

To: 1. Minister for Social Security and Disability

2. Secretary of State

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Date: 30 August 2024

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Department
for Work &
Pensions

Charities and Organisations Green Paper Response Summary

Summary

1. Following our initial review of 25 charities and organisations provided on 16 August, this submission provides a detailed review of all 115 organisational responses to the *Modernising Support for Independent Living* consultation.
2. This review provides sentiment analysis, key themes, policy recommendations and policy pertinent points from charities and organisations. The names of the organisations are at Annex B, and the review of their responses at Annex C.
3. We only reviewed responses received before the consultation closed on 22 July at 23:59.

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Background

5. The PIP consultation included 39 questions, across 4 chapters, of which 32 were open and 7 closed. We received a total of 115 responses from 113 respondents via email and post from disability charities and organisations. Responses varied in length and depth, ranging from 2 to 41 pages.
6. Some charities and organisations answered all consultation questions, and others focused on specific questions or chapters. We can provide any organisational response you wish to review.

Key Information

Review of all charity and organisation responses – main headlines

7. 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 and that in some cases, health conditions can be initially misdiagnosed, making waiting for a correct diagnosis difficult. 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 reviews were unnecessary and amplified stress levels.
8. 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 saw 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.
9. 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 how they spend their PIP award and that removing this choice reduces people's autonomy and independence to manage the costs of their health condition 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.
10. 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 and that PIP, the NHS and local authorities all serve different purposes and should therefore remain separate. 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.

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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. Charities and organisations denoted with a '*' sent two responses.

Access in Dudley	Contact
Association of Liberal Democrat Trade Unionists	Cystic Fibrosis Trust
Alliance Party of Northern Ireland	Diabetes UK
Assist (Staffordshire)	Disability Benefits Consortium
Assistance dogs	Disability Positive
Association of Disabled Professionals	Disability Rights UK*
Auriga Services	Dystonia UK
Blackburn and District Trades Union Council	End Fuel Poverty Coalition
Blue Ribbon for the Awareness of Myalgic Encephalomyelitis	Epilepsy Scotland
Bright Blue Campaign	Equality Commission for Northern Ireland
British Association for Counselling and Psychotherapy	Equity Trade Union
British Deaf Association	Expert Link
British Sign Language Advisory Board	Greater Manchester Coalition of Disabled People
Business Services Association	Greater Manchester Disabled People's Panel
Cardiff & Vale Regional Advice Network	Health and Social Care Alliance Scotland
Cardiomyopathy UK	Help for Heroes
Carers UK	Hertfordshire County Council Money Advice Unit
Central England Law Centre	Huntington's Disease Association
Centre for Disability Studies at the University of Leeds	Inclusion Barnet
Challenging Behaviour Foundation	Institute for Fiscal Studies
Child Poverty Action Group with input from Changing Realities	KUWG - Kilburn Unemployed Workers Group
Citizens Advice	Law Centre Northern Ireland
Citizens Advice Bureau Service for Nuneaton & Bedworth and Rugby and North Warwickshire Citizens Advice	Learning Disability England
Citizens Advice Darlington, Redcar and Cleveland	Long Covid Support
Citizens Advice Manchester	Macmillan Cancer Support
Citizens Advice North Somerset	Marie Curie
Citizens Advice West Northants and Cherwell	MCS-Aware 'multiple chemical sensitivity'

