
05 **What matters to families – a right to a good life**



Everyday life can be far from simple when you have a loved one with a learning disability. While it can be very rewarding, it can also involve some really big challenges. If you don't have the right practical and emotional support when you need it, it can leave families struggling to manage situations, having a negative effect on family life.

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The impact of caring

The impact of caring on families with learning disability is wide ranging. When it feels like your family life is so different to that of others, there is a risk that you can withdraw from the community. This is often because of fears that people may not understand what you are going through. Many families also report that it can sometimes feel like a battle to get the right services in place for their loved one; the stress of this can impact social, physical and mental health.

There are also many positives associated with families who have lived experience of caring. The pleasure of spending time with a loved one, seeing their achievements, having new experiences and opportunities together, can all be incredibly bonding. Families with lived experience of supporting a person with learning disabilities are some of the strongest and most resilient; they often have excellent communication and problem-solving skills and show real compassion and empathy for others.



Remember: you are not alone

It can feel scary and overwhelming when your child is diagnosed, or you have a family member with additional needs. It may mean that the life you had imagined for you and your family will very look different, and it may mean you will have a lifelong role as a family carer. However, it is important to remember you are not alone. Reaching out and talking to others who can relate can stop small worries from building up and becoming bigger issues. It also helps to reduce the risk of isolation and is an important coping strategy for us all.

Many families find it invaluable to connect with other families in similar situations. There are many active family carer groups at both local and national levels. These can provide families with much-needed peer support, friendship, advocacy, and advice. Many families report how important it is to be able to talk openly and honestly about their experience, without any fear of judgment. Having that outlet can counter the risk of loneliness and isolation.

There are many different strands of support available out there. For example, alongside informal support, you may wish to speak to your G.P. if you feel you would benefit from some individual emotional support or need an outlet to talk about your feelings. Speaking with your social care worker can also help you share your experience as a family and provide support with more practical aspects of care, like accessing training, information, community services etc.

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Positive Behaviour Support (PBS) is an approach that can help to identify what is important to your family member's quality of life

Knowledge is empowering

There are so many resources available to families to help support them in their caring role. Access to these can give families knowledge around diagnosis, suggest different ways of communicating and provide case studies from families in similar situations. If your loved one sometimes finds it hard to manage behaviours in situations that can cause stress or anxiety, learning about techniques can also help you to cope better and respond.

Positive Behaviour Support (PBS) is an approach that can help to identify what is important to your family member's quality of life, and how focusing on why someone feels or behaves a certain way can help to minimise distressed behaviour. Developing that knowledge can give families greater resilience: it helps us to not take distressed behaviour personally and can give us a way of helping others to understand, so they don't judge.

It is also important for families to develop an understanding around their rights and the services available to them, as well as the many charities and organisations that can support and advocate on their behalf. Knowing our rights means we can feel more confident in asking for and accessing the right support.

Although reaching out can feel like yet another thing a family has to take on, it is often a process that families who have 'been through it' really appreciate; get as much information as you can, and you will have far more confidence to make choices and keep control over care and support.



Focussing on what 'can be done' and not only on negatives

It's so important that families are supported to celebrate what can be achieved and the unique abilities of the people they support. This is not to minimise the difficulties that some families can face. Our culture often focusses on the negative, seeing risk and danger as a primary concern. For many families they spend a lifetime fighting for risk to be a part of their loved ones lives, and where behaviour can sometimes get in the way of this, families need to feel empowered to use techniques that can remove barriers to inclusion and risk taking.

It is important for families to be recognised as equals in working together with community support to look consciously for the positive moments and person-centred solutions. By working together to co-design a plan that is owned by the person and their family, we can ensure families remain connected to their communities and can cope with situations that arise. This helps to ensure better emotional physical well-being for everyone.

Positive Behaviour Support is one of the methods that can help families to start to focus positively on what can be done, and how barriers can be broken down. One step at a time.

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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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