



Consultation Submission from the Organise community: Modernising support for independent living: the health and disability green paper

Executive Summary
July 2024

FAO The Department for Work and Pensions; Liz Kendall, Secretary of State for Work and Pensions

Organise is a worker-led platform with over one million members, where people from all sectors, professions and work situations come together to change the working lives of millions of people.

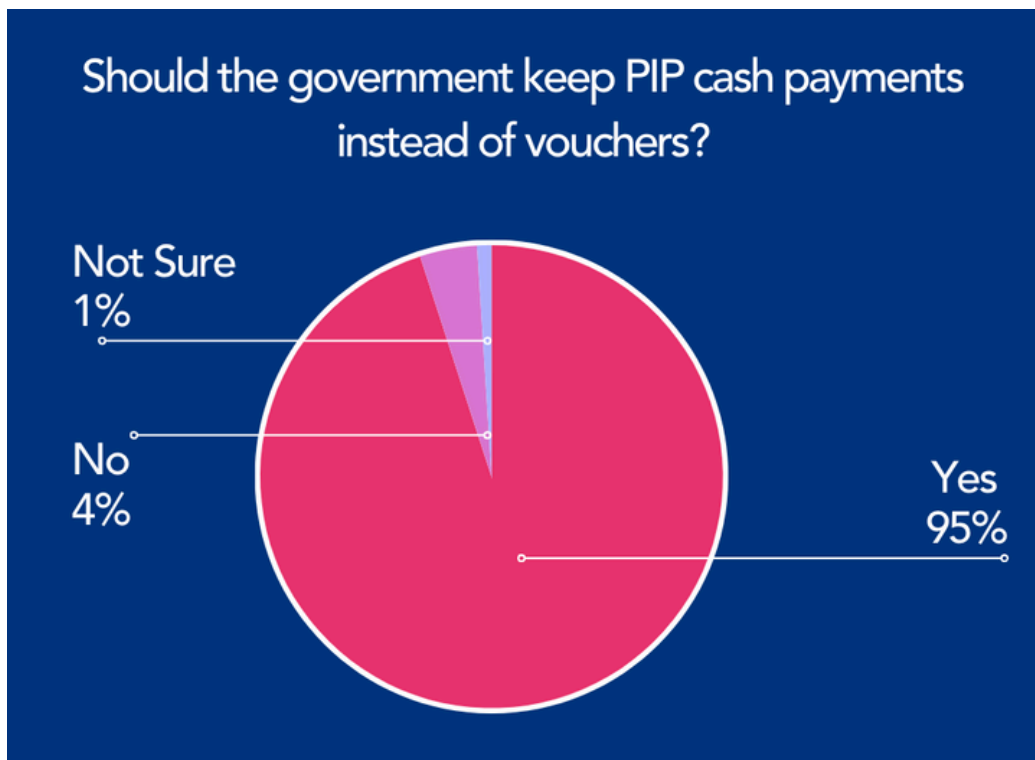
This submission contains over 21,193 responses from Organise members to the DWP's open consultation: Modernising support for independent living: the health and disability green paper.

A further 47,850 Organise members have signed a petition urging the new Secretary of State for Work and Pensions, Liz Kendall, to not replace PIP cash payments with vouchers.

The personal testimonies included in this report come from members of the public, many of whom are disabled, unpaid carers, and benefits claimants.

The Headlines:

Over 95% of people agree that the government should keep PIP cash payments, instead of replacing with a voucher or grant scheme



3

☛ Disabled people, their families and carers are worried about the impact of replacing PIP with vouchers on their health and wellbeing

☛ Organise members are extremely concerned about the feasibility of replacing PIP with vouchers, or any of a grant scheme, a catalogue or receipt-based system



"I have always worked as much as I can over the years but there is no safety net for me apart from PIP. I am so very grateful that I can use PIP to pay for my basic living needs. I can't see how vouchers or a catalogue would work for someone in my position and it would limit independence severely. Limiting independence and choice in turn negatively affects mental health and self esteem which in turn reduces health, wellbeing and ability to work."

What Organise members are saying:

"People manage their disabilities in all sorts of ways that cost money. Some are obvious, like mobility/sensory aids and carers. Some people need to spend money on things like specific foods for dietary requirements, or supplements. Also some things are personal, like incontinence aids, and not everyone wants to/ is able to submit receipts for everything they've purchased."

