Money and Mental Health's submission to the Department for Work and Pensions consultation on Modernising support for independent living: the health and disability green paper

Introduction

The Money and Mental Health Policy Institute is a research charity established by Martin Lewis to break the vicious cycle of money and mental health problems. We aim to be a world-class centre of expertise developing practical policy solutions, working in partnership with those providing services, those who shape them, and those using them to find out what works. Everything we do is rooted in the lived experience of our Research Community, a group of 5,000 people with personal experience of mental health problems.

This response draws on our wider body of research. Unless otherwise specified, all quotes in this response are drawn directly from the Research Community.

Background

- In any given year, one in four people will experience a mental health problem which affects their cognitive and psychological functioning.[1] Over a lifetime, this proportion rises to nearly half the population.[2]
- Living with mental health problems often comes with additional costs. These can include care and support needs around monitoring and reminders for medication; help with chores around the home due to fatigue or lack of motivation; and emotional support to travel on public transport or pay for private taxis.[3]
- Personal Independence Payment (PIP) is therefore a lifeline for thousands of people with mental health problems. It can make the difference between having a clean and habitable home, and a phone to call your crisis team, or living in disarray and increasing isolation.
- However, the PIP assessment routinely fails to capture the effects of living with a mental health problem, and people with these conditions are one of the groups most likely to be rejected for PIP,[4] and who tend to receive lower awards.[5]

[1] McManus S et al. Adult psychiatric morbidity in England, 2007. Results of a household survey. NHS Information Centre for Health and Social Care. 2009.
[2] Mental Health Foundation. Fundamental facts about mental health. 2016.
[3] Department for Work and Pensions and Government Social Research. Uses of Health and Disability Benefits.
[4] Department for Work and Pensions. Evidence Pack: Modernising Support for Independent Living: The Health and Disability Green Paper. June 2024.
[5] Scope's analysis of Stat Xplore PIP statistics shows people claiming for a mental health related issue received on average £125 per week, lower than the average claim overall. They compared PIP award data by disability, for caseload in January 2024 and for identified mental health conditions.

Summary

- We strongly oppose the whole premise of this consultation. The government is right to recognise that the number of people claiming PIP for mental health reasons is increasing, but making it even harder for people with these conditions to receive PIP is not the solution.
- Any proposal that suggests people with mental health problems deserve less support than those with physical health problems is ripping up progress made in achieving parity of esteem between mental and physical health over the last few decades.
- People with mental health problems can face significant and ongoing costs as a result of their condition.[6] PIP is crucial to ensuring that people with mental health problems can afford to meet these additional needs, which are often essential to keeping people safe and creating the right conditions for recovery.
- Instead of taking away vital support, the government should focus on addressing the underlying drivers of rises in poor mental health, including financial difficulty and limited access to timely and effective mental health support.
- Wider steps should also be taken to ensure the PIP assessment better captures the effects of living with a mental health problem, and stops people with mental health problems from being routinely denied the support they are entitled to.

Chapter 1 – PIP – Overview and assessment reform

Q1. What are your views on an assessment that places more emphasis on condition rather than the functional impact of a condition on the person?

We oppose the proposal to place more emphasis on condition rather than the functional impact of a condition. While there are many issues with how the current functional assessment fails to capture mental health problems as we will outline in our response to Q13 and Q14, shifting to focus just on the condition could further reduce the Department for Work and Pensions (DWP) ability to capture how someone's condition affects their daily life.

A description of a condition alone isn't sufficient to illustrate how an individual's everyday activities are affected by it. What's more, two people with the same condition can be affected by their mental health very differently, and such an approach would fail to account for this.

"A diagnosis does not give any true reflection of how that individual struggles in daily life."
Expert by experience

"I've met many others with the same 'diagnosis' as me. Not one of us is affected the same. Some function incredibly well and hold down jobs and have families whereas myself and others

[6] Department for Work and Pensions and Government Social Research. Uses of Health and Disability Benefits.

can't manage basic daily functions or activities. And yet on paper we would be considered equal." Expert by experience

A key change that we would like to see is greater trust placed in an individual's testimony of how their condition affects them. Too often this is routinely ignored, misconstrued and undermined.

Q2. What are your views on people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional?

We disagree with an approach that only exempts people from assessments if they have certain health conditions or disabilities as evidenced by a healthcare professional. Instead, we'd like to see a shift to assessments not being used as default, and decisions being made on someone's application form and supporting evidence alone if this clearly demonstrates why they need PIP, regardless of what condition they do or don't have a diagnosis for.

