Department
for Work &
Pensions

To: **1. Minister for Social Security and Disability**

2. Secretary of State

From: [redacted]

SCS Clearance: [redacted]
[redacted]

Date: 16 August 2024

[redacted] [redacted]

Charities and Organisations Green Paper Response Summary

Summary

1. Following advice provided on the 9 August regarding the next steps on the Personal Independence Payment (PIP) Green Paper consultation and analysis of 1,600 individual responses, this submission provides the headlines and a detailed review of 25 influential charity and professional organisation responses for you to consider.

2. The review provides sentiment analysis, key themes, policy recommendations and policy red-lines, together with quotes from charities and organisations. The list of the 25 organisations is included in Annex B, with the detailed review of their responses in Annex C.

Recommendation

3. That you note the views and sentiments provided by 25 charities and organisations for the PIP Green Paper Consultation in Annex C.

Background

4. The PIP consultation included 39 questions, across 4 chapters, of which 32 were open and 7 closed. We have received a total of 115 responses via email and post from disability charities and organisations. Responses varied in length and depth, the longest being 41 pages.

5. Given the volume of charity, DPOs and other organisation responses received, the vast majority of which were submitted in the final days of the consultation, we include a summary of the most influential 25 in this submission and will provide a full summary of the 115 responses during the w/c 26 August. [redacted] [redacted]. We can provide any organisational response you wish to review.

Key Information

Review of 25 charity and organisation responses – main headlines

6. Chapter 1 explored the potential for making changes to the PIP assessment by introducing an alternative assessment model. The overall sentiment was negative: charities and organisations are largely against moving to an assessment that places more emphasis on condition than functional impact, suggesting that everyone's condition impacts them in different ways. We also heard that a condition-based approach would move away from the Social Model of Disability, which posits that people are disabled by barriers in society, not by their impairment or difference. However, most charities and organisations supported not doing award reviews for people claiming PIP who have a long-term health condition that is unlikely to improve, suggesting these were unnecessary and amplify stress levels.

7. Chapter 2 explored retaining the current PIP assessment but making changes to the PIP eligibility criteria, including whether changes should be made to activities, descriptors, entitlement thresholds and qualifying periods. There were mixed views on this chapter, for example, disability groups with members that rely on aids/appliances/prompting see this as evidence of ongoing costs. Whereas some disability groups opposed this, arguing that some health conditions may not require aids/appliances/prompting but still encounter additional costs. On entitlement thresholds, most responses highlighted that they are currently too high and on qualifying periods, most responses were in favour of maintaining the status quo.

8. Chapter 3 explored whether DWP should find alternative ways to contribute to the extra costs and needs of people claiming PIP, rather than a cash award. The overall sentiment to these options was negative. Reasons for this include that disabled people should be able to choose freely what they spend their PIP award on and that removing choice on how to spend an award reduces people's autonomy and suggests a lack of trust by DWP. In addition, it was suggested that such a change could push people further into poverty as people claiming PIP tend to pool their PIP award with the rest of their household income to pay bills.

9. Chapter 4 explored whether we should align the support offered by PIP with existing health, care and other local authority provision for disabled people and people with health conditions. Responses consistently highlighted concerns that the NHS and local authorities are currently underfunded and overstretched, and that closer alignment would exacerbate these issues. It was felt that giving local areas flexibility to decide their priorities could lead to funds and resources being reallocated elsewhere – missing the intended purpose. There were also concerns raised around the potential for diverging levels of support in meeting the needs of disabled people, regarded as a post-code lottery.

Next Steps

10. We will provide a full summary, which includes all 115 responses, during the week commencing 26 August.

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5.10 [redacted]

Annex B: Charities and organisations reviewed as part of this submission

List of charities and organisations that were reviewed for the purpose of drafting this document.