"I'm grateful for PIP as it is, but fear for all disabled people if it were to change and be so limited and so disempowering as to be in the form of coupons."

"My wife has several conditions which are progressive and will never be cured and only get worse . She has a motobility car which without she would never leave the house . We are both on state pension and without cash payments would struggle to pay for everyday needs which change depending on her needs"

"I rely on pip to cover fuel bills covering my hospital trips I have stage 4 cancer and without pip I wouldn't be able to make my hospital appointments."

"PIP gives my grandson a tiny foothold in independence."

What Organise members are saying:

"I am a disabled wheelchair user with various long term illnesses. My husband works hard full time whilst also caring for me. My 14yr old son is a young carer too. We will not cope financially if PIP is replaced. We are only just surviving now. We can't afford to buy our own home, cannot afford a holiday and very rarely get to go out. It will be even more demoralising to have to use coupons to get through normal day to day living."

"The PIP payments are my lifeline to my survival and independence."

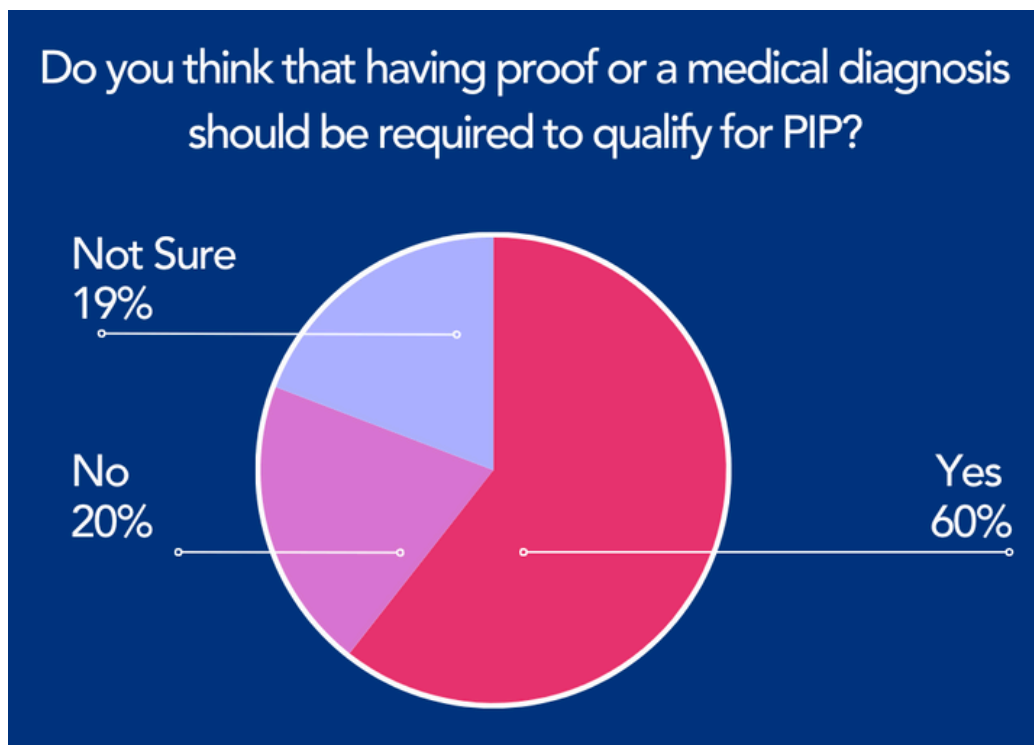
"I think it's really important for people with debilitating health conditions to have autonomy over their finances & care. None of us imagined we would be in this position"

"Life is hard, especially when you have to have PIP. My partner had a massive stroke just over 5 years ago and is now in receipt of PIP. He no longer works, and I am an unpaid carer for him. Last year we got a car through the scheme and it has been wonderful."

