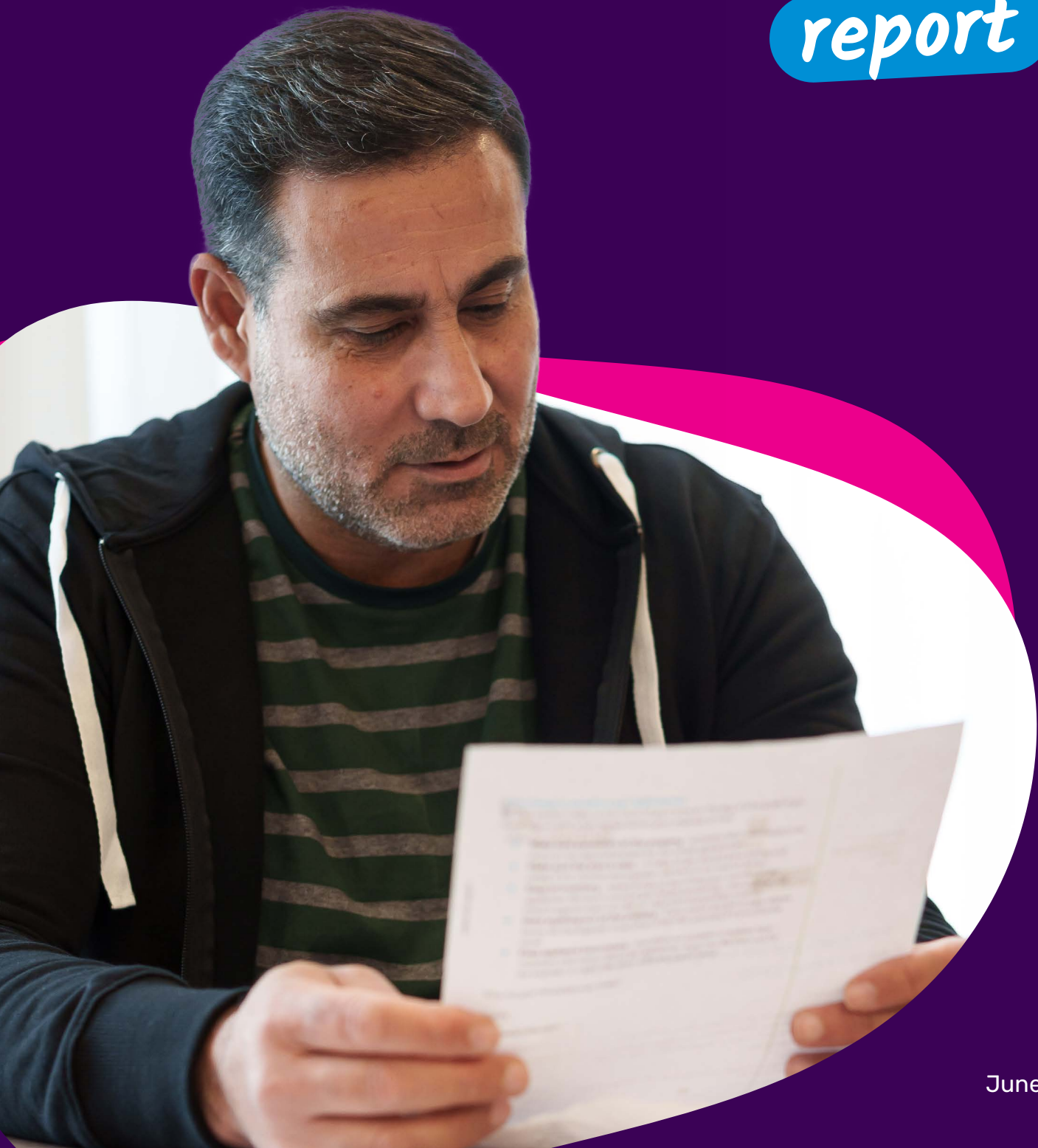




Executive Summary

Rethinking PIP

report



Photographs in this report are used for illustrative purposes and do not represent the person quoted.



Executive Summary

Purpose

Co-produced with 24 people severely affected by mental illness with current or previous experience of claiming Personal Independence Payment (PIP) - this report outlines how PIP enables people living with mental illness to live their lives, where the current system falls short, and what needs to change. Drawing on lived experience, it highlights both the value of PIP and the challenges people face in accessing and navigating the system. It is both a stand-alone report and forms Rethink Mental Illness' response to the Timms Review of PIP Call for Evidence.