One of the key reasons we disagree with this approach is that it could create a false hierarchy of need. As outlined in our response to Q1, people with the same condition can be affected by their mental health problems very differently, and medical evidence of a condition does not necessarily indicate how that condition affects someone's daily life.

Furthermore, this requirement to have a condition that is evidenced by a healthcare professional could actively disadvantage people with mental health problems who can face barriers to receiving a diagnosis. In a survey with members of our Research Community, a concerning proportion of respondents were unable to access mental health support, with 35% saying they'd been denied mental health support from their GP.[7] This is especially worrying given that GPs are often a gateway to diagnoses and other mental health services. We also hear of respondents facing long wait times to access services that can provide them with a diagnosis.

"*It creates problems for people who are outside of the system and have no diagnosis.*" Expert by experience

What's more, for some people with mental health problems, a diagnosis is not necessarily helpful or even desirable, and people should not be penalised for not having one.

"*It is hard to get formal diagnosis from consultants, and people often don't want labelling. Getting labels boils someone's life, personality, experiences down to a single word or stereotypes.*" Expert by experience

[7] Money and Mental Health survey. Base for this question: 270 people.

This is why we would like to see the DWP adopt a similar approach to that taken by Social Security Scotland with Adult Disability Payment (ADP). Social Security Scotland only uses assessments when they've been requested by the applicant, or when a decision can't be made using the application form and supporting evidence alone. This approach means people aren't being unnecessarily asked to attend assessments which can be incredibly stressful; and ensures an assessment can't be automatically required if an applicant doesn't have a specific diagnosis.

Q3. What are your views on PIP claimants not being subject to an award review if they have a specific health condition or disability as evidenced by a healthcare professional?

We support the government's proposal of a Severe Disability Group. We are keen that, as well as being used to fast track applicants to the higher rate of disability benefit without having to go through the usual application and assessment process, this group is also afforded respite from repeat assessments.

Q4. Do you agree or disagree on making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP?

Agree
Disagree
Don't know

Q5. In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.

We disagree with the requirement for making evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP. It isn't the most effective way of capturing how someone's mental health problem affects them, and risks presenting further barriers to accessing PIP for people with mental health problems.

As outlined in our response to Q1, two people with the same condition or diagnosis can be affected by their mental health problem very differently, and medical evidence or a diagnosis is not necessarily the best way of capturing how someone's condition affects their day-to-day life.

"*That's how it used to be under DLA; then the DWP acknowledged that two people with the same diagnosis can have very different presentations of the condition.*" Expert by experience

"*Because, for example, PTSD can vary from mild to extreme and its symptoms can vary from person to person. Every case is individual and therefore you can't assess it in that way. Or, with*

my DID, it is so rare that no one really understands it within the medical profession, so they would have to let us describe how it affects us as most medical professionals I have dealt with do not have a clue." Expert by experience

We'd also be concerned that this approach would result in certain applicants being refused PIP because they don't have the 'right' medical evidence or diagnosis. The government has argued that people claiming PIP for 'milder' anxiety and depressive disorders do not have the same additional needs and requirements for financial support as those with more severe mental illness. As we will outline in our response to Q19, this claim is unfounded. We're concerned that this approach would see those with more common mental health disorders such as anxiety and depression being refused PIP.

"*Everyone's experience is different and each person handles disability differently. This approach may also exclude people entirely based on if they don't have the 'right' diagnosis.*" Expert by experience

What's more, as outlined in our response to Q2, people with mental health problems can face barriers to receiving a diagnosis, and for some people with mental health problems a diagnosis is not necessarily helpful or even desirable. People should not be penalised for not having one.

Finally, a diagnosis-based approach would also be challenging when, as many applicants do, people have multiple and overlapping conditions. Questions arise about if and what diagnoses would take priority, or how an applicant would be assessed if the conditions for which they had the 'right' evidence or diagnosis for, were not those that had the most debilitating impact on their life.

We would like to see more trust placed in an applicant's medical evidence, however. Similar to how applicants' individual testimonies are routinely ignored, misconstrued and undermined, the DWP often takes a comparable approach to medical evidence. While such evidence shouldn't be a requirement for people to receive PIP, where it is provided, it should be taken seriously and applicants shouldn't have to re-prove the information it states.

"*Because a diagnosis should be enough! The stress of having to explain to a person again and again why you can't do what the world perceives as 'normal' is horrific. I'm not exaggerating when I say horrific. If a mental health professional or a medical professional has already confirmed I have the condition, why do I need to re-prove it?*" Expert by experience

"*I feel conflicted about this. I don't think that it's a question of either/or. The DWP should pay attention to both the diagnosis and impact of the diagnosis.*" Expert by experience

Q7. Do you agree or disagree that eligibility for PIP should be based more on condition?

