Elaine placed her discussion within the context of the Government's 'crack down on shirkers not workers'. There was an understanding by some of the participants that savings need to be made, however there was a feeling that the Government is targeting the most vulnerable in society:

It's all very well saying oh yeah we need to cut the Welfare bill, they need to look a lot more detail into that. And I'm sure there must be other disability groups that are suffering as well. If you've got some other physical disability that gets better that's something different, but we're talking about things that don't get better. And that's what is really crucial – trying to get that message across. You can't fake deafblindness. (Dominic)

Because I can't work, because you can't get childcare for a 16 year old. I feel like families with disabled children, I feel like we are being targeted for everything at the moment. I'm actually getting emails from my Local Authority they are making cuts to the transport to schools – we're struggling with transport to college at the moment. I just feel as though they are cutting in the wrong place. They're looking at us who are claiming benefits when there are so many other places that they could be looking. (Lindsay)

Tony and David also identified that there is not much joined up thinking between those in charge of supporting people with disabilities, arguing that things are given with one hand but taken away with the other. As Tony commented:

There's a bit of a contradiction in terms here as they are actually writing me off in one Government department but are saying you're alright for your DLA. They're giving me a bus pass because I am registered blind but they're saying you're not getting top level DLA. That's the thing that grates me so much. On one side of the fence you're telling me that I can't work, you're telling me that I've got a free bus

pass, you're telling me that I've got a free cinema ticket, you're telling me I've got a free train ticket, you're telling me that I don't actively have to go back for a medical because this thing is incurable but you won't give me top level DLA. (Tony)

Elaine also placed PIP within the wider scope of Welfare Reform, so although she was satisfied with the current outcome for her son Owen, there was an understanding that things could change at any moment:

There has also been so much change in disability services, this is a fairly major one, but change of any sort is unnerving, unsettling, stressful, so it's been yet more paperwork and yet more change. But yep it's worked out for us so let's hope that they stick with this system for a little while. (Elaine)

## **Discussion and conclusions**

In this final section the findings of this phase of work are summarised and discussed under the following three headings (which make reference to research objectives):

- Key findings in relation to PIP and PIP outcomes;
- Key findings in relation to PIP application process;
- Limitations and recommendations for methods adopted in the next phase of the research.

The scale of this research is such that the experiences of the fourteen participants cannot be generalised and must be considered cautiously. Even so, their experiences of PIP assessments are insightful and provide specific 'sensory impairment cases' which can be compared and contrasted with broader research (both current and future). For this reason, in the final section we also offer tentative implications of the findings.

### **Key findings in relation to PIP outcomes**

The objective of PIP was to target those with greatest need, with an assumption that it would result in a 20 percent reduction in caseload and expenditure: however, there is a higher projected success rate for new claims (Gray, 2014). This research presents evidence which is broadly positive in terms of the outcomes of the PIP application process for these participants:

- All seven participants who had received an award letter had a successful outcome (in that they were awarded PIP at some level).
- Four out of five participants who were previously in receipt of DLA appeared to have matched (two) or improved (two) the monetary value of the benefit they received following the award of PIP. One participant appeared to have a lower award (although this seemed ambiguous).
- At time of interview, all participants appeared satisfied with the outcome. The exceptions to this were two participants who were not satisfied with the points score from the assessment. One participant appealed and the points were adjusted which led to a successful change in the award. A second participant had reached the threshold points to gain the award to which he felt entitled, but still considered the points score was too low. Given an appeal could not improve the award he received, he had not appealed (although he was worried the threshold may change in the future).



Unsurprisingly, PIP (or an equivalent) was seen as important. Participants identified the many aspects of their daily life to which the award contributed. Overall, the most frequently mentioned uses of the income generated by DLA or PIP were transport, equipment (either high end communication equipment such as iPads and electronic screen reading software, or everyday equipment such as scales and vegetable choppers), and generic 'daily life'. Some of the additional costs of sensory impairment highlighted were often subtle and normalised, and perhaps not immediately obvious (including to the participants themselves). For example additional washing costs required because cleanliness of clothes could not be easily checked, and additional cost of lighting to support visual tasks. Some costs were linked to the additional disabilities and/or health problems (which were common amongst the participants), e.g. additional heating costs linked to anaemia, and the cost of cleaning and wipes for young people with severe learning disabilities.

### **Implications:**

Although we must be extremely cautious at this early stage of PIP rollout, the following implications have been identified:

- The findings of this research imply that people with visual and dual sensory impairment (and/or their appointees) – whether a new applicant or in receipt of DLA – should apply for PIP confident in the mind that others have been successful in securing a satisfactory award. Those already in receipt of DLA might consider choosing to apply for PIP before the required deadline as it may lead to an increased award (but given there is a risk involved, this would need to be done after careful analysis). The case studies in this report may help applicants and their advisors decide upon whether to apply or not.
- Specialist voluntary sector organisations (such as RNIB, Sense, Action for Blind People) might offer positive, albeit cautious, advice that application for PIP can lead to the successful entitlement award. Similarly, appealing against a perceived low PIP award can lead to a successful adjustment. This might challenge the belief in some that application for PIP should be avoided. Nevertheless, it should also be noted that applying for PIP can be a stressful and time-consuming process.
- Those advising people with visual and dual sensory impairment (whether organisations or professionals advising individuals) could usefully offer clear guidance on the additional costs of disability and how it can be effectively represented in the PIP assessment process. This is likely to require careful analysis far beyond that presented in

this report, although it could draw upon existing literature as well as ongoing research (e.g. work by Loughborough University in relation to disability and minimum living standards, with particular reference to sensory impairments).

## **Key findings in relation to PIP application process**

The experience of the PIP application process was generally a negative one for the participants involved in this study. Participants were often anxious in anticipation of the application process. The process itself was often slow and delayed, and inaccessible to many people with sensory impairments. Although the sample was small (just eleven of the fourteen participants had direct experience of the applying for PIP themselves, and three had not yet applied), all the participants raised concerns and frustrations with the process. Key summary points can be usefully summarised under the sub-headings:

- Appointees;
- Application process;
- Assessment;
- Length of time of the process;
- Concerns about being assessed for PIP and definitions of disability.

