

Written evidence from Mind (PIP0016)

Background and summary of response

1. We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We campaign to improve services, raise awareness and promote understanding.
2. In March 2017 we surveyed over 800 people with mental health problems who have had experience of making a claim to PIP:
 - **8%** told us that their assessor understood the impact their mental health problem had on them.
 - **7%** reported that their GP had been contacted for evidence, with a further 35% saying they were unsure if there had been contact.
 - **52%** had taken steps to challenge their decision through mandatory reconsideration or appeal.
 - **87%** said the process of claiming PIP had a negative impact on their mental health.
3. Those who had better experiences of claiming PIP highlighted skilled and experienced assessors who were able to demonstrate that they understood mental health, and ask sensitive questions. Often those with positive experiences were supported throughout the process by welfare rights advisers, friends or family members.
4. The worst experiences tended to involve assessors who lacked a basic understanding of mental health, and who made assumptions about a person's mental state without asking detailed and sensitive questions. This was often compounded by a lack of transparency in how decisions were made, including through the mandatory reconsideration process. In many cases, the people we heard from had never been informed in any detail about why their claim wasn't successful, and so were left to conclude that they had simply not been listened to.
5. In addition we spoke to welfare rights advisers from 12 Local Minds, independent charities that provide different kinds of support services for people with mental health problems in their area. All of the organisations we spoke to highlighted a significant increase in the number of people they are seeing who need support to appeal a PIP decision. Several mentioned that over the past year PIP had become the welfare issue they were contacted about most frequently by people with mental health

problems.

6. This response highlights concerns with the following aspects of the PIP process:
 - The PIP form
 - The face-to-face assessment
 - Collecting medical evidence
 - Skills and experience of assessors
 - Quality of healthcare professionals' reports
 - Transparency of the PIP process
 - Mandatory reconsideration
 - Mental health and mobility
7. While this response makes recommendations about specific aspects of the PIP process, we are increasingly concerned about how PIP is operating as a whole. Statistics released by the Department for Work and Pensions in December 2016 found that 55% of people with mental health problems had lost support in the migration from Disability Living Allowance to PIP. As the rollout has accelerated in recent months, we have seen a significant number of people with mental health problems raise concerns about poor decision-making, and inappropriate treatment during assessments. It's crucial that the Department for Work and Pensions commits to transparently monitoring and evaluating the PIP rollout in order to allow greater scrutiny of the process.

The PIP form

"I think the PIP form is too complicated for someone with mental issues to understand when struggling with reading and communication. It's too long with 15 question each broken down into three parts. The form is intimidating- over 30 pages long, and needs a booklet to explain it!"

"I wish they would make the forms easier to complete and a separate one for mental health would greatly help. I'm currently going through it all again waiting to see if they accept my renewal forms etc."

8. Many of the individuals who responded to our survey told us that they found the PIP1 form difficult to complete without support. Most comments focused on the length of the form and the associated guidance, as well as the difficulty people experienced in writing at length about how their mental health affects them. There was a general perception that the form was focused too heavily on physical disabilities or health problems, and that it was not clear where people could write about the impact of their mental health problem.
9. Several expressed that they would prefer to have a form which focused on mental health or other hidden impairments – although it was noted that

this approach would not work for people who were claiming PIP for multiple conditions.

10. To improve the PIP form for people with mental health problems the Department of Work and Pensions should trial improvements to the form with people with input from people with mental health problems and other hidden impairments.

The face-to-face assessment

“I had my assessment today it completely raised my anxiety levels. I had to arrange a friend to take time off from her job to come with me.[...]I hated the waiting room and felt uncomfortable around a lot of people. I was so glad to get away. I had to travel by train and even with my friend it was difficult. I’m now feeling very low due to having to talk in depth about how my mental health affects me.”

