Modernising support for independent living

Citizens Advice response to the health and disability green paper

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July 2024

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About Citizens Advice

Citizens Advice provides free, confidential and independent advice to help people overcome their problems. In 2023-24, we gave advice to 1.6 million people, almost half (48%) of whom were disabled or had a long-term health condition. We are the largest charity provider of advice on disability benefits in the UK. In the past year, we helped almost 370,000 people with disability benefits: more than 1,000 people each day.[1]

Unless otherwise specified, the data in this response covers England and Wales.

Our response to this consultation is informed by:

- Research with frontline advisers, conducted in June 2024, across the network of our local offices in England and Wales. We explored advisers' experiences of supporting people with Personal Independence Payment (PIP) and thoughts on the proposed reforms, through:
    - 3 discussion groups with a total of 30 advisers
    - A survey of 256 advisers.
- Evidence forms[2] submitted by advisers about issues the people they help face concerning PIP and additional health-related costs.
- Citizens Advice caseload data.
- Citizens Advice debt advice data, including income and expenditure data.[3]

Our response is based on the experience of the people coming to us for help, our advisers who support them, and the evidence we see every day. We have answered only those questions to which we feel our expertise is relevant. Alongside our own response we're aware that many local Citizens Advice offices will be submitting responses to the consultation drawing on their respective expertise.

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[1] In 2023-24, we helped 364,282 people with issues related to Disability Living Allowance, Attendance Allowance, Employment Support Allowance, Personal Independence Payment, and the Limited Capability for Work elements of Universal Credit.

[2] Frontline advisers submit evidence forms to highlight the problems the people we support face when interacting with the benefits system.

[3] Citizens Advice debt advice helps people go through their income and spending to set a minimal, sustainable budget. Since 2019, more than 300,000 people have gone through this process with us, giving us one of the largest and most detailed datasets on the spending choices of people at the sharp end of the living standards crisis.

The role of PIP

The need for person centred reform

PIP is a crucial source of support for the people we help, but it's far from a perfect system. Claiming PIP is complex, drawn out, and involves endless cycles of re-assessments. The average waiting time for a PIP decision peaked at 6 months in August 2021, and still stood at 14 weeks in April 2024. Too often the wrong decision is reached on PIP claims, and people can't access the support they need. About a quarter (23%) of completed Mandatory Reconsiderations (MRs) result in a changed award. For PIP appeals at tribunal stage, 69% are ruled in favour of the claimant.

However, we're concerned that any approach to reform built around the "sustainability of the current model", potentially resulting in a reduction in PIP expenditure, will come at the cost of hardship for the people we help. PIP urgently needs reforming, but with the aim of improving access to support at its centre.

PIP is vital for the people we support, who are already likely to be facing financial hardship

Half a million disabled people and people with long-term health conditions received advice from us in 2023-24. Our data suggests that disabled people and those with long-term health conditions are more likely to be facing severe hardship and that this trend has worsened in recent years:

- Each month, we help thousands more disabled people and people with long-term health conditions with food bank referrals than non-disabled people.
- Since 2021, more disabled people and people with long-term health conditions have needed help with homelessness issues compared to non-disabled people - a reversal of the trend of the previous 6 years.

- Almost 1 in 10 households with a disabled person are in a negative budget, meaning their income isn't enough to cover their essential costs each month, compared to 1 in 15 households in Britain overall.[4]

PIP is by no means a perfect solution to this hardship: 17% of the people we advised about PIP last year also needed a food bank referral, and 44% of our debt clients who receive PIP are in a negative budget. However, PIP is vital for the people we support. Receiving PIP can make the difference between breaking even, and falling deeper into the red each month. The disabled people we help with debt are 10% less likely to be in a negative budget if they receive PIP.

Figure 1: ***Negative budget rate of disabled people we help with debt***

Source: Citizens Advice debt client data

We can already see the impact losing PIP has for the disabled people and people with long-term health conditions we support with debt. When these clients stop receiving PIP, they cut back their spending on health and care costs by an average of over £200 per month, and on food by £130 per month. Cutting back on disability-related costs, and on essential costs like food and heating (which are often higher *as a result* of health conditions or areas where people seek savings to manage disability or health related costs), is likely to lead to worsening health outcomes.

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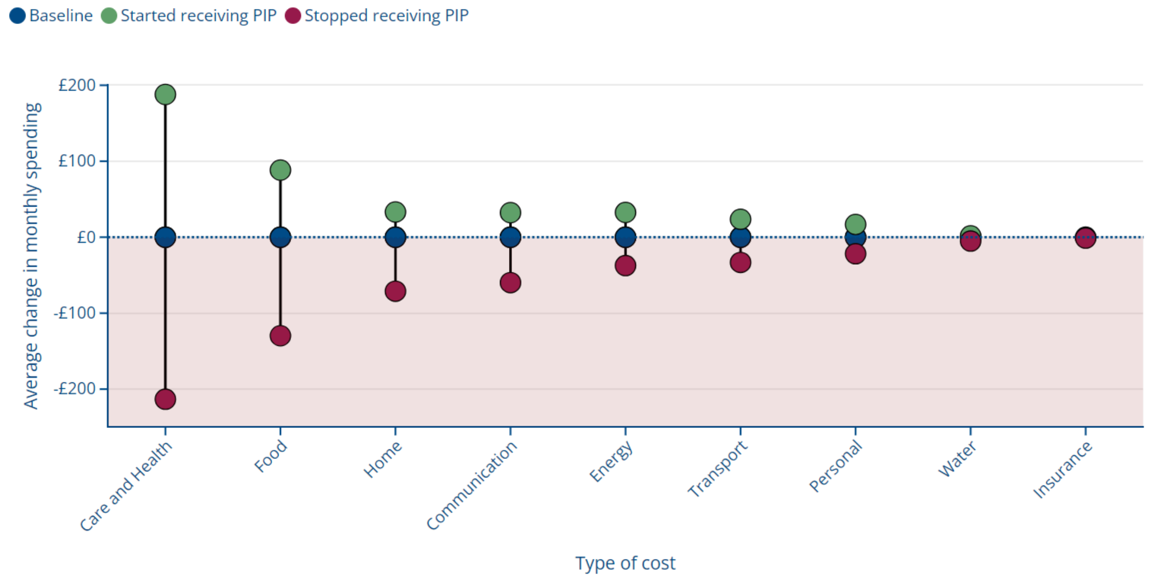
[4] Note that the Citizens Advice national red index includes England, Scotland and Wales but not Northern Ireland.

