



Being Misunderstood

London & SE 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 London and the South East. 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 London and South East

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 223 families from London and South East.

1. Diagnoses

Answer Options	London	National
Yes, given what I feel is a correct diagnosis	33%	32%
Yes, but I feel it is incomplete	22%	22%
Yes, but not one I agree with	3%	3%
Still waiting for a formal diagnosis	15%	14%
Not requested / been offered a formal diagnosis	4%	7%
Other... (shown below)	23%	23%

- 1 *We sought private diagnosis of PDA as part of the tribunal proceedings NHS in Herts didn't accept PDA existed when we tried to get help*
- 2 *Has ASD diagnosis. In our area PDA is not diagnosed unless we go privately - and then it is not recognized by the school.*
- 3 *My son has Down's Syndrome (diagnosed at birth) and Autism (diagnosed at age 15). Last year (aged 16.5) he was diagnosed with 'demand avoidance traits'. His severe learning difficulty complicates matters.*
- 4 *Cannot be diagnosed because PDA is not in the diagnostic manual used by Springfield CAHMS where he has been under the care of the L.*
- 5 *Paid for privately*
- 6 *Isn't recognised in my local authority*
- 7 *Not offered a PDA diagnosis by professionals. They don't recognise PDA. My daughter has had the following mentioned about her but nothing formally diagnosed- odd, clinical anxiety? Asperger. ADD, emerging personality disorder.*
- 8 *ASD diagnosis, but won't diagnose PDA (or SPD) in my area*
- 9 *Diagnosis ASD but didn't give PDA then*
- 10 *He has recently been assessed and diagnosed with autism from Lorna Wing Centre. Disappointing because I was hoping he would get ASD with demand avoidant profile but they have not said this. I have no idea what to do next. Feel very lost.*
- 11 *Diagnosed with Asperger as a teenager but I couldn't see that fit many of her traits. On reading up however PDA DOES*

- 12 *Diagnosed with ASD aspergers. I self-diagnosed PDA as not diagnosed in my area*
- 13 *diagnosis of ASD but Hertfordshire does not recognise PDA and would not fund an assessment at Elizabeth Newson Centre*
- 14 *I've asked and asked I was sure that all along there has been something wrong , this has been going on for over two years , and we're in the constant circle with the sbas and the school about him being lazy and myself being a terrible parent , I've asked for help telling them there's something but they just come back with his lazy , the doctors have told me literally we need family councillors which I've tried , and that I have mental health problems because of how I'll this process has made me.*
- 15 *My health authority has no expertise in PDA so cannot asses her. I requested a referral to an outside the area NHS or independent specialist but this funding was refused.*
- 16 *Contacted Lorna wing centre for help*
- 17 *PDA not recognised in Surrey. Demand avoidance described in ASD diagnosis*
- 18 *Diagnosis of "PDA traits" by private psychologist (Surrey do not diagnose PDA)*
- 19 *We have an open diagnosis of High Functioning ASD. No profiles, nothing was suggested - somebody whose own child has PDA pointed me to some information after she noticed traits in my daughter. It's very fitting for her.*
- 20 *ASD diagnosis but our county don't recognise/diagnose PDA*
- 21 *We have tried to get a diagnosis but been dismissed as being bad parenting:0 (*
- 22 *Diagnosed with PDA symptoms*
- 23 *Suggestion of oppositional defiance disorder...*
- 24 *H/F ASD diagnosed at Springfield Hospital at 15 yrs old, but told PDA not a recognised diagnosis.*
- 25 *she has a diagnosis of ASD specifically Aspergers but has lots of elements of PDA*
- 26 *Not of PDA but severe autism*
- 27 *Given ASD diagnosis*
- 28 *Midway through the diagnosis.*
- 29 *CAMHS were largely useless*
- 30 *I requested diagnosis years ago but denied.*
- 31 *Was told nhs do not give it.*
- 32 *Diagnosis of ASD. CAHMS Surrey report highlights PDA / Severe Demand Avoidance*
- 33 *I had too much of a battle with the psychiatrist, I had to let it go.*
- 34 *Requested in writing by me as a parent, but not granted/pushed forward by GP.*

35 *ASD with a PDA profile
Sensory processing
Attachment disorder*

36 *Not formal by a PDA specialist but agreed by Ed Psych*

37 *Refused to acknowledge PDA but acknowledged we find PDA strategies helpful and have stated he has demand avoidance.*

38 *Rec'd a diagnosis privately and took it to our community paediatrician for formal NHS diagnosis, which we now have.*

39 *Having had to older boys with ADHD, this is so different,*

And at moment fill he is being let down by the system due to being missed understood , due to unawareness of the condition

40 *Verbal diagnosis of ASD. Was deemed too young and complex to complete*

41 *Parents had to inform the professionals about it as they didn't know about PDA.*

42 *Absolutely disagree with the diagnosis of PDD Other, as she has the full triad of impairments of Asperger's and they knew she had AS but there is a story as to why they misdiagnosed her ASD subtype. She (and her sibling, which I forgot to say on the other survey I did for her sibling) have both been confirmed to have PDA by Help4Psychology via a consultation and screening questionnaires, but no formal diagnosis of PDA. She also has hypermobility verbally confirmed by an NHS physiotherapist.*

43 *Saving to go private*

44 *Demand avoidance was given as a later additional diagnosis to original HFA diagnosis, but they said she did not have PDA because she didn't demonstrate it much at school. She does have full PDA and her next school noticed some demand avoidance although she masks a lot in school.*

45 *Has ASD diagnosis. PDA not diagnosed where we live*

46 *I've spoken to paediatrician- he agrees she fits PDA but says no point going for diagnosis at the moment because CAMHS so busy that she won't get seen unless eg. suicidal. Plus she's in an MLD / complex LD school where at the moment she is getting the support she needs*

47 *Aspergers diagnosis (Oxfordshire) but we work with a PDA one ourselves (nothing formal)*

48 *Not recognized in Berkshire NHS*

49 *Diagnosis of ASD with demand avoidant behaviour as don't / didn't diagnose PDA routinely at paed in my area*

50 *No. Paediatrician agreed he had demand avoidant traits but said she couldn't/wouldn't diagnose him, or add it to his ASD diagnosis.*

She then went on to demonstrate (by what she said about autism) that she had no idea about what PDA was actually about, and when she said he was demand avoidant she was referring it in its most simplistic form of avoiding the obvious demands she was making of him.

51 *Our son got a diagnosis of Dyslexia from an Ed Psych and Dyspraxia 'with odd and eccentric behaviours' from NHS Child Devt Unit. We tried to tell the paediatrician about his meltdowns*

and refusals (sometimes trying to hurt himself to avoid schools ie repeatedly throwing himself down stairs) but paediatrician said best not to go to psychologist for any ASD type diagnosis because it would impact on my extremely bright son's (iq 142) professional life in future and that actually my son was relatively manageable. I explained that this is because I kill myself trying to manage, enable and advocate for him but instead of offering help the paediatrician praises me! However, as my son enters puberty and he is big enough to hit us and lock us in a room, things getting more problematic and we need help.