Mencap	Sheffield ME and Fibromyalgia Group
Mental Health and Money Advice	Signs of a Rainbow CIC
Merton Centre for Independent Living	Sinn Féin
Mind	Society of Occupational Medicine*
Money and Mental Health	South East London ME Support Group
Motability Foundation	Sport England
Motor Neurone Disease Association	Staffordshire North & Stoke Citizens Advice Specialist Benefits Team
Multiple Sclerosis Society	Stepping Stones - deaf active
Multiple Sclerosis Trust	Tainted Blood and the Contaminated Blood Campaign
Multiple System Atrophy Trust	Thalidomide Trust
National Aids Trust	The Migraine Trust
National Association of Welfare Rights Advisers	The Salvation Army United Kingdom and Ireland Territory
National Survivor User Network	Trades Union Congress
Neuroendocrine Cancer UK	Turn2us
North Wales Regional Advice Network and the 6 North Wales Citizens Advice	UK Women's Budget Group
Organise	Voluntary Organisations Disability Group
Parkinson's UK	Waterside Women's Centre
Peabody Housing Trust	WECIL (West of England Centre for Inclusive Living)
Pregnancy Associated Osteoporosis	Welsh Government officials
Pulmonary Hypertension Association	West Midlands Regional Stakeholder Network
Rare Autoimmune Rheumatic Disease Alliance	Whizz Kidz
Rethink Mental Illness	WinVisible (women with visible & invisible disabilities)
Royal National Institute of Blind People	Women's Policy Group Northern Ireland
Royal National Institute for Deaf People	Women's Regional Consortium
Royal British Legion	Women's Platform
Royal College of Occupational Therapists	WOWpetition/WOWCampaign
Royal College of Psychiatrists	YMCA
SCOPE	Young Lives vs Cancer
SEDSConnective	Z2K
Sense	

Annex C: Review of all 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 78 responses to this question, 64 were negative, 12 were neutral and 2 were positive towards placing more emphasis on condition. Reasons included that individuals' health conditions can impact them in diverse ways and would require a balance. Therefore, assessments should continue to measure the functional impact of conditions on the lives of people who make PIP claims. Organisations would welcome opportunities to collaborate with DWP and their partners to help them better understand conditions and its impact on cognition, movement and mental health.

- ☞ *“Conditions like HIV and Hepatitis C can be variable, and they present in different ways. A functional assessment enables the nuances to be drawn out provided it is competently delivered and sensitively designed and takes full account of the pattern of variability over days and weeks.” – Tainted Blood and the Contaminated Blood Campaign*
- ☞ *“This appears contrary to human rights obligations, as a condition-based approach removes the ability to consider the specific manifestation of a condition for each individual, which may vary significantly, and also removes agency for an individual to be heard and describe their needs.” – Women’s Platform*
- ☞ *“... a claimant may present with two less severe conditions, but together they interact with each other, and cause the client’s situation to become worse... There could be multiple permutations that may mean assessing on the basis of condition becomes very difficult.” - Auriga Services*
- ☞ *“There is a danger by making eligibility condition-specific that people with cardiomyopathy would be ineligible for PIP. This would be compounded when you consider that some people with cardiomyopathy are initially misdiagnosed, and face long waiting lists for diagnostic tests and for a cardiologist appointment.” – Cardiomyopathy UK*
- ☞ 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**

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.
- *“PIP should remain based on the functional impact of one or more health conditions, assessed based on experiences of their condition(s) from the claimant.” – Greater Manchester Coalition of Disabled People*

- *“As the government now considers moving back towards condition-based assessments, it may be valuable for DWP to revisit the reasons for moving away from this in the 2010s, and to consider the lessons learned from the DLA system.” - Institute for Fiscal Studies*

In addition, 32 organisations of the 42 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 4 were neutral and 6 were positive.

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?

Of the 59 responses, 18 were positive, 24 were negative and 17 were neutral. Key points included that not having an assessment will be welcomed in reducing 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 individuals receiving incorrect diagnosis, individuals staying on a fixed PIP award and their circumstances not being taken into consideration and that individuals' health conditions impact them differently.

