

Rethink
Mental
Illness.

'It's
broken
her'

**Assessments
for disability
benefits and
mental health**

'That appeal was a nightmare and it's broken her. It's really broken her and it'll take two years to get right. It's always two years.'

Carer for someone with bipolar and anxiety disorders

'I have no problem when people don't understand mental health; it's when they have an opinion on something they don't know anything about.'

James (Full case study page 6)

'The decision is ultimately made about you but not with you, and that's just not the case for medical treatment.'

Hannah (Full case study page 8)

'The whole process was demeaning and stressful for us all.'

Jenny (Full case study page 12)

'After being declined PIP for a second time, I was self-harming and took an overdose. I ended up in hospital.'

Jack (Full case study page 15)

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Summary

Employment Support Allowance (ESA) and Personal Independence Payments (PIP) are vital for many people living with mental illnesses.*

ESA is paid when you are too unwell to work, and PIP is designed to cover the extra costs of living with a disability or long term condition. They help keep bills paid, food in the fridge and allow people to maintain their independence.

The money these benefits provide can mean the difference between not being able to leave the house and being an active member of society.

However, the assessment processes for both benefits are broken, and this is particularly true for mental illness.

People have shared their stories with Rethink Mental Illness of being hospitalised after assessments, of having to increase their medication, and of suicide attempts. The stories in this report clearly show that the current system is unfit for purpose, and is in desperate need of reform.

Our report explores some of the reasons that assessments are a major source of anxiety, trauma, and harm for people severely affected by mental illness.

Our recommendations (see page 5) for reform of these assessments are intended to create an assessment system that actually works for people with mental illness, and for the Government.

Reform of the assessment processes for ESA and PIP should start with these significant changes, in order to ensure that these assessments no longer worsen the mental health of those who undergo them.

'The detriment to my mental health because of the whole process and the unknown elements shows it is an appalling way to treat another human being.'

PIP respondent

* The background and full explanation of ESA and PIP is provided in the Appendix.

Our three key recommendations

1

A major reform of the PIP assessment and the WCA for ESA is needed.

This should result in both assessments reducing the distress caused to people affected by mental illness and that better reflect the realities of living with a condition of this type. Such reform would reduce the need for appeals and the associated costs to the DWP and HM Courts & Tribunals Service (HMCTS).

2

The Government should review the way in which people with mental illness are assessed.

Where clear medical evidence exists that claimants have severe forms of mental illness, they should be exempt from face-to-face assessments. Where face-to-face assessments are necessary, claimants should be encouraged to seek support from carers, friends or family members.

3

All assessors and DWP decision-makers should be appropriately trained in mental health.

The scandal of inappropriately trained and experienced assessors making critical decisions about the lives of people affected by mental illness must end.

James



I'm 53 and I've worked my whole life. I was let go three years ago after taking too much time off from work due to my depression. I couldn't pay my mortgage and was taken to court several times. I had a PIP assessment by an ex-mental health nurse, which put me at ease, listened to me, and I had hope coming out of the assessment that I'll be looked after.



'I have no problem when people don't understand mental health; it's when they have an opinion on something they don't know anything about.'

'A few weeks ago, I had an ESA assessment by a physiotherapist. The assessor wanted yes or no answers to various questions like "can you leave the house?" I tried to explain that some days I can leave the house or answer the door, and other days it's not possible because of my mental health, and the response from the assessor was "is that a yes or a no then?"

'I have no problem when people don't understand mental health; it's when they have an opinion on something they don't know anything about.

'There weren't any specific questions exploring my mental health. At the end of the assessment, the assessor asked me to touch my toes, and I felt that the whole assessment was set up so people with mental illness fail.

'I came out of the assessment feeling let down, and not listened to, and later I made two attempts on my life. I'm still waiting for the result of my WCA.'

Introduction

People with mental health problems and disabilities can receive financial support from a variety of different benefits. This report looks at the assessments that are used to determine whether people qualify for two of these benefits - PIP and ESA.

Rethink Mental Illness has conducted qualitative and quantitative research into the assessment process for PIP and the Work Capability Assessment (WCA), which determines someone's suitability for ESA.

