



Being Misunderstood

East Midlands 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 East Midlands. 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 East Midlands

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 65 families from the East Midlands.

1. Diagnoses

Answer Options	E Mids.	National
Yes, given what I feel is a correct diagnosis	37%	32%
Yes, but I feel it is incomplete	22%	22%
Yes, but not one I agree with	0%	3%
Still waiting for a formal diagnosis	11%	14%
Not requested / been offered a formal diagnosis	6%	7%
Other... (shown below)	25%	23%

1 *Awaiting ASD assessment, won't be asking for PDA assessment.*

2 *We are at the very beginning of getting a formal diagnosis*

3 *Yes, autism spectrum diagnosis. He is extremely demand avoidance though when I asked if pda could be part of the diagnosis I was told it's all under the one umbrella of asd*

4 *We asked the paediatrician if it was worth going for diagnosis after she got her ASD diagnosis - they said no.*

5 *Notts CC does not support funding for PDA Assessment. Family not able to finance themselves. We have asked our GP to investigate a specialist sensory OT Assessment. Still waiting.*

6 *Diagnosed with high functioning asd but within the report was would benefit from pda strategies.*

7 *Assessed for ASD. We were told it's not ASD so have been told her behaviours fit the profile of a child with PDA but are caused by her Noonan Syndrome. I'm not convinced because not all children with NS behave like she does - only those with an asd/pda diagnosis*

8 *My sons Paediatrician did not like the PDA diagnosis preferring to say he has "ASD with severe anxiety & avoidance traits"*

9 *Only of ASD as PDA is not recognised in Leicestershire.*

10 *originally diagnosed asc in 2011 but recently updated last year to include demand avoidance but not pda specified*

11 *How would I get him to engage with anyone who could provide a diagnosis?*

12 *Dr refused to get a diagnosis because my son is asd and she said it comes under the same umbrella*

13 Asd with significant demand avoidance secondary to anxiety (pda strategies to be used)

14 Currently being refused a diagnosis on the basis that our NHS trust "doesn't offer it" hoping that I will be able to persuade the GP to refer us to somewhere out of area that will provide it.

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	E Mids.	National
Need to feel in control	97%	96%
Challenging behaviour	89%	89%
Difficulty with daily routine e.g. morning / bed.	83%	78%
Severe Anxiety	82%	81%
Sensory Issues	75%	91%

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	E Mids.	National
Yes, all the time	40%	41%
Regularly	27%	25%
Sometimes	11%	15%
Occasionally	8%	10%
Never	13%	8%

4. Involvement of local services

78% of families had involvement from local services, often multiple services, over the past 2 years. This included 53% 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	E Mids.	National
Completely	3%	1%
Very	8%	4%
Moderately	13%	13%
Slightly	20%	24%
Not at all	42%	45%
Not applicable	14%	12%

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

Answer Options	E Mids.	National
Very satisfied	5%	3%
Fairly satisfied	10%	14%

Neither satisfied nor dissatisfied	10%	15%
Fairly dissatisfied	7%	19%
Very dissatisfied	34%	48%

Some explained their experiences of local services.

- 1 *The professionals we have had for him being deaf have been fantastic. Nearly all of the other professionals seem fairly useless and lack training and understanding.*
- 3 *They tried to take my daughter from me. I had to take my LA to the high court in the end and won.*
- 4 *The help from the working together team xxx has been a big big help*
- 5 *The meetings I have had so far have been very helpful but they are typically nine months apart. I feel that I can't access support or unlock support at school until I have a diagnosis for my son.*
- 6 *Only had two leaflets from Autism outreach service about PDA. the rest we have found ourselves*
- 7 *The provision of support while daughter was at home required me to teach the support and monitor how to work with my daughter - often the support does not follow the requested methods of support, tailored and stepped programmes for enabling new skills etc. It is time consuming and often have to crisis manage when we hoped that we could step back a little to allow our daughter to become more independent i.e. the support which is supposed to enable and teach appears to be quite inflexible and not able to provide quite the support required.*
- 8 *He has not had any support since he was 16*
- 9 *School have been helpful in providing TA time, which is only partially funded by LA. However, xxx's difficulties have been a huge challenge to his (small) school in terms of expertise and funding.*
- 10 *Exceptionally lucky to have had a paediatrician and CAMHS clinical psych who got and accepted PDA they did help however many agencies it's my role to help them understand, if they are willing.*
- 11 *Child educational psychology service have always been helpful but very limited access, short interventions in primary school.*
- 12 *No help from services except Camhs but their help is limited*
- 13 *Local services? There are none. Waiting once again on cahms waiting list after going private for diagnosis.*
- 14 *school fully understand him, our ewo fully understands him. the psychiatrist understands him. the specialist dentist we see understands him. The LEA themselves do not understand him, and neither do the autism services that the ccg have tendered, the local and national nhs trusts also do not understand him, but the barrier as far as they are concerned is that it is not in the manuals.*
- 15 *An excellent special school and Autism specific adult services*
- 16 *Parents made the diagnosis. The school would not support a referral for a diagnosis (even with our oldest son being diagnosed ASD), problems were put down to behaviour/depression. By year 4 it was impossible, so we changed schools to a very small school, who were very happy to support the referral for a diagnosis - this did take a year from leaving the old school, appealing to get a place at the new school and settling into the new school.*

GP sent us on various parenting courses, which we did, but they were of very limited help, we were already equipped with a great deal more parenting skills with our children than other parents on the courses (which were not aimed at children with ASD). It wasn't until we could go to the GP and say we had read about PDA and it was like it had been written about our son and with the school support that they made a referral for a diagnosis. Our research taught us about PDA. Pin Point has been a help.