11. The face-to-face assessment is a particularly difficult experience for many people with mental health problems, particularly where someone doesn't have access to support to help them with their claim. People find the experience challenging for a variety of reasons including:

- Many people find it difficult to talk to someone unfamiliar about their mental health because of stigma, embarrassment or worries about being perceived as weak or unable to cope.
- Many people will look to minimise the impact their condition has on their day-to-day life and instead look to focus on their hopes for recovery and what they are able to do.
- Some people with mental health problems experience problems with their memory, thinking and orientation, making it difficult to understand and talk about how their condition affects them.
- Even where someone has good insight into their condition, feelings of anxiety or distress can make it very difficult for someone to articulate themselves, and to challenge assumptions or comments which they disagree with.
- The experience of talking about stressful or traumatic issues without support can be damaging to a person’s mental health and recovery.

12. Through our survey we heard from a number of people whose mental health deteriorated during or after their assessment. This included people who experienced panic attacks, paranoid thoughts, and some who self-harmed or attempted suicide following their assessment.

13. While later in this response we highlight significant issues with the current process, it is worth emphasising that face-to-face benefits assessments

are, by their very nature, likely to be stressful and difficult experiences for many people with mental health problems. **For this reason we believe it's crucial that the Department for Work and Pensions and providers take action to reduce the number of unnecessary assessments. This should include a far more proactive approach to collecting medical evidence from healthcare professionals, and an increased use of long-term awards to avoid unnecessary reassessments.**

14. The Department for Work and Pensions should also put in place systems to take into account how the timing of a PIP decision might coincide with an ESA reassessment, and avoid situations where people with mental health problems are expected to go through several stressful and time-consuming assessments within a short space of time.

Collecting medical evidence

“It was not clear at the beginning of the process that I needed to gather medical evidence. I assumed, because they ask for the details, that they would contact the doctors and specialists.”

15. The vast majority of the individuals and organisations we spoke to in gathering evidence for this submission were clear that assessors do not routinely contact GPs of people with mental health problems claiming PIP. Only 7% of those surveyed said their GP has been contacted, with a further 35% saying they were unsure. By contrast most people with mental health problems we talked to expected and assumed their GP would be contacted after including their details on the PIP1 form.
16. Better and more frequent evidence collection from GPs would not by itself solve all of the issues with the PIP process. Some people with mental health problems will have a positive and trusting relationship with their GP, but for others their GP will not be in a position to provide evidence that will be useful for the assessment. However, even if an assessor still decides to proceed with a face-to-face assessment, speaking to someone's healthcare professional first can help them prepare and increase the likelihood that they ask relevant and sensitive questions.
17. Some people with mental health problems will be supported by a range of healthcare professionals including therapists, psychiatrists, psychiatric nurses, and care co-ordinators. While assessors have the option of asking GPs for medical evidence using a 'factual report form' (and compensate them for filling it out) this option does not exist for other kinds of healthcare professional. As a result assessment providers are very rarely willing or able to seek their input before a face-to-face assessment.
18. Making it easier to gather evidence from mental healthcare professionals would make a difference to many people with mental health problems, but

it's vital that assessors do not make assumptions about someone's condition based on the kind of support they are able to access. There are still serious gaps in mental healthcare provision, which mean that in England 75% of people don't have access to any kind of treatment at all. Assessors should gather medical evidence where it is available, but we have seen many cases where PIP assessors have taken a lack of available evidence to mean that someone is not in real need of support.

19. Some people with mental health problems will look to gather their own evidence in advance of an assessment, sometimes incurring a cost to do so. Often this evidence consists of medical notes about their condition, which do not address the specific PIP criteria, and so do not make a difference to their claim. While we strongly believe that the responsibility for gathering medical evidence should rest with the provider, there should be more guidance for individuals who choose to gather their own evidence.
20. Many of the Local Minds we spoke to told us that evidence provided by support workers or carers was rarely taken into account during the assessment process, despite the fact that they will often be in a better position than other professionals to talk about the day-to-day impact someone's condition has on them. This concern was also highlighted in the Second Independent Review of PIP published in March 2017. It has been suggested that this is likely a result of a perception that support workers will have a closer day-to-day relationship with someone making a claim and will therefore be less likely to be impartial. We would emphasise that while DWP decision-makers will make their own decisions about how to prioritise evidence, it's absolutely crucial that assessors do not simply omit relevant evidence from their reports to the DWP. Doing so simply increases the risk of poor and inaccurate decision-making, and denies people with mental health problems the chance to make sure that those who know them well are able to inform their claim.
21. To improve the process of collecting medical evidence, we recommend that the Department for Work and Pensions:
 - **Require providers to proactively collect medical evidence wherever a person is claiming PIP primarily for a mental health problem or other hidden impairment.**
 - **Change the factual report form for GPs to include questions about the prognosis of a person's condition. This would better inform decision-makers' use of long-term awards.**
 - **Set an expectation that evidence from support workers should be collected and included in the healthcare professionals' report in the same way as other evidence.**