- ☞ *“We think this is a very bad idea. Because it is likely that the award rate would also be fixed. So, for example, people with M.E/ CFS might always get an award of standard care and standard mobility, no matter how the condition affects their needs.” – Stepping Stones Deaf Active*
- ☞ *“The notion that people receive PIP without an assessment if they have a specific health condition or disability as evidenced by a health professional will bar support for those who have a disabling condition that has yet to be medically identified.” – Sheffield ME and Fibromyalgia Group*
- ☞ *“We know that there are often significant delays to diagnosis... Therefore, providing evidence of a specific health condition causing a person's debilitating symptoms can sometimes be impossible, which would, under this suggested system, present significant barriers to accessing the support they badly need.” - Rare Autoimmune Rheumatic Disease Alliance*
- ☞ *“It will not recognise variation and poorly understood impairments/conditions. It will fail to adjust for needs of the individual.” – Greater Manchester Disabled People's Panel*

Responses with a more positive sentiment are below:

- ☞ *“We would support provisions to allow people to be passported to PIP entitlement without an assessment if they have specified conditions that impact strongly on daily living activities or mobility.” – Hertfordshire County Council Money Advice Unit*

- ☞ *"This would be a positive move for many with certain conditions and disabilities. It would be vital not to overload the NHS or to place a cost burden on the individual claimant."* – **Women's Policy Group Northern Ireland**
- ☞ **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.

Recommendations:

- *"We recommend that eligibility is based on needs, rather than on condition."* – **Cardiomyopathy UK**
- *"Reform should be led by disabled people with the social model of disability at its heart and should include a full and proper consultation."* – **Equity Trade Union**
- *"This should be resourced specifically and should take the form of a pro forma that doctors or other medical personnel can complete without additional cost... Fundamentally, this approach represents a switch towards trusting the evidence of medical personnel and as such is to be welcomed."* – **Women's Policy Group Northern Ireland**
- *"...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**
- *"...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**

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 64 responses, 38 were positive, 8 negative and 18 neutral. There was strong sentiment for people being exempted from award reviews when the impact of a lifelong or progressive 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 and will remove the need for the person claiming PIP to repeatedly explain how their health condition impacts them. However, there were suggestions that this may not work for all as the same condition may have different symptoms and reviews are appropriate. Questions were raised as to whether or not the healthcare system has the capacity to support assessments and award reviews.

- ☞ *"We agree that short-term regular reviews for people with conditions not likely to improve are unfair. However, there are variations in symptoms in some of these conditions, so it is doubtful that this will work based on a health condition alone."* – **Epilepsy Scotland**
- ☞ *"Different health conditions and disabilities affect different people in different ways, and this was the reason a Conservative government gave for changing the system from DLA to PIP in the first place."* - **Kilburn Unemployed Workers Group – KUWG**

- ☞ *“Disability is a fluid and variable condition which is hard to easily capture in an assessment. In practice such assessments are often snapshots. This disproportionately disadvantages individuals with variable conditions such as people with mental health problems and conditions like Fibromyalgia.” – **Citizen’s Advice Darlington, Redcar and Cleveland Recommendations***
- ☞ *“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***
- ☞ *“If a claimant’s condition is progressive, chronic or severe with no likelihood of improving then it should not be subject to award review.” – **Women’s Regional Consortium***

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***
- *“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***
- *“We have long advocated for this. Anyone with a progressive condition who is receiving the enhanced rate of PIP should not be reviewed as their condition will only ever stay the same or get worse.” – **Multiple System Atrophy Trust***
- *“Strongly recommend that the DWP find ways to reduce the number of reassessments for PIP and reassessments should be less frequent.” - **Mind***

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 57 responses, 49 disagreed, 3 agreed and 5 responded ‘Don’t know’. Reasons for this view (**Question 5**) include that many people claiming PIP will be at a disadvantage as they may be unable to obtain medical evidence or a medical diagnosis for a long period of time due to long NHS waiting lists. There were also concerns that making provision of evidence or a formal diagnosis by a medical expert could root PIP too much in the medical model rather than the social model of disability, resulting in societal barriers not being taken into account when considering a person’s disability or health condition.