Figure 2: ***Average change in spending for our debt clients who started or stopped receiving PIP***



Source: Citizens Advice debt client data.[5]

PIP should reflect the reality of extra costs

The people we support use PIP to cover varied and on-going costs. In addition to the hardship that would result from tightening eligibility for PIP, we're concerned that this consultation doesn't recognise the reality of the additional costs of being disabled or having a long-term health condition. Our advisers emphasise that what may look like "cost of living" expenditure often reflects the additional costs of disability, for example as a result of needing to spend more time at home.

Additionally, the same condition may impact people's lives and therefore any additional costs differently. Likewise, many people are affected by multiple conditions, and use PIP to cover the range of additional costs incurred as a result. The design of PIP must reflect this.

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[5] Clients included here are debt clients since 2019 and who came for advice and returned for a follow-up within a year. The green group went from not receiving PIP to receiving PIP, and the red group went from receiving PIP to not receiving PIP. The inflation that took place between the first and second visits is not controlled for, making these estimates slightly conservative.

PIP should recognise the extra costs associated with mental health conditions

We're deeply concerned by the broader narrative surrounding this Green Paper: "it is not clear" that "people claiming PIP citing anxiety or depression as their main condition...have the same degree of increased living costs as those with physical conditions". This does not reflect the lives of the people we support.

People with mental health conditions often need just as much support with daily living tasks as those with physical conditions, (for example needing help to wash, dress, eat), and as a result face similar additional costs. As one adviser told us, the current system already "does not understand how debilitating chronic depression is - you can't work, can't function, can't look after yourself."

We see this reflected in our data. When we compare the budgets of the people we help with debt who receive PIP and have either mental or physical health conditions, we see no meaningful difference in the amount people spend on care and health costs, or living costs more generally.

Frontline advisers also emphasise that it's very difficult for people with mental health conditions to qualify for PIP, regardless of the severity of their condition. Advisers tell us that the current eligibility and assessment model doesn't work well for people with mental health conditions, and is better suited to capturing the functional impacts of physical health conditions.

Jodie* came to her local Citizens Advice for support appealing her PIP decision, when she was awarded 0 points. Jodie has previously experienced domestic abuse, and her anxiety and depression make it very hard for her to look after herself. She finds it very difficult to leave the house alone, including to buy more food when she runs out. Jodie's mother and grandmother help her care for her 4 year old daughter, taking her to nursery and bringing over food almost every day. After a lengthy and stressful appeals process, the tribunal ruled in Jodie's favour. She was awarded the enhanced rate for both daily living and mobility components of PIP, and is due nearly £9,000 from the backdating of her award.

* All names have been changed

The risk of a step backwards

If implemented, many of the proposals set out in the Green Paper would be deeply harmful for the thousands of people we support with PIP each year. We're concerned that these proposals would:

- Weaken the link between need and entitlement, if PIP moves away from a functional impact approach, to placing greater weight on condition as this can be a poor proxy for additional health-related costs.
- Tighten eligibility for PIP, including through requiring medical evidence and/or formal diagnosis, and so remove much needed support, in particular from people with mental health conditions.
- Fail to recognise the varied, on-going and individual nature of health-related additional costs by reducing cash support, thereby leading to:
    - an increase in the significant financial hardship many of the disabled people and people with long-term health conditions we support already face.
    - a restriction in people's ability to prioritise their own needs and choose how best to meet them.

Looking ahead

In our recent report Disability benefits: Lessons from the frontline, we called on the government to resist the temptation to enact reforms in this area hastily, based on a misdiagnosis of the problem. We believe an independent commission is necessary to ensure future disability benefits policy is based on solid evidence, and centres the experience of disabled people. This government has the opportunity to rebuild disability benefits in the UK, placing disabled people, and people with long-term health conditions, at the heart of the process.

PIP - overview and assessment reform

Should eligibility for PIP be based more on condition?

We have serious concerns about the proposal that PIP eligibility be based more on condition, and less on the functional impact of someone's condition. This change would make PIP less well-aligned with the additional health-related costs of the people we support and would amount to "a backward step, [moving] away from providing help based on actual personal need", in the words of one frontline adviser.

Relying too much on condition would fail to capture the variation in how people are affected by their conditions. Advisers tell us it would not be fair if, under condition-based eligibility, PIP treated all claimants with the same condition alike, regardless of the inevitable variation in how claimants were functionally affected by their disability and/or health condition(s). This proposal could negatively impact people who are misdiagnosed, and who would therefore receive the wrong support if PIP eligibility were more focused on condition. It's also unclear how this approach would work for people who have multiple health conditions.

