



What Personal Independence Payment (PIP) makes possible and what must change

Rethinking PIP

report

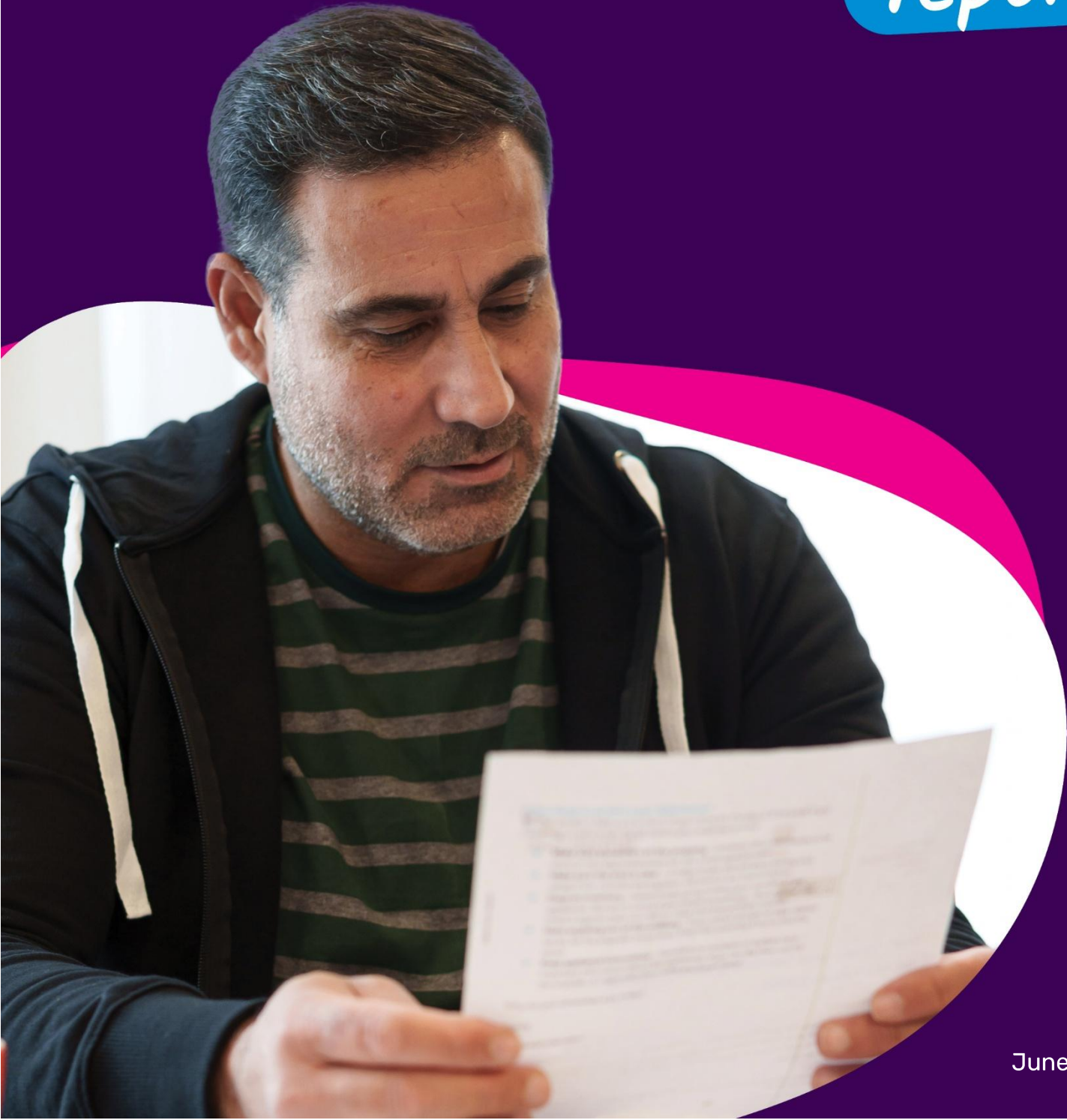


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Executive summary

Purpose

Co-produced with 24 people severely affected by mental illness, this report outlines how Personal Independence Payment (PIP) enables people with mental illness to live their lives, where it currently fails and what needs to change. It is both a stand-alone report and forms Rethink's 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 with lived experience described it as the financial foundation that enables them to manage fluctuating illness, access timely mental health care which the NHS hasn't been able to provide, sustain safe and suitable housing, maintain relationships, travel when public transport is inaccessible, and engage in meaningful activity, including paid work for some. PIP makes autonomy possible, by allowing 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
- a fluctuation rule built around averages that does not reflect how mental illness actually presents
- assessment reports that distort or contradict what claimants have said
- an assessor pool and a lack of matching assessors, with insufficient mental health expertise
- 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.

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 and forming a vicious cycle.

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 what independence truly means. 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.

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.

Introduction

Personal Independence Payment (PIP) plays a key role in the lives of people severely affected by mental illness. For many claimants, PIP helps them to manage health, maintain housing, participate in society, and avoid mental health and financial crises. It is a stabilising resource as people navigate public services which are often fragmented, overstretched, or inaccessible.

This report situates PIP within that wider context. Drawing on lived experience, it shows how PIP enables what we call supported autonomy: the combination of financial security, flexibility, and choice that makes dignity, participation, and recovery possible while living with ongoing illness. PIP often compensates for gaps between what people need and what is available, but more importantly it gives them choice and flexibility in their support. PIP enables a level of equity of opportunity and quality of life comparable to that experienced by people without being severely affected by mental illness, by offsetting the structural and financial barriers that would otherwise limit participation. It creates the conditions for a more equal footing in everyday life.

The way PIP is being used also reveals deeper structural problems. When timely mental health care, social care, suitable housing, advocacy, or accessible transport are unavailable, unmet need is absorbed elsewhere. PIP is increasingly relied upon to mitigate harms generated across health, housing, employment, and social care – particularly against a backdrop of rising living costs. This signals systemic imbalance. It is not a failure of claimants or of PIP's core purpose.

As long as these interconnected systems remain under-resourced or misaligned, demand for PIP will remain high. Further restrictions to PIP would generate distress and hardship and push costs elsewhere in the system. The answer is neither restricting access to PIP nor reframing it as a substitute for public services. It is coordinated action across government to address the drivers of ill health and exclusion upstream, while preserving PIP as a vital source of support for disabled people.

The Timms Review of PIP arrives at a critical moment. PIP reform must be shaped by lived experience. People severely affected by mental illness have been central to recent narratives about PIP yet are too often spoken about rather than listened to. At the same time, research from More in Common for the [Head On campaign](#) has shown that 3 out of 4 people think mental health is as important as physical health, and that the broad cross section of British public think government needs to more to improve the mental health system.

At Rethink Mental Illness, our mission is to bring meaningful change to how society and systems view mental illness, improving people's lives through accessible services and

fair policies. Working alongside people with lived experience is central to this, and this project was made possible through the support of Lloyds Bank Foundation for England & Wales. Co-production was the golden thread throughout this project. A lived experience partner was involved from the outset across recruitment, engagement, analysis, and reporting.

We recruited 24 people with current or previous experience of claiming PIP while living with mental illness, often alongside other conditions. All engagement was delivered virtually to reduce barriers around travel, energy levels, and anxiety. The journey was carefully designed for structure, support, and choice:

- Individual sessions with each person to build trust, explain the project, and explore their personal experiences of applying for and receiving PIP.
- A group pre-meeting to introduce participants and outline the next stage.
- Organised group sessions co-facilitated by the Lived Experience Insights team and our lived experience partner, structured around Rethink's Communities that Care pillars.
- A group debrief for reflection, questions, and feedback.