The role PIP plays for people living with mental illness

When PIP works, it is life changing. People described it as the financial foundation that enables them to manage fluctuating illness and avoid crisis, particularly in the context of long NHS waiting times and limited access to consistent care. It allows claimants to access timely and personalised care, maintain safe and suitable housing, sustain relationships, travel when public transport is inaccessible, and engage in meaningful activity, including paid work for some. It also supports people to meet everyday living needs, from managing their physical health and nutrition to accessing practical support, maintaining a home, and covering the additional costs associated with mental illness.

These forms of support were described as essential to maintaining dignity and a sense of normality, allowing people to live on a more equal footing with others. People emphasised that these forms of support are interconnected, and that stability in one area supports participation in other areas of daily life. PIP makes autonomy possible, by enabling choice, control, and participation while living with mental illness.



Where the system fails

PIP creates avoidable harm. We heard about five common problems experienced by people accessing PIP:

- an activity-based assessment model that captures whether tasks are completed but not the emotional, mental, and financial cost of completing them
- an assessment rule based on how often symptoms occur, using averages that do not reflect how mental illness actually presents over time
- assessment reports that distort or contradict what claimants have said
- assessments often carried out by people with insufficient mental health expertise, leading to poor understanding of fluctuating and invisible conditions
- an administrative process so burdensome and confusing that many claimants disengage when they most need this financial support. Many require the support of others to navigate the system but do not have it.

My name is Emily

I'm an ally to people that often aren't heard in society or not recognised. I'm someone with a very big heart and I care deeply about people and the issues they face. I love humour and music, I find music very helpful to my mental health and to inspire myself and I like to inspire others. I listen to music pretty much 24 hours a day. I struggle to sleep without music, and I love playing it too. I love creativity - writing poetry and I recently got back into colouring.

What's important to me is caring about people and helping people to be autonomous in their own decisions and own life. I'm a very caring person but I'm also learning how to care about myself as well.

For me, receiving PIP meant I was able to access life. When I first got it, I was in a dark situation and couldn't have afforded the basics like bills. Receiving PIP is like accessing safety, because you can't be safe without money. There are negative stories in the media about what people do with PIP but for me, getting PIP payment means eating that month or putting the heating on.

“

It means I can contribute to society with or without working and I can contribute in other ways, like smiling to a stranger. I can afford to heat my home, see my niece who lives far away, can access training and my appointments and the world in a way most people take for granted.”



Government changes may mean some people could go into poverty, so these changes are really important. It's important for the government to understand the impact for people with severe mental illness and the impact of reducing amounts or changing the process. It risks people falling through the cracks. I'm a firm believer of Maslow's hierarchy of needs – all of which you need money for. You can't improve your mental or physical health if you don't have a home.

Even working full time, it's hard to afford the cost of living, especially in London. PIP doesn't provide a luxury lifestyle, and it shouldn't, but it can provide support. It enables me to do ad hoc work like this, when I can give my all to help lived experience influencing.

For me, applying for PIP was a fairly straightforward process that I don't hear from many people. I was lucky and was well supported from professionals. It took a long time to access this support, but when I did, it was straightforward and they knew the system and the words to say to the right people. The support was very helpful but the process leading up to it was difficult.

My tagline is

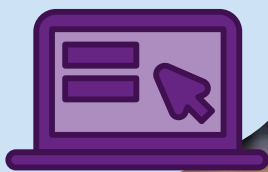
'compassion is critical to change'. I'm really enthusiastic about that, especially with this project. Context can mean everything when it comes to complex situations.



My name is Nina

I'm 31 and identify as queer and disabled. I live with SMI and am physically disabled with long-term health conditions. I work part-time across various things, but because of the way my disability works, I can't feasibly work full-time. I've worked in tech, inclusion and with children and young people. The things in life that give me purpose are singing and theatre, I love trying to get outdoors but living with a physical disability makes that difficult.

PIP has made a positive difference in a lot of ways. I receive the enhanced rate for both mobility and daily living and this makes transport a lot easier. I don't have a driving licence because of my bipolar disorder, so this allows me more transport security. But I can never quite make the PIP payments reach what I need to manage. I always worry about PIP being taken away and those reviews are terrifying. If the application process could be more fair, it would be better as it has made a difference with barriers of living independently, but it's a double-edged sword.



