



**The Challenging
Behaviour Foundation**

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



POSITIVE BEHAVIOURAL SUPPORT (PBS)

AN INFORMATION PACK FOR FAMILY CARERS

Positive Behavioural Support (PBS): an Information Pack for Family Carers has been produced by the PBS Academy and the Challenging Behaviour Foundation (CBF). This resource was originally split into 5 separate resources which have been put together. All resources are the same as the separate resources with the exception of resource 5, which has been updated.



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Acknowledgements

The development of *Positive Behavioural Support (PBS): an Information Pack for Family Carers* was made possible with the help of a number of individuals and organisations. We would like to thank:

- Viv Cooper, Jen Fookes, Nick Gore, Jacqui Shurlock and Serena Brady for their contribution to the content.
- Family carers who provided us with examples of their experiences.
- Jen Fookes and her son and Kate Farmer and her daughter, who allowed us to use their photographs.
- The Challenging Behaviour National Strategy Group and The Challenging Behaviour Foundation Family Carers' Review Panel, for their feedback on draft documents.
- The Early Intervention Project, funded by the Department of Health, for contributions to content and for the cover design.
- Skills for Care for the use of their facilities.

Louise Denne and Alison Branch chaired this working group and were responsible for writing, editing and producing the overall content. Richard Hastings and Steve Noone were part of the Steering Group for this project.

We would like to thank Alison Branch and Jill Chaplin for their work updating *Resource 5* with support from the UK Behaviour Analysis PBS Special Interest Group.

Finally, we are extremely grateful to Mencap who gave us funding for the completion of this project, as well as help with the production of this resource.

Further information

To see all resources in this pack and additional information from The PBS Academy, The Challenging Behaviour Foundation and the CBF & CDC's Early Intervention Project go to: www.pbs-academy.com www.challengingbehaviour.org.uk

¹The PBS Coalition laid the foundation for the establishment of the PBS Academy and all materials are now published under the PBS Academy name.

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Positive Behavioural Support: A family carer perspective

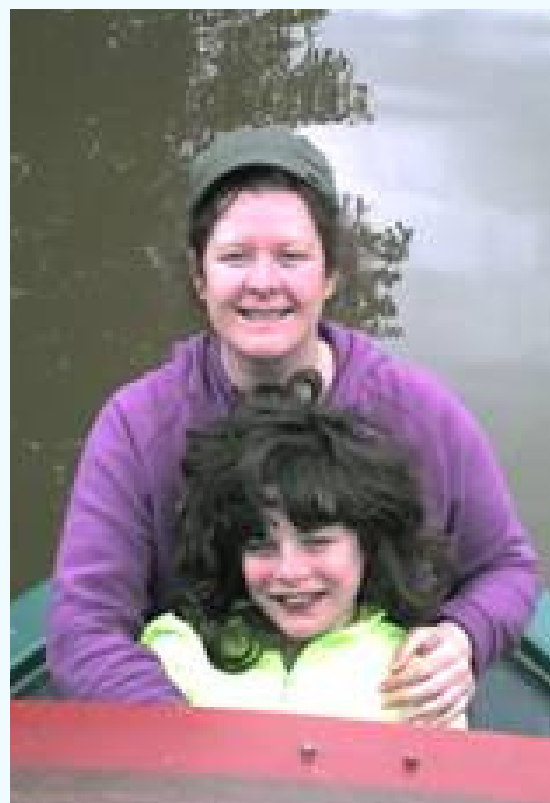


I had never heard of Positive Behavioural Support until I met the Challenging Behaviour Foundation in 2008-9. I found this was the best way to support my daughter, taking into account who she is, how she experiences life and what she might want in her life. This entails a cohesive approach from all sides (family and all professionals). It is not always easy to work out what it is that my daughter wants. It can be difficult putting in place activities and things that may not be of her choosing but are needed to either broaden her world or get essentials done.

It can be difficult achieving a consensus – sometimes there is a difference of opinion between family and professionals, this is never easy to overcome, and families are systematically placed in the wrong. It was hard to get the right people on board and their commitment – carers and other professionals. There is not very much available in the community to support people with severe learning disabilities.

What were the benefits for your family?

We started experiencing joy in caring for and supporting our daughter. Her self-worth rocketed. Her behaviour became less challenging and she was less confused and able to communicate her needs better. This made it possible to put in place strategies and plans to meet those needs and also, to find ways of helping her understand her world and how it merges with other people's worlds a bit better. We started seeing our daughter's strengths and valuing her as an equal in the family. We had been seeing her behaviour as a difficulty which needed to be fixed and PBS helped us realise that it was us who needed to make changes to our perception and values – understanding that behaviour = communication. We are currently living together again and it seems to be working.



Thanks to Kate for sharing her experiences and pictures of her daughter.

How to use this information pack

This pack of resources aims to provide information about Positive Behavioural Support (PBS)². It explains what it is; what it looks like in practice; provides questions to ask to check that PBS is being delivered well in the setting you are looking at, and guidance on how family carers can find out more including advice on training.

There are a number of things that people need to know and do in order to deliver PBS well and these are outlined in the PBS Competence Framework. The information in this pack is based on this framework, you can find [further information here](#).

We have tried to use words that are easy to understand throughout this pack. However, there are some words used in PBS that you may be unfamiliar with. We have explained these where possible in *Resource 2* so you can use this as a reference when faced with words that require explanation. However, you should always ask people to explain what they mean if you are in a situation where you are unclear.

There are **FIVE** resources in this pack. They can be used individually or together as a whole, depending on what kind of information you require.



Resource 1 – What is Positive Behavioural Support?

This will help you understand what PBS is and offers links to other sources of information to develop your knowledge (page 6).



Resource 2 – What should Positive Behavioural Support look like?

This will help you learn more about PBS and what you might see in a PBS service/school. It will tell you what people should be doing to support your relative and things you can ask to have a look at. For example, a Behaviour Support Plan (page 11).



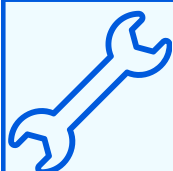
Resource 3 – Questions to ask to check whether Positive Behavioural Support is being used well

This will provide you with some questions to ask of a professional or service about the quality of PBS being offered. This might be helpful if you are choosing a provider or as a way of preparing for an assessment of your relatives's needs (page 28).



Resource 4 – Family carers using Positive Behavioural Support

This will help you understand what PBS is and offers links to other sources of information to develop your knowledge (Page 41).



Resource 5 – Practical tools

Here are a range of examples and templates to help you use and understand PBS (page 46).

² Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour.

Resource 1

What is Positive Behavioural Support?



What is Positive Behavioural Support?

Positive Behavioural Support (PBS)³ is an effective and ethical way of supporting people with learning disabilities who are at risk of behaviour that challenges. PBS is a framework for developing an understanding of behaviour that challenges rather than a single therapeutic approach, treatment or philosophy. It is based on an assessment of the broad social, physical and individual context in which the behaviour occurs, and uses this information to develop interventions.

The overall goal of PBS is to improve the person's quality of life and of those around them, thus reducing the likelihood of challenging behaviour occurring in the first place. When a person receives PBS, it is unlikely to come from just one individual, one professional group or one service. Families, carers, professionals, service providers and commissioners need to work together, and each play their part in supporting that person.

The PBS framework is made up of ten core elements each of which should be included and visible if a service is providing PBS. The elements relate to the values that underpin PBS, the theory and evidence base that supports PBS interventions, and the process, i.e. the methods used to implement PBS (see page 8).

PBS and/or its components have been recommended in a number of policy documents and professional guidelines⁴ including the NICE guidelines for Challenging Behaviour; Ensuring Quality Services; Positive and Proactive Care: Reducing the need for Restrictive Interventions and A Positive and Proactive Workforce.

³Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour.

⁴Full references are provided at the end of each resource.

Box 1: The Core Elements of PBS (Gore et al., 2013)

Values

1. The core aim of PBS is to improve the quality of life of the person and those around them by preventing and reducing challenging behaviour.
2. It works by developing and building skills of the person and of those who support them rather than using aversive (i.e. unpleasant) or restrictive (i.e. limits the person's movement or activities) interventions.
3. Practitioners work in partnership with the person and all of those who are important to them including their family and friends, carers, and other professionals and actively include them in assessments, defining targets, implementing interventions, and reviews.

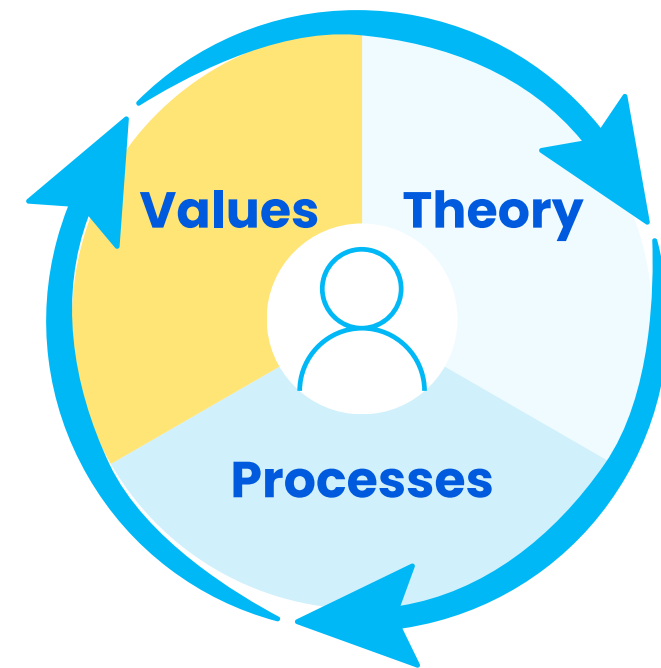
Theory

4. All behaviour, including challenging behaviour, happens for a reason - understanding what this is (practitioners call it the function of the behaviour) can suggest how to make sure the person has access to the things they need in other ways (e.g. by changing the environment, teaching them new skills etc.).
5. PBS uses the principles and procedures from behaviour analysis to assess and support skills teaching and behaviour change.
6. Other, complementary evidence-based approaches may be included in PBS plans (e.g. Cognitive Behaviour Therapy, Parent training for children who display challenging behaviour, early intervention for children aged 3-5 with emerging challenging behaviour).