Eight people continued through co-analysis, working with the team to refine themes and messages, and six people remained involved during the reporting phase. We offered payment to participants in recognition of their expertise and signposted further support after engagement.

Participants reflected positively on this approach.

- **"I'm not alone in the struggles I've had with DWP processes. Being part of this project has given me real optimism, knowing these conversations are happening and that people genuinely want to create positive change."**
- **"I've witnessed firsthand system change in my area so I know it can be done. I feel heard, and I've really valued listening to others. I hope to see and benefit from improvements in my lifetime."**
- "Sharing and utilising my lived experience I feel is helpful to enabling decision-makers to make more informed decisions, that better meet the needs of those with mental health difficulties. It's a valuable perspective that deserves to be heard at all levels. This project has helped me feel more positive about my own mental health challenges and the wider system, particularly the PIP process."

When PIP works: stability, participation, and prevention

This section primarily addresses Theme 1 of the Timms Review with significant relevance to Theme 4.

PIP is a flexible resource that enables participation, covering the financial costs necessary for disabled people to manage daily life. It also compensates for gaps in public provision. The accounts in this section show what becomes possible when financial support is available, flexible, and trusted to be directed by people themselves. With access to PIP, people felt increased confidence, dignity, and self-worth, alongside reduced anxiety and a greater sense of stability. These outcomes are integral to recovery and participation, yet remain insufficiently recognised within current assessment frameworks

Choice and agency in health management

People frequently described using PIP to fund support for health and wellbeing that goes beyond what the NHS currently provides (e.g., specialist therapies, longer therapeutic courses, aids to manage medication side-effects). They described being able to choose services that reflected individual needs and preferences, supporting a more personalised approach and greater involvement in treatment decisions. This flexibility was associated with greater agency over recovery.

PIP also fills gaps and prevents deterioration and crisis during NHS waits. Timely access to psychiatric, therapeutic, and physical healthcare was seen as vital for maintaining mental stability and supporting recovery by reducing the cumulative stress of prolonged untreated illness. Our previous researchⁱ has shown gaps in treatment increase the risk of crisis, hospitalisation, and loss of housing or employment. **Five times** as many people are waiting **over 18 months** for specialist community mental health care for people with serious mental illness than for all elective physical health treatmentⁱⁱ, yet mental health has been excluded from the government's flagship plan to reduce long waits and waiting lists. Until NHS provision improves, PIP remains an indispensable means through which claimants can exercise choice and prevent deterioration.

- “Yes, it makes a huge difference. It's enabled me to afford private therapy that I would otherwise have to wait years for on the NHS (I was told a minimum wait of two to three years). This is massively helpful for my mental health as I am getting the support that I need.”
- “PIP enabled me to see a psychiatrist privately. Without this, I wouldn't have been able to get diagnosed.”

- “PIP helped me get a private MRI. The doctor did reluctantly say she'd give me an MRI, but the routine wait where I am is five to six months, which it's just ridiculous if you are in pain. It just wasn't realistic to wait that long. So that's what that PIP enables, that access to faster healthcare when you need it.”
- “There were very long waiting lists for therapy in the NHS, and I really couldn't have waited. So, I accessed private therapy with my PIP.”

Mental and physical health were often described as interdependent. PIP funded physiotherapy, pain management, exercise, and support to attend appointments. It also helped cover costs associated with managing the side effects of psychiatric medication. For example, gym memberships, swimming, and exercise classes were important for mitigating medication-related weight gain and supporting healthier routines. Some people described spending more on pre-prepared food, particularly helpful for those living with physical disabilities alongside mental illness. These uses are preventative as they sustain healthier habits, reduce secondary conditions, and avert future crisis.

People also used PIP to pay for support workers or accredited micro-providers who help them attend appointments, understand treatment options, take notes, provide translation, and advocate on their behalf. This is important for claimants without family or friends available to accompany them, and who are unable to access commissioned advocacy services or social care direct payments due to eligibility thresholds, limited availability, or waiting times.

- “PIP can be used to pay someone to help you get to appointments or access services, especially if you don't have family or friends to support you - what's sometimes called a micro provider in my area.”
- “It makes a real difference to my physical health because I can invest in what helps me, without barriers. That might be trying acupuncture, buying a supportive pillow for pain, or getting a heat pad—that sort of thing.”
- “I struggle with nutrition, struggle with cooking, struggle with chopping vegetables and so end up having a fairly unbalanced diet in that sense. But when I do have enough money through PIP, it lets me get things like pre-chopped veg, it lets me try and make changes in that way.”
- “With type 2 diabetes, I need to follow a very specific diet and take medication...by getting PIP I'm able to make healthier choices that are beneficial *for me, both*

physically and mentally. I can afford to buy fresh fruit and get prepared vegetables. Without the PIP, I wouldn't be able to do that. It can't be understated the importance of having a healthy diet."

Sustainable social connection

Social isolation is both a cause and consequence of mental illness. PIP enables safe participation in manageable, sustainable social activities, from peer support groups to cultural, faith-based, and LGBTQ+ spaces. Hobbies like gaming, music, writing, yoga, cycling, choir, painting, and learning languages were described as a form of "preventative medicine" and positive coping mechanisms. Social prescribing often involves group activities that carry small upfront costs or accumulate expenses over time. Therapeutic value depends on continuity, and PIP provides the financial basis for sustaining participation.

- "I think it can empower you to feel more independent, in terms of not feeling that you have to rely on your friends and family as much because the money enables you to have other options. So it might be, for example, rather than having a friend or family member to come out and clean your house, you could pay for a cleaner and it takes the pressure off other people. And then you can have more of a normal relationship with those people and not feel that there's a lot around feeling a burden to other people... Not having that, particularly in terms of the mental health aspect, feeling like other people have to do things for you and can't do things for yourself."

PIP also reduces overreliance on informal care, enabling more balanced relationships with family and friends. By funding paid support, it eases the domestic responsibilities often placed on loved ones and shifts relationships away from a caregiving dynamic. People emphasised the value of no longer feeling like a "burden" and being able to reciprocate emotionally and financially. PIP also covers transport costs that make regular visits possible, allowing claimants to be more emotionally present as friends, partners, and family members. Social connection and community are being built with PIP.

- "It has helped me create social connections. I've been able to create different opportunities for different people, including taking some people to different writing groups or if there's a drama group for safeguarding and different things. It's helped me build my connections. And one of my friends, he had really bad anxiety, but he's set up his own group now and it's grown really big. And it's helped friends and family. So yeah, it's been a huge... it's been like one of those like mind map trees."

Housing stability and therapeutic home environments

PIP provides **recognised evidence of disability or health-related needs**, which may **support housing assessments**, applications for council tax reductions (where available), and access to priority service registers. It can help substantiate medical or vulnerability-based need and reduce the burden of repeatedly explaining or justifying one's circumstances. People described how PIP enabled housing providers and local authorities to take their needs more seriously, and to better understand specific requirements such as the need for ground-floor accommodation or accessible layouts.

- "One of the things that was good about being in receipt of PIP was that it was very clear what my needs were. And that served as evidence in itself. So, I went on to priority for health reasons. And I didn't have to over explain that, because PIP in itself is a gateway to like other things."
- "It helped when the council was assessing my housing, they asked what benefits I was on and then they took me a lot more seriously in terms of getting secure housing. The thing I would say is that it was life changing and life-saving and it's completely changed my mental health."