### **Appointees**

Three of the interviewees were appointees (a person – in these cases parents – who will act in the disabled individual's best interest in spending/saving the income generated from PIP). Becoming an appointee involves an assessment by DWP. This was generally viewed as straightforward by participants, although inconsistent across the three cases (two were interviewed with their disabled child present, one without). Some anxiety was associated with the process. In part this was linked to significant changes in their children's lives as they entered adulthood. Nevertheless, anxiety was also associated with lack of information and, in one case, incorrect information being given (about potential loss of another benefit). Participants were happy with the agreed outcome of becoming an appointee (and a fourth participant was similarly happy with his son making his own application). The relative simplicity of the process was viewed pragmatically and favourably, but it raised questions amongst the participants about the rigour of the process and the potential arbitrary nature of the decisions about appointees for some young people.

### **Implications:**

- It would be helpful for DWP to provide greater clarity about the appointee process. Similarly, supporting professionals and sector organisations could target information and guidance of this process to people with visual and dual sensory impairment (and/or their family and carers).

## **Application process**

The HoC Committee of Public Accounts (2014: pg 4) argued that claiming PIP can be “difficult for claimants, increasing the risk of delays and incorrect decisions”. Some health and social care professionals as well as Department of Work and Pensions staff have been reported as saying that elements of the process should be reviewed to tailor support in the process better to some groups of disabled people (Gray, 2014). In support of this, for many in this study the mechanics of the process of applying for PIP was **inaccessible** – the requirement to access printed text meant that many participants with visual impairments could not, or could not easily, access important written information, e.g. the application forms and the award letter. Similarly, the use of a telephone to carry out the initial PIP1 assessment was inaccessible to many people with deafness/hearing impairment. Sainsbury and Corden (2014: pg 86), from their early process evaluation for the DWP, have said that “DWP may want to consider potential gains in making paper PIP1s more generally available, and promoting claimant choice in communication methods”: this would benefit people with a range of impairments or support needs. The challenges of accessibility could put applicants under **time pressures** and necessitated most participants requiring support to navigate the application process.

The **support** participants required went far beyond the accessing written material. Support was also often needed for understanding the content of the questions and the emotional support for a challenging and difficult process. Family members were often key (spouses, parents and grandparents), as were GPs. Health and social care professionals (including GPs) have expressed a tension between their commitment to providing evidence for PIP claimants and their capacity to do so (Gray 2014). Specialist advisors and professionals (e.g. based at RNIB or Sense) were identified as being extremely important in helping to interpret questions and formulate responses. Web sites and users groups (e.g. other parents in the cases of appointees).

Previous research into DLA application provides strong evidence that timely advice and support is associated with successful application

outcomes (Douglas et al, 2008). There is evidence that the participants in the current research valued such advice enormously, but some found it hard to obtain (including from the specialist voluntary sector).

The points system incorporated in the PIP assessment proved complex, intimidating and unfamiliar for many participants, in particular the assessment focus upon the functional impact(s) of a condition upon activities in daily living and mobility (rather than the condition itself). Given this, it is vital to provide timely and informed support and guidance to help people with sensory impairments best represent themselves in these assessments.

### **Implications:**

- In line with recommendations made by others, DWP should promote and respond to claimant choice in methods of communication. Claimants, their advisors, and organisations advocating and campaigning on their behalf, should demand this choice of communication. Given the additional time pressure that poor accessibility and complex lives can place upon claimants, it is also important that they can easily be given extra time to navigate the application process (e.g. to complete application forms).
- Leading sensory impairment sector organisations should develop and maintain clear and accessible written advice in relation to PIP application. For example, existing websites (e.g. those offered by Sense, RNIB and Action for Blind People) offer useful information and could be developed further. Such guidance should be far reaching, offering details on all aspects of the process (e.g. the non-means tested nature of the benefit and its philosophical principles, the role of an appointee, the points system, and application procedures). Guidance should also be written for multiple audiences (most notably people with visual and dual sensory impairments but also welfare advisors and advocates). The availability of knowledgeable advisors is extremely important for many claimants and an analysis and communication of their availability would be helpful.

### **Assessment**

Many participants were apprehensive and anxious about the face-to-face assessment. There was concern that the assessor would not understand their situation, and would not have the experience to make appropriate judgements. However, all four participants who had direct experience of a face-to-face assessment suggested that it was straightforward, and that the assessor was agreeable and pleasant.

These four assessments took place in the participants own homes rather than an assessment centre. A further four participants received their PIP award as a result of a paper-based review, rather than a face-to-face assessment. Information about the mode of assessment was lacking and participants were unclear as to why they had not had a face-to-face assessment, and received mixed information about whether they would have an assessment or not. Nevertheless, given the positive award outcome, they were pleased not to have a face-to-face assessment.

The assessment mode for those participating in this study does not reflect those of disabled people in general as whilst the DWP anticipated 75 percent of assessments would be face-to-face (at 75 minutes on average), in 2014 it was reported that over 97 percent of assessments to date were face to face (taking 120 minutes, on average) (HoC Committee of Public Accounts, 2014). In contrast four from seven of our participants who were awarded PIP had not received a face-to-face assessment. This might reflect the nature of our (albeit small) sample or something more general about people with visual or dual sensory impairments. Age and impairment related (e.g. communication) factors, and the representation of disabled people with appointees, may each be significant in relation to this sample (see the section to follow, “Limitations and recommendations for methods adopted in the next phase of the research”).

More generic studies concerning welfare reform suggest that for some disabled people anxiety may result from previous experience of assessments (e.g. for ESA) and as a result of the actual or potential cumulative impact of reform (and austerity) for disabled people (e.g. see Lister et al, 2014).

### **Implications:**

- Clearer and accessible information from DWP about the assessment, including the criteria for the likely format the assessment takes, would be extremely helpful.

