



Mind submission to the Personal Independence Payment Assessment - Independent Review

Introduction

Mind is only making a brief submission to the Independent Review as we are a co-signatory to the Disability Benefits Consortium (DBC) submission, which draws on broader sources of data and raises all the key concerns we wish the Independent Review team to consider.

However, we did wish to make a number of brief points that are particular to people with mental health problems and to share some initial data we have collected on people's experience of applying for PIP.

Context

Mind was certainly not opposed to the reform of DLA. The benefit was not particularly accessible to people with mental health problems when it was first established and, although take-up has increased through growing awareness and changes in case law, only about 16 per cent of claims are primarily for mental health (compared to about a third of ESA claims).

However, it is far from clear that the changes we wanted to see (in terms of better access for people with mental health problems) and the changes the Government wanted to see (more frequent reassessment and more face-to-face assessments) required the abolition of DLA and the introduction of PIP.

The new benefit was fundamentally undermined in the eyes of disabled people from the beginning, due to the fact that it was announced in the 2010 budget as a means to save 20 per cent of the DLA budget by 2015. From this compromised starting point, it was always going to be difficult to have any faith in Government reassurances that the reforms would be principled. The subsequent emphasis on supporting those in the 'greatest need' has only served to increase fears that those with more moderate needs are set to lose out.

Most people with mental health problems receive the lower rates of DLA. As a result, although the new assessment has more explicit reference to mental health than DLA, we expect many people we represent will struggle to qualify for PIP due to the raised threshold. Cutting this small amount of support to people with moderate needs will lead to greater costs for health and social care services.

Any reform of DLA should have started from the understanding that the best way to reduce the cost of supporting disabled people is to help them overcome the barriers they face where possible, and ensure that their support prevents a deterioration of their condition. By instead looking to restrict support to those with the most severe needs, we believe that the Government's approach will disadvantage many disabled people and cost more in the long term.

Our experience of PIP so far

We are yet to see enough robust and extensive data, or to hear from enough people with mental health problems who have been through the assessment process, to have a clear view on how the new system is operating.

The initial data from the DWP suggest that a greater proportion of PIP claims are going to people with mental health problems than was the case with DLA. However, it is not yet clear whether this translates to more people in total accessing this support or if mental health is simply getting a larger slice of a smaller pie.

Apart from the DWP data, and the data collected by the DBC, the only additional evidence we have access to are the small number of people who have contacted us about their experience of PIP and around 40 people who have completed part or all of a survey system we have set up to monitor people's experience of the new benefit.

This survey system attempts to remove the potential bias of people only completing the survey once they have the outcome of their assessment, by asking them to respond to questions at multiple points in the application process. We hope that, in the longer term, this will prove to be a valuable source of information on PIP.

We have included the initial findings from this system as an annex, but due to the small number of responses so far we appreciate that this only provides a snapshot of a few people's experiences.

Key concerns

As stated above, our key concerns are covered by the DBC submission to the Independent Review, which we are signed up to. However, there are a few areas where we would like to emphasise the impact of these issues on people with mental health problems:

- **Delays to the process** – as the DBC surveys and the comments in the annex demonstrate, the length of time people are having to wait to be assessed for PIP is a significant concern. This can be a particular issue for people with mental health problems because of the anxiety that this can cause and the knock on impact this can have on their health.
- **Speed of rollout** – although there have been some revisions to the roll-out of PIP in response to arising issues, we remain concerned that people are being reassessed from DLA before it is clear that the assessment process is working effectively and we would urge the review to call for a halt to this reassessment process until there is adequate data to come to an informed conclusion about how PIP is operating.
- **Access to support and advice** – as demonstrated by some of the comments in the annex, people with mental health problems face particular problems in negotiating complex application and assessment processes because of the anxiety this can cause and problems with self-advocating. We believe

the review should consider and comment on the impact of difficulties in accessing advice and support for people with disabilities (but particularly mental health problems) in terms of their experience of the application process and the likelihood of them receiving the right outcome.