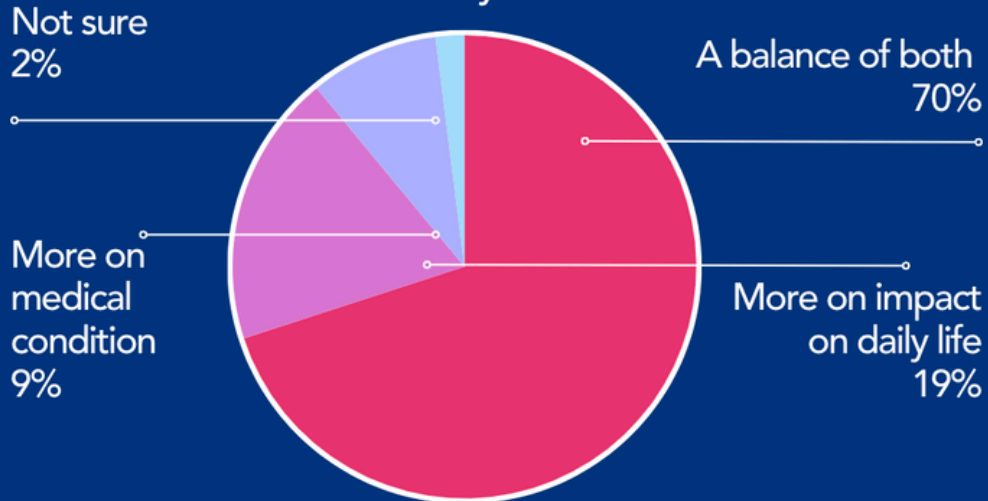
"I am a wheelchair user with Spina Bifida, I rely on my PIP as a cash payment so that I can decide and use the fund independently. I then can make choices as to what needs are essential as they may change monthly."

In response to proposed changes to qualification and eligibility for PIP:

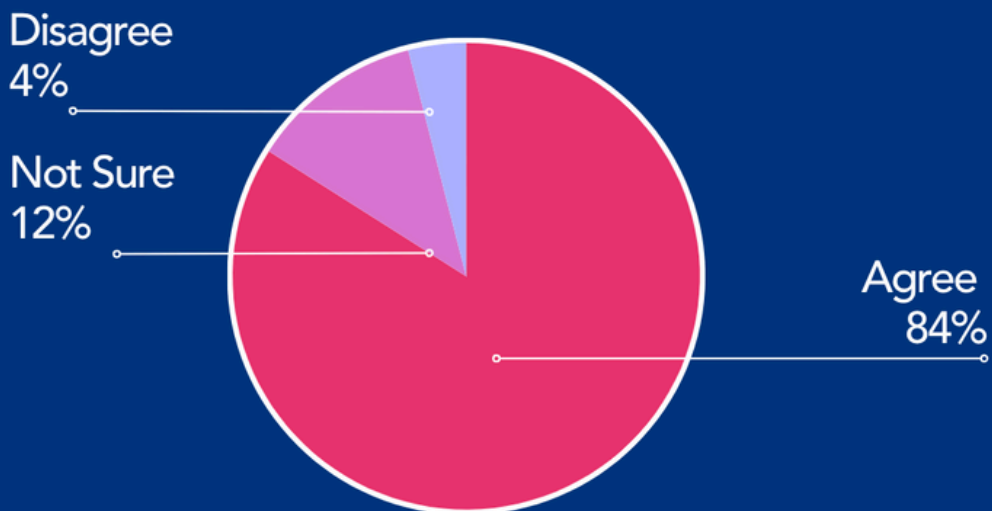
- A majority think that some proof or medical diagnosis should be required to qualify for PIP
- There is opposition to having more emphasis on medical condition than on the real impact on a persons daily life. Instead, over 70% think that a balance of both needs to considered
- There is broad agreement with the proposal that if you have a confirmed health condition or disability you can skip award reviews



Do you think that eligibility for PIP should be based more on the medical condition rather than how it affects a person's daily life?



Do you agree that PIP claimants with a confirmed health condition or disability can skip award reviews?



In response to proposed changes to activities, qualification periods and thresholds for PIP:

- There is no clear consensus on changes to rules and activities - however Organise members provide a number of suggestions for activities that can merge and/or be removed.
- There is strong encouragement for greater flexibility, compassion and fairness for PIP assessments.
- A number of members in the Organise community call for greater impartiality by moving assessments inhouse and including GPs or other medical professionals.