> *"A diagnosis is not a statement of the impact…By replacing a functional assessment, which is an impact assessment, with a clinical diagnosis, you're replacing real evidence from people who actually know the person involved, with an educated guess from a GP that might see you once every 6 months if you're lucky".* - Citizens Advice adviser

Advisers emphasise that conditions vary in severity and impact as a result of factors like age, other health conditions, and personal circumstances. For this reason, the current functional impact model is better aligned with the social model of disability, which recognises 'that people are disabled by barriers in society, not by their impairment or difference'. The proposed condition-based eligibility would be a worrying return to a more medical model of disability.

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 urgently need a fresh approach to PIP assessments. Our advisers tell us that too often, the people we help meet with assessors who have a limited understanding of their condition(s). This results in a poor quality medical report, incorrect decision-making and lengthy review processes before PIP is finally awarded. The current model works particularly badly for people with certain conditions. Our advisers tell us that people with fluctuating or episodic conditions often have poor experiences at PIP assessments, especially if they are having a 'good day', where their symptoms are less prominent.

> *"The classic is when you get a physiotherapist who's doing an assessment with somebody who's got long-term mental health problems. I've had that a couple of times, and you see the assessment afterwards and you think goodness me".*
> - Citizens Advice adviser

However, while we would welcome greater expertise among assessors, careful thought is needed as to how this would work in practice. For many people, it's the cumulative impact of multiple conditions which leads to additional costs. An assessment that places emphasis on condition could risk focusing on one 'primary condition' at the expense of assessing the full cumulative impacts of additional conditions. Our advisers tell us this issue already exists in the current system, and placing more emphasis on condition could exacerbate it further.

> *"Sometimes the effect of a condition, or the combined effect of multiple conditions, is more debilitating than the condition would indicate. Plus people are different and respond differently. People should be treated as individuals, not tick boxes."* - Citizens Advice adviser

We encourage the government to take a broader look at reforming the current assessment model. Lessons could be drawn from Scotland, where the government has removed routine face-to-face assessments from Adult Disability Payment applications altogether. If the current assessment framework does remain, then any emphasis on condition must be on the training and expertise among assessors (and potentially also the option for Decision Makers to access more specialist expertise, drawing again on the Scottish model) to improve the quality of assessments. This must not come at the expense of claimants being considered in the whole rather than being reduced to just one condition.

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?

The proposal for people to receive PIP without an assessment if they have specific health conditions or a disability could benefit some of the people we support. We welcome efforts to reduce the overall assessment burden on claimants. Our advisers tell us that too often, the people they help have to go through unnecessary assessments, which at best are time-consuming, and at worst can be a distressing process which negatively impacts health, particularly mental health.

Our advisers tell us that this proposal could be appropriate for people with conditions including multiple sclerosis (MS), motor neurone disease (MND), and cancer (for those who meet PIP criteria, but whose prognosis is not terminal and are therefore unable to access PIP through the fast-track special rules process).

> *“We've got cancer patients that were going to go through chemotherapy and have quite intrusive treatments and surgeries, and they would likely meet the criteria for PIP, but they still had to formally go through all of the claiming conditions and processes. Whereas if that could be avoided, they would get the benefit much more quickly, if they would automatically be on a certain rate of PIP because of a formal diagnosis.”* - Citizens Advice adviser
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> *"We had someone with a brain injury that medical evidence showed the person needed life-long support, but they still had to have an assessment. Common sense about some conditions would be good."* - Citizens Advice adviser

We have some concerns that, if implemented, reform in this area could disadvantage non-exempted claimants or people who’ve yet to receive a formal diagnosis of a relevant condition. Providing exemptions for assessments would need to be an additional way to receive PIP, rather than replacing the current pathway. Additionally, without an assessment process, it’s unclear how eligibility for the enhanced versus the standard rate of PIP would be determined, and presumably, such an approach could only work if people were being fast-tracked to the highest levels of support.

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 welcome steps to reduce the number of claimants subject to unnecessary award reviews. Our advisers tell us that this would be a positive change for those with disabilities and chronic conditions which won't improve or change over time and that lifelong conditions could be better supported through lifelong awards. Advisers highlight that it's particularly unnecessary to go through the often lengthy and draining PIP review process for people with conditions including MS, MND, Parkinson's, or Huntington's disease, once claimants have reached the highest level of entitlement.

> *"There are conditions that aren't going to be cured and to subject those people to reviews, and filling in a 50 page form, and the terrible fear that they're going to lose whatever they're getting already - this is cruel."* - Citizens Advice adviser

Mandy* has had epilepsy since birth, and her frequent seizures have a big impact on her daily life. Since applying for PIP, Mandy has been receiving the enhanced rate for both daily living and mobility. Despite having a lifelong condition which will not improve, she was only given a 2 year award, and now her award is being reviewed. When Mandy came to her local Citizens Advice for help with the review form, she was very distressed. Her advisers were concerned that the stress of the review process was exacerbating her health conditions.

*All names have been changed.

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)

Disagree

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

Making medical evidence or formal diagnosis a mandatory requirement for eligibility for PIP, especially if the onus for collating evidence is on claimants, not the DWP, risks excluding people currently eligible for support.

