Department
for Work &
Pensions

Modernising Support for Independent Living - Consultation Response Overview

18th July 2024

Overview of Green Paper

Personal Independence Payment (PIP) is intended to provide cash support to help people with the extra costs of their disability or health condition. There are challenges around whether PIP remains fit for purpose, supports the best outcomes for disabled people and provides value for money for the taxpayer.

The Green Paper is guided by three priorities:

Providing the right support to the people who need it most

Targeting our resources most effectively

Supporting disabled people to reach their full potential and live independently

Consultation responses sample

- The consultation includes 39 questions, 32 of which are open-ended, across 4 chapters. To date, we have received 9,700 responses. Following a review of a sample of 350 individual responses, there are several initial high-level insights. The very first 350 consultation responses were not used for this sample as many of the initial responses do not provide as much detail as responses provided at a later date. Instead, 300 responses within response numbers 1,500-2,000 and a further 50 responses from response numbers 4,850-4,900 were used.

- Please note that as most of the consultation questions (32 of the 39) are open ended, as opposed to being ‘Agree’ / ‘Disagree’ type questions, the most common themes have been captured throughout the responses, rather than the proportion of people that either agree or disagree to a certain idea or policy. Therefore, for many responses there is often more than one theme raised by the respondent.

High level key messages by chapter

Chapter 1 - Overall views on a condition-based assessment are negative. There is some positivity towards a severe disability group passported straight to PIP with serious conditions. Mandating evidence was met with a mixed response.

Chapter 2 - The overall response to amending PIP eligibility was mixed across the various proposals.

Chapter 3 - The most common sentiment associated with moving PIP to a new system focused on either a catalogue, voucher, receipt or one-off grant was negative.

Chapter 4 - The overall response to aligning services was negative, due to the current strains already placed on the system. There was some positivity that localising could reduce the assessment burden.

Chapter 1 overview

Chapter 1 of the GP focusses on reforming the PIP assessment to align more with a person's diagnosis:

"We want to understand if evidence of a clinical diagnosis made by a healthcare professional could provide a more objective assessment of need than the current functional assessment. This would mean that people could receive entitlement to PIP based on specific health conditions or disability, evidenced by a health care professional, without undergoing an assessment."

The GP also asks whether we should consider a new or hybrid approach based entirely or partly on the diagnosis given to an individual.

Chapter 1 responses

Question	Response
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?	There was strong sentiment against placing more emphasis on condition for assessments. The most common theme, highlighted in 51% of responses, was that the impact of a condition varies for each person and that there is no one-size fits all approach to a conditions-based assessment.
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?	Sentiment was broadly positive towards people receiving PIP without an assessment if they have specific health conditions or a disability as evidenced by a healthcare professional . The most common theme, in 35% of responses, was that it made sense to remove assessments for people with specific conditions or disabilities if there was an appropriate health care professional available for diagnosis and there is appropriate evidence in place. The second most common theme recorded in 27% of responses, was also in favour of this change, but only for specific and life-long conditions. However, another common theme, raised in 20% of responses, was that both diagnosis and functional impact are important factors to take into consideration, rather than just condition.
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?	Most common response is 49% agree for specific conditions and if person is not likely to get better.
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	When asked if making the provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP, 44% of responses agreed and 44% disagreed. 12% did not know.

Chapter 1 responses

Question	Response
Q5. In relation to Question 4, please explain your answer and provide evidence or your opinion to support further development of our approach.	Most common theme 42% is consideration should be evidence based, was some surprise we were asking this question. Highlight risk of missing people who are misdiagnosesd (29%). Some people also felt if we did this would push up NHS waiting times (19%).
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.	Most common theme is a provide access to medical records (42%). Second most is 23% say increase NHS support and funding. 18% thought it is not possible and would put a strain on the NHS.
Q7. Do you agree or disagree that eligibility for PIP should be based more on condition? • Agree • Disagree • Don't know	44% of responses disagreed that eligibility for PIP should be based more on condition while 35% agreed. 20% said they didn't know.
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.	This has been hard to analyse. Split into fluctuation. severity, potential cures. Some mentioned no reference to the words in the question but mentioned that medical evidence could be used to categorise conditions. Most common but generic. 11% for conditions that could be cured could assess eligiblity based on treatment impact and current support.

