Learning Disability England

# Experiences of Positive Behaviour Support

What we heard May – July 2025

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## About Learning Disability England

**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

## About this work

The elected members Representative Body decided Learning Disability England should ask members about their experiences of Positive Behaviour Support (PBS).
Read about what they said here

Learning Disability England did this to understand more about members' experiences of PBS.
We wanted to hear ideas from people with direct experience.

How we did this means we did not hear directly from more than 1 or 2 people with a learning disability.
We think this is a big gap and means we did not hear an important view.


This is a short report on what we heard.

## About Positive Behaviour Support and ABA

Positive Behaviour Support is a way of working that aims to understand people's behaviour, especially if someone's behaviour is challenging to other people or causing that person harm or distress.

It aims to help supporters understand what matters to someone and support them well.


There is some easy-read information from the UK society for Behaviour Analysis here.

It has become more common for PBS to be used by provider organisations and for commissioners of support to request it.

Sometimes PBS is criticised for being like Applied Behaviour Analysis.

Applied Behaviour Analysis (ABA) is a way of working that focuses on understanding behaviour and through collecting information and reinforcement, increase positive behaviours and decrease negative behaviours.

People who are positive about ABA say it can help people learn new skills or change how they behave.

Some people think ABA is controlling and does not respect people's identity.

Some people in their replies to us talked about ABA.

Most people said PBS is different to ABA and focused on quality of life, but a few people said they think ABA is a good way of working.

## What we did

We told people about the Neurodiverse Connection campaign that says PBS does not work for autistic people.

At the same time we asked members 'What is your experience?'

We had a survey open from 28th 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.

We also had some conversations with members and a members meeting with some Neurodiverse Connection reps.

## Who we heard from

115 people replied to the survey.

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

75 people identified as being in paid supporter roles

3 people told us they have a learning disability

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


From the comments people made we could work out their roles.

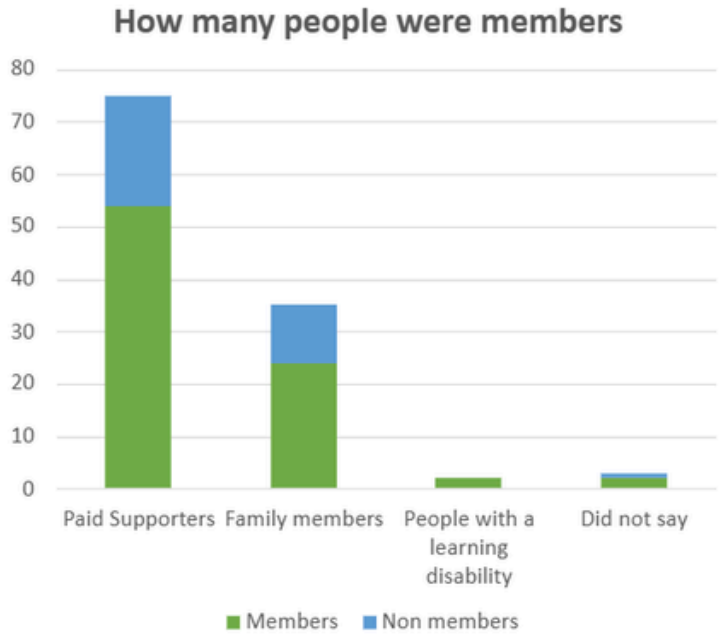
We did not directly ask people their roles so these are our version of what people said.

We could be wrong so we share these as an indication only.

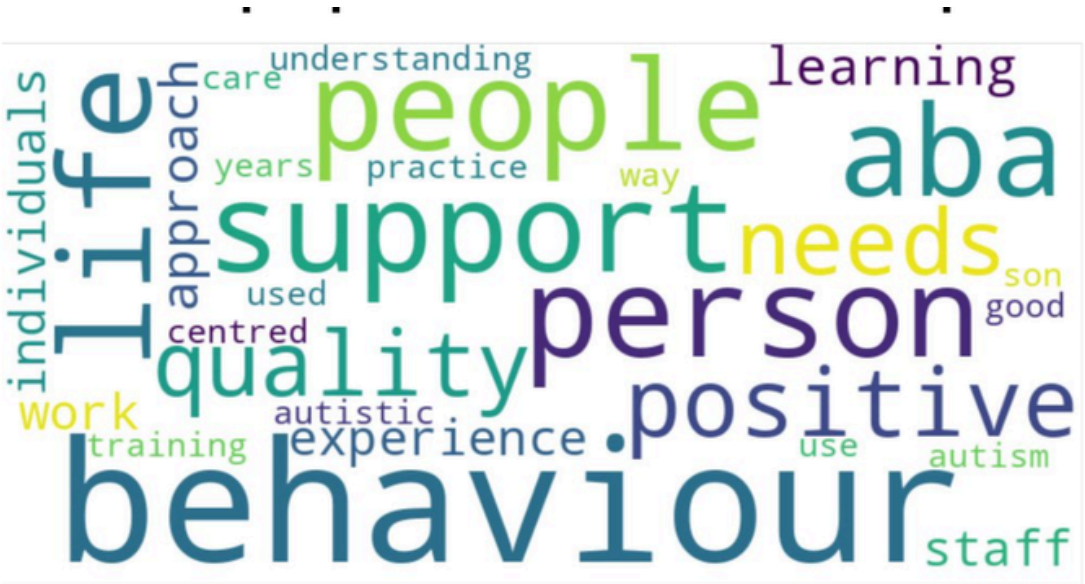
75 of those identified as being in paid supporter roles:

- Service Managers or Team Leaders (15 people said this)
- Direct Support Staff (4 people said this)
- PBS leads or coaches in services or academic roles (51 said this)
- Registered nurses (5 said this)

Most of the people who shared experiences said they were a member themselves or part of a member organisation.




