# Second Independent Review of the Personal Independence Payment assessment – call for evidence

## Royal National Institute of Blind People (RNIB) & Thomas Pocklington Trust – joint submission





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15 September 2016

Questions for individuals or organisations with a professional interest in the PIP process

### About you

**1. Are you responding as an organisation or part of an organisation?**

Joint response from two organisations.

**o Name of organisation**

Royal National Institute of Blind People (RNIB) and Thomas Pocklington Trust (joint submission).

**o Who does the organisation represent?**

Blind and partially sighted people.

**o Where applicable, explain how the views of the members were gathered**

From client evaluations at the end of each case and discussions with the client throughout the case.

**Does your organisation directly support people claiming PIP?**

Yes – RNIB Legal Rights Service represents 200-300 PIP clients at Mandatory Reconsiderations (MRs) and Lower and Upper Tribunals each year.

**2. We may want to follow up further information with you or quote your evidence in our report. If you are happy for us to contact you please provide the following details**

**• Name**

Jean French

**• Address**

Legal Rights Service

RNIB

105 Judd Street

London

WC1H 9NE

**• Email**

Jean.French@rnib.org.uk

**• Telephone number**

020 7391 3284

### Further evidence

**During the PIP claim process, claimants are asked to provide any relevant evidence or information they already have that explains their circumstances (known as further evidence). Claimants can send supporting evidence with their ‘How your disability affects you’ form but they do not have to do so. This might include prescription lists, care plans, reports or information from professionals who help the claimant, such as a GP, hospital doctor, specialist nurse, community psychiatric nurse, occupational therapist, social worker, counsellor or support worker.**

**If appropriate when conducting an assessment and providing advice on a claim to DWP, Atos and Capita health professionals can consider requesting additional evidence to help them from people listed on the claimant’s form. Most assessments require a face-to-face consultation but some assessments can be completed on the basis of a review of the available paper based evidence without the need for a face-to-face consultation as there is sufficient evidence available.**

**We are investigating how effectively further evidence is being used to assist the correct claim decision and identify whether a face-to-face consultation is required, exploring the balance between how much and the type of evidence DWP sources and what the claimant is asked to provide.**

**3. In your experience what types of further evidence do claimants send in as part of their claim?**

When making a claim many clients send no supporting evidence.

Where additional evidence is sent, it is most often a Certificate of Visual Impairment (CVI) which contains information about the client’s visual acuity and visual field in both eyes.

Where clients have other health issues or disabilities they sometimes send in prescription lists and/ or letters from consultants and GPs but these are rarely sent if blindness or sight loss is the only disabling condition.

**4. In your experience what further evidence does Atos/ Capita request on claimants’ behalf? Is this requested on time and used appropriately and fairly?**

We have never seen any evidence requested by Atos/ Capita in any of our clients’ case files. Indeed, we have never seen any evidence that Atos/ Capita request further evidence at any stage.

**5. Is it clear what further evidence is being asked of claimants? Please briefly explain your answer.**

The notes on the application form inviting claimants to send additional evidence are now clear. It might be helpful for blind and partially sighted people if the CVI were specifically mentioned on this part of the application form as a potential piece of evidence.

When an MR is requested by phone claimants are generally, though not always, told to send in any additional evidence they have. There is, however, very rarely any discussion at this point about what might constitute further evidence. Our clients would find a discussion about this very helpful, not least because some of them find the notes on the application form inaccessible. If staff at the PIP Enquiry Line could go through a list of potential evidence, such as the one currently on the claim form during the MR request stage, this might ensure that further evidence is before the Decision Maker at the earliest opportunity.

There is nothing on the SSCS1 form to remind clients that they can send in further evidence before the tribunal hearing. There is a checklist at the end of the form reminding clients that they need to attach the MR decision etc. Notes about what additional evidence might be helpful could also be added to the form here, with of course a proviso that this can be sent in later and not to delay submitting the SSCS1form while waiting for evidence.

**6. From your understanding, when claimants submit their claim how important do they think it is to submit further evidence? Please briefly explain your answer.**

Some understand that this might be helpful and what sort of evidence might be submitted, but many do not.

We explain possible sources of evidence in all of our information resources for blind and partially sighted people and suggest they think about :

* submitting their CVI, prescription lists or any consultant letters they have;
* asking their GP/ consultant for supporting letters; or
* keeping a care diary.

For clients who are not in contact with us until the MR stage we always discuss what further evidence they might have and this is then sent at that stage.

**7. Are there any barriers for claimants in providing further evidence? Please provide examples.**

Cost is an issue. Many GPs will charge for a letter explaining the claimant’s current medical situation.

Relevance is also an issue. Many claimants are unsure about what may or may not be relevant and would like to talk this over with someone.

For our clients, accessibility is obviously an issue – if forms, letters and information resources are not in an accessible format they will not be in a position to know when to send in further evidence or what evidence might be useful.