The assessments for ESA and PIP are not the only issue with the welfare system for people severely affected by mental illness, but the inadequacy of assessment is a significant theme which unites the benefits. These inadequacies and the unnecessary delays they lead to demonstrate the fact that the current system does not work well for either claimants or the taxpayer.

Many personal stories and experiences were shared with us. These stories repeatedly touched on the same issues with these assessment processes, and demonstrated that both processes are inappropriate for people affected by mental illnesses.

Key issues

Assessments can be traumatising and anxiety-inducing for the following reasons:

- There are numerous issues with the paper forms that claimants must submit, including their complexity, length and the inflexible nature of the questions they ask.

- Claimants must collect their own medical evidence, which is extremely burdensome, often expensive, and time-consuming.
- Staff who perform face-to-face assessments frequently have a poor understanding of mental illnesses.
- Delays in Mandatory Reconsideration and appeals to the tribunal mean that claimants may have to wait many months for the correct result.

The number of decisions eventually overturned at tribunal show that incorrect decisions are being made far too frequently.

If the assessment process were to be improved so that appropriate decisions were made earlier, these time consuming, expensive and distressing delays could be avoided. These problems run counter to what the central aim of the benefits system should be – providing the necessary financial assistance to those who are too unwell to work and offering tailored support to those who can.

Our research

In this report, we draw on research from two separate sources. The first is a series of interviews and a focus group-style discussion of the WCA by people with personal experience of the WCA and of mental illness which took place in January 2017.

This research was originally commissioned by Rethink Mental Illness from Qa Research, in order to inform a detailed research report which was submitted as part of Rethink

Mental Illness' response to the Work, health and disability: improving lives Green Paper.*

The second piece of research was an online survey conducted by Rethink Mental Illness as part of its submission to the Work and Pensions Select Committee Enquiry on PIP.¹ The survey, which we ran in April 2017, had over 650 respondents.

The report concludes by offering recommendations to improve the system for the benefit of those who rely on it when they are vulnerable.

'Last year I had to have the medical assessment for ESA as well as the PIP assessment. It very nearly pulled me over the edge. Just when I thought maybe I could breathe again I got another form from the DWP [Department of Work and Pensions] in February for another medical assessment for ESA. I put on the form I think they are persecuting me, it certainly feels like it.'

PIP respondent

Hannah



'I haven't been through the full assessment process for PIP or ESA, because I faced such major barriers even applying in the first place. I was receiving ESA as I had filled in the paper forms, and was scheduled to have a face-to-face assessment, but I couldn't attend it because I became very unwell and had to go into hospital.'

'When I came out of hospital, they were bothering me because I hadn't attended my assessment. I eventually managed to get it rescheduled. Given that I'd just come out of hospital, the prospect of being questioned about whether I was ill enough to qualify was harmful to my recovery.'

'On the morning of the appointment they cancelled it saying that they had received new medical information about me. They were going to reschedule it again in the future but in the end I went back to work because I knew that I would get turned down. It wasn't worth the stress and the cost to my mental health to fight for ESA, so going back to work was the only

* Further detail about the methodology for this research is available in the original research report.



'Given that I'd just come out of hospital, the prospect of being questioned about whether I was ill enough to qualify was harmful to my recovery.'

way to stay afloat, even though I wasn't ready to return.

'I've had the same issues with applying for PIP more recently. I was encouraged to apply for PIP because I've had financial issues. I hadn't considered it as I didn't see my mental illness as being a disability.

'The written form is just not suitable for mental health. The questions are all about physical health, and what you're describing basically says you're physically fit, so it's very stressful. There's no online system, which might be more suitable for people with mental illnesses who aren't comfortable with long phone conversations.

'You're constantly asking yourself if they'll believe you're really ill. Indeed, the system makes you feel that you are

not properly ill or worthy of help. Then if you manage to fill in the form you get invited for an assessment and the only thought running through your head is "how do I prove I'm ill?" I just couldn't do it.

'I just decided not to apply because I couldn't deal with the stress of waiting for weeks and weeks for no help. You have to crawl over glass to get this support. You never know how long it's going to take, and you have no idea where your claim is in the system. There needs to be more transparency in the system, because there's no way of knowing if it's actually performing, so there's no pressure to change.