British Association for Counselling and Psychotherapy	National Association of Welfare Rights Advisers
British Sign Language (BSL) Advisory Board	Peabody Housing Trust
Business Services Association	Pulmonary Hypertension Association (PHA UK)
Central England Law Centre	RNIB (Royal National Institute of Blind People)
Child Poverty Action Group with input from Changing Realities	RNID (Royal National Institute for Deaf People)
Diabetes UK	Royal College of Occupational Therapists
Disability Benefits Consortium	Royal College of Psychiatrists
Disability Rights UK	Scope
Law Centre Northern Ireland	Sense
Marie Curie	Society of Occupational Medicine
Mencap	Sport England
Mind	Trades Union Congress (TUC)
Multiple Sclerosis Society (MS Society)	

Annex C: Review of 25 charity and organisation responses

Chapter 1 – Overview and assessment reform

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?

Of the 16 responses to this question, 15 were negative and 1 was neutral towards placing more emphasis on condition. Reasons include that people's health conditions can impact them in different ways and would provide limited information on the specific barriers someone faces. Therefore, assessments should continue to measure the functional impact of conditions on the lives of people who make PIP claims.

- *"MS is a progressive, complex and highly variable condition, which affects different people in different ways over time. Moving to a condition-based approach would therefore make the current situation much worse for our community. It has a much higher chance that people would not get the right support or would exclude them from support entirely."* - **Multiple Sclerosis Trust (MS Society)**
- *"We understand the attraction of getting away from the notoriously inconsistent and too often inadequate functional assessments that are currently used to determine PIP entitlement. However, we see a move to a more clinical approach, based on the condition diagnosed, as inconsistent with the social model of disability."* **- Disability Benefits Consortium**
- "*We have significant concerns that this could unfairly restrict eligibility to PIP for some blind and partially sighted people despite facing additional costs due to sight loss…Placing greater emphasis on a condition in the PIP assessment risks unfairly excluding people who need support and face extra costs but do not have a CVI [certification of a visual impairment].*" – **The Royal National Institute of Blind People (RNIB)**

Red lines:

- Moving to a condition-based assessment would move the PIP assessment further away from the social model of disability, which posits that people are disabled by barriers in society, not by their impairment or difference. – **Mencap, Scope, MS Society**
- *"It could only result in a league table of qualifying conditions with fixed entitlements and not reflect the disability-related costs of individual PIP claimants."* – **Disability Rights UK**

Recommendations:

- **Scope** recommends the Government invest the money needed to employ appropriate specialist assessors who truly evaluate the needs and extra costs faced by disabled people based on their circumstances. This must be a fair, professional assessment instead of just an acknowledgement of their condition.
- Several responses including from **Society of Occupational Medicine, RNIB, and the Royal College of Occupational Therapists, and Mencap** strongly

felt that assessments should continue to primarily explore the functional impact of conditions, rather than the diagnosis itself.

In addition, 9 organisations of the 10 that responded to this question disagreed that eligibility for PIP should be based more on condition **(Question 7 - Do you agree or disagree that eligibility for PIP should be based more on condition?)**, while 1 was neutral.

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?

Responses to this question were mixed. Of the 13 responses, 5 were positive, 4 were negative and 4 were neutral. Key points included that not having an assessment would reduce the burden and stress on people claiming PIP and that the current health assessments fail to consider the full impact of a claimant's health condition. While this approach may have benefits and eliminate assessments, there were concerns around healthcare professionals' capacity to provide evidence and long waiting lists to see one.

Mind welcome this as an extra route to receiving PIP for people with mental health problems with less common diagnoses being able to receive PIP without an assessment.

- *"Whilst evidence from a Health Care Professional would be ideal, it is not always possible, and you should be mindful that a reliance on specialist input can create demand for referrals…"* – **Peabody Housing Trust**
- *"When addressing diagnoses for mental health it can be very moveable feast! A patient might present one set of symptoms; fitting one diagnosis at one assessment, then different symptoms meriting a different diagnosis at a second. People make recoveries then relapse into different symptomatology."* - **National Association of Welfare Rights Advisers**

Red lines:

- This approach would put significant pressure both in terms of time and resource on healthcare professionals with specialist input – **Peabody Housing Trust and MS Society**
- *"…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."* – **Marie Curie**

Recommendations:

- There should be measures to simplify the assessment process and make this more accessible to disabled people **– Sport England**
- Using evidence from professionals or individuals who know the claimant best such as nurses, support workers and carers would be more useful. – **National Association of Welfare Rights Advisers**

- *"However, we are supportive of the process which reduces the number of people who have to go through an assessment, due to how stressful and detrimental these can be to people's mental health."* - **Mind**
- *"It is our view that there should be an aim to increase the level of paper-based reviews, supported by better access to and consideration of medical evidence."* – **Law Centre Northern Ireland**

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?