- ☞ *“...It isn’t the most effective way of capturing how someone’s mental health problem affects them, and risks presenting further barriers to accessing PIP for people with mental health problems.” – **Money and Mental Health Advice***

- ☞ *“There are some people who may be severely limited, but they do not have a diagnosis, and in the most extreme cases some people can go many months or even years before a formal diagnosis is given. In these cases, a person may need to meet costs incurred.” – Auriga Services*
- ☞ *“Some conditions take time to diagnose, and ensuring support at an early stage is often the best way to support rehabilitation and recovery.” – Women’s Platform*
- ☞ *“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*
- ☞ *“We do not believe that medical evidence or diagnosis should be mandatory for all, and therefore by default the only way that eligibility for PIP can be determined...” – Young Lives vs Cancer*

Recommendations:

- *“A case-by-case assessment is the most secure and effective way to ensure those who need support can access it. It is also the best way to ensure efficiency and stability in the system, as medical diagnosis and evidence is constantly evolving and changing.” – Women’s Platform*
- *“For hearing loss and deafness, experts, including NICE (National Institute for Health and Care Excellence), agree that the fitting of hearing aids should be based on need rather than hearing thresholds alone.” - RNID*
- *“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 53 responses to this question, 21 were positive, 17 neutral and 15 were negative. There was agreement from many organisations that while use of aids 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. Some referred to this applies mainly to physical restrictions and that individual needs vary greatly.

- ☞ *“With regard to aids and appliances being a good indicator of extra costs, this can be one element of determining additional costs, but needs to remain as one part of a broader picture.” – Citizens Advice Manchester*

- ☞ *“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*
- ☞ *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*
- ☞ *“Conditions that fluctuate might necessitate aids intermittently, and some individuals are embarrassed to use them. While aids do entail additional costs - some of which may be ongoing - they are not always a reliable indicator of ongoing costs” - North Wales Regional Advice Network and the 6 North Wales Citizens Advice*
- ☞ *“...many people are unable to access the aids and appliances they need, due to scarcity of assessments from occupational therapists. Using a self-reported need for aids could under-estimate the degree of unmet need.” – Multiple Sclerosis Trust*
- ☞ *“The fact that no alternative is being suggested implies that the intention is simply to stop taking aids and appliances into account in order to reduce the number of successful claims. We reject this totally.” - Greater Manchester Coalition of Disabled People*

Recommendations:

- *“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*
- 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.”*
- *“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 48 responses, 31 agreed that prompting was a good indicator of extra costs, 11 were neutral, and 6 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 and that without prompting and encouragement, some disabled people would be in danger of self-neglect and harm. It was however noted that prompting could also be a poor indicator, and that while

prompting may apply to some people, it may not apply to others, therefore this should be taken into consideration.

- ☞ *“... A person living with HD can experience cognitive impairment, leading them to struggle to plan their day and undertake daily living activities, such as washing and eating. Therefore, paid carers are often needed to provide prompting and supervision.” – **Huntingdon’s Disease Association***
- ☞ *“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***
- ☞ *“It is unclear why this would be the case, and without clarification, the need for prompting should not be considered in isolation. There are multiple reasons why people may need prompting, and the context is vital to assessing whether this reflects additional support needs.” – **Women’s Platform***
- ☞ *“...will vary significantly between people with different impairments as well as between people who have the same impairment but experience different limitations upon their day-to-day lives.” – **Centre for Disability Studies at the University of Leeds***
- ☞ *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 42 responses, 21 thought thresholds were set too high or were generally negative about the assessment process, 12 responses were neutral, and 9 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. On the other hand, more positive responses included charities and organisations stating that current thresholds are at the right level

- ☞ *“Our recent research indicates that too few people who would benefit are able to access mobility support, because they have not been awarded the enhanced component of PIP. This is leading to isolation and an inability to engage in work, leisure and daily activities.” – **Multiple Sclerosis Trust***
- ☞ *“...has significant concerns about the quality of DWP decision-making for PIP.” – **Central England Law Centre***

- ☞ *“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*
- ☞ *“The current entitlement thresholds are too high, meaning people who need PIP are denied it. More people should get PIP.” – Greater Manchester Disabled People’s Panel*
- ☞ *Government support is not going far enough - “40% of disabled people with mental health problems are living in materially deprived households.”- Mind*