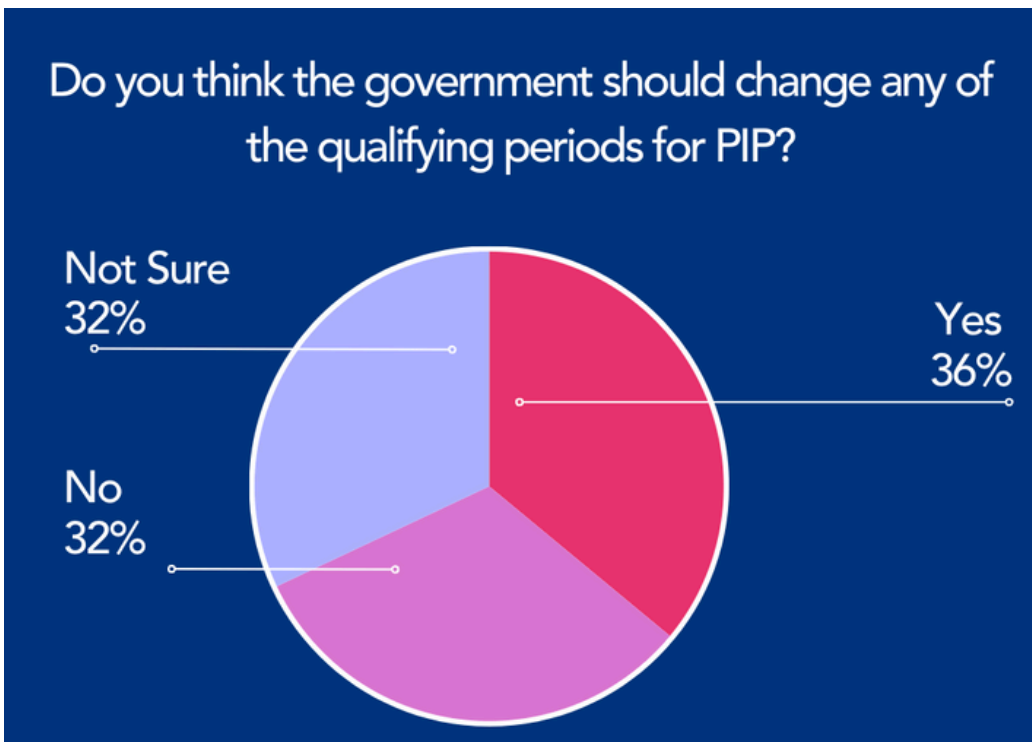
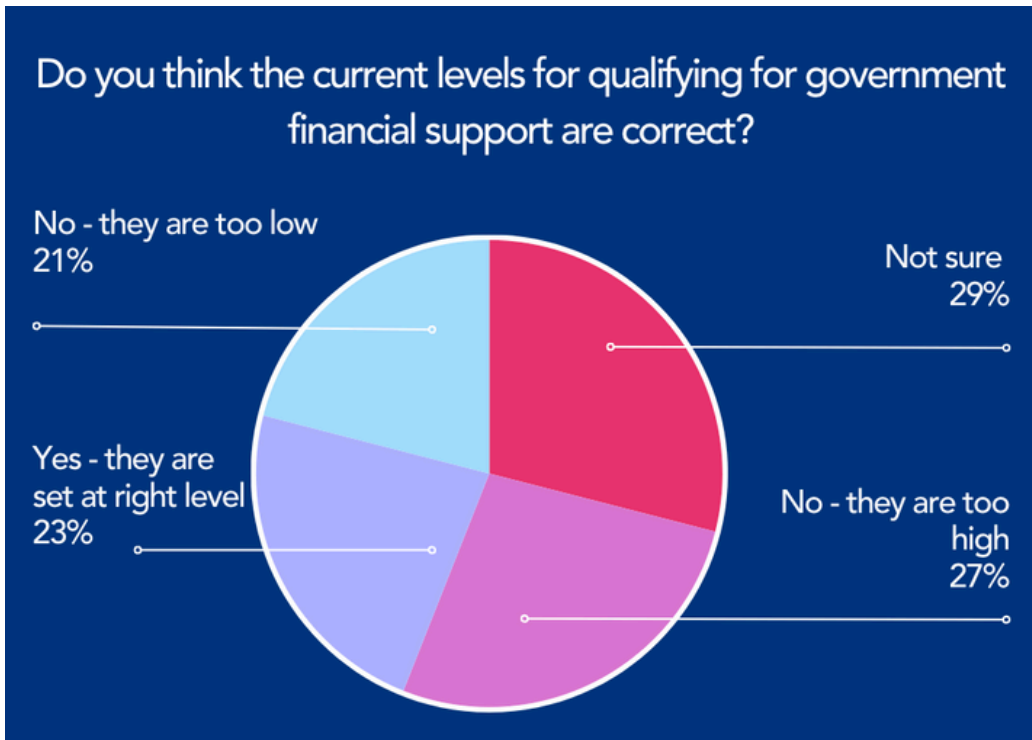
What do you think about the current rules and activities for qualifying for PIP?

