

Early life

Even as a baby, my son seemed more anxious than other babies. He cried a lot and liked to be constantly held and fed. He never crawled or held up his arms to me like other babies did. He walked late but was running around within days of learning.

At two he went to nursery. I raised concerns about his lack of speech and constant sorting of cars and other items into colour and size. I told them how he would strip naked in the car on the way to nursery and scream. They said he was fine and that they had no concerns. At three and a half, out of the blue, he started talking in sentences after having no recognisable words.

School

At four, he went to school. I noticed that other children drew faces but my son drew scribbles. Half way through reception, he presented me with a drawing of a person with ten fingers, ten toes, a neck, ears and eyebrows, when the picture before was an attempted circle in which the lines did not even meet.

It was tough to get him to school. They told me that he was shy and emotionally immature. He cried and had to be carried in but seemed fine when he got there, although his development was not the same as other children's.

By year one, he was labelled as lazy by his teacher. I believed that he was dyslexic and due to the school's refusal to give him extra support and his obvious unhappiness, I moved him to another school.

Referral and diagnosis

Things were better but he still had problems. He didn't fit in so was bullied. He would hide under the table when he had to switch classrooms and was very dependent on certain friends. At six, I took him to my GP and said that I suspected autism, something that I had experience of in my profession and family life, and he was referred for assessment. The school was on the whole supportive and he was eventually tested for dyslexia (at seven) which he had. He caught up quickly after that academically but the social anxiety remained and he was also selectively mute.

Two and a half years later, he finally had his assessment under the ADOS framework they use here in the UK (involving a range of professionals including speech and language, a paediatrician, a child psychologist etc) but it proved inconclusive. By this time my son was very violent at home and had attempted self harm, including trying to get hold of bleach to drink to avoid school. No one seemed to take it seriously. He was given an open diagnosis of profound anxiety with autistic traits and sent to CAMHS (child and adolescence mental health service) to work on his anxiety.

A change of scene

I thought that perhaps moving to the countryside and a smaller school would help so when he was eight that's what we did. He had his CAMHS appointments but because he did not recognise his emotions their self calming techniques did not work and they said he was likely to be autistic. He was referred back to the autism team and once again his diagnosis was left open as it stood. About this time, he started school with even more violent refusal, but never showed that side at school. Due to his anxiety, he was given a full time teaching assistant and support at school but nothing helped. His refusals were so violent that I was constantly bruised and at times fearing for my life. I felt he needed specialist help and wanted him to attend a specialist school but funding was turned down. I felt that I was not believed as he masked a lot at school and I was at my wit's end.

Discovering PDA

Trawling the national autism website for answers about his school refusal, I came across the term PDA. I read up on it. It was my son. I showed my dad and he could not believe how well it described my son. I wrote to the school and the diagnostic team with the PDA diagnostic criteria copied into the letter. Previously he had met the autism criteria in all areas but he was considered 'too social', yet here was a form of autism that was social. He was diagnosed with autism a week later using the PDA diagnostic criteria. I was told that in my area however, PDA was not recognised, so they could not mention it. As a result my son's support was not targeted properly and he got worse to the point of total school refusal and I was threatened with court and even foster care. My son by this time would not even leave his room and even the smallest demand would cause a fit of rage so great that he was a danger to himself and to me.

During the school holidays, I attended a PDA workshop with the PDA society. They talked about reducing demands and the amount of reduction being in line with the level of anxiety and demand avoidance shown. I came home and stopped all demands that I could. My son began to improve and I also found a canine therapist to work with my son. This really helped. When holding the lead of the therapy dog, my son could speak to people and function. The minute he didn't have it he couldn't. Finally, I could see a way forward.

Disappointment

At the start of the Autumn term, I contacted the school and asked if the canine therapy could take place in school. I explained about PDA and reducing demands. Six weeks later, a meeting was called. The canine therapy I had found was turned down and instead they had decided to send my highly sweet and anxious ten year old child, who had never misbehaved in school, other than to hide or cry, to a centre for juvenile delinquents. I was told that they had a therapy dog but it turned out to be just a dog belonging to a member of staff. I fought hard but they would not budge. I had to go along with it or go to court. I agreed to try it for a week but would not give my consent for a longer period until I had seen what they offered. They were supposed to have experience with PDA and ASD but it was obvious from the outset that they were just used to bullying 'difficult' children into doing what they wanted them to do. It greatly traumatised my son. I stopped it after three sessions. It was clear at this point that his (mainstream) school did not want him back.

For the next seven months I fought to get my son appropriate help, watching him all the time decline. He did eventually get the therapy dog but not in school and having to go somewhere new was too much for him. I continued to work with him with minimal demands but all the appointments etc made that difficult. I attempted to get him into an independent school but was turned down because of his failure to engage. (He would sit catatonic and mute at the introduction days or burst into tears and hide under the table). He was barely sleeping or eating. His self esteem became so low due to all this that he even talked about suicide and tried to run away.

One day I was trying to get him to interventions after forcing him downstairs, as I had to every time (despite this being only for an hour three times a week and the only education he was having). He was physically sick with the anxiety and I looked at him and thought, " I can't do this to him anymore". I took him out of the school system the very next day, closed my business and implemented zero demands. Finally, I apologised to him for what I had put him through and told him things would be different.

No demands

Zero demands means asking nothing of your child, not questioning them, not hinting they bath or get up or do anything. It was drastic but the situation was desperate and I was prepared to try

anything. For about a month, he barely left his room but he gradually became more relaxed. He slept better, the violence and the nitpicking about everything stopped. He asked for food (as opposed to me just taking it up and leaving it for him), he started engaging with his toys again and he started conversation. Eventually, he started coming out of his room, going to sleep before midnight, getting up in the mornings, asking to have a bath, brushing his teeth, asking to get dressed and as the weeks went by, he was soon reading, writing and going out and seeing his friends.

My son is eleven and still an anxious child by nature, but six months on from leaving school, he is clean, sings in the car, engages with people and cracks jokes. He has tea with his friends, can have visitors to the house, walks the dog once a week, engages fully with home education, goes to the museum and to the theatre, never hits me and he tells me he loves me every day.

People ask me when I started reintroducing demands. The truth is I never have. He has the environment now where he feels safe, so he is able to do the things that he has always wanted to do and be in his words, "a normal kid". Today, he had his haircut at his request for the first time since he left school. Things are not perfect and there are still challenges at times. He can be very demanding of me, especially if there are things making him anxious, but overall the improvement is massive. It is a complete turnaround that I thought I would never see. I truly believe children like him will (do things) when they can (feel safe).