

→ SPOTLIGHT



PDA: working with parents and carers

Natalie Menagh talks about the importance of collaborating with parents and carers of children with Pathological Demand Avoidance (PDA) in order to help achieve the best possible outcomes.

The needs of children with PDA are often very difficult to manage at home and families can be under enormous emotional stress and pressure on a daily basis. Parents may also suffer from poor mental health due to the ongoing strain of responding to extreme behaviours, which can isolate them socially and leave them with an ongoing sense of failure and helplessness.

Support from school must be non-judgemental, open and honest and reflect

a shared school commitment to individual outcomes. Professionals can make an enormous difference by giving some key messages that let families know that they are believed, that the school is committed to working with them to overcome the difficulties and that the child will be placed at the centre of all decisions made.

The severity of needs can fluctuate over time depending on the child's levels of anxiety, which can change frequently and rapidly. A child with PDA is likely to place a lot of demands on caregivers, be explosive at home, be violent and may show a level of

emotional distress which is heartbreakingly witnessed. Caregivers may live with continuously high levels of stress, along with their child, as they persist in trying to make the right choices and parent successfully whilst receiving very little support or guidance.

One significant struggle which parents often face is when the child with PDA gives significant resistance to the demands of morning routines such as washing, dressing, breakfast time and making the transition to school. For the child with PDA, these little routines are seen as a build-up towards a huge demand i.e. going in to school.

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**IDEAS TO SUPPORT PARTNERSHIP WORKING**

- Build a clear profile of the child with parents; include lists of the positives, interests and abilities and then a list of their difficulties, what works, what does not work, how people can help and the outcomes everyone is aiming for.
- Use a home-school diary with honest, open dialogue communicating aspects of the child's day.
- Hold coffee mornings with the SENCO where caregivers can meet each other and have the chance to talk and gather information about local services or groups. Parents often learn the most about what is available from other parents.
- Hold a collaborative PDA training session with key staff and parents (more CPD opportunities should involve parents and school staff learning together).
- Person-centred planning meetings are not just for pupils with an EHCP. They can foster excellent relationships, as well as gather vital information to inform SEND support planning.
- Regular, open and honest communication with parents and carers, which may involve giving difficult messages, if followed with options, choices and clear plans for how staff will respond, can be a much more positive conversation.

RECOGNISE PARENTS' EFFORTS

Why do children with PDA often resist or even refuse school? School can be seen as representing a long list of demands from start to finish, imposed rules and expectations, questions, sensory overload and social difficulties. Unless we can build positive relationships, provide opportunities to relax and give sufficient flexibility, the likelihood of school refusal only increases.

As professionals, we must ensure that the efforts of parents are recognised, and meaningful adjustments are considered to help improve the situation. When a parent speaks to school about issues such as resistance in the morning, it is important that professionals really listen and avoid statements such 'they are fine once they are in school'. To the parent, this communicates two messages; the first being that they are doing something wrong with their child

and the second that it is their problem to solve. This is incorrect, it is everyone's problem to solve and it is only through a child-centred discussion that we can begin to tease out the various factors affecting this.

If you have a child with PDA in your setting who is presenting with high anxiety about coming into school, consider the following:

- What is their first activity upon arrival? There may need to be a consistent activity period each morning to help reduce anxiety and give the child time to adjust to being in the setting. This can include simple games with an adult, sensory play in a quiet space, listening to an audio book, building a small LEGO set, engaging in visual activities like word searches or mazes or feeding the school fish! Giving the child a purpose for going into school can help to distract from their anxiety and avoidance.

Knowing that they will have a short time to engage in an activity they enjoy when they arrive can help massively with the morning transition from home to school.

- What is happening with their friendship group? Don't assume that the child with PDA will have told staff about a difficulty they

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face in the playground as often they strongly desire to just fit in and can dislike drawing attention to problems. They can be extremely vulnerable to peer pressure, being provoked and, in the worst cases, bullied. Other children can find their extreme behaviours amusing and may even encourage this. A child with PDA can also respond to peers negatively or become controlling, which may ultimately ruin potential friendships with peers and lead to the child's social isolation. Social interactions should be monitored carefully, and school may need to consider additional support from an adult in the playground.

- Is there a particular part of their day which always seems to be a source of stress for the child? How can this be planned around, or the impact lessened? I worked with a child with PDA who found the dinner hall intolerable which led to refusal to come to school. We had to learn a lot about what a day in school was like for him and tracked him to see what the trigger was but once we discovered this, we were able to adjust.
- Consider how their day started and whether a plan that the child had in their mind reached

a natural finish before school or whether the parent had to stop them in the middle of something in order to get them in. Children with PDA need to see things through to completion and being prevented from doing this can lead to significant stress. The parent may need practical advice to plan their mornings to reduce the chance of this happening.

We can sometimes assume that our desire to work together is obvious to parents, but this may need to be made explicit. They need to feel that the school is working with them, so they need reassurance that the school knows there are issues, that there is work to be done and that they will do it with them; let's remove the 'I' and the 'you' from discussions and start using 'we'.

“As professionals, we must ensure that the efforts of parents are recognised.”



BIO

NATALIE MENAGH

Natalie is an Inclusion Manager and qualified SENCO who has many years of experience in managing provision for children with SEND in mainstream settings. She has also worked as part of the Whole School SEND team as a Deputy Regional Leader for SEND in the North region and has been an assessor for the Inclusion Quality Mark. Natalie is also a parent of a child with ASC/PDA.