'The decision is ultimately made about you but not with you, and that's just not the case for medical treatment.'

'The decision is ultimately made about you but not with you, and that's just not the case for medical treatment.'

The assessment process

The Written Assessment

The PIP assessment and the WCA both start with different paper forms. For both assessments the form is extremely long and complex (25 pages for the WCA form).

A recent survey by the Disability Benefits Consortium found that over 71% of respondents to the survey found the PIP2 form (34 pages long) 'hard' or 'very hard', and 11% were unable to complete it.²

Many participants in our research also noted that the questions on the form are for the most part focussed on physical health, and that even questions about mental health are framed in terms of the impact of physical health on mental wellbeing.

'Some of the things that you want to put down, you're not allowed to put down... it doesn't allow for such things as how the illness actually affects you, how you feel at the time, how you can be suddenly fine one minute and the next minute something can click and you can be in a really dark place.'

WCA respondent

Many respondents relied on support from friends, carers, or charities to complete the paper form, and felt that this support was the only way they were able to express their issues so that their needs would be taken seriously.

'The whole process was very stressful for me and affected my mental health terribly. The wording of the letters I received and the paperwork was very scary to me and caused me so much distress that I took an

overdose and had to be taken to hospital. On other occasions during the process the stress affected my bipolar disorder so much that I could not sleep, my anxiety became awful and I was self-harming on a daily basis until the process was over. My neighbour read a lot of the letters and paperwork as I needed her help in dealing with them and said that she found it written in a very inappropriate way for someone with mental health problems to deal with. I could not have coped with or filled out the PIP paperwork on my own.'

PIP respondent

Medical evidence

Both the PIP form and the WCA require claimants to collate medical evidence related to their condition alongside the written forms. The organisational and financial burden of collecting this evidence is placed on the claimant. On many occasions, claimants already in financial difficulty are charged for this process being carried out and the quality of evidence provided by medical professionals can often vary.

This whole process can be very difficult for unwell and financially insecure claimants. It creates an artificially high bar for access at even the very first stage of the process. The collection of medical evidence can be time-consuming, and there are strict deadlines in place for the submission of the paper forms for both assessments.

'I don't drive, and I have to get public transport to my doctors so it's all additional stress. You can't get in to see your doctor anyway so you've got to speak to the doctor's staff and say this is what I need,

so it does have a negative impact because it's another additional worry, it's not just the form, it's everything else that goes with it that you've got to make sure you get in within the time limits.'

WCA respondent

Many respondents enquired whether the burden of collecting medical evidence could be shifted to the DWP, with the consent of the claimant, since it is easily available within their medical records. The Government has previously proposed trialling collecting medical evidence from doctors and psychiatrists on behalf of claimants, but this has not yet transpired.³

'I think they have completely ignored all my mental illnesses. They have allowed me the lowest daily living only which relates only to my physical disability. They should consider all information sent in with the application, and contact my doctors, nurses, counsellors, and consultants... It is without doubt the most ill-thought, distressing and complicated process that has ever been introduced.'

PIP respondent

Finally, respondents were sceptical about the value of the paper form and their collected medical evidence, since most were invariably called to attend a face-to-face assessment.

Most respondents to our PIP research felt that assessor didn't even take the evidence it took them so long to collate into account. Only 17% of respondents felt assessors looked at the additional information. So the stress, anxiety, and financial cost of submitting this accompanying evidence is seen as meaningless.

'Despite being asked how often I self-harm, which can be daily, the assessor chose not to include anything about this in her report.'

She, and the DWP in the Mandatory Reconsideration, completely ignored relevant medical evidence from my GP, a psychiatrist, and a psychotherapist.'

PIP respondent

'All the time I was thinking "I might not get it"... I was worrying about it. And all the time while we were waiting for the result to come through, like I were hoping once we sent the form in, we wouldn't have to go for a face-to-face, I thought the form would be good enough and I was a bit disappointed when I had to go for a face-to-face.'

