

**Written evidence submitted by
The National Deaf Children's Society**

November 2017



1. About us

- 1.1. We are the National Deaf Children's Society, the leading charity for deaf children. We give expert support on childhood deafness, raise awareness and campaign for deaf children's rights, so they have the same opportunities as everyone else.
- 1.2. As an organisation we provide support to deaf young people aged 16-25 with all stages of the PIP process, from enquiries to our Helpline, support with the application form, support with Mandatory Reconsiderations and advocacy at Social Security Tribunals.
- 1.3. When we support deaf young people to appeal to a Tribunal, 70% of the Department for Work and Pensions (DWP)'s decisions are overturned and the deaf young people are awarded PIP. This is a clear sign to us that something is going wrong with the assessment and decision making stages of the process.
- 1.4. We have focused this submission of evidence on PIP since the majority of our benefits casework is on Disability Living Allowance (DLA) and PIP.

2. Summary

- 2.1. Contractor assessors do not possess sufficient expertise in childhood deafness to be able to carry out accurate assessments of deaf young people.
- 2.2. Contractor assessors do not understand the limitations of hearing technology and thus routinely advise too few points on Activity 7.
- 2.3. Contractor assessors do not understand how a young person's deafness impacts on their ability to engage with people face to face.
- 2.4. Contractor assessors do not understand that many deaf young people have problems with reading and numeracy. This impacts on Activities 8 and 10, however is not picked up by assessors.
- 2.5. Deaf young people have been subject to inaccurate 'hearing tests' during PIP assessments. We believe this is both unreliable and unacceptable.
- 2.6. Assessments are carried out in ideal listening conditions, which do not replicate the majority of situations in the deaf young person's everyday life.
- 2.7. Assessors do not ask probing enough questions of deaf young people to elicit the relevant information.
- 2.8. The PIP Assessment Guide published by the DWP still needs to contain more detail and explanation about deafness in young people. It should also be published more regularly.
- 2.9. The DWP does not have oversight over the Condition Insight Reports produced by contractor assessors. It is not clear whether assessors are using these reports routinely in order to improve their understanding of deafness.
- 2.10. Initial decisions routinely 'rubber stamp' the assessors' recommendations, even when these defy common sense or are contradicted by other evidence.
- 2.11. Mandatory Reconsideration decisions routinely 'rubber stamp' what the original decision maker had said.
- 2.12. We are concerned that the DWP has an internal target in relation to the percentage of original decisions that should be upheld at Mandatory Reconsideration stage.
- 2.13. A huge proportion of deaf young people are awarded PIP at Tribunal stage, indicating they are legally entitled to PIP and something is going wrong earlier in the process.

- 2.14. The lack of an online application and claim process is a significant barrier to deaf young people in accessing the PIP process.
- 2.15. The PIP assessment process is confusing and distressing for young deaf claimants, particularly for people aged between 16 and 18.
- 2.16. PIP assessment centres are not accessible for deaf young people who cannot use the intercom system.

3. Recommendations

- 3.1. The Committee should look into the lack of specialist assessors and decision makers, and the impact this is having on the quality of assessments and decisions.
- 3.2. The PIP Assessment Guide should be promptly updated whenever there are new developments such as case law or amendment of the Regulations.
- 3.3. The PIP Assessment Guide should be revised to include more detail around deafness and its impact on a person's functional ability.
- 3.4. The Condition Insight Reports used by the two assessment contract providers should be the same and overseen by the DWP.
- 3.5. The Mandatory Reconsideration process should be urgently reviewed, as it is currently ineffective and does not look critically enough at the case.
- 3.6. Information from Tribunals should routinely be fed back to the assessment providers and decision makers. Where training needs are evident from poor quality assessment or decision making, these should be addressed.
- 3.7. The PIP2 form should be fundamentally re-drafted so that it includes specific questions on all descriptors, not just the low scoring ones.
- 3.8. During the face to face assessment, the most relevant descriptors should be considered first, known as the 'function first' approach.
- 3.9. The Committee should look into the quality of training that assessors and decision makers receive about conditions and disabilities.
- 3.10. Assessment providers should routinely be requesting relevant further evidence from the deaf young person, their family, friends and colleagues, and the right professionals who actually know about the claimant's difficulties.
- 3.11. Contributions from a person accompanying the claimant to the assessment should be recorded by the assessor. The assessor should consider whether such contributions are evidence that the deaf young person needs prompting, communication or social support.
- 3.12. The PIP descriptors and scoring system should be sent to the claimant with the PIP2 form to improve understanding of what they will be assessed on.
- 3.13. Communications need to be improved to help young people understand the PIP process. For instance social media content, interactive content, video content.

