



Being Misunderstood

South West Report

Experiences of the
Pathological Demand Avoidance Profile
of ASD

May 2019

Introduction

There is a group of autistic people for whom the conventional highly structured approaches are not only unhelpful but can lead to increased and debilitating stress. Instead, collaborative approaches to learning and daily living tasks are significantly more effective.

This need for a different approach makes it essential for this group to be identified, even though research into causation and relationship to other conditions is in its infancy.

The PDA Society conducted an online survey for two weeks in March 2018 through their website and social media. 1,445 parents, professionals, adults with PDA and their partners or family members contributed. The results are available online via the PDA Society in a report entitled 'Being Misunderstood'.

This regional report details some of the experiences described by parents living in the South West. The comments powerfully demonstrate the impact that the lack of understanding can have.

Overall, the results demonstrated that in practice, a constellation of traits is being identified by some who diagnose ASD. When identified it is most often done through use of terminology which reflects the idea of a 'Pathological Demand Avoidance profile of ASD'.

However, parents report that a lack of understanding (and sometimes acceptance of the profile) is the biggest barrier to getting support. Adults and children are regularly being misunderstood, with services consequently failing in their duty to be needs-based and outcomes-focused.

For outcomes to improve, professionals need to know that they can speak openly about this group using unambiguous terminology and, most importantly, promote appropriate strategies.

For this to happen, local leaders of adult and children's services which support autistic people must frame the way in which this complex autism can be managed. This is likely to be best achieved through publication of a 'position statement' for professionals and service users, along with resources for staff development.

National Key Findings:

70% of 969 young people were not able to tolerate their school environment or were home educated.

71% of 79 adults and 70% of 1194 parents reported that they had found a lack of acceptance or understanding of PDA a barrier to getting relevant support

67% of 675 parents reported that they were dissatisfied with the help received from their Child and Adolescent Mental Health Service (CAMHS); only 20 individuals reported that a CBT-type approach had helped.

49% of 768 young people with diagnoses had been given one that included PDA or a demand avoidant profile, or used similar terminology.

Survey of Parents in the South West

About the respondents

Demographic questions indicated that respondents were fairly representative of the population as a whole in terms of income and geography, but not of ethnicity, with just a handful of individuals from minority ethnicities involved.

The sample size was significant with 1,445 participants, and so this represents the largest survey on this topic conducted to date. The largest group were parents of children and young people who they had identified as or suspect may have a PDA profile of ASD. These made up 1,194 of the respondents, including 128 families from the South West.

1. Diagnoses

Answer Options	South West	National
Yes, given what I feel is a correct diagnosis	31%	32%
Yes, but I feel it is incomplete	21%	22%
Yes, but not one I agree with	6%	3%
Still waiting for a formal diagnosis	15%	14%
Not requested / been offered a formal diagnosis	7%	7%
Other... (shown below)	20%	23%

1 *Had a private clinical psychologist diagnose PDA*

2 *Adhd and asd*

3 *I discussed PFA with the psychiatrist in his last visit, he replied by saying it's part of being on the spectrum and was quite dismissive/didn't think it was important. What I find most annoying about that is parenting and caring skills are quite different when there is PDA, I find quite a lot of advice that is ASD driven doesn't apply or work with PDA. Camhs closed the case on that visit and I felt left with no useful guidance or direction. From then on I have followed pages on Facebook run by parents with PDA as their main focus has helped most.*

I'd just add that I don't think the PDA traits (or however it would be described by a professional or someone who knows more than I do) will ever be diagnosed or recognised for quite some time. I asked a support worker her opinion on my son and her reply was that my son doesn't have a meltdown at every 'demand'. She is right but I think a stereotype exists and no my son doesn't fit that stereotype. He withdraws instead of having a meltdown but inwardly is starting to have a meltdown.

4 *Diagnosis of ASD but PDA suspected by us and school*

5 *Yes, but we had to pay privately and travel to Norfolk from Devon.*

6 *Diagnosed ASC. Age 6.*

7 *No. Cornwall Camhs have advised they don't recognise demand avoidant profiles. Was given a no diagnosis for ASD. Camhs said the threshold for ASD diagnosis is very high and 200% of children are then referred back to them.*

