



Being Misunderstood

North West Report

Experiences of the
Pathological Demand Avoidance Profile
of ASD

May 2019

Introduction

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

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

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

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

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

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

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

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

National Key Findings:

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

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

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

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

Survey of Parents in the North West

About the respondents

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

The sample size was significant with 1,445 participants, and so this represents the largest survey on this topic conducted to date. The largest group were parents of children and young people who they had identified as or suspect may have a PDA profile of ASD. These made up 1,194 of the respondents, including 73 families from the North West.

1. Diagnoses

Answer Options	North West	National
Yes, given what I feel is a correct diagnosis	30%	32%
Yes, but I feel it is incomplete	18%	22%
Yes, but not one I agree with	7%	3%
Still waiting for a formal diagnosis	8%	14%
Not requested / been offered a formal diagnosis	11%	7%
Other... (shown below)	26%	23%

1 *Not given in south Cumbria*

2 *Not seen a professional yet*

3 *For ASD but Manchester does not diagnose PDA. He is classed as having anxiety lead avoidance issues. They are just reluctant to put a name to it.*

4 *Just starting the process*

5 *I agree most but has also 'associated attachment problems' vague who came to that conclusion and also the interpretation of these.*

6 *We are trying to get him assessed. A letter was sent to the wrong address followed by a letter to the correct address informing both my wife and I that because we hadn't responded to the first letter they were going to remove him from the waiting list for being assessed. We*

7 *A formal diagnosis of ASD but PDA not recognised...*

8 *Diagnosis from a relevant professional, at the parents' request, so not "official"*

9 *After 13 Mo the we've persuaded the paediatrician to add PDA tendencies to the original diagnosis.*

10 *Have a diagnosis it is not what I would like which is PDA but it does refer to demand avoidance and is not per say incomplete.*

11 *ASD diagnosis only. It was the LEA ED Psych Who picked up the demand avoidance*

12 *Yes but via private EP assessment as considered "not autistic enough" to refer to CAHMS*

- 13 Privately diagnosed as ASD/PDA
Still waiting for formal assessment on NHS
- 14 Yes she has a diagnosis of ASD. Which all the professionals agree is along the lines of PDA.
- 15 We live in Stockport and they gave her a diagnosis of ASD-anxiety based avoidance as they can't diagnose PDA. They agreed informally that she has PDA.
- 16 PDA recognised after ASD diagnosis

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	North West	National
Need to feel in control	96%	96%
Severe Anxiety	89%	81%
Challenging behaviour	88%	89%
Sensory Issues	84%	91%
Difficulty with daily routine eg morning / bed	78%	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	North West	National
Yes, all the time	45%	41%
Regularly	18%	25%
Sometimes	14%	15%
Occasionally	14%	10%
Never	10%	8%

4. Involvement of local services

79% of families had involvement from local services, often multiple services, over the past 2 years. This included two thirds (66%) 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	North West	National
Completely	1%	1%
Very	3%	4%
Moderately	18%	13%
Slightly	22%	24%
Not at all	47%	45%
Not applicable	8%	12%

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

Answer Options	North West	National
Very satisfied	5%	3%
Fairly satisfied	21%	14%
Neither satisfied nor dissatisfied	10%	15%
Fairly dissatisfied	21%	19%
Very dissatisfied	44%	48%

Some explained their experiences of local services.

- 1 *PDA discussed with CAMHS professionals. School placement who are PDA aware and use correct strategies.*
- 2 *The resource provision, my son attends accepts he has PDA and they have been a great help*
- 3 *We have been offered no support with PDA. Had to pay for private assessments. All research has been done by ourselves.*
- 4 *To understand my child better I have had to take it upon myself to research and attend conferences*
- 5 *Not from local services...purely down to my own determination to educate myself to understand and support my child. 35 page private report included SPD / ASD / PDA helped too*
- 6 *Listening to my ex husband about what my daughter may be feeling has helped. Pretty sure he has PDA. He now lives in almost complete isolation*
- 7 *We received a diagnosis in December but have not received any follow up since then but it was useful as we were able to research PDA ourselves.*
- 8 *It's one thing to know that his behaviour stems from anxiety and not having needs met; it's quite another to know how to solve these problems, especially in the school environment where I have no control, little say and next to no information! Frequently feel at loggerheads with teaching staff who think they know best and are patronising.*
- 9 *The only answer was medication without offering other support*
- 10 *It varies from service providers and individuals*
- 11 *I paid for private assessment for my daughter and relied on self-directed learning to understand her needs.*
- 12 *We are still in the process of trying to get him assessed.*
- 13 *A lot has been from us reading up, getting him into a general special needs class and then talking to the teacher*
- 14 *Anxiety workshop slightly helpful. Other offers and things imposed on us unhelpful and harmful*
- 15 *I have found by doing my own research, and doing courses has given me better knowledge.*