Processes

7. PBS bases decisions on information gathered about a person's skills, behaviour, and needs.
8. A functional assessment helps to identify the reasons (function) for a person's behaviour and is used to create a clear and structured plan of action.
9. A PBS plan will include **proactive strategies** to prevent challenging behaviour from happening, strategies to teach new skills to make the challenging behaviour less likely and **reactive strategies** that minimise restriction if it does occur.
10. PBS is not a quick fix: the aim is to actively support people over the long-term and to monitor and maintain their quality of life.

Each of the 10 elements must be included and visible in any service delivering PBS; and each must have as their central focus, the person being supported and their family.



Other resources to help you understand more about PBS

The following resources are available free of charge:

A short animation

The British Institute of Learning Disabilities (BILD) have produced a six-minute animation which summarises PBS. You can access it at: <https://vimeo.com/347636344> or you can email BILD to ask them to send you a copy: capbs@bild.org.uk

Information sheets

The Challenging Behaviour Foundation provides information and support for family carers of people with severe learning disabilities and behaviours described as challenging. The information sheet about [Positive Behaviour Support planning](#) provides information on supporting a family member who displays challenging behaviour. It explains what a Positive Behaviour Support Plan is, who needs one and why.

It should be read alongside the information sheets [Understanding challenging behaviour](#) and [Finding the reasons for challenging behaviour](#). All of our Information Sheets can be found at: <https://www.challengingbehaviour.org.uk/information-and-guidance/> or can be ordered free of charge by emailing info@theCBF.org.uk.

Video resources for family carers

Challenging Behaviour: Supporting Change. This two-part video is free to view on our at: <https://www.challengingbehaviour.org.uk/understanding-challenging-behaviour/what-is-challenging-behaviour/video-resource-challenging-behaviour-supporting-change/>

References

Department of Health (2014) *Positive and Proactive Care: Reducing the need for restrictive interventions*, London: DH. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JR_A_DoH_Guidance_on_RP_web_accessible.pdf

Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, C., Baker, P., Hastings, R.P., Noone S., & Denne, L. (2013). *Definition and Scope for Positive Behavioural Support*. International Journal of Positive Behavioural Support 3 (2) 14-23.

NHS England & Local Government Association (2014) *Ensuring quality services: Core principles for the commissioning of services for children, young people, adults and older adults with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges*. London: NHS England & LGA. Available at <https://www.local.gov.uk/sites/default/files/documents/ensuring-quality-services-701.pdf>

NICE (2015) *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges*. NICE guideline 11. Available at <https://www.nice.org.uk/guidance/ng11> [NICE guideline]

Positive Behavioural Support (PBS) Coalition UK. (2015) *Positive Behavioural Support (PBS): A Competence Framework*. Available at <https://pbs-academy.com/wp-content/uploads/2016/11/Positive-Behavioural-Support-Competence-Framework-May-2015.pdf>

Department of Health, Skills for Health and Skills for Care (2014) *A positive and proactive workforce. A guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health*, London: DH. Available at <https://www.skillsforhealth.org.uk/images/images/news/A%20positive%20and%20proactive%20workforce.pdf>

The Challenging Behaviour Foundation. *Information sheet on Positive Behaviour Support Planning: Part 3*. Available from <http://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf>

Resource 2

What should Positive Behavioural Support look like?



What should Positive Behaviour Support look like?

How to use this resource

You might be about to visit a service or school that you are considering using for your relative. You could be thinking about the service/school that currently provides support. Or you might be preparing for a home visit from a professional and you want to check that they have a good understanding of Positive Behavioural Support (PBS)⁵. Use this resource to help you “get a feel” of whether the service/school/professional is really doing what they claim in relation to PBS. If a service/school is providing PBS well, there will be some key things that you should be able to see and experience in the way people are supported.

These are essential aspects of PBS, and each one is considered in turn within this resource:

- People are valued and respected
- Supporting communication, health and well being
- Involving everyone and working in partnership
- Functional assessment (an assessment to understand why challenging behaviour is happening)
- Developing and using a Behaviour Support Plan
- Skills teaching and development
- Staff skills and support

Under each of these headings, other families tell us what best practice looks like for them and their relative. A checklist is then provided of things that you should look for, experience or ask to see when you visit or meet a professional providing PBS.

If it is helpful, you can tick these things off during or after your visit. There is also a space to make notes should you wish to do so.

You may then want to consider what you have seen and discuss your views with other family members/friends, the professional/service/school themselves, their manager, your care co-ordinator etc.

Resource 3 will help you ask more detailed questions (should you wish to do so) where you will be able to check things out further. At the end of Resource 3 there is some information on what to do if you are unhappy about what you have seen or do not receive satisfactory answers to your questions.

⁵ Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour

People are valued and respected as individuals



Best Practice Examples

Family carers say my relative's individuality is respected and supported by...

"Having his own communication placemat and a Positive Behaviour Support Plan that all people who work with him read and understand thoroughly. By working around his needs, as he is less able to adapt. By having a familiar routine that is adhered to daily. Different routines for different settings."

"Making sure that she has regular opportunities for trips out to go for walks, to visit shops, to buy the odd takeaway and go for drives. To be able to use her annual season ticket to visit the zoo."

"Making sure no one else goes into his room either when he is there or when the room is empty. Also to make sure that his belongings are not used, abused or lost by staff or other residents."

"Offering appropriate choices during the day to allow him to participate in activities that he enjoys. Choices should include what to do, what to wear and what to eat/drink. Being able to change into nightwear instead of going to bed in his day clothes."

Things you should see:

- ☐ People are supported to make and be involved in decisions about their support, e.g. where they live, what they do throughout the day, who they spend time with etc.
- ☐ The person is at the centre of the support they receive, and staff recognise each person's abilities and needs.
- ☐ Staff are friendly and talk to everyone with dignity, warmth, respect, empathy and compassion.
- ☐ People are supported to have lots of choices throughout the day for a range of things, e.g. the clothes they wear, food, activities etc.
- ☐ People's religious and cultural needs are supported, e.g. they are supported to go to their place of worship if they want to.
- ☐ Staff use a range of ways to find out what each person likes and dislikes, e.g. asking the person or others who know them and respecting these when providing support.
- ☐ People spend time doing activities and meeting other people in the local community.
- ☐ People are supported to make friends and to keep in contact with people they are close to, e.g. by phone, using Zoom or Facetime, writing letters, arranging social events etc.
- ☐ People are supported take part in lots of different activities and are encouraged (but not forced) to try new things.

Things to ask to have a look at:

- ❑ A **person-centred plan** (an individual plan developed by the person and others who know them well, which looks at all aspects of their life, their goals and dreams. Usually facilitated by someone with expertise in this area). You should be able to see how staff are working with the person to get the things they identified as their goals. Remember there may be some goals that are private to the person and written information about their progress may be kept confidentially.
- ❑ A **one-page profile** (one sheet of paper capturing all the important information about a person under three simple headings: what people appreciate about me, what's important to me and how best to support me).
- ❑ A **support plan** just for an individual, detailing how to support that person in their routines. There should be evidence of what a person likes and dislikes in this.
- ❑ A plan of **what is going to happen** each day, somewhere that the person can easily see. This plan might have pictures or symbols on it (visual timetable) as well as pictures of staff that will be on shift.
- ❑ A list of things that someone **likes and dislikes**.

Your Notes

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Supporting communication, health and well-being



Best Practice Examples

Family carers say my relative's communication needs are supported by...

"Offering regular access to the staff rota and updating him frequently on staff movements as he needs to know who is working, and who is on the next shift."

"Using symbols and photographs at school."

"Using key words in short sentences as confusion sets in easily which leads to challenging behaviour. Not chattering too much, especially if he is upset for whatever reason."

"Not ignoring him, or giving him something different to what he asked for. Not breaking promises."

"Keeping photographs nearby as these are very important to him, including photos of family and other favourites nearby. Helping him send photos and cards home now and again, these are so very precious to us."



Best Practice Examples

Family carers say my relative's physical and mental health are supported by...

"Having a stable, predictable life, walks in the country side at weekends and holidays, plenty of music at home and school including music therapy and top quality food/diet."

"Regularly offering the activities he enjoys such as kicking a football around and going for walks."

"Socialising. My son really enjoys the company of staff members to chat to and to socialise with."

"Listening to music. Allowing her to choose and listen to music of her own choice and for this pleasure not to be interrupted by others."

"Offering some activities which give him a chance to have some time away from other residents as the communal area can be very difficult for him with all the noise."

Things you should see:

- ☐ Staff talk to people using their preferred method of communication (e.g. signing) and change how they talk to people when needed.
- ☐ Staff involve family/carers, the person and other professionals in assessing and developing support plans for the person's communication, health and well-being.
- ☐ Staff keep a check on each person's health and well-being and investigate any changes in behaviour, mood or activity levels that might suggest these are getting worse and take appropriate action, e.g. book a GP appointment.
- ☐ Each person has regular health checks.
- ☐ Each person is supported to use a range of health services as needed, e.g. the GP, the dentist, diabetes nurse, dietician, chiropodist, have blood taken, etc.
- ☐ Staff support people to be involved in managing their own health, e.g. taking tablets, writing things down, exercise, using creams.
- ☐ Staff help people to make choices about their health and lifestyle by providing information and support, e.g. about healthy diet. Staff should respect a person's right to live the lifestyle they choose.

Things to ask to have a look at:

- ☐ A **health care plan** that is specific for each person.
- ☐ Use of **communication passports** (a brief snapshot about the person's likes, dislikes, how they communicate and how best to communicate with them).
- ☐ Systems that staff use to **monitor progress** with things like teaching something new, amount of medication used, weight loss, etc.
- ☐ **Data** (information on charts, in notes and assessments) recorded about communication, health and wellbeing.
- ☐ Communication aids around the service, e.g. signs/labels on things, visual timetables, **social stories** (short descriptions of a situation or activity, which include specific information about what to expect and why) etc.

Your Notes

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Involving everyone and working in partnership



Best Practice Examples

Family carers say we are be involved by...

"Doing activities and eating well to keep me well and happy so that I can take care of him well (my son is unhappy if I am unhappy)."

"We are the main carers for our son. We provide the food our son eats, (he does have school dinners too), provide clean and dry clothes for him to wear, collect and take him to and from school and keep his home clean and tidy. His father takes him out after tea and weekend mornings and showers him before bed. A care worker looks after our child once a fortnight to give us a break."

