
06 Siblings – their role in Positive Behaviour Support

Having a brother or a sister with a learning disability or other additional needs can have a big impact on your life and may mean your everyday experiences differ greatly from your peers. Sibling carers have an important role in the lives of their disabled brother or sister. For example, siblings are often our first and our longest friendships and play a big part in our social lives, in developing skills, and sharing new experiences. Siblings are likely to have a role in providing emotional and/or physical care and should be recognised for the valuable role they have.

Siblings are also highly likely to be advocates, and often help their brother or sister to get the support they need to live a good life.



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Growing up with a unique perspective.

With all of these extra responsibilities most siblings grow up faster than their peers, especially when it comes to emotional maturity. Siblings learn first-hand the skills of patience, empathy, creative communication and how important it is to see the whole person, not just their diagnosis or difficulties. Although the role sibling's play is hugely significant, they can often be overlooked, with society not always valuing the long-term role that they play in their brother or sister's lives. When this happens, there can be costs to their development and wellbeing if their role is not recognised.

Family pressures.

Sometimes there are pressures on the family to be able to give the sibling as much attention as they would like to as a result of the caring needs for their brother or sister. Many parents report one of their biggest stresses is managing to give equal time and attention. While siblings often understand this, it can lead to feelings of being unintentionally left out. Some siblings can be left feeling that their everyday experiences are so different to that of their peers, that they struggle to find things in common. This is particularly true when it comes to emotional maturity, as many siblings have a greater sense of empathy and compassion at an earlier age.

They also may not have as many opportunities for social or recreational activities as a result of the family's shared caring role. This can be because the family lacks time to take the sibling to other activities, may have issues with finances, or there are anxieties about public perception when the whole family is out in the community. These shared pressures can sometimes place siblings at greater risk of isolation or exclusion. This risk is further increased when their brother or sister can sometimes display behaviours that others might find strange or concerning. These factors can really test a person's wellbeing and resilience.

Finding support.

There are many resources available to parents and siblings to help support the role they play. These might involve helping others to develop a greater understanding around their brother or sister's diagnosis, or the different ways of communicating and interacting that can be used. If a sibling can sometimes display behaviours that are concerning, learning about this, and the possible reasons for it, can help siblings to cope better and respond positively. Positive Behaviour Support (PBS) is an approach that siblings have a right to learn about because it will help them to put into practice ideas and solutions that support their brother or sister's quality of life, helping them to minimise distressed behaviour. Developing our understanding of this can help build resilience, and it can give us different ways of explaining the behaviour to others, such as peers or professionals, so they can understand better and do not judge.

PBS can be used alongside other techniques to help people to live a good and happier life. It is especially useful for adults and children who can sometimes display behaviours that cause concern and may need help to manage them in a way that they feel is right. PBS helps us to think about the person's life experience and wellbeing as a whole rather than just focusing on behaviour. The main aim of PBS is to improve the person's quality of life, making them feel more confident in their world and therefore more confident in managing behaviour.

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The PBS process – how it works.

PBS involves:

- Getting to know the person; their likes and interests, how they communicate, and how they prefer to experience and interact with the world around them. The person, their family and their circle of support will be involved. It has roots in a person-centred approach and connects to the 'what matters to me' conversations.
- Identifying events or situations the person finds difficult or distressing – that can set certain behaviours off are referred to as 'triggers'. We look at how the person expresses themselves when something is not quite right. Having a clear picture of what the person's behaviours are when they are unhappy or anxious can help everyone to respond both helpfully and consistently. We then work out together what the person was trying to communicate or achieve when they used this behaviour, because that will help us to understand the meaning behind it. The goal is to predict when behaviours are likely to occur, describe what the behaviours look like, and develop an understanding of what the purpose or reason is.



- We use this learning to create a person-centred support plan that lists all of the things that are important to support the person to feel happy, included, safe and secure. For example, how to communicate, how the person enjoys spending their time, or how we support their physical health. The plan would also list the person's potential 'triggers' and what we can do together to reduce them. In the case of those triggers that cannot be avoided, the plan might include practical options around skills and techniques that help. For example, if crowded places are a trigger, then the plan would include distraction techniques and communication aids that might help the family member to cope better. All of these elements are focused on supporting the person's wellbeing and reducing the need for them to use behaviours that are difficult for them to manage. We call these **Proactive Strategies**, and they should make up the biggest part of the plan. In addition to Proactive Strategies, it also includes clear strategies for how to respond if a behaviour does occur. These are called **Reactive Strategies**. The strategies will depend on what the behaviour looks like, what the meaning is behind it, and how we can support the person to manage the behaviour as safely and as respectfully as possible.

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- Everything we do in PBS is guided by the understanding all behaviour is meaningful, and if we can look for the message instead of just seeing the behaviour, we can respond to a person's needs in a way that they feel in control of. When everyone understands that the person is not intentionally being disruptive or trying to cause hurt, we can actively support the person instead of resorting to reactive punishment or taking it personally when the behaviour does occur.

Being an important partner.

Siblings should also be involved in regularly reviewing and updating plans to ensure they continue to fully reflect their brother or sister's needs. Often bringing a unique understanding, siblings can really help support to get things right.

Further information

For local general support for families and carers contact
All Wales Forum: www.allwalesforum.org.uk

For support with behaviour that challenges contact
Challenging Behaviour Foundation:
www.challengingbehaviour.org.uk

See *Additional Resources* document for more information.

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