16 *Social services asked both my husband and myself to do a third parenting course... even though we were both youth workers. The family worker was unable to engage with my son after a few sessions and discharged him*

5. The Challenges

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

1 *Not being able to help my child and not being able to get people to see behind the behaviour also getting professionals to listen or consider a diagnosis*

2 *Ensuring my other children are not adversely affected by incidents and behaviours. Keeping my marriage together.*

3 *Aggressive, violent and abusive behaviour from my child towards me and the frequent destruction of our home or threats to destroy our home or to kill me or the family dog.*

4 *Continually feeling stressed & on edge.*

5 *Meltdowns. We got him to a specialist autism school class and thought finally other parents would be in the same position but then discovered we were still very different in terms of what he can cope with.*

Seeing how anxious he gets and knowing whether to try and help him cope as best he can with a challenge or let him stay at home all the time as he'd like. Trying to reason with him and understand his ways and reasons for wanting to do things and view of the world.

6 *Discipline. He does not do as asked ever. Control of my life. Bullying of sibling. I can't split these.*

7 *How small your world and that of your family becomes. Relinquishing so much control over your own life and that of siblings. Rarely being able to plan anything. Being unable to do the most simple things such as go to the shop for a pint of milk with him.*

8 *Realising that this condition would not magically go away. Worrying about the future.*

9 *Seeing my child struggle so much and her having to fail at every level before the next stage of support could be put in. Our family has had to get to crisis point before we could access help, It's heart breaking what happened to early intervention*

10 *To date, grappling with an education system that thinks all autistic children are the same and when one doesn't fit using unhelpful labels such as attachment disorder rather than being open to understanding my experiences as a parent and recognising my expertise in my child's behaviours.*

11 *Understanding and perceiving the huge gap between physical age and intelligence and his emotional immaturity, and finding ways to manage behaviour which aren't typical of classical autism or Asperger's syndrome.*

12 *Learning to remove the demand and re-phrasing. Also, learning that a non stressor one day can result in a melt down tomorrow.*

13 *The 10 year wait and threat of removal of children from us by Social Services as they thought I had Munchausens (after 18 months they decided they shouldn't have been involved in the first place).*

- 14 *Being judged by others as an inadequate parent*
- 15 *Difficulties getting our son through the basics of every day i.e eating, getting dressed, going to school, getting ready for bed, sleeping through the night. It wears you down when every aspect of your child's life, every request is a battle.*
- 16 *Proving that my child is not just rude, naughty and defiant & that her 'behaviour' is not down to my parenting... being a single parent, I experience this attitude often / neighbors/school/ shopping etc.*

6. Final comments

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

- 1 *Unless you live with a person with PDA it is very hard to grasp the day to day struggles of both the person with PDA and the family*
- 2 *Just thank you*
- 3 *With the right accommodations our son is thriving, has a good social circle and is learning himself to manage his PDA. I hope this gives hope to others who are where we were a few years ago (school refusal and expressing a wish to die, bleak prospects).*
- 4 *Such an uphill struggle to get the right help for our grandson and advice for careers.*
- 5 *I attended a PDA conference late last year. During an explanation of the new diagnostic for ASD. I asked a question about labels and how they are useful. I mentioned my son has PDA. I got completely belittled and shut down. According to that conference PDA was not a component of ASD. Told my child would not get any help for a PDA profile. I was really sorry I mentioned it. Actually, it made me quite belligerent on the subject I mention it whenever I can now.*
- 6 *Feel that forced into home education due to no support in my area who don't recognise PDA*
- 7 *I believe that I am also autistic and have Demand Avoidance traits. Worked this out due to my daughter's diagnostic journey*
- 8 *We just want to know where and how to get help*
- 9 *This has been a journey of discovery, largely on my own. It's only since referring my child via our go for ADHD that I realised there was more to it.*

When I had talked with the head of the school about my daughters resistance to attending and evening meltdowns I was told (rather oddly I thought) there was no point in having her assessed because there's no funding for a child like mine! Eventually this led me to considering having her assessed (which had never entered my mind before that comment!)