### **Length of time of the process**

DWP had originally proposed that 97% of assessments would take place within six weeks from the submission of the PIP application form. Of the seven participants who had received their decision letter (all of whom were awarded PIP) none of them appears to have received the letter within the original DWP timescale. Four of the participants appear to have received the decision letter within a 26 week target timescale (the

times ranged from three to six months). Twenty six weeks (six months) appears to be current DWP estimated timescale based upon PIP enquiry line. For three participants the process took longer than 26 weeks (between seven and eleven months). Another participant who is still awaiting the decision letter has already been in the system for eight months.

These timescales are recognised as unacceptable. In the independent review of the PIP assessment, Gray (2014) noted “The claimant journey during the early implementation of PIP has been characterised for many by the impact of delays and backlogs. The resulting progress-chasing calls have been time-consuming and frustrating for claimants and costly for the Department and assessment providers.” Gray (2014) also expressed concern that the commitment of DWP and providers to speed up the process must not impact on accuracy of assessments. While the negative impact of these delays was significant for most of the participants in the current research, it was particularly acute for one participant. Jim was a new claimant for a disability related benefit. As such he did not receive benefits (DLA) while his application was being processed. Furthermore due to his employment arrangements he did not have any other support to fall back on. Jim’s application took seven months to process. He described the situation at the time: “It was very very stressful and it caused a few arguments in the house because money was tight and we still had bills coming in.” This was all taking place at a time when Jim had just lost his sight. HoC Committee of Public Accounts (2014) underline the importance of Jim’s experience and how this may for other claimants result in health/impairment effects, stating that delays can lead to distress and can additionally have physical and/or mental health consequences.

### **Implications:**

- In the short term the DWP might more clearly communicate timetable challenges to claimants. Importantly, the delays have particularly negative impacts upon new claimants (i.e. those who are applying for a disability-related benefit for the first time, as opposed to those switching from DLA), because they do not have existing benefits while their application is being processed. The DWP might consider fast-tracking these particularly vulnerable new claimants.

### **Concerns about being assessed for PIP and definitions of disability**

An interesting theme emerged in relation to how some participants

rationalised PIP (or an equivalent) in relation to their particular impairment. For some, their situation (visual impairment, dual sensory impairment, or complex sets of needs) was viewed as a 'real' and demonstrable impairment/disability which gave legitimacy to the receipt of benefits (whether DLA or PIP). For some, their application had some associated guilt because they had a job or could cope financially without the benefit. However, they should not feel guilty: PIP is a non-means tested benefit designed to cover some of the additional costs of disability irrespective of employment and/or other sources of income. In a climate of general austerity in the UK and fundamental welfare reform, it is perhaps unsurprising that the interviews about disability-related benefits generated a strong theme about the discomfort of being assessed and judged, and the definition of disability.

### **Implications:**

- An important role of advisers and advocates for people with disabilities is to remind potential claimants of the legitimacy of their application.

It is also interesting that participants made some reference to medical aspects of their disability because PIP is an assessment of functional impact not of medical/impairment conditions. As Gray (2014) notes, "The key premise [of PIP] is that different people with the same underlying conditions may well experience significantly different functional impacts on their activities in daily living and on their mobility" (p2). For some participants there was a mismatch between their own value systems compared with that of the benefit and its underlying assessment procedure.

Gray (2014) noted that stakeholders appear to be finding this mismatch difficult to navigate ("PIP is widely perceived as a medical process rather than as an assessment of functional impact" p8), and "some concerns expressed about the credentials of particular health professionals conducting the assessments" (p58). So to this extent the findings in relation to people with sensory impairments do chime with the broader findings in relation to PIP.

There was evidence that this mismatch had some fundamental challenges for many participants. The assessment procedures felt negative and deficit, and focussing participants upon what they cannot do. Understandably, participants were dispirited that the independence that they worked hard to achieve (in themselves or their children) may work against them in relation to gaining the PIP award. In some cases

there was evidence of a potential 'benefits trap' in which people may feel a disincentive to develop and increase their independence in fear of losing their PIP.

Given the stated aim of PIP to reduce claimants and overall costs, it is unsurprising that the policy rationales for PIP have been questioned both from an anti-austerity perspective (e.g. Cross, 2013) and from a policy researcher and analyst perspective (e.g. Morris 2011). Such critiques highlight concerns that disabled people may feel punished for gaining some independence, by processes which fail to properly understand the value of a non-means tested benefit that enables people to live their lives on a more equal footing. Morris (2011) expressed strongly in the early part of the Coalition government that whilst the social model was an implicit basis for DLA, PIP corrupts this by potentially taking away benefits that might support independence from disabled people who are demonstrating they are not substantially dependent on others. Whilst this research does not provide evidence of this happening, the fear of this happening was clearly expressed.

#### **Implications:**

- Future research might usefully explore this potential phenomenon further.

### **Limitations and recommendations for methods adopted in the next phase of the research**

Phase 1 of this research project was planned to be of a relatively small scale qualitative piece of research. The small numbers of participants (just fourteen) and the purposeful nature of the sampling mean that the findings have no statistical generalisability. Similar experiences have been reported elsewhere: Sainsbury and Corden (2014) stated that 'one group of claimants, people with sensory impairments, proved difficult to recruit ... principally because they only constitute a very small percentage of the overall claiming\* population' (\*i.e. rather than potentially eligible)'.

Nevertheless, the experiences of these participants provides rich understandings of how the PIP application process has worked for them, and offers an insight into how it might also be for other people in similar situations and with similar characteristics. We spoke to people in a range of circumstances, with a range of sensory impairments and other disabilities and/or health problems. They were also at different points in the PIP application process. Important points are as follows:



- 12 of the 14 participants had **severe** sight impairments
- Seven participants had a dual sensory impairment (and five of these had Usher syndrome).
- Nine of the participants could be broadly described as having additional disabilities and/or health conditions beyond their visual impairment or dual sensory impairment.
- Three of the case studies involved people who had appointees who had applied for PIP on their behalf because of the complexity of their situation (all of whom were under the age of 25 years).