- 8 *ASD and Agoraphobia but no-one wants to further diagnose and she's unable to engage with professionals*
- 9 *PDA not recognised in this area but described as PDA traits*
- 10 *ASD diagnosed and awaiting specialist assessment for PDA profile.*
- 11 *Relapsing so considering the possibility of autistic Catatonia now too due to complete mutism and other regressions*
- 12 *In Cornwall where we live, it is not possible to get a PDA diagnosis!*
- 13 *Given ASD Aspergers with PDA profile, as PDA itself isn't in the DSM-5 manual and so cannot be diagnosed (that's what the paediatrician told us)*
- 14 *My child has always had all the symptoms of PDA but it was not recognised in West Sussex.
My child is now having education in an alternative education setting and it is currently going well, therefore I do not feel the need to pursue a diagnosis, even though we now live in Wiltshire.*
- 15 *Aspergers/asd but refused pda*
- 16 *ASD then suggested by the Clinical psychologist that he is showing traits of PDA in writing.*
- 17 *PDA is not recognised or diagnosed here in South Devon*
- 18 *Hampshire does not accept PDA as a condition.*
- 19 *Diagnosed with ASD but not mentioned PDA which she definitely has.*
- 20 *Specialist camhs nor Great ormond St would diagnose (2013) not in Dsm therefore not a thing*
- 21 *Only for ASD not PDA profile (Maudsley), but 1 report from Oxford said ASD traits with characteristics consistent with what is described as PDA.*
- 22 *Our region doesn't recognise PDA*
- 23 *We have a diagnosis of Autism my area won't diagnose PDA.*
- 24 *Child refuses to engage or leave the house for appointments. ASD pathway offered but unable to pursue*

2. Difficulties experienced

These young people face significant challenges, with all parents identifying a range of issues including school refusal and eating problems. The **top 5 concerns** were in line with the national picture:

Answer Options	South West	National
Need to feel in control	98%	96%
Challenging behaviour	89%	89%
Sensory Issues	85%	91%
Severe Anxiety	83%	81%
Difficulty with daily routine eg morning / bed.	80%	78%

3. Getting into school

Parents were asked whether their child had difficulty getting into school. These figures include children who are home-schooled.

Answer Options	South West	National
Yes, all the time	45%	41%
Regularly	21%	25%
Sometimes	12%	15%
Occasionally	14%	10%
Never	8%	8%

4. Involvement of local services

88% of families had involvement from local services, often multiple services, over the past 2 years. This included 60% who had attended CAMHS services.

Respondents were asked whether the help they had from local services had enabled them to understand their child better and/or enabled them to manage any difficulties better. The responses demonstrate the complete ineffectiveness of services.

Answer Options	South West	National
Completely	2%	1%
Very	5%	4%
Moderately	13%	13%
Slightly	30%	24%
Not at all	41%	45%
Not applicable	9%	12%

Of those who had visited CAMHS, the satisfaction levels were generally poor.

Answer Options	South West	National
Very satisfied	4%	3%
Fairly satisfied	12%	14%
Neither satisfied nor dissatisfied	6%	15%
Fairly dissatisfied	20%	19%
Very dissatisfied	58%	48%

Some explained their experiences of local services.

1 *What help?*

Professionals seem to think they know better than us parents and can be critical and dismissive when we refuse to do as they say because we know it would exacerbate matters rather than help.

2 *Really the only help has been from CAMHS-prescribed medication (an SSRI) which has helped tone down our daughter's violent meltdowns, though not helped the PDA or the crippling anxiety & accompanying school refusal*

3 *A CAMHS social worker, told me to just "get him upstairs and make him use the toilet", as he was still not using the toilet at 10 years, because of his sensory issues, he said it was like a tunnel, made him very anxious and he refused to go in. However since having a bigger bathroom built downstairs, from*

day 1 in fact, he has not had an accident !! They did not understand him at all. From using PDA methods, ie.) picking your battles, not being demanding and relaxing a bit more, instead of disciplining, he has come a very long way

- 4 *I'm a lucky parent who has a good team around him. Although diagnosis took a years they always worked with me and helped. He has always been a complex case. His school are amazing too which has such a positive impact. He has been very close to being sent to residential, however school and Camhs are working extremely hard to make it work.*
- 5 *We have been criticised and we have even had statements such as " is a diagnosis for yourself or for your child". You are coping you do not need a diagnosis. Your child is 'normal'. No wonder she is the way she is if you take her to certain clubs .*
- 6 *Yes with regards to the autism, however we have had to learn our own way with the PDA.*
- 7 *After some fighting, I managed to persuade my GP to contact Camhs in house pyschiatrist to prescribe Melatonin. My child had suffered Insomnia for years. I had previously been sent on a Sleep solutions course.*
- 8 *We have only had help in a special school, but they are currently relying on me to inform them better about PDA*
- 9 *Once you have a diagnosis your left on your own.*
- 10 *No help from nhs had private diagnosis from Dr Judy Eaton . Nhs not interested in helping or advising and SS not interested in helping and only blaming parenting.*
- 11 *I learnt about ASD and PDA myself. The ASD support worker we were finally given was extremely knowledgeable and helped to confirm that i was doing the correct things and gave me some great tips and advice. I was given this help far too late.*
- 12 *I have had to pay for all services received, or got funding from Charities.*
- 13 *No help from CAMHS or any other 'professionals'. We paid for a PDA course ourselves, bought various PDA books and read up on PDA on internet to educate ourselves and support our daughter.*
- 14 *Help has been from PDA society and Facebook groups*
- 15 *No PDA specific support other than a leaflet given to us by the paediatrician at the diagnosis meeting. Other parents gave he much more information and I did a huge amount of research myself.*
- 16 *I am an Sen teacher of children with complex needs and I usually have more knowledge than the professionals that I meet*
- 17 *Received no help whatsoever for my child with PDA*
- 18 *I had no help whatsoever. I had to self educate myself about PDA mainly online and in parents forums*
- 19 *Got help but out of county and not from our local Services.*
- 20 *I requested help from CAMHS as I was concerned about my daughters mental health and was told that as she has an ASD diagnosis they cannot offer support. Horrific!*
- 21 *I have just recently completed an ASCEND course, which gave me some suggestions on how to manage some of the behaviour and I am working through using this.*

