

Jack

Despite being diagnosed with Asperger's & ADHD at 5, it was clear that Jack didn't really fit the Asperger's profile. PDA isn't recognised in our area, but everyone can see that anxiety is at the root of his behaviour. PDA strategies that are engaging and adaptive are the most effective with him. As well as 1:1 support, Jack's Education Health and Care Plan (EHCP) enabled other accommodations and flexibility at school. Despite this school remains really challenging for Jack and a change in support personnel has been very unsettling.

Jack was a very easy baby and is extremely bright - he taught himself the Arabic alphabet from YouTube videos and could read fluently and count into the thousands by the age of 3. But by the time he went to nursery he could be quite aggressive with other children, wouldn't follow instructions, didn't respond to traditional rewards/consequences and had problems with delayed toilet training. We first raised concerns when he started primary school, and on the SENCO's recommendation we sought a psychological referral.

The process was fast and smooth thanks to several factors – we had the school's support, the clinicians were excellent, we were well-informed and Jack doesn't mask his challenging behaviour so he was easy to observe. He was diagnosed with high-functioning ASD and symptoms of ADHD by the time he was 5 and a half.

Over time it was increasingly evident that Jack didn't really fit an Asperger's profile. He's extremely sociable and when he is relaxed and happy he can be articulate and charming, making good eye contact. He has an active imagination, enjoys jokes and is often quick to perceive sarcasm. The key aspects of Jack's autism are needing to be in control, extreme demand avoidance and emotional volatility.

We found PDA through our own online research. I joined various PDA support groups online and built up my knowledge, using a blend of strategies with Jack at home. I've found PDA behavioural explanations and management tools invaluable. Jack is clearly autistic, but just as clearly does not fit the behavioural model for

Asperger Syndrome whereas he ticks a lot more of the boxes for PDA. I think there is also some blurring because of the ADHD, though I'm not wholly convinced he has ADHD and feel that it may just be a manifestation of his PDA coping strategies. Regardless, treating Jack as a child with PDA has been much more productive. His school also uses a mix of strategies, including a lot of flexibility and demand reduction.

Our local CAMHS doesn't recognise PDA, but they agreed that Jack's anxiety is very high and that this lies at the root of his behaviour. I can see both sides of the argument when it comes to a differentiated diagnosis. Autism is a spectrum and each child is unique, so interventions and accommodations should focus on a child's individual needs. However, not everyone involved with your child will have the same level of understanding. Most people's interpretation of 'high functioning autism' is Asperger Syndrome, but this is very different to PDA and if treated the same the results can be disastrous. Personally I feel that PDA children are the most challenging, as behaviour can be so erratic and carers need to be engaging, adaptive and thick-skinned. One moment they can seem perfectly normal and 'above-average'; the next they revert to the behaviour of a much younger child for no obviously discernible reason. They often have huge academic potential, but anxiety and demand avoidance gets in the way of learning.

Jack's behaviour is much more challenging at school than at home, although we do see increased anxiety and resultant behaviour at home during the term which usually lessens during the holidays. He often gets up and moves around the classroom; fiddles with objects instead of working; argues with teachers and tries to change the subject; wants to dictate his own way of doing a task; disturbs other children; lies on the floor and refuses to move; and can become upset and aggressive with staff, other children, the furniture or himself. Whilst he likes some aspects of school, there are very few days without some kind of challenging incident. Even on his best days, Jack requires constant 1:1 support and intervention.

We've had good and bad patches. In Year 2 school was not sure that his needs could be met, and this is when we obtained an EHCP. This gave access to full time 1:1 support, an adapted curriculum with frequent learning breaks and the ability to opt out of some lessons if he's particularly anxious, along with other accommodations such as altering his homework so that he doesn't have to write so much. Transitions heighten Jack's anxiety, so I drop off and pick up from the office so that he isn't so impacted by the arrival/home time chaos. Whilst this works for school and Jack, it unfortunately means that I don't get to socialise with other parents as much as I'd like to.

Currently Jack is going through a rough period and we're battling with school refusal - he says he hates school, that school is Hell and it is killing him - but doesn't report any specific issues except boredom. He's also been unsettled by a change in his support team - he has had two TAs who work with him at different times of the day, as he's too challenging for one person to work with the whole day. However they are both leaving and other staff aren't managing to work with Jack successfully so his school has decided that they're no longer able to meet his needs. Our Local Authority will reassess him in September with a view to specialist provision. Recently the Outreach adviser asked us all to complete the EDA-Q and everyone – parents, SENCO, TA – all scored him over 50 which 'identifies individuals with an elevated risk of having a profile consistent with PDA'. So despite school really trying hard and him having an EHCP, it just shows how challenging PDA can be in the school environment.

Jack is so intelligent and can be so sociable, so I really hope that as he gets older he'll learn better how to manage his own emotions and reactions so that he can lead a largely normal life, though I think he will always need some degree of support.