To this extent the participants we worked with have relatively complex and severe conditions in comparison to the broader population identified in the research brief. For example, the broad term visual impairment might also include people with moderate sight impairments (compared to the severe sight impairments experienced by the participants in the study). Interviews with people with less severe conditions may have revealed very different experiences of the PIP application process, and different outcomes. For example, all Phase 1 participants were assessed in their home and none had gone to an assessment centre.

In contrast, our participants did not include people who are profoundly deaf and/or use British Sign Language to communicate. Again the experiences of people with these characteristics may well highlight different issues.

Research of this kind always involves some recruitment bias related to 'self-selection'. Nine of our participants who were already in receipt of DLA were required to apply for PIP (if they wished to continue receiving this disability related benefit). To this extent they were less 'self selecting' for the research project because their engagement with PIP was beyond their control. In contrast, two participants who were in receipt of DLA had **chosen** to apply for PIP. To this extent they may have been more confident that their application would be successful, otherwise why would they risk losing their DLA award? Similarly, one participant who was in receipt of DLA had not applied for PIP at this stage, and two others lived in areas of the country where application was not possible. The point being made here is that at this early stage of PIP rollout there are all sorts of motivations and circumstances which mean that Phase 1 participants may be similar or different to PIP applicants in the future.

Based upon figures available through DWP's Stat-Xplore website (available at: <https://stat-xplore.dwp.gov.uk/>), as of October 2014 just

2,101 people with 'visual diseases', and 1,006 with 'hearing disorders' had applied for PIP (of a total number of 207,530). Therefore, it appears to be relatively rare at this stage for people with sensory impairments to be applying for PIP. This may be explained by the observation made in the proposal by colleagues at NatCen that people with sensory impairments tend to have indefinite DLA awards and therefore are not likely to have applied for PIP at this stage. The low numbers also may go some way to explaining why recruitment was so difficult in Phase 1 of the project.

Given recruitment was difficult in Phase 1, it may be useful to reflect upon what approaches may work in the next phases. Firstly, the timing of the Phase 1 meant that we were not able to approach Local Authority Rehabilitation Teams (time did not allow us to apply for ethical approval through the ADASS and Local Authority Research Governance Framework (RGF) committees). We would predict that these contacts, as well as local visual impairment charities, would be very helpful in recruiting participants. Importantly, our general flyers were unsuccessful in recruiting. More useful was making personal contacts with professionals and advisors who could approach individuals with sensory impairments on the research team's behalf. It was these personal contacts which proved most successful.

Given Phase 2 involves tracking participants as they work through the phases of PIP application, it may be helpful to build upon some of the recruitment in Phase 1. Seven Phase 1 participants do not yet have a PIP outcome and it would seem sensible to ask their permission to be involved in the next phase of work. We anticipate all would be interested.

In addition to points made above about recruitment and participant characteristics, we hope the themes identified in Phase 1 will prove useful areas for exploration and clarification in the research phases going forward.

### **Summary of recommendations for Phase 2:**

- Consider recruiting participants with characteristics which will add to the experiences gathered in Phase 1. The sample size in Phase 1 was very small, but particularly under-represented were participants with less severe visual impairment and less complex additional disabilities and health conditions. Also in Phase 1 we did not recruit any participants who were profoundly deaf and/or communicated through British Sign Language.
- Consider recruiting participants through Local Authority Rehabilitation

Teams and local visual impairment charities. Given the very low numbers of claimants with sensory impairments at this stage of the PIP rollout (as reflected in the DWP figures), making personal contacts with professionals and advisors who can approach individuals on the research team's behalf may prove more useful than general flyers and adverts.

- Given Phase 2 involves tracking participants as they work through the phases of PIP application, it may be helpful to build upon some of the recruitment in Phase 1. Seven Phase 1 participants do not yet have a PIP outcome and it would seem sensible to ask their permission to be involved in the next phase of work.
- The themes identified in Phase 1 will hopefully prove useful areas for exploration and clarification in Phase 2.

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# Appendix 1 – Case studies

**Table 3 Summary of the case studies**

<b>Name (age)</b>	<b>VI / DSI (condition if relevant)</b>	<b>Additional disability / health conditions</b>	<b>Point in PIP application process (outcome if relevant)</b>	<b>Previous / current DLA?</b>	<b>Additional information</b>
Owen (16)	DSI	Complex medical needs and profound learning difficulties	Enhanced for mobility and daily living	Higher rate for mobility and care	Elaine (mother) was interviewed as appointee
Jim (57)	VI (linked to diabetes)	Diabetes	Enhanced for mobility and daily living	Not previously on DLA	Newly registered as having a visual impairment (SSI)
Lyn (54)	VI (linked to brain aneurism)	Including: memory problems, poor circulation, stiffness in her legs, migraines, pain	Enhanced for mobility and daily living	Fixed term higher rate for mobility and care	Successful PIP following mandatory reconsideration.
Yazan (24)	VI (linked to RP)	Managed epilepsy	Standard for mobility and daily living	Not previously on DLA	No reported assessment.
Tony (47)	DSI (linked to Usher Type 3)	None beyond: moderate progressive hearing loss; severe sight impairment	Completed application - waiting to hear from DWP.	DLA lowest level for care and mobility	Application prompted by disappointment with DLA outcome.
Matt (35)	DSI (linked to Usher Type 2)	None beyond: hearing loss; severe sight impairment	Enhanced for mobility and daily living	DLA lowest level for care and mobility	Application prompted hope PIP would provide a higher award.
David (40)	VI (linked to RP)	None beyond severe sight impairment	Not yet applied for PIP	DLA lowest level for care and	Anxious about potential reduction in award due to

