

Timms Review of Personal Independence Payment (PIP): ‘Workshop in a box’ activity

**Findings from Mencap-facilitated workshops with
people with a learning disability in receipt of PIP**

1. Background

The Timms Review ‘workshop in a box’ resources were designed to capture qualitative insights on how Personal Independence Payment (PIP) impacts disabled people. Following guidance that the resources be used flexibly, Mencap facilitated nine synchronous sessions and received two written responses asynchronously, engaging a total of 81 participants. 78 participants were people with a learning disability, all of whom who receive PIP; 3 were family carers or supporters. Further details about the workshops and sample can be found in Tables 1 and 2. We obtained informed consent from all participants to take part and to have their summarised insights submitted to the Timms Review.

Further demographic information was collected via the ‘About me’ form or summarised by workshop facilitators for a minority of participants (n=15). To protect participant anonymity and avoid potential identification, a detailed breakdown by group is not provided. However, we can share that the sample included people with a learning disability with a range of co-occurring disabilities and long-term health conditions.

Group name	Group reach	Region	Geographic focus	Workshop date	Workshop format
Pennine Mencap	Local	England	Urban	24.06.26	Online
Solihull Action Through Advocacy	Local	England	Urban	06.07.26	Online
Mencap Voices Council	National	England, Northern Ireland, Wales	Urban, Rural, Coastal	07.07.26	Online
Croydon Mencap	Local	England	Urban	08.07.26	In-person
Lancaster People First	Local	England	Urban	09.07.26	In-person
Bournemouth Gateway Club	Local	England	Urban	10.07.26	In-person
Bexley Mencap	Local	England	Urban	13.07.26	In-person
Mencap Power and Influence Group	National	England,	Urban, Rural, Coastal	14.07.26	Online
Mencap Northern Ireland	Regional	Northern Ireland	Urban, Rural, Coastal	N/A	Written response
Stepping Stones	Local	England	Urban	13.07.26	In-person

Table 1. Summary of participating groups and workshop details.

Group name	People with a learning disability	Family carers and supporters	All participants
Pennine Mencap	13	0	13
Solihull Action Through Advocacy	10	0	10
Mencap Voices Council	3	0	3
Croydon Mencap	14	2	16
Lancaster People First	8	1	9
Bournemouth Gateway Club	12	0	12
Bexley Mencap	8	0	8
Mencap Power and Influence Group	3	0	3
Mencap Northern Ireland	2	0	2
Stepping Stones	5	0	5
Total number of participants	78	3	81

Table 2. Summary of participant identities, broken down by group.

2. Method

Alongside the two written submissions, notes were taken by the facilitator(s) at the synchronous session to capture insights and direct quotes from participants. A thematic analysis of this data was conducted, whereby responses to the workshop questions were systematically examined to identify recurring patterns of meaning. ‘Codes’ were generated to capture meaningful units of information relevant to the focus of the Timms review. Following a process of inter-coder agreement, codes were then prioritised and grouped to form higher-order themes and sub-themes, based on prevalence and significance. Codes were inductive, meaning they were developed from the data itself.

3. Findings

3.1. The impact of PIP

3.1.1. Extra costs of a learning disability

Participants with a learning disability described how PIP supported them to meet the extra and unavoidable costs of being disabled. Specific costs discussed included: buying medication and specialised clothing/footwear; having higher utility and grocery bills; funding support workers, transport adaptations and activities or services that support wellbeing and access to the community.

Across all sessions, there was a sense that PIP was integral to participants’ incomes, without which they wouldn’t be able to cover the cost of living with a learning disability (particularly as costs rise). One participant said: “[Without PIP] I wouldn’t be able to buy food”. A minority of participants considered the amount of

PIP they received to be adequate in contributing towards these costs. However, there was a sense more broadly that people with a learning disability continue to struggle financially despite being in receipt of PIP.

Some participants felt that their household bills were higher due to their disability. For example, participants spoke about needing to keep the heating on more due to associated health conditions, showering more frequently or having to replace items including mattresses and bedding because of incontinence. Others described having to buy new clothes more regularly because their disability meant they often spilled food on themselves. Another group described using PIP to pay for groceries from local shops, where prices were often higher, because they found online shopping difficult or were unable to travel easily to larger supermarkets.