- **Wider policy context** – We believe that it is vital that the introduction of PIP and the reassessment of people receiving DLA is not treated in isolation. Cuts and changes to other benefits and social care support means that the outcome of an application for PIP will have particular importance for many people. A raising of the threshold of eligibility across a number of support systems risks leaving people who have mild to moderate support needs with little or no access to support. For people with mental health problems, this is likely to lead to a deterioration in their condition which will be traumatic for them and will end up costing more in more acute support service. We encourage the review to try and take on board and comment on this wider context.

Annex – Responses to Mind’s ongoing PIP survey

What stage are you at in the application process?

I have filled in my application form but have not yet had a face-to-face assessment	20
I have had a face-to-face assessment but have not yet been told the outcome	7
I have had a face-to-face assessment and have been told the outcome	14

Initial application

How did you find the initial phone call?

Very easy	3
Easy	9
Neither easy nor difficult	5
Not sure	3
Difficult	8
Very difficult	4

Total	32
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How did you find filling in the application form?

Easy	1
Neither easy nor difficult	7
Difficult	13
Very difficult	11

Total	32
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I was able to communicate about my mental health problems in the form

Strongly agree	1
Agree	7
Don't know	1
Neither agree nor disagree	10
Disagree	3
Strongly disagree	10
Total	32

Face-to-face assessment

The assessor understood mental health

Strongly agree	1
Agree	4
Neither agree nor disagree	4
Disagree	1
Strongly disagree	3
Total	13

The assessor took on board what I said about my mental health

Strongly agree	2
Agree	2
Don't know	1
Neither agree nor disagree	1
Disagree	3
Strongly disagree	1
Total	10

I had the opportunity to explain how my condition fluctuates

Strongly agree	3
Agree	3
Neither agree nor disagree	1
Disagree	4
Strongly disagree	3
Total	14

The assessor gathered an accurate picture of the impact of my mental health problems

Strongly agree	1
Agree	2
Don't know	1
Neither agree nor disagree	4
Disagree	1
Strongly disagree	4
Total	14

The assessor explained what was recorded about me

Agree	2
Neither agree nor disagree	4
Disagree	4
Strongly disagree	3
Total	13

The assessment process was stressful

Strongly agree	7
Agree	4
Neither agree nor disagree	2
Total	13

The assessment process damaged my mental health

Strongly agree	5
Agree	5
Neither agree nor disagree	1
Total	11

Receiving a decision

The decision about my eligibility reflects the reality of the impact of my condition

Strongly agree	1
Agree	1
Disagree	4
Strongly disagree	7
Total	13

The decision was explained to me by the DWP

Strongly agree	1
Agree	1
Disagree	6
Strongly disagree	6
Total	14

Overall process

The process was straightforward

Agree	1
Disagree	3
Strongly disagree	10
Total	14

The process was stressful

Strongly agree	12
Agree	2
Total	14

The process damaged my mental health

Strongly agree	10
Agree	4
Total	14

Qualitative responses

Comments on the application form

"Form was more geared to mental health than DLA one as I remember. I got help with the form from my local Mind (Rushden). DWP originally told me I would hear in 5 weeks about medical and would all be sorted before DLA finished in May. Then when I called after 5 weeks was told it takes 15-20 weeks and I would have to call at end of DLA to check they would continue paying. Have had a letter saying Capita are dealing, but not had an appointment yet. Started the process in January! Just always on my mind, fuelling my anxiety and causes such conflict with my recovery...."

"Finding process very stressful, as I rely on DLA to survive, plus experiencing very long wait for reply after submitting form. Your questionnaire doesn't allow for 'not applicable' answers - eg to needing help with form."

"Phone call- I spoke on behalf of my 17 year old daughter. She still had to speak on the phone and had a panic attack, i had to take over, but the operator was understanding."

"The form took many hours of online research to get it right."

"I have never openly discussed my health problems due to the likely detrimental effect it will have upon my current/future employment. So completing the form was very stressful and indeed knocked my self-esteem."

"Huge form! Not relevant for mental issues! Long wait now for medical. I have waited 7 months for ESA medical, so God knows how long I will have to wait for this!"

"I was told not to include any medical forms from my doctor as they would get these so that I will not be charged, however this did not happen and my claim was disallowed. Upon the mandatory reconsideration, I had to go to my doctor and get my medical records."