Some people reported using PIP to **manage rent shortfalls** where Housing Benefit or Universal Credit failed to cover the cost, especially in the private rented sector. With Local Housing Allowance rates widely recognised as failing to keep pace with market rents, and housing costs continuing to rise, some claimants reported being effectively compelled to use PIP to maintain their housing and this is an understandable decision. Housing stability was repeatedly identified as foundational for mental health, with insecurity or repeated moves only exacerbating distress and hindering recovery.

- "Having that financial stability, and knowing I'm supported where I live, has made a huge difference to what I can access and the people I'm able to connect with."
- "Getting PIP meant I could really look at my living situation. It gave me a sense of financial security - knowing I could live somewhere suitable and use the money as it was intended."

People also described using PIP to **manage the additional costs of moving home**, which can be higher for people with long-term health conditions or disabilities. These may include the need for physical assistance and overall greater logistical support, particularly where moves are unplanned or frequent. Some people reported that PIP helped them **navigate transitions out of temporary or supported accommodations** as well.

Living in a clean, organised, and accessible home environment was identified as an important part of managing mental illness and supporting recovery. PIP enabled people to meet disability-related daily living needs within the home, particularly where other grants or statutory support were unavailable or insufficient. The adjustments create a **comfortable and accessible home environment that is vital to stability, recovery, and independent living**. This included: paying for cleaning or gardening support where tasks were physically or mentally overwhelming; making modest home adjustments not covered by existing schemes, such as sensory adaptations (e.g. blackout curtains or adjusted lighting); and purchasing accessible furniture or equipment, including shower chairs.

- “It’s also made a real difference to being able to make my home accessible. Accessibility isn’t always about obvious physical aids or making a home feel clinical. For me, it’s things like choosing fabrics that work with my sensory needs, getting blackout curtains, or having something you can pull out in the kitchen for your cupboard. PIP has allowed me to make my home work for me while still feeling like my space, not something clinical.”
- “Now with PIP, I can actually spend on things that I need, like buying a shower chair today. It’s not getting eaten up in city living costs. I can actually now use it like kind of what it was intended for, rather than getting eaten up on sort of city living.”
- “I have a cleaner who comes round. She does the things that I physically can't do for myself... But she comes to my house, and she does things that I can't do and that makes me feel better as well. I know the week before she comes, everything in the house is dirty and I can't do anything but after she's been it looks clean and it smells nice and that always boosts my mental well-being.”

Preventing financial and mental health crises

Financial instability exacerbates mental illness. Its effects are felt more severely by people living with mental illness, who face both constrained incomes and additional disability-related costs. PIP was described as a source of financial stability, especially when low-paid work or out-of-work benefits such as the Universal Credit standard allowance fail to keep pace with the cost of living. This stability supports both recovery and prevention, including during transitions between inpatient settings and the community.

Although PIP is not intended to cover essential living costs such as rent or utilities, people severely affected by mental illness often do rely on it for day-to-day financial security, and this reflects a wider structural gap in welfare and labour market systems.

Living with severe mental illness involves additional, often unavoidable costs. There were some condition-related expenses discussed, such as cleaning products for those with OCD or food-related costs for those with eating disorders, alongside pressures linked to budgeting and debt during periods of poor mental health. Benefit rates remain low relative to rising living costs, despite the increase introduced through the UC Act 2025, and many people living with mental illness are unable to work regularly or are in low-paid, insecure employment. PIP plays a preventative role: helping people cover additional and essential costs, manage budgets, reduce or avoid debt, and ease financial stress that would otherwise exacerbate mental illness and increase the likelihood of crisis.

Prevention is itself a hopeful function. It speaks to a system that can, when it works, keep people out of crisis rather than catching them after it.

- “It does make a difference to how I manage money because it gives you that safety blanket, it takes away that stress and anxiety.”
- “Having the PIP does make a difference because the budgeting aspects of life can be extremely challenging. With support from my support workers, I’m able to manage my bills and organise my finances. That financial support means I’m not having sleepless nights wondering how I’m going to pay bills.”
- “Learning to manage a budget, nobody taught me how to do that, not my parents or anything. I’ve learned that through making mistakes and wishing that I’d spend money frivolously on things. I do manage my money very well, but without the PIP, I’d really struggle, because it’s all the unexpected cost you have.”

Space for meaningful activity, inside and outside of work

People we spoke to were explicit that PIP should not be treated as an employment-related benefit. Entitlement should not be contingent on work, work-readiness, or progression toward employment. Its purpose, as described by people with lived experience, is to support people to manage the impact of ill-health and disability, regardless of whether they are in employment or not, including many for whom employment remains a distant or unrealistic goal due to the severity and/or fluctuation of their mental illness.

Where engagement is possible, PIP enables education, training, volunteering and, for some, paid employment. PIP helps pay for noise-cancelling headphones and fidget tools that make engagement possible for people living with mental illness and neurodivergence; for digital access and equipment such as tablets or second-hand laptops; and for course fees, training costs, and learning materials.

PIP also reduces pressure to engage in work prematurely, allowing recovery-led pacing. This financial security lets people work or volunteer at a pace that reflects fluctuating capacity, take part in flexible or part-time activity, and build confidence gradually rather than being forced into unsuitable employment. Activities like volunteering are manageable precisely because they accommodate fluctuation. A claimant might do one hour of volunteering in six weeks and then ten hours in one week.

- “PIP helped take a bit of pressure off in terms of having to rush out and get work because I've been able to access exercise, drive to my physio appointment, I'm now back in work. It's given me the capacity and choice to get there. Because I get that help, I'm contributing back into society and the economy again. I only do about 4 to 8 hours a week of work, but because I've had that money to be able to look after myself, I can then give back as well.”
- “Having PIP means that even if someone is poorly and they need to take some time off, they know they've got that guaranteed income so that when they do go back to work, they're not finding themselves digging out of debt straight away.”
- “It just enables me to leave the house and take part in work, education, training, or volunteering or whatever it may be. It also helps me to be able to buy the resources I need to be able to do training and stuff like notebooks and pens and stuff, all of it really.”

The benefits of participation, when supported without conditionality and paced appropriately, are extensive: regular routine and structure, a sense of purpose, new skills, social connection, and renewed hope about the future. For many, these activities are steps in recovery.

PIP also supports participation in the workplace by helping claimants self-fund adjustments rather than relying solely on employer-provided accommodations or waiting on delayed and tightening Access to Work grants. This affords a degree of independence and choice over how working life looks, including what to share about a diagnosis with an employer.

- “The independence bit of PIP, which is what it is, and it not being an employment related benefit means that I can go to work. It means that I pay tax, it means that I have meaningful activity, it means that I help other people, it means I have structure. It affords me all those things.”
- “When I was struggling and receiving PIP, I'd been diagnosed with anorexia nervosa and generalised anxiety disorder. And as part of my recovery, it's so important to be able to fund things that give you purpose and meaning. Something positive to focus on away from your mental health or your own

struggles and stuff - is massive. It's having hope for the future that things can get better and that you can get involved in things at a time when you're really struggling, step by step."

Removing barriers through transport and technology

Transport is a crosscutting enabler of participation. Anxiety, past trauma, sensory needs, and physical inaccessibility can prevent people severely affected by mental illness from using public transport. Many cannot drive due to their health or medication side-effects, so PIP funds taxis and other suitable transport to maintain social contact, access services, and attend healthcare appointments. For many, reliance on taxis is an ongoing necessity during periods of poor mental health and in rural settings. Access to appropriate transport is critical in preventing people from becoming house-bound and in enabling independent participation in daily life. Conversely, the loss of transport-related support, such as Motability vehicles, was described as having an immediate and disproportionate impact on independence, access, and quality of life.