> *"As a benefit that is impact related rather than diagnosis dependent, medical evidence is not always the best indicator of eligibility. Barriers to access to medical support - GP availability, lengthy wait times for diagnosis, in some cases, charges for medical evidence - could exclude otherwise eligible people from making a claim."* - Citizens Advice adviser

Barriers to medical evidence and diagnosis

Challenges in getting GP appointments risks delays in accessing medical evidence. And the wait for specialist appointments and diagnosis can run into months, even years. Waiting time targets are being missed across key diagnostic tests.[6] Advisers frequently raise concerns about autism diagnoses in particular, where recent median wait times from referral to first appointment were over 9 months.[7]

> *"There are plenty of conditions that go undiagnosed, or for whom the waiting lists are so long that diagnosis is impossible, that to make a diagnosis mandatory would negatively impact many of our clients."* - Citizens Advice adviser

And then there are conditions that even once under the care of a specialist, it can still take years to formally confirm a diagnosis. Advisers are concerned that mandatory diagnosis could exclude those with harder to diagnose or long-term chronic conditions from PIP.

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[6] For 15 key diagnostic tests (covering imaging, physiological measurements and endoscopy tests), the operational target of less than 1% of patients waiting 6 weeks or more from referral for a diagnostic test was met for none of these 15 tests in April 2024. NHS Diagnostic Waiting Times and Activity Data (2024) April 2024 Monthly Report.

[7] National Institute for Health and Care Excellence (NICE) guidance is that patients with a suspected autism referral should have started a diagnostic assessment within 3 months.

> *“People are suffering and in constant pain while waiting to see a specialist, and then have to go through tests and try different medication before a diagnosis is even discussed. For fibromyalgia or arthritis it takes years before your doctor will actually tell you that you have this condition.“* - Citizens Advice adviser

This proposal would be especially detrimental for those with multiple health conditions, who could be required to have a diagnosis for each condition to qualify for their full PIP entitlement.

Andrei* has multiple health conditions, and receives the LCWRA element of Universal Credit. He came to his local Citizens Advice for help completing a PIP application. Andrei has been officially diagnosed with autism and PTSD, but how much he can do daily tasks or move around independently are also affected by other conditions, which haven’t been formally diagnosed - including dyslexia, anxiety, depression, and obsessive-compulsive disorder (OCD). He has been referred to hospital appointments and is undergoing many diagnostic tests for these other conditions, but getting diagnoses is being delayed by long wait times for specialist appointments.

*All names have been changed

Advisers also tell us that seeing GPs and other medical professionals, and getting medical evidence (which may also be sent digitally), is more challenging for people who are digitally excluded.

What’s more, while GPs are required to provide evidence requested by the DWP directly for free, they can charge patients for medical evidence. The cost of doctors’ notes is already a problem; if claimants are required to obtain medical evidence themselves, absorbing the cost of more NHS charges would be very difficult, if not impossible for the people we help.

Limited usefulness and quality of medical evidence

Advisers raise concerns that medical evidence GPs in particular could provide for patients’ PIP applications would be limited. Because effects of conditions vary, GPs can’t necessarily provide evidence on the functional effects of disabilities or health conditions. More limited contact between patients and GPs[8] further restricts GPs' ability to provide this evidence, particularly about the impact of a combination of several health conditions.

There are also issues with the quality of medical evidence already provided to the people we support.

> *"Some GPs give a comprehensive account of the client's health condition, others give a three or four line résumé that can actually have the effect of not fairly representing the client's health condition."* - Citizens Advice adviser

Medical evidence is treated inconsistently

Medical evidence already plays a part in PIP claims, but advisers tell us it's often disregarded or distorted during the application process.

Advisers report cases of the DWP challenging or disregarding medical evidence or diagnoses. An adviser who had been sitting in on PIP assessments told us the DWP sometimes didn't look at, or take into account, the medical evidence a claimant had collated. Advisers also recalled cases where the DWP had challenged DS1500 forms[9], or misinterpreted a GP saying they didn't know how the claimant was affected by their condition, as evidence that the condition didn't affect the claimant.

Q6. How could we prevent the provision of evidence or a formal diagnosis by a medical expert from impacting the NHS? Please explain your answer and provide evidence or your opinion to support further development of our approach.

We're concerned that unless the DWP makes additional provision for the NHS to provide medical evidence, funding constraints in the NHS will result in costs being passed on to individuals. GPs are able to charge individuals for medical

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[8] Advisers gave examples of the challenge of getting a GP appointment, meaning that patients see their GP less frequently; GPs commonly being able to only see their patients for 10 minutes; GPs commonly discouraging patients from discussing more than one issue per appointment.

[9] DS1500 forms, now replaced by SR1 forms, were part of the 'Special Rules' application process for claimants with progressive diseases who are expected to live less than 12 months.

evidence they request, but aren't able to charge for statutory certificates directly for the DWP. Cost is already a barrier to obtaining medical evidence, and given the financial hardship facing many disabled people we support, any additional charges would increase barriers to accessing PIP.

Q7. Do you agree or disagree that eligibility for PIP should be based more on condition? (Agree/Disagree/Don't know)

Disagree

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

- **Conditions that fluctuate**
- **Conditions that vary in severity**
- **Conditions that might be cured, or have access to better / new/ novel treatments over time**
- **Please explain your answer and provide evidence or your opinion to support further development of our approach.**

We're not a disabled person's organisation and don't feel we have the necessary specialism/expertise to respond. Local Citizens Advice offices are able to submit their own consultation responses, and may be better placed to respond to these questions.