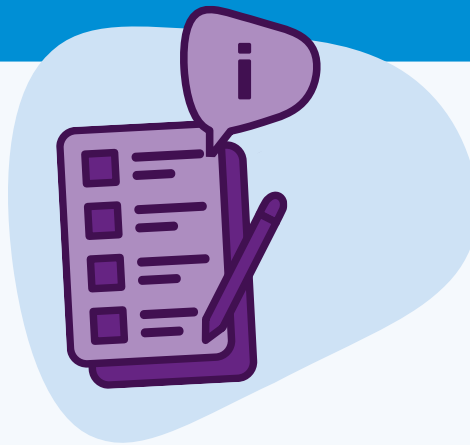
The positives are great but the negatives can be drastic. I'm not convinced they understand you can live with two types of illnesses (plus). Being able to receive PIP does make worries like paying the bills a bit less severe, and it helps me to put on the heating for a bit longer, but it doesn't cover all the extra costs of living with a mental and physical disability.

I've had three assessments which were traumatic. One was through a social worker and the other through a phone assessment at the height of the pandemic. I live with PTSD and she touched on my trauma without warning. I was really taken aback and had a panic attack.

“

I had an in-person assessment in 2024 and went into a full-blown mental health crisis.

My mum had to come from London to keep me safe from the process and made sure I could go there in the first place. I genuinely don't know what I would have done if she couldn't come.”



The process feels very vulnerable, like that person is there to tick boxes and doesn't know your condition. I can feel very judged. You're so often made to feel that you're asking for too much when you're just saying what life is like and answering their questions. It's like you're a failure or burden. It's as if the questions are designed to trip you up - I struggle parsing them and have to have someone to support me. They're geared more towards physical health than mental health, not how they both affect you. It feels way too formulaic and less nuanced than people living with physical and mental illness actually are. I get why it is like that and they need a set of questions, but **I don't think it's fit for purpose.**

I feel like PIP could get taken away any minute because of government reforms and I'm never living with security. There's so much in the media that makes me nervous to even talk about it. It should be offered in different ways to access it more fairly. For example, I should be able to know the expertise of my assessor and know in advance whether I need to explain more about my conditions. The DWP never seem to understand that the people carrying out the assessment aren't always the right people to do it. You can get notes from your GP but how much is taken into account, I'm not sure.

These problems converge in what people described as a “recovery trap”. PIP funds activities such as therapy, volunteering, education and social contact, that supports recovery. However, at reassessment, the same activities can be used as evidence that support is no longer needed. Improvement enabled by this support becomes the basis for withdrawing the support - risking a reversal of progress and a decline in health.

While the introduction of the Right to Try signals an intention to protect engagement in work and other meaningful activity, fear that participation will continue to be used against claimants remains strong. Consequently, many people described feeling trapped in a cycle where efforts to improve their wellbeing risk undermining the financial foundation that made the progress possible.

“

The PIP award review is quite short-sighted, so it helps you to find meaningful activities or get involved in volunteering or training, education, employment.

However, once you then say to the assessors **when you get reassessed, that you're now engaged in said activities, it's almost like, oh, are you better?** ”

“

It's this really awkward scenario of if you use your PIP money to function better in life, you risk them taking away your PIP money... You then become too well for benefits, but **it's the benefits that are enabling you to be more well.**