"Getting regular updates by email or phone as to how he is and what he has been doing. We would like to be more involved. Our son is the most precious thing in our lives and we would like to be involved in his life the same as any other family even though he is in a residential placement. We would like to continue to visit him regularly and him us. If he is not well we would like a phone call and to know what is being done to help him. We would like to be invited to regular 6 month reviews and have an opportunity to voice concerns. We want to be taken seriously and treated as equals."



Best Practice Examples

Family carers say professionals and staff should...

"Understand that experience is the best teacher, families have a lot of that to offer."

"Have a trusting and respectful relationship with us. We would like to be treated as equals and have regular opportunities to play a full part in our son's life."

"Introduce us to new members of staff so we can develop a basic working relationship with them if possible. It would also be helpful to be told when someone is about to leave in case we would like to say goodbye. It is important to us that staff feel appreciated and valued. Anything that helps us demonstrate our appreciation would be very welcome. Please involve us in all significant decision making and health matters."

Things you should see:

- ☐ The person, family carers and others are treated as equal partners in the organisation and in the person's support, and they are recognised as playing an important role.
- ☐ Each person is supported to be involved in decisions, assessments, and planning, and is involved in whatever way they can be (e.g. by being part of meetings and planning, or indirectly through staff, family members or advocates).
- ☐ The person, family carers and others are involved in selecting goals and desired outcomes of PBS.
- ☐ The person, family carers and other key people are invited to meetings and reviews about the person's support.
- ☐ The person, family carers and other key people are involved in assessments (e.g. by contributing information) and help to develop interventions and supports.
- ☐ The person, family carers and other key people are kept informed (e.g. by receiving information and being given accessible copies of assessment results and plans). Regard is given to the person's right to confidentiality.
- ☐ The person, family carers and other key people are able to provide feedback in a range of ways (e.g. talking to staff informally, written feedback, attending meetings etc.) and this is used to improve the support they provide and celebrate good practice.
- ☐ Family carers and others are offered training in the key aspects of their relative's support, for example in how to implement their Behaviour Support Plan (written plan based on a functional assessment of behaviour which strategies designed to alter the environment and teach new skills), communication methods etc.
- ☐ Staff recognise that other people including family carers also have emotional needs and either provide support for this or information on other services that can help.
- ☐ The person, family carers and others are invited to be involved in shaping the organisation both formally (e.g. by being part of a steering group, attending organisational planning meetings, being on recruitment panels, co-facilitating workshops for staff etc.) and informally (e.g. by providing comments and suggestions to the service, by consulting on policy documents etc.).

Things to ask to have a look at:

- ☐ Written information about how everyone can be involved and provide feedback.
- ☐ Methods for everyone to provide feedback, e.g. comments form, email addresses etc.
- ☐ Written information / policies on how to share information with everyone and keep them informed.
- ☐ Evidence that copies of assessments and plans have been given to key people.
- ☐ Written information on training offered to everyone.
- ☐ Leaflets/information for family/carers on maintaining their own wellbeing, how the organisation can support this, and other services that can help.

Your Notes

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Good practice example – Gloucestershire PBS offer to families

Gloucestershire offer support to families to implement their relative's Positive Behaviour Support Plan. Depending on the needs of the individual and their family this support can include:

- **Consultations or class-based training** for families, carers and all those involved in the person's life around PBS approaches including functional assessments, prevention, de-escalation and reactive plans.
- **Support provided by the team** to implement the recommendations. This will involve modelling and demonstration of techniques/interventions or a competency-based training approach.
- **Training packages** on a case-by-case basis so the service provided is appropriate and relevant. It is likely training will be delivered in a bespoke way, although grounded in a competency-based approach.
- **Direct modelling** of proposed interventions where necessary. This will ensure that families and other stakeholders feel supported and confident in implementing the Behaviour Support Plan.

For further information [visit the Proud to Care Gloucestershire website](#)

Functional assessment

(An assessment to understand why challenging behaviour is happening)



Best Practice Examples

Family carers say to understand why challenging behaviour is occurring...

"We used a clinical psychologist. The Challenging Behaviour Foundation did a training course that school staff and I attended. We had several meetings and it was eventually worked out that the major trigger was people talking too much, and the pain caused by an ingrowing toenail. We eventually had this operated on with the assistance of the learning disability liaison nurses, which helped to make it happen. Intensive Interaction was also used, as was music therapy."

"We would like staff and family to work together when there are challenges to make use of the skills that everyone has to help. We would like our care provider to be open and fair so that we know what is going on. We would like help and advice if we face challenges on home visits."

"We would like a timely assessment by the in-house PBS specialist carried out and effective steps put in place to address the cause. We would like to be able to sit in on staff training."

Things you should see:

- ☐ A range of key people being involved in assessments, including professionals with expertise in behavioural approaches (if required).
- ☐ The results of assessments being fed back to the person (if possible) and key people and this information being used to design a Behaviour Support Plan.
- ☐ Staff writing things down about the person's behaviour and things that might affect it.
- ☐ An example could be ABC recording where staff record events in which challenging behaviour occurs, including what happened before (Antecedent), during (Behaviour), and after the behaviour (Consequences). Other things staff may record are the numbers of times the behaviour happens or how long it goes on for, communication skills, the person's health, staff issues (sickness rates, new staff, change in manager) etc.
- ☐ Information being collected about the person's quality of life (those things that are important to the person and make them happy).
- ☐ Staff trying to work out the function (the reason) for an individual's behaviour by using a range of methods. These may include directly observing the person, interviewing key people and staff/family members being asked to fill in questionnaires.

Things to ask to have a look at:

- ☐ Data (Information) collected on an individual's challenging behaviour and other things that may affect it, e.g. their health, level of activity etc. This might be on paper or on a computer.
- ☐ Results from a functional assessment and other relevant assessments, e.g. communication assessment or skills assessment.

Your Notes

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Developing and using a Behaviour Support Plan



Best Practice Examples

Family carers say to develop and use a Behaviour Support Plan for my relative...

"We worked with school staff. The plan included major triggers, how to keep him calm, what to do if challenging behaviour occurred, how to calmly assert yourself and give positive instruction."

"You need to understand that my son is environmentally sensitive. All new staff need to be properly trained and made aware of my son's needs before they work with him. My son does not like the dark, animals and especially is phobic about cats. Staff need to make sure appropriate steps are taken to prevent distress. He also finds the spray from vehicles in the rain hard to tolerate when travelling. Noise, flickering lights and flying creatures are also hard for him to cope with."

"We worked out why my son was self injuring with careful work via an ABA trained professional and worked out a safe replacement behaviour."

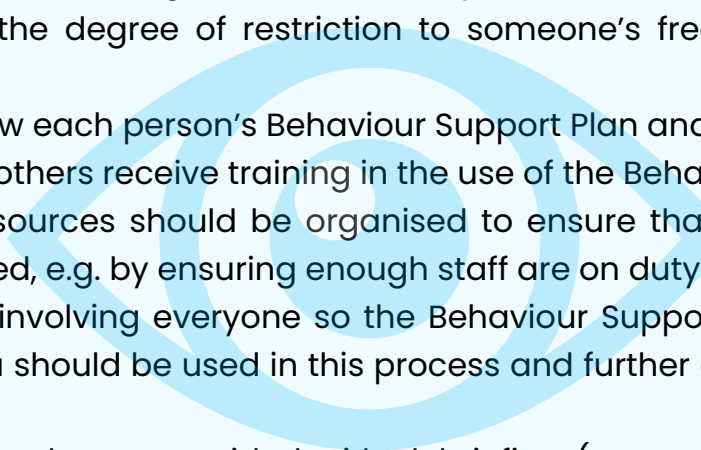
"People need to know my son. For example, he has no sense of danger therefore staff must always stay close to him as he could step out into a road, into the path of a vehicle or other danger."

"Everyone reads and understands the same important information about my relative and have the understanding and ability to support people with severe learning disabilities and autism."

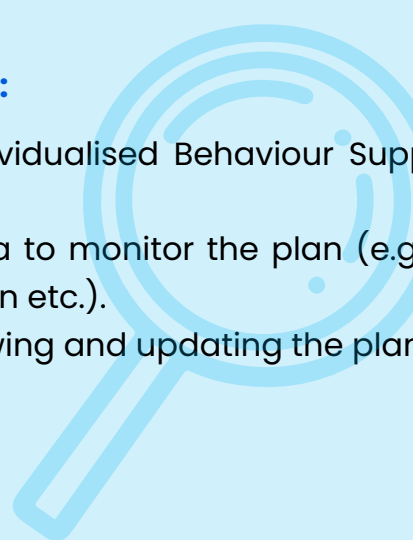
"People support my relative in accordance with her Behaviour Support Plan and care plan. Being trained in the relevant skills."

Things you should see:

- ☐ A Behaviour Support Plan (written plan based on a functional assessment of behaviour which contains different strategies designed to alter the environment and teach new skills to reduce challenging behaviour and increase quality of life) being developed for an individual, where everyone is involved.
- ☐ This plan should reflect the person's needs and likes/dislikes and have strategies that are acceptable to them and others involved.
- ☐ **Preventative strategies** (things used to reduce the likelihood of behaviour occurring) included in the plan and routinely used. These include skills teaching, environmental changes and strategies which promote quality of life (e.g. increasing inclusion in the community, supporting social relationships etc.).

- 
- ☐ A hierarchy of **reactive strategies** (things that are used after a behaviour occurs) are included in the plan to manage behaviour safely and to ensure that the least restrictive strategy (limiting the degree of restriction to someone's freedom of liberty) will be used.
 - ☐ All staff should know each person's Behaviour Support Plan and follow it.
 - ☐ Staff, families and others receive training in the use of the Behaviour Support Plan.
 - ☐ Staff rotas and resources should be organised to ensure that the Behaviour Support Plan can be followed, e.g. by ensuring enough staff are on duty.
 - ☐ Regular meetings involving everyone so the Behaviour Support Plan can be reviewed and updated. Data should be used in this process and further assessments completed if needed.
 - ☐ Staff and other people are provided with debriefing (opportunity to talk through an incident and consider changes of how to respond in future) after incidents of challenging behaviour to maintain everyone's wellbeing.

