

Modernising Support for Independent Living: The Health and Disability Green Paper

Turn2us response July 2024

1. About Us

- 1.1 Turn2us is a national charity that provides practical information and support to people facing income shocks and financial insecurity. We work with others to challenge the systems and perceptions that cause financial insecurity.
- 1.2 We provide practical information and support to end financial insecurity through our Benefits Calculator and Grants Search which shows user what support they are entitled to. In 2021 we awarded over £3.6 million through 3780 grants. We have also helped over two million people understand their benefit entitlement through our benefits calculator tool in the last year.
- 1.3 Turn2us are members of the Disability Benefits Consortium and we do not support the assumption set out by this consultation that Personal Independence Payments (PIP) should be restricted or abolished. We will therefore not be commenting on the specific questions but have instead provided insight into the views of people with first-hand experience of accessing disability benefits.

2. Turn2us PIP Helper Tool

- 2.1 In addition to our [Benefits Calculator](#) and [Grants Search Tool](#), in 2022 Turn2us began creating a tool to help people to better understand how to apply for PIP. A PIP award, after housing costs can double the income of disabled people. 54% of people use Turn2us Benefits Calculator who self-identify as ill or disabled are not receiving any disability benefit and PIP information webpages on the Turn2us website but beyond providing basic information about PIP don't deliver the information people need to apply for the benefit.¹
- 2.2 The Turn2us PIP Helper Tool simplifies the complex application process, making it more accessible and less daunting. It is entirely co-produced with disabled people, and health and disability charities to ensure relevance and build trust, and it's therefore highly accessible. The tool walks claimants through each stage of the PIP application, checks what PIP award is likely and provides personalised tips on how to fill in a PIP application form, making it transparent and manageable.

¹ Turn2us Internal Data, 2023.

2.3 Turn2us and co-production

2.4 People facing financial insecurity play a core role within Turn2us and are at the centre of our policy and decision-making. We seek to put people at the centre of the service development and decisions which affect them. This approach empowers people to advocate for themselves and have a stake in the tools, programme or policies which are designed to support them.

2.5 We co-produced the response to this consultation with nine partners, who were also involved in developing our Turn2us PIP Helper Tool and are in receipt of PIP or support other people to access the benefit. They come from a wide range of backgrounds and have different experiences of claiming PIP. The views of those who use and rely on PIP are prominent throughout this response.

3. Key Issues

3.1 Increasing cost of disability benefits

3.2 The rhetoric around disability benefits has consistently been negative, blaming disabled people and people with health conditions for not wanting to work or being accused of exaggerating their sickness or condition to claim benefit payments. We have heard from some of the people we work with that there are several reasons why they claim PIP. Some have always worked but became ill and struggled to access timely diagnoses and treatment which has worsened their conditions, particularly for those with mental health problems.

3.3 PIP is a non-means tested benefit and is frequently conflated with participation in the workforce. Many of the co-production partners involved in this response worked but could not sustain full time work or could only work periodically, and PIP gave them the option of reducing their hours to prioritise their health and support themselves financially. The increase in the number of claims in disability benefits is a complex.

3.4 The recent increases in the cost of living may have forced sick and disabled people, who once were managing financially to look for extra support which may have led to an increase in claims. Additionally, it is well established that the Covid 19 pandemic caused an overall decline in the nations Mental Health. In 2020, The Centre for Mental Health estimated that up to 10 million people, including 1.5 million children and young people under 18, may need mental health support in the aftermath of the pandemic.²

3.5 The varied and complex reasons for the increased uptake of disability benefit does not support the negative rhetoric around disability benefit claimants. The social security system was set up to support everyone, especially those who need it the most. We know from our own work delivering grants that this support needs to be based on compassion and trust to

² Centre for Mental Health(2020) Up to 10 million people in England may need support for their mental health as a result of the pandemic available at <https://www.centreformentalhealth.org.uk/news/item/10-million-people-england-may-need-support-their-mental-health-result-pandemic-says-centre-mental-health/>

give people space to get back on their feet before problems escalate, and it needs to take account of modern challenges rather than punishing the people who need it most.