				highest for mobility	PIP and impact upon him and his family
Fiona (33)	DSI (sight loss linked to diabetes)	Diabetes; awaiting kidney and pancreas transplant; anaemic	Completed application - waiting to hear from DWP.	In receipt of DLA	
Dominic (50s)	DSI (linked to Usher Type 2)	Severe sight impairment; high blood pressure, and swelling of hands; mild depression	Not yet applied for PIP	Unknown rate for care and highest for mobility	Anxious about potential reduction in award due to PIP
Alistair (57)	DSI (linked to Usher Type 3)	Severe sight impairment; Bilateral hearing loss; Depression.	Not yet applied for PIP	Higher rate for mobility and care	Anxious about the PIP application process.
Alexander (16)	VI	Complex medical needs and learning difficulties – autism, epilepsy and wheelchair user	No formal application for PIP – appointee reported she was told Alexander would automatically be transferred to PIP from DLA	Higher rate for mobility and care	Becky (mother) was interviewed as appointee
Ryan (16)	VI	Sight impairment, but his fragile condition means that further sight loss is possible following a knock to the head.	Enhanced for mobility and daily living	Lower rate for mobility and care	Mike (father) was interviewed (with Ryan's permission); Better off under PIP than DLA
Sophie (18)	VI (linked to albinism)	Severe sight impaired; Related	Completed application and	In receipt of DLA	Worked closely with her mother in the

		migraines	assessment - waiting to hear from DWP.		application process.
Ricky (17)	DSI (linked to Usher Type 2)	Sight impairment; moderate hearing loss. No other health issues / disabilities	Enhanced rate daily living and standard rate for mobility	In receipt of DLA	Lindsay (mother) was interviewed as appointee

## Owen

Owen is 16 and enjoys horse riding and playing with his favourite musical toys. Owen attends a specialist residential school for children who have a visual impairment and multiple disabilities. He is deafblind and registered as blind. Owen has complex medical and learning needs, as his mother Elaine explains, "His diagnoses are: Down's syndrome, West syndrome, multi-sensory impairment, registered blind, sensory processing delay, multiple and profound learning difficulties, bowel problems." Owen is non-verbal and prefers to use body language, vocalisations and facial expressions to communicate. Owen walks independently but he tires easily and for safety reasons due to behavioural issues Owen usually uses a wheelchair outside in unfamiliar areas. If Owen is not using his wheelchair when out and about in unfamiliar areas he always has 2:1 support. Elaine is Owen's mother and his appointee, and she shares her experiences of claiming PIP for Owen. Elaine applied for PIP Owen as he had turned 16 (he had previously received DLA at the higher rate for both mobility and care). Owen did not have an assessment. **Owen was awarded the enhanced rate of PIP for mobility and daily living.**

Elaine appears confident and articulate in explaining her son's needs, and feels that she has had a lot of experience in this as she has had to advocate for her son for the past 16 years, however she still was anxious about the PIP process, especially with regards to the lack of communication, particularly in relation to becoming an appointee for her son. As one of the first people to go through the PIP application process Elaine found the Sense website very helpful - Elaine's friends are now turning to her for help advice in completing PIP application forms. From filling in the application for to receiving an award it took around 4 months. Elaine also feels that the financial costs of caring for someone with complex needs such as her son are not met by the income



generated by PIP, even at the enhanced level.

## Jim

Jim is 57. He enjoys going to local cafes with his wife Sue whom he has been married to for 37 years, and getting to grips with his new iPad. He used to be a parcel delivery driver but had to give up work when he suddenly lost his sight last year due to issues related to diabetes. As Jim was a newly visually impaired person, and not previously in receipt of DLA, he was applying for a disability related benefit for the first time. Apart from his diabetes Jim has no other significant health problems or disabilities that he identified on his PIP application form. Jim is registered as severely sight impaired and uses a long cane. Jim uses a handheld electronic magnifier to access written documents. An assessor came to Jim's house to conduct his assessment. **Jim was awarded the enhanced rate for mobility and daily living.**

Jim found the PIP application form excessively long and his wife had to help him complete it by reading the questions to him and filling in his responses as he was unable to access the form. Jim also found the length of time to hear from the Department of Work and Pensions (DWP) especially frustrating and stressful, so much so that he contacted his local MP and asked him to intervene in the process. Nevertheless it still took 7-8 months before Jim was awarded PIP, this was particularly difficult for Jim as not only was he having to come to terms with being visually impaired, and learning new skills such as using a long cane, he had also had to give up work, so his income had dramatically reduced. (People who are moving from DLA to PIP remain on DLA until their PIP application is awarded or otherwise). Jim was also unimpressed with the assessment process as he did not feel it was very rigorous and that the assessor did not fully understand his situation.

## Lyn

Lyn is 54 years old and a mother to two teenage children. She enjoys crafts and looking after her many animals. Lyn used to be a childminder but had to give up work after a brain aneurism six years ago. The aneurism caused Lyn to have a visual impairment and she is registered as sight impaired. As well as the visual impairment Lyn also has memory problems, poor circulation, stiffness in her legs, migraines, pain in her face due to trigeminal neuralgia, and she has to take anticonvulsant medication. Her husband is now her registered carer. She uses either a symbol cane or a long cane, and reads documents in large print. Lyn applied for PIP as her DLA award was coming to an end. An assessor

came to Lyn's house to conduct her assessment. **Lyn was awarded the enhanced rate for mobility and daily living after a Mandatory Reconsideration.**

Lyn found the PIP application process relatively straightforward and timely. She received support from a support worker in completing her application form and discussed some of the tensions that she felt in being more informed than her support worker. Lyn's experiences of PIP were intertwined with instances from applying for ESA (employment and support allowance) and other benefits. It was very important to Lyn that the DWP had the full story of the way in which her disability affects her, and not necessarily because it might lead to a better outcome, and so asked for a mandatory reconsideration of her first award which gave her zero marks in the 'making decisions about money' category. On reconsideration she was awarded 2 marks in this category which meant that Lyn would now be in receipt of the enhanced rate for daily living, as well as for mobility.