Excerpt from a Pen Portrait

"I got the mobility car and the difference that made meant I had independence. I could go out and have a social life, drive 30 minutes to the Peak District and for a coffee with a friend. I was diagnosed with diabetes and that was a bit of a game changer, but I was able to go swimming because I had a car to get me to the swimming pool which also benefits my mental health. Because I was getting PIP, it meant I got the blue badge for the parking and a discount on the sports membership and the difference that that made to my quality of life is night and day.

"I had a review the year before last and there was no in-person interview. It was all paper-based and on a telephone call and my support worker was with me and I also had a supporting letter from my GP. Unfortunately, they decided to drop me down to standard, which meant that I got my vehicle taken away a year ago this week. My quality of life from then till now, it is diminished by probably about 90% because I'm not able to get out for even the basic things like food shopping or meeting a friend."

- "I think that, for me, all avenues have definitely been closed off by simply lowering my award and removing that vehicle. Because for me, I can't get on public transport, I've got extreme social anxiety. I can't have people too close to me. I'm very sensitive to my environment. I can't have things too loud. I can't have things too bright. It's a physical impossibility, but it's also a mental impossibility."

Digital access and equipment are similarly important, especially where conditions limit the ability to leave home. During periods of heightened anxiety, paranoia, trauma responses, or severe depression, in-person engagement may be impossible. Digital

technologies and internet connection then become the primary route to appointments, meaningful activity, and social contact. Without financial support for these costs, people risk becoming housebound and excluded.

- “PIP, if you're able to set that money aside, can be used to pay for technology and digital access, in the same way others might use it for mobility, such as through a Motability car.”
- “Access to technology that supports meaningful activities, work, and learning. Many health and social care services, including therapy groups and courses, are now online. That makes technology essential for wellbeing, yet not everyone has access. Being able to use PIP to buy something like an iPad or a second-hand laptop, and to build the skills to use it, can make a huge difference and is a really positive use of that support.”

The cost of autonomy

This section addresses Theme 1 of the Timms Review, with significant relevance to Theme 2 and Theme 3.

The preceding section showed what PIP enables. This section examines the cost to claimants of accessing and keeping that support, and what would change if the assessment recognised the realities of living with mental illness.

Beyond independence

The PIP assessment framework rests on a limited understanding of independence: a person is either dependent and eligible for support, or independent and not entitled. This binary does not reflect the reality of living with mental illness.

For people severely affected by mental illness, independence rarely means self-sufficiency. It is better understood as supported autonomy: the financial, practical, and relational support that makes choice, control, and participation possible, while recognising that illness persists. PIP is the mechanism through which a degree of independence becomes achievable. Yet the assessment process requires claimants to emphasise dependence in order to access the very support that enables their quality of life. The system does not account for the fact that **support and functioning are not opposites but mutually reinforcing**.

- “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.”

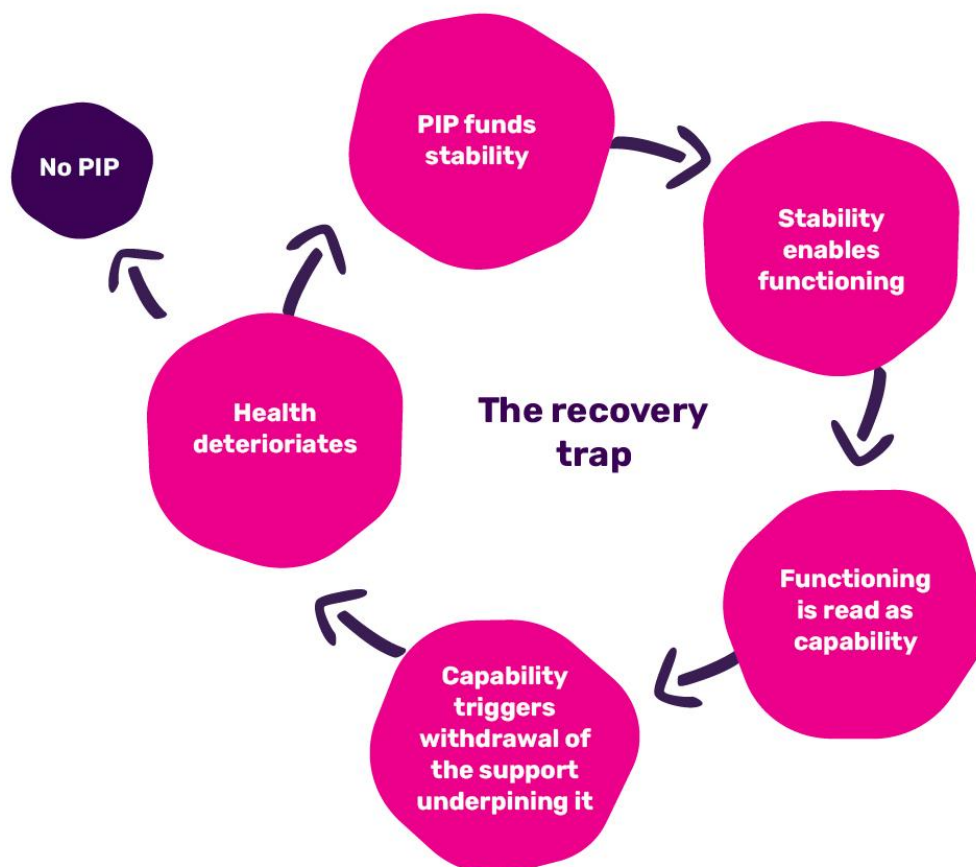
The ‘recovery trap’

Claimants are encouraged, in principle, to live independently, yet penalised when they demonstrate that independence in practice. Improvements in functioning are frequently treated as evidence of reduced need, rather than as outcomes enabled by support. People regularly described this contradiction as a “recovery trap” fixed in the PIP system. PIP allows claimants to engage in activities that support recovery, such as volunteering, employment, education, social connection, and other structured routines and hobbies, which is exactly the outcomes a well-functioning disability benefit should encourage. At reassessment, those same activities are interpreted as proof that support is no longer required. The award that enabled recovery is removed because recovery occurred.

Excerpt from a Pen Portrait

“When I was in hospital, I worked with a social worker to fill the forms. It took a while and the first payment came in a chunk. I was in hospital for a while so nothing changed then when my review came through, they took it all away as I was home and not in touch as much with services. I was functioning and about to go to uni but still living at home because I needed support. I had extra physical health needs too, so I felt that panic. None of it made sense to me and I had to reapply and go through the whole process again. Compared to what I was receiving at first, the second time it was 75% less but I couldn’t function without anything. It’s hard having to explain the extent you’ve gone through and the impact it had on me then was huge. It was hard to fight for yourself when you know it’s something that’s needed.”

This forces claimants into an impossible position: either improve their wellbeing and risk the financial security that got them there or restrict their lives to protect that security. People described feeling “stuck” in a cycle, unable to safely progress without fear of judgement or punishment.



- “We’re supposed to be supporting ourselves to be independent. That is what the money is supposed to be for... But when we are then classed as independent, we are penalised.”
- “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 Right to Try legislation signals positive intent and provides limited legal assurance that paid or voluntary work will not, in itself, trigger reassessment. But fear that engagement could still result in the loss of benefits remains strong.

One person described attending a local art therapy group where they were asked for their National Insurance number; shortly afterwards, they were informed their participation had been identified by DWP. This led to complications with their PIP award and ultimately compelled them to stop attending.

People described a “domino effect” when PIP is lost, including the loss of concessions and passported benefits such as the Blue Badge, Motability Scheme, and carer passes. As passported benefits are regularly embedded across different systems, People described a sudden and disorienting collapse of support, often marked by reduced mobility and social withdrawal. The speed and breadth of this collapse underlines how much of a claimant’s daily life depends on PIP.

