

Funded by



**making a difference  
to the lives of people with  
severe learning disabilities**

## **Making positive behaviour support (PBS) work: meet Rebecca**

Rebecca has a rare genetic condition which presents as a severe learning disability, autism, an eating disorder and mild self-harm.

When Rebecca moved into a shared residential home from her family home, the number of incidents of behavior that challenge increased. This prompted her support team to introduce PBS and Rebecca moved into her own flat. Since then her wellbeing has improved and she is more active in her community. In this case study, her Mum explains how PBS has supported Rebecca and what her PBS plan includes.

### **Background**

As a child Rebecca lived at home, attended the local special school and went on family holidays abroad without incident. Rebecca spent about two years in an unsuccessful residential special college placement followed by ten years back in the family home.

We worked hard and with some success at providing her with skills to communicate more effectively without having to challenge. She then tried living in a local residential home, but found sharing with nine other people too restrictive and her challenges re-appeared.

The psychiatrist felt that the residential home was an unsuitable environment and Rebecca needed a whole new way of support that sees behaviour that challenges as part of Rebecca and a form of communication, not something to get rid of. This is when we started using PBS.

Rebecca also moved into her own flat. Space is important for Rebecca as she doesn't like sitting next to other people or her things being moved from where she left them. In the residential home Rebecca was often stressed by sharing space with other people. In her flat Rebecca can have her own space, but can also choose to join in with other people when she wants to.

## Implementing PBS

I was very much involved in the PBS process as I have a background in working with people with special educational needs (SEN). – I was a partner in developing the PBS plan with Rebecca and her support team, and led the implementation of PBS. The professionals involved were happy to be led by me researching strategies such as PBS to try with Rebecca.

The support plan contains as much information as possible about Rebecca. It makes the most of the things that Rebecca enjoys, and details the things to avoid that she finds stressful, such as people talking about her while she is in the room.

It also has information about behaviours that challenge and strategies for proactive support, depending on how calm or stressed Rebecca is. Embedded in this is a focus on communication and a way of thinking about behaviour as a method of communication. This has helped us to find out the reasons for specific behaviours, and I can meet with professionals to discuss what they might be trying to tell us. These can be general things such as not wanting to wait, to very specific things such as certain weather conditions. This helps us to implement more effective strategies to support Rebecca.

It is a document that Rebecca doesn't mind having around the flat. Rebecca doesn't like having certain documents around if she perceives them as negative, so the behaviour support plan is very positive with lots of pictures, so that Rebecca is comfortable with staff having and reading the plan.

There are two versions of the behaviour support plan - a full detailed plan and a shorter version which can be accessed quickly day to day. To familiarise themselves with the plan in practice, new staff shadow more experienced staff so they understand how to implement the plan properly.

## How has PBS improved Rebecca's quality of life?

One of the biggest changes about how Rebecca is supported by using PBS, is **choice**. Her staff team have a culture where they are there to facilitate what she chooses to do, not to direct her or make choices for her.

Rebecca uses photos and the choice of one of two hands to make her own decisions about all kinds of things, such as where to go or what to eat.

She also has picture timetables to explain what is happening during the day and which carers will be coming that week. These pictures have helped Rebecca choose her own staff – for example when Rebecca repeatedly took down the picture of one staff member it was clear that she didn't want them to support her. They also help her to understand who will be supporting her in the future - she is able to see who will be coming that week and help staff to explain when someone will be away for a little while. Photo stories help explain events that will be stressful or upsetting, such as when Rebecca's favourite

carer went on maternity leave, a photo story explained that she will be away for a while, but will come back.

Staff use creative and innovative ways to support Rebecca, such as using whatsapp to send photos to family. This is an effective channel of communication so that Rebecca can share what she is doing with family, and see what they are doing as well.

Through PBS Rebecca's preferences can be better met and she can be actively involved in day to day activities – they are not all 'done' for her. For example Rebecca enjoys spending lots of time in the community now, whereas in the residential home she had to take turns in accessing the community as there was limited staff and transport. Now she has much more flexibility to decide what she wants to do, and plans can be made around her needs. Staff have a contingency fund to help avoid stressful situations, so if the bus is too full or the train is delayed, they can get a taxi instead.

PBS has helped to reduce incidents of behaviours that challenge, and has meant that Rebecca now takes significantly less medication than when she left the residential home. When PBS was started, Rebecca took three different kinds of medication in addition to PRN medication. Now, Rebecca takes a very small dose of one medication with no PRN. I had serious concerns that if Rebecca's support was not changed when she was in the residential home, that Rebecca would become extremely highly medicated.

### **Challenges of using PBS**

One of the biggest challenges with this approach has been keeping staff on board as it can be easy to lapse into 'lazy' ways of working and a 'caring control' attitude. It is important that staff keep making the effort to give Rebecca real choices, the time to make those choices and making sure that they understand her choice.

### **Staff support**

Rebecca has six staff members who all support Rebecca 1:1 one day per week. This has worked well as they start fresh and prepared to support Rebecca when they arrive, rather than using easy ways of 'caring control'. Staff attitudes have been an important factor throughout the process, as they have found creative ways of supporting Rebecca to allow her to do the things she enjoys and having a good life.

### **Benefits of PBS**

A PBS approach has led to improvements in quality of life for all involved.

There have been big differences for Rebecca. As well as greatly reducing the medication she was taking, I think that Rebecca is less anxious and is now more trusting of the people who support her. Before PBS was introduced, Rebecca's life was very narrow and centred around watching videos and eating snacks. Now she has a very busy diary

and eagerly looks forward to activities rather than having to be constantly cajoled.

I also now feel like a parent rather than a carer, and can do things with Rebecca as with my other children, such as going round to visit or meeting for coffee.

For Rebecca's support staff, I think that they are now able to develop more strategies for a good relationship with Rebecca.

### **Challenging Behaviour Foundation, 2018**

Thank you to Rebecca's mum for providing this case study. Rebecca's name has been changed to protect her identity.