PIP was also used to pay for disability-specific aids, essential to the lives of the participants. This included funding support workers and enabling family members, particularly parents, to provide additional support with practical tasks and for accessing social and community opportunities.

A strong theme was that participants understood how PIP helped them live full lives and participate in their community: **“It should help you live better”**. PIP was used to pay for specialist activity groups and hobbies (such as football, cycling and cooking clubs) which often are more expensive due to the level of specialist support provided, as well as social groups where attendees are supported to meet others in a safe and inclusive environment. One person said: **“I’d like to join summer schemes but they cost money. PIP helps me to do this”**. Participants emphasised how activities like these often involve additional costs (such as for support workers), making them substantially more expensive than for non-disabled people.

Transport was furthermore identified as a significant cost that PIP contributed towards covering. Being able to travel was regarded as crucial in preventing social isolation and maintaining participant independence, but many participants spoke about the inaccessibility of public transport. As a result, they often relied on taxis or having access to adapted vehicles. These challenges were particularly pronounced for those living in rural, or less well-connected areas, where limited public transport options increased reliance on more expensive forms of transport. As one participant explained, **“I live in the country and access to buses are not good and I do not drive. Taxis would be the only way to get out without relying on my family”**.

3.1.2. Why PIP is important

Many people with a learning disability described PIP as providing them with greater independence, specifically enabling access to work even though the benefit is

unrelated to employment status. These benefits contributed towards participants feeling able to do the same things and have the same opportunities as their non-disabled peers. As one participant explained, PIP “helps people do the same things as everybody else”, while another said that “[PIP] is important because it helps me feel more ‘normal’ and allows me to feel a sense of independence”.

The role of PIP in supporting independence was a key theme. Often, participants said that having PIP allowed them to make their own choices about how they spent their time. PIP was said to provide “confidence, independence and freedom”. Another participant reflected, “If PIP wasn’t there, being independent would be difficult. If it was taken away or wasn’t available, life would be different”.

For some, independence was closely linked to financial autonomy. Being able to buy their own food or pay for activities themselves reduced reliance on family members and gave them a greater sense of control over their lives. More generally, participants spoke positively about being able to manage their own money and make decisions about how it was spent. However, a small number of participants said that needing to ask for support could sometimes make them feel different to people without a disability. As one participant noted, it is “like you can’t be independent without help”.

Across all sessions, participants highlighted the significant role that PIP played in connecting them to others, reducing loneliness and supporting wellbeing. Functionally, PIP meant people could afford to access their community, whereby going out and spending time with others was crucial for their mental health and wellbeing: “[PIP] gives me the ability to go out and do the things I need to do and get to the places I need to go”. Beyond facilitating participation, it helped expand participants’ sense of what was possible for them to achieve, creating opportunities they otherwise believe would be out of reach: “Gives me opportunity that I think I would never be able to do if I didn’t get PIP”. Other participants reflected on the consequences of not receiving PIP, stating that “[without PIP] I couldn’t go to social clubs/meet friends. I would be lonely and isolated”; “If I didn’t get PIP, I wouldn’t be able to go out”.

Participants described how people with a learning disability can already face barriers to finding work and earning their own income, and felt these difficulties would be exacerbated without PIP. As one participant explained, “If we did not have PIP we would struggle trying to find jobs and earning our own money”. At the same time some expressed concerns that being in work could affect their entitlement, despite recognition that PIP is not an out-of-work benefit.

3.2. Experiences of the PIP application process

3.2.1. A harmful process

Despite the clear importance of PIP in contributing towards the essential and additional costs of living with a learning disability, maintaining independence and participating fully in society, experiences of the application process were described in overwhelmingly negative terms. Participants spoke about feelings of shame, anxiety and uncertainty, alongside a persistent fear of losing their benefits. There was a strong perception that the process tries to prevent people who need support from being able to access it.