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 6 concerns** were in line with the national picture:

Answer Options	London	National
Need to feel in control	97%	96%
Challenging behaviour	91%	89%
Severe anxiety	79%	81%
Low Self Esteem	78%	73%
Sensory Issues	76%	81%
Difficulty with daily routine eg morning / bed...	75%	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	London	National
Yes, all the time	40%	41%
Regularly	24%	25%
Sometimes	17%	15%
Occasionally	11%	10%
Never	8%	8%

4. Involvement of local services

82% of families had involvement from local services, often multiple services, over the past 2 years. This included nearly two thirds (62%) 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	London	National
Completely	0%	1%
Very	5%	4%
Moderately	15%	13%
Slightly	28%	24%
Not at all	41%	45%
Not applicable	11%	12%

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

Answer Options	London	National
Very satisfied	1%	3%
Fairly satisfied	13%	14%
Neither satisfied nor dissatisfied	17%	15%
Fairly dissatisfied	23%	19%
Very dissatisfied	46%	48%

Some explained their experiences of local services.

1 *I understand him better than anyone. They do not understand his condition and believe that all they need is to implement non-violent resistant and everything will be fine. they don't understand the need to control or meltdowns.*

2 *My understanding comes from my own research & privately funded interventions*

3 *Local services have provided little, understanding has come from my research and attending talks, training*

4 *I knew far more about PDA than the person running the course for parents of children newly diagnosed with ASD. However, I learnt a little more about sensory issues, helping me to understand that toileting problems might be a vicious circle of interoceptive problems and demand avoidance.*

5 *CAMHS refused to help even when in hospital after suicide attempts, saying that ASD is not a mental illness.*

6 *No help even given.*

Luckily for most parents/careers the PDA website and NAS website offer valuable extensive information, of which I would of been helpless without.

7 *Our child now goes to a weekly boarding special school and has equine therapy which has really helped*

8 *We had to go private to get the original ASD diagnosis and again to explore PDA. Thereafter with a lot of problems relating to anxiety/trauma (after a cancer diagnosis in the family) I requested a referral to CAMHS for mental health support. This was utterly useless but more because the psychologist knew absolutely nothing about how to relate to someone with a SLD. All his behaviours were ascribed to that with no willingness to explore anything else. However, my son's social worker has been amazing - absolutely recognised the PDA-type behaviours. Similarly my son's school - his teacher came to PDA training with me and has implemented all the recommended strategies.*

However, I believe that at the level of the Local Authority there is a complete lack of awareness about what causes someone to refuse to attend school and no structures in place to support parents with this, which can create a massive problem. (My son's attendance has been under 70% due to school refusal). You are expected just to stay at home with them!! My son is now nearly 18 but can't be left at home alone for all but short periods because of his SLD but the education service's responsibility finishes at 16. Also the school is willing to help but only once he crosses the threshold... it is left up to me to get him there.

9 *We are waiting for help from an ITF worker*

10 *We are still waiting to meet with some professionals.*

- 11 *Most of what has helped are things I have discovered myself and fought hard with education and health services to get any support. Without Lawyer would not have either.*
- 12 *The best / most helpful support I have had has been attending a course called 'parenting the challenging and violent child using non-violent resistance.'*
- 13 *Not had any support after diagnosis.*
- 14 *We have had to find out everything for ourselves!*
- 15 *I have had absolutely no help whatsoever from local services, there are very few in my area and an extremely long waiting list for CAMHS for which I am about to get my son referred*
- 16 *I worked out it was PDA from reading online. A diagnosis of ASD aspergers didn't completely fit.*
- 17 *School refused to acknowledge that he had SEND, telling him he was s bright boy who could and just wouldn't. The senco told him he was a rude boy and could speak to grown up like that because he said he wanted to go home. She also told him he wasn't going to win. We finally got him diagnosed when he was seven and was refused an EHCP. It took another 18 months for us to get this.*
- He became a school refuser in Year 6, when the senco took away his 1:1 support worker that he had had for two years, without prior warning or transition. We asked fir Home tuition, but it was emphatically refused. He has had no schooling since September and we are being threatened with prosecution.*
- The senco has now filled in a MARF and accused us of emotionally abusing our beloved child and on Monday two disability social workers arrived with only a phone call to tell us they were coming. The authority have sent us his amended EHCP but have not put in the amendments that have been recommended by NAS Lorna Wing after their diagnosis of ASD with PDA traits with high anxiety. It seems and complaint to the local authority is resulting in more threats.*
- 18 *Saw CAHMS age 10. Said it was parenting.*
- 19 *We have had to find external support and fight for ASC help*
- 20 *I was offered six weeks of advice from CAMHS. The support worker did not tell me anything I did not know and did not understand high anxiety or PDA.*
- 21 *However, had to ask for financial help from family to pay for a private occupational therapy assessment and sessions which cost almost £1,000 in total. However, it is the first time we are on the same page as the school. Daughter's assessment confirmed a developmental delay which causes very high anxiety and sensory processing difficulties etc. Selective eating and loss of weight led to referral to local NHS paediatric dietician, however only after OP Report recommended this. As daughter's anxiety leads to severe avoidance, myself and husband attended appointment without her. Dietician has now referred us on to CAMHS. The waiting times are very long, and it's impossible to persuade our daughter to attend. I wish home visits were offered, as this would make a huge difference to our family. I wouldn't want any other child to go through what our daughter has been through, it has been an absolute ordeal for her.*
- 22 *Only recently, the help of a specialist provision (Spectrum Space, www.spectrumspace.org) has been a God-send*
- 23 *NAS Early Birds Plus run by local children services was helpful*
- 24 *It is only through my own research that I have been able to work out what is going on with my son, and I believe him to have PDA. He has a mental health youth worker and sees the GP about once*

every 6 weeks but it was me that suggested he needs an assessment for autism. He has been on the waiting list for almost a year, and the assessment will take place in a month. The lack of help and support is terrible, and if it weren't for me fighting for him to get even a bit of what he needs, he wouldn't have that. It feels like he slipped through the net at school and college and after college he's had no work so it's all been down to me.

25 However the private psychiatrist has

26 All help and support has been from websites, PDA Facebook groups and books.

27 I ended up paying for a private child psychologist to help my child manage his emotions

28 He is in Year 6 and has been a school refuser since September 2017 when the school removed his LSA of two years without prior warning or transition. We have been accused of mentally abusing xxx since 2014 and a MARF has been issued. Despite our request for Home tuition xxx has had no education since then. We have requested the Anderson NAS school for his senior school, but the authority want to send him to a mainstream school with an ARP. The school refused to acknowledge he was ASD until we managed to get him to GHOSH. The Lorna Wing diagnosed his PDA and high anxiety in December 17. We are in despair.