PIP - eligibility reform

Q9. Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?

We’re not a disabled person’s organisation and don’t feel we have the necessary specialism/expertise to respond. Local Citizens Advice offices are able to submit their own consultation responses, and may be better placed to respond to these questions.

Q10. Do you think the need for prompting is a good/bad indicator of extra ongoing costs and why?

We’re not a disabled person’s organisation and don’t feel we have the necessary specialism/expertise to respond. Local Citizens Advice offices are able to submit their own consultation responses, and may be better placed to respond to these questions.

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?

Often the people we help who have a high level of need - and therefore extra costs - are awarded PIP on the basis of multiple low points rather than a few high points. The bar is set high, even to receive the lowest level of points for each descriptor. We would therefore be extremely concerned about any proposal that would remove or reduce support for those who accumulate low points across several activities.

> *“Scoring low points across several descriptors still suggests that that claimant has significant difficulties with multiple activities most days. Therefore daily life could be impacted just as much as a claimant who scored highly in one area.”* - Citizens Advice adviser

When someone accumulates points across multiple activities the impact can be even greater in some cases than for someone with the same number of points across one activity. For example, a need for supervision or prompting to cook, get dressed and wash indicates a high level of need.

> *“Different tasks relate to each other and don’t stand alone. Seen in isolation those restrictions may not be severe, but together they are more than the sum of their parts.”* - Citizens Advice adviser
>
> *“[Discounting lower scores] risks oversimplifying the assessment of needs and failing to capture the cumulative impact of multiple minor impairments, potentially leaving some vulnerable individuals without the support they require to maintain their independence and quality of life. A holistic approach that considers the overall burden of multiple low-level difficulties is crucial for fair and effective support allocation.”* - Citizens Advice adviser

Our advisers tell us that people with certain conditions may be particularly likely to accumulate low points across a range of activities, rather than scoring highly in one or more. These include invisible and/or fluctuating conditions, such as COPD, long COVID-19 and mental health conditions.

Martin* currently receives the standard rate of the daily living component of PIP. Following a stroke, his level of need has increased, so he came to his local Citizens Advice for help submitting a PIP review form. Despite a high level of need, Martin is likely to receive low points across a range of daily living activities, rather than high points in one or more activity. For example, his adviser expects he will score 2 points for both washing and bathing and managing toilet needs or incontinence, as he requires aids to complete these activities. Despite scoring low points, he has a range of extra costs associated with his health conditions. These include one-off costs like grab rails and a stool for the shower, as well as ongoing costs. For example, he can’t prepare meals from scratch himself, so he buys pre-prepared meals, which are significantly more expensive. The time it takes to complete activities like showering also means his utility bills have increased.

*All names have been changed

Q12. Do you think any of the PIP activities measure similar functions and could be merged?

Given the barriers people coming to us for support already face accessing PIP we would not propose merging, therefore reducing, any of the existing activities.

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

Many of our advisers tell us that PIP activities need rewriting, either to improve clarity and understanding of the criteria, or to better reflect the experiences of the people they help. In particular, many of our advisers say that the current list of activities don't fully capture the needs of people with mental health conditions.

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

A third of the advisers we asked said that there should be new PIP activities. One of the most popular suggestions was to include an activity that captures activities relating to maintaining a home, including cleaning and other household tasks like laundry. These activities can be physically demanding, which poses difficulties for people who may struggle with tasks that include bending over or carrying heavy objects. They can also pose difficulties for people with certain mental health conditions.

However, several of our advisers said that simply adding new activities isn't necessarily the way forward, and that instead a complete review of the current approach to eligibility was required.

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?

The threshold for PIP is already high; many of our clients who need support with the extra costs resulting from their disability or health condition struggle to access PIP as it stands. Advisers say the threshold can be particularly difficult to meet for those with mental health conditions. Others mention that the threshold is high compared to Disability Living Allowance (DLA).[10]

> *"In addition to removing an equivalent of the lowest rate of the care component of DLA, PIP removed any distinction between night and day and radically altered how supervision is considered, leaving many people out of entitlement who would otherwise have received middle rate care DLA."* - Citizens Advice adviser

Raising entitlement thresholds would push disabled people into poverty and lead to worsening health outcomes. For the people we help with debt who are disabled, receiving PIP is often the difference between being able to make ends meet or falling into the red. On average, our debt clients who receive PIP have a monthly budget surplus of £16 - meaning they only have £16 left after covering their essential costs. We predict that nearly 9 in 10 of our debt clients receiving PIP (and no other disability benefits) would be in a negative budget if they lost access to PIP - meaning they wouldn't be able to cover their essential costs. And our data shows that when people stop receiving PIP, they tend to cut back on essential living costs. When the people we help with debt start or stop receiving PIP, we see the biggest changes in their spending in health and care costs, followed by food and housing. For many of these people, losing PIP would leave them in an impossible financial situation.

When we asked our advisers about the current threshold levels, more than a third said that the real issue is how eligibility is assessed, rather than the thresholds themselves. Despite clearly being eligible, people are too often turned down and have to fight through appeals processes to receive the support they need. The DWP must take steps to improve the quality of decision-making.

> *"The entitlement thresholds are fair, however the assessors' application of the entitlement threshold is the problem - on paper the criteria for PIP makes sense, however repeatedly we support clients with applications whose actual scores are far off what our PIP Specialist would have awarded them in theory."* - Citizens Advice adviser

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[10] DLA is a tax-free benefit for disabled people who need help with mobility or care costs. DLA was replaced by PIP in 2013. You can now only make a new claim for DLA if you're under 16.