"I found the first phone call very difficult as i hate the phone and the man on the other end was very dismissive the end result was i ended the phone call in tears, without even getting the form .i went to my local mind for help in the end and they phoned up for me and helped me fill in the form in, without their help and support i would not have seen the process though"

"I don't have problems completing forms other than I find the process humiliating and degrading. My care worker filled out the form for me which I regret as she has limited understanding of my illness."

"When you suffer from attention problems it takes a long time to complete mixed with depression it becomes a very stressful and long process."

Comments on decision and process

“The actual assessment was pure torture, didn't take into account the additional stress this causes to someone's mental health and the impact the process had.”

“I wasn't allowed to complete my original form. My medical notes were not requested. They made a decision on inaccurate info given by the assessor, as he had deliberately left out relative facts. When I challenged them with the facts, they still took the assessors word. I don't know how to appeal.”

“My application was submitted in May 2013. I had an at-home assessment by Capita on 9/08/13. I received a decision on 7/04/14. After months of phonecalls and emails. They lost my case notes, lied about progress. In the end I had to involve my local MP who got things moving in a fortnight. I have PTSD, Health Anxiety, Depression and severe anxiety. All triggered by the death of my 7 year old son from cancer in 2012. It's a very, very long process.”

“The application is very complicated. My 18 year old daughter would not have been able to put down all the ways in which her mental illness (bipolar, self-harm, eating disorder, anxiety and phobias) impact on her life. It is so over-complex, needing one to decipher how the descriptors apply to the individuals mental illness, not just what mental illness they actually have. My daughter was distraught when she read the form and did not want to apply, it was such personal and traumatic information that she would never share outside of the counselling situation. She has rightly been awarded the Enhanced level as these things impact so much on her life every day, but without help she would not have got anything (and she could not have ever told an adviser of the things I had to put on the form and the accompanying pages). At the face-to-face I put a note to the assessor from my daughter stating that she cannot talk over any triggering information i.e. self-harm. The assessor accepted that. I gave copies of all the medical letters with the form so the DWP knew she had these issues from her psychiatrist.”

“Nurse did not even consider my OCD which clashes with my ME/CFS. I had stitches from biopsy on day she came and she was trying to get me to do exercises. She told me she could go to police over a private issue. I was scared and OCD was made worse by her visit.”

“For people with personality disorders, stress and anxiety this process is not ideal. I was initially told it would take between 10 and 15 weeks, that was on the 06.01.2014 so it was around the 20 week mark before I heard anything and found out I have not been awarded anything.”

“The main basis of my claim is that I am depressed and therefore have little motivation to do everyday tasks. I was told that because I was able to do the tasks it was my choice not to do the (washing). Even though I haven't cooked for over 17 months was told I just needed prompting. I said I couldn't concentrate to read and have to re reread sentences frequently to understand them. I was told that as my previous employment was a primary school teacher I couldn't have a problem reading. I wasn't asked about everything I'd written in the face to face interview then told I'd made no comment even though welfare rights helped with my form and thought I had a good chance of getting an award. Farce. Mental health problems not catered for. Most unfair.”

Any other comments

“Capita are rubbish and I have awaited nearly 9 months for outcome they still staying its compile they blocked my messages and emails and ignored my local MP's texts and emails to point he asked for a meeting with chairman of Capita all in all dire”

“My advocate let me down on the day 'ill' I had to go alone I completely ran on adrenaline probably looked happy as anything! Could not get out of bed for the next 4 days!”

“The assessor was a CPN. She was very understanding of mental health issues.”

“The lady did not wear a name badge, she walked far ahead of me and my partner without talking to us. She proceeded to ask questions and just took notes. It was very formal, I did not feel relaxed and my rejection was entirely based on my behaviour at the face to face assessment. I have panic disorder but as I kept eye contact and didn't 'panic', I was found to not suffer from any cognitive impairment. In addition, she made me do a range of physical exercises which I found unnecessary and embarrassing.”

“I felt intimidated, coerced. I have severe OCD, social anxiety, ME/CFS and pre-cancer cells which have needed 3 surgeries to date, due another and I am entitled to nothing.”

“My fluctuating moods were not taken into consideration.”