

## **Mind and SAMH submission to the Work and Pensions Committee inquiry on PIP and ESA assessments**

### Mind

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 provide advice and support to empower anyone experiencing a mental health problem. We campaign to improve services, raise awareness and promote understanding.

### SAMH

SAMH is the Scottish Association for Mental Health. Around since 1923, SAMH currently operates over 60 services in communities across Scotland providing mental health social care support, homelessness, addictions and employment services, among others. These services together with our national programme work in See Me, respect me, suicide prevention, sport and physical activity; inform our policy and campaign work to influence positive social change.

## **Background and summary of response**

1. This submission is based on Mind and SAMH's engagement with people with mental health problems who have experience of PIP and ESA assessments. This includes information gathered from local services as well as surveys of 800 people with mental health problems claiming PIP and 2000 people claiming ESA in 2017.<sup>1,2</sup>
2. In this response we highlight the need to improve skills and training of assessors, the need to change the style and structure of assessments, and the need to reduce unnecessary face-to-face reassessments through better evidence collection as three of the most urgent reforms needed to both ESA and PIP assessments. Too many people tell us that when they go to assessments they do not have an opportunity to talk about how their mental health really affects their life, or that when they do so their evidence is not taken into account. We know that there are practical steps the Department for Work and Pensions can take to change this.
3. However we also know that for many people with mental health problems, the barriers they face in the benefits system are cumulative. Complicated letters and forms, difficulties securing adjustments, and a lack of transparency behind decision-making can make applying for either benefit stressful, time-consuming and impossible to navigate without support. This can have a real effect on a person's mental health, disrupting their recovery and making it harder for them to focus on the things that keep them well. This submission contains recommendations to reduce the pressure and complexity that people with mental health problems face throughout the process.

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<sup>1</sup> [Mind submission to the Work and Pensions Committee's inquiry into PIP](#) (2017)

<sup>2</sup> [Mental health sector response to the Work, Health and Disability Green Paper](#) (2017)

## I. Improving the assessment process

"It is hard to be honest with the person during the assessments as you do not know or trust them and often feel ashamed of not being able to do normal things so it is hard to admit how things really are." – WCA

"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." – PIP

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

### Skills and experiences of assessors

4. The skills of benefits assessors for both PIP and ESA can vary significantly. However we hear frequently from people with mental health problems who have been assessed by healthcare professionals who lack a basic understanding of mental health. Often in these cases the problem is not that assessors lack specific clinical knowledge, but that they do not have good understanding of what it's like to have a mental health problem or do not ask sensitive questions about how someone's mental health affects them. The most common experiences we hear are:

#### 4.1 The use of 'informal observations' in assessment reports

Frequently people are described as 'well-groomed' or 'able to make eye contact', in healthcare professionals' reports. These comments are based on a misunderstanding of how mental health problems manifest themselves. A person's appearance is not an indication of their mental health, and how someone seems during an assessment will not necessarily reflect how they are on most days or in most situations. Regardless of how much weight decision-makers place on these observations, we know that when they are included in assessment reports people with mental health problems understandably lose trust in the wider process.

#### 4.2 Insensitive questions about self-harm or suicide.

This can include asking questions abruptly or without warning, assessors looking visibly uncomfortable throughout the conversation, or unnecessarily detailed questions about methods of self-harm. We have heard from several people who report being asked the question 'What has stopped you from killing yourself?' during a PIP assessment. This suggests that assessors have tried to find out whether a person has support in place, but have through lack of skills or training framed the question in a distressing and potentially harmful way.