Of the 12 responses, 10 were positive, 1 negative and 1 neutral. There was strong sentiment for people being exempted from award reviews when the impact of a lifelong condition is unlikely to change. Having to regularly undergo assessments for PIP can be a significant cause of distress for a person and removing this will help them. However, there were suggestions that this may not work as the same condition may have totally different symptoms and there are questions as to whether or not the healthcare system has the capacity to support assessments and award reviews.

- "*Repeat reviews are just an administrative cost for the DWP and a source of great fear for claimants. Where a condition has no known cure and is likely to become progressively worse, it seems pointless to target resources at this*." - **Peabody Housing Trust**
- *"People with a learning disability and their families often tell us that it is the prospect of perpetual review and reassessment that proves most tiresome, repetitious, anxiety inducing and in the worst cases, harmful. Therefore, there is merit in people being exempted from award reviews when the impact of a lifelong, unchanging condition is unlikely to change."* – **Mencap**

Red lines:

- This approach would put significant pressure both in terms of time and resource on healthcare professionals with specialist input – **Peabody Housing Trust and MS Society**
- *"Strongly recommend that the DWP find ways to reduce the number of reassessments for PIP and reassessments should be less frequent."* - **Mind**
- Obtaining evidence of an MS diagnosis, or of a particular form of MS, is very limited in what it can tell us about the specific barriers an individual faces. *"We don't believe this proposal is practical for people with MS."* – **MS Society**

Recommendations:

- *"DWP should make sure those on the highest rates get lifetime awards and are not subjected to distressing and unnecessary award reviews."* – **MS Society**
- *"Where a condition has no known cure and is likely to become progressively worse, it seems pointless to target resources at cases that would likely be unchanged."* – **Peabody Housing Trust**

- *"We strongly recommend that the Department for Work and Pensions find ways to reduce the number of reassessments for PIP. Reassessments for everyone receiving PIP should be less frequent."* – **Mind**
- *"CELC would be supportive of this proposal for those with congenital, degenerative and lifelong health conditions and disabilities, if the list of prescribed conditions was sufficiently expansive and inclusive."* - **Central England Law Centre**

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?

Of the 12 responses, 11 disagreed and 1 responded 'Don't know'. Reasons for this view **(Question 5)** include that many people claiming PIP will be at a huge disadvantage as they may be unable to obtain medical evidence or a medical diagnosis. Furthermore, charities and organisations representing people claiming PIP with visual and hearing impairments as well as mental health will be at a huge disadvantage compared to other disability groups.

- *"People with mental health problems face significant barriers in receiving a diagnosis or seeing a medical expert, due to long-term underinvestment in mental health services. This could leave people with mental health problems at a significant disadvantage compared to other health problems when applying for PIP."* **– Mind**
- *"Disagree, this will bar support for those who have a disabling condition that has yet to be medically identified. Mind reports that around two million people are sitting on waiting lists for mental health support."* – ***Disability Rights UK***
- *"Firstly, it will massively slow down access to PIP for new claimants. Secondly, it risks removing eligibility for existing PIP claimants if they do not already have a diagnosis. Thirdly, it further medicalises the assessment process."* **– *Scope***

Red lines:

- The same diagnosis can range in severity and impact people differently. Relying entirely on condition would result in unfairness – not all conditions are diagnosed yet can be very disabling – flexibility must be maintained - **National Association of Welfare Rights Advisers**
- *"Making a formal diagnosis a requirement for eligibility for PIP would therefore mean that some disabled people with significant barriers to independent living would miss out on vital support with their extra costs."* – **Sense**
- ***Mind*** strongly disagree with making provision of evidence or a formal diagnosis by a medical expert a mandatory requirement for eligibility for PIP. This could leave people with mental health problems at a significant disadvantage compared to other health problems.
- *"According to Sense polling [1000 people with complex disabilities in receipt of benefits between 24 May and 30 May 2024], were polled half of people with complex disabilities on PIP found it difficult to provide medical evidence of their condition or impairment."* - **Sense**