- **Extend the 'factual report form' for GPs to a wider range of mental healthcare professionals.**
- **Produce and promote a version of the report form for GPs that people with mental health problems and those supporting them can use to help them gather their own evidence.**

Skills and experience of assessors around mental health

"I felt that the assessor saw me when I was fairly well and didn't take into account the change in how I feel. For example I have bipolar how I am when I am feeling well is very different to times of crisis. I feel the questions asked were mainly about physical problems so someone with a mental health problem would struggle to meet the criteria."

"I was also asked dangerous trigger questions without warning during the assessment."

"My assessment was with a physiotherapist who was visibly uncomfortable with the details of my self-harming and experiences it was awful."

22. Of the people we surveyed, only 8% told us their assessor understood how their mental health affected them. We heard frequently that assessors did not ask people how their mental health or functioning fluctuated over time, despite this being a requirement of the PIP process. Others told us that even when they went out of the way to explain how their condition varied, this information did not make it into their final report.
23. We heard many individual examples of assessors lacking sensitivity in the way they conducted the assessment. Examples included not allowing people time to take breaks or leave the room, visible discomfort when talking about mental health, and insensitive language and lines of questioning.
24. A significant number of people we heard from were unhappy with the way assessors had included informal observations in their final reports. These observations frequently included comments about the way a person was dressed, their ability to make eye contact, or how articulate they appeared to be during the assessment. Often the fact that a person had travelled to the assessment centre was used to indicate they did not have mobility needs, even where a support worker or family member had accompanied them.
25. Many of these informal observations do not provide insight into someone's mental health or how it affects them. The fact that assessors had not

explicitly discussed these observations before recording them also meant that they had not taken the time to consider whether they provided a representative picture of how that person usually is. The responses to our survey show that the way these observations are used damages trust in the process by depriving people with mental health problems of the chance to address issues that will affect the outcome of their claim. There is no reason why assessors should not be able to discuss any observations during the assessment itself.

26. Those who were claiming PIP as a result of multiple conditions frequently mentioned that their assessor focused excessively on physical conditions and often did not give them the space to talk about their mental health.
27. To improve the assessment process for people with mental health problems, we recommend that the Department for Work and Pensions and providers:
 - **Pilot the introduction of specialist assessors, with a focus on mental health and other hidden impairments.**
 - **Make sure that all assessors have face-to-face mental health training that focuses on how someone's mental health can affect how they engage with the assessment process, and practical steps an assessor can take to support someone during an assessment.**
 - **Give assessors specific guidance and training about the use of informal observations.**
 - **Make sure through training, guidance, and quality assurance processes that assessors always ask questions about whether someone can complete an activity, safely, reliably, and as often as needed.**
 - **Give assessors specific training and guidance around the mental health of people with long-term physical, cognitive, or sensory conditions.**
 - **Design internal processes so that assessors have enough time to read a person's PIP claim documents, and request specialist advice or coaching before the assessment takes place.**

Quality of healthcare professionals' reports

28. Many respondents told us that when they were able to access the reports that assessors had sent to the DWP, they found these to contain factual

inaccuracies or significant omissions. In one case an individual had talked about how she hoped to be able to manage weekly grocery shopping as part of her recovery. She later found that the report from her assessor simply said that she was able to do a weekly shop without support.