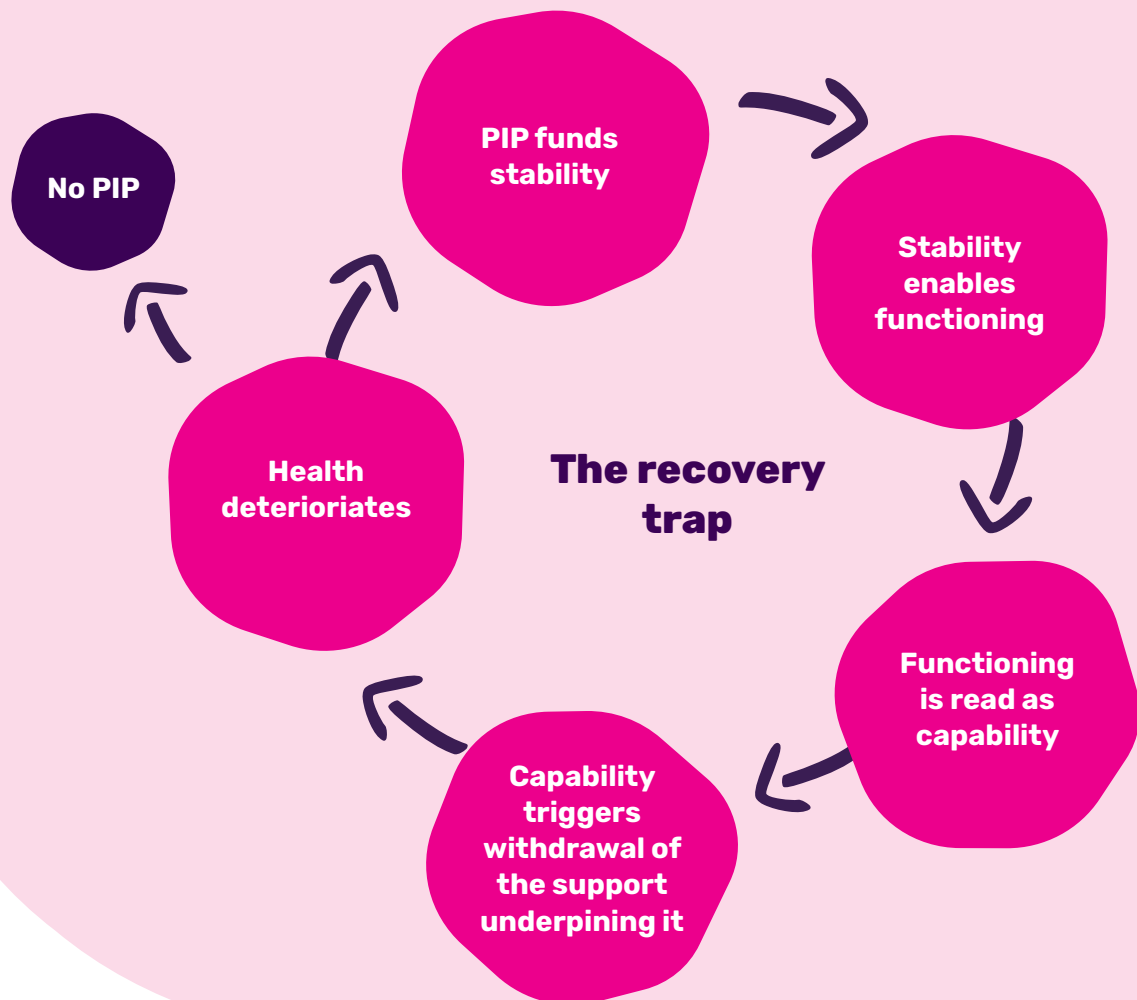
I think it's just unfortunately something that we don't actually have access to because even if the gate is open for us, we will be kicked back out as soon as we walk through it.

”



The recovery trap reflects a broader lack of understanding of how invisible and fluctuating conditions present in everyday life.

Assessments often rely on surface-level indicators, such as engagement in activities or exercise, as signs of improvement, without recognising the effort, support, and recovery required to sustain them.



For example, engagement in volunteering may be interpreted as recovery, despite often being flexible, carefully managed, and dependent on support. Similarly, wellbeing is often judged based on physical appearance, meaning conditions that are not outwardly visible are less likely to be recognised. Being well-presented is misinterpreted as evidence of wellness, reinforcing stereotypes of what mental illness 'should' look like. As a result, there is a mismatch between how need is assessed and the lived experience of severe mental illness.

“

Because if they ask me about it, they will go, 'she is well enough to do this, it involves engaging with people, it's physical, it's this'. It wouldn't matter that I went there and it exhausted me and I came back and it was deeply difficult.”

The impact of this mismatch is significant. People described feeling disbelieved and discredited, particularly when their experiences did not align with visible or stereotypical expectations of illness. This created pressure to manage their presentation, avoid activities that support recovery, and, in some cases, feel that they needed to 'maintain' their illness to keep receiving support. Pressures to prove severity contributed to feelings of unworthiness. Consequently, many people questioned the legitimacy of their own illness and monitored their behaviour in order to justify their entitlement, including feeling guilty about self-care and spending. Rather than supporting recovery, the system embeds a cycle of fear and mistrust.

