Supporting Parents of Children with Autism and Pathological Demand Avoidance

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IT'S UNFORTUNATE THAT MOTHERHOOD IS SUBJECTED TO EXTERNAL OPINIONS/ JUDGMENT; THIS IS OFTEN THE CASE FOR PARENTS RAISING A CHILD WITH PDA. THIS ARTICLE OFFERS SOME TIPS FOR PARENTS EXPERIENCING "BAD PRESS".

Pathological demand avoidance (PDA) is characterized in children by a continual resistance to everyday demands through social manipulation which has, at its root, an anxiety-driven need to be in control. This inability to cooperate with simple requests can make everyday family life a battlefield.

Parents have to make constant adjustments to get through the routines of the day, and this is exhausting. In the long term, this becomes such a normal way of living that parents forget what it is like to live an ordinary family life.

The stresses of living this way are enormous, and most parents have felt at one time or another that they have reached the end of their resources, and they don't know where to turn for help. As friends, wider family members, or professionals, we need to be the support mechanisms that parents need to adjust successfully to the complex situations they find themselves in.

"One of the hardest things I find about parenting a child with demand avoidance is that sometimes they appear so normal that others think there isn't a problem—but I know I can never relax—others don't see the groundwork and the thinking I have to do to make the simplest thing a success; it is completely exhausting," says the parent of a child diagnosed with PDA.

Common negative experiences

Parents of children with PDA tend to have some common experiences when dealing with professionals in the formative years. Knowledge of the condition is still limited amongst early help providers. This often translates to parents being told that there isn't a problem with their child but that their parenting style and a lack of consistency is at fault.

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Many parents have attended parenting courses where they have been taught to put in stronger boundaries with a series of rewards and sanctions for wanted or unwanted behavior. This approach tends to increase the anxieties in children as a direct result of the increased demands, and therefore the need to resist is stronger. This leads to exacerbated avoidant behaviors and a sense of confusion for the parent.

Many parents begin to believe such "bad press" when they cannot get their children to conform, however hard they try. In many cases, this has led to a deep-seated fear that their children will be taken away from them because they cannot help their children comply with societal norms and behavior. This may include being unable to prevent aggressive outbursts in the community, anti-social behavior such as stripping in public, not being able to get to school on time, or even being able to attend school at all.

By the time parents find a professional that knows about and understands the condition, they can be in a very precarious position with strained family relationships and a sense of despair that things will never be any different.

"I have tried everything that professionals have suggested to me and have been on so many parenting courses. Nothing works and I don't know where to turn. I can't go on like this" says the parent of a child with a demand avoidant profile attending a parent open day at The Link School.

Key support strategies

Thankfully, practitioner research on PDA has helped professionals and parents make discoveries about best practices for supporting families affected by this condition.

It is vital that professionals understand PDA presentation and the different ways it affects individuals, rather than assuming a parenting course will be the solution. Parents need to be listened to and their experiences recognized without prejudice.

Doctors should acknowledge the strategies that parents have discovered along the way to pacify and lower their child's anxieties. Parents have often found some innovative and exceptional strategies that, when pointed out to them, will help them realize what extraordinary parents they are.

"I feel so much better about myself these days—I know I'm a good Mum and I can see that what I do every day is making a real difference to my son," says a parent from the PANDA support group at The Link School.

Giving parents permission to try out unconventional parenting techniques can provide a huge sense of relief, particularly when these techniques prove (very quickly) to have a positive impact. Strategies like reducing/disguising demands, or depersonalizing demands to make an authority figure responsible for unpopular decisions, are easy to put into place and tend to be effective.

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Being able to ignore rather than punish undesirable conduct can be very freeing, particularly when doing so prevents escalation of more challenging behavior. Positive interactions—such as parents exploring their child's special interests—in combination with role play can often encourage the child to perform routines that must be done as a matter of urgency or safety.

It is helpful for parents to realize that they don't have to work on every issue at the same time. Learning to prioritize concerns and choose appropriate battles to work on, with the support of a professional team, can give a sense of hope. Having other people to celebrate with on good days, and for commiseration on dark days, helps parents to maintain their efforts and even introduces humor and optimism into their lives.

"Thank you for always seeing the best part of my son, whatever he does. I no longer dread picking my child up from school because I know that even when he has had a bad day, you will say, 'it's a new day tomorrow,'" says the parent of a child with demand avoidance who attends The Link School.

Top tips for supporting parents

1. Research PDA so that you know challenging behaviors come from a place of anxiety rather than bad parenting
2. Give parents hope by valuing the child for the personality that is hidden behind the anxiety
3. Be honest about children's difficulties, but always believe there is a solution

4. Understand that parents' energies are often exhausted by looking after their child; they need support to advocate with professionals that may not understand the PDA condition

5. Keep up with a child's motivations and interests so that you have a way to engage successfully with them

6. Allow parents to be more involved in their child's individual learning programs if it helps reduce their anxiety and improves access to learning

7. Be resolute through the tougher times to help parents overcome exceptional challenges

8. Consider setting up a bespoke parent support group so parents know they do not have to manage alone

Conclusion

Recognition of the PDA condition is improving among professionals and therefore, support for parents is more likely to be forthcoming in the future. It is vital that parents are not made to feel that their child is "just naughty" or that their child's complex behavior is their fault.

There is evidence that, when given the right support, parents can recognize their strengths, overcome their negative past experiences, and develop the new skills they need to successfully parent their extraordinary children.

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