Things to ask to have a look at:

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- ☐ A comprehensive and individualised Behaviour Support Plan (see Resource 5 for an example).
 - ☐ Methods for collecting data to monitor the plan (e.g. physical data sheets, computer programs for data collection etc.).
 - ☐ A system in place for reviewing and updating the plan and who is responsible for this.

Your Notes

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Skills teaching and development



Best Practice Examples

Family carers say my relative is supported to learn new skills through...

"A programme of domestic and self help tasks around the home."

"Providing regular opportunities to go out and experience the environment and community, to suggest new things and not be afraid to try new ventures."

"Working in partnership with the school on targets and taking any opportunity which arises at home to teach new skills."

Things you should see:

- ☐ Family carers, staff and other professionals are involved in assessments and plans for skills teaching.
- ☐ Everyone uses techniques from behaviour analysis (the science of behaviour which uses an understanding of why behaviour occurs to address a wide range of social issues, including helping individuals to learn) to teach new skills.
- ☐ Everyone is given training and support (e.g. direct coaching, modelling, feedback) in skills teaching methods.
- ☐ Techniques for promoting generalisation (where a skill is performed in different situations with different people) and maintenance (where a skill continues to be performed over time even after teaching or a specific intervention has stopped) are routinely used.
- ☐ Skills teaching enabling the individual to have more independence, choice, and control over their lives which in turn leads to an increase in their quality of life.
- ☐ Assessment of skills are repeated regularly to monitor effectiveness of skills teaching plans.

Things to ask to have a look at:

- ☐ Information on skills assessments (collected over time).
- ☐ Plans for teaching a person new skills (which may be included in the individual's Behaviour Support Plan and/or separate).
- ☐ Detailed written guidance for teaching each new skill.
- ☐ Methods for collecting information (e.g. physical data sheets, computer programs for data collection etc.) to check progress.
- ☐ Evidence of behavioural techniques being used, e.g. task analysis sheets (where a task is broken down into its smaller steps), discrete trial teaching record forms (is a method of teaching where the skill is broken down into small steps and "built-up" teaching each step one at a time).

Your Notes

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Staff skills & support



Best Practice Examples

Family carers say my relative is supported to learn new skills through...

"Training in relevant health needs e.g. epilepsy."

"Training in PBS and the ability to use PBS techniques."

"Skill, patience and empathy."

"Given the need for total support with personal care we would expect some training on basic hygiene to be provided and initial training to also include an appreciation of DoLS (Deprivation of Liberty Safeguards), best interests and safeguarding. First aid would also be advisable."

"As a parent I have experience, plenty of patience, unconditional love, assertiveness, I have learnt on the job and have attended a number of courses, read books and attended talks by experts and autistic people to help me understand my child's disability."

Things you should see:

- ☐ Staff work as a team within the service and provide support and feedback to each other.
- ☐ Staff are provided with regular supervision from supervisors/managers and receive ongoing development using behavioural skills training (a method of training that consists of instruction, modelling, practising, and being given feedback).
- ☐ Staff reflect on their working practice and how their behaviour may impact the people they support and other staff.
- ☐ Staff seek support when required, both from other staff and from managers/supervisors.
- ☐ Managers/supervisors are physically present and support staff to undertake their role and improve their practice.
- ☐ Staff rotas/timetables allow time for training, team meetings, and supervision.
- ☐ Staff are provided with debriefing following an incident of challenging behaviour.
- ☐ Staff turnover is low; staff enjoy their role and are valued by people they work with, their families, other staff, managers, and the service as a whole.
- ☐ New staff are recruited when necessary and recruitment processes involve the people supported by the service, their families and others. Recruitment procedures recognise the importance of identifying potential staff who respect and value people as individuals and who have appropriate training and qualifications.

Things to ask to have a look at:

- ☐ Staff rotas/timetables displayed with evidence of time for training and team meetings.
- ☐ Evidence that staff are valued, such as information about staff social events, evidence of celebrating good practice, written information on training and workshops available to staff, written information on ways that staff can get additional support etc.
- ☐ Guidance on relevant legislation, e.g. posters relating to safeguarding, the mental capacity act, health and safety etc.

Your Notes

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Resource 3

**Questions to ask to check
whether Positive Behavioural
Support is being used well**



Questions to ask to check PBS is being used well

How to use this resource

This resource provides you with a list of core questions that you can choose to ask services/professionals (either in person or in a letter/email) to identify whether they provide Positive Behavioural Support (PBS)⁶.



Each core question is marked with this symbol, so you can find them easily.

For each core question, examples are given of some of the key components of good answers and some specific features of answers that might be considered “alarm bells” which you should try to get more information about. Alarm bell answers do not necessarily mean that the service does not provide PBS, but you should use the follow up questions provided after the core questions to get more information.

You may want to consider asking questions to different types of staff within the organisation (i.e. direct support staff, supervisors/managers, specific professionals such as behaviour analysts etc.) if you need more information about a particular key area.

Remember that, as a family carer, it is your right to ask these questions and to learn more about the service. Good services/professionals should not be put off by you asking these questions and should be happy to answer them. If a service/professional avoids answering your questions, this may be an alarm bell and you may want to seek answers for your questions from a different source (e.g. by contacting a manager/supervisor directly, emailing the service etc.).

At the end of this resource there is some information on what to do if you don't receive satisfactory answers to your questions or you don't observe enough using the checklist provided in Resource 2.

⁶ Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour.

People are valued and respected as individuals



How would you respect and support my relative as an individual?

Good answers could include:

- Finding out your relative's likes and dislikes (by talking to them, family members and testing things out) and making sure these are part of the support offered.
- Making sure the support takes into account your relative's individual needs (e.g. the right amount of help to do things, using their preferred communication method etc.) and respecting religious/cultural needs.
- Providing choices in lots of ways (e.g. food, activities, clothing).
- Supporting your relative's independence (e.g. by teaching skills, giving the right amount of help).
- Supporting your relative to make new friends as well as maintain important relationships with family etc.

Alarm bell answers:

- Service organises support around the service's needs, rather than your relative's (e.g. arranging rotas in a way most convenient to them, a rigid structure that is not sensitive to your relative's needs, activities offered based on staff availability).
- A suggestion that everyone is supported in exactly the same way and that support is not tailored to individual needs.
- A fixed number/type of activities and no suggestion that new activities will be identified or explored based on your relative's like/dislikes.
- No consideration of teaching new skills.
- No consideration of how to support your relative to both maintain and develop new relationships.

If you don't get a satisfactory answer you could use these follow up questions:

- How would choice be built into my relative's daily life?
- How would my relative's independence be promoted?
- How would my relative be supported to develop and maintain relationships with their family, friends, peers, and community?
- What would you do to make sure that my relative feels valued?
- Give examples of the kinds of activities that my relative could get involved in and how they would be supported to do these?
- How would you structure my relative's day to day activities?
- How is the service flexible when trying to meet an individual's needs (e.g. staffing rotas, timetables)?

Supporting communication, health and wellbeing



How would you identify and support my relative's communication needs?

Good answers could include:

- Discussion about assessment of communication which involves your relative, family and professionals, (e.g. Speech and Language Therapist).
- Staff use your relative's preferred communication method and alter their communication when necessary (e.g. according to your relative's mood/wellbeing) Staff help your relative to develop communication skills.
- The service as a whole supports your relative's communication – e.g. labels/signs, visual timetables etc.
- Everyone uses your relative's preferred communication method, and this is written into his or her own communication plan/passport.

Alarm bell answers:

- Only using one communication approach for everyone they support and not tailoring communication based on your relative's needs.
- No way of assessing communication, or assessments only conducted when your relative joins the service.
- Support provided by only one professional (e.g. a speech and language therapist) and all support staff cannot assess or support communication.



Laura has a communication passport to help others understand the best ways to communicate with her.

Supporting communication, health and wellbeing



How would you support my relative's physical and mental health and recognise any deterioration?

Good answers could include:

- Knowing your relative well will help us to recognise any changes in their behaviour, mood, or activity (which could suggest a change in their physical/mental health) and then investigate reasons for this.
- An understanding that other factors can influence health/wellbeing – e.g. life events, diagnoses etc.
- Supporting your relative to access health and wellbeing services in the community, and specialist services if required.
- Staff able to support your relative's health, e.g. administer medication (and monitor this), follow specialist diets etc.
- Supporting your relative to monitor their health, lead a healthy lifestyle and respecting their right to lead the lifestyle they choose, e.g. Checking their blood sugars regularly, achieving a healthy balance in their diet and having regular physical health checks as part of a diabetes management plan.

Alarm bell answers:

- No system of assessing and monitoring your relative's health and wellbeing.
- No involvement of your relative/you/others who know you relative in assessing and monitoring your relative's health and wellbeing.
- Support for health only provided within the service (e.g. having an in-house doctor/dentist).
- Evidence that your relative would not have a choice about aspects of their lifestyle (e.g. their diet) as the service provides the same diet/exercise for all the people they support.

If you don't get a satisfactory answer you could use this follow up question:

- How will my relative be supported to make informed choices and have independence relating to their health and lifestyle?



Raj's behaviours became more challenging, and his family and support staff could not understand why. They took him to the GP for a health check-up and found he had an ear infection.

Involving everyone and working in partnership



How will I/other family members/close friends be involved in my relative's support?

Good answers could include:

- You, your relative, and others who know your relative well are involved in assessments, support, and planning.
- There are a range of ways that people can be involved based on their own preferences – e.g. formally in meetings or reviews, or informally by talking with staff.
- A range of ways for you and others to provide feedback to the service about the support they provide, and evidence that this feedback is used in a number of ways (e.g. to improve support to your relative or service wide practice, and to celebrate good practice).
- Discussion of ways that you and other people will be kept informed (in line with data protection laws with a recognition that your relative may have to consent to this if they are over 18).

Alarm bell answers:

- Only limited examples of keeping you and others informed, and no consideration of whether your relative would be asked to consent to this.
- No indication that you, your relative, or others would be involved in assessments and planning (e.g. staff set goals for your relative, assessments are only done by professionals etc.).
- A suggestion that others would need to initiate involvement (e.g. by phoning the service) rather than their involvement being actively supported by the service.
- No discussion of how people can provide feedback to the service.

If you don't get a satisfactory answer you could use these follow up questions:

- How will my relative be involved in decisions about their support, activities and goals?
- What things might you keep me/other people who are important to my relative informed about?
- How do you go about getting feedback from those that you support and their relatives, and how would this be used?