We also received a response from the **DBC**. They state:

• We understand the attraction of getting away from the notoriously inconsistent and too often inadequate functional assessments. However, we see a move to a more clinical approach, based on the condition diagnosed, as inconsistent with the social model of disability.

•There is merit in a “Severe Disability Group” and in fast-tracking of claims where a condition is such that a functional assessment would be inappropriate or pointless, but other than that, we believe that the answer must lie in markedly improving the quality and relevance of assessments – something that a more substantial and constructive review would address.

Marie Curie also state:

- While Marie Curie supports the Special Rules for End of Life providing automatic entitlement, it is important that this is not replaced with a condition-specific automatic entitlement to PIP

Chapter 1 discussion

Chapter 2 overview

- Chapter 2 of the Green Paper considers options for amending PIP eligibility within the current functional assessment framework. Broadly, there are five different work strands within chapter 2:

General re-writing: Includes re-writing, removing and merging activities

Specific changes: Includes halving or removing points for aids and appliances and prompting descriptors

Thresholds: Includes raising thresholds for standard and enhanced daily living component by 2 of 4 points and introducing an eligibility requirement to score 4 points or more in one activity.

Qualifying Period: Extending/removing/changing the qualifying period and or/prospective test.

Chapter 2 responses

Question	Response
Q9. Do you think the need for an aid or appliance is a good/bad indicator of extra ongoing costs and why?	• 24% of responses said that A&A are a good indicator because they can be expensive to buy, repair and replace • 18% of responses highlighted that they are a bad indicator because not all aids and appliances incur ongoing costs and some conditions do not require an aid or appliance. • Disability Rights UK: "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?	• 30% of responses said that prompting is a good indicator of extra costs as the need for prompting has several costs associated with it, such as the need for support from a carer. • 5% of responses said that prompting is not applicable for every support need, such as invisible conditions, and is not the only way to determine the need for extra ongoing costs. • 25% were a nil response. • Disability Rights UK: "Prompting is a very good indicator ...It is worrying that it is being so now as a consideration of how to reduce PIP eligibility. "
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?	• 27% of responses said that an individual's needs are person-specific and where one person may need more assistance in one activity, others may not and there should not be generalisations made on this topic. • 20% of responses, were 'Yes', with no rationale provided. • Disability Rights UK: "We fear this question is designed to provide justification for removing low scoring descriptors and so reducing the cost of PIP."
Q12. Do you think any of the PIP activities measure similar functions and could be merged?	• 13% of responses were yes but did not provide rationale.31% of responses were no but no rationale was provided • 5% said yes to merging specific or proposed suggestions • 32% were a nil response.
Q13. Do you think any of the PIP activities should be removed or re-written and why?	• 25% of responses said no changes were needed • 23% of responses said the descriptors and activities could be improved. • 27% of responses were a nil response. • Disability Rights UK: "Any meaningful or valid reforms cannot be considered in the absence of the active engagement by Disabled people and our organisations. Any future changes to the PIP system must be co-produced with Disabled people."

Chapter 2 responses

Question	Response
Q14. Should we consider adding any new activities? If so, which activities should be added and why?	• 8% said personal assistance should be considered, including activities on personal care, housework, social skills • 11% said there should be more activities to assess mental health and cognitive impairments • 10% said no, there are already enough activities or don't want to overcomplicate it • 36% were a nil response. • Disability Rights UK: "The only way to add new activities would be by co-producing the entire application system with Disabled people, 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?	• 28% of responses said that the current threshold levels are set at the right level, but with no specific or common reason recorded. • 13% and 12% of responses, respectively, said that current levels are not set at the right level, with no specific or common reason provided, and that thresholds are too high and should be lowered. • 28% were a nil response. • Disability Rights UK: "Yes, because they are providing additional support to millions of people and any changes are likely to be aimed at reducing that support."
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?	• 34% of responses said that the qualifying period should not change • 27% of responses said that the qualifying period should be condition-based, with some conditions being exempt from this period. • 12% of responses said it should change, this included reducing the qualifying period to between 1-2 months whole some said the qualifying period should be increased. • Disability Rights UK: "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?	• 23% of responses said the prospective test period should not change. • 16% of responses said the prospective test should be based on condition. • 28% were a nil response.