Agree
Disagree
Don't know

Q8. How could we determine eligibility for the following conditions?

Please explain your answer and provide evidence or your opinion to support further development of our approach.

- **Conditions that fluctuate**

As it stands, the assessment criteria for PIP requires that someone is affected by their condition for at least 50% of days in a 12 month period. People with mental health problems can experience significant fluctuations regarding their symptoms, and placing such a rigid requirement on how frequently someone's mental health problem affects them contradicts this reality.

We have therefore engaged with the Department's decision to test a Health Impact Record through the Health Transformation Programme. Our hope is that this could provide an opportunity to gain a more realistic understanding of how people's conditions affect them. It's vital, however, that this record does not penalise people who don't experience symptoms within a specific timeframe.

Of particular concern is that the research DWP has commissioned into fluctuating conditions will only draw on diary entries that are made over the course of a month.[8] For some people with mental health problems, they could experience a period of relative good health for longer than a month, before experiencing some of the more extreme symptoms of their condition that make it hard for them to go about their daily lives.

"Worst of all [is] that it is an illness that fluctuates, and your physical state fluctuates with your mental state. I can be ill for months and then have 3 days or 3 weeks feeling good, then be ill for months again." Expert by experience

This record should also not add unnecessary delay to someone receiving an assessment. People should therefore be able to provide retrospective entries to this record and discuss how

[8] Insight from a Health Transformation Programme meeting on the 20th July 2023.

their condition has affected them over a period of time in the past, so they aren't required to wait a certain amount of time to complete this record before they can attend an assessment.

In terms of the format this record should take, DWP should consult with individuals about what channels they would like to provide this record via. This provides a good opportunity to shift beyond just written medical evidence, and DWP should therefore be open to different mediums such as audio and video recordings.

Crucially, it's important that this record is optional, and people aren't penalised for not completing one. This is because for some people it might create additional work and emotional stress when their evidence and testimony already provides a sufficient account of their condition and how it fluctuates. We know that when people with mental health problems are unwell, undertaking day-to-day tasks such as keeping up with bills and payments can be difficult. Therefore expecting people to accurately record how their condition is affecting them is not always realistic, and in some instances could be distressing if people are having to constantly dwell on and log the challenges they face daily.

- **Conditions that vary in severity**

Similarly to the fluctuating nature of mental health problems, such conditions can also vary in severity. It is vital, therefore, that the PIP assessment process recognises this, and does not make presumptions about people's capacity based on periods of better mental health.

Chapter 2 – PIP – Eligibility reform

Q11. Do you think people who accumulate low points across activities have the same level of extra costs as those who score highly in one or more activities?

We fundamentally disagree with the premise of ranking the level of extra costs that people face. What's important is ensuring that the eligibility thresholds for PIP aren't restricted to just those with more severe mental health problems.

People with more common mental health problems like anxiety and depression might score lower points across a range of activities, but still face significant additional costs. For example, a person struggling with anxiety wouldn't necessarily score high points for the activities relating to preparing food, taking nutrition, and planning and following journeys due to being able to do so without supervision and assistance. However, they could still face significant extra costs as a result of their condition due to: having to pay to have their food delivered because shopping is too stressful for them; having to pay for taxis because public transport is too anxiety provoking; and having to spend more on heating because they struggle to leave their home as a result of their condition.

Q13. Do you think any of the PIP activities should be removed or re-written and why?

PIP's activities and descriptors are skewed in their focus on people's physical ability to carry out activities, such as moving around, preparing a meal or picking things up. The physical focus of these activities and descriptors means people with mental health problems often have to translate how their mental ill health affects their ability to complete tasks. But this requires a level of mental dexterity that people with mental health problems can struggle with. More fundamentally, this signifies PIP's inability to effectively capture the impacts of having a mental health problem. Members of our Research Community report how the questions that are aimed at understanding mental health problems are limited, and do not cover the full range of their symptoms. This risks the impacts of people's mental health problems being unaccounted for by the PIP assessment.[9]

"All of the questions about how your health is affected by your illness were geared towards having a physical disability. I found it extremely difficult to explain that although I can physically do certain tasks, it is the motivation, ability to remember, communication, feelings of anxiety etc, that affects me." Expert by experience

As outlined in our response to Q14, there are therefore a number of additional activities and descriptors that we would like to see added to enable mental health problems to be better captured by the PIP assessment. In addition to this, we would also like to see revisions to the wording and framing of existing activities and descriptors, so they feel more applicable to people with mental health problems.

