







Personal Independence Payment (PIP) Consultation

Learning Disability England's Members Response

Summary

	<p>Learning Disability England members took part in an online session, survey and sent feedback by email to help us write this shared member's response.</p>												
	<p>Members are very worried about the 4 suggested changes to PIP in the consultation</p>												
	<p>Members want a benefits system that is coproduced with people with learning disabilities and gives everyone a decent standard of living.</p>												
 <table border="1" data-bbox="368 1659 523 1883"><thead><tr><th colspan="2">Needs</th></tr></thead><tbody><tr><td>1 <input checked="" type="checkbox"/></td><td>6 <input checked="" type="checkbox"/></td></tr><tr><td>2 <input checked="" type="checkbox"/></td><td>7 <input checked="" type="checkbox"/></td></tr><tr><td>3 <input checked="" type="checkbox"/></td><td>8 <input checked="" type="checkbox"/></td></tr><tr><td>4 <input checked="" type="checkbox"/></td><td>9 <input checked="" type="checkbox"/></td></tr><tr><td>5 <input checked="" type="checkbox"/></td><td>10 <input checked="" type="checkbox"/></td></tr></tbody></table>	Needs		1 <input checked="" type="checkbox"/>	6 <input checked="" type="checkbox"/>	2 <input checked="" type="checkbox"/>	7 <input checked="" type="checkbox"/>	3 <input checked="" type="checkbox"/>	8 <input checked="" type="checkbox"/>	4 <input checked="" type="checkbox"/>	9 <input checked="" type="checkbox"/>	5 <input checked="" type="checkbox"/>	10 <input checked="" type="checkbox"/>	<p>1. The consultation discusses changing how the PIP assessment happens, so it looks at peoples diagnosis, instead of how your disability affects your day-to-day life.</p> <p>Members didn't agree which was the best approach.</p>
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Some members thought getting a life-long award based on your diagnosis would reduce stress and workload.

Other people were worried about what this would mean for people who don't have a formal diagnosis from the doctor, or if you have a condition that is rarer and isn't well known and if this would leave you disadvantaged.



2. The consultation talks about changing how PIP assessments work now. Members talked about how it needs to change because many people have a bad experience.

Members want to see a new way of working co-designed with disabled people. An assessment that is fair and person centred.



3. The consultation talked about paying people PIP in different ways. Members argue to receive their PIP as cash, it gives them freedom to choose how to manage their money.

They didn't like the other ideas.



4. The consultation talks about increasing the health and social care professionals working with the department of work and pensions.

Members weren't sure how doctors or social workers would have time when they are already

	<p>very busy. They worried because often doctors and social workers don't know how to work with autistic people or people with learning disabilities well.</p>
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Full Members Response

During 2024 over 400 Learning Disability England Members came together to develop the [Good Lives Manifesto](#), sharing the priorities of people with learning disabilities, their families and supporters. One of the pledges included in that was to *'Help people with learning disabilities get the jobs they want supported by a system that recognises contributions not forcing poverty'*. We ask the government to *'Co-produce the benefits system that recognises everyone's right to an adequate standard of living and values individual's contribution not penalising disability'*. We hope any updates to PIP by the new government can be within the principle of these asks. Members are "frustrated, confused and distressed" by the proposed change and deeply concerned about what would happen should people be left without PIP.

We know that people with learning disabilities are more likely to live in poverty than non-disabled people and are being hit hard by the cost-of-living crisis. [Joseph Rowntree Foundation](#) found almost 6 in 10 disabled households were experiencing food insecurity in April/May 2023. 71% going without essentials between November and May. On average, disabled households need an additional £975 a month to have the same standard of living as non-disabled households. PIP is an essential contribution to disabled people's income.

Learning Disability England members (people with learning disabilities, family members and people in paid roles as supporters, managers or policy leads) have come together through online sessions and a survey to offer joint feedback on this consultation. The feedback is laid out as a response to the easy read consultation information.

Changing how we do PIP assessments

There were distinct groups of opinion when discussing if a diagnosis should be used instead of a needs assessment for PIP.