29. In other cases the details most frequently omitted were around how a person's condition fluctuated over time or what support they needed to be able to carry out an activity safely. For example several people told us that the fact that they needed family members to prompt them to eat or get dressed was not recorded in their report, despite being relevant to the PIP criteria.
30. We note that the Second Independent Review of PIP raised concerns about inconsistencies in providers' approaches to when reports are written, and recommended that this should always happen directly after an assessment to minimise the risk that important information is omitted.
31. To improve the quality of healthcare professionals' reports, we recommend that:
 - **The Department for Work and Pensions improve the standards to which assessment providers are held. The Department should adopt more robust and transparent ways to investigate the quality of reports.**
 - **Assessment providers allow more time for assessors to write reports, and make sure these are completed directly following an assessment.**

Transparency of the PIP process

32. The majority of people who contacted us did not think their decision was fair. 52% had challenged their decision through mandatory reconsideration or appeal. A further 22% did not feel their decision was fair but did not have plans to challenge it, often because they were concerned about the impact on their mental health of going through a lengthy appeal. This lack of trust in the system is exacerbated by the fact that people are not routinely given copies of their healthcare professional's report unless they request it. This means that, regardless of the quality of decision-making, people simply have no way of knowing why the evidence they gave at their face-to-face assessment wasn't taken into account.
33. Few of the people we spoke to were aware that they could choose to record their assessment, and some mentioned practical difficulties in obtaining the relevant equipment or getting permission from their assessor. Where someone does choose to record their assessment, this

can be vital in improving the quality of decisions made at mandatory reconsideration or appeal.

34. To improve the transparency of the PIP process, we recommend that the Department for Work and Pensions:

- **Send healthcare professionals' reports to people claiming PIP as a matter of course.**
- **Make it easier for people claiming PIP to choose to have their assessment recorded. This should include making sure the necessary equipment is on hand, and explaining this option at the start of each face-to-face assessment.**
- **Take steps to make sure that where someone has requested that those supporting them are included in correspondence, that wish is respected in every instance.**

Mandatory reconsideration

35. Respondents frequently told us that they were not given any information about why their original decision was upheld at mandatory reconsideration. Organisations also told us that the lack of a standard form and the expectation that people should call the DWP to request a mandatory reconsideration was a real barrier to access, particularly for people who struggle to talk to unfamiliar people on the phone.

36. To improve the transparency of the PIP process, we recommend that the Department for Work and Pensions:

- **Create a mechanism for independent oversight and scrutiny of the mandatory reconsideration process.**
- **Make the process for requesting a mandatory consideration clearer and simpler, including through an online form.**

Mental health and mobility

“Having to use public transport or being around people I don't will keep me awake for nights beforehand and if my husband doesn't support me I wouldn't go anywhere.”

“Not being able to cope with going out has a major impact on my existence. I rarely see people, am even limited in what food I can eat as I can't deal with supermarkets at all. I take diazepam if I have no choice but to go out and this makes my responses very slow and people get impatient and sometimes are really rude. But I got zero points for mobility.”

37. Respondents to our survey identified extra transport costs as the second most common reason for claiming PIP (after costs associated with increased household bills). Despite this a significant number of people described difficulty in scoring points under the mobility descriptors of PIP. This reflects the situation nationally, where 62% of people with mental health problems who receive PIP do not receive any support through the mobility component. The equivalent figure under Disability Living Allowance is currently 11%.
38. Recent changes to the PIP regulations mean that people who cannot plan or follow journeys because of psychological distress will be prohibited from scoring points under several of the mobility descriptors. Examples provided by the Department of Work and Pensions show that this means people with mental health problems will only be able to access the enhanced mobility rate if they can demonstrate that their condition causes significant impairment to their cognitive function. People who struggle to make journeys because of overwhelming anxiety, panic attacks, or the need for psychological support will not be entitled to the higher rate.
39. We are very concerned that these changes contradict the intention of PIP to cover the extra costs of disability, regardless of what kind of condition a person has.
40. We also believe the wording of the new regulations is likely to lead to unintended consequences, as it requires assessors to distinguish psychological distress from other symptoms of a mental health problem. This requires a level of understanding around mental health which simply does not yet exist within the current system. We are not aware of whether the Department of Work and Pensions plans to issue further guidance or training for assessors which will address these issues.
- 41. We recommend that the Government repeal these regulations in order to restore the original intent of PIP as a benefit which is awarded on the basis of how a person's condition affects them, and not the nature of the condition itself.**

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