- 22 *I researched all the information I have on PDA. I have pestered CAMHS and anyone else involved to look at PDA as the cause of her behavioural issues but it was always discounted on the grounds that PDA is not in the 'manual' of psychiatric disorders/conditions. I was always told that her eye contact and understanding of others was too good to be autism.*
- 23 *Have learnt a lot from researching internet and books*
- 24 *No local services; have paid for private help and training myself*
- 25 *No help from local services. Have found your website and Phil Christie book most helpful*
- 26 *We were offered parenting classes to understand my son's diagnosis. School SENDco also excellent.*
- 27 *Sensory workshop helpful. Sadly, no help or advice on challenging behaviours, anxiety and sleep issues.*
- 28 *Most helpful information I have sourced myself online and from other parents of older PDA children*
- 29 *I seem to have to tell CAMHS how it is and what works or doesn't. No advice. I have brought up VCB a few times and they refuse to discuss*
- 30 *All useful info re coping has come from own research online and via books. I feel I am educating the so called experts!*
- 31 *They have been no help, more hindrance.*
- 32 *I am and always have known more than the experts (not to sound high and mighty but parents of PDA are the experts in my view)*
- 33 *School mainly*
- 34 *I am a very knowledgeable adopter. Have sat on NICE guideline development groups looking at attachment and child abuse and neglect. I have fine my best to get the great and good to understand the complexity of presentations of traumatised (previously maltreated) children.*
- 35 *I've had to educate them!*
- 36 *Received NVR training but diagnosis process was prolonged as reluctant to see him in first place. As soon as he was seen he was diagnosed with ASD. Nothing after that.*
- 37 *Charities have helped*
- 38 *I learnt from PDA parent support groups. They are the only people that gave advice that actually helped. Professionals did not offer much useful help and I felt like I was teaching them.*
- 39 *Assuming by local services you mean NHS. We have had support from a private OT locally for SPD but local NHS will not diagnose PDA or put any mention of demand avoidance in an ASD diagnosis. They are also delaying proper assessments based on surface sociability and eye contact being made*
- 40 *Much of my knowledge and strategy comes from my own research and reading.*
- 41 *I was seeing CAMHS alone as it was felt it would be better to support me to support my grandson. They then said they would like to meet him. We were in the room 10 mins if that because they insisted on talking to him when I specifically told them to wait for him to engage so he started throwing things and kicking things. We were asked to leave and discharged*
- 42 *Camhs didn't even mention PDA. I don't think they know much about it. He was discharged after generic ASD diagnosis and they refused to diagnose ADHD. I found out about PDA myself and*

everything I know about it is what I have found out for myself. I'm the one who's had to provide info to school and other clubs that my son attends. Most people have never heard of it. Many people in the SEN world have heard of it but don't know much about it.

- 43 *Most help has been from my own learning on PDA Facebook groups, books and websites*
- 44 *Still waiting for an assessment and all they want to discuss is anxiety and providing groups for parents. No groups or help for my daughter provided. I work full time and can't access the groups offered to me.*
- 45 *They don't work with PDA. So I used the PDA website instead. That helped. But it conflicts with advice I am given.*
- 46 *Most of what I have learned about ASD and PDA is what I have learned from online and speaking to other parents. Apart from the early birds course when he was first diagnosed, we have had no other help.*
- 47 *The diagnosing CDC spotted that our daughter likes physical play*
- 48 *Most of our understanding around PDA has come from me researching via forums / websites / books and attending conferences. The only real support I had from services was the paediatric nurse who was involved in my sons anxiety assessment and the specialist education other than at school my son spent his year 11 at due to medical grounds (anxiety).*
- 49 *Dx last month, so waiting for initial follow up appointment. Information we have and strategies we've had success with have been self researched. We would not have got the dx if we hadn't pushed. The one exception to this is our input from a local, privately funded organisation, where the support has been exceptional. We have had to pay for this though!*

5. Challenges faced

124 people described the challenges they faced. A few examples are included here.