29 I've had no help. Involvement of services yes but no actual help !!! Took years to get ADHD dx. Get medication but no help. Did mean I had access to psychiatrist though which was useful when anxiety became so bad that challenging behavior was a massive issue. Again only help was medication. Did then manage to get on an Nvr course through which I discovered there were other services I could have been offered. Since fairly recent asd dx not been able to access any of the specialist support I was always told would only be available with dx. Currently illegally excluded, struggling to find appropriate education setting to move them to.

30 I have had to educate any support workers, they have not helped me understand his issues at all. That does not mean that they have been no help but they have been more of a sounding board for me rather than any direct help to my son - he has consistently avoided support!

31 Have researched myself and found useful courses and seminars

32 A lot of talking was done
Even medicated for ADHD which I find rather distasteful for a young child. When medication is handed out without diagnosis, it is ridiculous! I felt largely ignored and talked down to. Really unpleasant.

33 Pda not recognised as a separate thing in kent I'm told

34 Brilliant leader of Cygnet course who was accepting of PDA as a thing!

35 Our Dr at CAHMS told us about PDA but due to where we live could only work with my son around atypical autistic traits. We have sought support from other areas -PDA society, NAS, PAST.

36 Paediatrician said she fell under the umbrella of Aspergers but would not formally diagnose. Camhs reluctant to put forward for diagnosis and say they do not diagnose PDA

37 Educational Support at home - fantastic individuals who helped us enormously.

38 I have ASD/ADD & ADHD diagnosis myself - which gives me a greater understanding of my child's diagnosis. I also feel more able to understand PDA because of this & can relate to the many traits in my child & also myself & other family members with the same profile as us.

39 Help only provided from Camhs & Social Services once my son had burn out & total school refusal set in. He became disengaged with life at age 7yrs. School failed my son as they sought advice

from agencies (at my constant request) but failed to implement strategies. I worked on my son's S&L & Sensory needs for years but needed help to put additional strategies in place. Camhs took 8 months for psychiatrist to be involved despite request from Paediatrician- once involved my son's care did improve.

40 The first person we saw at CAMHS said his issues were due to problems at home, a lack of boundaries and even recommended in her report on my child who refused to speak to her that my husband and I went to relate.(If we had time to do that we would have any problems!!)

41 It has sometimes felt more that I was helping them understand.

Suggestions have usually been what We are doing anyway or not what works for him.

42 Local charity ADD-Vance did coaching sessions with us which were excellent but nothing from local services.

43 Just got diagnosis in last 30 dsys

44 Early bird training ASSIST. They have been helpful in adapting the strategies they advise to our particular situation. We explained at the beginning of the course we feel our son has PDA.

45 No help offered or provided after diagnosis.

46 The OT did a programme with him, and we are using some of the techniques and so is school

47 It takes so long to make any progress because people don't want to or don't think to attribute problems to PDA. Eventually I have convinced people, but it is still a challenge to keep them on board with the correct way to deal with a PDA child.

It took two years and three referrals to get into camhs to help with emotional regulation. This 8-week Bernardo buddy program has just started. Fingers crossed.

48 Mostly my own research as PDA not really an accepted diagnosis

Statement of Educational Needs enabled him to attend an excellent ASD aware school with small classes

OT for sensory issues (privately)

Specialist Teaching Service - ASD teacher

49 We had to actively seek out help and it was given on a short term basis by Autism Sussex. At the initial assessment the lady seemed to 'get' the issues and the lady who came was lovely but the help didn't address her individual needs at all

50 Everything I have learned has been self-learned and self-funded. I have even paid for my daughter's school to attend training. I have had no help from NHS or local services

51 CAMHS psychiatrist does not recognise PDA as it isn't in the DSM-V. 9 year old daughter now taking antipsychotic and antidepressant medications and remains without a school placement for the third year; the last 10 months of which is despite her having an EHCP.

52 I started using pda techniques when I suspected it while starting the diagnostic process. It worked wonders and when we got the diagnosis I was told nothing will change because I was already using appropriate techniques. No support was offered following diagnosis.

- 53 *Everything I've learned is through my own research and online support groups, other parents of children with PDA.*
- 54 *All had so far is a meeting with school. My child's issues are scattered over a wide span so he doesn't fit into any boxes for receiving help. 6 years wanting help for social skills & making friends hardly had any help so still not acquired the skills.*
- 55 *Not particularly but the 3 year involvement with our utterly beleaguered CAMHS service did help us. They have hardly any resources to provide anything therapeutically and they have my sympathy. The pressure on our service is immeasurable. They helped us twofold. 1) We eventually ended up seeing the Family systemic therapist fortnightly for 2 years but without our 3 children! She helped us hold ourselves ; our marriage ; our family together during a very bleak 3 year period. 2). Our child was not able to engage with them and they did their very best with what they had. I don't think at that point ; age 9-12) he was able to engage really with anyone therapeutically. However, they really went out of their way to help refer us to another team for assessment ; wrote reports supporting our belief in pda ; helped us by supporting the process to find a residential special school. They really were supportive just not directly with our child.*
- 56 *Have not had any and CAMHS are clueless. They don't understand a child cannot engage because of their PDA. She only had medication from CAMHS (Sertraline) which didn't work. She refused to see them for therapy but I know they would not have been competent from the experiences we had with our other PDA child. She previously had privately recommended Aripiprazole and Risperidone neither of which were effective.*
- 57 *We haven't received help as such. People have come round to "visit" xxx and chat with him. We've done the talking and research about PDA. We've educated local services about PDA.*
- 58 *Everything I've learned about PDA in particular has been through training I've received as a teacher or research I've carried out myself. I feel more expert in the area than any of the professionals that have been involved with my daughter*
- 59 *We seem to know more than the professionals. The only help we got was to get melatonin in repeat prescription but we had to get appreciate prescription first as we couldn't get an appointment to see anyone in the NHS who could prescribe it*
- 60 *Local services in Sutton/Merton not enough funding to be considered eligible, as not severe enough. Paid for private diagnosis as knew wouldn't get help otherwise.*
- 61 *More help from private sources. I.e. Private psychologists/ psychiatrist*
- Endless rounds of CAHMS support but with little improvement due to misperceptions.*
- 62 *v difficult to get support after diagnosis. I am passed around from service to service with no one prepared to give help. School just say it's a home problem so don't help.*
- 63 *Hey see estella as a very complex case so we are being referred out of county to the Maudsley.*
- 64 *Eha work has helped to speak with the schools. Bibic centre helped hugely but that's not local and we paid*
- 65 *Meds for ADHD has helped a lot. Social care PB has been helpful to pay for trips to trampoline park to calm down and hopefully a PA soon (taken a year to find someone to take the position!!!). Social Worker (disability team) has been very supportive at meetings with schools and la as our son keeps getting excluded/moved on from schools and la are quite happy for him to sit at home for months - SW pushes hard for right support - also got CAMHS to manage meds. All other support has been far less helpful.*

66 *I've done so much research to help my child myself. CAMHS dismissed my child as he wouldn't engage with them and never had heard of PDA. Still awaiting assessments for ASD.*

67 *The private diagnosis has however since there seems limited awareness/understanding of the condition from other individuals.*

68 *Have received no targeted help, all my knowledge and understanding of PDA has come from the PDA Society website, Facebook groups, attending conferences and workshops, and reading Phil's and Jane's books.*

There knowledge is less than mine.