The NAS Early Bird Plus programme had already given us a good understanding of ASD with our oldest son (that was the best course we had done). We would love to be able to help his anxiety/depression/low self-esteem but struggle to help manage/support him with this - we do try and manage/support but don't see improvements. CBT (through CAMHS, which again we were so pleased to get and had a lot of hopes on) didn't really help. They couldn't seem to break into his negative cycle of thinking, which was very disappointing. We thought that we would see some positive results from this, so it was so disappointing we didn't, but I don't know if to be dissatisfied with them (we question if a different person with a better understanding of PDA may have had better strategies to help) or not.

- 17 *My son can be very violent and up till now no one has been able to help me with this*
- 18 *I have passed my information on the them and done my own research after being constantly told it PDA does not exist*
- 19 *Social care has been brilliant. We have been awarded direct payments and overnight respite*
- 20 *He has support for challenging behaviour but never any attempt to find out why it is so challenging other than his Down Syndrome. PDA not recognised in my county and my request for out of county referral for PDA assessment has been turned down by commissioners because PDA is not recognised as a diagnosis*
- 21 *Have not had help from local services as yet.*

5. The challenges

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

- 1 *The amount of time and attention he needs when there's even more paperwork and organising than a child without special needs. It's exhausting.*
- 2 *Making others (family - including my partner and my older children, friends, school teachers, strangers, etc.) to understand and to not judge. The feeling of being on my own with all of it.*
- 3 *Oh gosh! So much. It's hard. No one can understand unless they have walked this path.*

I worry constantly about his future and whether he will be able to live an independent, and what will happen to him once I'm no longer here to be his interpreter to the world. He feels the world is out to trick him and it's such high maintenance work keeping in a 'just right' state, like a delicate seesaw.

I worry he'll continue to 'not respect' authority, and he's a fighter not a flighter, but also incredibly naive and gullible. I worry a lot about what that might mean in adulthood.

I worry he'll be lonely because he craves friends but lacks the skills (currently) to maintain friendship

without huge input from me. He feels lonely a lot - his sister is amazing in that respect - but then he gets jealous if she has her own friends and I worry about the long term effect that will have on her.

- 4 *Lack of a normal life. Everything requires intense planning and preparation and often not getting to do things I want to do,*
- 5 *Lack of support when she was under 18, people not listening or following constructive advice (wrecked her education), constantly battling for benefits, health, social support - everything taking months and years to sort out and still waiting for therapies trying to keep a marriage together and support other children within the family ... health crashed loss of family income and then family dismissing the issues and then blaming me for the behaviour as my bad parenting - struggling with mental health issues as a result of chronic isolation as other parents and families did not understand*
- 6 *Struggling to get the right help, particularly his schooling. If we cannot get an EHCP we have no choice and have already been told by his primary and prospective secondary school that the setting would not meet his needs and would be unsafe.*
- 8 *Coping with how he is with his siblings*
- 9 *Not having school "friends"*
- 10 *Staying Positive due to the impact of challenging behaviour.*
- 11 *Day to day living....far more difficult when she was younger. Increased independence has made things easier. Trying to leave the house to go anyway used to be a complete nightmare. Meal times were difficult. Trying to give attention to her brother was impossible. Coping with her meltdowns both public and private were hard. Being verbally and physically abused by our own child was/is horrendous. Pretending to cope in front of others because they had no idea what was going on and would think I was crazy for just trying to explain what our home life was like.*

Secondary school - we have had two years of absolute hell. I've fought a permanent exclusion and I've got her an ehcp but the battle to get what she needs/deserves is far from over. She has been failed massively in the education system and without me knowing what I do (I'm a teacher and Senco) she'd have been out of school with no support two years ago. So not one biggest challenge- everything is and is far bigger a challenge than anyone else would ever know
- 12 *Other people and institutions, and post school finding the next thing each year. I have no idea how he will function independently.*
- 13 *Keeping her in education.*
- 15 *Unpredictability of life, the strain on our marriage and the impact on siblings. Being afraid of my own child.*
- 16 *Understanding my son, but having the professionals just see it as bad parenting etc. Getting the correct education placement took over 6 months battle with lea*
- 17 *We seem to struggle through the day from getting up, brushing hair/teeth, school, homework, meals, his depression/negativity/anger can dominate. Weekends can have no demands (although meals at mealtimes would be good), but even then we may have a visitor/need to pop out (he won't be left without a parent home) and it can seem impossible. The guitar playing is great, but he can get frustrated with that too.*
- 18 *Trying to get people to take PDA as a actual disability. Trying to get people to understand her behaviour is due to her disability and not her being naughty. Finding professional who, instead of*

listening and taking on board my comments, decided to 'pass the book' because they cannot manage her or are not willing to look into PDA and use the strategies. Meltdowns are a huge issue for us