Scotland has made important steps in achieving this with the ADP application process. Despite using the same activities and descriptors as PIP, the ADP application form has been redesigned to include further prompts and examples about how the different activities and descriptors could relate to a range of disabilities and conditions.[10] There is scope for the PIP application form to adopt a similar approach.

Q14. Should we consider adding any new activities? If so, which activities should be added and why?

We have long called for new questions assessing mental health problems to be developed for the Work Capability Assessment (WCA) and PIP forms that go beyond generic challenges relating to coping with change and interpersonal relationships. This would allow the DWP to

[9] Bond N, Braverman R and Evans K. The Benefits Assault Course: Making the UK benefits system more accessible for people with mental health problems. The Money and Mental Health Policy Institute. 2019.
[10] Social Security Scotland. Making our application forms accessible. March 2023.

more accurately ascertain how difficulties affect people's lives on a daily basis.[11] Insights from our Research Community provide some examples of how having a mental health problem can impact people beyond that captured by the existing PIP activities and descriptors. These include:

- Low energy and motivation - which affects your ability to undertake daily tasks such as getting out of bed, washing or feeding yourself. Existing activities and descriptors focus on these tasks from the perspective of having a physical health condition, which can make questions hard for people with mental health problems to answer.
- Difficulties sleeping - which can be driven by both the symptoms of having a mental health problem and the side-effects of medication. The resultant fatigue and exhaustion can make it hard for people to commit to regular routines and stay awake and focused during the day.
- Sensory challenges - which people with mental health problems can face when in certain spaces, including those that are crowded or noisy. This can lead to people feeling overwhelmed, confused, stressed and anxious. It can make day-to-day settings like shops, public transport and workplaces inaccessible to some people with mental health problems.
- Reduced ability to deal with pressurised or difficult situations - in particular, people spoke about the challenges they faced when confronted with seemingly small challenges, which for them can result in disproportionate stress and anxiety, and in some instances, dissociation.
- Inability to plan or organise - having a mental health problem can make it extremely difficult to organise and commit to even the smallest of plans. People routinely spoke about the fact that, without the support of others, they wouldn't be able to organise or maintain commitments.

"I find it very difficult to sleep as a result of trauma. This for me is a substantial problem but I cannot claim any points for this difficulty. The questions don't really address the experience of being mentally ill. They are more targeted at people with physical disabilities. It's also difficult to complete the form if you have a variable condition like bipolar disorder." Expert by experience

"Mental health is very much being a prisoner in your own mind. Some days I simply can't get out of bed. Not because of physical pain but because I just can't do it. I can't make simple decisions. I catastrophize too, so the thought of say making toast of ends (in my head) me burning to death in a house fire. So I then plan how I'd escape the fire. Which means I don't make toast. It's a permanent state of confusion, overwhelm and panic. So even doing things I'd enjoy are impossible, my brain just won't work, won't let me just be." Expert by experience

[11] Bond N, Braverman R and Evans K. The Benefits Assault Course: Making the UK benefits system more accessible for people with mental health problems. The Money and Mental Health Policy Institute. 2019.

"*The side effects of psychiatric medication - fatigue, brain fog can be as bad as the actual condition.*" Expert by experience

The above list is neither exhaustive nor representative of all the challenges people with mental health problems face. Instead, it aims to exemplify some of the other ways that having a mental health problem can affect people that aren't currently captured by the PIP assessment. This should encourage the DWP to establish a more encompassing set of activities and descriptors for capturing the impact of living with mental health problems, by working with those who have lived experience of these conditions.

Q15. Do you think the current entitlement thresholds levels are set at the right levels to define the need for Government financial support and why?

Contrary to the government's argument, there is limited evidence to suggest it is 'easier' to be awarded disability benefits today, with award rates for new PIP claims broadly steady at around 45% since 2015-16.[12] What's more, people with mental health problems are one of the groups who are most likely to be rejected for PIP,[13] and who tend to receive lower awards.[14] We therefore believe the government's primary focus should be improving the quality of PIP decision-making, so fewer people are having to challenge assessment decisions to get the support they're entitled to.

For the period from January 2019 to December 2023, 25% of the PIP assessments that were taken to appeal were "lapsed" (which is where DWP changes the decision in the customer's favour after an appeal is lodged but before it is heard at tribunal), and 69% were "overturned" (which is where the decision is revised in favour of the customer).[15] The number of original assessment decisions that are being overturned in favour of the applicant at the appeal stage, is compelling evidence for the fact that the initial assessment is failing to award people the level of support they need.

