



Learning Disability England

**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 exists to make life better for and with people with Learning Disabilities and their families.

## How we work

**Support** others work

**Celebrate** others action or achievements

**Lead** when taking action together is best

## We do this through

1. Membership – for people and organisations creating stronger links together
2. Influence and campaigning – speaking up and sharing others important work
3. Solving problems together & sharing what works
4. Share information and build networks so we learn together



Learning Disability England





# Learning Disability England

**Members work together to build a world where people with learning disabilities have good lives with equal choices and opportunities as others.**

At the end of March 2025 there were

171 organisation or group members

535 individual members



# Positive Behaviour Support



## What we did

Told people about the Neurodiverse Connection campaign

Asked members – what is your experience?

Had a survey open from 28<sup>th</sup> May until 25th July

It was only sent in the members newsletter but some people shared it wider so we added a question asking if people were a member.

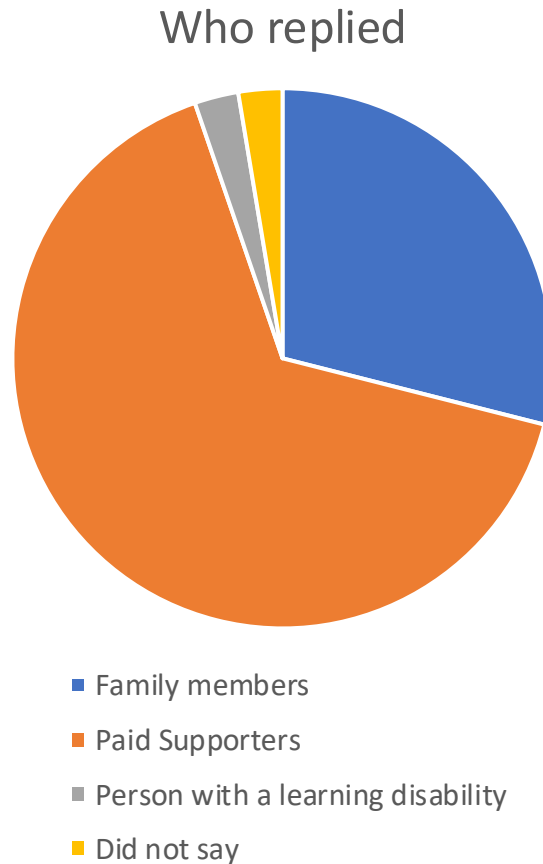
Had some conversations with members



# Positive Behaviour Support

## Who we heard from

115 people replied to the survey (at 25th July)



75 of those identified as being in paid supporter roles

- Service Managers
- Direct Support Staff
- PBS leads in services or academic roles

34 people told us they are family members of someone with a learning disability

3 people told us they have a learning disability

3 people didn't tell us what kind of member they are

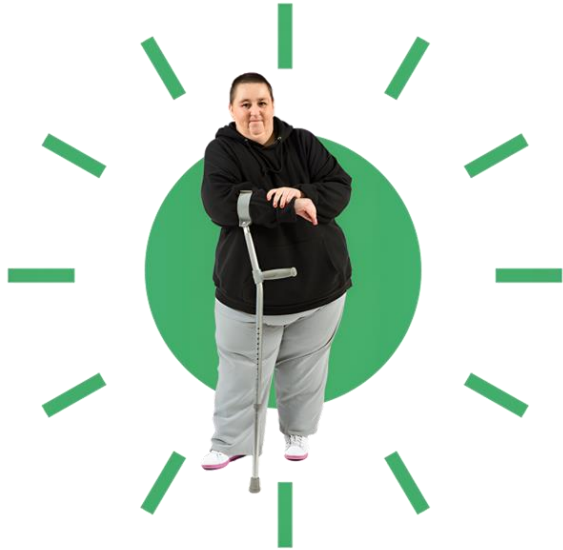
# What is working for people

There were lots of examples from families and paid supporters where the use of PBS has had a positive impact on the quality of people's lives.

Particularly where PBS focuses on great communication, trust and understanding what is important to the person and how they live their life.

**'We change the environment not the person, we change the way staff support and not the person. '**

Another member described PBS as **'a compassionate, values-based approach that puts empathy and patience at its core. It's about seeing the person first — not just the behaviour — and supporting them in ways that are respectful, meaningful, and sustainable.'**



# What is working for people



We heard that people are happier, less anxious, not having to take psychotropic medication and living fuller lives - going out and doing more things and learning new skills.

**'PBS is the way I would want to be treated, it works for our family and our daughter who has a severe learning disability and is autistic. It is my behaviour that had to change as a parent, when I understood that the behaviours we found challenging were a form of communication, and we understood what my daughter was trying to tell us, and then provided what she needed everything improved immediately.'**



# What is working for people



PBS was described by some members as being most useful when it is used alongside other approaches such as active support and person centred planning.

Feedback from both paid supporters and family members described PBS as a framework that focuses on quality of life and therefore more useful for people with a learning disability who might not otherwise be listened to properly:

**'it's a method of allowing the 'voice' of a very disabled person to be heard... I would be EXTREMELY concerned if his 'voice' were not heard'**



# What is not working for people



There was a lack of clarity amongst members about what PBS actually is:

**'I don't know what PBS really is. I don't fully understand it. I do not think it is properly regulated and people can say they understand it when they don't. '**

This lack of clarity links to other points raised by members are more likely to happen

Some members find the use of the word behaviour in the name unhelpful.

# What is not working for people

Many members raise the concern that PBS practice can vary across the country, when it is used by people who do not understand its purpose.



Poor practice can be restrictive, with a focus on managing and changing behaviour.

**'When used well, the experience for people with learning disabilities and/or autism can be fantastic .... the problem is that it is not always done well.'**

# What is not working for people



Understanding autism and what this means for someone who also has a learning disability was seen as really important and not always present:

**'if there was good autism practice and understanding, much PBS would not even be needed in the first place'**



There was a concern from some members that PBS has become a "Buzz Term" enabling a range of practice and skill which isn't always good enough - and at times damaging to the person.

This can happen more often if the use of PBS plans are required by commissioners with outcomes measured by the number of incidents and numbers of staff trained in physical intervention training.

# What next?



We did not hear from self advocates or members who have experienced PBS for themselves.

We know this was a limitation of doing a survey. 2 people who identified as a learning disabled member were negative about being judged.

Making sure people with learning disabilities who experience PBS are heard in their own lives and the wider PBS debate is an important part of understanding better the issues being raised.

# What next?



How do we understand how the use of PBS has really improved someone's quality of life?

This includes how quality of life is measured and by whom - paid supporters? family members? commissioners? the person themselves?

The feedback shows how PBS is making a difference for some people.

It also raise concerns about whether it is understood in the same way by everyone and whether the quality of practice is consistently good enough. Without this, it is likely that PBS as a framework will continue to be misunderstood and practiced.