Recommendations:

- *"With long NHS waiting lists and not everyone with sight loss able to access a diagnosis, we feel strongly that an objective functional assessment for PIP must remain."* – **RNIB**

Chapter 2 – Eligibility Reform

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

Of the 11 responses to this question, 7 were positive and 4 were negative. There was agreement from many organisations that while they are a useful indicator of extra costs, aids and appliances cannot in themselves be deemed solely determinative of the costs of disability. Reasons given included that aids and appliances apply mainly to physical restrictions and that individual needs vary greatly. Also, that the costs of aids and appliances can present a financial burden for disabled people and people with long term health conditions.

- *"The cost of aids and appliances can present a financial burden for disabled people and people with long term health conditions. Additionally, it can be an indicator that they face greater in-tangible living costs due to barriers in accessing services and products with or without their aid."* – **Royal National Institute for Deaf People (RNID)**
- **"***Mental health problems must be taken as seriously as physical health problems. The need for an aid or appliance can be a good indicator of extra ongoing costs, but it could not be used as the only indicator, as people with mental health problems are more likely to face costs that do not fall under this category."* **– Mind**
- *"As the barriers to independent living disabled people face vary from person to person, no single indicator in an assessment could ever capture all of the extra costs faced by a disabled person."* - **Sense**
- *"Some aids are likely to incur ongoing costs and others not. The need of aids or appliances suggest functional limitation but the type of restriction they are supporting can vary widely."* - **Society of Occupational Medicine**

Red lines:

- Aids and appliances cannot in themselves be deemed solely determinative of disability costs as they tend to focus on mobility impairments. There are also ongoing costs, such as utility bills, that are not accounted for within aids and appliances. - **Multiple organisations, including Multiple Sclerosis Trust**

Recommendations:

- The **Society of Occupational Medicine** recommended the need for an aid or appliance "*should be used in conjunction with other markers"* because *"the current PIP assessment criteria focuses on specific activities and the aids needed for those, however engagement in day to day life and challenges that are faced from the reason for the restriction can be much more widespread."*

- *"Improving DWP PIP Guidance by having more worked examples which relate to how the descriptors may apply to blind and partially sighted people and the factors stated under PIP regulation…"* - **RNIB**
- *"It would be helpful to place extra costs in the context of disabled people's financial wellbeing more generally. For disabled people, and particularly people with complex disabilities, benefits should cover the extra essential costs they face."* - **Sense**

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

Of the 9 responses, 7 agreed that prompting was a good indicator of extra costs and 2 disagreed. Charities and organisations particularly raised the importance of prompting as a descriptor for those with learning disability, with mental health conditions or who were blind or partially sighted. The importance of viewing prompting alongside other descriptors to determine someone's functional ability was raised across the board by those who agreed and disagreed that prompting is a good indicator.

- "*The need for prompting means the individual might struggle to carry out activities themselves. This then incurs extra costs as they will have to pay for support, which may mean paying an individual or a service to help them.*" - **Mind**
- **Disability Rights UK** highlighted the importance of prompting for safety *"Without prompting and encouragement some Disabled people would be in danger of self-neglect and harm"* and the **RNIB** stated that prompting *"is a good indicator of extra ongoing costs for blind and partially sighted people."*
- However, **Society of Occupational Medicine** mentioned current practice should be improved on and that prompting should always be considered alongside other functional activities otherwise it "*might not give a full indication of function and may need to be considered alongside other factors. It may also be important to not only look at whether tasks are started but whether these can be completed and whether they are effective.*"
- **Central England Law Centre** also reiterated this stating prompting *"cannot be deemed solely determinative of disability costs because the type of expenses disabled people encounter as a result of their disabilities vary considerably."*

Red lines:

- *"We believe it's reductive to generalise whether using an aid or appliance, or having the need for 'prompting', are 'good' or 'bad' indicators of extra ongoing costs."* - **MS Society**
- As the barriers to independent living disabled people face vary from person to person, no single indicator in an assessment could ever capture all of the extra costs faced by a disabled person. - **Sense**

Recommendations:

- Continue to consider prompting alongside other functional indicators – **MS Society, Society of Occupational Medicine**

- Review the definition of prompting to ensure it is clearly defined - **Society of Occupational Medicine**
- Provide more worked examples of how prompting may apply to blind or partially sighted people – **RNIB**

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?