Professionals treat us as equal partners; they listen and respect our knowledge and expertise as family carers.

Involving everyone and working in partnership



How will you work in equal partnership with me/us (families, carers, others)?

Good answers could include:

- Recognition of the vital role that family/ carers play in their relative's life and in their support.
- Examples of how the service support family carers – e.g. through training, emotional wellbeing support, networking with other family carers etc.
- Examples of how family/carers are involved in shaping the organisation – e.g. through steering groups, providing feedback and suggestions, sitting on recruitment panels, attending organisational planning meetings etc.
- Emphasis given to the partnership between family carers and the organisation, both in relation to their relative's support and the organisation more generally.

Alarm bell answers:

- No understanding of the important role that family/carers play in their relative's life and support. Family carers are involved only minimally, e.g. by receiving weekly updates etc.
- No discussion of how family/carers can be involved in shaping the organisation more generally.
- A suggestion that supporting the emotional wellbeing of family/carers is not within the remit of the service or is not considered by the service.

If you don't get a satisfactory answer you could use these follow up questions:

- How do you identify the needs of families/carers?
- What training do you provide to families/carers?
- What is your engagement with families/carers?
- How do you involve families/carers in decision making/policy formation/recruitment/shaping the organisation?



We were involved in the interview panel for our son's new support staff and helped run some of their induction training.

Functional assessment

(An assessment to understand why challenging behaviour is happening)



What strategies do you/the service use to understand why challenging behaviour is occurring?

Good answers could include:

- An understanding that all behaviours, including challenging behaviours, are a way for your relative to get the things they need.
- Use of a range of strategies within a functional assessment including observations of behaviour, interviews with stakeholders, rating scales and questionnaires.
- An understanding that many things influence behaviour – e.g. your relative's health/wellbeing, staff behaviour, aspects of the environment (e.g. noise or light).
- Information from a functional assessment is used to develop an understanding of why the behaviour might be occurring and to inform intervention approaches.
- The involvement of a range of people and of professionals with expertise in behavioural approaches (if necessary).

Alarm bell answers:

- No understanding that all behaviour has a function (reason) for the person.
- Only one type of information is collected about behaviour (e.g. incident reports).
- No indication that information (data) is used to understand why challenging behaviour occurs and to inform interventions.
- An indication that the responsibility for understanding, assessing, and supporting behaviour lies with a specific behavioural team or individual.
- Support staff do not appear to appreciate their role in relation to understanding behaviour.

If you don't get a satisfactory answer you could use these follow up questions:

- What information (data) is collected about challenging behaviour and how is this used?
- What is your role in the assessment and management of challenging behaviour?



The local Positive Behavioural Support service did a functional assessment of Lucas' behaviour. Lots of information was used to do the assessment including observing Lucas and talking with key people in his life and ABC charts.

Developing and using a Behaviour Support Plan



Tell me how you would develop a Behaviour Support Plan for my relative (i.e. the process used) and what it would include (i.e. what types of information, strategies etc.)?

Good answers could include:

- Different types of information are used (e.g. data from assessments, information about your relative's skills, health, and wellbeing) including information from the family and people who know the person well.
- All staff have a role in the development of a Behaviour Support Plan and should be able to tell you about their role. Professionals with expertise in behavioural approaches are involved if needed.
- The Behaviour Support Plan would be developed for your relative's unique needs and be individualised.
- The service would consider the resources needed to use the Behaviour Support Plan and ensure that these are in place.
- The Behaviour Support Plan would include strategies to improve your relative's quality of life and prevent behaviour occurring and a hierarchy (from least to most restrictive) of strategies to manage behaviour safely if it does occur.

Alarm bell answers:

- An indication that a Behaviour Support Plan is created by one individual or team, with no input from others.
- No indication that the plan will include information relating to broader factors, such as health and wellbeing, communication, skills, staff behaviour etc.
- A suggestion that one Behaviour Support Plan is used for each person and would not be individualised for your relative.
- An indication that the Behaviour Support Plan would focus solely on reducing behaviour and using **reactive strategies**.
- A suggestion that the Behaviour Support Plan would be developed in relation to the resources that the service already has, and that this would influence the strategies included in the plan.

If you don't get a satisfactory answer you could use these follow up questions:

- What assessments and information would you use?
- What is your role in the development of a Behaviour Support Plan?
- Who else is involved in the development of a Behaviour Support Plan?
- How would you know that the resources are available and in place to deliver my relative's Behaviour Support Plan?

Andrew's mum explained that an afternoon nap prevents tiredness leading to challenging behaviours, so this was incorporated into his Behaviour Support Plan.

Developing and using a Behaviour Support Plan



How will everyone supporting my relative know how to do so in relation their behaviour and how will you know if the support is effective?

Good answers could include:

- All staff know your relative's Behaviour Support Plan and their role in using it.
- Everyone involved in supporting your relative (i.e. staff, family members, friends etc.) receive training and supervision to ensure they are able to use the plan accurately. This may include coaching, modelling, peer support, observations, and feedback.
- Data is collected on whether the plan is used consistently by everyone.
- Data is collected on outcomes related to the Behaviour Support Plan (e.g. quality of life, skills, communication, behaviour, health and wellbeing) to enable the service to monitor the effectiveness of the plan.
- There is a procedure for regularly reviewing the plan in light of data (e.g. if challenging behaviour is increasing or emergency management strategies needed).

Alarm bell answers:

- A suggestion that everyone is supported in the same way (e.g. a focus only on how to manage behaviour).
- No systematic way of training staff and others in using the Behaviour Support Plan, or no on-going training and supervision. Focuses only on training direct support staff and not others who may be involved in your relative's support.
- No data collected on whether the plan is used properly. Data collected only on challenging behaviour and not other things such as skills, communication, health and wellbeing, staff behaviour, use of **reactive strategies** etc.
- No clear procedure for reviewing and updating the plan, or an indication that this is done at routine intervals, without reference to data, or by the service without input from others.

If you don't get a satisfactory answer you could use these follow up questions:

- How is the Behaviour Support Plan used in everyday life?
- How will you know if my relative's Behaviour Support Plan is effective?
- Give me an example of a strategy that you have used here to prevent someone's challenging behaviour.
- What is the person's crisis management strategy?
- How do you know when to use reactive behaviour management strategies and which strategies to use?
- How will my relative's Behaviour Support Plan be reviewed and updated?

Anyana's parents and staff at school were supported by the behaviour analyst to deliver the Behaviour Support Plan. She showed them what to do and met them regularly at the start.

Skills teaching and development



How will you support my relative to learn and develop new skills?

Good answers could include:

- Assessment of current skills and communication would be completed with the person and involve families, carers and professionals.
- A written plan would be devised relating to skills teaching (which may be included in the Behaviour Support Plan) and would emphasise skills related to your relative's goals, promote independence and quality of life, or are related to their behaviour.
- Examples of skills teaching are based on techniques from the science of behaviour analysis (e.g. modelling, prompting, shaping, discrete trial teaching) and focus on the skill being used in different places, with different people (generalisation) and will last over time (maintenance).
- All those who support your relative receive training and supervision to ensure they are able to support your relative to learn new skills.
- On-going data collected to check they are learning new skills and your relative's skills teaching plan is reviewed in light of this.

Alarm bell answers:

- No systematic way of identifying your relative's current skills and abilities.
- A suggestion that the responsibility for teaching your relative skills lies with one individual, team, or professional.
- Goals for skills teaching devised by staff without input from other people or only informed by the person-centred plan or Behaviour Support Plan.
- No clear description of techniques used for teaching skills or a suggestion that skills teaching takes place only at certain times of the day/week.
- No procedures for monitoring whether your relative's skills are improving, or reviews planned only at fixed intervals (e.g. every 6 months).
- Each member of staff teaches in their own way.

If you don't get a satisfactory answer you could use these follow up questions:

- How will my relative's skills be assessed and what is your role in this?
- Give me an example of how you have taught a new skill?
- How will decisions be made about which skills my relative should be supported to develop?
- How will you know if my relative's skills are improving?

Everyone supporting Tina helped her to learn to sign "stop" so she did not need to become aggressive when she needed an activity to end. Her family and staff were taught how to reinforce this behaviour.

Staff skills and support



What qualifications and skills do you/staff have to support my relative?

Good answers could include:

- Training in PBS, communication methods, health and wellbeing, teaching skills, behavioural approaches, safeguarding, **reactive strategies** including physical interventions (where required) is regularly updated.
- Staff are supported to develop new skills (through behavioural skills training), reflect on their practice and how it influences the people they support/other staff, and maintain their own wellbeing.
- Staff recruitment practices identify individuals who value and respect people they support. This applies to the wider organisation also, meaning that staff are valued in a range of ways (e.g. through celebrating good practice, organising social events, providing support for staff etc.).
- Staff work as a team and participate in team meetings and training, provide peer support and feedback to each other.

Alarm bell answers:

- Staff only receive training at the beginning of their role with updates only to statutory training (e.g. safeguarding, manual handling, health and safety etc.) and not more practice-based training, e.g. relating to PBS or skills teaching.
- No reference to the values that staff should have in order to work in the service.
- No indication that staff supervision is provided for a range of purposes (e.g. improving practice, skills development, reflective practice, emotional wellbeing) rather than just monitoring performance.
- No clear procedures for supporting team working, peer support, or reflective practice (or no recognition of the importance of these for providing consistent support).
- No indication of how staff are valued.
- References to high staff turnover (which may indicate that staff do not feel valued or are not well supported by the service).
- Service sends the minimum amount of staff on training, expecting them to “cascade” the training to others without appropriate skills and knowledge of how to do this.