WCA respondent

Recommendations

- The DWP should undertake a thorough, co-produced review of written assessments that allows claimants to appropriately reflect on how their mental illness actually impacts on their lives.
- Guidance from the DWP for claimants with mental health problems to accompany the paper assessment forms is needed. This should be developed in conjunction with health professionals and organisations that support people affected by mental illness.
- The deadline for claimants to submit their PIP2 and ESA50 form should also be extended from the current period of 1 month.
- Assessors should be obligated to review all supporting evidence provided by the claimant and be penalised if they do not.
- Providing a claimant gives their consent, responsibility for collating medical evidence should be transferred to the DWP.

Jenny



...My son was invited for a face-to-face assessment in Brighton. I encouraged him to wear clean clothes. I drove us down and accompanied him to the interview. He was still under Crisis Team care, as he'd recently been discharged from mental health treatment. He didn't really understand why he had to have this assessment. In his head it was all part of the process of being held under section.



'In his experience he thought that if he presented as being "unwell" then he would have to go back to hospital. So he said he was feeling very well, and that he did voluntary work. When I interrupted, she asked me to let him talk. He played down the amount he drank. He claimed he was never paranoid or delusional. The assessment lasted 20 minutes. When we got outside, my son said "I think she knows that I am well and don't need to return to hospital."

'The whole process was demeaning and stressful for us all.'

'We heard that his PIP application had been turned down and immediately applied for mandatory reconsideration. The Care Coordinator wrote a letter to support my son's claim even though we had already sent a very comprehensive report from her. Eventually, we heard that he had been awarded the standard rate for daily living allowance.

'The whole process was demeaning and stressful for us all. I am a carer that sees my son every day and supports him in every aspect of his life.

'I fail to see why a claimant who has a fully documented diagnosis of a severe and enduring mental condition, and has suffered with this debilitating condition for seventeen years cannot just submit up-to-date medical reports as evidence of the disability.

'It is hugely ironic that just weeks before his assessment, my son was in a locked mental health facility. He was not well enough to leave the hospital unaccompanied. Yet a few weeks later, still under the care of the Crisis Team, he had to be judged by an individual who had little knowledge of the challenges of paranoid schizophrenia.'

The face-to-face assessment

Having been through the stressful and lengthy process of written assessment, most claimants with mental illnesses are then asked to attend a face-to-face assessment.

The negative perception of face-to-face assessments and the detrimental impact they have on claimants affected by mental health problems is overwhelming. Many respondents reported that the assessors do have a poor understanding of mental illness, that questions at the assessment seemed confrontational or intended to trip them up, and that the process of attending the assessment all worked to the detriment to their mental health.

'My health significantly declined immediately after the PIP assessment due to the belittlement and invalidation I experienced from the assessor. I was admitted to hospital that night.'

PIP respondent

The location of the assessment was often difficult for respondents. People found it difficult to access areas which were often unfamiliar, which added to their anxiety about the whole event. Many people were unaware of the option for a home assessment, or were simply not offered it.

'I think it would make you more relaxed in your own home rather than just a little tiny room, them staring at you, tapping on their computer, not really taking much notice of what you're saying.'

WCA respondent

Many claimants are unaware of the option of bringing someone to accompany them to

their assessment. As a result people often attend them alone. Those who brought a friend, advocate, or carer with them found that their reception varied.

In some instances, people reported that those who accompanied them were told they were not allowed to speak, which is incorrect.

'When I'm extremely anxious I can't speak. My grandmother, who was my carer at the time, was initially not allowed to speak on my behalf even if I gave her permission to do so. This prompted me to have a meltdown during which I self-harmed. The assessor at that point contacted head office and then allowed my grandmother to speak for me, without me even being present.'

PIP respondent

People reported that the level of understanding that assessors had of mental health was often poor, with some being assessed by medical professionals from unsuitable disciplines.

'Absolutely not, nowhere near enough [assessors with mental health skills/knowledge]. They need to have more than just a basic awareness, or recruit different specialists... You wouldn't see a doctor for your back that was a specialist in eyes or something would you? It's no different.'

WCA respondent

A shockingly low proportion of respondents to our survey on PIP felt that their assessors understood their mental health condition.