Of the 7 responses, 6 thought thresholds were set too high or were generally negative about the assessment process and 1 thought current thresholds were set at the right level. Reasons included concerns that thresholds were set too high for certain disabilities or about the quality of decision making, highlighting the high number of people claiming PIP who have their award changed on review.

- *"The current entitlement threshold levels are very high and should not be set any higher."* - **Mind**
- "*For many blind and partially sighted people the current entitlement thresholds levels are not set at the right levels to define the need for Government financial support." -* **RNIB**
- "*Deaf BSL users with (with no other long-term illnesses or conditions) currently qualify for the lower weekly rate of £72.65 if they need communication support to be able to express or understand basic verbal information, however this is not enough to cover the estimated monthly cost of communication support." -* **RNID**
- "*…has significant concerns about the quality of DWP decision-making for PIP"* with **Scope** providing evidence that "*in the three months leading up to January 2024 around a quarter (26%) of Mandatory Reconsiderations resulted in a change in award*." – **Central England Law Centre**

Red lines:

- **Scope** strongly recommended that entitlement thresholds are revised as they are set too high. Too many disabled people are rejected for PIP initially only to find on appeal that they were eligible.
- Government support is not going far enough - *"40% of disabled people with mental health problems are living in materially deprived households."*- **Mind**

Recommendations:

- To address these systemic flaws [with assessment process, given the number of changes to awards following review] Scope recommends that DWP moves to a trust-based assessment model. In the meantime, the award thresholds should be lowered to make it more attainable to access PIP – **Scope**

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?

There were 10 responses to this question, of which 7 responded that the 3-month test is fair and should not be altered, 2 had mixed views and 1 recommended removing the qualifying period entirely. Reasons included 3 months being an adequate time for the functional impact of conditions to arise with others raising the financial impact of the lengthening the qualifying period. Some responses also raised the impact of the 3-month threshold on certain conditions. There were suggestions with the qualifying period being based on an individual's condition.

- *"…for deafness, hearing loss and tinnitus it can be difficult to establish when their condition began having a functional impact and could lead to more claimants having to go to appeal instead of being awarded [support] during their initial application."* - **RNID**

Red lines:

- People need quicker access to PIP support, not slower – **RNIB**
- *"We also reject the notion that disabled people should be forced to wait 3 months to prove their condition has a functional impact… most conditions do not take 3 months to start impacting people's lives… and extra costs often begin immediately, meaning the 3-month wait time risks more and more people falling behind on their bills and going into debt."* – **Scope**
- "*…oppose measures to lengthen the qualifying period, as doing so would, in Central England Law Centre's view, drive more disabled people into poverty leaving them without the support they need for long periods.*" – **Central England Law Centre**
- *"However, it was discussed that the onset should be considered from date of symptoms as opposed to date of medical evidence as there might be some latency in terms of medical input."* - **Society of Occupational Medicine**

Recommendations:

- *"DWP should remove the qualifying period and allow disabled people to access PIP more quickly. The combination of a 3-month qualifying period and a lengthy wait from assessment to decision means many disabled people are waiting more than 6 months to access PIP."* - **Scope**
- *"The onset should be considered from date of symptoms as opposed to date of medical evidence as there might be some latency in terms of medical input."* - **Society of Occupational Medicine**
- "*Any reform of the qualifying period should also not negatively impact the Special Rules for End of Life (SREL) exemption*."[1] – **Scope**

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?

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[1] SREL means that those who have 12 months or less to live do not need to wait for the qualifying period to end before they get their first payment.

Of the 9 responses to this question, 5 were in favour of retaining the 9-month prospective test, 2 think the test should be reduced or otherwise reformed and the remaining 2 had neutral or mixed views. Some responses focused on the impact of the current prospective test for different conditions including mental health and cancer while others discussed the benefit of creating a new category for conditions which will not improve.