- 4.3 A lack of awareness of how mental health conditions fluctuate.  
Points for both ESA and PIP should be awarded when the relevant descriptor applies for the majority of time. However too often people with mental health problems are not asked questions about how often they are able to undertake an activity, the kind of support they need to do it, or how they feel afterwards. Often questions are asked in quick succession, making it harder for people with mental health problems to interject or explain the way their condition fluctuates.
- 4.4 A lack of understanding about motivation and mental health  
Some mental health conditions can affect a person's motivation to carry out the kind of day-to-day tasks that could help keep them well. For example many of the people we hear from struggle to leave the house in order to get to the shops to buy ingredients or food as a result of severe and long-term depression. This can be just as much as a barrier to being able to prepare a meal as other kinds of physical or cognitive restrictions. Not eating regularly will further affect their mental and physical health. However they often do not score points under the relevant PIP descriptor because, once in the kitchen, with ingredients in front of them, they would physically be able to prepare a meal. Assessors very rarely ask questions about symptoms related to motivation, or explore these issues in depth. As a result people with mental health problems often assume they are only being asked about their physical ability to carry out the activity. This means they cannot access financial support to cover the costs of a care worker or to help manage reduced household income if a partner or family member spends time on their care.
- 4.5 Assumptions about access to mental health services  
We hear from many people who have found comments in their assessment reports that suggest that, because they are not receiving treatment from secondary mental health care services, their condition does not have a substantial effect on their lives. However there is a significant treatment gap with only a third of people with mental health problems get any kind of treatment or support at all. In many areas pressures on services mean that the majority of people will receive support from their GP even if they have a clear need for specialist treatment and support.<sup>3</sup>

**5. We recommend that the Department for Work and Pensions:**

- ***Pilot the use of specialist assessors where someone is claiming primarily for a mental health problem. This should be evaluated on the basis of the impact it has on people's experiences of assessments as well as the quality and consistency of assessment reports.***

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<sup>3</sup> [Mind \(2016\) Mental health in primary care](#)

- ***Require assessment providers to publish information about the professional backgrounds of their assessors and their training requirements.***
- ***Amend guidance and training materials for assessors to set an expectation that informal observations should be discussed during someone's assessment before they are included on an assessment report.***
- ***Require assessment providers to make sure that all assessment centre staff and call agents are trained to understand mental health problems and offer support and reassurance about the process.***

### **Accuracy of assessment reports**

6. While we do not have specific knowledge of the Department for Work and Pensions' quality control processes, people with mental health problems, Local Minds and SAMH services tell us that reports often contain significant factual errors. These can often be as fundamental as whether an assessment took place in someone's home or whether they were accompanied by a family member. Having the option to record an assessment would increase transparency. However securing permission to make a recording is complex and requires people to buy expensive and difficult to obtain equipment. ***We recommend that the Department for Work and Pensions require assessment providers to make recording equipment available and proactively offer anyone the option to record an assessment.***

### **Structure of assessments**

7. Both PIP and ESA assessments are often structured in ways which are hard for people with mental health problems. Some people will find it difficult to understand or articulate how their conditions affect them. Others may find the process difficult because of feelings of shame or fear of stigma. Many people try to focus on what they can do and their hopes for recovery, finding it distressing to have to spend time focusing on the ways in which their mental health problem can limit the things that they are able to do.<sup>4</sup>
8. While we believe the experience of assessments can be significantly improved for people with mental health problems, it is also vital that no-one should be required to attend a face-to-face assessment if there is any way this can be avoided. We note that under proposed arrangements for devolving powers relating to PIP to Scotland, the Scottish Government intends to significantly reduce the number of face to face

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<sup>4</sup> See Mind (2015) [Tribunal encourages Government to trial changes to fit-for-work benefits test](#)

assessments required. We suggest there may be learning to be gained from this process.

9. People tell us that they are often asked extensive questions about their physical capabilities, for example their ability to stand or walk, even when they are solely claiming the benefit because of a mental health problem. This is often described as distressing or humiliating, and damages people's trust that their assessor has read their application form or will understand their mental health.
10. Often one set of symptoms will affect someone's life in a range of ways. For example someone with severe social anxiety might find themselves unable to use public transport to make journeys, unable to go to the shops to buy essentials, unable to open letters to manage bills, and unable to engage socially with others. Yet the current structure of assessments will require people to repeat themselves in response to questions about each activity. This can be difficult and confusing, particularly given that many people struggle to talk about their mental health even with friends, family and healthcare professionals.