Chapter 2 discussion

Chapter 3 Overview

- Some people on PIP may have relatively small one-off or ongoing additional costs related to their disability fully covered by their award while others may find the current system doesn't provide enough support to meet their needs.

- We want to consider whether supporting people through direct, regular cash payments is still the best approach or whether alternative approaches would support people who need it most.

Alternative models in scope:

Catalogue/shop system – an approved list from which disabled people could choose items at reduced or no cost.

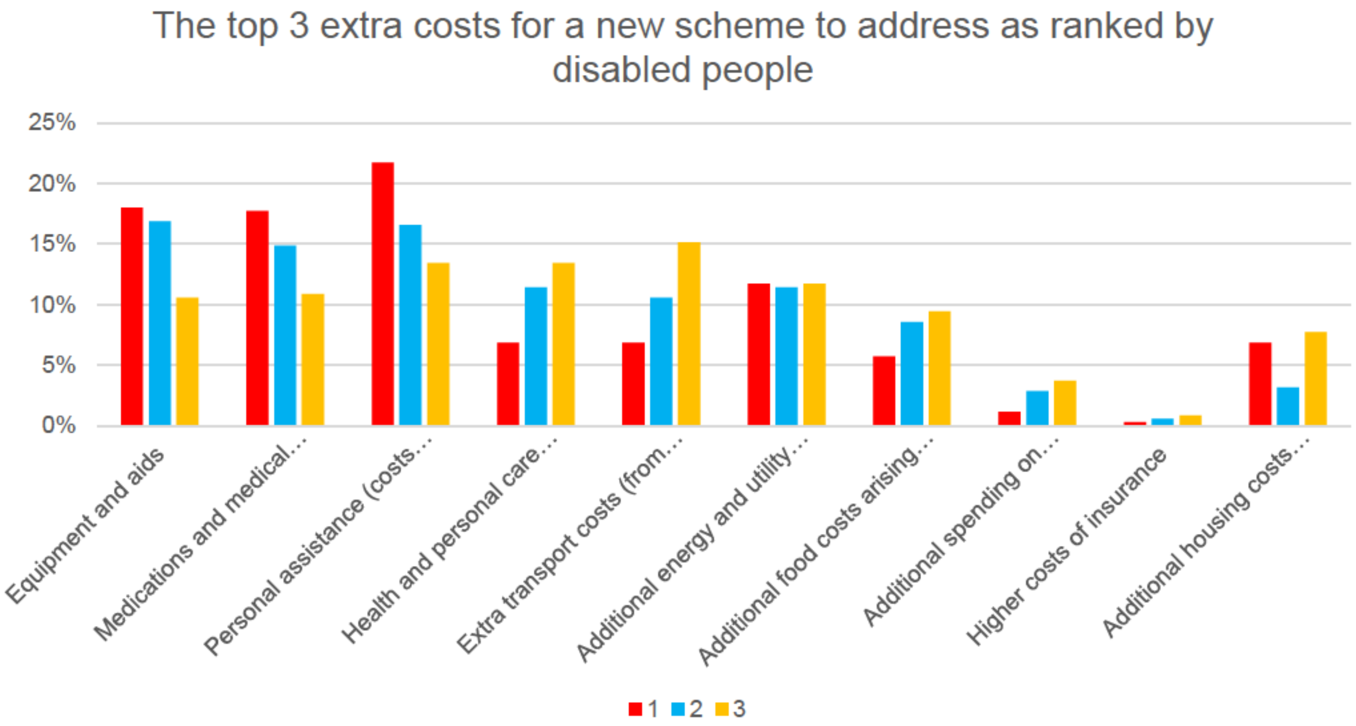
Voucher scheme – disabled people could receive vouchers to contribute/meet their costs

Receipts based system – claimants buying aids, appliances or services themselves and then providing proof of their purchase

One-off grants – these could contribute towards significant costs such as home adaptations or expensive equipment

Chapter 3 responses

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.