- "*9 months qualifying condition going forwards is useful as it shows how a condition could improve, or may improve with further treatment.*" **- Peabody Housing Trust**
- *"While we understand that it is necessary to differentiate long-term conditions and disabilities from short-term illnesses, we do not have any evidence suggesting whether the test is the best way to achieve this."* - **RNID**
- "*Some conditions, for example cancer, a person could have very severe impacts that might not last a full year but which create a great deal of need."* when considering the length of the prospective test. – **National Association of Welfare Rights**

Red lines:

- *"The prospective test period works effectively as it is and does not need changing."* - **Disability Rights UK**
- *"CELC would welcome a reduction of the nine-month prospective test used to determine eligibility for PIP."* - **Central England Law Centre**

Recommendations:

- "*…adaptability is key to supporting disabled people. The Government needs to move away from stringent criteria and towards more accommodating and flexible criteria based on specialist input and guided by disabled people. This must include reforming the prospective test.*" - **Scope**
- "*Using a shorter test of six-months would make it easier for someone to be positive about their future, while accessing the support they need.*" - **Mind**
- "*…Allow the healthcare professional conducting the assessment to advise a referral period, based on medical knowledge of the condition.*" - **Society of Occupational Medicine**
- *"RNID do think that it would be worth considering creating a new category for conditions that are not going to improve so that people will not have to be reassessed or provide evidence to meet the nine-month prospective test."* - **RNID**

Chapter 3 – What do we provide support for?

Q20-23 – What are the benefits and disadvantages of moving to a new system for PIP claimants? (Catalogue, Voucher, Receipts and One-off grants)

Due to the nature of the questions posed in chapter 3, we have grouped them together. The table below identifies the total number of responses and the sentiment of each response.

There was a largely negative response to each of the proposed delivery models. The most common sentiment was that removing a cash payment entirely and replacing it with a catalogue, voucher, receipts-based or shop-based system would remove people’s independence and autonomy to spend their PIP award freely on their extra needs and costs. Also, responses highlighted that most people combine their PIP award with their other household income to pay for energy bills and food which could mean they could not afford to pay for expenses they deem important. Respondents raised concerns that these proposals could lead to an increase in poverty.

☐	**Catalogue**	**Voucher**	**Receipts-based**	**One-off grant**
Total responses	12	15	14	12
Disagree	75% (9)	87% (13)	79% (11)	92% (11)
Neutral	25% (3)	13% (2)	21% (3)	8% (1)
Agree	0% (0)	0%	0% (0)	0% (0)

- *“Moving to an alternative scheme as suggested in the consultation such as a shop or voucher scheme, a receipt-based system or one-off grants would take away this autonomy from recipients. The majority of additional costs associated with a terminal illness are continuous and these proposed solutions do not consider these ongoing costs."* – **Marie Curie**
- *“Cash-based benefits are vital for the flexibility and autonomy needed to manage household expenses and the extra costs associated with being disabled or having a long-term condition. Financial support should empower individuals, not restrict their autonomy.”* – **Royal College of Occupational Therapists**
- *“People should be allowed to choose how they want to spend their PIP to best help themselves. They know what they need. The suggested proposals are unnecessarily bureaucratic & undermine a person's ability to make decisions about their own care & takes away their control. The freedom to choose priorities should remain with the individual or their carers. I think it would cause serious harm. Many in receipt of PIP are in poverty to begin with. How can you pay for items up front with no money?”* – **Mencap**

National Association of Welfare Rights Advisers *had the following response to this* chapter - *“In respect of the four alternative methods of support proposed, they:*

- *Revoke the autonomy of claimants and reduce PIP’s flexibility to meet the varied needs of an individual – one respondent commented ‘PIP claimants are disabled adults, not naughty children that cannot be trusted to spend their own money’;*
- *Do not empower disabled people to maintain their independence, thus undermining the policy intention behind PIP; [and they] Risk being stigmatising and humiliating, taking away people’s dignity.”*

Although responses were largely negative, there was a more neutral response from the **Society of Occupational Medicine**, for example, who stated:

- *"When discussed with the group it was felt that a catalogue or shop scheme could result in enhances with regard to cost effectiveness. It also allows approved or recommended suppliers to be used or suggested."*
- "This (a receipts-based system) would allow a lot more control for service users for example in choosing what the funds are spent on and which providers to use."