***11. We recommend that the Department for Work and Pensions:***

- ***Work with people with mental health problems to restructure assessment interviews in order to make it easier for people to talk about how their mental health affects their everyday life.***
- ***Prioritise avoiding unnecessary assessments through improving evidence-collection and increasing the use of longer-term awards.***

**Assessment criteria**

12. We frequently hear from people with mental health problems who tell us that both PIP and ESA assessments fail to take into account their mental health. However in some cases it can be difficult to determine where problems lie with the criteria themselves and where they lie with the way the criteria are being assessed in practice.

12.1 PIP daily living activities

Many of the PIP daily living activities should be applicable to anyone regardless of their condition. Most frequently we hear from people who have applied for PIP because they need support to engage with other people, make budgeting decisions, or to read and understand complex information. However these criteria are often not applied correctly by assessors or Department for Work and Pensions decision-makers due to inaccuracies in assessment reports and a lack of understanding of mental health conditions throughout the process. Until these

issues are addressed it is difficult to determine whether the criteria themselves are fit for purpose.

## 12.2 PIP mobility activities

Following changes to the criteria in March 2017, three descriptors that form part of the PIP mobility criteria now explicitly exclude people who struggle to plan or follow journeys because of 'psychological distress'.<sup>5</sup> We believe the new criteria run contrary to the spirit of PIP as an assessment which was designed to assess the impact a person's condition has on their life, regardless of the nature of the condition. People who struggle to make journeys because of psychological distress are just as restricted in their mobility as other disabled people, and face the same higher costs associated with support workers and taxi fares. They also face the same strains on their household income if a partner or family member needs to take time away from work to support them.

## 12.3 Work Capability Assessment criteria

The current Work Capability Assessment criteria are abstract and centred around a set of tasks that a person might have to complete in a generic workplace. These criteria often don't take into account the real barriers that might cause someone with a mental health problem to fall out of work. For example, someone who might be able to interact socially with their close family and healthcare professionals, may struggle in an environment which involved many interactions with customers and co-workers.

### ***13. We recommend that the Department for Work and Pensions:***

- ***For PIP – remove the restriction on people who experience psychological distress qualifying for the enhanced mobility rate.***
- ***For the WCA – work with people with mental health problems and disabled people more widely to redesign the criteria, with a particular focus on creating a system which assesses the real barriers that people face in specific kinds of jobs and workplace environments.***

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<sup>5</sup> [Mind briefing on changes to the mobility criteria](#)

## The Government's proposed reform of the Work Capability Assessment

14. In the Work, Health and Disability Green Paper, the Government proposed reforming the purpose of the Work Capability Assessment. In the suggested new model, the assessment would only be used to determine the level of financial support a person should be entitled to. There would then be a separate assessment to determine someone's employment support needs.
15. We would note that in the current system a person's employment support needs are determined by their Work Coach when they attend an appointment at a Jobcentre. Work Coaches have a wide amount of discretion to decide what support to refer someone to. The recently introduced 'Health and Work Conversation' was described by the Department as an early intervention that would help Work Coaches understand more about a person's barriers to work and tailor their support accordingly. So the separate assessment for employment support described in the Green Paper, has in effect already been introduced.
16. The only substantive difference between the current situation and the proposal set out in the Green Paper relates to conditionality and sanctions. Currently whether someone is placed in the WRAG group or Support Group will determine whether they can be required to engage with support or whether this will be voluntary. The Green Paper proposal would remove this distinction, so that those in the Support Group would still receive a higher level of benefit entitlement, but would be subject to mandatory requirements, at the discretion of Jobcentre staff.
17. Based on what we hear from people with mental health problems we do not believe this proposed change would improve the experience of the assessment for people with mental health problems or help them move towards employment. Instead this reform would leave thousands of people with the most severe mental health problems, who have been assessed by the Government's own system as too unwell to work, exposed to the risk of benefits sanctions for the first time. There is no evidence that this approach will achieve the Government's aim of supporting more people into work, and a growing body of evidence which suggests that it could push people further away from work and damage trust in the wider employment support system.<sup>6</sup>
18. ***We recommend that the Department for Work and Pensions does not adopt the model for the Work Capability Assessment proposed in the Green Paper.*** We believe there is a real opportunity to improve the experience of these assessments for thousands of people with mental health problems. This would require improving the skills and training of assessors, making greater use of medical evidence, changing the way assessment interviews are structured, and changing the

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<sup>6</sup> [Mind \(2017\) Employment and Support Allowance trials briefing](#)

criteria so that they reflect more of the barriers that people with mental health problems face in real workplaces.