“

I might have a good week, and in that week, I think, 'do I actually really need this?' Because I'm doing this and I'm doing that. I'm still working, but actually on a whole, the bad days outweigh the good. And then I actually have to remind myself that no, I do have needs and I do need care and I shouldn't feel guilty. I am still working and trying to stay in employment and I should be entitled to it and I shouldn't have to then feel that you need to prove that you constantly need it.

So, I think that's a really hard, I certainly have an inner battle, self-battle with that. And then I get scared at review times because I think, oh God, they're going to say that you've had improvement in this area, so you don't need it anymore. You feel that you have to justify for why you're getting it.

”

My name is Daniel

I was diagnosed at a young age, and have lived with bipolar now for many years, which has resulted in me being detained in hospital under the Mental Health Act on a dozen different occasions. Being hospitalised and living every day with bipolar, I have experienced both sides of the coin so to speak!



Being hospitalised means you miss out on so much of life, like spending time with family and friends and making wonderful memories as, after discharge from hospital, it can take up to twelve months for you to get back into daily life and proper routines.

I am more than capable of being employed but having bipolar stops you from working full time as your brain cannot cope with the everyday stress of it. You are completely out of your comfort zone. So, you work permitted hours and claim benefits, but people think you're lazy and a scrounger and come out with hurtful comments like "get a life" or "you could work if you really wanted to"!

There's a lot of stigma and discrimination surrounding mental illness as unlike a physical disability you can't see it. People don't choose to have a mental illness and if you do it impacts the way people relate or treat you.



Even applying for benefits such as PIP (Personal Independence Payment) can become a nightmare unless you happen to get an assessor who is empathic. PIP is scored against the criteria, a points system, and if on the day of your assessment you happen to be having an ok day the assessor may take that at face value, not considering that on any other day you're just about managing to cope and get through your day.

“PIP massively helps with my quality of life but the stress that comes with applying for PIP or any benefit is overwhelming often leading to sleepless nights and depression.

The system needs to change drastically to allow for people with a mental health diagnosis to have easier not painful experiences of the Benefit System as it is at present.”

Every day with bipolar is different but having the support from your family and close friends keeps you focused and grounded. Most importantly, I have my faith and that's what gives me the strength to live everyday life the best way I can.

My name is Tessa

I'm 38 and recently married. I use she/her pronouns, am neurodivergent and live with chronic illness and disability. What's important to me are my social connections as my friends are my family. I enjoy writing books, my pets, advocating for disability and lived experience participation.



Access to health and social care is something I'm finding difficult at the moment because I'm not able to get referrals for what I need. For example, I've just been bounced back from an NHS mental health referral. I have a social housing association property which is good and gives me some security, so I'm happy about that, but it was hard getting the right property with trauma associated with the process, so there were positives and negatives.

I haven't worked since I graduated which was a long time ago now. I tried to do some volunteering recently but wasn't able to, which was disappointing to me. My physical health is very up and down, especially living with a chronic illness which people don't often see. I have strong social connections and a very good, close-knit circle of friends who all understand mental health and disability. I'm very lucky, the only downside if I don't get to see them very much.

I can't think of money without thinking of PIP. It's been a constant rollercoaster and like living on thin ice. Having PIP gives me the freedom and agency to choose for myself the things that will enable me.

I need treatments like acupuncture, supplements, a comforting pillow – some people don't understand how important these are. It also enables me to do the little things that are essential for disabled people, like buy prechopped vegetables when I can't chop the vegetables myself, and it enables me to have a car. What it stands for and what it does, it enables freedom.

Unfortunately, the process of applying for PIP severely affects my quality of life to the point I've been told I have CPTSD (complex post-traumatic stress disorder) from the way I have been treated by the DWP over the last decade. So in terms of quality of life, that's a huge detriment and my mental wellbeing has never been as worse since I started claiming PIP. Every time I've been through the process claiming for PIP, apart from the last review I've had, I've had to go to tribunal. That means I've had at least six tribunals overall and four of those for PIP.



It's been a very detrimental experience because the things said in the documentation, it's like hearing the worst things about yourself in black and white, telling you these and saying things couldn't possibly be that bad. Or they say it's not true.



I explained how I struggle to do food for myself and when I got the report back, they wrote 'We have decided this is not true as x appears well nourished and overweight.' When you have received so many documents about yourself worded in that way, you start to hear that voice as an intrusive voice when you are doing things and you start to question yourself.