- 1 *Being able to care for my other daughter as well as my suspected pda daughter.. Its really hard trying to balance it out because my Pda daughter likes all the attention all of the time.. I'm also a lone parent so have to manage it all myself..*

However learning about pda and using pda type parenting techniques has been a big help! I had been trying every other parenting type techniques, parenting courses, setting firm boundaries, reward charts the naughty step! None of those worked some made the problems worse.. Pda type parenting techniques has been the only thing that helped us.
- 2 *Often it's keeping her safe, keeping us safe. But for us the biggest challenge was getting her any support for schooling at all. School refused to recognise the challenges whilst she was masking, even when the mask slipped there was a stand off as they wouldn't really back down, I managed to get her from having no support to an EHCP and a placement in a specialist School inside of 8 months. It was totally worth all that hard work!*
- 3 *Lack of understanding & resultant isolation even from family, combined with sleep deprivation.*

- 4 *Feeling powerless in being able to make things better for my child. We do all the recommended strategies but life is still incredibly hard for her and watching that and coming to terms with that is very hard. Seeing how a basic task like brushing teeth or having a bath can reduce her to tears and raise her anxiety through the roof and not being able to change that for her is heart breaking.*
- 5 *Being given wrong advice- wrong parenting and typical ASd strategies do not work. It exacerbated the situation, and we had a lot of violence.*
- 6 *Nobody listening and understanding the anxiety let alone anything else that comes on top, like behaviour and school refusal. Schools and authority figures having the stance of " They need to be in school "*
- 7 *Learning to phrase demands in a different way and explaining repeatedly to people we meet, the best way to speak to her. I do get a lot of people raise eyebrows as if to say "you're pandering to her" it's hard to ignore but you do get to learn what works and I'd rather seem like I'm pandering than have a whole day of screaming.*
- 8 *Every single thing has been a massive challenge. Dealing with difficult behaviour, not knowing what his difficulties were until he was 10, fighting for a diagnosis , being blamed for his problems. Every step of the way has been extremely difficult and challenging!*
- 9 *Managing my son when he has meltdowns as he gets very violent and also becomes dangerous to himself and to others. I have to be the one to take the brunt of the batterings as there isn't anyone else, also I have to restrain him to keep him safe (he can run into roads etc) I am concerned that as he gets bigger he will hurt more but also he will be stronger and I want be able to hold him and him safe.*
- 10 *The constant need to be in control.*
- 11 *Guilt - I have two other children and feel guilty every second of every day about the impact on their lives.*
- 12 *Getting the support she needs. Dealing with her needs and those of her younger brother who has Asperger's. My husband and I struggle to have time together at all.*
- 13 *Dealing with his mood swings and violent behaviour*
- 14 *The ability to accept the difficulty my son has in performing the smallest of tasks and finding an educational pathway.*
- 15 *Being able to make others understand why your child behaves a particular way. People are easy to judge you and your child as 'poor parenting' and 'naughty child'. It's hard to make friends with other parents as your child often cannot maintain friends(often mean) which affects friendships with the parent. Need help and support with raising awareness so others can accept this condition.*

6. Final comments

At the end of the survey, respondents were asked if they had anything to add. These are the comments provided.

- 1 *What social groups could my son attend to maximise his chances of making friends, I have tried so many timeswithout success*

- 2 *Our young person has become isolated and practically housebound due to her anxiety and paranoia e.g. Avoiding all sorts of recording such as CCTV.*
- 3 *Struggled for years now, been to court a few times*
- 4 *Primary school was hell and caused the most damage, to every member of our family (5 people). Strain on relationship, sibling mental health issues (my youngest is very concerned for my well being and thinks I will die). He has low self-esteem and thinks he is a burden (he has no asd issues). Life choices; jobs, house moves, schools all revolve around our Eldest son. My daughter has compromised having friends round, attending any clubs. Small things that have had a big impact on their lives as we live in a house where we are on high alert - treading on egg shells. Primary school had little knowledge, blamed me, didn't listen despite my desperate pleas, a lot more could have been done, but it was ignored.*
- 5 *That children with PDA and their parents are all amazing. Authority figures need to be trained in mental health issues/disabilities and learn some lessons in basic empathy. Mainstream schooling is damaging our children's health and derailing opportunities to reach their full potential.*
- 6 *It's hard work trying to understand these children and I feel we as parents don't get enough support.*
- 7 *Our experience of educational support within a specialist independent school for ASD was a disaster and faced limited knowledge and skills within the school for supporting a child with PDA. Huge waiting times within CAMHS for diagnosis of ASD and subsequent therapies. Had to threatening CAMHS with serious escalation if priority not given to our son. Limited support from Local authority. 'Parent power' is very much required to drive progress across all health and educational organisations.*
- 8 *We are so grateful that the PDA Society exists!*
- 9 *it's not all doom and gloom. We have met and interacted with some highly motivated and skilled professionals. It has just been really hard to access them due to underfunding/long waiting lists. We have often been the most knowledgable people of PDA in the room filled with 'experts' who don't get PDA and think that they do.*
- 10 *It's been an awful journey full of battles and only achieved success by paying privately and even then game barriers to pad. Both nhs consultants I spoke with do not agree with pda. The paediatrician was useless. You have to go through too many uneducated gatekeepers like teachers senco occ therapist paediatrician gp all who do not know or believe in pda and because it's like the opposite of classic autism or aspergers they think the child is fine. It's horrendous and the parental blame card is used a lot to the detriment of the parents mental health*
- 11 *The stress and demands of trying to fit into everyday life has caused severe mental illness. Despite this very difficult to access suitable support and help.*
- 12 *Ive been struggling with my child's behaviour since he was 3 and had conflicting opinions about a diagnosis. Schools just say it's poor parenting. Not suitable support and education for highly intelligent children with ASD and associated conditions who can't cope with huge mainstream schools.*
- 13 *Everything can change in a year! I'd never have believed such huge transformations were possible, but we are living the dream. Mummagrizzlybear shares more detail on her page!*
- 14 *I don't think my son will ever have a diagnosis that incorporates PDA, this concerns me since it's the PDA that causes him most difficulties. My son managed the whole of primary school with no diagnosis of anything (signs of anxiety though). As soon as he went to an Academy (and I am being specific about an Academy, I worked in nearly all schools in this area before and after they became Academies) he had difficulties that they did not address or think worthy of bothering with. The*