Without stronger and more explicit protections governing how recovery-supporting activity is interpreted, meaningful engagement continues to feel unsafe for many claimants.

- “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?’”
- “I think that PIP is actually incredibly restrictive for work, volunteering, and education. I really wanted to do some volunteering for the Blue Cross. I wanted to use my camera, take photos, but decided I wasn’t actually well enough to do it. Then, after thinking about it and having a conversation with a friend just a few days ago, I realised that it’s my fear that stops me doing it. Because if [DWP] ask

me about it, [DWP] will say, 'she is well enough to do this, it involves engaging with people, it's physical'. It wouldn't matter that it exhausted me and I came back and it was deeply difficult. I still wanted to do it for my own wellbeing. But that wouldn't matter."

Suspicion, stigma, and self-surveillance

Living with mental illness often feels like being under heightened suspicion. People described invisible and fluctuating conditions being treated by assessors as less legitimate than visible physical disabilities or illnesses, reinforced by public narratives suggesting PIP is claimed for "mild" mental health issues or exaggerated need. The result is constant pressure to prove severity, downplay recovery, and repeatedly justify entitlement.

This atmosphere creates guilt and feelings of unworthiness, even where eligibility criteria are clearly met. Guilt was most acute during periods of relative stability, when people questioned whether they "really needed" PIP, even though, over time, difficult periods outweighed good ones.

The result is ongoing self-surveillance, with claimants monitoring their behaviour and wellbeing to justify continued entitlement, sometimes neglecting needs and avoiding the support that would help. However, people emphasised that the ability to do small enjoyable things was central to sustaining a sense of equal standing and a life beyond mere survival. As one put it, without these moments, people severely affected by mental illness may not "have any sort of life at all."

- "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. And you feel that you have to justify for why you're getting it."

The language of independence

People raised concerns about the language of PIP itself, which sends a message of its own. The term "independence" was widely experienced as setting an unrealistic benchmark, framing ongoing support needs as personal failure rather than a legitimate and often permanent consequence of disability.

People proposed alternative framings. "Life management payment" and "wellness management payment" highlight the practical reality of what the money is used for,

without importing assumptions about self-reliance. Several people noted that the legacy benefit, Disability Living Allowance, more accurately acknowledged both the barriers imposed by disability and the permanence of support needs. Language shapes assessment culture, claimant experience, and public perception. A framework centred on “living with disability” invites fundamentally different judgements than one centred on “independence.”

- “I was receiving it when it was the old style DLA, Disability Living Allowance, and I think that is a more accurate title for the people that are trying to claim the benefit and also what the benefit is there for, because it doesn't matter whether it's a physical or a [mental] health issue. It's about the fact that we do live in a very ableist society and because we can't do that, we need that extra financial input. Whether that be hiring somebody to help you or being able to buy different aids and equipment. So, I think the name PIP, Independent, I'll never be independent ever. I can't do it. I've gone beyond that now.”

Language is a complex area and whereas changing the name of the payment will have less practical impact than other improvements, it should be conceptualised using the least stigmatising, strengths-based language. Different people with disabilities may have different views. Government should consult disabled people on what would be the most language to frame and call the payment.

What this feels like in practice, and why it is unfair by design

This section addresses Theme 2 and Theme 3 of the Timms Review.

The people severely affected by mental illness who contributed to this work did so because they believe the system can be made fairer and safer, and the Timms Review represents the most significant opportunity in over a decade to do that work.

Our previous report on benefit assessmentsⁱⁱⁱ highlighted that our social security system is frequently ill-equipped to respond to the realities of mental illness and can actively hinder recovery. The insights gathered for this report reinforces and deepens our understanding of their experiences navigating the PIP process. We listened to stories about a **system that misunderstands mental illness, places disproportionate burden on claimants, and produces inconsistent and often harmful outcomes.**

A system that does not recognise mental illness on its own terms

People often spoke about **not being believed**. Personal accounts and medical evidence were treated with scepticism, creating a sense that claimants must continually prove their legitimacy. Those with multiple conditions spoke at length about how mental and physical health were considered in isolation rather than cumulatively, with mental health being overshadowed by physical health.

One person described being immediately awarded the enhanced rate when claiming for their physical health issues, having previously struggled to secure the same rate based on mental illness alone. Another explained how they failed to consider the relevance of a history of anorexia and osteoporosis after having fractured their shoulder, and this is despite these issues being communicated.

People felt **actively discredited by the process**, with their accounts treated as less reliable than those of professionals. In practice, this created a perception that supporting evidence from clinicians, support workers, or services was given greater weight than claimants' own lived experience, despite claimants being best placed to describe the day-to-day impact of their condition.

- "Never underestimate the breadth and depth of disbelief."

This was made worse by **appearance-based judgements**, where assessors relied on narrow assumptions about what mental illness "should" look like. Being well-presented, making eye contact, or engaging in isolated activities were interpreted as evidence of capability, even where these behaviours masked significant distress. Claimants who did not conform to stereotypes of visible illness felt invalidated. These dynamics produced a perception that entitlement depended on performing illness in recognisable ways.

- “I don’t think people living with mental illness can access PIP fairly at the moment. The assessors are not mental health trained. I’ve had marks knocked off for hoovering my living room, being well dressed and looking them in the eye and these not being compatible with depression. When I went in person, I was marked down for getting there on the bus.”

At a structural level, this reflects the limitation of a fixed **activity-based assessment model**, which captures whether tasks can be completed but not the cost, recovery time, or consequences of doing so. For people severely affected by mental illness, disability rarely presents as a complete inability to carry out a task. Engaging in ordinary activities such as socialising, attending appointments, or volunteering often requires extensive planning, paid or informal support, and significant emotional and physical effort, followed by exhaustion and recovery time. By prioritising observable task completion and frequency, over severity and impact, the assessment systematically underestimates need and fails to capture the indirect impacts of mental illness such as depletion, avoidance, medication side-effects, and impaired sleep or morning functioning.

- “You have to score against the criteria, the set questions that are on the form. And I do feel that the whole PIP, the way it's worded, is mainly for people with physical illnesses and physical disabilities rather than mental health difficulties. So, if they can change the form so that it is more directly applicable to people experiencing mental health issues, then that will be a good thing.”

Failure to capture fluctuation and cumulative impact

The PIP regulations assess entitlement by considering whether a claimant is likely to meet specific activity descriptors on more than 50% of days across the required period, broadly comprising the three months before and nine months after the decision date. While intended to accommodate fluctuation, this rests on assumptions about the distribution and comparability of the limited activities being assessed, which do not align with the lived experience of many people with mental illness.

People described their mental health as fluctuating in **uneven and often clustered patterns, with periods of relative stability punctuated by episodes of significant deterioration**, rather than a regular alternation between good and bad days. Although the regulations permit aggregation where no single descriptor dominates, the emphasis on frequency still count more functional days even where periods of deterioration carry greater consequences for safety, independence, and continuity.

A claimant who can prepare food on four days of the week but is unable to leave bed on the remaining three may, on paper, appear to have trouble less than half the time. Yet those three days may be decisive in determining whether they eat, maintain their tenancy, or avoid crisis intervention. By prioritising the proportion of days on which an activity can be completed over the severity and consequences of days when it cannot,

the framework fails to capture the lived reality of managing a long-term, fluctuating 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.”
- “It’s not black and white being able to take part in things and it’s a very ableist view to think that there’s no consequences for people who claim PIP and find everyday things difficult.”
- “I know for me, my energy levels and my output are very limited and restricted. So it may be that I’ve got a meeting on a Monday for two hours online and that’s okay, I can do that. But then the Tuesday, I’m going to be wiped out. I can’t even put two words together to create a sentence. You know, my anxiety is at an all-time high and I’ve got no energy to do anything... I know for a fact my diary is so finely balanced.”