69 *Help from school he's in a specialist ASD school*

70 *In our case, early days with intervention from agencies. I have learnt more myself, from reading and attending courses.*

71 *No one has ever suggested any strategies that have worked. The things that have worked I have got from PDA books and the PDA society.*

72 *By reading a book on PDA (I haven't read for pleasure in years as my kindle only has books on my child's conditions with a few books id like to read but never get the time to), I discovered that I could ask his school for a personal tutor to develop a relationship with him where they could encourage personal and emotional self knowledge which would help him a great deal as he is so over listening to us, his parents. I learnt that us letting him have more control over what happens isn't lazy parenting as ALL my friends constantly tell me.*

Even the ones with dyspraxic or dyslexic children will tell me how damaging it is for me to let my son play on his iPad if I need to cook a meal or not force him to go to football because he is putting on weight - because their damn kids are biddable and get dressed when told or will willingly go to the shoe shop. I spend half my life returning online shoes because he won't go shopping (unless persuaded with a treat after which he literally goes straight home). Anyway, I've had to teach myself 80% of what I know.

73 *This is hard to answer as some are very much so - others not a lot of difference.*

Notable positive: NHS dietitian found the PDA diagnosis very telling in her assessment and it guided her proposals for working with his eating issues more than the ASD (which is all school had put on his referral form, unhelpfully)

Not so helpful - earlybird plus course - because whilst we recognised a lot of the ASD traits, many of the strategies don't work for PDA.

Local specialist teaching and learning team have been helpful - understand PDA and were the first to suggest it as a possible diagnosis

74 *Have researched myself and found useful courses and seminars*

5. The Challenges

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

- 1 *Other opinions because it just looks like I have no control over my son, the more people judge/moan, the worse the behaviour!*
- 2 *Getting others to accept that he can not cope with certain situations and getting them to agree to do what works for him.*
- 3 *The violent behaviour, dealing with harm to myself (mum), his sibling, our home and possessions*
- 4 *Biggest challenge was trying to understand how to parent him in the most effective way that got results. Also, trying to parent him in a different way from my NT child seemed very unfair and it seems he 'gets away' with things that she wouldn't. Taking two years to get an ASD diagnosis did not help because it was hard to know if he was just very challenging and difficult or whether was in fact more to it.*
- 5 *A complete lack of knowledge and acceptance of PDA by the health professionals, local authority, teachers friends and family. We are always being blamed for bad parenting or spoiling him*
- 6 *As a grandparent in a caring role it is all a challenge. Currently the most difficult aspect is his switch from PDA mode to non PDA mode; from calmness to anger. The unpredictability. It's like switching a light on. I find myself walking on eggshells most of the time.*
- 7 *Keeping them alive*
- 8 *Alot. The huge demands for bed time and the impact on my older children and relationships. Its hard to have professional staff see the "horrible side" a lot rather than "good side" of my 8 year old girl. Having to make simply adjustments in everyday task from what's for breakfast and to trips to the local stores. Celebrations are hard also and for strangers to understand what's wrong with my child and to politely say "leave my child alone" they fine and when ready will join in.*
- 9 *Getting school to understand & provide the right support for my son's education. Violent behaviour as a consequence of anxiety from attending school.*
- 10 *Dealing with so called professionals/teachers/local authorities/family members with a know-best mentality and attitude which has undermined my natural instincts and knowledge of what's best for my son!*
- 11 *Living constantly in a state of fight or flight and needing to time in to my child's needs at every moment. This has damaged our family life and means I have little time for my son and husband.*
- 12 *The constant parent blaming and not being listened to. Violence and destruction is hard and also seeing the absolute heartbreak of my son after he has destroyed things and been violent to me and he genuinely can't help it ??*
- 13 *Getting used to the idea my child has an additional need... defining the needs and changing my approach.*
- 14 *Too many to list but it's constant*

6. Final comments

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

1 *Ignorance of others who do not wish to understand. They just think he is a 'job'*

2 *Sometimes our life was a nightmare. It didn't have to be as bad as it was, but everything I got was hard fought for & I believe that without a private diagnosis we would never have achieved the subsequent medication with Sertraline, meaning we would never have broken the dangerous downward trajectory of my son's life.*

We wish the anxiety behind my son's behaviour could have been identified earlier and Sertraline offered earlier, rather than waiting for us to demand it. This drug should be more easily available to those that need it, rather than making families go through years of hell & children suffer crippling anxiety & lost educational opportunities for years

3 *Our mainstream school are amazing but they could be better if they didn't believe what the lea tell them about funding. I'm struggling to get more support as she gets 32 hours 1:1 so there's nothing else available!*

Also social services are so far useless, we don't meet the criteria for complicated needs team, despite our challenges and the fact school struggle most days, I'm trying to safeguard my three year old who's physically and verbally abused daily but it seems they don't want to help.

4 *I don't think it would be wise to open the floodgates...*

5 *It is an absolute disgrace how children are being let down by professionals and the local authorities. I had to pay £2995 for a private diagnosis. I was constantly getting calls from school to pick my son up. I had to facilitate a reduced timetable, appointments, meetings and of course at the same time deal with my son's condition whilst holding down a job and meeting the needs of my neuro typical children. I now have the pleasure of having to battle again for a school that has offered a placement and appeal against his EHCP that was deceiving. It's like snakes and ladders. Professionals often say it's a long process but why should it be. What benefit does that have on my child only a negative one. This is all because (the local authorities words) 'we don't recognise PDA'. What a get out of jail card.*

6 *We fostered and then adopted our daughter at 8 months which led to confusion over what was attachment difficulties and what was special needs and it took a long time to untangle*

7 *It has took 5 years to get ASD diagnosis. PDA now diagnosed too. School refused to do Ed Psych assessment, ASD support, or EHCP which was refused as now too ill to access. No CAMHS home visits till A&E visit.*

8 *Being given Phil Christie's book and discovering PDA was an absolute lightbulb moment. If only we had known about it years ago!*

9 *I am frustrated with the education system which must also be very frustrating for teachers. There is a lot of talk about making mainstream schools work for those who are not considered nerotypical. But it dosnt seem to be working. These kids are not able to use their strengths and feel alienated at not fulfilling their potential.*

10 *As with most parents with a PDA child, we had that lightning bolt moment after receiving an ASD diagnosis that we didn't feel quite fit our son, only to stumble across PDA which ticked all the boxes.*

Unfortunately, CAMHS and school shot us down, insisting that it's simply just autism. As they were the professionals, we regretfully followed their recommendations which unsurprisingly led to 18 months of daily battles and our son missing out on his education. His school at the time simply removed him from the classroom when he became agitated and put him in the sick bay.