"*They seem to be just looking for ways of getting out of paying PIP to people. The system is unbelievably hard to qualify for now, without them making it any harder. It's nearly impossible to get and I only managed it because I took them to a tribunal and won and had a heart attack on*

[12] Judge L and Murphy L. Under strain: Investigating trends in working-age disability and incapacity benefits. The Resolution Foundation. June 2024.
[13] Department for Work and Pensions. Evidence Pack: Modernising Support for Independent Living: The Health and Disability Green Paper. June 2024.
[14] Scope's analysis of Stat Xplore PIP statistics shows people claiming for a mental health related issue received on average £125 per week, lower than the average claim overall. They compared PIP award data by disability, for caseload in January 2024 and for identified mental health conditions.
[15] Department for Work and Pensions. Personal Independence Payment: Official Statistics to April 2024. June 2024.

top of it. I don't think I would have gotten it had those things not happened to me. It's really impossible to get pip for mental health issues anyway. Why make it even harder?...They just don't seem to realise how hard living with mental health can be." Expert by experience

We also believe that instead of trying to make it harder for people with mental health problems to receive PIP, the government should be addressing the wider contextual factors that are likely to be driving the number of people claiming PIP for mental health reasons.

While the drivers behind rising levels of poor mental health are likely to be multiple and complex, at Money and Mental Health we are not surprised by these increases because some of the known financial drivers of poor mental health have been escalating. The pandemic, followed by the cost of living crisis, has placed significant pressures on people's finances. Our research has found that more than half of UK adults (54%) have felt either anxious, depressed, filled with dread or unable to cope - or a combination of these emotions - due to concerns about their finances in light of the cost of living crisis. For some this was particularly acute, with one in six (17%) saying that they had experienced suicidal thoughts or feelings as a result of the rise in the cost of living.[16]

As well as these financial drivers of poor mental health, many people are also struggling to access timely and effective mental health support. Long wait times deter some Research Community members from registering for support in the first place. For others it means they are advised to find private services instead, which many are unable to afford.[17] People also frequently speak about not being eligible for a service. Many have been told that their mental health condition was either not severe enough or too severe to access a service. Others were told they weren't eligible because they were already receiving support from another service, despite the fact that this was often helping with a different aspect of their mental health. As of 2021, around 8 million people with mental health needs were not in contact with the services they required.[18] Not being able to access the right support in a timely manner can take a huge toll on people's mental health, with members of our Research Community frequently speaking about how this led to a deterioration of their condition.

Finally, it's important that increasing demand for PIP isn't seen in detachment from the erosion of the value of working-age benefits. Changes to the benefits system over the last decade have strengthened the incentive to claim incapacity and disability benefits. In April 2010, a single person claiming unemployment benefit received £98 a week (in 2024-25 prices); by April 2024,

[16] D'Arcy, C. Bombarded: reducing the psychological harm caused by the cost of living crisis. The Money and Mental Health Policy Institute. December 2022.
[17] Stacey, B. Mental health service wait times: a postcode lottery. The Money and Mental Health Policy Institute. August 2022.
[18] National Audit Office. Progress in improving mental health services in England. February 2023.

that figure had fallen by 7.6% to £91, a loss especially hard-felt in the cost of living crisis.[19] We know that PIP can sometimes form part of a household budget that struggles to cope with, for example, basic food shopping or rent. Conversations about expenditure on extra cost benefits, can't be had without considering their adequacy or that of the benefits alongside which they sit.

Q16. What are your views on changing the length of the current three-month qualifying period for PIP which is used to establish that the functional effects of a health condition or impairment have been present for a certain time period before entitlement can start?

We oppose changes to the current three-month qualifying period, specifically the lengthening of this. People's mental health problems can onset very rapidly, and take a significant toll in a short space of time.

Prolonging the length of time that someone has to wait to be eligible for PIP, extends the length of time that someone can be facing very real and significant challenges with their mental health without any financial support to support them with this. The extra costs someone faces don't suddenly appear after a certain point in time. They are often there from the onset of the condition itself.

What's more, people already face significant delays in receiving PIP. The latest figures show that as of April 2024, the median wait from registration to a PIP decision being made was 14 weeks. Those who then went on to challenge their initial PIP decision were waiting on average 62 days for a Mandatory Reconsideration.[20] For those who decide to then appeal a Mandatory Reconsideration decision, there's at least a further 6 months to wait for a case to be heard by a Tribunal.[21] While PIP is back-paid to the date someone made their claim, changes to this qualifying period could create further unnecessary delays to people receiving the support they need.