Some members felt strongly that a diagnosis should allow you life-time access to PIP, reducing the need for ongoing assessments when your condition is long term or lifelong. This would massively reduce the stress people experience as part of the PIP process and reduce the need for additional paperwork to be completed.

Other members were less sure about using diagnosis over a needs assessment. When PIP was first introduced, a diagnosis was not included as part of the eligibility criteria to move away from a medical model of disability and instead focus on how someone's disability actually affects their life. This felt important to this group as it felt more person centred.

Members discussed how difficult it can be to get an official diagnosis, especially an autism diagnosis currently through the NHS. They worried about how not having an official diagnosis or having one that isn't properly recorded would be a barrier to getting PIP. More rare chromosome conditions were also mentioned as diagnosis that are often misunderstood or not known about.

They also note that a diagnosis doesn't offer a 'one size fits all' explanation of what support you need.

People with learning disabilities and families told us how difficult PIP assessments currently are in having to talk about your 'worst day' and what support you need as very disempowering. People said assessments don't allow you to talk about your life as a whole or in a more positive way because that will just mean you get less PIP support than your situation means you need.

While members were split on which approach to the assessment was best, they agreed that the process must be as easy and stress free as possible, whilst also working in a person-centred way. This is an opportunity to coproduce a solution with a range of disabled people who have experience of PIP to find a positive person-centred proportionate assessment method.

Making changes to the PIP assessment we have now

Members want to see assessments be more human and kinder, they often felt the assessment was designed to catch them out and had poor experiences of assessors who often made (incorrect) assumptions about them and their life.

One member described their PIP assessment as 'humiliating, distressing and upsetting', another said their experience was 'cruel and impersonal'. One member told us the assessor asked to see their surgery scar, which was deeply inappropriate.

Some disabled people told us they were told they couldn't bring a family member or supporter with them to their appointment, leaving them feeling vulnerable and without the necessary support to complete the assessment fully. Members want to see better support offered throughout the PIP process, both when signing up and throughout the assessment.

People feel the assessment is currently too long and people felt the questions jumped from topic to topic too quickly, which was very confusing and disorientating. Members want to see assessors be more curious in their approach to asking questions and offering prompts to help explore topics fully. A member said 'we are the experts, trust us to know the answers'.

Changing how we pay PIP

Members were very concerned about proposed alternatives to paying PIP as cash.

One member described vouchers as a 'really petrifying' and disabling idea. People were uneasy that all the proposals restrict their choice about how and where they could spend the money and worried it might leave them isolated as some people used it for travel and to see family and friends rather than physical items you can get from a catalogue. Being able to use PIP to see and do activities with family and friends is very important, the [Belonging Forum](#) found in a 2024 poll that 40% of disabled people reported experiencing loneliness and social isolation. Being socially connected was associated in the poll with higher levels of health, mental health and life satisfaction. Using PIP to support social connection is good way to prevent poor outcomes from loneliness.

People were also concerned about how the proposed alternatives would be administered, the additional costs that would bring and how this might delay people having access to the resource or leave them waiting for payment. All the members felt the proposed alternatives all felt would cost more in administration than the current approach.

People worried that vouchers would be difficult to spend, requiring you to either shop in person or online, both can have barriers to disabled people. They also worried that some equipment that people need is so specialist that you wouldn't be able to get it with a voucher.

Members were distrustful of the proposal of individuals paying for what they need then being paid back. They questioned what would happen if your purchase wasn't approved to be refunded and how many people would be left out of pocket. Members also did not think people would always have the money for the initial purchase which would either leave people in additional financial difficulty or without the things they needed to live well, work or keep safe.

Members felt the current approach of a regular payment worked, including the frequency of payments. A bank payment enables peoples independence, choice and control. It offers flexibility over how people spend their money allows people to save their money or plan for the future with some resource to mitigate the additional costs related to being disabled.