## The words people used most in their responses



## Big Messages

Many members shared positive experiences of PBS but members and non members made similar points on:

**1. PBS means different things to different people**

Many people said PBS is values and rights driven focused on quality of life.

A few people said it controls people.

Others saw a link to ABA either as positive or negative.

Some people told us they don't know what it is or understand the purpose.

**2. Experiences of PBS are mixed**

We heard of experiences where PBS has been positive and 'life changing' (quote from a family member).

Also, we heard concerns about approaches that:

- try to change people,
- are well not implemented
- not well understood by some teams


**3. Implementation, and culture are critical**


Many people's experiences included feedback on how important it is PBS tools are well implemented with a strong values framework.

Some of the negative experiences shared were linked to poor skills, management or values.

For example a family member told us:

*"Our adult son was 43 when we organised a reputable PBS provider to work with him [..]. He now has strategies to help him avoid meltdowns and he is able to hold more sensible conversations with other people having learned how to show an interest in their activities. As parents we are very pleased with the progress he has made - it is not a miraculous overnight success - he can still be difficult on occasions but he is a more content and complete person now...*

*...The only difficulty I can report is that our son lives in a residential setting which claims to deliver PBS but clearly does no such thing. It appears that a company director believes they are sufficiently knowledgeable to train staff members to deliver PBS. The PBS Plan produced for our son was frankly laughable - a cut and paste exercise which bears little resemblance to the monthly reports we receive from the reputable provider whose team are fully qualified - UKBA(cert) and Board Certified Behaviour Analysts as well as a Chartered Psychologist."*

A Social care deputy Manager told us:

*"I have found pbs helpful but at times it can be confusing and words that are used can be hard to pick up and use the correct terms"*

**3. Quality, training and regulation**

Many of the people who replied talked about the importance of PBS knowledge and skills, regulation and quality measurement.

*Someone said:*

*'I'll start with the primary limitation. Positive Behavioural Support (PBS) is not currently a regulated field. Practitioners enter the field from a variety of professional backgrounds—some are psychologists, others are behaviour analysts, learning disability nurses, or social workers. Consequently, the quality of PBS provision varies widely. This inconsistency makes it difficult to assess PBS as a unified field, as not all practitioners possess the same level of training or expertise required to deliver services to a consistently high standard.'*

## People's experiences

### What family members said

Most family members were positive about their family members' experience of PBS saying things like:

*"We've had positive experiences of PBS for our son. It has enabled him to live a fuller life."*

*"PBS helps support people in a way that makes life better, not just trying to fix behaviour."*

*"PBS has been life-changing. It does not use aversive and is not a method of control. Rather, it is a method of allowing the 'voice' of a very disabled person to be heard. It is a framework which focuses on quality of life."*

There were negative experiences shared though:

"My *sibling has LD & Autism, her challenging behaviours are "managed" by PBS rather than changing relations with staff or changing the environment, plus chemical coshing."*

*"In my experience PBS is rubbish and there must be a different way to use positive behaviour then what is out there, my own son team use it but actually its more ABA then PBS is used incorrectly and staff most of the time done to understand how to use it I am against its methods."*

## What is working well

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.

People said:

*"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."*

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.

Someone said:

*"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."*

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.

Someone said:

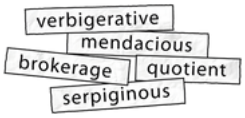
"It's a method of allowing the 'voice' of a very disabled person to be heard... I would be EXTREMELY concerned if his 'voice' were not heard' (Family member)"

## What is not working well

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 of quality and reliable practice.




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



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."*

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 if incidents and numbers of staff trained in physical intervention training.

## What member reps think and what next

Member reps said:

The direct experience of learning disabled people supported with PBS approaches is not really included in the experiences we heard.

A limitation of doing a survey means the voice of families and provider members were heard more than self advocates or people who have experienced PBS themselves.

The two people who identified as learning disabled members were negative about being judged.

We think it is important that people who have experienced PBS as part of their support are heard in terms of what they think.

As reps we are left unsure if sometimes PBS is being 'done to' people.


We are left with some areas we think people practicing, commissioning or regulating PBS support need to work on more:

**1. Defining Quality of Life**

How do commissioners and support providers 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.

We think the person (and their family) should decide what matters.

We think there needs to be clearer standards and monitoring to make sure any PBS is good.

**2. Understanding what PBS is and where it fits in good support**

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

It also raises concerns about whether it is understood in the same way by everyone and whether the quality of practice is consistently good enough.


**3. Control and consent**

We would like to see people's voice leading all their support (including PBS). There are good ways of understanding what matters and making decisions with people.

This is more important if someone does not use words to communicate.'

## What next?

We will:

- Share this feedback with UK-SBA and ask to meet with them to understand how the feedback will be used, especially how people themselves can be better heard in relation to the use of PBS.

- Make sure all members know about this and check if they want to add anything.

- Look for chances to help learning disabled people's direct experiences be heard in research.

- Keep campaigning for all support to be rights based focused on a good life as part of our work as part of Good Lives.