Q17. What are your views on retaining, removing, or changing the length of the current nine-month prospective test which is used to determine if the functional effects of a health condition or impairment are likely to continue long-term?

We oppose changes to the current nine-month prospective test, specifically the lengthening of this. As outlined in our response to Q8 and Q16, the impact of people's mental health problems can fluctuate significantly, and take a very significant toll in a short period of time.

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[19] Judge L and Murphy L. Under strain: Investigating trends in working-age disability and incapacity benefits. The Resolution Foundation. June 2024.
[20] Department for Work and Pensions. Personal Independence Payment: Official Statistics to April 2024. June 2024.
[21] https://www.gov.uk/appeal-benefit-decision/after-submit-appeal#

Further restricting eligibility to PIP to those whose conditions have a consistent and ongoing effect, would mean a failure to support a large group of people with mental health problems whose conditions are more prone to fluctuations, but who still face significant and recurring costs as a result of their condition.

Chapter 3 – PIP– What do we provide support for?

Q19. In relation to Question 18, please explain your answer below and tell us about any other important kinds of costs not listed above.

The additional costs that people with mental health problems face as a result of their condition are multiple and varied. Research conducted by the National Centre for Social Research (NatCen) demonstrated that while the extra needs people with mental health problems have might not be as immediately visible as those with physical conditions and disabilities, they still have as significant an impact on their lives.[22]

We are particularly opposed to the DWP's presumption that the recent rises in people claiming PIP for 'milder' anxiety and depressive disorders do not have the same additional needs and requirement for financial support as those with more severe mental illness. When we asked members of our Research Community to list what extra costs they face as a result of their mental health problem, what was striking was how similar the costs faced by those with more common mental health disorders were to those faced by people with more severe mental illness. Of the 102 respondents, the most commonly cited extra costs were:

- Mental health support (9 respondents with CMD cited this, and 6 with SMI). Respondents frequently spoke of the fact that long wait times and tight eligibility criteria for NHS mental health services meant their only option to receive timely and effective mental health support was to access this privately. For many people receiving PIP, private mental health support remains unaffordable. However, for some, PIP plays a crucial role in making such support accessible.
- Assistance with household and daily chores (14 respondents with CMD cited this, and 17 with SMI). Common symptoms associated with mental health problems, such as fatigue and a lack of motivation, can make simple daily tasks such as cleaning or opening post impossible. Many respondents need to pay people to support them with these tasks.
- Higher food costs (14 respondents with CMD cited this, and 17 with SMI). Many respondents struggle to leave the house and access busy environments such as supermarkets. As a result, they depend on buying food online, which can incur delivery

[22] Department for Work and Pensions and Government Social Research. Uses of Health and Disability Benefits.

costs. What's more, fatigue and a lack of motivation can also make cooking impossible, so people have to buy prepared ready meals which are more expensive than buying individual ingredients.

- The cost of shopping on the internet (5 respondents with CMD cited this, and 6 with SMI). Beyond supermarkets, accessing other shops such as clothes shops or pharmacists can also be extremely challenging for people with mental health problems. As a result, some respondents had to do all their shopping online, which can again incur delivery costs. Low motivation and difficulties undertaking simple administrative tasks also meant some respondents weren't able to return unwanted items, again resulting in additional costs.
- Higher utility costs (9 respondents with CMD cited this, and 9 with SMI). Many respondents' utility bills were high as a result of challenges leaving the house and therefore being home most of the time. What's more, anxiety-related incontinence and night-sweats led to some respondents having to use the washing machine daily, again resulting in higher energy bills.
- Higher travel costs (21 respondents with CMD cited this, and 21 with SMI). For many people with mental health problems, public transport can be anxiety inducing. Respondents therefore often cited needing to pay for emotional support to travel on public transport, or for private taxis to enable them to get around.
- Care costs (3 respondents with CMD cited this, and 10 with SMI). The care people need can range from support with monitoring or remembering to take medication to avoid under or overdosing; to requiring assistance with personal hygiene due to fatigue and low-motivation making personal-care difficult, and emotional support when going out.
- Activities (2 respondents with CMD cited this, and 7 with SMI). Respondents cited that a range of activities - from attending the gym or exercise classes, to music groups - were key to supporting wellbeing. In addition, animals, typically pet dogs, played a therapeutic role in supporting mental wellbeing.