The timing of tribunals can be a barrier if the client has received no support up to this point, as tribunals are listed very quickly and there may simply not be the time to get additional evidence. While we understand that everyone wants to get cases heard as quickly as possible it would be good to have some room for rescheduling hearings where evidence has been requested but not yet received.

**8. In your experience, when claimants go through the appeals system do they submit further evidence at this point? Why?**

We always talk with our clients before an MR or an appeal to a tribunal about whether they have a CVI and if it has been submitted. We will also talk with them about any further evidence they may have in addition to a CVI. For many of our clients a CVI will be sufficient.

Many have not considered what other evidence may be helpful or they presume that Atos/ Capita will contact the GP/ consultant or other professional whose contact details they have provided on the claim form.

Most of our clients only realise that they can submit further evidence for a tribunal appeal when they have talked to one of our legal rights officers.

### Data sharing

**We are looking at whether further data should be shared across DWP and with external organisations, such as the health and social care sector, to support the claim process and to improve the support offered to claimants. This could include sharing information between DWP benefit systems, for example sharing recent Work Capability Assessment reports with health professionals working on PIP. It could also include gathering information from social care assessments or healthcare providers. Personal information would be subject to appropriate data protection, as set out in the DWP’s Personal Information Charter.**

**9. Are you aware of technology that DWP should consider using to improve the PIP data collection process? Please provide examples or suggestions.**

We do not have relevant information on this point.

**10. Are you aware of any specific ways that DWP could share information gained from the PIP assessment with other organisations to improve health and care services? Please provide examples or suggestions.**

We do not have relevant information on this point.

**11. In your experience, how effective are current PIP IT systems in delivering the PIP claim process? Please provide examples.**

We do not have relevant information on this point.

### Claimant experience

**Consider the PIP claim process. This includes making a claim, the assessment and getting a decision.**

**12. From your experience, how could the PIP claim process be improved? Please provide examples or suggestions.**

A key improvement for our clients would be the prompt development of an online PIP claim form. Given the correct IT, an online form would significantly address the accessibility issues many of our clients have when claiming PIP.

A significant number of clients tell us that when they turned up at the medical assessment the assessor seemed to be unaware that their main disabling condition is sight loss – suggesting that all too often there has been no review of the papers before the assessment. We would like to suggest that assessors do fully review the case papers before each assessment.

There is a range of different ways assessors assess visual acuity. For instance, some assessors ask clients to take a Snellen test, but other assessors pass them written information and ask them to read or ask them if they can read a poster on the wall – tests that at best are hardly accurate. We suggest that the Snellen test is used for accuracy and consistency.

There is a poor understanding of how the descriptors should be applied among some decision makers. For instance we have had clients awarded no points for mobility when they use a long white cane on every trip outside. We suggest better training and better DWP PIP guidance in relation to the descriptors and blindness and sight loss.

More diligent reviews of cases at the MR stage are essential. For example, in June and July 2016 RNIB Legal Rights Service took 51 cases to MR or Lower Tribunal. Of these 15 were changed in the client’s favour at MR and 2 were changed in the client’s favour after MR but before the tribunal hearing. Of the remainder, 33 out of 34 were reviewed at MR but no change was made to the decision. All 34 cases were however changed in the client’s favour at tribunal. These figures suggest to us that Decision Makers are not undertaking thorough reviews at the MR stage as we did not submit any additional evidence at the tribunal that was not before the MR Decision Maker in these cases.

MR decision letters should clearly state that this is the MR decision – this does not always happen and can cause confusion for everyone involved in the process. Also clear acknowledgements that MR requests have been received and are being looked into are not always sent.

**13. From your experience, what impact do awards of PIP have on claimants’ ability to stay in, or return, to employment?**

Our clients tell us they use PIP for a number of employment related expenses, for instance:

* Taxi costs, where access to work are not funding taxis.
* Course fees, especially for attending IT courses.
* Purchase of IT to support them in work.
* Socialising with colleagues outside of the workplace.

Clients also mention that they have claimed PIP when moving from full time to part time work because of sight loss to try to mitigate the subsequent fall in income.

**14. How does the PIP process compare to similar assessments (e.g. ESA, an occupational health assessment)?**

Unfortunately, clients attending both PIP and ESA assessments report experiencing delays in getting assessments and poor quality assessments. Clients, their family and friends report assessors jumping to unsubstantiated conclusions from informal observations of behaviour. For instance, a client who judges where to walk when inside a building by trailing their hand along the wall was reported to walk unaided, despite always needing someone to guide her when she was outside. We believe that better training in how people manage when blind or partially sighted would improve assessments and get better decisions the first time round.

**15. In your experience, what are the reasons for people making an appeal to Her Majesty’s Courts and Tribunal Service (HMCTS) and what is their experience of this process? Please provide examples.**

Poor quality MRs. Please see our comments at 12 above. We believe many PIP cases are currently going to tribunal hearings unnecessarily because of poor quality MRs.

Clients can find it frustrating that a copy of the MR decision needs to be sent with the tribunal application, as these can be misplaced and then finding the document again can be time consuming for blind and partially sighted clients.