## **Yazan**

Yazan is 24 years old and studying Business Management and Functional Skills, as English is not his first language. Yazan has retinitis pigmentosa (RP) and is registered as severely sight impaired. As well as RP Yazan has epilepsy that is well managed with medication. Yazan reads documents electronically using a screen reader and uses a long cane to support his mobility. This was Yazan's first application for disability related benefits and was on the recommendation of a friend who suggested that PIP might be beneficial to him. Yazan did not have an assessment. **Yazan was awarded the standard rate of PIP for mobility and daily living.**

Overall Yazan found applying for PIP a worthwhile process – having some money was better than having none. He had support from a 'friend of a friend' to complete the application form as due to his visual impairment he was unable to access the application form, as well as requiring support due to English not being his first language. Without the support from this person Yazan believes that he would not have been able to apply for PIP and would have struggled significantly financially. Similarly Yazan was unable to read the award letter as it was not provided in an accessible format. Yazan is thinking about asking for support and advice (although where from was unclear to Yazan) about his award level, with the view to challenging the outcome if these people think that award level is wrong.

## Tony

Tony is 47 years old and lives in Scotland. He enjoys going out with friends, foreign holidays, and tandem cycling. Tony has Usher syndrome type 3. He has a dual sensory impairment and is registered severely sight impaired. Tony has a moderate progressive hearing loss and is well aided with hearing aids. He communicates using speech. Tony has no other disabilities or health problems. Tony has recently had to give up work as he was unable to continue working due to his combined hearing and sight loss. Tony has a guide dog and accesses written documents using electronic enlargement. Tony decided to apply for PIP as he was unhappy with his DLA decision (which was at the lowest level for care and lower level for mobility) and felt that he would be better off under PIP. **Tony has completed his PIP application form and is now waiting to hear from DWP.**

After all the difficulties associated with his DLA application including two appeal hearings, Tony is confident that he will be better off under PIP as there is less focus on the medical definition of the impairment and more focus on what the individual can or cannot do. The difficulties with the benefits system are particularly frustrating for Tony as he has made National Insurance contributions for nearly 30 years and believes that he should receive the appropriate level of benefit. Tony also fears the assessment process as he does not believe that assessors will have the knowledge and understanding of what it is like to have Usher syndrome and a dual sensory impairment to accurately capture his experiences. He is also worried that he might be penalised for being 'too independent' in certain areas. Tony is not expecting a quick response from DWP as he received a text message saying that he will hear within 26 weeks.

## Matt

Matt is 35 years old and enjoys going to the pub and meals out with friends, blind cricket, and going for long walks up mountains with his guide dog Benji. He was recently made redundant from his part-time job installing computer software. Matt has Usher syndrome type 2 and is registered as severely sight impaired. Matt has a dual sensory impairment and wears two hearing aids. Matt uses speech to communicate, however he needs a quiet background to be able to communicate effectively. Matt has no other health problems or disabilities. A friend who is deafblind suggested to Matt that he could be better off on PIP rather than DLA hence why he decided to apply for PIP (Matt was previously on the lowest rate for care and the lower rate for

mobility). Matt prefers someone to read written documents to him, although he can access very short documents in large print. A nurse came to Matt's home to conduct his assessment. **Matt was awarded the enhanced rate of PIP for mobility and daily living.**

Overall Matt was pleased with the PIP process and indeed he was financially better off under PIP than DLA (he used to get the low rate for mobility and care under DLA), although he recognised that he had "nothing to lose" by applying for PIP whereas those already on the higher rates may be more cautious. It did however take 8 months from the initial phone call to DWP to Matt receiving the benefit. He also found it ironic that he was unable to read his award letter, as it was only provided in standard print, and it was only when the researcher arrived and that he was able to know the full content of the letter. Matt had support from a support worker (not specialising in sensory impairment) to complete his PIP application form.

## David

David is 40 years old and the father of two young children. He works in Higher Education in the field of rehabilitation. David has retinitis pigmentosa with associated nystagmus and cataracts. David is registered as severely sight impaired and uses a long cane to support his mobility. David accesses written documents in large print, LVAs and electronic enlargement. David has no other health problems or disabilities. **David is in receipt of DLA (mobility at the higher rate and care at the lowest rate) and has not yet applied for PIP.**

Although not yet requested to move over from DLA to PIP, the forthcoming changes were very much at the forefront of David's mind. In particular he was concerned as to whether he would continue to get the enhanced rate of the mobility component which allows him to lease a car through Motability. After searching for information he felt reassured that as a long cane user he would receive the enhanced rate for mobility, but he preferred the DLA's medical definition of visual impairment rather than leaving it to individuals to explain their difficulties as with PIP. He was also concerned that he may be penalised for being 'too independent' and 'coping too well'. David also felt that PIP does not recognise his role as a father, and as with other people, suggested that talking about what you cannot do (cf. what you can do) is very difficult and often demoralising.

## Fiona

Fiona is 33 years old and works full time for a charitable organisation that supports people with a visual impairment. Fiona has a dual sensory impairment and is registered as severely sight impaired. Fiona's visual impairment is a result of diabetic retinopathy which occurred suddenly when she was 25 years old. The cause of Fiona's hearing loss is unknown and it began about 5 years ago. She is deaf in her left ear. Fiona did not describe herself as dual sensory impaired but instead choose to highlight the difficulties of a hearing loss for someone with a visual impairment, particularly when trying to track where people are. As well as having diabetes Fiona is on the kidney and pancreas transplant list. Fiona is also anaemic which means that she gets tired easily and is always cold. Fiona prefers to access written documents through audio, however she also uses a screenreader or voiceover on her iPhone or iPad. Fiona uses a long cane. **Fiona has completed her PIP application form and is now waiting to hear from DWP.**

Fiona preferred the DLA application form as she found the questions on the PIP form less relevant to visually impaired people. She also mentioned that the form was very long – around 50 pages when completed. Fiona had support from her grandmother to complete her form – she did not want to let her boyfriend know how much she struggles on a daily basis. Fiona was very clear about the uses of her income generated by DLA/PIP and the extra costs that she faces as a visually impaired person. Additionally Fiona was concerned that some visually impaired people might feel compelled to lie, either on their application form or at their assessment, in order to receive benefit as the process does not understand the particular needs of visually impaired people.