## **Evidence collection**

- 19.** The majority of people we speak to expect that their GP will be contacted if they have listed them on their PIP or ESA form. However we know that often this evidence is either not requested by providers or not received in time for the assessment. This means that people often assume their assessor will be more familiar with their history and their condition than is the case.
- 20.** Where people choose to collect their own evidence from GPs or other professionals, this can often be generic and not targeted towards either the ESA or PIP criteria. This reduces the likelihood that the evidence will be used as part of their assessment. People rarely receive an explanation as to why this evidence was not used as part of their assessment, understandably leading them to conclude that the views of the people supporting them have been ignored.

### ***21. We recommend that the Department for Work and Pensions:***

- ***Require assessment providers to routinely request further medical evidence from GPs prior to a face-to-face assessment.***
- ***Require assessment providers to publish information about how frequently they request further medical evidence from GPs and other healthcare professionals, and how often this is received.***
- ***Provide greater clarity about the questions a person should ask of their GP or healthcare professional if they choose to gather their own evidence. This should include making a simple pro-forma available.***

## II. Making it easier to navigate the system

“I was denied PIP originally, my mandatory reconsideration was rejected and I was only awarded PIP following a tribunal. The eight months it took to receive the correct outcome were some of the worst in my life. My mental health deteriorated, I began self-harming again, suicidal thoughts increased, I shut down during therapy and couldn't speak, relationships became strained and I felt completely alone. It was humiliating and I'm terrified that I'll have to go through the process again in a year.”  
– PIP

“Personally it was a disaster. I received the form to fill in first. I had two weeks to gather evidence but that wasn't enough time. I made a request for a private room, but when I got there I ended up being locked in a room with a security guard. My appointment should have been at eleven o'clock and I didn't actually get to see anybody until quarter to one. There were no windows I had anxiety and I was having panic attacks.” – WCA

### The initial application

22. Many people with mental health problems tell us that they struggle to understand letters from the Department for Work and Pensions, and that they find the forms for both ESA and PIP difficult to relate to their mental health.
23. When someone first calls the Department for Work and Pensions to make a claim for PIP and ESA they will be screened for vulnerability. Usually those who are identified as vulnerable will be given extra time to complete their application or automatically referred to a face-to-face assessment if they do not complete their form in time. However we know that many people can struggle to disclose sensitive information about their mental health over the phone, and so will not be identified at this stage.

#### ***24. We recommend that the Department for Work and Pensions:***

- ***Review the PIP2 and ESA50 forms and test prompts and language that will make it easier for people with mental health problems to relate the questions to their own experiences.***
- ***Give people explicit information about any adjustments to the process they can request when they first make their claim.***

## Data sharing

25. While PIP and ESA are different benefits which have different purposes, we also know there are a significant number of people with mental health problems who claim both concurrently. Often lengthy waiting times for assessments and appeals, together with short award lengths, mean that a person may spend most months of the year in the process of applying for one of the two benefits. This lack of financial security can have a real impact on a person's mental health. It means that people with mental health problems often find themselves having to spend their time and energy repeatedly proving that they are unwell rather than focusing on their recovery.

***26. We recommend that the Department for Work and Pensions consult with disabled people about options for data-sharing between PIP and ESA assessments as well as between the Department and the wider health and social care system. This should be based on individual consent and include options that would allow the Department to avoid scheduling reassessments for both benefits within a short period of time.***

## Home assessments

27. Currently assessment providers have a wide degree of discretion about when to offer a home assessment. They are also able to require that a person provides medical evidence in order to secure a home assessment. We are contacted by many people who have had to pay for a GP letter as a result. This is inconsistent with the approach the Department takes to requesting GP evidence for assessments themselves, where their intention is that providers should bear the costs.