While clients can find the experience of appealing to a tribunal daunting, when we talk after a hearing most are happy with the how the proceedings were managed and feel that appropriate questions were asked, that they were treated with respect, and that they were given the opportunity to say what they needed to say.

### Progress since the last review

16. Since the first PIP Independent Review, DWP has implemented a number of the suggested recommendations. In your experience, how have these changes altered the experience of people going through the PIP claim process?

The pattern of issues relating to PIP, as described above, has in our experience been broadly similar over time.

**17. Do you have any further comments regarding the PIP assessment process?**

Regulation 4 of the PIP Regulations makes it clear that a Decision Maker should take into account whether a person can undertake an activity reliably. We repeatedly see cases where the first and the MR Decision Makers have not taken this into account despite the client having provided information about, for instance, the hazards they experience when cooking, how long it takes them to wash or dress, how long it will take them to read with a magnifier or the fact that they become tired or get headaches after using a magnifier for a limited period of time.

DWP PIP Guidance could be improved by having more worked examples which relate to how the descriptors may apply to blind and partially sighted people

Where clients have a condition which is not going to improve, better use should be made of longer award periods.

It would be very helpful to have an Adviser Helpline as advisers currently have to wait for a significant amount of time to talk with staff about the progress of individual claims.

**Research**

RNIB and the Thomas Pocklington Trust have recently collaborated with Sense to commission, from NatCen Social Research and the University of Birmingham, research on claimants’ experiences of the transition from Disability Living Allowance to PIP. This is shortly to be published as “Experience of Personal Independence Payment for people with sensory loss”. We summarise below the principal findings and recommendations:

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

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

**Key findings**

**Experience of the application process**

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

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

Necessity for support to navigate the PIP application process: participants who lived with family often relied upon them for help, whereas those who lived alone were more likely to access support from advocacy and support organisations or charities.

Inaccessible initial correspondence from DWP to participants: Part 1 of the application process happens by phone, where claimants should be asked if they want any further correspondence in large print, braille or audio format. However, the research found that for many participants the on-going correspondence was largely sent via letter using standard print, resulting in participants having to rely on support from friends, family or support workers to explain the contents of any correspondence from the DWP. While one group of participants was accepting of this need for support, another group was frustrated that they were not given the choice to access correspondence from the DWP independently.

Inaccessible PIP2 form: participants reported that they found the PIP2 form (that most claimants complete as part of the application process) was inaccessible because it was neither provided in the font size needed nor made available online. Again, it was necessary for participants to rely on family, friends, or advocacy and support organisations to complete the form. A frustration among participants was that they had no choice but to access support. This was felt particularly by participants who did not want to share how their impairment limited their ability to do day-to-day activities.

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

The first and most common approach involved participants employing a strategy to ‘prove’ their eligibility for PIP. Participants discussed using ‘worst case scenarios’ in their PIP2 form such as examples of bad experiences or accidents resulting from their sensory impairment. Participants felt that showcasing themselves in this way was the only option to ensure they were awarded PIP. Previous negative experiences of claiming other disability benefits, and advice from other PIP applicants or support from advice or advocacy organisations underpinned this particular strategy.

The second approach, in contrast to the first, was for participants to highlight their ability to ‘cope’ with their sensory impairment. Participants who took this approach received an initial ‘negative’ financial outcome. ‘Negative’ financial outcomes are defined as being found ineligible for PIP, or receiving a lower PIP award compared to DLA. These negative financial outcomes were eventually overturned at a mandatory reconsideration or tribunal.

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

**PIP outcome**

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

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

**The importance of PIP**

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

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

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

**Recommendations**

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

 Accessibility:

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

Ensure that all applicants are asked about their accessibility requirements at the start of the process (which is usually carried out over the telephone).

Ensure that the PIP2 form is provided in an accessible format for people with a sensory impairment.

Ensure that all on-going correspondence (e.g. letters inviting people to make a claim to PIP and the application outcome letter) is provided in the PIP applicant’s chosen format.

Increase the length of time people with a sensory impairment have to complete the PIP2 form.

Raise awareness among applicants about the requirements for assessment providers that all people with a sensory impairment are given the choice of location for the face-to-face consultation (e.g. at their own home or at the provider’s assessment centre provided that it is fully accessible).

Support:

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

The DWP should provide a list of the existing resources for applicants to access, if needed, to support them at any point of the application process.

Sensory impairment charities and local and national advocacy organisations should ensure that those who request support are supported until the point of their PIP outcome. This will ensure PIP applicants are followed through the process to identify any points they might need help with.

Sensory impairment charities need to provide information on the resources and guidance available for those embarking on an appeals process.

Appropriate help and support should be available to people with a sensory impairment that require it. This could be achieved by providing additional funding to third sector organisations to provide this support. Study participants who used third sector support during the application process used it for its accuracy, reliability and trustworthiness.

Training:

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

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

DWP administrative data:

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

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