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?

In most cases, some time is needed to fully understand the effects a condition has on someone's daily life. However, the current 3 month qualifying period should not be lengthened. Often, very large expenses appear immediately after a health condition begins. Whilst some people may have savings to cover these costs, many are left struggling while they wait for support.

> *"Definitely shouldn't be any longer. If people have a condition that severely affects their daily lives, ability to work, look after family etc, they need to have resources to access the help they need as soon as possible."* - Citizens Advice adviser

The qualifying period does not exist in a vacuum. Huge delays in scheduling assessments, decision-making and reviews means that in reality many are waiting much longer than 3 months before accessing support.

> *"3 months is a long time to wait, especially with the combined wait for the assessment, mandatory reconsideration, appeal and then tribunal. The entire process seems to take between 6-9 months as it is*." - Citizens Advice adviser

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?

Together with the 3 month qualifying period, the 9 month prospective test reflects the definition of a 'long-term' disability or health condition under the Equality Act 2010. Lengthening this time risks applying a different definition of disability in relation to benefits compared to elsewhere.

Some people who are eligible for PIP already struggle to demonstrate that the impact of their condition will last for 9 months. Our advisers said this was especially the case for people with conditions including depression or long COVID-19, the length of which can be difficult to predict. It can also create difficulties for people with fluctuating conditions which may vary in impact over time in a way which is hard to predict. Extending the prospective test would make it even more difficult for these groups to access PIP.

> *"If they extended it there might be difficulties [for people with mental health conditions]. The view at the moment is that with input and counselling, people should be expected to improve...[extending the period] would make mental health claims more difficult because it would be more difficult to establish you are likely to be affected in the same way for that length of time. It's easier with physical conditions to know that, but not so much with mental health."* - Citizens Advice adviser

PIP - what do we provide support for?

Q18. PIP provides a contribution towards extra costs. Which extra costs incurred by disabled people are the most important for a new scheme to address?

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

Additional expenses people face as a result of their health condition can depend on their:

- condition, their stage, type and severity, and how this interacts with other health issues;
- personal circumstances, such as their housing situation, family and friends, location, and
- access to healthcare, local support and public services more generally.

The idea that there can be a general formula for ranking extra costs is ill-judged and fails to reflect the diversity of need among people accessing PIP. Each individual should be able to determine their own priorities.

> *"Ranking need like that - which things are most important - it's not recognising the fact that these are all based on individuals. What's most important for one person is not for another, so putting it that way is fairly meaningless."* - Citizens Advice adviser

Q20-23 What are the benefits and disadvantages of moving to a new system for PIP claimants?

We strongly disagree with the proposal to replace PIP cash payments with an alternative system. When it was first introduced, one of the main goals of PIP was to enable disabled people to "lead full and independent lives". This would be significantly undermined if claimants weren't able to decide what support best met their needs, and instead support was limited to goods and services specified by the government. Our advisers described these proposals as "humiliating", "insulting", "dehumanising" and "completely missing the point" of an independence-promoting benefit.

> *“People should be treated like adults and be able to choose for themselves how to spend the money. The government has no idea what would make the most difference to someone. It's actually quite insulting to tell people what they can and can't have.”* - Citizens Advice adviser

Moving from a cash-based system risks implying that disabled people can’t be trusted to spend PIP appropriately, even if this is not the intention of these proposals. Based on our advisers’ experience supporting over 1,000 people each day with disability benefits, we know that disabled people often feel like the system is designed to deny them support, not get them the help they need. Limiting support to catalogues, vouchers or requiring receipts would further erode trust in disability benefits.

What’s more, disability-related expenditure is not always predictable, static or easily measured. Advisers we spoke to were concerned that less obvious costs would not be accounted for in non-cash alternatives, while ongoing needs, (such as taxis, special diets and care) would be either very difficult or impossible to meet through catalogues, vouchers, receipts, or one-off grants. Question 18 itself identifies the range of additional costs disabled people and those with long-term health conditions might incur. Many additional health-related costs are difficult to record, for example, separating where “regular” utility costs end, and where additional, health-related costs begin. The cash-based system offers a flexible way of meeting this wide range of needs.

> *“Some conditions require people to have a much higher water usage than others...Although it is in a way cost of living, you can't always break it down and say that this bit is associated with my disability and this bit is just cost of living....Although it is going to people's water bills, they have higher bills because of the disability.”* - Citizens Advice adviser

Additionally, accessing a non-cash benefit would significantly increase the administrative burden for the people we support, for whom claiming PIP is already time and energy intensive.

> *“The clients that I work with are the most vulnerable in our country. Usually they are people who don’t leave the house, don’t have any internet access, no support system. The thought of some of these clients with severe brain injuries for example, trying to access a voucher, or a booklet, or a scheme, or trying to get a quote for this or a receipt for that. It's not going to happen. They're just going to fall even further through the cracks.”* - Citizens Advice adviser

Moving away from a cash benefit would also entail significant new administrative responsibilities for the DWP, such as selecting providers, administering vouchers, verifying receipts and issuing payments. Existing delays mean the people we advise already go without much-needed support for too long. If the DWP were to deliver PIP through more administratively intensive means, the waiting time before claimants access support could increase. The government itself said that “measuring each individual’s expenditure would be administratively complex and expensive” when consulting on PIP back in 2010.