- 19 *The time and emotional and cognitive effort of trying to secure and maintain adequate provision and realising that it is unlikely that I'll ever be able to retire from having to do this.*

6. Final comments

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

- 1 *My daughter is 12 and was diagnosed with high functioning ASD before starting school. 2 years ago she had a 4 day fixed term exclusion and hasn't been to any school since. We have got through 3 autism outreach workers, all of whom were stopped from coming to the family home due to her violent outburst for their safety. LA do not recognise PDA and so those specific strategies have not been considered.*

CAMHS initially refused to get involved saying that her problems were due to my husband and my differing parenting styles which confused her and have caused/contributed to her current behaviour. They still refuse to get involved despite her refusing to leave her bedroom, wash, bathe, brush teeth or hair, engage at all with anyone family or otherwise and will starve rather than come out of her room to eat.

She is currently on roll at an independent specialist school whose headteacher comes to the home to try and engage with her 3 times a week. Disabled children's Service say the only support that they can offer is direct payments but I am not happy to leave a stranger in my house to care for her so I go out.

- 2 *There is so much to discuss - such as the impact upon siblings, friendships, marriage - how the funding cuts devoted fantastic support groups, the ability to good diagnosis and therapy (can't find any in the county ... still waiting 18 months later for permission to cross county into the city for therapy for my daughter !) Having to work so hard with the other children, relying on a grandparent to care for them while you battle for benefits, with teachers, etc*

How often with PDA the advice to give the child/adult time and space - to negotiate can lead to the person being spoilt, demanding, not learning to take responsibility etc ... so often there are plasters being offered when complex issues require phenomenal range of approaches varying from day to day, moment by moment as the person with PDA switches from role to role, to extreme manipulation and confrontational behaviour to sorrow and deep regret it can be a dreadful psychological roller-coaster which has the capacity to devastate families and relationships as well as health at all levels while suddenly being some of the most amazing brilliant and wonderful experiences as you see them excel and dazzle and charm and leaving you breathless.

- 3 *I blame the government for starving LA's of funds to support SEN children. I do not have a problem with those children going to mainstream schools PROVIDED THERE IS ADEQUATE FUNDING TO SUPPORT THOSE CHILDREN AND AN UNDERSTANDING BY STAFF OF THEIR NEEDS. There is a huge shortage of appropriate school places for ASD/PDA children.*

- 4 *After a number of failed residential school placements due to severe challenging behaviour I have come to realise that my son could not fit into an educational placement and required a small tailored package around him. His school fees on leaving were 287.000 a year. I have now a team of asd specialists who great knowledge of pda working with him as an adult. I used a solicitor on leaving education to ensure the right package.*

I find that Capita on behalf of pip are totally clueless and have created difficulties with their rigidity of protocol for assessments.

- 5 *Thank you for all the information on your website and for the support you give us*
- 6 *Education, education, education. The right educational placement has made the biggest impact on my son's anxiety and thus, to our family life.*
- 7 *I have struggled in giving my child the best support I can. Over time this has affected my strength and abilities. To give my child the best support would mean not to work but my working environment means I cannot do this as need time off during holidays as to get the care during holidays the company I work for won't adjust to that even though there is a policy there for it*
- 8 *Life has been HELL But.....with amazing support from someone VERY special with Mases of experience living / working with PDA we got through. Without her we would still be at the beginning. A nightmare beginning!!!*
- 9 *Every day is a challenge and we have worries for the future but try to take each day as it comes. Provision in school is far from ideal due to lack of finances and cuts across the board. The day we received the diagnosis was scary but we were determined to prove the professionals wrong and we have!*
- 10 *Living with PDA is hard, it is non-stop and exhausting as a parent of a 21 year old I worry about the future. He is able to drive, hold down a technician type apprenticeship and has qualifications...but where do I find an employer who can keep him on track? Nudge him and expect more of him with patience? The more time he spends at home the more he regresses and becomes dependent so I am dreading him finishing his apprenticeship. He is in the grey area between fully functional and needing support and there is very little out there in the world that will take him on with the management needs of pda*
- 11 *I have 3 children with an asd diagnosis. My eldest daughter (13 years) also has PDA. She is the most challenging out of all the children but we are learning to cope and she is much happier and more settled now she has left mainstream school due to a mental health breakdown and is now in a hospital school x*
- 12 *Not knowing where to go for help, not knowing next steps. Why CAMHS don't share knowledge between counsellors, doctors and key workers. Why do we feel like we have to fight to get anywhere and we have to be 'at crisis point' before anything is done.*
- 13 *Birmingham children's hospital put son on risperidone when he was in for 3 months but when discharged camhs wanted him off it. phso complaint regarding overseeing failure of medication upheld.*
- 14 *PDA is a complex but unique condition. Professionals need to accept this and help us teach our children in ways they can understand and cope with*
- 15 *Autism specific services seem to have an understanding of PDA but other service providers for those with a high level of need do not*

Conclusions

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

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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