- 3.14. The Committee should urgently look at the lack of digital application process for PIP and the impact this is having on, not only deaf claimants, but also any claimants that do not use the telephone for whatever reason.
- 3.15. In the case of deaf claimants, assessment providers should always request a 'speech in noise' test from the claimant's audiologist.
- 3.16. Assessors should ask more probing questions of deaf young people.
- 3.17. Contractor assessors should be obliged to read the Condition Insight Report on deafness before assessing a deaf young person for PIP.
- 3.18. Assessors must be banned from carrying out their own inaccurate 'hearing tests' on deaf young people.
- 3.19. Claimants under 18 should not be obliged to undergo a face-to-face assessment.
- 3.20. PIP assessment centres must be made accessible for deaf claimants who cannot use the intercom system to access the building.

4. Assessors and assessments

4.1. Do contractor assessors possess sufficient expertise to carry out assessments for people with a wide range of health conditions?

- 4.1.1. Contractor assessors do not possess sufficient expertise in childhood deafness. This lack of understanding results in poor quality of assessments, in which the impact of deafness on the young person's functionality is not recognised or reported. This is at the root of so many poor PIP decisions in relation to deaf young people.
- 4.1.2. One of the most common areas of misunderstanding is around hearing devices, when considering Activity 7. Contractor assessors do not understand that hearing aids, cochlear implants and other assistive listening devices do not restore normal hearing. A deaf young person using such technology will still not have full access to normal sound.

4.2. Is DWP quality control for contractors sufficient and effective?

- 4.2.1. The DWP PIP Assessment Guide does not contain sufficient guidance around deafness in young people. This is undoubtedly a source of the problems with assessments.
- 4.2.2. Furthermore, a revised version of the assessment guide had not been published for over a year and has only just been published in November 2017. During this time there have been important developments in case law which concerned mobility; and safety and supervision. The government amended the PIP Regulations, effective from March 2017 in response to the earlier decision. The haste with which the government amended the Regulations contrasts with the long delay in issuing the revised PIP assessment guide.
- 4.2.3. The delays in publishing guidance on changes in case law has put assessors in a position, for up to 17 months, of recommending descriptors that will result in unlawful decisions. Claimants have to appeal to Tribunals in order to get the entitlement the law already allows them.
- 4.2.4. PIP assessment contract providers have produced their own 'Condition Insight Reports' into many conditions, including deafness, but these are different for each provider and are seemingly not overseen by the DWP. Additionally, it is not clear whether assessors actually read the Insight Reports.

5. Mandatory Reconsideration and appeal

5.1. Why do claimants seek to overturn initial assessment outcomes?

- 5.1.1. Deaf young people seek to overturn the initial assessment outcome for PIP because they have not been awarded PIP but feel they should have been. They often feel that the assessor has not understood their deafness and the impact on their daily life. They feel that the difficulties they experience have not been recognised by the assessor or decision maker.
- 5.1.2. Where deaf young people have access to advice, advisers are able to inform them that they have been wrongly underscored on the descriptors.

5.2. Is the Mandatory Reconsideration process working well for claimants?

- 5.2.1. No; it is not working well for deaf young people. The Mandatory Reconsideration decision maker almost always repeats what the original decision maker has said. Deaf young people find that the stage merely 'rubber stamps' the PIP assessment report and the earlier decision. This stage drags out the process for the claimant and causes distress and confusion.
- 5.2.2. In May 2017 the DWP confirmed in a response to a FOI request that: *"The key measures which are used by the Department for Work and Pensions to monitor Mandatory Reconsideration (MR) performance are: a) 90% to be cleared within target. b) **80% of the original decisions are to be upheld.**"*
- 5.2.3. Such performance indicators are, in our view, unlawful. They make a mockery of the Mandatory Reconsideration scheme which, viewed against such performance measures becomes merely a means of delaying claimants' rights of appeal to a Tribunal. Civil servants have denied at meetings that the performance indicators exist but if this is the case, why was this FOI response issued?