Red lines

- Removing a cash payment could push people into poverty as they won't have the money to pay for household bills. - **Child Poverty Action Group**
- Removing a cash payment removes the autonomy and independence of people to spend their PIP cash award freely. **- RNIB, Disability Rights UK**
- One-off grants won't meet the significant, ongoing extra costs that disabled people and people with health conditions face. – **RNIB**
- A receipts-based system would negatively impact people claiming PIP as some won't have the money upfront to pay for aids, appliances or services and so will mean claimants could get further into debt. – **RNID**

Recommendations:

- *"Any future changes to the support provided via PIP should focus solely on increasing the already meagre financial support given to claimants and should be co-produced with Disabled people."* – **Disability Rights UK**

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)?

There were 11 responses to this question, 9 showed a negative sentiment, 1 was neutral and 1 was mixed. The majority of the organisations highlighted that improved access to NHS support and/or treatment should be provided in addition to financial support. This is because removing a cash payment would significantly reduce the independence and autonomy of people claiming PIP.

- *"While people with mental health problems are facing inexcusable barriers to accessing mental health support, this provision is separate to PIP and should not be mixed up. Investment in mental health services cannot come at the expense of financial support that can enable people with mental health problems to get through their daily lives."* – **Mind**

- *"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."* – **Disability Rights UK**

Red lines:

- Access to treatment should be provided in line with financial support, not instead of. - **National Association of Welfare Rights Advisers**

- *"If there is other support available, service users should probably already be getting this and the remit of PIP is to supply payments on top of support to facilitate independent living."* – **Society of Occupational Medicine**

Recommendations:

- *"The government should commit to or commission a thorough review of the extra costs of living with a disability to ensure PIP is commensurate with the needs of people with a learning disability."* - **Mencap**
- *"An independent body should be tasked with researching the adequacy of PIP rates, using a 'Standard of Living' approach which assumes that disabled households are required to spend more on special equipment, home adaptations, medicines and therapies compared to non-disabled people with the same income level."* - **Mencap**
- *"The review should set out how the government should reach this benchmark alongside annual uprating."* - **Mencap**
- *"The government should also recommit to the Disability Action Plan's Extra Costs Taskforce which should have the scope, resources and leadership to genuinely map out the additional costs disabled households face."* - **Mencap**
- *"As recommended by the Work and Pensions Committee, DWP should be part of the taskforce alongside national DPO representatives, disability charities, key industry leaders and relevant government departments and regulators"* - **Mencap**

Chapter 4 - Aligning support

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?

Of the 10 responses to this question, 9 were negative and 1 was neutral. The majority of charities and organisations responded by advising that aligning the support offered by PIP into existing local authority and NHS services could overwhelm the NHS and local authorities when there are already backlogs in support

- *"In May this year there were around 6.4 million people awaiting consultant-led care. Now is not the time for central government to devolve responsibility for supporting disabled people to already overstretched local services."* – **Scope**

The **National Association of Welfare Rights Advisers** provided a more neutral response to this question:

- *"This should not be considered until there is adequate funding across the board – it was remarked that it is difficult to align support with a health and social care system on the brink of collapse…"*

Red lines

- "It is our view based on experience that cuts to PIP would likely cost the Government more in health, social care, and welfare spending. These knock-on impacts have not been accounted for in these reforms." – **Scope**

- *"Local authorities and NHS trusts are already overwhelmed by costs and do not have the resources to take on additional provision. They shouldn't have any. Because individuals should be able to decide their own priorities and have the resources, via cash payments of PIP, to meet them."* – **Disability Rights UK**

Recommendations

- "*The Department for Health and Social Care should expand the rebate system to cover anyone running medical equipment at home, with the NHS being given the funding to do so.*" – **Sense**

- *"We strongly oppose the proposal to integrate PIP into existing health and social care services. Rather than improving things, we are concerned this would undermine blind and partially sighted people's autonomy and independence and could overwhelm already overstretched eye care and vision rehabilitation services."* – **RNIB**

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?

There were 8 responses to this question, of which 6 were negative, 1 was neutral and 1 was in agreement. The general sentiment was similar to that of Q34 in that charities and organisations didn't agree that aligning support would be beneficial for the number of assessments disabled people would have to undergo.