Thankfully we were able to move him to another mainstream primary with an ARP facility and more importantly a school with an ethos of listening, understanding and supporting children with additional needs.

They have been incredible and we have collectively come back to a resounding PDA verdict and are beginning to put new strategies in place to support our son. He is in Y5 and we will shortly be required to select a Secondary School for him which is our biggest challenge at the moment as the gut feel is that he will not manage in a mainstream setting but equally, we're battling to find a school that caters for PDA students.

11 Our son was diagnosed with ASD 4 years ago but our youngest daughter is so different to him in the way she presents that we're really struggling. It feels as if we've got a handle on how he's feeling etc but his sister is so complex and may not even get a diagnosis but I need someone professional to see the issues for me to feel more accepting.

12 Feeling incredibly disappointed that we have described my sons behaviour to so many clinicians and not one has offered PDA as a diagnosis. A friend sent me the questionnaire link and he scored highest in 24 of 26 questions (the whole family - separately) he so clearly has PDA. We now are treating it accordingly and are seeing results. Thank you to the PDA society. You have given us hope.

13 A living nightmare for all of us but especially our beautiful son who has been rejected and misunderstood by his school, friends and community. Everything is a battle. He was out of school for over a year while we went through EHCP process and we were lucky enough to be able to afford a lawyer. Trying to access support and services had been complex. And like wading through treacle. And while at 15 yrs we finally have this it's too little too late as now our son refuses to engage in therapy or schooling as he feels no-one and nothing has helped so what's the point. His current school - Roman Fields - are willing but too little too late

14 PDA has turned our world upside down, but we are finally seeing progress with all the support that has finally come our way, after a jolly good fight though. The general awareness of ASD and PDA in general is helping our cause too. Our son still gets restraint at school almost every other day and tries to escape his school but we are working tirelessly with school to make sure we are all on the same page. Including our son, we are very open with him, he has a great understanding of his own condition. We are very proud of him. Although he'd wish he'd had a sibling we are in a way thankful that he is an only child. I'm not sure I would have coped with another...

15 Support Groups are a life line!

Within Bucks some families have received PDA diagnosis while others are turned away without discussion. Consistency by clinicians is also not there!

16 I feel completely defeated at the moment having spent ages researching where to take him as no one really believed me and thought it was "behaviour" including his dad. Once I found Lorna Wing Centre through years of my own research and reading, we had to wait ten months. Everything was riding on that assessment and it came back with no diagnosis of demand avoidant very little guidance of what to do next apart from implement autism strategies, which I understand often do not work with a PDA person. It makes me afraid as my son is getting bigger and his violent meltdowns are often directed towards me. I am also afraid for his own emotional well being and mental health as it is already poor and I am concerned that as he becomes a teenager, it will get worse. Right now I feel very alone and hopeless with the situation.

17 *A child with PDA has become an adult with PDA. NOT FUN*

18 *I am so angry and frustrated regarding the treatment we have received. It feels like the blind are leading the blind and in the meantime my 9 year old son is missing out on an education whilst no one gets their act together.*

19 *I am aware of other parents from xxxs school who have been or are experiencing the same problems with the school inclusion officer/senco as we are, but our worries and concerns are swept aside and we are not believed, just as the victims of jimmy savill, Cyril Smith and their ilk were not believed.*

20 *My son now 22 continues to struggle but he lives in Cardiff. So we do not see what is happening with him. When he does not deal with day to day things and they get on top of him we worry about his health as he spirals downward. We will provide any info to help others in the future.*

21 *We have had terrible experiences and the way ASC is treated separately from mental health is at the root of the devastating failures in our child's care*

22 *It is exhausting having to look after and care for a child with PDA. It is a constant struggle. My wife and I get very little time for each other. If we have to make phone calls or look at something on the internet we have to do when he eventually goes to bed, by that time it's too late to call friends or we are exhausted.*

23 *I just want to help my son , I've tried and done everything I've been told , I'm on my own , I punish him with taking his favourite things away , which I'm not even sure is right , he has to be in control , I'm really at a loss hence filling this out and praying for help , he smashing his personal belongings up I can't afford to replace so he doesn't have much at all , I'm full of guilt but should I be , I'm completely confused , and need help please.*

24 *Nowhere to turn / negative effects on rest of family / already have an older child with ASD and is always the victim of the younger child in some way*

25 *Our son is definitely being dismissed by schools on the basis of his paper diagnosis without even meeting him. Feels like we are being forced into specialist provision even though we don't feel that it's right for him and almost asked to give up on academic achievement at a very young age.*

26 *The PDA Society has been a lifeline - it was there at the start of our PDA journey and has provided amazing, greatly valued support. I look forward to meeting more PDA parents at the conference to compare notes.*

The PDA Society is a great source of knowledge, information and support and the website is a great resource.

There is still much more work to do do raise awareness, stop the post-code lottery and move towards finding and offering PDA-friendly education provision nationwide.

27 *It is an isolating experience and I am looking forward to going to the conference in April.*

28 *I could fill pages in this section, especially if I were to discuss education, but I've spent longer than 10 minutes on this really worthwhile survey and I'm tired. Good night.*

29 *PDA seems to be the "elephant in the room" when discussing it with our local health professionals. They feel that an ASD diagnosis should be sufficient as PDA is part of ASD.*

I get given typical ASD techniques and strategies by ASD professionals eg strict routine, when I know that will only make anxiety even worse.

I get that PDA is a very complex and confusing (and at times contradictory) condition. As parents we have learnt what we know by trial and error (and by reading the amazing support groups online). We can't claim to know everything, but are more than happy to work with health professionals and educators to share our knowledge about PDA.