Chapter 3 responses

Question	Response
Q19. In relation to Question 18, please explain your answer below and tell us about any other important kinds of cost not listed above.	There were so many points raised and so many extra costs to choose from in Q18 that it is not feasible to draw specific themes related to each of the 10 extra costs. Quotes include "Many disabled people need to employ someone to help them with day to day living and the extra cost of getting around e.g taxi fares" "in rural areas where there is little or no public transport there needs to be some kind of taxi voucher scheme and discounted movie phone and internet services to allow for online shopping" "My disabilities are both physical and mental. I cannot take public transport due to also being immunocompromised and due to disabilities. I therefore need transportation, walking aids and assistance to keep me safe. My conditions also mean I need to have our rented home heated all year round so our energy bills have increased significantly, as have food costs for my specific dietary needs"
Q20. What are the benefits and disadvantages of moving to a new system for PIP claimants? A catalogue/shop scheme	31% of responses stated that there are no benefits to this change and that the current PIP system should remain in place. Quotes include: "people should be able to access any product not just from a catalogue" and " what can you put in a catalogue for someone suffering from severe depression or bipolar disorder?"
Q21. What are the benefits and disadvantages of moving to a new system for PIP claimants? A voucher scheme	38% of responses stated that a voucher scheme lacks flexibility and are more complex to understand and use. Quotes include "a voucher scheme is an awful idea. It would reduce flexibility and choice" and "wouldn't cover all our needs"
Q22. What are the benefits and disadvantages of moving to a new system for PIP claimants? A receipt-based system	• 24% were concerned about the complexity and administrative burden • 23% said there was a financial disadvantage to paying upfront cost prior to being reimbursed/ reduction in choice/ no benefits to this change
Q23. What are the benefits and disadvantages of moving to a new system for PIP claimants? One-off grants	• 33% said that one-off grants would not be suitable for ongoing costs • *"No benefits. Prices of food, fuel etc increase all the time, and are an ongoing expense."* • 15% said that one-off grants are suitable for some / short-term needs, particularly home adaptations or larger/expensive items

Chapter 3 responses

Question	Response
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	• 26% said that medical evidence, or proof from a doctor or medical expert could be used • 30% didn't understand the question or did not respond
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?	• 20% said that medical evidence, or proof from a doctor or medical expert could be used • 39% didn't understand the question or did not respond • DBC have advised the restriction of access to PIP would also reduce the number of disabled people accessing the health element of UC proposed in the White Paper. The abolition of PIP would undo that mechanism altogether
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)?	• 25% said that additional mental health support was required • 26% said that improved general treatment or support services e.g., reducing NHS waiting times was required • "Properly funding mental health services and growing the mental health workforce so that people can get the support they need without long delays would be a good place to start" - DBC
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)?	• 18% said that cash payments should be in addition to further support • 15% highlighted that those with mental health conditions would benefit from improved support rather than cash payments. • DBC rejected the idea that health and social care services could act as substitution for a cash benefit

Chapter 3 discussion

Chapter 4 overview

- We wanted to explore how to better align existing services and support available to disabled people locally with the support currently offered by PIP.
- Through the consultation responses we hoped to understand whether aligning the services could enhance the support offered, whilst reducing the assessment burden on individuals.

Overview of questions

- Do people already receive **support from their LA or NHS** with the needs or costs arising from their health condition or disability. Further detail around, who and what support is provided.
- Would aligning existing local support and PIP improve outcomes for disabled people.
- Would this **reduce the assessment burden** and duplication across systems.
- What **capacity** would be needed to better align PIP with LA and NHS services.
- What services/support provided by the community are the most important.