Inconsistent and unreliable decision-making

A recurring theme was the **lack of consistency and expertise within assessments**. People spoke about being assessed by healthcare professionals without a background in mental illness, leading to misinterpretation of symptoms as well as insensitive or inappropriate questioning. Many people felt assessors were actively seeking to avoid awarding PIP, creating a sense of being tricked or set up to fail.

- “Everyone’s experiences are different, whether depending on what assessor they’ve had. But it also does depend, unfortunately, on our different conditions, because if you have a condition that is very misunderstood and that is very stigmatised, your experience, no better or worse, but may be different to somebody else’s.”

Outcomes were widely seen as a **“lottery”**, heavily dependent on the individual assessor rather than the claimant’s circumstances. Similar cases could lead to vastly different decisions, diminishing their confidence in the fairness and integrity of the system. People also reported lengthy delays for reassessments and mandatory reconsiderations, even where health had significantly deteriorated.

- “I think to me it just speaks to the absolute lottery that it is when you come to who your assessor is, what your assessor’s background is, what they do and don’t ask you. I’ve always been lucky to not be asked about work or volunteering, but that won’t necessarily be the case going forward. It’s the fact it is so much of a lottery is something that just makes me furious.”

This inconsistency extended to the **assessment reports themselves**, where claimants described significant discrepancies between what they said and what was recorded. In some cases, distress or deterioration was reframed as evidence of wellbeing. Someone living with anorexia described not eating for three days due to assessment-related anxiety; the report recorded this as her “having a good day.” The process was described as “gaslighting,” with distress reframed as wellness and assessment reports reflecting what claimants described as “the worst things about themselves,” while minimising their impact. For some, the emotional cost was so severe that they disengaged or abandoned claims altogether, or it forced people into positions where they had to challenge the assessor’s reports.

- “I felt that my words had been manipulated and I needed to justify myself.”

These concerns were worsened by a lack of transparency in decision-making, with claimants not automatically receiving copies of their assessment reports unless they specifically request them. This limits the opportunity to challenge inaccuracies and undermines trust in the process.

A process that places a heavy burden on those least able to meet it

The system relies heavily on claimants to gather evidence, navigate complex procedures, and challenge incorrect decisions, often during period of severe mental ill-health. Administrative barriers including delays, lost documentation in the post, and unclear decision-making, intensify this burden. This burden is particularly arduous during fluctuating and episodic periods of illness, where capacity can change rapidly and unpredictably, rather than occurring only in clearly defined periods of crisis.

- “From the point of the review to the point of making a decision, living with that for nearly 18 months was horrendous stress... So, the system's broken in terms of how quickly they deal with these things and the stress it puts on people, particularly people with mental health issues.”

Completing the PIP process was like “*climbing a mountain when you’re not in the best place mentally.*” Many people depended on formal and informal support networks, like family, friends, or advocacy services, to complete applications or pursue appeals. Those without such support, or without the capacity to sustain prolonged challenges, were at greater risk of losing out on the support that they need through PIP. People described show unequal outcomes can reflect individual resources and advocacy, not need.

Additional barriers linked to cultural context and accessibility were also highlighted. Awareness and understanding of mental illness varies significantly across communities, and experiences of stigma may affect whether people seek support or feel able to disclose their needs. Where understanding of mental illness is limited, this may restrict access to benefits from the outset. There were also questions around whether PIP forms and assessment processes are sufficiently **accessible across different languages and cultural contexts**, including whether they allow people to

accurately describe their experiences in ways that are understood and appropriately interpreted.

People living in areas with limited NHS provision reported longer waits for diagnosis and treatment. Loss of transport-related support such as Motability vehicles has had a disproportionate effect, particularly where public transport infrastructure is poor or if using public transport causes severe anxiety with some people. Socio-economic disadvantages and geographic variation of services shaped their ability to engage effectively with the process from the start, all the way through to the end. One person felt he should have been awarded the enhanced rate due to their health but felt pressured to accept the standard rate due to financial concerns, fearing that challenge could lead to a lengthy process or loss of support entirely.

Beyond its administrative demands, the assessment process itself was widely described as **intrusive, distressing, and retraumatising**.

The process can exacerbate feelings of **shame and embarrassment associated with mental illness**, requiring claimants to repeatedly focus on their most difficult experiences in ways that feel exposing and degrading. For example, many were asked by assessors to unnecessarily detail personal information and likened to a “forensic examination” that sometimes triggered past trauma and humiliated them. Some people perceived that **assessors may become desensitised** to claimant experiences due to the high volume and intensity of cases processed, contributing to interactions that felt impersonal, rushed, or lacking in empathy.

These experiences have lasting effects. The anticipatory impact in the lead-up to assessments were described as **heightened anxiety, disrupted sleep, and periods of deterioration before the process had even begun**. More broadly, the assessment was often experienced as **overly negative and deficit-focused**, with limited space to reflect on coping strategies, effort, or progress.

Excerpt from a Pen Portrait

“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. 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.”

Poor communication about changes to awards is causing financial insecurity

Delays and unpredictability in reassessments and appeals create ongoing financial instability. People shared that payments may stop or change without warning, showing a lack of effective communication about award changes or administrative errors, which makes it difficult to budget or commit to expenses that support wellbeing. In some cases, large back-payments following delays were also experienced as difficult to manage. For some, the sudden influx of money resulted in pressure to repay those who provided informal care or support. As such, back-payments were identified as a risk factor for financial abuse as access to significant sums could attract undue pressure from those seeking repayment for costs that were disputed, informal, or never agreed. These risks can cause vulnerability at a point when claimants are already managing recovery and administrative stress.

A changing context: rising claims as system failure

A different question

The Timms Review's framing of Theme 4 invites us to explain rising PIP claims by reference to rising disability prevalence. Demand for PIP has risen because the systems around it (health, housing, social care, employment support, and income replacement) have failed to keep pace with need, and PIP is one of the few mechanisms that still works in cash, with flexibility, and at the discretion of the person.

The Independent Review into mental health conditions, ADHD and autism (March 2026) concluded that “current patterns are shaped as much by the design of systems as by underlying need.” It also found that some real changes in distress have occurred. **The prevalence of common mental disorders among adults in England has risen from around 15–16% in the early 1990s to around 23% by the mid-2020s**, with the sharpest increases among young adults. The historical age gradient has reversed, with young adults now reporting higher distress than older groups. Loneliness, sleep problems, and difficulties with concentration have worsened, and rates of self-harm reported as a coping strategy have risen. Critically, and contrary to any assumption that wider reporting reflects lower thresholds, more recent cohorts show *greater* functional impairment from these symptoms, not less. For severe mental illness specifically, the prevalence of conditions such as psychosis and bipolar disorder has remained broadly stable; rising service contact reflects more people needing PIP for longer. Parallel growth in adult recognition of autism and ADHD, particularly in women, reflects recognition catching up with previously unmet need rather than a sudden change in the underlying population.

The picture is of **genuine, concentrated increases in distress** in some groups, broadly stable underlying prevalence in others, and a system that processes all of them through a benefit increasingly required to fill gaps left by other services. The Independent Review's distinctions between population prevalence, administrative prevalence, recorded diagnosis, service demand, and underlying need, observing that these "do not necessarily move together," capture this directly.