I am trying to live the best life I can but I feel like I can't be proud of my achievements when my achievements can be used against me to take away this safety net that enables me. I can't celebrate my quality of life as I feel the moment I embrace quality of life, it will be taken away as they will say I don't need the support anymore. **It's a constant cycle of uncertainty and instability.** Right now I'm living in a state of limbo between PIP reviews, and I don't know when I'll get it back. You can't talk about quality of life without taking into account those things because the way it's handled absolutely affects quality of life. I've never had an award longer for 3 years but have claimed PIP since 2015. You don't get to experience the quality of life assurance that PIP should grant you.

The process has had such an impact because of how wrong they've got it each time. The process of applying is

very gruelling – the forms, the way you have to be so specific. I've been told the impact of going through so many tribunals is PTSD for the very reason I can't escape this PIP uncertainty cycle. I'm forever in it and I'll never be able to escape that trauma that is bring relived every time.

I've been told on two occasions the way my tribunal was handled by the DWP was unlawful.

The process of going to tribunal is harrowing. At my last tribunal, the PIP rep turned up unannounced to defend themselves, like we were in a court to argue. I found out 5 minutes before going in and had to sit there while this rep and the judge went back and forth to see if they could negotiate my points. They argued against me while I was explaining myself. The impact is catastrophic to have someone there representing everything I am afraid of with the DWP with no warning. And then the judge said the DWP had acted unlawfully as the previous appeal was upheld but then I had to go through it all again a year later when PIP was denied to me again.

The assessments are a version of gaslighting. When I have been very distressed, the report says "she was fine". Mentally and physically, I am much sicker because I'm on PIP. If I was wealthy and didn't need PIP, I wouldn't be having these experiences and be as ill as I am now, and that is a bitter pill to swallow.

PIP in its current form does not benefit disabled people but it could do if people didn't have to fight so hard to be believed.

In its current form, the payments are massively beneficial but the way it's awarded, the way information is treated as false until proved otherwise, is causing people so much unnecessary illness. I'm experiencing more and more anxiety because of the damaging things that are now said about disabled people.

Principles for reform



Trust people, their families, and wider support networks. People living with mental illness, alongside those who support them, are best placed to know what helps them stay well. A system built on repeated reassessments, scepticism, and surveillance of recovery activity produces poor decisions on PIP outcomes and harms the people it assesses.



Recognise interdependence. For people severely affected by mental illness, independence rarely looks like complete self-sufficiency. It looks like supported autonomy, which are the resources and stability needed to participate in daily life. PIP enables this and plays a preventative role, reducing avoidable demand on NHS, housing, and crisis services.



Plan across government. PIP, the NHS, housing, and social care are interdependent. When one system withdraws support, costs displace into others; they do not disappear. Preventative investment and joined-up planning across DWP, DHSC, MHCLG, and HM Treasury is the most efficient response to rising demand.

“

It absolutely is an investment in people, giving them the opportunity to improve their lives and hopefully rely less on other support services and, like the name suggests, become more independent. ”

“

That's part of PIP, isn't it, is having that independence, that respect, that choice that you can make decisions for yourself. ”

Headline recommendations



UK Government

1. Ensure the new cross-government mental health strategy aligns mental health, disability, and social policy around prevention and supported autonomy.



Department for Work and Pensions

2. Strengthen and extend the Right to Try Guarantee to cover therapeutic, educational, training, and civic activity.
3. Reform PIP assessments to be recovery-oriented and trauma-informed, with mental health expertise embedded where claims involve mental illness.
4. Redesign PIP activities, descriptors, and rules to reflect the lived impact of mental illness, including a formal “catch-all” activity and a statutory review mechanism.
5. Introduce safeguards around large back-payments, including voluntary staged payment options and signposting to financial and safeguarding support.



Department of Health and Social Care/NHS England

6. Strengthen mental health services, including access to therapeutic interventions and personalised care through the NHS, through the Modern Service Framework.
7. Enhance coordination and quality of services.
8. Fill in gaps in social care support.

Rethink Mental Illness

We are the charity for people severely affected by mental illness, no matter what they're going through.

For further information on Rethink Mental Illness
Phone: **0121 522 7007**
Email: **info@rethink.org**

rethink.org



Rethink Mental Illness, a company limited by guarantee. Registered in England Number 1227970. Registered Charity Number 271028. Registered Office 28 Albert Embankment, London, SE1 7GR. Authorised and regulated by the Financial Conduct Authority (Firm Registration Number 624502). © Rethink Mental Illness.