## **Dominic**

Dominic is in his 50s. He enjoys music and foreign travel, and provides information workshops on methods of communication with deafblind people. Dominic has Usher syndrome type 2 and has a dual sensory impairment. He is registered as severely sight impaired and accesses written documents by having them read to him or on audio, as well as sometimes using magnification equipment. He uses a long cane to support his mobility. Dominic has bilateral cochlear implants and uses speech to communicate. When accessing the local environment or meeting other people Dominic has support from a communicator guide. Dominic also has high blood pressure and swelling in his hands which means that he cannot do manual work, and sometimes even holding his cane is troublesome. He also has mild depression which is often

exacerbated by worries and anxieties surrounding benefits. **Dominic is in receipt of DLA for both mobility (higher rate) and care (data not collected in relation to rate) and has not yet applied for PIP.**

Although not yet in receipt of PIP, the movement from DLA to PIP was very keen in Dominic's mind. Dominic has been in receipt of disability related benefit for nearly 25 years and was frustrated that although 'they' have all the information about his condition and he will always be deaf and blind, and that his vision and hearing "will not get better", he will still have to repeat this yet again on the application form for PIP. Dominic also believes that DWP and its employers do not understand what it means to be a person with a significant sight and hearing loss. Dominic is very thankful that he has a small pension from his 12 years in employment which supports his income from benefits, as the communicator guide support provided by Social Services does not provide him with enough hours per week to take part in all the activities that he wishes to.

## **Alistair**

Alistair is 57 years old. He enjoys music, yoga, rowing and campaigning about disability issues. Alistair has Usher syndrome type 3 and has a dual sensory impairment. He is registered as severely sight impaired and uses a reader to access written documents. Alistair reads labels in braille. Alistair wears bilateral hearing aids and communicates using speech. He uses a long cane to support his mobility, and when out and about often has support from a communicator guide. Alistair also has depression and mental health difficulties. **Alistair is in receipt of DLA at the high rate for both mobility and care, and has not yet applied for PIP.**

Alistair's comments on the change to PIP from DLA are interconnected with his knowledge and experiences of other disability related benefits and legislative changes such as ESA and the Care Act. Alistair describes Sense as an excellent support in the past and believes that he will definitely be using their services when the time comes for him to apply for PIP. Alistair fears difficulties when applying for PIP as DWP often uses automated telephone services and it is very frustrating for him not to be able to talk to a 'real person', also as a deafblind person who does not use information technology he worries that his communication needs will not be met.

## **Alexander**

Alexander is 16 years old. He goes to a specialist school for children with profound and multiple disabilities. He is registered as severely sight impaired due to a brain condition known as septo-optic dysplasia. As well as having a visual impairment Alexander has a significant learning disability, autism and epilepsy. Alexander uses a limited number of symbols to communicate but generally makes his needs known through body language and gestures. Although Alexander can walk independently he often uses a wheelchair when out and about in order for him to feel safe. Becky, his mother, is the appointee for Alexander. Becky tells the story of her experiences of claiming PIP for Alexander, which was initiated due to the fact that he had turned 16 years old.

**Becky has not yet completed any paperwork for Alexander's application for PIP as she was told that Alexander would automatically be transferred to PIP from DLA.**

For Becky, negotiating the move from DLA to PIP, as Alexander was turning 16, was the first time that she had to think about her son as an adult, and she hints that being confronted with this was tricky for her emotionally. However the interview for Becky to become Alexander's appointee was straightforward and importantly Becky did not feel that she was being "scrutinised". It seems unusual that Becky was told that she did not have to fill in any paperwork to progress her application for Alexander's PIP but on being asked to comment on this twice, she was adamant that this was correct.

## Ryan

Ryan is 16 years old and attends a local mainstream school. Ryan has retinoschisis and is registered as sight impaired. Ryan has no vision in one eye, and the vision in his other eye can fluctuate. If Ryan has a vitreous bleed he can have no vision whatsoever, for 3 weeks or so at a time. Ryan uses a long cane to support his mobility and accesses written documents in large print. Ryan has also learnt braille. Ryan has no other health problems or disabilities, although he needs to avoid any bangs or knocks to the head and is supported 1:1 in school to help ensure that this happens. Ryan receives his PIP payment in his own name, however with his permission, his father Mike, who is Ryan's fulltime carer, tells the story of the family's experiences of claiming PIP. Ryan did not have an assessment. **Ryan has been awarded the enhanced rate of PIP for mobility and daily living.**

Ryan and Mike had support from their local RNIB Welfare Rights' officer to help complete Ryan's PIP application form. This was very useful as

the officer encouraged them to give details of the worst possible scenario, which they had not done on previous DLA applications. Consequently Ryan was better off under PIP than he had been under DLA (which had not been at the higher rate). This was particularly useful as the complications that Ryan has to deal with means that his vision can fluctuate quite considerably, and when there are times that Ryan needs to go to be in hospital it can be a 187 mile round trip everyday for many weeks. Although very pleased that his son gets PIP, Mike believes that 16 is too young for an individual to be in charge of such an income, and realistically because his son is still at school and living at home, the income should be coming to the family.

## **Sophie**

Sophie is 18 years old and studying health and social care at college. She describes herself as “a typical teenager”. She has recently been registered as severely sight impaired due to changes in her vision, previously she was registered sight impaired. Sophie has albinism, nystagmus, and photophobia. Sophie also gets severe migraines due to eye strain. Sophie uses a sighted guide to get around (when not in college this person is usually her mother or a friend). Sophie uses large print to access written documents, although this is becoming increasingly difficult. Sophie applied for PIP as her fixed term DLA was coming to an end. Sophie was unsure of her current DLA award but she believed that was on the middle rate for mobility, however this level does not exist, however it is believed that Sophie felt that she was in receipt of the appropriate level of DLA. Sophie had an assessment at home.