28. We have also seen cases where, having failed to secure a home assessment, a person's ability to travel to the assessment centre is taken as evidence that they do not have any mobility needs. This is often after people have managed to make the journey out of necessity and with intensive support from friends or family.

***29. We recommend that the Department for Work and Pensions:***

- ***Require assessment providers to cover the costs of collecting GP evidence where this is required to secure a home assessment.***
- ***Make sure that people are always aware of their right to request a home assessment, and their right to be reimbursed for the costs of travel.***

- ***Make clear through guidance to assessors and decision-makers that attending a benefits assessment should not be taken as evidence that a person can safely plan or follow journeys on most days.***

## Missed appointments

30. We have been contacted by many people with mental health problems who have had their benefit stopped after missing an assessment. Often this is because they were unwell, or had experienced significant anxiety or panic attacks before their assessment. In other cases people had not opened letters in several months because of anxiety, and missed the notice of their appointment date as a result.
31. The requirement to gather medical evidence to prove 'good reason' for missing an appointment can be particularly onerous, especially as it often comes when the person has already experienced a recent deterioration in their mental health. ***We recommend that the Department for Work and Pensions allow people the chance to reschedule a missed appointment without having to provide medical evidence of good cause.***

## Mandatory reconsideration

32. The majority of the people we hear from found that the Department for Work and Pensions' original decision was upheld at mandatory reconsideration. This includes many cases where the decision was then changed significantly at tribunal. In the decision letters we see, the reasons provided are brief and rarely engage with the grounds on which someone is challenging a particular decision.
33. People do not automatically receive a copy of their assessment report with their decision letter. This can make it harder to make an informed decision about whether to request a mandatory reconsideration and on what grounds. ***We recommend that the Department for Work and Pensions enclose these reports as a matter of course.***

## Appeals and advocacy

34. Many Local Minds which provide benefits advice have seen large increases in the number of people seeking benefits advice in recent years, with a significant proportion spending most of their time on PIP appeals. The demand on these and other advice services often means that people are not able to see an adviser face-to-face until they have reached the mandatory reconsideration or appeal stage of their claim. In 2016 the Scottish Government's 'Welfare Advocacy Pilot Project' found that advocacy support through PIP and ESA assessments reduced anxiety, increased confidence and led to more accurate decision-making.<sup>7</sup>

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<sup>7</sup> Alliance [Welfare Advocacy Support Project evaluation report](#) 2016

35. In England and Wales the 2012 reforms to legal aid have significantly reduced the number of social security cases eligible for state funding (from nearly 90,000 in 2013 to fewer than 150 in 2014).<sup>8</sup> This has meant that people with mental health problems who cannot find support from a welfare advocacy service have to represent themselves at tribunal, reducing their likelihood of success, or decide not to pursue an appeal. Without the possibility of legal redress at an early stage, the situation these individuals are facing is likely to worsen.
36. Frequently we see tribunals asking more nuanced and sensitive questions about fluctuation and the way a person's mental health affects them. While the process of attending a tribunal is often stressful and anxiety-inducing, we have heard from people with mental health problems who have told us that this is the first part of the assessment process where they felt the professional they were speaking to listened to them and understood how their mental health affects them.
37. While the Department for Work and Pensions has increased the number of presiding officers attending appeals, there is still no mechanism for assessment providers to hear the reasons behind an appeal decision. Unless both decision-makers and assessors understand these reasons, it is likely that poor practice will continue.

***38. We recommend that the Government:***

- ***Work across national and local Government to increase the provision of specialist advice and advocacy services.***
- ***In England and Wales reinstate legal aid eligibility for appeals to First Tier Tribunals for PIP and ESA***
- ***Create a mechanism that will allow representatives from assessment providers to attend appeal decisions and understand why so many claims have been overturned.***

## **Devolution**

39. A number of benefits are in the process of being devolved to Scotland including PIP. Other benefits, such as ESA and Universal Credit remaining reserved. The system is already complex and there will be two systems for many Scottish claimants, with different expectations and cultures. **There will therefore need to be ongoing coordination between the Scottish Government and Westminster over reserved powers and benefits.**

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<sup>8</sup> [SSAC \(2016\) Decision making and mandatory reconsideration](#)