management and cultures of the academy he was at could not give a damn about his mental health, because he was a high achiever they just wanted him to attend despite having chronic anxiety and depression....that would never happen to an adult in work (well maybe it would but there are more safeguards for adults than for a child not going to school).

- 15 *My son was diagnosed with severe autism, but none of the strategies worked with him, he was violent, non verbal and banging his head on the floor. As soon as his peadiatrician mentioned PDA, I started researching, and I found your site. The day after I started implementing PDA strategies, less routine, pick your battles, say things slightly different, and there was improvement in his behaviour, I actually sang the words sometimes, which seemed to work :)*

So many things have improved the list is endless, and if that one doctor had not of mentioned it, he would have been stuck in this anxious upset state, as nobody would have understood him. I have done my best to do it my way even though the professionals have not liked it. There was so much improvement I decided to have a downstairs toilet built for Liam, feeling confident with his progress, and believing we could cope with the stresses of builders, I applied to the council. We needed to be assessed for this, this was Feb of 2015 and have been seeing the social worker every six months since, even though she has never given me one bit of advice, for fear that they would take Liam away from me. I was devastated with her first report as we had in fact come such a long way, and being threatened that if I didn't engage, Liam would be put on the at risk register. (as I had told CAMHS previously they did not help), upset me so much. The social worker had another colleague at the start come to my house for afternoon visits, lasting for 8 weeks, to find no problems with my parenting, he in fact said there was no reason for him to come any more, and an occupational therapist that I found to assess him for his sensory issues, that said I was doing a fantastic job, she wrote a report which I believe from my last visit with social worker she has not read yet, this was back in September of 2016. All in all, Liam is doing fantastic, but that has had nothing to do with any outside help.

- 16 *It has been really difficult because there are no set patterns, no chink in his shell to access him and the fact that he always seems sad/at odds with himself. Never really happy.*

- 17 *Oak Tree in Cornwall are an amazing school with quite a few diagnosed with PDA. Some training there would be awesome.*

- 18 *He is very bright but so controlling that he can't be educated.*

- 19 *We have been blamed and I feel we should have gone for a private diagnosis / If I knew what i know now this is the out to take. i has taken a toll on my mental health and relationship when all we wanted was help and support*

- 20 *I have 4 children, 3 with ASC, and I think all 3 have PDA. I chose only one for this survey, so if you want me to fill out 2 more then contact me to do so.*

- 21 *I think from my understanding from the PDA parental support Facebook group, the general consensus is that there is a huge lack of professional support regarding PDA. Particularly from Camhs. Parents do not get any support and many are really struggling. Our experience with all professional bodies we have approached have left us dismayed and considering formal complaint.*

- 22 *So sad that instead of listening, and trying to help, u are always looked at as a bad parent, it is time we were heard for the sake of these poor children coping In a world they struggle to understand*

- 23 *It took us 10 years to get a diagnosis for our son and then we still had to go private. We got a diagnosis at the lorna wing centre in Kent, they were completely disgusted that my son was not given an assessment for ASD my our local camhs. Our camhs and social services are not at all informed about children who have a PDA profile. My wish is that it becomes apart of the diagnostic manuals asap! So families don't have to suffer like we did for so long.*