5.3. What accounts for the rate of overturned decisions at appeal for PIP?

- 5.3.1. The Tribunal is starting from a totally different perspective. Their primary function is not to follow DWP policy and they are not influenced by budget constraints. They have a legal responsibility to follow the law and look at the case completely fairly.
- 5.3.2. A high proportion of decisions are overturned at appeal because the earlier stages such as evidence gathering, assessment, and decision making, have not been of high enough quality to make a reliable and accurate decision.
- 5.3.3. The Tribunal has an inquisitorial duty and may ask more probing or relevant questions of the deaf young person.

5.4. What changes could be made to ensure fewer claimants feel they need to appeal?

- 5.4.1. An online system which clearly sets out the PIP activities, descriptors, scoring system, and guidance on further evidence would make it clearer to deaf young people about what they need to provide, which may result in assessors gathering more relevant information from the claimant.
- 5.4.2. The PIP2 form should be fundamentally re-designed to reflect the PIP descriptors and to give the claimant information on what they are and what the scores for them are. Most of the questions do not relate to the PIP descriptors. As claimants are not given copies of the descriptors or their scores, unless they have access to welfare rights advice, they are not likely to realise that this is the information that will make the difference between them qualifying or not for PIP.
- 5.4.3. The exact descriptors and scoring system should be sent out along with the PIP2 form. This would ensure the claimant would know exactly what they were being assessed on and may result in gathering more relevant evidence and the claimant giving more relevant information to the assessor and decision maker.
- 5.4.4. The quality of assessments of deaf young people needs to improve in order to gather useful information from the claimant about their functionality.
- 5.4.5. The 'function first' approach which has been trialled by the assessment providers should be taken forward. This approach refers to the order in which questions are asked during the assessment. The most relevant activities to the individual claimant should be discussed first and only once these have been explored should the assessor also cover the other ones. This would ensure that the most relevant activities would be discussed when the assessor and claimant were fresh.
- 5.4.6. Improved training for assessors around deafness and the barriers that deaf young people face in relation to the PIP activities.
- 5.4.7. More probing questioning around a deaf young person's functionality. Instead of saying "Do you have hearing aids?" asking questions about the limitations of the hearing aids. The assessor should ask probing questions about the deaf young person's ability to communicate in background noise, poor acoustics, group conversations and if they have poor access to lip patterns.
- 5.4.8. A change in approach to gathering further evidence. The emphasis seems to be on GPs. Deaf young people will not see their GP about their deafness. Assessors and case managers need to be aware of gathering further evidence from the claimant themselves, from family members, friends, colleagues, and the right professionals who actually know about the deaf young person.

5.4.9. DWP decision makers at the initial decision making stage and the Mandatory Reconsideration need to be looking at the case more critically. They should not automatically accept the healthcare professional's view if the evidence from the deaf young person, their family and the professionals who know the deaf young person well conflicts with this.

6. Claimant experiences

6.1. Do prospective claimants currently understand the purpose of the assessment?

- 6.1.1. The PIP assessment can be a difficult concept for deaf young people to understand, particularly if they are as young as 16. Deaf young people have often spent their whole lives trying to fit in and downplay their disability; consequently young people may find it particularly difficult and unnatural to talk about their difficulties.
- 6.1.2. Many deaf young people attend the assessment with a family member and rely on them for moral support and clarification. The person accompanying the claimant will often clarify things with them and may add to the claimant's contributions. Where such interventions take place, the assessor should record this and consider whether it demonstrates that the young person needs communication or social support.
- 6.1.3. Even if some claimants do understand that the purpose of the process is to get PIP, they do not understand the scoring mechanism for the descriptors, because they have not always seen this before hand.