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

o A catalogue/ shop scheme

A catalogue or shop scheme would restrict the support provided by PIP to a limited range of preselected items, and as a result would leave many of the people we support with unmet additional costs. As discussed throughout our response, most of the people we advise have multiple additional health-related costs, which also tend to be on-going and vary between individuals. A catalogue scheme would be unable to meet any needs beyond those for aids and appliances, and would therefore be a particularly restrictive and concerning replacement for cash support. It’s unclear how this model would be able to meet the needs of people with mental health conditions, for example.

> *“This approach doesn’t help them with the costs of mental health. You can’t pick prompting out of a catalogue”* - Citizens Advice adviser

Given the variation in the impact of conditions, we’re also concerned that limiting support to a preselected list of items will fail to capture the full range of appliance or aid-related needs, and lead to claimants ordering less suitable items because this is the only support available.

Advisers highlight that a catalogue scheme would be especially detrimental for specific groups, including people with lower literacy levels, for whom understanding a catalogue and navigating the associated bureaucratic processes would be particularly challenging.

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

o A voucher scheme

Generally, it's hard to see how a voucher system would be able to meet everyone's unique circumstances. There are many disability-related costs that people would struggle to pay for with a voucher, for example personal care or household cleaning. A voucher system would inevitably require the government to select providers that disabled people can purchase goods from. This takes away the autonomy to choose but also creates technical hurdles. A supermarket where vouchers can be redeemed might be far away from the claimant, or a provider might not offer specific features or products that are important for an individual.

> *"Letting claimants decide how to spend the PIP money gives them flexibility and control to use the money in ways that are available to them in their individual circumstances. We see problems in clients using Fuel Vouchers locally when the local shops will not accept them; this is likely to happen in any scheme mentioned above; also such schemes are more likely to require clients to go to a particular place/ use the internet for a particular scheme and they may not be able to do this independently."* - Citizens Advice adviser

Our advisers tell us that the people they help often feel that using vouchers was stigmatising. Vouchers are likely to increase the discomfort around transactions and, in some cases, limit take up (despite the need for support).

> *"Handing over a voucher could be a barrier due to pride. This was evidenced in the Healthy Start voucher scheme where a 'credit card' type of payment was agreed to lessen the obviousness that someone was in receipt of benefits."* - Citizens Advice adviser

> *“Money you spend is money. It's not identifying you in any way or saying anything about your characteristics...Whereas vouchers are going to be completely different, they do label you or say a certain thing about you...Lots of my clients won’t even ring a receptionist and ask for an appointment for their mental health - would they hand over a voucher that labels them as something to a cashier in a shop when they already find dealing with the cashier in the shop to be really anxiety inducing anyway?”* - Citizens Advice adviser

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

o A receipt-based system

This option would be particularly difficult to administer. While potentially trapping claimants in the constant cycle of “approval” of their extra disability costs, it would also generate millions of receipts per month, with each of them requiring individual verification. It’s hard to imagine the DWP having the capacity to do this. It would also be demeaning for claimants, who would need to constantly justify their costs and spend time on filling in the paperwork.

> “*It’s people with mental health problems who in many cases don’t have the motivation to tackle lots of bureaucracy and forms. If you’re moving towards receipts, they’ve got to keep all those and not lose them, and presumably fill in a form with breakdowns of costs. They’re going to end up coming to Citizens Advice to see us and get help to fill in these receipt claim forms. Sounds like a bureaucracy nightmare to me.*” - Citizens Advice adviser

A receipt-based system would place impossible requirements on an already financially disadvantaged group. With almost 1 in 10 households with a disabled person already in a negative budget, many people would simply not be able to pay the money upfront and wait for the reimbursement. A receipts-based system would also generate uncertainty as to whether a given expense would be approved.

> *“Receipts will increase interaction which lots of people are avoiding in their day-to-day life. Often if you pay for something, especially a service, you don’t always get a receipt, you have to ask for one...not everything is something you buy in Tesco. And just administratively, I just can’t imagine how a lot of my clients would deal with keeping track of receipts...It’s just unworkable."* - Citizens Advice adviser

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

o One-off grants

The Green Paper states that one-off grants could contribute towards specific, significant costs like home adaptations or expensive equipment. Our advisers questioned why this is proposed as an alternative to PIP, when it’s usually local authorities or housing associations who are responsible for home adaptations. Our advisers tell us that most people use PIP to cover ongoing needs, requiring regular and often unpredictable expenses that one-off grants would be unlikely to cover, like taxis, higher utility bills, and special diets. Our advisers also emphasised the importance of regular income in enabling people to budget effectively and manage ongoing conditions.

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’re concerned about the potential impact if PIP could no longer be used to determine eligibility to passport to other benefits and services. There’s a large risk that the burden of determining eligibility would fall on already overstretched service providers including local authorities, who may not have the resources to cope with the increased administrative role. This would likely increase waiting times for accessing things like Blue Badges, which already take longer for those not receiving PIP.

It would also increase the number of assessments people would be required to go through - one for each extra service, rather than the streamlined approach that comes with passporting from PIP.

This shift in responsibility could also lead to further restrictions in support. Many schemes that use PIP as a passporting benefit are likely to use any alternative national benefit in the same way. For example, local authorities may reform criteria for accessing support like Council Tax Support, bringing it in line with any national reforms. People who were previously eligible for PIP would risk seeing a domino effect on the rest of the support they rely on to cope with the additional costs of their disability or health condition.

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?