Recommendations:

- *“The government’s primary focus should be improving the quality of PIP decision-making, so fewer people are having to challenge assessment decisions to get the support they’re entitled to.” – Money and Mental Health Advice*
- *“Any future changes to the PIP system must be developed and designed with leadership from signing deaf people on all issues affecting us.” – British Deaf Association*
- *“Any changes should be done in co-production with disabled people and our organisations.” – Greater Manchester Disabled People’s Panel*
- *“We recommend that DWP move away from a rigid activity-based assessment and move towards a mutual trust model.” – 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 54 responses to this question, of which 25 responded that the 3-month test is fair and should not be altered, 16 had mixed views and 13 mentioned reducing or 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 lengthening the qualifying period. Some responses also raised the impact that the 3-month threshold can have on certain conditions, with suggestions that the qualifying period being based on an individual’s condition and that some larger expenses can occur after the health condition begins and therefore many people would struggle to get this support, therefore the qualifying period should not be changed.

- ☞ Multiple charities including **Mental Health and Money Advice** mentioned that the three-month qualifying period is fine as a minimum qualifying period and should remain.
- ☞ *“We would oppose any extension to this required period, particularly in light of the proposal that a specific diagnosis or medical evidence of a condition be implemented.” - Citizens Advice North Somerset*
- ☞ *“For many individuals, particularly those experiencing a sudden onset of a disability, the three-month waiting period can already be a considerable duration to live without the additional support. Extending this period could*

exacerbate the challenges that those with a rapid onset of disabilities face.” -
Institute for Fiscal Studies
“...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**

Recommendations:

- *“One way to deal with the difficulty of knowing whether a condition is long-lasting would be to give shorter awards with more frequent reassessments.” -* **Institute for Fiscal Studies**
- *“Reducing the three-month qualifying period would provide more timely support to individuals who experience sudden or severe onset of disability or illness.” -* **Citizens Advice West Northants and Cherwell**
- *“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**
- *“We strongly urge the proposals are not taken forward and instead a full and independent review of the benefit system and its adequacy is conducted.” -* **RNIB**

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?

Of the 47 responses to this question, 21 were in favour of retaining the 9-month prospective test, 15 think the test should be reduced or otherwise reformed and the remaining 11 had neutral or mixed views. Some responses focused on the impact of the current prospective test for different disability conditions including mental health and non-physical conditions. Others discussed the benefit of creating a new category for conditions which will not improve or taking into account an individual’s condition.

- ☞ *“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**
- ☞ *“HIV is a lifelong condition that only becomes harder to manage as a person ages and becomes more susceptible to comorbidities. For this reason, a nine-*

month period is unnecessary to decide whether the impact of certain health conditions are long term... – **National Aids Trust**

Recommendations:

- *“The prospective test period works effectively as it is and does not need changing.”* - **Disability Rights UK**
- *“The nine-month test is acceptable, but it sometimes creates challenges for people who have multiple conditions or multiple incidents like strokes where it is hard to determine when each set of needs began. Being able to consider overall health needs rather than each incident individually would be an advantage.”* – **Contact**
- *“CELC would welcome a reduction of the nine-month prospective test used to determine eligibility for PIP.”* - **Central England Law Centre**
- *“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**
- *“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. Charities and organisations also advised that restricted choice could disempower people from managing their own extra costs that arise as a result of their disability or health condition and could increase the administration burden on people claiming for extra costs and the additional burden on the Department.

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 the concern of the independence that PIP was brought in to provide will no longer be there if cash payments were replaced and that many claimants would need to pay for costs up front where a system such as receipts-based would be used, pushing people into debt.