- *"Local Authorities and NHS services are not in a position to be taking on extra duties and responsibilities, in circumstances where they have been underfunded for many years and are unable to deliver services to meet current demands."*– **Central England Law Centre**

- *"Many people with MS already receive support from their local authority and from the NHS, for example social care, support with home adaptations, and treatments such as physiotherapy. However, the needs assessments for these services are hugely different to the assessment for PIP eligibility."* **MS Society**

- **MIND** however had a more neutral response to the question, stating that *"Aligning PIP with local authority and NHS services could be beneficial for enabling passporting from social care and could eliminate some degree of assessment, however this cannot be the only route. This is because PIP assessments have a different purpose and evaluates the daily functionality of a person's life based on their disability or health condition."*

Red lines

- *"This should not be considered until there is adequate funding across the board – it was remarked that it is difficult to align support with a health and social care* *system on the brink of collapse."* – **National Association of Welfare Rights Advisers**

Recommendations

- *"Any alignment should aim to reduce the volume of assessments a person might have to undergo."* – **Society of Occupational Medicine**
- *"While this could be worthwhile, it would need heavy investment and good management to make it work."* – **National Association of Welfare Rights Advisers**
- *"We support reducing the assessment burden on individuals. In addition to the DWP's plans for a severe disability group, we would be interested in seeing further categories of fast-tracked PIP entitlement: for example, for individuals who had met a particular threshold in a local authority's adult social care or occupational health assessment."* **The Child Poverty Action Group**

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

There were 6 responses to this question, all of which displayed negative sentiment or were unable to see any benefits to the proposal of providing local authorities with flexibility in deciding on support prioritisation. Reasons ranged from postcode variations, differences in accessibility and the quality of support provided.

- *"We strongly oppose the proposal to integrate PIP into existing health and social care services and for local areas to have flexibility in deciding how PIP support is delivered. There is already huge variation in the delivery of vision rehabilitation support across England."* – **RNIB**

Red lines

- *"Devolving more responsibility and flexibility to local areas will have the inevitable consequence of perpetuating a postcode lottery, which would mean that disabled people, including people with mental health problems, will no longer have parity in experience or accessibility to the same quality of provision of support."* – **Mind**
- *"To inform our consultation response, RNIB ran focus groups with blind and partially sighted people. All of the participants opposed aligning PIP into existing local authority and NHS services."* - **RNIB**

Recommendations

- *"Everyone who needs it should be able to access PIP, so it must remain a national policy and should not be replaced by local support."* - **Mind**
- *"There needs to be very clear national rules about what rights disabled people have to access services, a proper independent tribunal service to hold local authorities to account, and the cost of that will cost more than the savings you think you will make."* – **Peabody Housing Trust**

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

Of the 6 responses to this question, 4 were negative and 2 were neutral. The responses that oppose better alignment of PIP into existing services mentioned that these services are already overstretched and expressed concerns that they would become overwhelmed.

Red lines

- *"RNIB's research found over a quarter of local authorities in England left people waiting for more than a year for a vision rehabilitation assessment and subsequent support. In March 2024, we estimate that 820,000 people across the UK were waiting for their first ophthalmology appointment and subsequent start of treatment or diagnosis."* - **RNIB**
- *"It would only work if legally binding, and would need Government to fully fund the remaining cost to the local authority. Anything less would simply mean more restriction, more assessment, in attempts to cut provision."* – **Peabody Housing Trust**

Recommendations

- *"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. It would, in any case, simply be an attempt to introduce cuts through the back door."* – **Disability Rights UK**
- *"If support is to be aligned to local service provision it should also be ensured this doesn't result in a loss of independence or autonomy for service users."* - **Society of Occupational Medicine**
- *"A middle way would be to say that certain levels of Activity and Descriptor in PIP passport a person to entitlement for Social and Occupational input, but the claimant must contribute a % of their award to use it."* – **Peabody Housing Trust**

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Redaction Summary

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Redaction 1.1

Exemptions/exceptions:

- S.40 - Personal Information

Redaction 1.2

Exemptions/exceptions:

- S.40 - Personal Information

Redaction 1.3

Exemptions/exceptions:

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