Consultation Responses overview

- On whether p**eople already receive support from their LA or NHS** with the needs or costs arising from their health condition or disability. **51%** of responses answered **'No' (vs 27% 'Yes')**
- The **types of support** people receive from their LA or NHS the majority of responses said **equipment and aids**, **medical products, health service and social care** (Q30). When asked which of the services/support provided by the community are the **most important** (Q36) respondents highlighted 'personal assistance, carer services and **social care** as well as targeted **services that address specific health conditions and disabilities**, such as mental health, autism and behavioural conditions'
- On **aligning PIP support** within local authorities and the NHS, **general sentiment was negative**. For example, when asked how conditions could improve for disabled people and people with health conditions if support offered by PIP was aligned into existing local authority or NHS services (Q34), the most common theme was **scepticism** and recorded within **24%** of responses. This theme relates to the negative impact this would have due to current system limitations in relation to funding, waiting times and an inability to absorb further demand from support alignment.
- When asked if respondents thought 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 (Q 35). The response provided was mixed, in **15% of responses 'No**' with no reason provided. Another common theme, within **12%** of responses, was that alignment would **exacerbate existing strains on assessment capacity** and waiting times, **13% of responses answered 'Yes**', but with no detail provided. **11% of responses, was 'maybe/possibly reduce assessments**' if certain items/priorities were in place, such as the sharing of health data, correct staffing levels, correct funding levels / based on condition. A large number of responses 28% answered 'not relevant/unsure'.

Chapter 4 responses

Question	Responses		
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?	**51%** of responses answered **'No' (vs 27% 'Yes')**		
Q30. Which of the following do local authorities or the NHS help with? (Q31 expand response) • Equipment and aids • Medical products • Personal assistance (eg. help with household tasks) • Health services • Social care • Respite • Transport • Utility costs • Other	Equipment and aids	191	20%
	Medical products	160	17%
	Personal assistance (e.g., help with household tasks)	83	9%
	Health services	154	16%
	Social care	132	14%
	Respite	76	8%
	Transport	82	9%
	Utility Costs	32	3%
	Other	46	5%
Q32. Which needs/costs that come with having a disability or health condition could local areas help with further? (Q33 expand on response) • Equipment and aids • Medical products • Personal assistance (eg. help with household tasks) • Health services • Social care • Respite • Transport • Utility costs • Other	Equipment and aids	152	12%
	Medical products	127	10%
	Personal assistance (e.g., help with household tasks)	178	14%
	Health services	139	11%
	Utility Costs	162	12%
	Transport	179	14%
	Respite	149	11%
	Social care	161	12%
	Other	55	4%

Chapter 4 Responses

Question	Responses
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?	On **aligning PIP support** within local authorities and the NHS, general sentiment was **negative.** The most common theme was **scepticism** and recorded within **24%** of responses. This theme relates to the negative impact this would have due to current system limitations in relation to funding, waiting times and an inability to absorb further demand from support alignment.
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?	The response provided was mixed, in **15% of responses 'No**' with no reason provided. **12%** of responses alignment would **exacerbate existing strains on assessment capacity** and waiting times, **13% of responses answered 'Yes**', but with no detail provided. **11% of responses, was 'maybe/possibly reduce assessments**' if certain items/priorities were in place, such as the sharing of health data, correct staffing levels, correct funding levels / based on condition. A large number of responses **28% answered 'not relevant/unsure**'.
Q36. What disability support services in your community are the most important services or support to deliver?	Respondents highlighted 'personal assistance, carer services and **social care** as well as targeted **services that address specific health conditions and disabilities**, such as mental health, autism and behavioural conditions' *'Mental health hubs, staffed by qualified professionals, not volunteers, available 24hrs a day, 7 days a week.* *'For my daugher it is her social care package which enables her to lead as independent a life as she is able to. She leads a full and happy life in her supported living home but this can only happen with a suitable care package.'*
Q37. How much flexibility should local areas have to decide their priorities in supporting people with disabilities and health conditions?	
Q38. What capacity and capability would be required to better align PIP with local authority and NHS services?	

Chapter 4 discussion