

# Carers' Resource – Responses to consultation on Health & Disability Green Paper

## 1.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 fundamentally disagree with this proposal. Carers, and those they care for, know that the same condition can have a very different impact on different people.

Equally, the same condition can affect the same individual very differently at different times, especially if it is a condition that is known to deteriorate.

This would result in a league table of qualifying conditions with fixed entitlements and not reflect the disability-related costs of individual PIP claimants.

# 2.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?

If this is the only criterion, it will bar support for those who have a disabling condition that has yet to be medically identified.

<u>Mind</u> reports that around two million people are sitting on waiting lists for mental health support.

Many of these people will be awaiting a formal diagnosis.

ADHD UK reports that waiting times for a diagnosis can be 18 months.

Requiring a formal diagnosis by a medical practitioner would inevitably impact on the NHS and delay any decisions.



# 3.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?

Again, if this is the only criterion, it will bar support for those who have a disabling condition that has yet to be medically identified.

Requiring a formal diagnosis by a medical practitioner would inevitably impact on the NHS and delay any decisions.

## 4.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?

Disagree

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

It will bar support for those who have a disabling condition that has yet to be medically identified.

Requiring a formal diagnosis by a medical practitioner would inevitably impact on the NHS and delay any decisions.

## 6.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.

This would inevitably impact the NHS. Either medical experts would be diverted from caring for patients because they had benefit claims to deal with, or they simply wouldn't prioritise benefits applications, and claimants would wait many months for the necessary evidence.

It would harm patients, further demoralise NHS staff and impact on waiting times and disadvantage PIP claimants.

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



#### Disagree

#### 8. 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

Eligibility for PIP should not be based on conditions but on the functional impact of the condition on the person's life.

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

Aids and appliances are perfectly reasonable indicators, the usage of which should not change.

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

Prompting is a very good indicator and was successful used for Disability Living Allowance and then for PIP itself. It is a good indicator because it is one which has been used successfully for PIP since the benefit was introduced.

#### 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?

This is an unanswerable question. Someone who scores low points across a range of activities may struggle with virtually every aspect of daily living and therefore have considerable costs spread over numerous activities. Someone who scores highly for just one activity may have considerable costs just for that single activity.

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



No.

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

No.

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

No. The only way to add new activities would be by co-producing the entire application system with Disabled people and carers, alongside a thorough evidenced review.

## 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?

Yes, because they are providing additional support to millions of people and any changes are likely to be aimed at reducing that support.

**Q16.** The qualifying period works effectively as it is and does not need changing.

# 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?

The qualifying period works effectively as it is and does not need changing.

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? Please rank the following options in your order of importance (with 1 being the most important and 10 being the least important). *Please drag and drop the answers to rank them*.

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



It is offensive for the DWP to produce a questionnaire which asks us to decide between food, medication, heating and other vital costs that Disabled people have to make.

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

A catalogue/ shop scheme Benefits Disadvantages Other

This is unacceptable. It takes away the independence and autonomy for Disabled people to decide what to spend their cash PIP benefit payments on.

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

A voucher scheme Benefits Disadvantages Other

This is unacceptable. It takes away the independence and autonomy for Disabled people to decide what to spend their cash PIP benefit payments on.

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

A receipt-based system Benefits Disadvantages Other

This is unacceptable. It takes away the independence and autonomy for Disabled people to decide what to spend their cash PIP benefit payments on.



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

One-off grants Benefits Disadvantages

This is unacceptable. It takes away the independence and autonomy for Disabled people to decide what to spend their cash PIP benefit payments on.

# 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 don't see any reason to change to an alternative method. There no suggestions given so it is impossible to understand the goal of this question. Any future changes to the PIP system must be co-produced with Disabled people and carers.

# 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?

Additional eligibility criteria may exist, but these would need to be the subject of co-production with Disabled people and carers.

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)?

There are undoubtedly people whose needs are not being met, but these would need to be in addition to current provision and involve co-production with Disabled people and carers.



# 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)?

No. Access to support or treatment should already be available from the NHS or local authority, regardless of whether you are a PIP claimant or not.

## 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?

It is not possible to answer this question.

Q29. In relation to Question 28, please explain your answer and provide evidence or your opinion to support further development of our approach The experience of a Disabled person in regard to the support they receive from local authorities and the NHS will vary from authority and health trust. We know that both bodies are already massively underfunded and require much more investment to deliver high-quality services.

#### Q30 – Q31. Which of the following do local authorities or the NHS help with?

- Equipment and aids
- Medical products
- Personal assistance (eg. help with household tasks)
- Health services
- Social care
- Respite
- Transport
- Utility costs
- Other

Support levels and quality vary greatly between different NHS regions and local authorities. So, it is not possible to accurately answer.

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



- Equipment and aids
- Medical products
- Personal assistance (eg. help with household tasks)
- Health services
- Social care
- Respite
- Transport
- Utility costs
- Other

Support levels and quality vary greatly between different NHS regions and local authorities. So, it is not possible to accurately answer.

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

Local authorities and NHS trusts are already overwhelmed by costs and do not have the resources to take on additional provision.

Individuals should be able to decide their own priorities and have the resources, via cash payments of PIP, to meet them.

## 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

There is no evidence to show this would improve things for disabled people and people with health conditions.

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

There is no way to rank which services are most important.

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



None. The goal of PIP is to allows individuals to decide their own priorities via the cash payments they receive. This should not change.

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

We don't believe that there should be any attempt to align PIP with local authority and NHS services as they are so variable around the country.

**Compulsory question Q39. Are you an individual or an organisation supporting claimants applying for PIP?** We advise and support carers of claimants applying for PIP.