'I feel like it's been designed for the good of headlines rather than the actual good of the people, so you know they can say yes, we are supporting disabled people. Look at this, but they're not actually asking disabled people what they need not considered how it works. They're just so that the general public who doesn't rely on these benefits can be like, Oh yeah, the support disabled people that's sorted, right. Let's talk about something ridiculous. It's not as important, in my opinion.' - co-production partner

4. Lack of understanding about disability

- 4.1** Since PIP was introduced, there have been several challenges with accessing the benefit that have not been addressed in this paper. The issues that have made claiming PIP arduous, such as poor assessments, have not been addressed in this consultation.
- 4.2** Co-production partners were asked about the proposed changes to the assessment, particularly the move to a focus on conditions and noted that it fails to understand the wide vast of experiences of disabled people and the diverse needs of PIP claimants such as those with fluctuating conditions. They expressed concern that receiving a diagnosis for their disability could be challenging due to waiting lists or the complexity of conditions. One partner noted that they had been waiting over two years for a diagnosis but was able to claim PIP to cover the cost of therapy that they were waiting for from the NHS. Due to the long waiting time for the therapy, they decided to cover the cost with their PIP payments.
- 4.3** Partners spoke of their experiences of waiting to receive treatment and expressed concern about the reliance on an already stretched NHS. They did not believe that the move to a condition-based model was feasible because of this. This type of assessment would risk leaving people without essential financial support until they were able to receive a diagnosis and worsen their health as the link between financial security and good health is well known.

'...should we rely more on medical evidence?

In some ways, that might make it easier because you'd say, OK, well, I've already got this letter from my doctor saying that my diagnosis and the thought of not having to go then through such a lengthy assessment may make it easier, but also it could make it harder for some people because a lot of people, especially with the NHS, the way it is now, are on massive waiting list, don't have a clear diagnosis, are waiting for a diagnosis or waiting for tests.' - co-production partner

- 4.4** Partners criticised the overarching culture and systemic issues in how society views and supports disabled people. They felt that they system needed to be compassionate and take an integrated approach to support disabled individuals. The approach outlined in the consultation was considered as a one size fits all approach that does not recognise a social

model of disability³ or the experiences of disabled people. This was a constant theme that arose; the consultation did not consider the experiences of the people who relied on PIP, meaning there was little to no understanding about the impact of the changes in the assessment or what disabled people actually use PIP for.

'I think it's the obsession of experiencing that condition... for example, I've got bipolar disorder. You can't just say everyone with bipolar disorder needs this, this and this...It's a lot more subtle than that. Then they'll say, oh, you get a certain amount for bipolar. If you need anything else, you have to apply for that separately... So it's just going to take more, more work to personalise things to people.' - co-production partner

- 4.5** The assessment is the gateway to financial support and it is critical that it is conducted in a holistic manner, recognising the complexity that comes with sickness and disability. The change to a condition-based model seeks to oversimplify sickness and disability and does not consider the effects of multiple conditions on functionality. Besides leaving people struggling to access timely healthcare without essential financial support, a simple list of conditions. It is also clear that the voices of the people who use the system were not involved in the changes.

'...if you've got comorbidities. Yeah. Life gets very complex. And I don't really feel that PIP really acknowledges that that well.' -co-production partner

5. Lack of fairness and compassion

- 5.1** The consultation intends to 'ensure that the (assessment) criteria are fair and that we focus support on people with the highest need'. Overwhelmingly, there was little faith from co-production partners that any changes would be fairly implemented, and that fairness is not the driving principle in the system, which is instead focused on saving money.
- 5.2** One partner raised the move to relying on aids and prompting mentioned in the eligibility section of the consultation. There was universal agreement in the group that this would not work for all people, especially those with mental health conditions. Partners were 'sceptical' and thought the reforms were 'vague' and that the government was 'responding to (people's) need instead of (government) finance...' There was confusion as to what exact alternative the government was proposing.

³ Scope define the social model of disability as people being disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things.

- 5.3** One partner raised the 20m rule mobility descriptor⁴ noting that: ‘you can't even get to a shopping centre on 20 metres.’ The descriptors were not practical and did not reflect real world situation, making them feel like the system was stacked against them.
- 5.4** Partners spoke at length about the perceived subjectivity of assessors and that most assessors were not qualified to understand different illness and conditions which led to them rigidly interpreting the descriptors and this was not a fair assessment.

‘The test isn't ideal, but I think it gets the job done as long as the assessor is actually following the guidelines.’ -co-production partner

Others described a lack of compassion in their experience of applying for PIP:

‘they treat you as if you're guilty and you've got to prove yourself innocent. I know when I was not guilty of anything, but that's the feeling that you get, isn't it? There's nothing wrong with you. You've got to prove that there is. Even if you've got your medical notes... And it is just that feeling, isn't it, that that you've got to prove that a lot of things that you've proved already... that's not really a very caring attitude.’ -co-production partner

Claimants also raised the distinction in the paper made between physical and mental health and the disparity in the way they are treated, creating an inherent unfairness in the system.