Many participants described the process as emotionally distressing. As one participant explained, "it makes me feel really worried and anxious". Another said: "I never feel like it's going to go well", reflecting how people with a learning disability can feel let down by the system. These concerns were often shaped by the wider political and social context, with participants describing how government benefit reforms and negative media coverage increased anxiety: "It can make you stressed if you hear things on the news or read things online about how things are changing"; "The media negativity around PIP doesn't help, it scares me to apply".

Across all workshops, participants explained how the application process stigmatised asking for support, "like asking for a bit of help is something to be ashamed of". This was particularly difficult for individuals who already found it challenging to ask for help. Some felt judged during the application process and questioned whether their experiences were believed, with one participant describing it as feeling "like you've done something wrong and they don't believe you".

The fear that benefits would be reduced or stopped together was also widely discussed. For some, this fear was based on previous experiences of reassessment or interruptions to payments. One participant recalled: "They stopped my PIP and had hardly any money to pay for the bills, and a week later they did it to my wife and they stopped it for nine months. She had to go up to London to fight for her PIP".

3.2.2. An inaccessible, unfair process

Participants were highly critical of the PIP application process, which many felt was difficult to navigate and did not allow for the experiences of people with a learning disability to be adequately understood. Some described the system as unfair, arguing that people had to 'fight' to receive support: "I am screaming out for help and nothing is being done".

The application form and assessment questions were frequently described as hard to understand, too general and often not relevant to the realities of living with a learning disability, making it unclear what information or evidence was required. One participant explained, “It’s so complicated and you’d need to spend a long time filling in forms”, and many relied heavily on family members to complete applications on their behalf. One person said, “My mum filled out the form on my behalf... I can’t remember [if I saw the form]”, while another explained, “I don’t do the form because I find it too confusing and my mum has to do it for me”. Participants felt this could be disempowering and left them with limited control over the process.

Other people with a learning disability felt that the assessment framework did not capture important aspects of their disability, including the need of specialist mobility equipment, mental health support, communication and social interaction difficulties, the support needed to manage money, access the community and avoid isolation, and the role of carers. Overall, they described the process as inflexible and reliant on forms of evidence that were not always available to them.

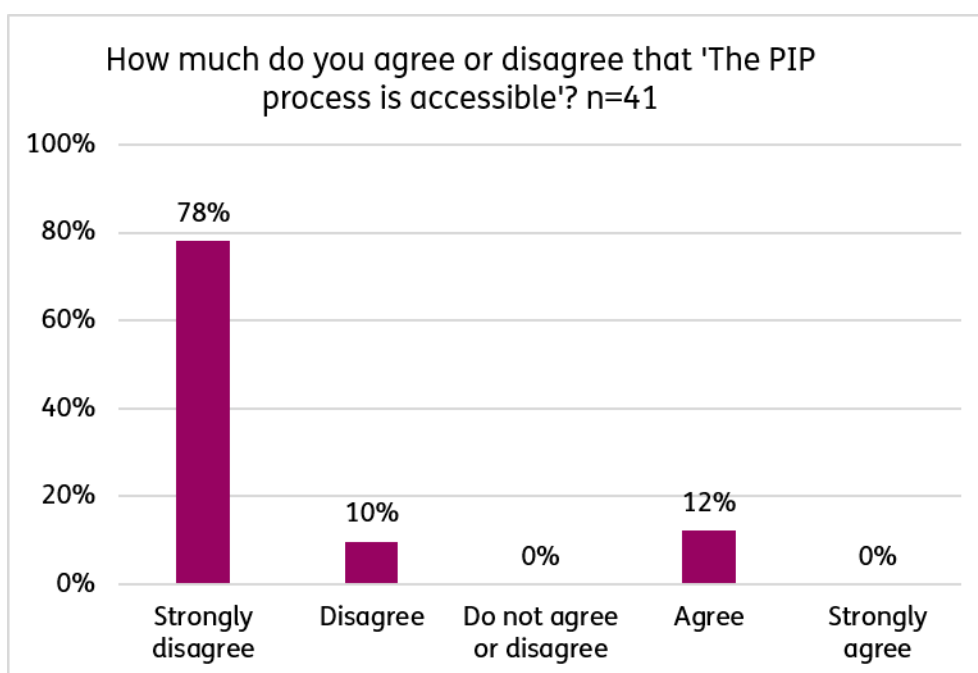


Figure 1. Chart shows the percentage of respondents (n=41) answering from ‘Strongly disagree’ to ‘Strongly agree’ in response to the statement ‘The PIP process is accessible’.