**Sophie has completed her PIP application form, and had an assessment, and is now waiting to hear from DWP.**

Due to issues in accessing her PIP application form, and difficulties in understanding the questions, Sophie’s mum acted as a reader and scribe for Sophie’s PIP application. As Sophie has been in receipt of DLA since she was 6 months old, she strongly felt that DWP should have all the necessary information and that it was a waste of time to repeat this information again. Sophie was also extremely frustrated that despite having had her assessment in August, she had not heard the outcome of her award 4 months later (mid-December). Calling this situation “a nightmare” and “ridiculous”, Sophie has been trying to chase the progress of her application. At present she knows that her case is with a manager, who she believes may have tried to call her on her mobile using a private number, and consequently she cannot get back in touch with him to return the call.



## Ricky

Ricky is 17 years old and is studying catering and hospitality at a local college. He has Usher syndrome type 2 and has a dual sensory impairment. Ricky is registered as sight impaired. Ricky wears bilateral hearing aids and has a moderate hearing loss. Ricky communicates by speech. Ricky accesses written documents in large print. He uses a long cane in unfamiliar areas or at night time. Ricky applied for PIP as he had turned 16. Ricky did not have an assessment. Ricky has no other health problems or disabilities. Ricky's mum Lindsay is Ricky's appointee and shares her experiences of claiming PIP for Ricky. **Ricky was awarded the enhanced rate for daily living and the standard rate for mobility.**

As Ricky's transfer from DLA to PIP occurred very early on in the roll out of PIP there was not much information available to Lindsay in helping her complete the PIP application form, however she felt particularly well supported by Sense and a specialist teacher of deafblind children, as well as another mother of a child with Usher syndrome. Lindsay described it as particularly hard to focus on the difficulties that Ricky encounters on a daily basis. At 16/17 years old Lindsay felt that Ricky did not have a strong grasp of the meaning of money so applied to be Ricky's appointee – this was confirmed in an assessment by DWP to check that it was suitable for Lindsay to be Ricky's appointee. Lindsay was very shocked to be awarded PIP without an assessment, although pleased that they did not have to go through the assessment as she felt it would have been very damaging to Ricky's self confidence. The length of time that this took (4 months) and the lack of communication and information, was also stressful for the family.

# **Appendix 2 - Interview schedule**

## **Case studies with people with a visual impairment or who are deafblind**

### **1. Recording?**

I would like to record the interview using a video camera/digital recorder. There are a number of benefits:

- I won't have to take too many notes
- It will help me to concentrate on the conversation
- I can record everything you say correctly.

I'd like to reassure you that only members of the research team will ever listen to/watch the recording. Is this ok?

Yes \_\_\_\_\_ No \_\_\_\_\_

### **2. Project summary.**

Just to summarise once again what the project is all about, we would like to talk to you about your experiences and opinions of Personal Independence Payment (PIP).

This interview is completely voluntary; you don't have to answer all of the questions.

You can give up or stop at any time if you no longer want to take part.

I can assure you that any information you tell me is entirely confidential – unless you tell me that you or someone you know is being seriously hurt.

Do you understand / is that ok?

Yes \_\_\_\_\_ No \_\_\_\_\_

### **Background information (confirmation of details if answered previously)**

Name; Age

Do you know the medical name of the condition that causes your

vision/hearing problems/deafness? Details.

Do you have any other health problems or disabilities? Details.

How do you prefer to communicate?

Are you registered as severely sight impaired (blind) or sight impaired (partially sighted)?

How would you describe the level of your hearing loss/deafness?

1. I would like to discuss the **PIP application process** with you, please can you share your thoughts/opinions/experiences on the process of applying for PIP.

**Prompts:**

- How did you know that you had to apply for PIP? How did you think/feel at this point? – if you got a letter was it accessible format, easy to understand?
- Initial contact with DWP - via telephone - help/support? How was this experience?
- Application form accessible? e.g. font size, clear English.
- One month to complete form – sufficient? Extension? Did you know that you could ask for extra time?
- Help/advice filling in application form? Who? How feel about this? Easy/difficult to find help/advice?
- Documentation
- Questions relevant? Clear?
- Overall? If you used to get DLA in the past was there anything better/not as good? What was difficult - practically and emotionally? What was easy? What was straightforward?

2. Please can you share your thoughts/opinions/experiences on the **assessment** for PIP.

**Prompts:**

- How long was before you heard from DWP?
- Face-to-face assessment? Home/centre? Accompanied/alone? Timing? Distance? Travel? Travel expenses? Information beforehand?
- What were you thinking/how did you feel **before** the assessment? What were you thinking/how did you feel **after** the assessment?
- Access? Communication?

3. Please can you share your thoughts/opinions/experiences on **your award and the outcome of your award.**

**Prompts:**

- Award level. Daily living/mobility? What you expected?
- Waiting time? Accessible information? Understand award?
- First application?
- Mandatory reconsideration?
- Appeal
- Support/advice
- Comparison with DLA. DLA in past? Better/worse off?

4 Please can you share your thoughts/opinions/experiences of the. **'points system'**.

**Prompts:**

- Awareness, knowledge.
- Did you calculate your score before submitting your application?
- Did you get the score that you that you would?
- Activities representative of life/life style?
- Improvements/changes?

5. Please can you share your thoughts/opinions/experiences of PIP on your **income and its impact on you.**

**Prompts:**

- Uses of PIP. Clearly identified spending or 'pot of money'?
- How important to you is the income that you get from PIP? Why?
- Allow you to do? Prevent you from doing?
- Knowledge of 'passporting'. Link to other benefits.
- Relate to wider Government/media implications.

6. **And finally** do you have any further thoughts/opinions/experiences of PIP?

**Prompts:**

- Overall process of applying for PIP?
- What help or advice would you say/give to anyone who was applying for PIP?
- What (if anything) would you change about the PIP application

process?

- What (if anything) would you keep the same about the PIP application process?