<input type="checkbox"/>	Catalogue	Voucher	Receipts-based	One-off grant
Total responses	67	73	65	63
Disagree	87% (58)	92% (67)	91% (59)	84% (53)

Neutral	13% (9)	8% (6)	9% (6)	16% (10)
Agree	0% (0)	0%	0% (0)	0% (0)

- ☞ *“A catalogue/shop scheme will limit the support available to a limited selection of goods and is likely to be inappropriate for many claimants. For example, mobility aids that may be too heavy or impractical for a person with energy limitation and chronic pain to fold and transport. It will not meet the needs of people with Long Covid for medication and nutritional supplementation” – **Long Covid Support***
- ☞ *“The key additional costs for people living with RAIRDs include several elements which cannot be easily purchased with vouchers – for example, for people who live rurally and have one local taxi company, there is no guarantee that they would accept a voucher” – **Rare Autoimmune Rheumatic Disease Alliance***
- ☞ *“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***
- ☞ *Removing a cash payment removes the autonomy and independence of people to spend their PIP cash award freely. - **RNIB, Disability Rights UK***

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***
 - *“We strongly recommend the current system of fixed monthly cash payments for PIP remains.” – **RNIB***
- “Any future changes to the PIP system must be co-produced with Disabled people.” – **Women’s Policy Group Northern Ireland***

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 52 responses to this question, 36 showed a negative sentiment, 14 were neutral and 2 were positive. Many charities and organisations highlighted that improved access to NHS support and/or treatment should be provided in addition to financial support and also expressed concern that PIP is used to access other services, therefore removing this would remove other support people may be entitled to.

- ☞ *“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*
- ☞ *“Support/treatment should be a given, not an option or an either/or. And just because this is being received does not negate the likelihood of additional costs.” – Money and Mental Health Advice*
- ☞ *“Many veterans claiming PIP for mental health illnesses would benefit from specialist support being more readily available... Easier access to pain clinics would help claimants manage their pain, and the impact the illness has on their day-to-day lives earlier.” - Help for Heroes*
- ☞ *“Removing cash payments for PIP would drive rates of poverty, destitution and homelessness for disabled people, particularly those whose only other income is means-tested benefits. The human costs of this would be significant, and would surely hinder rather than help wider efforts to drive down economic inactivity.” – Z2K*

Recommendations:

- ☞ *“Access to support or treatment should already be available from the NHS or local authority, regardless of whether you are PIP claimant or not.” – Stepping Stones Deaf Active*
- ☞ *“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*

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 45 responses to this question, 37 were negative, 6 were neutral and 2 were positive. Many charities and organisations responded by suggesting 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. They also stated that many disabled people are currently denied support by local authorities and that disabled people would be far worse off if support were to be aligned to local authorities.

A positive response noted:

- ☞ *“By aligning PIP, local authorities and the NHS, people living with HIV and other conditions can benefit from a coordinated approach to support their health and socioeconomic needs.” – National Aids Trust*

The negative responses noted:

- ☞ *“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*
- ☞ *“Aligning PIP into local authority and NHS services would be likely to reduce autonomy and greatly increase strain on LAs and the NHS.” - Hertfordshire County Council Money Advice Unit*
- ☞ *“We categorically oppose this proposal – it would be a dangerous total failure. There is no recent precedent that suggests that a combining of two vastly different systems of support would work – with Disabled people inevitably left worse off.” – Sheffield ME and Fibromyalgia Group*
- ☞ *“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*
- *“The postcode lottery in healthcare needs to end. For example, if a Long Covid patient in London can get access to neurological or vascular examinations, so should a person in the North of the country or in Scotland or Wales. Some support and therapy services can be localised, however NIHR and NICE guidance should be adhered to nationwide, and there needs to be consistency of service across countries and regions.” – Long Covid Support*

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 32 responses to this question, of which 18 were negative and 14 were neutral. The general sentiment was mixed with similar feedback 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. Charities and organisations also stated that different assessments assess different things, for

example the PIP assessment assesses extra costs whereas the Work Capability Assessment assesses ability to work and therefore it wouldn't be prudent to align services.