If you don't get a satisfactory answer you could use these follow up questions:

- | | |
|--|--|
| ● What training do staff receive and how is this done? | ● When did you last give your staff a pay rise? |
| ● How do staff work as a team? | ● What is your staff turnover ratio? |
| ● How are staff supported, supervised and valued? | ● What legislation is relevant to the service and how do staff use this legislation? |

If you are unhappy with the service(s) being offered to or provided for your relative you can:

- Explain why you are not happy to accept the service being offered because it does not meet the needs of your relative.
- Write to the Manager of the service or ask for a meeting. Write down or explain clearly and calmly your concerns and what is unsatisfactory about the service. Use the sections of this resource and the PBS Competence Framework to show where the service is not using PBS as it should.
- If your concerns are not addressed after explaining them to the provider of the service, you can take forward a formal complaint, either with the provider of the service, or with the statutory organisation responsible for commissioning (buying or arranging) the service. This could be:
 - The Director of Education or Head of Children's or Adults Services at the Local authority. If you have a complaint about your council that it is unable to sort out, you can contact the Local Government Ombudsman (0300 061 0614), which considers individual complaints about councils.
 - For Health Provision – your Integrated Care Board (ICB). You can find out details of your local CCG from your local authority or you can find them online at: <https://www.nhs.uk/>.
 - For specialist health provision, you can contact NHS England at: PO Box 16738, Redditch, B97 9PT, or email them at: england.contactus@nhs.net. Put 'For the attention of the complaints manager' in the subject line. Phone: 0300 311 22 33.

We have included an example template for drafting a letter about your concerns in Resource 5 of this document.

Resource 4

Family carers using Positive Behavioural Support



Accessing Further PBS Support

Research has shown that family interactions have a direct impact on the wellbeing and behaviour of the individual with a learning disability. Best practice recommends the development of Positive Behavioural Support (PBS)⁷ skills amongst all those who provide the person with support, families as well as professionals, in order to provide consistent support (Challenging Behaviour Foundation, 2014).

The PBS Competence Framework (PBS Coalition UK, 2015) suggests that family carers should be provided with information and support to develop an overview of PBS and an understanding of what to look for in a PBS service.

It says that family carers should receive coaching and support to implement a Behaviour Support Plan and can benefit from training in person-centred planning, communication and where necessary, ethical physical intervention.

Statutory Organisations

If you have not been offered this support you could request it from the following:

- **Your Local Authority**

If you are supporting an adult you can request a Carer's Assessment and explain your need for PBS skills as part of the assessment process. If your child is under 18 you have a right (Children and Families Act 2014) to a parent carer's needs assessment (PCNA), which is intended to lead to a better informed decision about the holistic package of support for disabled children and their families.

You can request the relevant assessment from your Local Authority who must consider as part of the assessment your needs in relation to the care you are providing. If your relative has a learning disability and behaviours that challenge, especially if they are living at home, you can explain as part of the assessment how PBS skills would help you to understand and manage challenging behaviours.

- **Your local NHS Service for People with Learning Disabilities**

This may be through a Community Learning Disability Team or by asking for this type of support from a Behaviour Specialist or Clinical Psychologist. Your GP can help you access these services by making a referral.

- **Your relative's school or care provider**

⁷Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour.

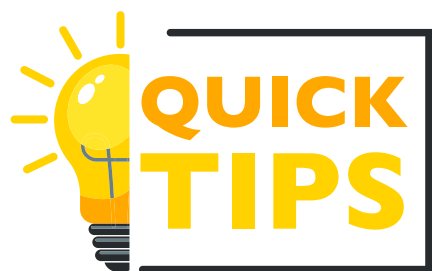
Training Providers

If local statutory agencies will not provide or fund coaching or training in Positive Behavioural Support, there are some independent courses available. Currently there is no scheme to regulate or accredit training courses or to properly recognise professionals qualified in PBS. This can mean that sometimes people claim to use PBS or to run a PBS training course, which may not actually meet the standards of the PBS Competence Framework.

PBS professionals offering training can come from a variety of backgrounds but should have some specific training and qualifications in PBS. In addition, they should be appropriately registered with an independent regulatory body responsible for setting and maintaining standards of practice, e.g. Nursing & Midwifery Council (NMC); Health Care Professionals Council (HCPC).

Some PBS professionals will also be registered with other regulatory organisations, e.g., Behaviour Analyst Certification Board® (BACB®).

For further information, go to <http://bacb.com/credentials>



We suggest that families use the questions/alarm bells in **Resource 3** of this pack to test the quality of any support or training offered. For further helpful information about PBS Professionals Qualifications and Training go to <https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/04/pbs4-qualifications.pdf>

Whilst there are many PBS providers offering training, there are very few courses directly aimed at family carers. However, The Challenging Behaviour Foundation does run 2 or 3 day workshops for family carers or family carers alongside professionals. The courses are person-centred and practical. They teach skills rather than answers. Participants gain knowledge in positive behavioural support (PBS) and learn how to analyse behaviour, understand why it happens and plan strategies to support the person to reduce the behaviour. Participants leave with the basis of a PBS plan for the person they support. Unfortunately, these cannot be provided for free and the CBF has to charge for these courses in order to run them. Some Local Authorities have paid for these courses to be delivered to local families.

Details can be found here: <http://www.challengingbehaviour.org.uk/workshops/pbs-workshops/pbs-workshops.html>

Where to go to get help with funding for PBS Training

Charities

If you can find a suitable training course, you could seek funding from a charity that awards grants direct to families to support their caring responsibilities. Family carers who meet the eligibility criteria could try applying for a grant from the following national charities where you can show that training in PBS would support you in your caring role or improve the quality of life of your relative.

- The Family Fund <http://www.familyfund.org.uk> gives grants to families who are raising a disabled or seriously ill child aged 17 and under on a low income. The Family Fund uses its own eligibility criteria.

To meet the Family Fund's disability criteria, children and young people must have additional complex needs, or have a serious or life-threatening illness and there must be evidence that the child or young person's additional needs impact on a family's choices and their opportunity to enjoy ordinary life. The degree of planning and support required to meet their needs must also be much greater than that usually required to meet the needs of children and young people. See more: https://www.disability-grants.org/family_fund.html

- There are also local charities in each area, which may consider funding a PBS course to help you support your relative. Further information about grants for families caring for a disabled relative, including how to find local grant giving charities, can be found at <http://www.disability-grants.org/grants-uk.html>

Skills for Care

May also be able to offer family carers funding for PBS training. Possible sources of funding change frequently and "pots" of money are often made available for time limited periods, with specific criteria attached to them. Applications can be made through Skills for Care for these different funding streams when available.

Families who employ their own care and support staff can also apply for funding from Skills for Care to cover the full cost of care related training for both themselves and their personal assistants. Skills for Care does not directly arrange training but can fund courses and qualifications that meets the learning needs of the individual employer and/or their personal assistant(s).

Visit <http://www.skillsforcare.org.uk/Learning-development/Funding/Funding.aspx> to find out what funding is currently available, along with eligibility criteria.

For more general information (not specifically for families) about buying and paying for PBS training go to: <https://www.skillsforcare.org.uk/Developing-your-workforce/Care-topics/Supporting-people-with-challenging-or-distressed-behaviour/Positive-behavioural-support.aspx>

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Resource 5

Practical Tools for Family Carers



Practical tools for family carers

Behaviour Support Plans

A Behaviour Support Plan (also known as a PBS plan, individual teaching plan, individual education plan etc.) is an essential component of Positive Behavioural Support (PBS)⁸. Behaviour Support Plans can be presented in different ways depending on who they are written by and who is going to use them.

A Behaviour Support Plan (BSP) sets out the support required to help someone achieve a good quality of life. What is needed to achieve a quality of life, and what that looks like for each of us, will be different because we all have different skills, needs and desires. A BSP is therefore personalised and unique. They all, however, should include key information about the person so that they can be used as a practical tool followed consistently by everyone involved in that person's care.

A BSP should be based on a good understanding of the reason(s) why a person uses behaviour that others may find challenging. This type of assessment is called a Functional Behaviour Assessment (FBA). Often a Functional Behaviour Assessment Report will be written. This gives a detailed summary of the FBA process and the assessment findings. It should give a clear understanding (formulation) of the behaviour and recommendations about what should happen next to help improve the person's quality of life and to prevent and reduce behaviour that challenges. A Behaviour Support Plan is developed based on information from the Functional Behaviour Assessment.

We have decided not to include an example of a BSP in this document as formats and styles vary so widely and depend on a person's situation and needs. A plan should always be written in a way that is most suitable for those who are using it to provide support to someone. Instead, we have provided an outline of the key elements that should be found in a good quality Behaviour Support Plan and provided examples of good and poor information for each. You can use these to identify whether your relative's plan has all the key elements and whether anything is missing or not well described. You should also check that the plan is based on a Functional Behaviour Assessment.

A **glossary** of some of the terms used in this resource can be found in **Resource 2** of this pack.

⁸Positive Behavioural Support is sometimes referred to as Positive Behaviour Support. The PBS Academy uses Positive Behavioural Support to ensure that the emphasis is not on specific behaviours but on a behavioural approach to understanding and working with challenging behaviour.

Key elements in a good Behaviour Support Plan

1. Information about your relative's life and the things and people that are important to them

This should include:

- People – family, friends, work colleagues, etc.
- Activities – at home, at school, at work, leisure, hobbies, etc.
- Objects – personal possessions, toys etc.
- Places – indoors/outdoors, busy/quiet, specific rooms/venues etc.

Good examples

John's best friend is Amelia and they see each other every day at school. John really likes reggae type music and will sway and rock when it is on. John lives at home with his Mum, Dad and brother Simon. He enjoys family trips out in the car and going to the cafe for hot chocolate. John always has Mickey Mouse with him. John is happy for Mickey to be placed on a shelf to watch what is going on when at school.

Jenny lives in a flat with her friend Sonja. Jenny has staff that support her. She goes to work at The Reuben Project three times a week where she works in the garden. Jenny loves the feel of soil on her hands and enjoys all the smells around her. Jenny has a great sense of humour and an infectious giggle. She has lots of friends at work – Maggie, Amal and Pru. She also enjoys going on the bus to her drama club on Friday evenings.

Mike is at a residential college and lives with Abdul and Mark. He has a close relationship with his Mum who visits every week. He has a sweet tooth and loves toffees. He has lots of energy and likes to be busy. Getting out in the fresh air every day is important to Mike regardless of the weather. His favourite place is Jubilee Park where he can feed the ducks, see the deer and enjoy the open space. He loves animals; enjoys horse riding (his favourite pony is Jasper) and likes looking at pictures, magazines and DVDs about animals/wildlife.

Poor examples

John lives with his family. He attends a special needs school where he takes part in a range of activities including music. John likes going out to cafes and his favourite toy is "Mickey".

Jenny lives in a supported flat with one other person. She attends the Reuben Centre regularly where she works in the garden. She has lots of friends and likes to go to clubs.

Mike lives with two other people in a unit at a residential school. His Mum visits regularly. Mike likes to be busy and enjoys parks, animals, food, magazines and watching DVDs.