"*Due to not going out much you end up using more gas and electricity during the winter months. We have to have the washing machine on more due to night terrors and sweating so much. If we go anywhere, we can only go by car. If my wife (who is my carer) needs to go out we then have to pay for someone to come in and stay with me.*" Expert by experience

"*I cannot use public transport as I find it too overwhelming and so have to rely on taxis which are expensive. I also pay for someone to come and clean my house once a week as I have zero motivation at times.*" Expert by experience

"*I don't cope with public transport so rarely use it and if I do I don't use it alone. This is a cost I have to cover for me and my support. I struggle to keep on top of all my medical appointments and diary so have had help to do this. I struggle with admin tasks and managing the home, I'll*

stay in bed and hide from the world and that stops me being able to do cooking, cleaning, shopping for food even." Expert by experience

"*I have to have everything delivered as I can't leave the house due to debilitating panic attacks. From food to medication to clothes and home shopping - even eye tests - have to be brought to me. Delivery costs mount up. I have to pay someone to post a letter or cut my lawn because of agoraphobia. My energy bills are high as I am constantly at home, 365 days a year.*" Expert by experience

Research by Citizens Advice has further challenged the assumption that people with mental health problems do not have the same additional needs and requirements for financial support as those with physical conditions and disabilities. When comparing the budgets of individuals with debt who receive PIP, no significant difference was found in the amount spent on care, health costs, or general living expenses, regardless of whether they have mental or physical health conditions.[23] Scope's 'disability price tag' analysis[24] indicates that extra costs may even be higher for some people with mental health conditions,[25] a finding supported by previous research.[26]

Citizens Advice research has also demonstrated the wider mental health premium that people with mental health problems face. Where poor mental health reduces someone's ability to carry out daily activities, they can incur costs of £1,100 - £1,550 each year as a result of inaccessible services, poor regulatory protections and inadequate support.[27]

It's clear from the evidence, therefore, that people with mental health problems face a range of additional and ongoing costs. Any proposal that suggests people with mental health problems deserve less support than those with physical health problems is ripping up progress made in achieving parity of esteem between mental and physical health over the last few decades.

Finally, we fundamentally disagree with the premise of ranking which additional costs are the most important as was suggested in Q18. This will vary depending on the individual, and the way their condition or disability affects them. For example, someone whose mental health problem affects their energy levels and motivation might feel that having assistance with cleaning their home and personal hygiene is the most essential cost they face. Whereas

[23] Berry C et al. Disability benefits: Lessons from the front line. Citizens Advice. June 2024.
[24] Scope's analysis (2024) of the Family Resources Survey 2022/2023.
[25] This research was unable to assess mental health independent of wider disabilities because many people in receipt of PIP have multiple conditions.
[26] Zaidi A and Burchardt T. Comparing Incomes When Needs Differ: Equivalization for the Extra Costs of Disability in the U.K. The Review of Income and Wealth. 2005.
[27] Rogers C, Poll H and Isaksen M. The mental health premium: The extra charges people with mental health problems pay for their essential services. Citizens Advice. March 2019.

someone who struggles to plan and make journeys might view support with getting taxis as the most important.

Q20. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A catalogue/ shop scheme

Benefits
Disadvantages
Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

People with mental health problems are best-placed to know how their PIP payments should be allocated to the extra costs they face. Replacing the cash-transfer system would undermine this trust, and risk individuals not being able to use this financial support in a way that effectively meets their needs.

We also know that some of the extra costs people with mental health problems face relate to care and support services. By the DWP's own admission, a catalogue or shop scheme would likely work better for equipment and aids rather than services.

Q21. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A voucher scheme

Benefits
Disadvantages
Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

People with mental health problems are best-placed to know how their PIP payments should be allocated to the extra costs they face. Replacing the cash-transfer system would undermine this trust, and risk individuals not being able to use this financial support in a way that effectively meets their needs.

We also know that some of the extra costs people with mental health problems face relate to care and support services. By the DWP's own admission, a voucher scheme would likely work better for equipment and aids rather than services.

Q22. What are the benefits and disadvantages of moving to a new system for PIP claimants?

A receipt-based system

Benefits
Disadvantages
Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

People with mental health problems are best-placed to know how their PIP payments should be allocated to the extra costs they face. Replacing the cash-transfer system would undermine this trust, and risk individuals not being able to use this financial support in a way that effectively meets their needs.

The extra costs that people with mental health problems face as a result of their condition are often frequent, and in some instances occur daily.[28] Expecting people to keep receipts and expense each of these costs places a huge administrative burden on individuals. This is likely to be especially challenging for people with mental health problems, as the cognitive impacts of such conditions can make it difficult to undertake simple administrative tasks.[29] It is unrealistic to expect this group to keep and expense receipts for all their costs, and doing so could actively worsen some people's mental health problems.