- ☞ *"Different authorities would choose to meet people's needs in different ways, leading to an utterly fragmented system. It might well be that in some areas you would have to undergo multiple assessments and in others very few"* – **Stepping Stones Deaf Active**
- ☞ *"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**
- ☞ *"If the disabled person has supporting evidence from assessments by local authorities and/or NHS services then this should be accepted and considered."* - **The Blue Ribbon for the Awareness of Myalgic Encephalomyelitis**
- ☞ *"Such a change risks placing the National Health Service and local authorities under further bureaucratic and financial strain."* – **Centre for Disability Studies at the University of Leeds**
- ☞ *"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**
- ☞ *"The consultation's proposal to "align" PIP with existing Local Authority and NHS services returns this whole exercise to the medical modelling which we rejected at the outset."* – **British Deaf Association**

Recommendations

- *"PIP should be retained in its current form of ongoing direct cash benefit awards in addition to adequate health and social care support through the NHS and by local authorities under the Care Act 2014 system."* - **Centre for Disability Studies at the University of Leeds**
- *"An effective way to align disability support assessment with the NHS is to build an additional assessment function into the role of NHS occupational therapists and specialist nurses and allocate responsibility for assessments to the NHS."* – **Parkinson's UK**
- *"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 37 responses to this question, 26 displayed a negative sentiment or were unable to see any benefits to the proposal of providing local authorities with flexibility

in deciding on support prioritisation and 11 displayed a neutral sentiment. Reasons ranged from postcode variations, differences in accessibility and that people claiming PIP should decide on their own priorities.

- ☞ *“We have repeatedly made the point that it is impossible to align support with health and social care services in their current state.” – **Women’s Regional Consortium***
- ☞ *“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***
- ☞ *“They should be able to set priorities based on need, however healthcare pathways in the NHS should be set nationally and be consistent across countries, regions and NHS trusts.” - **Long Covid Support***
- ☞ *“Disabled people are typically bottom priority for local authorities and health services. Non statutory services for disabled people are reduced because disabled people have less capacity to challenge cuts.” – **Contact***
- ☞ *“Local areas should not have flexibility (Q37) to decide their priorities in supporting people with disabilities: assigning priority to one area means deprivation elsewhere...” – **British Deaf Association***

Recommendations:

- *“Our peer consultants expressed the need to ingrain a standard package of services offered by all local authorities, and anything else delivered would be at the discretion of local government.” – **National Aids Trust***
- *“While provision should be addressed locally, it needs to be sensitive to individuals not a one size fits all.” – **Mental Health and Money Advice***
- *“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 33 responses to this question, 27 were negative and 6 were neutral. The responses mostly disagree with aligning PIP into existing services, with charities and organisations mentioning that services are already overstretched and expressed concerns that they would become overwhelmed and that there would be variations in support across the country. Charities and organisations also expressed that aligning PIP with local authority and NHS services could be reverting to the medical model of disability and not taking into account societal barriers. Also, that the different systems serve different purposes so aligning them wouldn't be effective.

- ☞ *“While aligning PIP with existing local authority and NHS services could potentially offer some benefits, there are significant concerns about the impact on individuals' independence and the logistical challenges involved, ... There are concerns about the potential impact on NHS services and waiting lists, and the possibility of the assessment process becoming a gatekeeping process.” - **Citizens Advice North Somerset***
- ☞ *“We believe there are significant reforms and investments needed in local authority and NHS services and these are long-term. We therefore don't believe that there should be any attempt to align PIP with local authority and NHS services.” – **Women's Regional Consortium***
- ☞ *“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***
- ☞ *“We oppose any efforts to align PIP with local authority and NHS services. Given the significant variation in service delivery across regions and the existing financial strains on both the NHS and local authorities, aligning PIP with these services could lead to reduced funding and compromised support for Disabled people.” – **West of England Centre for Independent Living***

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

Page 1

Redaction 1.1

Exemptions/exceptions:

- S.40 - Personal Information

Redaction 1.2

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Page 5**Redaction 5.1**

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