30 *i truly believe pda is a seperate profile on the as spectrum unlike my sons ex pyc who told us its a made up american condition and when he retired camh closed my sons case as it was an oportune time realy ?*

31 *If things get better I would be happy to talk to people but as things are we are just living day to day and that is stress enough knowing it is up to us to help our daughter and no one else can. We aren't able to attend conferences as I can't leave her alone all that time and my husband needs to work.*

32 *PDA not accepted as a diagnosis in Brighton & Hove even if I arranged for an assessment privately*

33 *xxx didn't talk until he was about four. We took him to speech therapy when he was 18 months and he had portage until he start nursery at 3. We knew there was something not right, but it wasn't until he was in Year 2 and his class was put into a mobile classroom that things really went wrong. The SENCO told him he was a bright boy who could and just wouldn't. She said he was rude and he wasn't going to win. She refused to acknowledge that there was anything wrong and it wasn't until we got him to GHOSH when he was 7 that he was diagnosed with ASD. It took 18 morning months for an EHCP to be prepared. xxx was sent home whenever he had a meltdown and couldn't cope. The school have recorded numerous occasions where xxx has caused disruption and attacked staff. It wasn't until the end of year 5 that they decided to guest him in their ARP. When he returned to Year 6 in september 18 they took away his LSA that he'd had for two years without prior warning or transition. He'd spent most of these two years in the corridor with her, but the school then said he hadn't learnt anything in these years. He went for the first morning and then refused to go back. We requested home tuition, but this was emphatically refused. He hadn't had any form of help from the school or authority. In December 2017 he was diagnosed by the NAS Lorna Wing with ASD with PDA traits and high levels of anxiety.*

My daughter has put in complaints, but we have been referred to, in writing, as serial complainers and the SENDCO has put a MARF in stating that we have been mentally abusing xxx since 2014. We are at present waiting for social services to visit us later today. All we, as a family have done is try to get the best for xxx so that he can learn to live with his disability and get the help he needs to learn and lead a worthwhile life.

34 *My daughter's diagnosis is Aspergers and, having left education at 18 years (she said that school was for children, and being 18 made her an adult), she moved to adult services. In our area there is no team that supports specifically people on the autistic spectrum. If the autism comes with a learning disability, then the person is put with the learning disability team; if the autism doesn't come with a learning disability, then the person is put with the adult mental health team.*

My daughter is under this latter team; this means that while she receives support from them, she is unable to access any wider services (such as counselling, or group support) because her issues don't come from a "place of psychosis", which is the criteria for accessing these services.

So once again she's a square peg in a round hole. There ought to be a specialist autism team for individuals diagnosed on the spectrum, irrespective of whether or not there is a learning disability.

One other thing I would like to say is that care services such as supported living and residential care homes were always looking to support my daughter to "achieve her best". The problem was, none of them were able to support her AT HER WORST. This meant that although there

were lovely care plans in place that spoke about independence and a fulfilling life, and maximising her potential, when she had meltdowns the placements would all fail. This meant that by the time she was 21 she'd had to endure 6 failed placements, and she'd been arrested twice. In fact on several occasions SHE would be the one to call the police and ask them to come and arrest her, as she didn't feel safe and would feel safer in a police cell.

In the end, about 18 months ago, when the last placement had failed and she was again back home with us (not managing at all) and her self-esteem was at an all-time low, I insisted on the main criteria for a new placement being that they could support her AT HER WORST. This meant that she ended up in a residential care setting where the other residents are all much more profoundly disabled; she's the only resident who's verbal, and the only one without a learning disability. On paper, it looks like we've institutionalised her; but the reality is that it's the only place where she feels properly secure, because she knows that however bad her behaviour gets, she's held, she's safe and it's not going to be catastrophic.

So I think that there ought to be a change in intention for local authority commissioners; instead of focusing on supporting individuals to achieve and make progress, they should focus on supporting individuals to feel safe. The achievements and progress will follow.

My daughter's now applied for an EHC plan to go back to college (which she swore she'd never do, as her experiences of education were horrendous), she's been volunteering in a local charity shop without any issues at all for many months, and she's now travelling independently. All of this is because - finally - she feels that she's living in an environment that can support the most challenging parts of her personality and accepts those just as much as all the good stuff.

I'm amazed that I can type here that I feel confident that finally my daughter will be able to make progress. For so long we thought she'd end up in the mortuary or in prison.

Our relief is tempered by the fact that now she's settled and making progress, our local authority want to move her..... but that's a whole other story and battle!

35 *Lack of general understanding and specialist support has made my life and his so much more difficult*

36 *I am currently trying to stop my son being taken into permanent care as social services clearly don't understand pda. So many problems with them that I will be suing them after it's sorted out, also trying to get him into a residential school for Asd that has gone to tribunal despite professionals recommending it. Everything is a fight, it is hard, it is exhausting but instead of getting help things are made harder and worse than ever.*

37 *The opportunity to interact with others dealing with similar situations via Facebook has been hugely reassuring*

38 *I would like PDA to be more widely accepted as a diagnosis, we have often felt that people think her behaviour is our fault, it has been hinted at many times, we have also been accused of hurting her as she has lied/exaggerated incidents that have happened and have had social services round, people have no idea how difficult a child with PDA is and how manipulative they can be*

39 *We are not asking to move mountains but for you to understand that to most professional they are a hospital number the file can be closed ready to see the next patient we can't do that we are left in limbo and this is our life trying our best to cope you do feel sometimes that you are so alone with what is happening when you see your daughter self harming and not understanding why it has happened you go to the doctors and they say what a good job you are doing but your crying out for help however how small to make things easier*

40 *Our lives completely changed (improved) within a fortnight when I realised his behaviour was anxiety driven. He was 6 and fairly non-verbal then. He seemed relieved I had finally understood.*

2 years ago I became very depressed and was struggling to hold it all together. I started exercising and it literally saved me.

41 *Pda not officially recognised in Surrey, but I've had great support as my other son has very severe ASD, and challenging behaviour. I have nearly always been taken seriously by professionals, although mainstream school staff are not understanding of the severe impact of both PDA and ASD especially when they see a 'perfect' child at school and believed everything was because of his brother. Unable to see the Pda at school until full refusal and breakdown happened.*

42 *CAMHS is only interested in helping those who are obviously ill. They hear but don't trust understand. It is largely lip service. I am shocked at how unprofessional some of the members behave, and even the way they talk to young children is quite abhorrent. When dealing with foreign workers much of what was said was misinterpreted in letters sent to my GP. It added more stress to an already fragile situation.*

43 *We are currently working, slowly, on trying to get our borough to recognise pda. Because our daughter masks, we really do have an atrocious time getting support, and it is only because I am very vocal that we do. I need to be vocal as an outlet for my own mental health.*

44 *Controversially I believe PDA to be attachment difficulties and asd together. Not through neglect or abuse (although that may also happen for some) but through parents, including myself, not navigating the experience of an autistic child's early development well enough through not understanding what was going on developmentally for the child. I dont believe, talking to fellow PDA parents and individuals with PDA that an individual is born PDA with little impact from the environment and early care. I hope one day we will have some definitive answers.*