- 24 *Our Consultant and local Gp and have been very supportive in ways that they could. Devon LEA have been ok, but very stretched. School have tried, but if the understanding is not there it won't work. My son is a clever boy, who has taught himself Guitar, drums and piano, and researches deeply, but finds the school environment too stressful and will come out of school with NO qualifications at all.*
- 25 *We are lucky in Cornwall as pda is recognised and families supported. The only thing lacking is mainstream schools understanding of pda. Leading to a lot of permanent exclusions or removals by parents. Wish the whole of the U.K. Recognised pda as then schools will deal with it appropriately.*
- 26 *Very few specialist schools around for PDA children who are bright, but struggle with challenging behaviour due to anxiety.*
- 27 *I live in Somerset and PDA is not recognised here.*
- It took 4 yrs to diagnose ASD when my son was 9.
He is now 10.5 yrs and still no profile of PDA.
We are now going to be seen in an NHS Complex Neurodisability Service in April/May time thanks to our G.P referring.
Our paed told me that she had sort advice from our lead Pysch in ASD at CAMHS re PDA.
The Pyschs response was. "PDA is term that originates from parent support groups and is a term used by parents to enable their children to avoid daily tasks".*
- "These children then grow up unable to cope in Society because they are given too much control as children". A truly shocking comment made by a so called specialist!!*
- 28 *I am the grandparent and offer a lot of support to my son who is a single parent with looking after his son our grandson. We try to offer as much support as possible and our grandson sleeps at our home 1 night a week. Our grandson can be very loving and funny but equally he can also be very challenging and aggressive which is becoming harder to manage the older he gets. Time and lots of patience are key as everything that he does can take a very long time. He attends mainstream school but this is a huge challenge for him and the school. He needs to attend a specialist school but this has been declined by the local authority, as a family we plan to fight this but it is very tiring and adds to our stress.*
- 29 *Last year we attended a 2 day course run by the Challenging Behaviour Foundation on managing challenging behaviour. It was immensely helpful to us, in order to recognise triggers of rising anxiety and how to de-escalate. Meltdowns are now rare, which is something I never imagined possible!*
- 30 *It's been tricky living with a pda child but there are some amazing professionals out there. We have come across a few now after two hospital admissions and being involved with a new service called Hope. Still lots of challenges to overcome getting full time education as school is not an option for my daughter abs the place she does go to called spectrum space can't legally operate over 17 hours!*
- 31 *I am researching the topic of pda and educational strategies for my dissertation subject. So am very interested in any research available*
- 32 *You get A LOT of judgement from other people when you are supporting your child through their meltdowns or violence. Everyone becomes a better expert at looking after your child than you, or so they think. They LOVE to tell you what they would have done or what you should do instead of whet you are doing.. they ALL know better.. but they aren't the ones who have to pick up the pieces at the end of the day!!!! Also it can be extremely isolating. Other parents don't want their children playing with yours and in some senses you can understand that but it doesn't make it easy. I try to do everything I can to guide, advise, stand in the gap when my son starts to lose control or gets excited as he cannot regulate, we go places that are extremely quiet, I am open and honest with those around me about his autism and it's hard, you know??.*

- 33 *The only support we've had was with our oldest child who was diagnosed aspergers (this is not the son with PDA that I filled in the form about). He started only eating half of his meals at age 14 just after his diagnosis. I referred him back to the diagnosing psych at CAMHS. A nutritionist - the only support we've ever had - saved his life. She told me to reverse engineer what you usually do, ie instead of low calorie spread put butter in his sandwich. The Psychiatrist was due to come to see my son at home but left a phone message that said another child needed the appointment more than my son and that another appointment would be made. No one made another appointment. What kind of message is that to send to a distressed child who is starving themselves - he learned that the people who are supposed to be there to help him don't even care enough about him to make an appointment to talk to him.*
- 34 *Being a parent of a child with PDA is the hardest thing I have ever done. Barriers and dead-ends block progress to a diagnosis and the correct education at every toss and turn - it is a nightmare and it feels very lonely at times.*
- 35 *My experience of the 'system' is that it does not work to support children and families seeking a diagnosis. It is a battle, an exhausting, frustrating, sound destroying battle. A huge amount of time and money is wasted with people sitting in meetings and not actually connecting with the child or family. The most helpful professionals actually came to our house, met the children and properly listened. I was put on two parenting courses and advised I needed to access the 'generalised services' before we could get to the next step - what a waste of my time and their money when what we really needed was a diagnosis for my daughter and an understanding that the violent behaviour she displays isn't because of inconsistent parenting techniques, it's because of her PDA. Unfortunately getting a diagnosis has also thrown up a lot of issues for my daughter - but there is still very little practical support available. It's a daily struggle.*
- 36 *I find that allowing my son to adopt a lifestyle that he chooses, minimising demands in his home life and keeping the demands consistent, we can minimise conflict and he accepts the demands of school more easily. Our problems come when circumstances beyond our control rock the boat.*
- 37 *Very difficult to manage child exacerbated by lack of acknowledgment and understanding of the disorder*
- 38 *My son attended Grammar school from ages 11-16. He was diagnosed at the age of 12 . By the time he reached year 11 he was exhausted and had a breakdown and remained at home where he received support (work sent home) from his school. He took his exams at home and gained 9 GCSE A -C grades. We are so incredibly proud of his achievements where at one point we did not know if he was well enough to complete any. We take one day at a time .*
- 39 *No-one and nowhere to turn to in South Devon. Virgin Care's Autism Assessment team does not recognise PDA - about time Branson trained his staff in order to be able to deliver diagnostic service here. Meanwhile, hundreds of families have been left in limbo*
- 40 *Only just home ed. as ex teacher feel really down about lack of SEN provision now and feel this is why we are driven out and judgment about bad behaviour. Very bad school climate at moment. It is sink or swim, gone are the days of every child matters. I dealt with school professionally and knowledgeably as someone who knows the system and not afraid to challenge whilst keeping working relationship priority. If I have failed what chance do other parents have trying to fight for provision and understanding? Head teachers need guidelines in dealing with PDA or even suspected PDA.*
- 41 *It has torn my family apart. I'm frazzled, so I'm moody, and I can't keep the others at home as she makes them miserable.*
- 42 *Everything takes too long! Too many different departments that don't communicate with each other. No practical advice.*