Only 18% of those assessed by Atos and 15%⁴ of those assessed by Capita felt that their condition was understood. This led to a perception of a lack of empathy and understanding in the assessment.

'I got very upset, crying and visibly shaking but the assessor stated in her report that I was "normal" and coped well with the assessment! The assessor was a physiotherapist and not qualified to be dealing with what my GP described in his report as "complex" mental health problems. She did not do a mental health examination at all. The questions she did ask about self-harming were not even included in her report.'

PIP respondent

This quote shows how problematic this can be, and that improving the understanding that assessors have of mental health problems, which may present in ways that assessors otherwise do not understand, and that the claimant is unable to communicate, is necessary.

The overarching issue with the face-to-face assessment for both benefits was seen to be a lack of empathy, understanding, and in the some cases humanity, from the assessors. Some respondents noted that the report produced by the assessor seemed to be completely different from their recollection of the assessment, and that the outcome was incorrect as a result.

Only 26% of respondents to our PIP survey felt that the outcome of their assessment was satisfactory. People recognised that the assessors were often doing the best they could in a difficult situation, but felt that the process was so stressful and demeaning that their health and wellbeing suffered.

'I live far less of anything that could be considered a normal life. My mental health is far worse because of the outcome of my assessment. I feel I would be far more useful to society if not effectively locked away at home because of the financial constraints of losing benefits and my mobility vehicle.'

PIP respondent

Recommendations

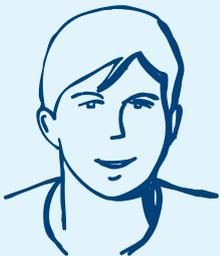
- Every claimant should be made aware that the option to ask for an assessment at their home exists.
- If people with severe mental health problems must undergo a face-to-face assessment, this should only be conducted by a fully qualified mental health professional.
- Assessors should be given guidance on what is and is not appropriate to ask people severely affected by mental illness. Assumptions about the severity of mental health conditions should not be made based on whether or not they are accessing mental health services.
- Questions should be given to claimants in advance, and every claimant should be given the opportunity to bring a supporting person to their assessment and informed that this person will be allowed to contribute.
- The assessment should be recorded so that any discrepancies can be investigated – with the consent of the claimant. Claimants should also be given the opportunity to sign written reports following an assessment, indicating that they believe the content is a fair reflection of what was discussed.

Jack



I have applied for both PIP and ESA, due to my diagnosis of Borderline Personality Disorder, Depression and Anxiety.

‘On the day of my PIP assessment I had a panic attack. My mum took me to the assessment, and she stayed with me as I was very anxious. The assessor wrote in their report that I showed no signs of anxiety and attended the assessment alone, which was then perceived as an ability to do things by myself.’



‘I was awarded zero points. The PIP assessment caused me a lot of stress and anxiety, and I ended up struggling financially. I was facing homelessness because the rent was more than my Housing Benefit, and I didn’t have enough money for food.’

‘After being declined PIP for a second time, I was self-harming and took an overdose. I ended up in hospital.’

‘I applied for Mandatory Reconsideration and received zero points again. After being declined PIP for a second time, I was self-harming and took an overdose. I ended up in hospital.’

‘After that I requested an urgent tribunal. At the start of my hearing, the judge immediately told me there was enough evidence in my application for an award of the standard rate of care. This was despite no further evidence being submitted, and so it was based on what the Department of Work and Pensions decision makers would have had available. At the end of my tribunal, I was awarded enhanced care and standard mobility for three years.’

‘I had a much better experience applying for ESA earlier this year. I sought advice from ‘Benefits and Work’ and the CAB checked all of my forms. The assessor’s partner was a mental health nurse and noted my anxiety and stress straight away, which really eased me into the assessment. As result of the assessment I was placed in the support group for two years.’

Appeals

Mandatory Reconsideration

The first stage in the appeals process for PIP and ESA is Mandatory Reconsideration, which often upholds the original decision by the DWP – 84% of PIP Reconsiderations resulted in no change to the original award between 2013 and 2017,⁵ while 87% of WCA decisions were unaffected.⁶

As such, it is mostly seen as an unnecessary and stressful delay for claimants, as they are often aware that the original decision is more than likely to be upheld, and they perceive the process as lacking independence.