45 *Can be violent when can't get what she wants. Won't go on school bus as not in charge as no friends on bus. Is horrid to me when out in public as no empathy. Won't talk to me as her life is none of my business. Very hard. She swears. Hates me .*

46 *Please keep raising awareness. I feel in 10 years time we will be in a different position. Right now everything is a battle, and the second hardest challenge (after violent and challenging behaviour) is the fight for support and acceptance and help with PDA.*

47 *Would like more professionals to understand pda.*

48 *Only recently learnt about PDA and felt sure that these traits are present in our son. Was distressed that his already challenging behaviours could become worse if he doesn't get more specialist help at school if PDA is part of his condition.*

49 *Where did I start? I started writing a book a couple of years ago! There's just so much to talk about.*

50 *Want help and professionals know but a month on still waiting*

51 *It is undoubtedly been and still is the challenge of my life that isn't over yet. My son is number 6 of 7 children.*

52 *Too much to write here but happy to supply another time. Also need to write to Sendist right now & currently feeling emotionally drained by yet another LA Sen team game this week!*

53 *So tired of banging my head against the brick wall of CAMHS whilst managing two children one with diagnosed ASD and the other with ASD/PDA issues whilst waiting for diagnosis, keeping my*

job, my home, my marriage and my sanity is a daily challenge especially now the menopause is approaching. I've opted for counselling over medication but stress and depression are a constant battle for me.

In the middle are my two challenging but lovely sons who deserve someone who can help and support them not just cling on to the basics by her fingernails from day to day. I need external help to do this and not the threat of social services...

54 *I would be interested in conducting a survey on the epidemiology of PDA. I am a Biomedicine graduate and would appreciate the help of the society if possible.*

55 *A quite depressing future is all I can see. Battle to fight for health & education needs*

56 *So pleased to have found out about PDA. The profile fits my daughter to a T!! We have started to implement some strategies and seen improvement. Feels like I can begin to understand my daughter and help!*

57 *When we adopted two young boys we were not prepared for the extent of the challenges they would bring to us. Our older son has exhibited a reactive attachment and our younger, who is the subject of this survey has the autistic traits and Learning difficulties, has had a very strong attachment to us but very challenging behaviour. psychiatrist at CAMHS understood but prescribing med all that really helped as he would not attend any groups. Behaviour support staff didn't really understand him - adult services have been much more supportive. Our Church has been our biggest support, even more so than extended family, esp church friends who were foster carers. Adoption UK and Essex post adoption Teams have also been helpful in past.*

58 *We just recently got our child diagnosis with ASD and PDA and still don't know where to go for support for us, the parents. It is hard because friends and family pull away and don't support you as much when they find out our child is Autistic. Neither my wife or my family live in this country and we find it extremely hard to find rest bite and we don't get to spend much alone time or do many things as couple and is extremely hard on us. It is like having one full time job and then have to come home and work another full time job being a career for our daughter.*

59 *I feel the NHS needs to provide help for sensory issues which our council does not provide. In my son's case, this is a crucial part of his problem. He also is not provided with hands on help for his OT needs. He is at least two years behind his peers (according to a private assessment) but the NHS OT has said he is fine. He can barely do any PE and no sports.*

60 *I started a Facebook page in October to get awareness of the condition, I'm in contact with 16 families from Brighton and hove with the condition , and been rising awareness of the condition on Facebook*

61 *Getting the diagnosis was tough now he is 19 and finished his apprenticeship he is finding it very hard to get a job. He presents as completely normal and has learnt to deal with people's emotions but can be very clever in changing conventions etc, to something he is interested in. I feel that at the age of 19 he because he has learnt to cope with the pda we have been completely abandoned by the system. I would really value some help with getting him a job.*

62 *It has been hard for me from the start. I knew she was made up different from being a mum already. The lack of sleep from early start was first sign. I wished her mainstream primary school were more funded and had knowledge of certain profiles as I feel they let her down very badly from the 2 years she was there. She is only in year 3 now.*

63 *I'd be here all day! In short I'd like to see more in the way of education about the syndrome and it's similarities and differences to other types of ASD - for health professionals (who often know less than we do) and for educators (who in our experience seem to think that if disabilities are invisible they're not a problem) and for the public in general. It would also help to be taken seriously when asking for help because all services seem to link in with each other and we are*

tired of having our parenting/children's behaviour questioned. We get DLA for another child and our PDAer probably has more support and care needs but because she has had no intervention we cannot get DLA or access to other useful services for her

64 *I am now DCO for SEND in Buckinghamshire hence why I can't speak to a journalist. Living with PDA had been very challenging but has also helped to equip me for what I do now.*

65 *Getting help for a PDA child is extremely difficult especially if that child's anxiety makes them violent and terribly misunderstood. There is little help for single parents struggling to juggle all the demands, educators believe they know it all and are actually extremely detrimental to the health of the child if they don't believe parents. Social services offer little or no help as view child as non disabled therefore not able to qualify for respite or help. Social services create more work and stress for already exhausted families.*

66 *I have said this before that the pda forum really helped particularly in my darkest and depressed moments. Knowing there were others unfortunately experiencing similar devastating experiences as us was oddly comforting and reassured me I was not alone or going completely insane. Having a child with these difficulties has taken me and our family into a place that would have been unthinkable several years ago. It has had a profound effect.*

67 *I feel pda needs to be recognised more. The amount of other families I meet with children displaying the same traits as my son and yet not one health professional even likes to consider it*

68 *I would not wish this condition on anyone.*

69 *The parent-blame and false accusations against autism families have to stop.*

70 *I'd love to become a PDA ambassador and help other parents. I've done a PDA course and believe I have the skills to help other parents with PDA children through my own experiences. I would love to spread the word. I would love to be given the chance to share my story with others!*

71 *The highly dangerous false accusations against parents of autistic children, are so damaging to the children as well as the parents. It has to stop.*

72 *Pda not being recognised by many people has been a big problem for both myself, my husband & my child. He was seen as naughty even when he had a diagnoses. People tend to say oh yes I understand autism & don't get that the strategies used for autism just don't work for pda. It's been a fight from the very beginning to get school to understand what my child needed & it was too little too late which had a detrimental effect on my child, myself & my husband.*

73 *I wish there was more help and understanding available and it was less of a battle to get diagnosed*

74 *When I received training at my school about PDA it was like being hit with a bus ... I walked around in a daze for about 3 days. The information in the training was like someone had videoed my life and condensed it into half an hour. I swung wildly from being relieved that finally I understood why her ASD diagnosis didn't fit and why ASD strategies didn't work (and being secretly proud of myself for coming up with strategies that did work ... that were literally text book strategies according to the educational psychologist who delivered the training) to being incredibly angry that I / we had gone so long without knowing PDA even existed ... and being angry for all the other parents out there who aren't fortunate enough to work in my field and have the information I've now got.*

It also angers me that so many professionals still deny its existence, preferring to blame e.g. poor parenting

75 *we attended conference two or three years ago when son 11 and school refusing.*

Now 14 and in autism school - not ideal as he is clever and very limited educational opportunities but a couple of great teachers are thrilled with him (as he doesn't fit in) and work very flexibly with him. He is now doing a tiny bit of work and gcse's on the horizon and feel slightly possible.