We are also concerned about the DWP's administrative capacity to run a receipts-based system. As outlined in our response to Q16, people already face significant delays to receiving PIP. We believe a receipts-based system would just create further unnecessary barriers to people getting the support people need in a timely fashion.

Q23. What are the benefits and disadvantages of moving to a new system for PIP claimants?

[28] Department for Work and Pensions and Government Social Research. Uses of Health and Disability Benefits.
[29] Holkar M. Seeing through the fog: how mental health problems affect financial capability. Money and Mental Health Policy Institute. January 2017.

One-off grants

Benefits
Disadvantages
Other

Please explain your answer and provide evidence or your opinion to support further development of our approach.

People with mental health problems are best-placed to know how their PIP payments should be allocated to the extra costs they face. Replacing the cash-transfer system would undermine this trust, and risk individuals not being able to use this financial support in a way that effectively meets their needs.

As outlined in our response to Q19, the costs associated with having a mental health problem are commonly ongoing and frequent. Providing a one-off grant to support people with mental health problems, would therefore fail to match and support the reality of the additional needs this group face.

Q24. If PIP could no longer be used to determine eligibility to passport to other benefits and services, what alternative ways could service providers use to determine disability status?

We believe PIP should continue to be used to determine eligibility to passport to other benefits and services. We oppose the creation of another system that disabled people would have to apply to or be assessed by, as this would just create yet another barrier to people receiving the support that they need.

Q25. If PIP could no longer be used as the eligibility criteria to additional financial support in Universal Credit, what alternative ways of determining eligibility should we use?

As it stands, we oppose the PIP assessment replacing the WCA. For the reasons outlined in our response to Q13, the PIP assessment routinely fails to capture mental health problems, and is not a reliable way of determining whether or not someone should be entitled to additional financial support in Universal Credit (UC).

That's not to say the WCA is currently fit for purpose, or a good way of determining whether someone should be entitled to additional financial support in UC. But at least there isn't currently one high-stakes assessment that could result in everyone losing their benefits income, which is what this proposal to introduce a single assessment would create.

Instead, we want to see a focus on making significant improvements to the existing health and disability assessments so they adequately capture mental health problems, and correctly award people the support they need at their initial assessment.

Q26. Are there specific groups of people whose needs are not being met by the current PIP provision and have a need for a greater level of support? What form should this support take (eg. help with specific extra costs, access to improved healthcare such as mental health provision or enhanced local authority support such as care packages and respite)?

As outlined in our response to Q13 and Q14, the key issue is that the PIP assessment routinely fails to capture mental health problems, and too many people are therefore being wrongly denied this support, or having to go through a lengthy process of challenging decisions to receive it. To ensure the needs of people with mental health problems are being met by the current PIP provision, the steps outlined in our response to Q13 and 14 need to be taken.

We strongly oppose the suggestion that people could receive talking therapies treatment in lieu of PIP. It's true that action needs to be taken to improve people's access to timely and effective mental health support, but increased access to talking therapies should not be used as an argument to remove PIP from people with mental health problems. As was outlined in our response to Q19, people with mental health problems face many extra costs beyond that of private mental health care, and improved mental health support does not justify the removal of this financial support.

Q27. Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?

As outlined in our response to Q26, investment to improve access to mental health support should be provided alongside, not in place of, PIP.

<u>Chapter 4 – PIP– Aligning support</u>

Q34. If we align the support offered by PIP into existing local authority and NHS services, how could this improve things for disabled people and people with health conditions?

As it stands, almost a third of English local authorities are concerned that they will not be able to meet duties under the Care Act in 2025/2026. This is primarily due to limited social care funding, but also workforce recruitment and retention, increased demand and complexity of

demand, and an inability to invest in prevention because of budget pressures and immediate needs.[30] Furthermore, mental healthcare is under huge pressure with many services unable to provide the care that patients need and that they want to provide.[31]

We do not believe it is realistic, therefore, to suggest that NHS services or local authorities are in a position to be taking on extra roles and responsibilities at this point in time. Especially not without significant steps to improve the provision and scope of health and social care support.

Even if the adequacy of health and social care was improved, this still isn't a substitute for the financial support that people need to cover the extra costs associated with their condition or disability. It would be vital, therefore, that access to health and social care services isn't seen as an alternative to receiving a cash-based extra costs benefit like PIP.

[30] Local Government Association. The Care Act 2014: Ten years on from Royal Assent. May 2024.
[31] British Medical Association. "It's broken": Doctors' experiences on the frontline of a failing mental healthcare system. March 2024.