The changes since 2013 that matter most for this report's participants sit in other departments' policy choices. As explained in a previous section: mental health waiting times have lengthened, Local Housing Allowance has fallen behind market rents, Access to Work has been hard to access, Universal Credit's standard allowance does not cover essential costs, the labour market has shifted further toward insecure and short-hours work that does not accommodate fluctuating health, while employer mental health adjustments remain under-resourced and inconsistently delivered.

Each represents a failure to invest upwards that is being absorbed downstream by PIP. The lived experience evidence in earlier sections of this report, including private therapy, housing shortfalls, and self-funded workplace adjustments, is a direct mapping of these failures onto the use of PIP.

Restricting PIP would not remove the need these patterns reflect, but it would move the cost to emergency and urgent services, homelessness pathways, and the carers, often themselves disabled, who would be required to fill the gap.

Choice, quality, and addressing root causes

The displacement of unmet need onto PIP creates a temptation to design alternatives that look like solutions but aggravate the underlying problem. Voucher systems or in-kind substitutes are the most prominent of these, and they should be **resisted**.

The core of what makes PIP work, as the evidence in this report demonstrates, is **choice and flexibility** in what would best support them through recovery, which helps reach **autonomy**. People and their support networks know what enables their participation better than anyone else. The same money may pay for transport one week, a cleaner the next, sensory adjustments the month after, depending on the trajectory of someone's illness. A voucher system cannot anticipate this and would place more administrative burden on them when they need to shift services.

The honest response to PIP being used to plug gaps in other systems is to address those systems, not to constrain the one that works when correctly accessed. People need timely mental health treatment, affordable housing, accessible social care, and meaningful employment support. Where those things exist and work, PIP can return

more closely to its intended function. Where they do not, PIP is what stands between someone and a crisis. If the underlying failures are not addressed, the population that needs PIP will continue to grow.

- **“Before I had access to PIP, I was in crisis a lot more and having access to the PIP actually helped me get out of hospital and stay out of hospital for longer. It really did as it's intended for, like it did really help with my independence.”**

PIP, work, and fiscal sustainability

The people involved in this project were **unambiguous that PIP must remain a non-work-related benefit**, and earlier sections set out why the recovery trap makes any conflation between PIP and work assessment damaging. The labour market changes since 2013 reinforce the case for keeping PIP non-conditional. PIP is what allows someone to volunteer one hour in six weeks and ten hours the next, to take part-time or fluctuating work without falling into debt during a relapse, and to fund the transport, equipment, and adjustments that make any participation possible.

This is also why linking access to UC Health only through PIP entitlement once the WCA is abolished, as planned, would raise the stakes of PIP assessment to a level the assessment process **cannot bear**. PIP assessments are already inconsistent, error-prone, and retraumatising. To make them the gateway to additional income replacement would worsen every problem we have documented. The cost of a bad decision would become the difference between a relatively stable life and destitution. UC Health entitlement could be linked to PIP entitlement, but it **should not be the only route**, and it should also be determined through its **own appropriate route**, not linked to a PIP assessment never designed for the purpose. We would also welcome a wider move, in future debate about benefit conditionality more generally, **towards occupational therapy-informed approaches** that assess what enables participation in everyday life, including environmental adaptation and the cost of doing things, not only whether they can be done.

The Review asks how PIP can remain within fixed financial limits. The relevant cost question is therefore not "what does PIP cost DWP" but "what does PIP-related policy choice cost the whole system."

- “PIP is often seen as a cost, but it’s also an investment. It enables people to improve their health and wellbeing, and for some, that means returning to work. Not everyone will, of course. we’re all different but many can and do. It’s about looking at the longer-term impact: supporting people earlier can prevent crises, reduce reliance on emergency services, and improve outcomes overall. It’s not just money going out; it’s investment in people’s lives, with benefits that come back in different ways.”
- “There’s a strong focus on cutting welfare costs, but it’s important to look at the bigger picture. A long hospital stay can cost thousands, even tens of thousands of pounds. In comparison, providing PIP is relatively small, yet it can help people stay well and avoid reaching crisis point. Without that support, people may become overwhelmed, unwell, and end up needing far more intensive and expensive care. Supporting people to live independently with their mental health, stay out of hospital, and remain well is not only better for them. it also reduces pressure and costs across the NHS.”

Recommendations

UK Government

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

As the government develops its cross-government mental health strategy, it should be used to address the systemic drivers that shape demand for PIP and other forms of support, working across DWP, DHSC, NHS England, MHCLG, HM Treasury, and other relevant departments. This strategy should:

- a. Recognise PIP as a permanent and essential form of support for disabled people should allow people to attain supported autonomy, while acknowledging its increased use as a compensatory mechanism for gaps in health, housing, social care, and employment systems.
- b. Commit to addressing unmet need through timely mental health care, social care, housing stability, advocacy, and accessible transport, reducing the likelihood of crisis and avoidable deterioration.
- c. Ensure that policy reforms across departments are aligned, avoiding situations in which changes in one system increase pressure or risk in another (for example, withdrawing welfare support without corresponding improvements in health or housing provision).
- d. Embed prevention and autonomy as shared outcomes across government, recognising that stability, participation, and recovery require coordinated investment.
- e. Maintain full and equitable access to PIP for disabled people, recognising that no system will eliminate the need for flexible financial support, and that PIP must not be weakened as a precondition for wider reform.
- f. Ensure that UC Health entitlement is determined through its own appropriate route, independent of a PIP assessment which is not designed for this purpose.

Department for Work and Pensions

All reforms should be co-designed with disabled people, including those severely affected by mental illness, ensuring that the system is built on lived experience, delivers fairness and dignity, and supports recovery and participation in society.

2. Strengthen and extend the Right to Try Guarantee

The DWP should action the recommendations made by the Social Security Advisory Committee on the Right to Try, and we recommend expanding it so that participation in recovery-supporting activity including therapeutic, educational, training, and civic activity, is treated equivalently to paid or voluntary work for the purposes of PIP reassessment and evidence of functional capability.

To ensure this protection operates in practice, the Right to Try Guarantee must be supported by clear, consistent, and co-produced communications. This should include clear guidance on the duration and limits of permitted activity, ensuring claimants understand how long they can engage in such activities without affecting their entitlement, and be applied uniformly.

3. Reform PIP assessments to be recovery-oriented, trauma-informed, and co-produced

The PIP assessment process should be fundamentally reformed to ensure it is safe, accurate, and fit for people severely affected by mental illness. A reformed system should adopt a more compassionate, non-stigmatising approach, recognising that limited understanding of mental illness can reinforce bias and affect decision-making. Assessment design and delivery should be grounded in lived experience and relevant clinical expertise, and explicitly support recovery, autonomy, and dignity. This should apply across the full PIP journey, including initial assessment, reassessment, guidance, and workforce training.

A reformed PIP assessment model must:

- Redesign scoring and descriptors to reflect the complexity, variability, and cumulative impact of lived experience, while enabling meaningful space for claimants to describe their needs in their own words
- Recognise fluctuation, effort, safety, and recovery cost over time, rather than relying on narrow judgements of task completion at a single point in time
- Embed appropriate expertise, ensuring that where mental illness forms part of a claim, assessments are conducted or overseen by professionals with relevant mental health qualifications and understanding
- Address stigma through improved training, ensuring assessors understand the realities of living with mental illness, including the effort required to maintain stability and participate in daily life
- Adopt a trauma-informed, non-adversarial approach, proactively identifying and honouring reasonable adjustments and ensuring emotional and psychological safety
- Treat claimants as credible partners, recognising their accounts as central evidence in understanding need and functional impact

- Improve consistency and reliability, reducing variability driven by assessor discretion or differences in claimant advocacy capacity
- Enable flexible, person-centred delivery, including choice over assessment format, timing, and setting, in line with claimant needs and preferences
- Reduce unnecessary assessments, enabling paper-based decisions where robust evidence is available

4. Redesign PIP activities, descriptors, and rules to operationalise this model

To give effect to a recovery-oriented assessment model, PIP activities, descriptors, and associated rules must be comprehensively revised through co-production with disabled people and clinicians, including those with lived experience of mental illness.