Assessments themselves were viewed negatively, with participants describing in-person appointments as anxiety-inducing, particularly when they involved travelling to unfamiliar locations. Some stated a preference for telephone assessments, although these too could be stressful. Questions were explained to

be overly personal and intrusive, with some participants becoming upset when discussing sensitive topics or past experiences. As one participant explained, "I found it hard talking about my disability and how it affects my day-to-day life", while another noted that "if they just ask how do you manage that, it's hard to explain". Several participants felt unable to fully express their experiences, with one stating simply: "My voice is not heard".

A common concern throughout all sessions was that assessments felt unfair and focused on catching people out. Participants described carefully planning their answers for fear of saying the wrong thing to assessors and losing their PIP. As one participant noted, "They're nice to you to your face, then they say there's nothing wrong with you in the report". Some also criticised assessments for not exploring the overall impact of their learning disability. At the same time, it was felt that the assessment looked past the most challenging parts of their learning disability. One participant explained, "It focuses on what we can do and asks questions to trick us". Lastly, delays and uncertainty through the applications and reassessment process further added to participants' stress and anxiety, reinforcing the idea that accessing and maintaining PIP is a continuous battle.

3.2.3. Poor understanding of learning disability

Overall, participants said that the current PIP process did not fairly assess the needs of people with a learning disability. A common concern was that the application form and assessment questions were not designed in a way that reflected how a learning disability affects people's everyday lives. Some participants found it difficult to talk about their disability, particularly when questions were vague or required them to infer what information assessors were looking for. This was especially challenging for people who experience communication or social interactions difficult.

Participants also felt that assessments failed to capture the complexity of their needs. Some described how fluctuating needs were overlooked, with one participant explaining that "[the PIP assessment] doesn't capture that my disability can vary day to day... doesn't allow flexibility if you're feeling better one day and finding it hard the next day". Others felt the assessment focused too narrowly on whether a task could be completed, rather than the level of support required to complete it, or what happened when support was unavailable. As one participant commented, "It doesn't ask deeper questions. For example, if I can cook – I can make beans on toast but that's about it".

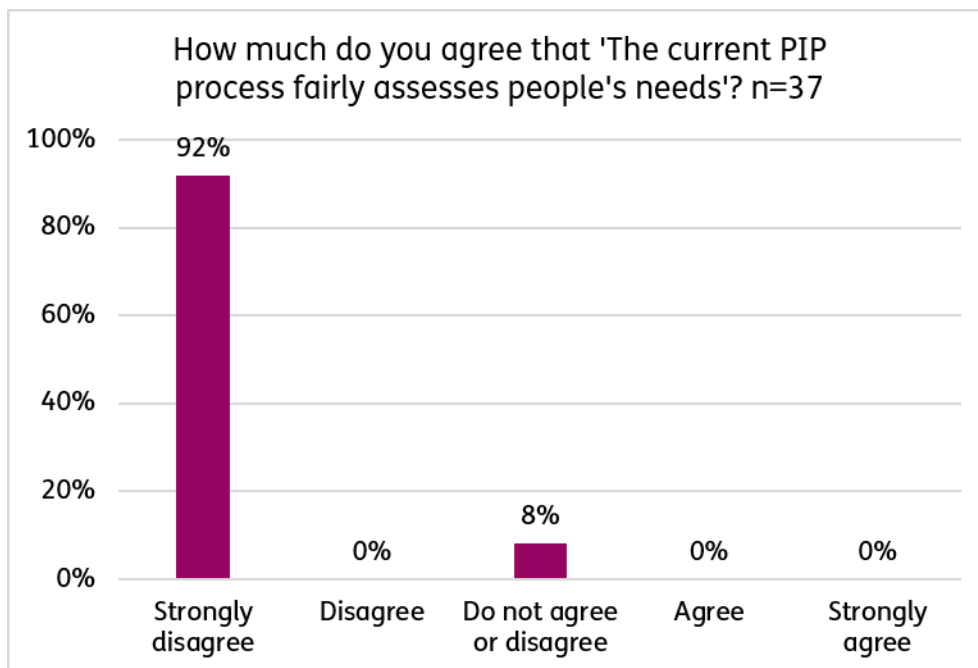


Figure 2. Chart shows the percentage of respondents (n=4) answering from 'Strongly disagree' to 'Strongly agree' in response to the statement 'The PIP process is accessible'.