43 *We have been to hell and back as a family. Living in extreme PDA darkness can ruin lives. We are so fortunate to have learned of PDA when we did, found a way forwards.. Plus support via equine therapy via the local authority. Our daughter is only 12 yrs old. She has extreme PDA but come so far, equine therapy saved her life. today horses are her life. She is writing a book on horsemanship she is working to improve treatment of horses, she competes, she works with and trains challenging ponies she is on the road to a great life of helping animals and others. Already she is paving a new path in the equestrian world. PDA makes her see things in new ways, makes her determined and persistent and nothing can stand in the way of what she believes in. I am so proud of who she is and her PDA is a big part of that.*

44 *I'd like to attend a conference but I am unable to travel that far due to my own limitations. I hope the campaign to raise awareness of PDA is successful as it's a postcode lottery at present. As a parent, when my daughter was of school age I was made to feel a failure and complicit in some sort of crime against the educational system [even though my older 4 children, 3 with other variants of ASD had full attendance]. It's the only area where an individual can be convicted of a crime committed by someone else [a teen's refusal to attend school when they have medical justification and are too big to physically haul them in, but the system can fine or jail the parent!]*

As a young adult she has been discharged by CAMHS and after a year still no contact by adult mental health services. Thankfully we have a good GP.

This is a condition that threatens to destroy entire families [as with many mental health issues] yet it is ignored, trivialised and mislabelled as poor parenting or rebellion. My whole family has war wounds from this lack of understanding. It is not my daughter's fault. She is who she is. This is because of lack of support and understanding by the safety nets that are supposed to be there. If she was bipolar, schizophrenic or epileptic we would get empathy. I mention PDA, they just label us as 'bad parent and naughty child'. I'm a great parent, I can overcome a 5-hour meltdown of a young adult in public. I can stop her self-harm escalating to the point of no return. I can make it up to her siblings. I can love her unconditionally. But at present only other PDA families will understand my achievements, and the long way she has come.

The public need educating, the medics need educating and we need inclusion of a formal diagnosis and conformity within the NHS guidelines.

45 *Our son masks at school and we struggle to get anyone from school to see what we deal with at home and out and about this is really heartbreaking for us.*

46 *I feel very strongly that professionals (esp camhs) need to be so much more open about the needs of previously maltreated children, especially those adopted from care. Their presentation can be very complex and change throughout childhood into adulthood.*

pda is one of the many many difficulties our c & yp suffer with every waking hour of every day.

47 *total need for control makes parenting nigh on impossible. Complete lack of social awareness means behaviour is constant wherever we are.*

48 *Filled in the form for my older child but I also have a 3 year old on the diagnostic pathway for suspected PDA*

49 *We started our diagnostic journey over 3 years ago. We are still waiting to go through the scamp process. There seems to be a total lack of knowledge with the professionals we have seen so far about asd girls in particular and pda is seen as an excuse for ineffective parenting. It wasn't until the police were called to our home after a particularly awful meltdown (she attacked me with scissors) that the paediatrician reluctantly referred her for aspergers/pda, and only then because I presented him with pages and pages of evidence. I feel I have had to do all the research, re-educate myself and cope on my own with no help. Basically I've done all the hard work and had to fight every step of the way.*

50 *The PDA society forum has been a lifeline for me during this difficult time.*

51 *The total refusal to recognise pda in our area has blighted our lives. I fought for help for my son and even managed to get a full time TA and later an EHCP (he had already left school by then though). I believe my son was traumatised by school and repeatedly asked why school wouldn't listen to me when I 'got it'. While at school my son was very violent up to 5 times a day with me. 2 relationships broke down because partners could not understand my son's needs. CAMHs was helpful during diagnoses (I hadn't heard of PDA then) but in my area they do not diagnose neurological issues only treat mental health the diagnoses of ASD alone took 5 years from referral by GP. Interventions tried to drag my son from his bed and then maliciously reported me when I said this was unacceptable. I believe I am suffering PTSD because of all the stress of them threatening to take my son away and the fight for services. I worked for 20 years with autistic children and adults and yet was not believed, I have it on record that I am an excellent parent. My son has been home ed for a year after 10 months of refusals. I use PDA strategies after going on your workshop two years ago this coming July. My son is no longer violent although is still recovering from the experiences at school and will only go out a couple of times a week. He has taken well to home education (initially unschool and now child led approach). I feel my son has been discriminated against because he really wanted to go to school and really tried and it was made impossible for him. He was signed off as much improved and improving by the paediatrician 6 months ago and that was the last contact we had with any professional. Social services say I have been totally vindicated in my approach as my son is so much improved (they haven't seen him in two years just a phone call in the first 3 months of home ed), they have no concerns. I love teaching my son and our relationship is repaired after years of me forcing him to school but I feel I let him down by not getting enough support in time to help him stay at school.... I wouldn't wish any of it in my worst enemy and seeing my son now I know much of it was completely avoidable as we have the most wonderful relationship and he tries so very hard.*