If PIP wasn’t used to determine eligibility for the health element within Universal Credit, the DWP would need to develop an alternative means for determining eligibility. This neatly illustrates the risks of incremental system reform and why reform needs to be looked at in the whole through an independent commission.

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)?

Our experience is rooted in supporting people through the PIP application and appeals process, and as such we don’t have the experience or evidence in terms of the wider support needs of disabled people or those living with long-term health conditions to answer this question.

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)?

We’re troubled by this proposal’s implication that disabled people and people with long-term health conditions would receive either a cash payment *or* access to treatment/support. Disabled people and those with long-term health conditions should already be able to access the care they need (though with record NHS waiting lists[11] and stretched social care services, this is not always the case) and *at the same time* be supported, through PIP, to cover the additional costs of their disability or health condition. What's more, people often need financial support in order to be able to access, and fully benefit, from treatment - like needing to pay for a taxi to travel to a health appointment.

Not all conditions that can be improved through treatment, will be. Across health conditions, the efficacy of treatment is rarely certain, and progress can be difficult to predict and non-linear. For example, only 59% of people completing a course of counselling for depression in 2022-23, and 61% of those completing a course of Cognitive Behavioural Therapy (CBT), had an outcome of therapy-based improvement. Our advisers also raise concerns about the variability in the standards and quality of treatment.

We're also concerned as to whether claimants would even be able to access medical treatment or support under this proposal. As one adviser expressed: "Tell me where all these therapies are? They're just not there". It's unclear whether this would be additional, newly commissioned support or relying on existing services, both of which are problematic; with the first option it's hard to see where the skilled staff would come from, and the latter would rely on services, many of which are already at breaking point.

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[11] For example, according to the Handbook to the NHS Constitution, patients referred for consultant-led treatment should start treatment within 18 weeks. There's a 'zero tolerance' policy on patients waiting over a year. In April 2024, there were over 300,000 people in England who had been waiting over a year for consultant-led treatment, and the target of 92% of patients starting treatment within 18 weeks was being missed by over 25 weeks. See: Statistical Press Notice, NHS referral to treatment (RTT) waiting times data, April 2024 and House of Commons Library (2024) NHS key statistics: England.

PIP - aligning support

Q28. Do people already receive support from local authorities or the NHS with the need/costs that come with having a disability or health condition? (Yes/No/Don't know)

Don't know

Q29. In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach.

Our advisers tell us that the people they support struggle to access support from local authorities and the NHS with the need/costs that come with being disabled or having a health condition. Local services are buckling under pressure and are struggling to provide consistent and accessible support. Our advisers describe a postcode lottery system, where what you can access depends on where you live.

> *"How can you join up services when there aren't services? Like doing a dot to dot without the dots."* - Citizens Advice adviser

Where local services do exist, there's lots of barriers to accessing them. People are often not aware of any support that's available locally. Applications can be complex and often require a level of digital skills and access many of the people we support don't have. Then once people have applied for help, waiting lists are often long - one adviser helped someone who waited so long to receive support from her local authority to pay for home adaptations that she paid for them herself, despite having a low income.

Q30. Which of the following do local authorities or the NHS help with?

Q31. In relation to Question 30, please explain your answer and provide evidence or your opinion to support further development of our approach.

As we have touched on in previous answers, there's huge variability in the support on offer and some of this support is not guaranteed on a long-term basis. For example, the Household Support Fund can provide emergency support with utility costs but this is due to end in September and even if extended, people are often limited in the number of times they can access it.

Q32. Which needs/costs that come with having a disability or health condition could local areas help with further?

Q33. In relation to Question 32, please explain your answer and provide evidence or your opinion to support further development of our approach.

Given the points already discussed regarding how stretched local services are, and the postcode lottery of local support, this is clearly an area that requires further investment. However, even if local areas were better able to provide support for the additional needs/costs that come with being disabled, this would still not negate the need for PIP.

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?

While investment in local services and ensuring people are able to access support in their local area is important, this does not negate the need for PIP as a cash benefit.

Q35. Do you think aligning PIP with local authority and NHS services could reduce the number of assessments a person with a disability or health condition would have to undergo? Would this help to reduce duplication?

Undergoing multiple assessments can be an extremely stressful process and we would welcome steps to reduce this burden on the people we help. In this respect, we would like to see a more joined-up approach between PIP and local services in terms of information sharing. For example, people who receive PIP could be automatically flagged to local service providers, who could either process applications automatically or contact the claimant to inform them of their eligibility. Assessments themselves could also be reviewed to identify areas of overlap or duplication in order to offer a more streamlined process for claimants.

However, we would be concerned about any localisation of the support currently provided through PIP. Local services don’t have the resources to deliver support on the scale that would be required, and this would likely create a postcode lottery system that would result in massive reductions in support for many disabled people. The variability now seen in Council Tax Support is evidence of what happens when benefits are devolved to the local level.

Q36. What disability support services in your community are the most important services or support to deliver?

Responding at a national level we lack the local knowledge to answer this question.

Q37. How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?

It is difficult to answer this question given the pressure currently on local services. We are concerned that prioritising one area would come at the expense of cutting others.

Q38. What capacity and capability would be required to better align PIP with local authority and NHS services?

Our evidence largely comes from supporting people with the PIP application process and therefore we don’t have the necessary expertise to comment. Local Citizens Advice offices are able to submit their own consultation responses, and may be better placed to respond to these questions.

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Published July 2024.

Citizens Advice is an operating name of The National Association of Citizens Advice Bureaux.

Registered charity number 279057.