Parent support after an autism diagnosis

Getting a diagnosis of autism for your child can be an overwhelming and scary experience.

I have worked with autistic children for the last ten years and in that time I have supported parents with their concerns, questions and ideas, as well as increasing their understanding of autism. It’s comforting for parents to discuss these things with someone who has heard their concerns before, and who believes in their ability to support their child. It also allows them to feel that they aren’t alone.

Far too often, parents are not given the time and support they need to build their confidence in parenting their autistic child. They end up becoming ‘warriors’ for their child rather than the ‘typical’ idea of what it means to be a parent. I have been told by many parents that they feel as though they are fighting a constant battle and as much as children need a break and understanding – parents do too.

I have an open-door policy for parents to contact me with whatever their struggle may be. They can contact me via email or my direct phone line. I feel that allowing parents to know that they have somewhere to turn can often be a massive comfort.

I have many aims and goals for parents; although as in teaching or parenting, they change on a regular and individual basis. I do strive to build parents confidence in their ability to deal with this new pathway that their life has taken.

Parents often feel as though they have lost control of how to parent an autistic child, and that they can’t keep up with everything they ‘should’ be doing. I remind parents that parental instinct is still a strong resource to have in supporting their child, and that they actually understand more than they may think. Parents know their children, and even though they now have this diagnosis, they are still just a child and one that in many respects, parents know best!
Building communities of support

Building a community with strong links is important for an autistic child’s development, and to ensure consistency of approaches. I have found that this can sometimes be difficult in different cultures. Therefore, I host parent support groups and coffee mornings where parents can come along and chat to other parents about their struggles and achievements. It is really heart-warming to watch parents come together and discuss ways in which they helped their families understand their child’s diagnosis. It can be comforting to speak to other families from similar backgrounds and discuss which strategies worked best for them.

As much as I am a specialist in autism, there is something very powerful about connecting parents. A deeper understanding and trust develops when you can openly speak to someone who has been through some of the same things you have. It is also powerful to hear the stories of achievements and positive viewpoints on autism. I find that parent groups are vital to the wellbeing of parents who are striving to understand more about their autistic loved one.

I also provide some training sessions for parents to learn about different supports and strategies that we use in school. We often have a speech and language therapist and occupational therapist support us in this as well.

Accepting and understanding the diagnosis

Parent support does bring its own challenges – for example it can often be difficult for parents to make the first step in an autistic environment or support group, depending on how accepting they are of the diagnosis. As they need to make the first step in order to be identified, I feel as though I do not reach as many parents as would benefit from the support. Getting parents through the door for the first time can be a massive challenge.

GPs can downplay the diagnosis and instead of encouraging parents to get the support they need, they can tend to push them into denial and a misunderstanding of the diagnosis. Obviously this doesn’t apply to all GPs but I have heard about it far more than I would like!

Truly understanding and accepting a child’s diagnosis of autism can be life changing, although I know that it isn’t always easy. Once parents cross that bridge they will be on a path to embracing and empowering their child; this is where I want all parents to be.

One of my parents struggled so much at the beginning of her child’s post-diagnosis pathway that she wouldn’t even say the word ‘autism’ for the first year. She had family members that didn’t believe in the diagnosis, and she really struggled to build the confidence to stand up to her family and embrace her son’s different personality traits.

I am happy to say that 2 years later she began to accept the diagnosis and 3 years later was coming to every parent support group and supporting other families in the same situation. She now finds herself less frustrated and more understanding of her son needs. She just needed a non-threatening and patient environment to develop and grow her ability to embrace and empower her son. Today she is a wealth of knowledge and still shows up to the parent groups.
If we want our children to grow up and be proud of who they are, we have to get there first! I hope to continue to support families to do this, and help them realise that autism is a collection of personality traits that need some creative intervention, but their children can achieve their highest potential with a supportive environment and consistent approaches. I aspire for our parent group to consistently offer that support!

**Further information**

[The National Autistic Society – Local branches](#)

[The National Autistic Society – MyWorld autism resources](#)