‘They kind of make this allusion to the idea that there are some people that are worthy of having more support from PIP and worthy of potentially getting PIP just based on their diagnosis and they shouldn't have to do an assessment, but they give no detail around what kind of diagnosis that would be...they've kind of implied that they're trying to distinguish between people's extra costs related to a mental health condition and extra costs related to a physical impairments and implying that those with a mental health condition have less extra cost than a physical impairment. -co-production partner

- 5.5** Some partners noted that the Green Paper did not outline the options for those who did not require aids or adaptations (those with mental health conditions) but who used PIP to pay for extra costs. It would be difficult to estimate exactly what their extra costs are from month to month and it would be unfair to continually have to justify their extra costs.
- 5.6** However, one partner thought there were some positives in the reforms such as integrating support. They would like to believe that it would result in more personalised support, but ultimately they did not think that the reforms would be done in a compassionate manner:

‘there's no trust that it will be done with the right culture...with a social model of disability and value disabled people's lives, not kind of in a sort of “you're worthless if you can't work,” which is the typical attitude.’ - co-production partner

⁴ Activity 2 in the PIP assessment considers a claimant's physical ability to move around without severe discomfort, such as breathlessness, pain or fatigue. This includes the ability to stand and then move up to 20 metres, up to 50 metres, up to 200 metres and over 200 metres. As with all the other activities, a claimant is to be assessed as satisfying a descriptor only if they can do so reliably.

- 5.7** The attitude towards lack of compassion and fairness in the system was raised constantly throughout the workshop. It was felt that PIP in its current form, and the reforms, are not trying to support disabled people to live dignified lives but instead are about trying to save money. There was widespread agreement that government has not adequately included the views of disabled people in the consultation and that the proposed reforms need to be more compassionate and fairer reflecting real-life experiences. There was a strong need for more a nuanced, individualised, and genuinely supportive approach to disability benefits.

6. Removal of cash payments

- 6.1** Turn2us does not dispute that the cost of disability benefits has been increasing over time and the government has a responsibility to manage costs. However, the Green Paper proposes radical changes to manage the rising cost of disability benefits. As the international comparisons in the Green Paper show, cash payments from PIP are a unique way to deliver support for sick and disabled people. For many these cash payments are the strength in the system. The payments are empowering and allow them to live a dignified life.

'I did it with my PIP money, but it gave me pleasure in being able to go out for the day...to a garden centre where I went in and spent £12 and then felt guilty about it afterwards because but that's my mental health, you know, it's given me a reason to go out and enjoyment of planting them all. You know that to me is a huge treat and it shouldn't be, should it, you know, to go out and spend £12 on something that seems a little bit not non-essential.' - co-production partner

- 6.2** Partners were 'anxious', 'scared' and 'worried' about the removal of cash payments. It reiterated that the payments were not being used to fund lavish lifestyles but on small non-essential items that made a difference to their quality of life. Vouchers, grants or a catalogue system were universally rejected. Vouchers were considered stigmatising and an infringement on privacy, making individuals feel that they could not be trusted to manage their finances independently. The discussion addressed what level of money was deemed necessary to survive and what is needed for a decent quality of life. There was concern that PIP should not be reduced to covering only the most basic needs but should also support a reasonable quality of life.

7. Financial security and benefit adequacy

- 7.1** Many coproduction partners used their cash payments to support their household budgets, but also to cover extra costs that arose from their disability such as 'home help' or having the heating on longer. Some participants in our workshop were employed but said that with the increased cost of living their wages did not go far enough and PIP was valuable in filling in gaps in their household budgets.

'I do work full time, but even just my salary on its own, just generally with the rising cost of living, I would find it really difficult and I would need to rely more on things like overdrafts.' -co-production partner

- 7.2** According to the Joseph Rowntree Foundation, around nine in 10 low-income households receiving Universal Credit were unable to afford essentials and the basic rate of Universal Credit's standard allowance is at its lowest for almost 40 years.⁵ Compounded by the sharp increase in living costs and the volatile nature of Universal Credit, for many sick and disabled people PIP allows them to keep afloat financially and not fall into debt. For others, cash payments from PIP allowed partners to be full members of society and the concern was that they wouldn't be able to decide between what they need and what they want.