52 *The journey to get any diagnosis for my daughter has been 6 years which we have had lots of criticism of our parenting I've read paper work blaming my mental health I was fine it's her mental health and fighting for the right support that's effected the whole family. I had to give up the job I loved, I've lost friends my relationship has suffered. Watching your child struggle every day destroys you.*

I've had to fight for an EHCP by myself as she didn't attend senior school as the right transition wasn't put in place as they didn't listen to my concerns and thought she would just go. She spent 2 years in a behaviour unit without the right support despite every professional agreeing it wasn't behavioural. Each service we accessed people left or the funding run out so we had no evidence to back an EHCP. Yet she had no education for 2 years, no friends peer group which let me having to be her parent, friend, CAMHS worker and everything else she needed.

53 *My son's nursery started complaining about his behaviour when he was about 18 months old, and made me feel like I was the one to blame. They didn't have a clue he had SEN, and if they did they didn't let me know. The same happened when he started school. It took until he was nearly 6 that I worked out that he has ADHD (though I still didn't realise he is autistic and I was already self diagnosed with Asperger's). Even camhs said they were surprised that he qualified for an ASD diagnosis when they did the ADOS.*

He has finally been diagnosed privately with atypical ASD with PDA profile. I think most educational / childcare settings and even camhs will only notice ASD if there are very stereotypical traits. My son was seen as a neurotypical boy who was very naughty and didn't want to do what he was told. I was seen as a parent who didn't teach my son how to behave properly.

The experience has left my son with very low self esteem and me with very low confidence in being a parent, and nervous of being judged by ignorant people in public places and in the school playground, and also by other services.

54 *I have found that accessing any help difficult due to my son cannot cope with any appointments, visitors, leaving the house much or seeing a doctor. It therefore just feels your on your own especially as a single parent too. Very isolating and lonely in a PDA family.*

- 55 *I have set up a government petition for health care professionals to recognise and understand PDA*
- 56 *More money is needed to fund CAMHS. Wait times need to reduce dramatically. 9 months so far.. If it was a physical illness a person could be dead my now. My child has a daily struggle with control and it's emotionally painful to watch.*
- 57 *Too much to say but too little time.*
- 58 *Battling for support has been very time consuming.*
- Some of the support obtained has been paid for privately through training, child-led CBT and other therapies.*
- We are incredibly lucky that he attends a very supportive mainstream school, but we have been led to believe that it is not a given that he will make it to the end of primary school due to the aggressive behaviour. It is a worry.*
- 59 *When two of you have PDA it can be very, very difficult to function as a family at all. It is damaging all of us and I hate it.*

Conclusions

This report illustrates the experiences of those with a PDA profile of ASD who are living in the South West.

Reading about these experiences should be a wake-up call to those supporting and providing services to the autistic community. Individuals who may be described as having a PDA profile are being neglected and even discriminated against because of a lack of acceptance and understanding of their needs, leading to a failure to put in place reasonable adjustments.

At the same time, the results demonstrate that explanatory terminology is being very widely used in some parts of the country. Where this happens, understanding of strategies can follow. Even then, much more support is needed for local services to become sufficiently familiar with useful interventions.

It is unacceptable that 70% of young people in families surveyed are either at home or struggling to access school environments, and because their needs are being misunderstood, many are missing out on education. Local services, including children and adolescent mental health services were found to be completely ineffectual, which compounds problems and leads to parents finding themselves unable to cope.

It is in the interest of everyone that professionals are empowered to see the individual and focus on improving outcomes. The national report provides a detailed list of recommendations for action, summarised here:

Local Authorities and Commissioners across the country must urgently communicate their position on the PDA profile of ASD to service providers and their clients, to clear up the confusion over assessments and service availability that currently exists.

Government and autism leaders must consider why so many people are being failed and press Local Authorities and Commissioners to create the conditions so that needs are assessed fully and in a collaborative manner, so services can be truly outcomes-focused.

Education services and schools must increase their awareness of the needs of individuals with a PDA profile of ASD, and how to make reasonable accommodations.

Autism education and training providers should ensure that differing responses of individuals across the autism spectrum, including those with a PDA profile, should be included in autism courses and literature.

Providers of mental health and autism services need to ensure that their staff are equipped to identify and work with those with a PDA profile, whatever terminology they choose to use.

Professionals should ask themselves what more they can do to develop their own understanding and that of others, and challenge themselves to be open to the explanations of individuals and parents.

About the PDA Society

The PDA Society was set up to provide information and advice to parents and is currently in touch with over 14,500 people through its membership, forum and social media. Its volunteers directly advise up to 2,000 people each year and training courses are available for parents and professionals. The Society's website includes a range of resources including webinars, links to books and academic papers.

www.pdasociety.org.uk

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