6.2. How could claimants be helped to better understand the assessment process?

- 6.2.1. Sending a clear breakdown of the PIP descriptors and the scoring system in advance of the assessment would help people to understand what they will actually be assessed on.
- 6.2.2. Information about the PIP process needs to be conveyed in a more accessible format for young people, using social media platforms and video content.
- 6.2.3. Introducing an online system is something that would help many claimants to better understand the whole process. This could be in a chronology, timeline format, showing the claimant the different steps of the process and what's coming next.
- 6.2.4. Another argument for introducing an online system is that many deaf claimants report experiencing problems with having to use the telephone for certain stages of the PIP process, and with receiving missed calls from the DWP and the assessment providers.
- 6.2.5. Many deaf young people cannot access the telephone. Therefore, they cannot apply for PIP, and be contacted about PIP in the same way as another claimant.
- 6.2.6. We have been informed that the online system has been developed and is effectively 'ready to go'. The barrier is in getting the funding from the Treasury to actually roll this out.
- 6.2.7. We are keen to see a digital journey implemented as soon as possible. This is long overdue and has been clearly recommended by Paul Gray in his second independent review of PIP.

6.2.8. **Example** *“First problem I came across was pretty obvious. The only way I could get the application form was contacting them via phone, now obviously I can’t do this at all.” (Deaf claimant, 24 at the time).*

6.3. Are some groups of claimants particularly likely to encounter problems with their assessments?

6.3.1. Many deaf young people report poor experiences of PIP assessments. Most of the problems arise as a result of a lack of understanding on the part of the assessors.

6.3.2. One of the main problems with the assessments is that they are carried out in almost perfect listening conditions. Typically they take place in a small quiet room and will involve one-to-one communication. This is not representative of the situations that deaf young people face on a daily basis. A deaf young person may communicate well in perfect listening conditions but will find it extremely difficult in noisy classrooms and public spaces where there is lots of background noise and different people talking at the same time.

6.3.3. Hearing aids and cochlear implants amplify all sounds, including background noise, and the instrument wearer does not have the ability a ‘normally hearing’ person does to filter out the sound they want to ignore. Therefore, the assessor will not be seeing an accurate display of the deaf young person’s functionality, as they will be observing the claimant in optimum listening conditions.

6.3.4. We believe it is vital for assessors to request that a ‘speech in noise’ test is carried out by the claimant’s audiologist, in every case.

6.3.5. **Example** *“We attended and we’re taken to a very small quiet room. My son lip read her throughout. I felt that every question was there to trick my son. For example she said ‘can you hear and understand me’ and he said ‘yes’, but I told him to explain why he could i.e. it was a very quiet room, no background noise, he was close to her to lip read.” (Parent of a young deaf claimant).*

6.3.6. Assessors do not understand deafness. This results in assessors misinterpreting a deaf young person’s behaviour as functioning well. Often the deaf young person will be looking directly at the assessor, because they are relying on reading the assessors face and lips in order to try to understand what’s being said. The assessor will often judge this to be evidence of good communication, understanding and engagement.

6.3.7. **Example** The mother of a young deaf woman got in touch with us to say, *“They also said in their report that my daughter’s eyesight helped to compensate for being deaf.”*

6.3.8. Deaf young people are rarely awarded points for Activity 8 and Activity 10 following the assessment, but often are at Tribunal stage. We don’t think assessors are aware of the

impact that being deaf has on areas such as language, reading and numeracy. A reference to this needs to be added to the PIP Assessment Guide.

6.3.9. We know that some deaf claimants experience inaccurate hearing tests at the hands of the assessors, which they report to find degrading. The assessor will ask the deaf young person to face a wall and crudely test whether or not they can hear certain words. This does not qualify as an accurate test of someone's hearing and does not effectively assess the barriers that they will face in relation to the descriptors. This practice must be banned.

6.3.10. **Example** *"My daughter who wears a hearing aid in left ear when she went for pip assessment was told to stand in the corner facing the wall and the assessor came up behind her and said can you hear me? I find this very disrespectful."* (Parent of a deaf young person)

6.4. Should the assessment processes for PIP and ESA be more closely integrated?

7.4.1. No. The ESA descriptors are too different from the PIP descriptors. It would not be accurate.

6.5. Impact on the wellbeing of deaf young people

6.5.1. We are concerned about the impact of the PIP process on deaf young people. At the age of 16, young people are going through a difficult time with exams, transition from school to college etc. We do not think claimants under the age of 18, who are still children, should be obliged to go for a face to face PIP assessment.

6.6. Access to PIP assessment centres for deaf claimants

6.6.1. It recently came to light that claimants attending a PIP assessment centre have to use an intercom in order to speak to the Site Coordinator and access the building. This presents a barrier in even entering the building, which is bound to make the whole experience more stressful.

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