'And are we saying then that PIP is only for essential cost? So basically things that keep you alive or are we saying that PIP is for things that improve your quality of life because there's things that I might not need if I wasn't going to say if I said OK, I'm not going to go out the house because that's not an essential need.' - co-production partner

8. Lack of trust and lived experience

- 8.1** The lack of trust and lived experience was raised again by participants, with a visually impaired co-production partner not being confident that their specific equipment needs would be catered for. Technology and equipment had to be tried and tested, ensuring it feels comfortable for them. They believed that the options offered by vouchers or in a catalogue would not be suitable, meaning that they would be digitally excluded. They referenced their local authority support scheme for assistive technology but found that it was limited. This compounded the feeling that there was a lack of understanding about what disabled people need, removing their agency.

'Anything that proposes moving cash benefit to any of the systems they proposed, whether it's vouchers, grants, catalogue or reimbursements, is extremely worrying because who is then making the decision around what you need?

What is deemed worthy of needing what is deemed and essentially how are they deciding what they deem as a want and what do they deem as a need?' -co-production partner

9. Aligning financial, health and local authority support

- 9.1** The ambition set out in the consultation is to 'align the support offered by PIP with existing health, care and local authority provision for disabled people and people with health conditions... and offer better joined up and streamlined support than the current system'.⁶ Turn2us supports a joined up approach to health and financial security, however access to health and social care services should not be a substitute for a cash benefit.

- 9.2** Co-production partners highlighted the difficulty in accessing NHS services and referred to the long waiting lists for treatment. Where there is a reliance on local government, such as for

⁵ Joseph Rowntree Foundation, Inadequate Universal Credit and barriers to work available at <https://www.jrf.org.uk/social-security/inadequate-universal-credit-and-barriers-to-work>

⁶ Modernising Support for Independent Living: The Health and Disability Green Paper p.23

social care or grants for adaptations, they noted that support was likely to be inconsistent. Partners were concerned that aligning support in this way would be an invasion of privacy especially if there was a strong local element. One partner who is active in her community was concerned about grants and vouchers being delivered locally:

'...but for finances, I don't think people should locally need to know my business. I don't know if that makes sense to anyone, but that's how I feel about things being too local to where you are.' - co-production partner

- 9.3** Many partners felt that applying for support from local authorities was stigmatising with many saying that they don't apply for the support that they need because they are made to provide so much information and constantly repeat it. They also felt the level of detail they had to provide was an invasion of privacy and in some cases involved the wider family:

'And I think I just to me, I don't apply for anything. I'm not desperate for and there's probably a lot of things I could, but that involves trying into your private life to a greater extent and involves involving, for instance, my son who is sort of my carer as well.' - co-production partner

- 9.4** Partners saw this consultation predominantly as an exercise in saving money and not in improving services for sick and disabled people. There was a strong feeling that it wouldn't save as much money as was hoped. Mainly because spending would show up in other areas of government expenditure. Moving more services to local authorities, would save the DWP money, but increase local government spending making no impact on the overall government spending. Removing the cash payments that allowed people to manage their health would lead to worse health outcomes increasing expenditure in the NHS.

'Create a decent health service that has a good mental health service... everybody's just getting, you know, worse. They're making a nation of very sick people and the (benefits) bill would be reduced drastically if they had a decent health service.' - co-production partner

10. Conclusion

- 10.1** As a financial insecurity charity, our main concern with this Green Paper is removing essential cash payments. If these proposals go ahead, they will be detrimental to the financial security of disabled people and have a further effect on their health. It is clear, and as our coproduction workshops have shown, that there is a lack of understanding in the reforms about how PIP is used by disabled people and the perception that some disabilities are more deserving than others.
- 10.2** Turn2us developed our PIP Helper Tool in response to the challenges in the current PIP system and to help people apply for the benefit. The proposals in this Green Paper don't address any of those long-standing challenges and risks making the PIP system more complicated, jeopardising disabled people's financial security.

- 10.3** As the overriding aim of this Green Paper is to reduce the amount of money that the government is spending on disability benefits, Turn2us agrees with the Disability Benefits Consortium, that these reforms cannot be the basis for policy in relation to PIP. PIP is an important part of the social security system and should be designed to work for the people who it is there to support. Future reforms to the PIP system should focus on stigma-free support, prioritising fairness and compassion, which will allow disabled people to live independent and dignified lives in turn supporting them to thrive.

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