76 *Much more recognition in our local area over the last year. Local authorities/CAHMS still struggle to support us and we are often passed on to a local PDA support group.*

However, this recognition has taken many many years and we are one of the many families that blame has been placed upon for poor parenting et cetera.

Recognition of the condition is also harder when you have other children with severe disabilities. My child with PDA is a girl – she has been very adept at masking and is academically quite able - therefore, the local authorities believed her school refusal and erratic behaviour at home (typically very well behaved at school!) to be down to stress and bad parenting.

My daughter needs specialist support but currently has no EHCP (refusal to assess) - I have not worked for nearly 5 years due to school refusal and lack of support.

Both my children, now have a diagnosis of Aspergers. The local authority and professionals denied the possibility for years - eventually neither were diagnosed by CAHMS but one child privately and the other by Great Ormond Street.

It has taken years to get this far but I worry how many children are out there with parents who are struggling without the money and support to get the acknowledgement/ diagnosis/help they truly need.

77 *1) It took me 2-3 years to get used to my elder child (nearly 9) having a special need... I feel so much more able to cope now I've 'transitioned' into a new mind space... 2) I feel that access to additional support is really key. Not everyone can afford that which is massive disadvantage in my opinion. If we had had to have done this without money it would have made life intolerable at times 3) a genuinely understanding support group is a must!*

78 *Disappointed that local services not informed about PDA and therefore having to pay for private assessment*

79 *not treated in NHS or Schools*

80 *its very hard and little support from NHS and schools*

81 *Our experience has been hell. Especially getting appropriate treatment through CAMHS who do not support my private diagnosis (which I paid over £3000 for in sheer desperation) which has resorted in me being issued with a child protection plan for neglect.....and I'm still not getting the correct support or help through camhs. My Son no longer has a school that can manage his behaviour and I cannot work to support us, I am a single parent.*

82 *v frustrating to get help/recognition of day to day struggles. Please have a conference in Oxford!!*

83 *Professionals need to start listening to parents, we are the ones who love and care for our children 24/7, stop judging parenting techniques, and if insisting on parenting course please make sure they are relevant ones!*

84 *I feel it's wrong that teacher and professional are taught how to deal with violent behaviour however parent see the worst of this and are left to deal with it alone. No woman would be left to*

deal with a violent partner yet parents are dealing with levels of aggression with no real help or training to deal with it.

85 *Since discovering PDA a few weeks ago and adopting strategies things have been easier and calmer. There's a light at the end of tunnel, however, I still fear for my daughter and what will become of her.*

86 *I have Social Services involved at the moment which came about as referrals to get my son extra help and support were turned down and so I was left with an anxious, violent and destructive child and no support or help around me. I was pointed to PDA by chance and on reading about it, am 100% convinced my son has it.*

Unfortunately Social Services became involved about 2 months before I found out about PDA and even though I have been putting strategies in place which have dramatically reduced my son's anxiety and violent behaviour, Social Services are telling me that I have to attend autism workshops and follow autism parenting guidelines and strategies that do not work and never have done and do not believe that PDA is a cause. I am seriously going to lose my son due to professionals ignorance and understanding of PDA

87 *Just feel so frustrated at the school system that is so rigid and will not bend to accommodate children with pda - a few adjustments would mean our son could have a School place where now it looks like no school (even independents) will take him - his behaviour is not violent but verbal abuse at school, we use pda/cps/gentle parenting and home life is ok - school just won't do this and insist on forcing him to comply then punish/exclude when he panics and behaves - he was out of School for 2 years with little to no education (few weeks of home School) and his school levels improved - he went to his current school (tiny specialist independent) 9 months ago and has gone backwards in his school grades by 2/3 of a year instead of progressing 2/3 of a year.*

It shows that forcing him to work gets you nowhere but letting him do what he wants leads to learning. The constant exclusions and being moved from school to school and now looking like there is no school for him to go to has left our 13 year old very depressed and hopeless - I am very cross

88 *Parenting a child is hard enough but when you have to fight every step of the way to get your child what they need really takes its toll.*

89 *My son has been my greatest challenge as a parent and my greatest reward in the appreciation of what others take for granted. His difficulties has left an imprint and forced a change in every environment/ situation he has been through. He has changed peoples beliefs and made them relook at their text book thinking. He and others like him shine a light on diversity and they break the mould.*

90 *As my son is so young was diagnosed at 3.5 we were really unsure about school provision , he was not managing at nursery and we pursued a specialist provision as no unit placement available and options were mainstream with 30 hours support or specialist provision. As he is 'high functioning' my fears were that he would not have an appropriate peer group as a high proportion of his peers are non verbal but it was felt to meet his needs and manage his behaviour this was appropriate, I don't think he is pushed academically to what he is capable of however I think in order to manage his behaviour he is absolutely in the right placement his behaviour is cyclical and when he struggles he is very challenging and they cope and manage that so well , when calmer and in a better place they try and stretch him .*

A mainstream school even with support would not manage his challenging or demanding behaviour , he is always one step ahead and tries to manipulate situations for him to remain in control . He is a lovely amenable chappie who is very endearing and all those who meet him can see the positive side of things .

91 *The NAS education support service has been fantastic. Your PDA forum is a lifeline. Please carry out and publish more research on older teens and young adults.*

92 *The biggest support we've had along the way is the South Bucks PDA support group. We have learnt so much and come such a long way since being part of this group. I would recommend joining a local support group to anyone with a child who has PDA. It is so vital to have this support in a society where PDA is not always recognised/believed.*

93 *My son fits the PDA profile perfectly apart from 2 things.. he was not a passive baby..in fact quite the opposite, he was a very active, always seeking the next step.. walking, talking happed very quickly, as did reading.*

Secondly when he goes into imaginary play.. it's very structured.. so he will pretend to be an underground line and be the train dropping people off an reciting every station on the line along with the interchanges.

94 *Unconscious incompetence on the part of senior leaders at school has been hugely damaging to our child - we can't find any psychological support to help him with the resulting extreme anxiety - CAMHS refused referral (they are not commissioned for children with ASD under 11 years old). We would love a PDA Society listing of helpful child psychologists who provide appropriate therapy.*

Conclusions

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

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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