'My son had been on DLA for over 10 years and I was surprised that since his health hadn't changed that he was turned down for PIP. The whole process from receiving his first letter about the change, filling in the forms and his assessment had been such a stressful time and to the detriment of his health. Strangely the assessor at the time appeared to be understanding and even commented that my son didn't appear too stable and even suggested other medications that could be tried for his illness. I can only guess that either he didn't get this over on his report or that the decision maker who read the report decided to turn him down for PIP regardless.'

PIP claimant

Our research shows that some people decide not to appeal their decision because they couldn't face continuing with the process and its impact on their health or the health of a loved one.

Tribunals

The majority of ESA and PIP decisions which are taken to tribunals are overturned. The difference in outcomes between the Mandatory Reconsideration and appeals stages may explain why many respondents felt that in its current form, the Mandatory Reconsideration is perceived as an obstacle to prevent claimants taking their case further.

Our respondents felt that the high success rate at the appeals stage was because the tribunal was the first time the evidence had been properly looked at, with claimants given a proper opportunity to state their case, and judged by people qualified to do so.

'They [the tribunal] could see I was scared when I went in and they took the time to put me at ease. They took the time to really listen to me, they weren't reading off a script. They treated me with respect.'

PIP respondent

Data from tribunals supports this; 64% of PIP decisions are overturned by the tribunal, as are 70% of ESA decisions.⁷

Whilst those claimants who get decisions overturned at appeal are relieved, the difficulties that very long waits for tribunal hearings can cause – including the loss of financial support during the time that they wait for their appeal – can be damaging for both their health and finances.

38% of respondents to Rethink Mental Illness' PIP survey felt that delays in decisions meant deterioration in their

mental health, and 19% had to take higher doses of medication in order to cope with the increased stress as a result. 5% of respondents said the assessment process had contributed to their admission, or readmission, to hospital.⁸

'I had a PIP appeal this year. It took nine months to get to the tribunal stage. I found this extremely difficult and without support from a mental health advocate I think I would have cracked up. I won my appeal... My euphoria lasted until I received a letter from the DWP to say they were appealing the court decision. I really couldn't believe it and I have been feeling very low and extremely anxious as I am now waiting to see what is going to happen now.'

PIP respondent

This research shows that while tribunals are able to give claimants the support they deserve, a great deal of time, anxiety, and difficulty for vulnerable people could be spared if the original decision had taken full account of their mental illness.

'I am due to be reassessed next year [for PIP], and am currently having my ESA reviewed. Just constantly having to jump through hurdles, leaves me feeling very insecure and does nothing for my state of mind. Not surprised people just give up and face crisis.'

PIP claimant

Recommendations

- All DWP decision makers should be given regular and high quality, accredited training in mental health so they are able to interpret recommendations correctly.
- The mandatory reconsideration process should be reformed. Claimants should be given a guarantee that their points and financial awards from their initial assessment will not be reduced if they choose to go through this process, and all medical evidence should be considered at this stage.

Conclusions and policy recommendations

Our policy recommendations would dramatically improve the benefits system for people with mental illnesses, as well as saving the Government the vast costs that are currently incurred due to persistent incorrect decisions made early in the process.

'It is the most stressful thing I have ever done, and the frequency for reassessment means you never get a break from the cycle. It's all so uncertain and upsetting.'

PIP respondent

The current assessment system inherently discriminates against people with mental illnesses and must be reformed as a matter of urgency. Our recommendations are informed by the stories that people have shared with us throughout this research, and would address the issues which we have raised throughout this report.

- **A major reform of the PIP assessment and the WCA is needed.** This should result in both assessments reducing the distress caused to people affected by mental illness and that better reflect the realities of living with a condition of this type. Such reform would reduce the need for appeals and the associated costs to the DWP and HM Courts & Tribunals Service (HMCTS).
- **The Government should review the way in which people with mental illness are assessed.** Where clear medical evidence exists that claimants have severe forms of mental illness, they should be exempt from face-to-face

assessments. Where face-to-face assessments are necessary, claimants should be encouraged to seek support from carers, friends or family members.