2. Information about your relative’s needs and how these might relate to their behaviour

This may include:

- Physical health.
- Mental health.
- Sensory needs/issues.
- Communication difficulties.

This information may be available in other documents, e.g. a communication passport, Health Action Plan etc. If this is the case, it is important that this information is linked to your relative’s Behaviour Support Plan.

Good examples	Poor examples
John suffers from regular painful ear infections. When he has an ear infection, he is more likely to hit his head as he may be experiencing pain, and he may get frustrated when he is asked to do things.	John gets lots of ear infections.
Jenny is partially sighted which means she can only see the shape of large objects. She is more likely to scream in unfamiliar places unless given extra help and support by her staff to move around the environment.	Jenny has some sensory needs but is generally fit and healthy.
Mike has a diagnosis of depression. This can mean during periods of depression he can be less motivated to do everyday activities e.g. completing chores in his home or at college.	Mike has a history of low mood.

3. Information about your relative's behaviour

This should include:

- What the behaviour looks like (a clear description).
- Early warning signs (things that happen before the behaviour occurs or as the behaviour starts to change).
- The function (reason) for the behaviour.
- Things/situations/settings that might make the behaviour likely to occur.

Good examples	Poor examples
John will hit himself on the right side of his head with his right hand. This behaviour occurs in bursts of 4-5 hits, on average twice per day. The behaviour can lead to reddening of the skin. Before he hits himself, John will usually rock backward and forwards and say 'mmmmm'. He will also rub the right side of his head and his ear with his right shoulder. He may look paler than usual and develop dark lines under his eyes. John is more likely to hit himself when he has an ear infection. The reason John does this is to tell us he is in pain.	John self-injures.
Jenny will shout and kick staff on the shin. This behaviour occurs on average twice per week. This behaviour can lead to bruising of the skin. The behaviour is more likely when staff help Jenny with self care, for example when helping her undress for a bath. It occurs more often when staff try to rush Jenny. There aren't many warning signs. We know when Jenny wants to take a bath because she will smile when asked if she is ready for her bath. We think Jenny kicks staff because she wants to avoid undressing.	Jenny is aggressive and kicks out at staff whenever they are near her.
Mike will ask the same question, 'Where's Mum?' repeatedly. This behaviour occurs on average 10 times per hour. The behaviour is more likely to happen when staff are supporting Mike's housemate. We think Mike asks questions as a way to start conversations and get staff to interact with him.	Mike asks the same question constantly.

4. Information on best ways to support your relative to have a good quality of life

These approaches are often called **proactive strategies**. They are one of the most important parts of the plan as they improve the overall quality of life for a person and therefore, make it less likely that they will need to use behaviours which challenge.

This should include:

- How to ensure the person’s physical and emotional well-being are met.
- How to match the environment to the person’s abilities and needs.
- The best way of communicating with the person.
- The type of support required for someone to be involved in activities and opportunities to learn new skills.

Good examples	Poor examples
Family should check John’s ears daily for signs of infection. Signs of infection are reddening of the ear and surrounding area, strong smell, discharge. If you notice early warning signs i.e. ‘mmmm’ sound and rubbing right ear with right shoulder, staff should give PRN Paracetamol and make an appointment at the GP.	Make sure John’s ears are checked regularly for signs of infection.
Named staff member to be identified each shift to support Jenny with her bath. Ensure at least 30 minutes for Jenny to have her bath at her pace. Jenny can take up to 30 minutes to start her bath routine and it is important she is not rushed. Activity script specifying each step in bathing process and how Jenny is best supported during this activity to be developed with Jenny and staff group	All staff to follow consistent bathing routine.
Mike likes lots of different things and to be kept busy. Ensure Mike has a visual timetable of activities that are to occur regularly throughout the day.	Keep Mike busy, he loves horse riding, watching wildlife videos and walks in the park.

5. Information on teaching strategies to help your relative learn new skills and alternative ways to get their needs met. These are very important as learning new ways to get their needs met will replace the need to use behaviour which challenges.

This should include information about:

- The person’s goals in relation to developing a new skill or behaviour.
- How this skill/behaviour will be taught.
- How this new behaviour will be rewarded, (reinforced) so they learn to use it regularly.

Sometimes it can be very difficult to teach a person an alternative way to get their needs met. For instance, if the person is unable to understand the concepts involved in teaching the new skill. If this is the case this should be stated clearly in the plan.

Good examples	Poor examples
Teaching goal: For John to indicate when he is in pain without presenting self-injurious behaviour. If John is rocking back and forwards and saying “mmmmm”, staff should check his ear. If there is clear reddening to John’s ear (which indicates that there is an infection), using hand over hand support John to touch the ear with his fingertips. Following this, praise John and provide PRN Paracetamol. The long-term aim is to fade back the hand over hand support and introduce a gestural prompt for John to touch his ear.	There are no identified skills teaching programmes at present.
Teaching goal: Jenny will be able to take off her own jumper/top at bath time. Steps to teach the goal: 1. Staff to follow the activity script for the bath. 2. Ask Jenny “ready to get undressed?” a. If Jenny does not respond after 30 seconds, ask again “ready to get undressed?”. b. Repeat the above three times, if Jenny does not respond on the third occasion move to step 4. 3. Jenny will either say “yes” or start to take off her top 4. If Jenny says yes (or has not responded) provide a gestural prompt to take off her jumper by touching your own top whilst looking at Jenny. 5. When Jenny moves to take off her top say “great” and smile. 6. Jenny will pull the bottom of her top up over her head and then remove her arms from the sleeves.	Jenny will be encouraged to learn to get undressed herself. Once Jenny is ready to take a bath, ask Jenny to get undressed. She usually starts with her top half. If Jenny doesn’t initiate undressing, help her a little to get her on her way. When she has successfully removed her top clothing, tell her well done.

7. Once the jumper is off, praise Jenny and then support Jenny to remove the rest of her clothes ready for the bath.
8. Once Jenny has finished her bath, staff must ensure they fill out the skill development sheet.

Notes: The skill development sheet should be reviewed weekly by Jenny's keyworker and monthly during the team meetings. Once Jenny has completed has taken her jumper off successfully three times in a row, a plan will be developed to support Jenny to take off her t-shirt. If Jenny requires additional support to remove the top two times in a row the above plan will be edited to make the skill steps easier so Jenny can be successful, the plan will then move forward to build on this success.

Teaching goal: Mike will choose 4 activities to go onto his visual planner every morning.

Steps to teach the goal: Once Mike has finished his breakfast, support Mike to do the following:

1. Say, "planning time" and then get out the blue box of symbols and bring the planner from the fridge to the coffee table.
2. Lay out six symbols onto the coffee table. Ensure they are all facing the same way with the bottom of the symbol towards Mike.
3. Say "Mike choose".
4. Mike will then choose one symbol.
5. Praise Mike and say "Mike, stick on planner".
6. Mike will then stick the symbol onto the planner, praise Mike.
7. Repeat step 3 to 6 three more times so that Mike has chosen a total of four symbols.
8. Once the planner is full give Mike the completed planner and say "planner on fridge".
9. Mike will then plan the planner back onto the fridge.
10. Praise Mike and then prepare to start the first activity on the planner.

Notes: The blue box should be checked every week by the keyworker to ensure the symbols are all present and in a good state of repair. Any missing or broken symbols should be replaced. A list of the symbols that should be in the box can be found in Mike's file.

Mike will choose his morning activities every day after breakfast. Encourage Mike to get his planner and box of symbols. Ask Mike to choose some activities for the morning. Encourage him to Velcro them to his visual planner. Once he has finished this activity it will be time to get ready to start the day.

6. Information on ways to support your relative when early signs of behaviour/distress occur

These approaches are often called **preventative strategies** and are designed to provide support to a person in order to prevent the behaviour getting worse.

This may include:

- Distraction techniques
- Active learning
- Reassurance
- Communication

Good examples

John should be given pain relief and/or medication prescribed by his GP. Staff should familiarise themselves with the medication guidelines. Ensure John is not expected to engage in all his scheduled activities and demands are kept to a minimum. Holding Mickey Mouse can comfort John when he is in pain and discomfort.

Ensure Jenny is given the opportunity to choose to have her bath later if she is showing signs of distress. If Jenny wants to have a bath (she is smiling when asked), make sure the identified staff member follows the activity script. Give her plenty of time to undress and keep prompts to a minimum.

If Mike starts to ask for his Mum over and over, use the visual planner and ask Mike to choose the next activity. If Mike is struggling to do this, point to the symbol on the planner and say, "time for x. Let's get our shoes and coat on, etc."

Poor examples

Make sure John has medication at regular times.

Tell Jenny it isn't a good time to have her bath as she is a bit agitated, and we will do it later.

Explain to Mike that his Mum isn't due to visit today and find something else to do.

7. Information on how to safely support your relative should the behaviour occur

These are often called **reactive strategies** and are only used when all other strategies have been exhausted. They are designed to keep everyone safe and bring a swift resolution to the situation.

Information should include:

- A range of strategies starting with the least restrictive ones.
- If restrictive strategies are included, a plan about how these will be reduced in the future.

Good examples

John should continue to be given all medication regularly. A further urgent GP appointment should be sought if John is hitting his ear repeatedly. Withdraw all demands from John. Offer him quiet time, warm drinks like hot chocolate. Wearing a soft warm hat can help provide some comfort. Hold his hand if he is willing. He likes gentle hand-massage, which he may find soothing and prevent him from banging his ear. Do not restrain his hands as this makes him even more frustrated.

If Jenny kicks staff, move away from her. Give her space and ensure she knows that she has plenty of time to undress for her bath. Offer the option of not bathing. If she starts to undress her top half, this indicates she does want to bathe. Allow her to undress in her own time.

If Mike continues to ask for his Mum over and over, offer another activity on the visual planner and ask Mike to choose something else. If Mike is struggling to do this, point to the symbol on the planner yourself or choose a highly preferred activity e.g. going outside for a walk to the park.

Poor examples

Seek urgent medical advice and continue to give all medication. If he is banging his ear really badly, try and stop him by holding his hands.

If Jenny kicks staff, tell her it isn't a good idea to have a bath now as she is distressed. Encourage her to come out of the bathroom and do something else.

Explain to Mike that he cannot keep asking for his Mum. She is due to visit on Saturday.

