

NAS Surrey Branch Meeting Report

Introduction to Pathological Demand Avoidance

Clare Truman gave a very helpful and interesting talk about demand avoidance and PDA in Guildford on 23rd March 2019.

Clare Truman is director of Spectrum Space <https://spectrumspace.org/> a not for profit, community interest company providing personalised education programmes for children and young people aged between eight and nineteen years old with complex social communication needs and/or autism spectrum disorders who find it difficult to access school-based learning. Clare has been teaching for ten years and specialised in autism for seven. She is also working on a PhD in understanding the support needs of children with autism who display extreme demand avoidance. She has a brother on the spectrum.

Clare explained Pathological Demand Avoidance (PDA) is recognised by many as part of the autism spectrum, but does not appear in diagnostic manuals – there is an explanation on the NAS website: <http://www.autism.org.uk/about/what-is/pda.aspx> However, Clare explained that the presentation of individuals with a PDA profile is very different to classic autism as people who have it have an anxiety-driven need to avoid demands.

Strategies to Help

Strategies that the team at Spectrum Space use include grading a child's emotional state from very anxious > anxious > calmish > calm and ready to learn, then assessing what they can do in each state. If they are highly anxious, the only priority is to keep them and others safe. Once they are calmer, they can move to making wise choices and once fully calm, to being challenged with new things to learn.

Many of the questions were about issues with school. Clare suggested that adopting a joint problem-solving approach may help. Focussing on the fact that everyone involved wants to help the child learn and feel comfortable at school and that using traditional strategies so far has not helped to achieve that so can we try the PDA strategies and see if that leads to the child feeling more comfortable and learning more. There is helpful guidance for schools to follow, endorsed by the Department of Education, here: <https://bit.ly/2WtwZhJ>

Questions from parents included:

Q1: QWhat is the difference between PDA and ODD?

A: There is a lot of debate about this and some scholars think that there isn't much difference. However, those that do argue that there is a difference say that the main differences are that children and young people with ODD are more concerned about maintaining their reputation with their peers than those with PDA and so those with ODD will not act in age inappropriate ways whereas those with PDA will. In addition, behavioural strategies such as clear rules with set rewards and consequences are seen to be effective for those with ODD and ineffective for those with PDA.

Q2. How can you diagnose PDA in a child with SLD, ADHD, ASD, Downs & non-verbal – or can you?

A: It is very difficult to get a diagnosis of PDA in this area and can be very difficult where

there are lots of co-occurring conditions. My advice to anyone is always to focus on the strategies rather than diagnosis. If you can get PDA friendly strategies into the EHCP this may be more important than having the diagnosis.

Q3: My son is very controlling of me and my husband – how can I manage this without disaster! It has built up over time.

A: Definitely pick one thing to focus on at a time. Complete the priority rating chart that we discussed in the talk, with your husband and prioritise the things that you rate as number one priorities. As you are tackling those priorities try to make everything else as low-demand as possible so that you are keeping anxiety levels in all other areas to a minimum. Try and present the new rules as fun challenges rather than new rules and offer choices wherever possible. If you present a range of choices that are acceptable for you and give your son the final say out of your shortlist this may help.

Q4: Last minute refusals – our daughter frequently refuses to do something she wants to do at very short notice. e.g. swimming lesson or drama club. She gets very angry with us and says we can't make her go. How best should we deal with this?

A: You may find that creating more opportunities for swimming or drama throughout the week, counter-intuitively, may reduce the pressure and expectation surrounding the one lesson and make it easier to go along to. I would reassure her that you are not going to make her go, while setting up all the conditions that make it easier for her to go when she wants to. So making sure her swimming bag is packed in advance and in the car/by the front door. Leaving a lot of time for the transition. Having distractions during the transition such as reading or playing games on the way to the car and in the car. Can she help you with a job during the transition so she is distracted from the stress of the transition and feels helpful?

Q5: How do you stop the violent behaviour?

A: Reducing the amount of anxiety all contributes to reducing challenging behaviour. So make sure the number of demands a child encounters in one day is kept to a minimum and that there are lots of opportunities to reduce stress through regular calming activities presented in a low demand way should all help reduce challenging behaviour. Surrey County Council may be able to provide more advice on practical tips to help keep you and other children safe when faced with violent behaviour.

Q6. What to do if the other parent doesn't believe the diagnosis?

A: This can be very challenging. I would approach this from a joint problem solving perspective. Ultimately you both want the best for your child so if you can approach the situation from a perspective of "what we have been doing so far hasn't been working, can we try some PDA strategies and see if they work better". If you both observe your child's anxiety reducing by using the PDA strategies then it may be possible to slowly introduce more.

There were several questions about school and school refusal including:

Q: My son has been refusing to go into school for 3 weeks. The teacher is using an approach of 'one size fits all', and says they can't treat him as an exception or all the other children will want special treatment. They give him detentions for breaking school

rules like being late, using a pen not a pencil in maths which are petty for a boy with ASD. Is the school supposed to use special strategies for a boy with ASD?

Q: How can you help a school refuser?

Q: How do you change the mindset of teachers at schools so your child isn't seen as defiant and refusing to co-operate all the time.

Q: How can I find out for sure if my child has a PDA profile and work with school to make his life happier?

Clare summarised information for parents dealing with issues around school / refusal: Adopting a joint problem solving approach may help. Focussing on the fact that everyone involved wants to help the child learn and feel comfortable at school and that using traditional strategies so far has not helped to achieve that so can we try the PDA strategies and see if that leads to the child feeling more comfortable and learning more.

She explained that there is great guidance for schools to follow, endorsed by the Department of Education, here:

<http://www.aettraininghubs.org.uk/wp-content/uploads/2012/05/5.2-strategies-for-teaching-pupils-with-PDA.pdf>

Other resources that may be useful if you support a child with PDA include:

- PDAResource.com
- PDA Society <https://www.pdasociety.org.uk/>
- Sally Cat's guide to PDA <http://www.sallycatpda.co.uk/>
- Julia Daunt's Blog <https://memyselfandpda.com/>
- Steph's Two Girls Blog <https://www.stephstwogirls.co.uk/>