- **All assessors and DWP decision-makers should be appropriately trained in mental health.** The scandal of inappropriately trained and experienced assessors making critical decisions about the lives of people affected by mental illness must end.

Appendix – the background

What is Employment Support Allowance?

Employment Support Allowance (ESA) is a benefit people can claim when they are not well enough to work and need financial support.

ESA and the WCA were introduced in 2008, replacing three older disability benefits.

What are Personal Independence Payments?

Personal Independence Payment (PIP) is a benefit which helps with the additional costs of disabilities or long-term health conditions.

PIP replaced Disability Living Allowance (DLA) in 2013, and the DWP expects that all existing working age DLA claimants will have been reassessed for PIP by 2019/20. Once introduced it is expected that around 600,000 fewer people will receive PIP than would have got DLA, and expenditure will be £2.5 billion a year lower than it would otherwise have been.⁹

The introduction of PIP will mean that almost 50% of disabled people and people with long-term conditions who are reassessed from DLA will lose access to some or all of their support, due to differences in the criteria for access to PIP.

'I used to get high care and low mobility on DLA. My needs have not changed but the criteria for PIP is different so now I only get low rate care. It is not fair. My only comfort is that they didn't target me personally – everyone I know has had a horrific experience of PIP. I wish I was strong enough to fight, but I'm not. My health has declined a lot this year due to PIP.'

PIP respondent

Who receives these benefits?

Not everyone will receive both, and those who do may receive different levels of each benefit. There are 775,111 people with mental illnesses in receipt of the highest level of ESA support (in the Support Group)¹⁰ and 523,728 receiving PIP for a 'psychiatric disorder',¹¹ as of the most recent data available.

Alongside PIP and ESA, other benefits provide significant support including Housing Benefit, tax credits, and the Carer's Allowance. People with mental illnesses can be entitled to some or all of these benefits, depending on their individual circumstances.

Due to the fact that these are different benefits, individuals go through the assessment process for each at different speeds and times. As a result, a traumatic process of assessment for one benefit can often be followed by a similarly distressing assessment for another.

How is ESA assessed?

Employment Support Allowance (ESA) is assessed through the Work Capability Assessment (WCA). This is a process which determines whether people who are claiming financial support are capable of working, and in turn whether they are eligible for ESA and which rate they receive.

The WCA comprises three stages: a paper assessment supported by medical evidence, a face-to-face assessment, and a consideration of recommendations from the previous two stages by the Department of Work and Pensions.

The WCA groups people into one of three categories:

- **‘Fit-for-work’**: people in this group are considered able to work and would not be entitled to ESA. They would be advised that they could claim Jobseeker’s Allowance.*
- **Work Related Activity Group (WRAG)**: people within this group are considered to have limited capability for work due to illness or disability. They would be entitled to ESA,† but would be expected to take steps towards moving into work.
- **Support Group**: people within this group are considered to have limited capability for work-related activity due to illness or disability. They would be entitled to ESA and are considered too impaired to make any steps towards work; they receive up to £109.65 per week.

What’s happened recently?

In 2013 a Judicial Review published an ‘interim judgment’ which considered the WCA to discriminate against people with mental health problems, learning disabilities and autism, and said that the DWP had failed to make reasonable adjustments in line with the Equality Act (2010).¹² The judgment suggested that changes to the WCA process should be piloted in order to resolve this issue, but also acknowledged that the courts did not have the power to compel the Government to make the necessary changes.¹³

In October 2016, the Department for Work and Pensions published the *Work, health and disability: improving lives* Green

Paper¹⁴ as part of their aim to help more disabled people into work. The Paper proposed significant reforms to the disability benefits system, including in part to the WCA, but did not explicitly address the Judicial Review.¹⁵

How is PIP assessed?

Personal Independence Payment is made up of two components:

- **Mobility component**, paid if you need help getting around.
- **Daily Living component**, paid if you need help with carrying out everyday activities, such as washing and dressing.