A recurring theme was the perception that assessors did not fully understanding learning disabilities or their impact, despite having a responsibility for making decisions about who receives PIP. Participants felt that this particularly disadvantaged those whose needs were less visible or who received less formal support, with a few suggesting that they were “set up to fail” from the outset.

Participants also questioned the need for repeated reassessments when their condition was permanent and their needs unlikely to change. Having to repeatedly complete forms and provide the same information was widely described as frustrating and unnecessary. As one participant put it, “stop the stupid assessments – I will always have a learning disability, I cannot be cured”. Another commented: “Don’t keep reassessing me, my condition is not going to improve – it’s not a broken arm”. However, a small number of participants highlighted examples of good practice from individual assessors, with one participant recalling how they felt listened to during their assessment: “When I had an assessment, the assessor could see that I had cerebral palsy and told me that I should never need another assessment... I felt listened to”.

Overall, participants felt that the process lacked a person-centred approach and did not adequately explore the individual impact of having a learning disability. As one participant explained, “It doesn’t focus on me as a person – the assessment is very cold and uncaring”.

3.2.4. Importance of support

A majority of participants described relying on family carers and support workers throughout the PIP process, including having support to complete forms, travel to assessments and answer questions confidently and accurately. This was particularly the case due to how inaccessible the process was found to be in its current form, as well as perceptions of limited understandings of learning disability. Workshop discussions centred around how supporters could help people with a learning disability to accurately explain their needs to secure necessary supports.

Across the sessions, participants suggested that “the outcome can depend heavily on whether someone has family, carers or another strong support network” highlighting how those without support may be disadvantaged in the process. Similarly, participants reflected that people with help can explain their needs more effectively and may receive a better outcome than people applying alone. When things go wrong, the impact of supporters was furthermore felt. One participant spoke about how they attended a PIP review without a supporter and the outcome of the review was that their PIP was stopped. This experience was distressing, but their support worker was able to get payments restarted.

4. Solutions identified by people with a learning disability in Workshop in a Box sessions

Barrier	Solution
Forms and information about PIP are hard to understand and complete.	Accessible forms and information about PIP - available in Easy Read
Questions on forms and in assessments are complex, vague and sometimes irrelevant. Fluctuating needs are not recognised.	More specific questions, tailoring application forms and assessments to someone's learning disability. Questions should also allow for fluctuating conditions to be better represented.
It can be challenging to explain impact of learning disability.	Ask for and attribute appropriate weight to input from people who know individuals applying for PIP – like family carers and support workers.
High anxiety when attending in-person appointments in unfamiliar environments or when being assessed over the phone.	Clearly providing the option for Assessments to take place in someone's home or within their community if they'd prefer.
Assessors don't understand learning disability and don't act in a person-centred ways.	Assessors should take greater time to get to know individuals. Whoever assesses and makes decisions about

	PIP should receive learning disability-specific training.
Process doesn't take into account how an individual communicates and there is a lot of uncertainty.	Clearer communication at all stages of the process – including asking for communication preferences when someone first applies for PIP, and keeping people updated during periods of waiting for application and assessment outcomes.
People who do not have access to support or advocacy can be disadvantaged.	Provide free advocate services – particularly for people with a learning disability who may not have someone to support them

Figure 3. Summary of barriers to PIP being a fair and accessible process for people with a learning disability and solutions identified by participants. Note: Table does not comprehensively summarise barriers – focus is on the suggestions given for improving PIP application, assessment and decision processes. Note: these are suggestions from WIB participants and are not Mencap official policy positions