We asked members what they currently spend PIP on, this covered a wide range of services, items and activities. Including:

- Essentials like food and household expenses like utility bills.
- Transport costs from mobility cars to public transport.
- Social care costs: social care contributions to local authority, to fund private care costs, day services, Personal Assistant expenses
- Health expenses: Medication, hygienists, and dentist
- Disability related expenses: mobility aids, replacement of heavily used or easily damaged equipment, cleaning, clothes
- Visiting friends and family, social activities and contributions to holidays
- Building savings and emergency funds (for replacement equipment for example), building financial security.

Paying people cash is the only approach that would allow people to use PIP with the same flexibility for the same variety of things that they do currently.

Working together with other organisations

Generally, members think that joined up services would offer a better experience, reducing the need to tell their story or explain how their disability affects them repeatedly. However, they are worried about several issues regarding this.

Firstly, many people struggle to access their social worker or GP now so adding to their workload without significant resources to increase capacity is a real worry for both general health or social care access and access to benefits.

Secondly, although people don't report positive experiences of current assessors, they also don't always have positive experiences of social workers and doctors. While members are hopeful that programmes like the Oliver McGowan Mandatory Training will help improve learning disabled patient experience, they are aware this may not improve things. Developing more specific training for assessors is needed.

Thirdly, they are also worried about the potential need to pay for notes from the GP to prove their diagnosis. People with learning disabilities said affordability shouldn't be a barrier to accessing non-means tested benefits.

Finally, many people with learning disabilities are spending significant amounts of their PIP paying increasing social care charges. Should the Department of Work and Pensions be looking to manage PIP alongside Adult Social Care changes? Members think there should be an effort to understand how PIP is being spent and ensure that disproportionate amounts aren't being spend on social care changes.

Appendix

Here are some comments from members from the survey we held.

We asked, **what are your key messages about PIP to the new government? What is most important to you?**

"PIP supports individuals to cope and manage on a daily basis with various aspects of daily living. This potential change is causing significant stress for people in receipt of PIP and impacting their mental health."

"Find a fair way to assess disabled use someone who knows how to treat people with respect"

"The PIP money is just about keeping my son well. enabling him to get out and about and have some independence. It also helps offset a lot of the costs related to him having difficulties as a result of his disability (losing phones and bank cards and car keys, burning pans etc). I think if it ended, we'd have to look at more full time care for

him. My husband used to have lower level and when it stopped he became really depressed -feeling it meant he was not deserving of support.”

“People need to have their own money to make their own choices of how to live to an independent life.”

“It's important for the government to recognise people with a learning disability when they are setting their criteria. Sometimes it is not about how far a person can walk but how the environment can affect a person and impact not only on them but on people around them. Assessments can be quite black and white, particularly around physical ability and don't always consider particular complex needs and people's reactions.”

“Our adult son would be unable to live independently from us without PIP. He has a learning disability and autism and needs 24 hour care.”

“it is no surprise people apply for PIP to help secure some financial security and increased income to enjoy just some of lives little pleasures. JSA does not provide this and the constant grind of living day-to-day on the most basic of incomes can drive people to lose all hope and self-worth. Autistic people want to work and generate their own income but they are not given the opportunity by employers. Until this stops PIP will be a lifeline for long-term unemployed autistic people.”

“I would like to see more support provided for people claiming PIP; this would help contribute towards improving mental health and give people more independence.”

“PIP is essential. Flexibility to spend PIP is also essential. Introducing more bureaucracy (vouchers, claiming back spend etc.) would be an absolute nightmare for disabled people and their carers.”

“[my son] would not be able to have much quality of life and certainly with increasing costs his life is less active despite the fact that we are creative in facilitating low-cost options. Holiday on hold at the [moment] but saving for next year. However, PIP makes a huge difference and we value that its awarded to him.”

“PIP has been a great benefit to me and I don't want to worry about the government taking it away or putting restrictions for individuals who have PIP”

About Learning Disability England

Learning Disability England is bringing people and organisations together to create a movement for change where people with learning disabilities, families, friends, and paid supporters come together on an equal basis.

As a membership organisation, members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others.

Learning Disability England works nationally across England with 166 organisational members and over 500 individual members.

You can find out more about our work here:

<https://www.learningdisabilityengland.org.uk/>

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