The current indicators and activities are fine as they are:
11.3%

Some activities should be merged, removed, or re-written:
32.0%

New activities should be added to PIP assessments:
28.6%

Not sure:
28.1%



What Organise members are saying:

"The PIP process is not fit for purpose - it is long and difficult for those that are genuinely struggling with day to day living. There should be better understanding of chronic health conditions and more support available to those that want to work but physically can't."

"the process should be conducted by medical professionals who have NO other agenda to meet regarding their assessments and full capacity & knowledge to understand the person in front of them and to also have genuine empathy."

"When I needed to go to hospital I would have no warning before hand I would just be struck with horrific pain or vomiting. One of these hospital stays coincided with a PIP assessment. Despite my Dr telling PIP over the phone that I was in fact an inpatient it got put as a strike. I felt this was really unfair"

"To actually receive PIP, is harder than anything I have had to do before, and I have held high positions in the City. To now be told I may not be able to choose how to spend my money is frightening."

"PIP should remain non means tested. As a blind person I am concerned about the additional amount of admin I would have to do to keep track of the new proposals."

What Organise members are saying:

“the reliance on independent companies for assessments, which often profit from these evaluations, should be reconsidered. Instead, investing in direct support for individuals with disabilities and their caregivers, including financial assistance and access to necessary services, would better serve the needs of vulnerable populations.”

“Please allow us the financial independence to seek help and to get better, offer us support in training or work, but don’t try to force it “under threat of sanctions” - that will make the problem worse.”

“Assessors should not be given bonuses for seeing more people in a certain period or marking them down. They should read all the supporting information before the assessment. Their report should relate to the answers from the applicant and supporters during the session. It should not be a humiliating and judgmental experience.”

“I receive pip, not all but some of conditions are visible. Sometimes it’s hard to explain the how your conditions affect you. It would be more helpful if your GP was involved with the decision.”

“Offer a universal basic income. Enough with the constant reassessments and stopping of payments. The fear and stress is not only unbearable for disabled people, but is costing the taxpayer more in all the related admin.”

What Organise members are saying:

"As someone with a life limiting chronic illness which causes a whole lot of issues, seen and invisible, it sounds like a one rule fits all. What I need could be completely different from someone else with the same condition. Disability and disabled people are not tick boxes."

"Instead the system needs to approach claimants from a "how can we help" approach - improving NHS care, putting claimants in touch with treatment (which MUST be voluntary - no one should be forced to undergo treatments they don't feel comfortable with)"

"Vouchers support an idea that disability is transient and can be dealt with. It also suggests that disabled people can't be trusted to spend their financial support responsibly so they need monitoring. This isn't a cookie factory, we are all different and have differing levels of need in different areas of our lives. The current system isn't perfect but it does acknowledge the differences in individual support requirements."

"Sick and disabled people are limited in their abilities already and suffer a great deal with management of such conditions. It is hard enough to live with such conditions and changing how pip is received will create further stress, worries and isolation"

Thank you for reading this summary of responses from Organise members.

Organise members are calling on the Secretary of State for Work and Pensions Liz Kendall to confirm that this government will keep PIP cash payments.

We look forward to hearing your reply which we will share with Organise members.

To respond to this report please email Bex Hay from the Organise staff team on action@organise.network

Sources:

Organise surveys:

<https://the.organise.network/surveys/pip-consultation-july>

<https://the.organise.network/surveys/pip-consultation-anonymous>

<https://organise.network/actions/poll-do-you-think-it-s-wrong-for-the-gov-OGu3zHlg>

Organise petition: <https://organise.network/actions/petition-don-t-strip-pip-cash-payments-f-zlGf4YVe>