This should include:

- Expanding the activity framework to capture the lived impact of mental illness and cognitive, behavioural, and psychological disability, including executive function, emotional regulation, fatigue management, and psychological safety.
- Embedding structured narrative space in forms and assessments, ensuring claimants can describe the full scope of their experiences in their own words alongside descriptor-based assessment
- Introducing a formal 'catch-all' activity at Regulation level to capture significant functional limitations not adequately reflected elsewhere, preventing exclusion due to incomplete criteria
- Moving beyond binary task-completion tests, replacing “can/cannot do” approaches with assessment of graded impact, effort required, reliability, and the short- and long-term consequences of activity
- Rebalancing descriptors and scoring, ensuring mental and physical health are treated on equal footing and that descriptors capture initiation, planning, sequencing, self-regulation, and safety, and not only physical execution
- Establishing a statutory, independent review mechanism, involving disabled people and clinicians, to regularly review activities and descriptors in light of lived experience, emerging evidence, and case law.

Proposal to improve PIP Activity: Preparing food	Scoring
<p>Guidance:</p> <p>A simple meal means a basic dish made from fresh ingredients, using a conventional cooker or equivalent, requiring sequencing and safe handling.</p> <p>All descriptors must be interpreted in light of how physical, cognitive, psychological, or sensory functional limitations interact with the demands of preparing and cooking a simple meal.</p> <p>An activity must only be treated as achievable where it can be carried out:</p> <ul style="list-style-type: none"> • Safely, without causing harm or significant risk during or after completion • To an acceptable standard, in line with everyday expectations • Repeatedly, without causing prolonged deterioration, collapse, or loss of function • Sustainably, without exhausting the claimant’s functional capacity for subsequent hours or days • Without disproportionate after-effects, such as severe fatigue, pain, cognitive dysfunction, or distress that prevents engagement in other essential daily activities <p>Where completion of an activity predictably results in significant delayed after-effects, the activity must not be treated as achievable at that level even if the task can be performed once.</p>	N/A
<p>Can initiate, plan, and complete the preparation and cooking of a simple meal safely and without support.</p> <p>The activity can be completed independently without disproportionate effort, risk, or delayed exhaustion. Completion does not result in significant fatigue or loss of functional capacity later the same day or on subsequent days.</p>	0
<p>Can prepare and cook a simple meal where aids, appliances, or adaptations compensate for barriers, and does not require support from another person.</p> <p>The activity remains independently achievable, but only because adaptations reduce physical, cognitive, or sensory demands. Completion may be tiring but does not cause prolonged deterioration or prevent engagement in other essential activities later the same day.</p>	2
<p>Requires support from another person that enables the preparation and cooking of a simple meal by assisting with initiation, planning, sequencing, or self-regulation; without this support, the activity would not be completed acceptably or safely.</p> <p>Independent completion is not reliable. Even with support, completing the activity causes significant fatigue or depletion, often requiring rest and reducing the person’s capacity to undertake further activities that day.</p>	4

Without support, the activity is abandoned, unsafe, or inadequately completed.	
Requires another person to be present and actively engaged throughout the preparation and cooking of a simple meal in order to manage risk, prevent harm, regulate energy use, or stabilise the activity. The activity places substantial strain on the claimant’s physical or cognitive capacity. Completion predictably results in severe exhaustion, distress, or functional collapse, frequently requiring extended recovery and preventing meaningful activity for one or more subsequent days. Continuous support is necessary to manage both immediate and delayed risks.	6
Cannot prepare or cook a simple meal because the activity cannot be made safe, sustainable, or viable, even with continuous support, supervision, adaptation, or pacing. The activity is functionally inaccessible. Attempting to prepare or cook food would predictably result in serious deterioration, prolonged incapacity, or unacceptable risk. The claimant is wholly dependent on others or pre-prepared food, with significant consequences for autonomy, health, and daily functioning.	8

5. Implement a fair, efficient, and transparent evidence system

The DWP should reform evidence collection and use to reduce claimant burden, improve decision accuracy, and build trust.

This includes:

- Shifting responsibility for evidence collection from claimants to the DWP, with claimant consent and control
- Valuing a wide range of evidence, including non-medical sources such as social care, housing, and voluntary sector providers
- Introducing secure and accessible digital systems for evidence submission and sharing to reduce delays and loss
- Reducing duplication by enabling evidence reuse across assessments where appropriate
- Providing transparency in decision-making, including clear explanations of how evidence has been considered and why any evidence has been discounted

6. Introduce safeguards around PIP back-payments

To mitigate the risk of financial pressure or exploitation following large back-dated PIP payments, the DWP should offer voluntary, structured options for receiving arrears, such as staged monthly or bi-weekly payments, accompanied by clear explanations and signposting to independent financial and safeguarding support.

7. Co-design accessible forms, guidance, and communications

All claimant-facing materials should be redesigned to be clear, accessible, and supportive, and developed in partnership with people with lived experience, providing:

- Plain language, step-by-step guidance covering the full PIP journey
- Consistent, high-quality information provided at key stages of the process
- Clear explanation of expectations, rights, and outcomes, including examples and scenarios
- Accessible formats and channels, including both digital and non-digital options

8. Provide proactive access to independent support and advocacy

To address systemic barriers and reduce inequality in outcomes, the DWP should ensure all claimants can access high-quality, independent support, by providing:

- Proactive offer of independent advocacy and support services, particularly for people with complex needs
- Continuity of support, reducing the need for claimants to repeatedly recount their experiences
- Delivery through trusted, independent organisations, ensuring credibility and trust

Department of Health and Social Care / NHS England

9. Strengthen mental health services including access to therapeutic interventions and personalised care through the NHS, through the Modern Service Framework.

The Modern Service Framework for severe and enduring mental illness must ensure access to more timely, high quality and personalised mental health care. This includes the opportunity to expand access to further NICE-approved psychological therapies for patients living with severe mental illness, and autonomy-focused initiatives such as Personal Health Budgets.

10. Enhance coordination and quality of services

This can be achieved through nationwide rollout of 24/7 community mental health centres by 2035, This would provide open access to integrated and coordinated clinical and social support in every community in England, as and when it is needed. It is similarly important to ensure that mental health is a central consideration to the development of wider neighbourhood health services.

11. Fill in gaps in social care support

The current Casey Commission helps to deliver a long-term, sustainable solution for mental health social care, ensuring access to important services such as advocacy and support workers through these means. This is also crucial for the successful delivery of the reformed Mental Health Act.

References

ⁱ Rethink Mental Illness (2025) Right Treatment, Right Time. Available [here](#).

ⁱⁱ Calculation made by comparing the number of Incomplete RTT pathways lasting more than 78 weeks [NHS England (2026)] with the number of CMH referral-spells waiting more than 78 weeks for a 2nd contact that were still open at the end of the RP [NHS England (2026)]

[Mental Health Services Monthly Statistics - NHS England Digital Statistics » Consultant-led Referral to Treatment Waiting Times Data 2025-26](#)

ⁱⁱⁱ Rethink Mental Illness (2025) Set up to Fail. Available [here](#).

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
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