Both PIP components are payable at a standard or enhanced rate,[§] depending on the needs of the claimant. To determine the level of payment, individuals are assessed on their ability to complete a number of key everyday activities, for example relating to their ability to dress and undress, make budgeting decisions, communicate and get around, and awarded points for each activity. The number of points determines the level of the award.

PIP eligibility is assessed through a similar mechanism to the WCA – a paper assessment followed by a face to face interview, though the criteria that these claimants have to meet are different.

What’s happened recently?

Two Upper Tribunal judgments late in 2016 broadened the interpretation of eligibility descriptors for PIP. The most

* Up to £73.10 per week for over those aged over 25.

† ESA entitles recipients to up to £73.10 per week; this figure is the same as JSA in order to incentivise recipients to take steps towards work.

§ £55.65 (standard) or £83.10 (enhanced) per week for the Daily Living component, and £22 (standard) or £58 (enhanced) per week for the Mobility component.

important judgement related to activity around planning and following journeys, and broadened the interpretation of descriptors (which determine the number of points claimants receive) so as to give people with severe mental illness an increased chance of enhanced rate entitlements. The broadened interpretation would have resulted in an additional spending of £3.7bn on PIP, and benefited 160,000 people.¹⁶

The Government responded by putting regulations before Parliament to overturn the effect of the Upper Tribunal’s decision by stipulating that a claimant can only score points for the Mobility descriptors “for reasons other than psychological distress”. This undermined the tribunal ruling and excluded severe mental illness as a qualification for entitlement to an enhanced rate Mobility component.¹⁷ As a result, 160,000 people will not receive future additional support from PIP.

How does the assessment process work?

The evidence for the WCA and PIP is passed by an assessor (who work for external companies subcontracted by the DWP) on to the DWP, who make decisions on each claim.

As such, the appeals process for each involves asking the DWP for a Mandatory Reconsideration of the evidence before a case can be progressed to a tribunal. This merely means that the evidence is considered again by the DWP – as a result, the decision is often upheld (87% of WCA decisions were unchanged by the Mandatory Reconsideration stage for the most recent data available).¹⁸

After Mandatory Reconsideration, claimants can take their cases to a tribunal, which

often overturns the original decision. 64% of PIP decisions were overturned by the tribunal between January and March of 2017, as were 70% of ESA decisions.¹⁹ These figures fluctuate annually, but the high rate of decisions overturned demonstrates failings in the process up to the point of appeal.

Both the PIP assessment and the WCA entail assessors making decisions about the extent to which the health conditions of claimants affect their lives. As such, one major criticism for both assessment processes is that they are poor at recognising the extent to which mental illnesses can be severely debilitating.

Alongside the loss of appropriate financial support that results for vulnerable people, this lack of recognition is linked to the stigma and self-stigma – people may feel ashamed of their condition, uncomfortable speaking to a stranger, or unaware of how their condition affects them – experienced by those with mental illnesses, and this can be extremely traumatising for people who feel that their condition is inappropriately understood.

What is the current landscape?

Despite the extent to which the WCA and PIP assessment have been criticised by charities, claimants, and the judiciary, these flawed mechanisms are still relied on for determining the support that people receive.

The Government acknowledged in the 2016 Green Paper *Work, health and disability: improving lives* that reform of the WCA was needed. It is encouraging that reform is being considered, but the Green Paper did not address the flaws in the system which causes distress and anxiety for people with mental illnesses.

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Our three key recommendations

- **A major reform of the PIP assessment and the WCA is needed.** This should result in both assessments reducing the distress caused to people affected by mental illness and that better reflect the realities of living with a condition of this type. Such reform would reduce the need for appeals and the associated costs to the DWP and HM Courts & Tribunals Service (HMCTS).
- **The Government should review the way in which people with mental illness are assessed.** Where clear medical evidence exists that claimants have severe forms of mental illness, they should be exempt from face-to-face assessments. Where face-to-face assessments are necessary, claimants should be encouraged to seek support from carers, friends or family members.
- **All assessors and DWP decision-makers should be appropriately trained in mental health.** The scandal of inappropriately trained and experienced assessors making critical decisions about the lives of people affected by mental illness must end.



Leading the way to a better quality of life for everyone severely affected by mental illness.

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