

Research about the extra costs of living with a learning disability

Why do the research?

People with learning disabilities often spend more money than people without a learning disability on things they need.



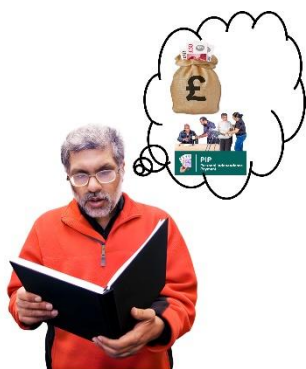
These extra costs are not always talked about or understood.



Mencap paid a company called Cordis Bright to do some research.

The research wanted to help people to understand:

- What extra things people with learning disabilities need to pay for
- How a benefit called PIP (Personal Independence Payment) helps them
- What might happen if the government changes PIP.



What did they do?



The research involved 15 interviews with people with learning disabilities and / or family members or carers who support them.



Mencap helped to find people to take part. The interviews happened over 3 weeks between February and April 2025.



About half of the people who took part had mild or moderate learning disabilities.



They took part in the interviews by themselves or with support from a family member.



About half of the people who took part had severe or profound and multiple learning disabilities.



Family members took part in the interviews and answered the questions for the person with severe or profound and multiple learning disabilities.



The study was made easier for people to take part in. For example:

- Using easy read information
- Having longer interviews
- Talking to different family members
- Having breaks during the interviews.

What did they find out?

Part 1: The extra costs of living with a Learning Disability



People with learning disabilities have to pay extra for lots of different and important things, including:



- Specialist clothing, shoes, and bedding. They need to replace these items often.



- High grocery bills to buy food because of problems with some foods and sensory needs.



- Medication, personal care products and therapies that you cannot get from the NHS.



- Sensory equipment and communication aids.



- Transport and changes to vehicles.



- Looking after their home and energy bills. For example, they might need to use more water for washing clothes and bedding or have the heating on more if they cannot move around to keep warm.



- Activities, hobbies and services that help them to stay well. For example, sports or arts and crafts.



All of these things are important. People need them to be safe and well.

Part 2: About PIP



People with a learning disability often find it difficult and stressful to apply for PIP because:



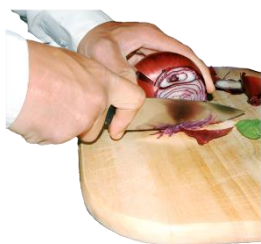
- The forms are hard to understand



- People who do not have support do not always know how to say what help they need



For example, they might say they can cook a meal...



But they do not say they need help to peel and cut vegetables, or to set the timer on the microwave.



People who apply for PIP feel that the people who look at the PIP applications and the people who do the assessments do not understand learning disability.



This means that people who should get PIP do not always get PIP...



Or they get the wrong amount of PIP.



This also means that sometimes people have to try to change the decision about their PIP application.



Some people said they got very upset and anxious when they tried to change the decision about their PIP application.



It is easy to see that people who have profound and multiple learning disabilities need a lot of help.



But carers and families of people with profound and multiple learning disabilities said they felt they had to prove that they need a lot of help before they could get PIP.



Most people said they do not get enough money from PIP to pay towards the extra cost of living with a learning disability.



This means they or their family might have to have to pay with their own money.

What might happen if the rules about PIP change?



If people did not get PIP, or got less money from PIP, life would be much harder.



People might not have enough money to:

- Pay for things they need
- Be independent
- Get the help they need
- Take part in their community.



Families and carers said they might have to provide more help.



They might have to work less hours to have enough time to do this.



Or they might have to use their savings to pay for help.



People are feeling anxious about the changes that might happen.



The changes they are most anxious about are:

- Having an assessment
- Who can get PIP
- The number of points you score.

The people who make the rules about PIP should:

- Listen to people with a learning disability
- Include people with a learning disability when deciding what changes to make
- Understand that people need PIP to pay towards the extra costs of living with a learning disability.



What will happen next?



Mencap plans to use this research to show government that people with a learning disability need a better way to get help with the extra costs of living with a learning disability.



Other people can use this research to help them to make sure that people with a learning disability are not left out.