8. Ways to support your relative after the behaviour has occurred

These are often called post incident strategies and are designed to support the person after an incident of behaviour has occurred.

Information should include:

- The type of support the person prefers after they have been distressed.
- How long this type of support is required for.
- Ways to know when the person is feeling calmer.

Good examples

Continue to offer reassurance (by asking John if he is okay) and regular pain relief. Treat any ear soreness appropriately. Offer John his favourite foods, activities and toys. Continue to keep demands to a minimum. When John is smiling again and not hitting his ear, slowly introduce some simple activities and routines.

Staff should follow Jenny's activity script to complete bathing if this was what Jenny wanted. Praise should be given for completion of her bathing routine. If Jenny chose not to continue with bathing, allow her space and time to feel better. Do not offer another bath that day – Jenny usually likes a few hours to calm. When Jenny is feeling better, she smiles and laughs.

Once Mike is busy doing things he really likes, he calms very quickly and stops repeating "Mum" over and over.

Poor examples

Continue with regular medication.

Staff should explain to Jenny it isn't nice to kick people. She wouldn't like it if people did that to her. Suggest she should have a bath in a little while and hopefully she will be kind to staff this time.

Explain that Mike's Mum will visit soon, and she would be very pleased with him now he isn't asking for her all the time. Well done.

9. Information about how the plan will be monitored

This is necessary to check to see if the plan is being used correctly and that the strategies work.

Information should include:

- This should include the type of information/factual information (data) that should be collected.
- There should be information here about increasing quality of life as well as reducing behaviours which challenge.
- If there is a restrictive practice as part of the reactive plan, this will also need to be monitored.

Good examples	Poor examples
John's mum and dad are to complete a daily log which records: ● Frequency of self-injury (hitting head). ● Whether he has any signs of infection. ● What to do when these signs occur. Mum and dad to complete a daily activity and participation record which records: ● What activities have been offered to John. ● What activities he has participated in. ● How much help and support he has required to participate in each activity. John's community nurse will visit every week and review this information with the family.	Staff to monitor John's behaviour regularly and to keep notes of his daily activities.
Jenny's staff to keep a record of how often she is offered a bath and whether she kicks out at this time. Staff to complete a record of undressing which records the steps in the activity and how much help and support Jenny requires to complete each of these steps.	Complete bath log.
Mike's Behaviour Specialist will conduct regular observations (time sampling using partial interval recording) to monitor how often he repeatedly asks for mum. This information will be graphed by the Behaviour Specialist and presented and discussed with whole staff team at monthly staff meeting. Mike's staff will complete a daily record of how planning time has gone including Mike's involvement in this and which activities he has chosen. Mike's psychologist will meet with him every week to review how he is feeling and how he thinks his planning is going.	Staff will complete daily notes.

10. Information on responsibilities and review of the plan

This is important so everyone knows their role and timescales for achieving goals for the person.

Information should include:

- Who is responsible for specific parts of the plan?
- Timescales.
- How and when the plan should be reviewed.

Good examples

John's daily log sheet is to be completed by mum and dad and reviewed weekly by John's Community Nurse who will monitor whether mum and dad are responding appropriately to signs of infection. Community Nurse to provide monthly graphs regarding frequency of self injury and relationship to ear infections. Community nurse will also link with GP as needed to ensure John and his family get quick and timely access to the GP as needed.

Jenny's senior support staff will review the monitoring of the undressing script weekly and amend this depending on Jenny's progress i.e. adjusting support and prompting as her independence increases or decreases. Staff team to be given graphical feedback about Jenny's involvement with undressing and opportunity to discuss the activity script etc. at monthly staff meetings. Jenny's PBS nurse will visit weekly for the next month and observe and give feedback to staff implementing the undressing script.

Mike's staff to complete daily logs regarding planning time. Logs to be reviewed monthly by Speech and Language Therapist. Behavioural Specialist to graph observation data and to feedback to staff at fortnightly MDT.

Poor examples

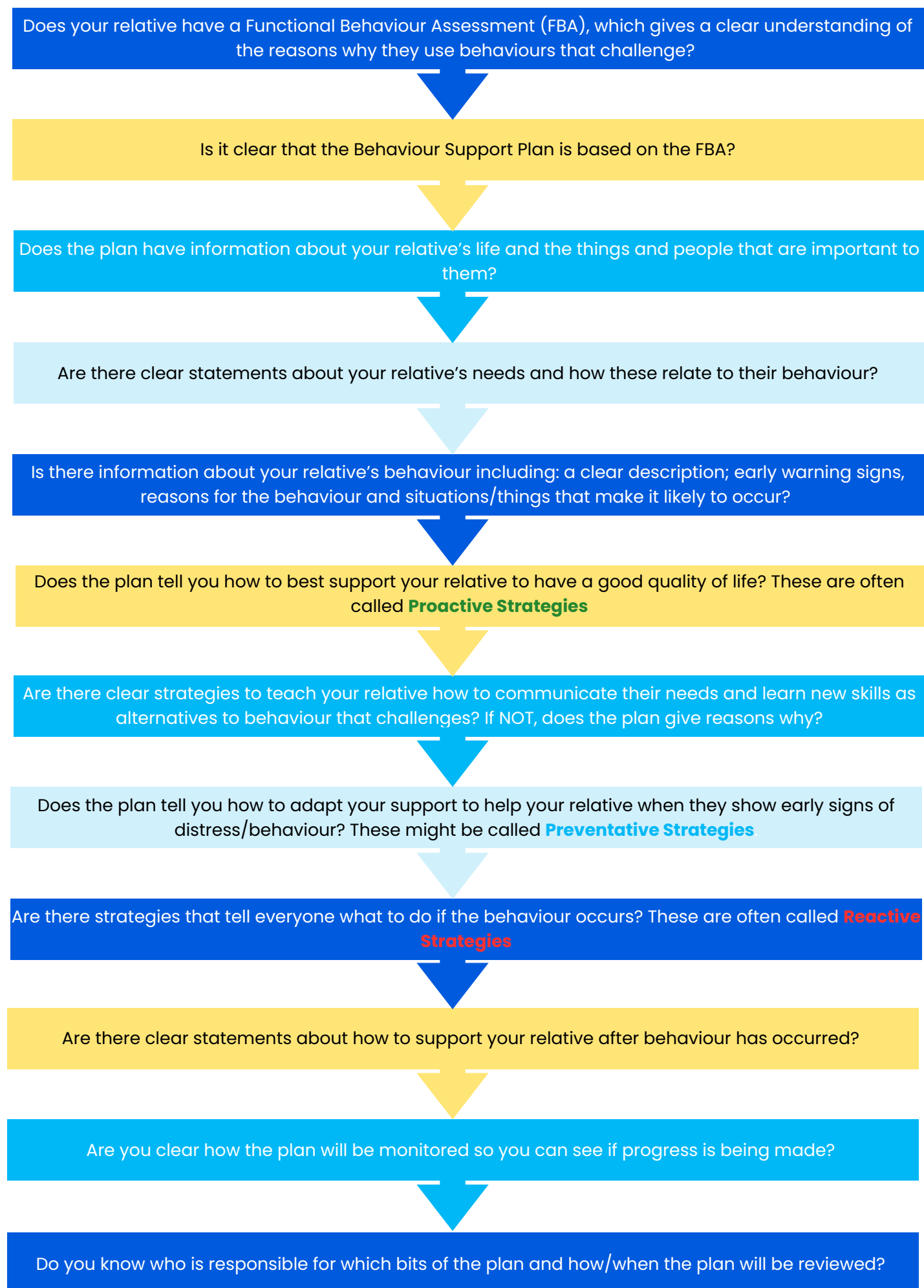
Everyone will complete daily records and discuss at John's MDT meetings.

Staff to monitor progress of undressing programme in daily notes.
Care plan to be reviewed monthly and updated.

Staff to complete all paperwork in daily log.

Regular review and discussion by all involved in providing Mike's support when required.

Flowchart to check the key elements in a Behaviour Support Plan



Checklist of Key Elements in a Behaviour Support Plan

Use this checklist to ensure that all key elements of a Behaviour Support Plan are present for your relative.

Element of a plan	Present in plan	Actions to improve plan
Information about your relative's life and the things and people that are important to them.		
Information about your relative's needs and how these might relate to their behaviour		
Information about your relative's behaviour		
Information on best ways to support your relative to have a good quality of life		
Information on teaching strategies		
Information on ways to support your relative when early signs of behaviour/distress occur		
Information on how to safely support your relative should the behaviour occur		
Ways to support your relative after the behaviour has occurred		
Information about how the plan will be monitored		
Information on responsibilities and review of the plan		

Taking forward concerns about PBS Support – sample text for letters or emails

If you are unhappy about the support your relative is receiving and believe this is not within a PBS framework, you can contact the support provider or the statutory organisation responsible for commissioning (buying or arranging) the service, to register your concerns and ask for them to be addressed. See Resource 3 for further information. Here is a template for a letter with suggested wording to help you state clearly your concerns, link these to current guidance and request a formal response.

Dear Sir or Madam,

(your relative's name) (date of birth)

I am writing as the parent of the above child/young person/adult who is being offered/receiving a service from **[name of provider]**.

NHS England and LGA guidance (*Ensuring Quality Services 2013*) recommends Positive Behavioural Support (PBS) as the framework of support built on the strongest evidence base for supporting individuals with a learning disability and behaviour that challenges.

PBS is also recommended in professional guidelines including the NICE guidelines for Challenging Behaviour; Positive and Proactive Care: Reducing the need for Restrictive Interventions; A Positive and Proactive Workforce; and Supporting Staff who work with people who Challenge services.

The PBS Competence Framework sets out all the elements that should be in place where PBS is being used.

[relative's name] has a learning disability and behaviours that challenge. I have checked the competence framework, and I am concerned that the following aspects of **[name of relative's]** service are not in place/satisfactory. **[cut and paste elements of framework which are not in place, ideally with examples, e.g.**

“We are not fully involved as equal partners in decisions about our daughter's care. We were not consulted on the development of the Behaviour Support Plan and did not have the chance to input or discuss with professionals.”]

I look forward to a reply explaining how you will address this issue and trust that it will not be necessary to take this matter further.

Yours sincerely,

[Your name]



We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@theCBF.org.uk, or visit our website: www.challengingbehaviour.org.uk

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