Another experience was one particularly stressful morning for my daughter...she clung on to me at school. A teaching assistant came and physically tried to pull her away from me saying if she didn't go in to school that the police would be called and I (mum) would be taken to jail.

This was the day we deregistered from school I thought with support from the head but when I look back it was actually actively 'encouraged' by the head!

- 10 Professionals don't wish to diagnose PDA as there is little understanding, it's not in ICD 10 or 11. There is next no help following any diagnosis for PDA OR ASC.
- 11 Realising our son has PDA was such a light bulb moment. We spent 2 years banging our heads against the wall asking why he was behaving the way he was in school. Now we know he has PDA school have been using PDA strategies and it is helping a lot
- 12 Local CAMHS recognise demand avoidant behaviour as an inevitable result of high anxiety, so they don't see a need for recognition of PDA as a separate diagnosis and also don't like the name - they are very averse to the 'pathological' bit. I feel that 'pervasive' might be a better name change for getting professionals to accept it, however they don't like any further labelling/categorisation of the autism spectrum at all - the good thing is that they accept that autism is a wide spectrum and each child is different.
- 13 Dreaming of open and honest communication instead of blaming between everyone involved with child knowing the potential fluctuations in behaviour generally and relating to people /environment - that triggers for 'explosive behaviour'
- 14 Trying to get the initial diagnosis and find the right help for our child is difficult.
- 15 I think the fact that we spent a year getting an ASD diagnosis but no one mentions that anxiety, sensory issues and PDA can be linked so we then had to read up and identify both of these as things which affect our son too.
- 16 My son was diagnosed at age 8 with ASD and pathological demand avoidance.

He then got an SPD diagnosed and recently age 14 ADHD. He had the disco assessment done by speech and language and the NHS paediatricians based in Liverpool. The main issues are the lack of knowledge that professionals have, some will not discuss anything to do with PDA it's tough when we have a diagnosed and still we are being challenged. Thank you for your time in reading this and keep up the good work.
- 17 Accessing support is financially very costly. A lack of state services drives us to private provision which is very expensive with little guidance on finding appropriate providers
- 18 CAMHS service and diagnostic pathway in Lancashire is non-existent
- 19 We have been very isolated because of the lack of support and lack of suitable educational provision.
- 20 Biggest issue I find is with school not understanding and putting the right support on as only interested in their academic stats and attendance figures
- 21 For 5 years I have fought for my sons needs at times the frustration I felt was at times too much to bear and was very lonely feeling like no one could see what I could. I sought a private diagnosis done by NHS staff who practiced privately they diagnosed and he scored 21 on the ados which tells a lot about the professionals I have come up against I will be making official complaints as I feel my son as been discriminated against because of me having good knowledge.
- 22 No one understands how hard living with PDA is unless they have done it
- 23 We need to start talking about the assets of these children rather than always focusing on their deficits. For example, their ability to understand others emotions is remarkable as well as their capacity for care and love. Social services were appalling - wanting to blame as was the paediatrician who initially diagnosed attachment disorder which was hugely unhelpful. If we wanted help from social care it came with the risk that this would be interpreted as poor parents. What worries me is what happens when we die? Who will be there to support them? I know that

whilst we are here we can be that support and help my children to develop as many skills as they can to develop resilience and thrive but what happens when we are gone?

- 24 *As a single parent I am under scrutiny all the time, my son abuses me and I have no one offering support even though we have a social worker (which I asked for!)*
- 25 *I can't emphasise enough how much the education system needs to be TAUGHT to embrace these children as currently it is damaging them*
- 26 *Not only have services failed to support my son and I they have frequently added to our stress. For example when I had an emotional breakdown in 2013 and my child was taken into care temporarily social services took me to court to try to take away my parental rights instead of offering help. It caused me to become very ill and placed me under huge strain for over 9 months, I had to undergo psychological evaluation and have several parenting assessments before they finally decided to drop the case.*
- We are again facing massive strain as now the special education team have chosen to cancel all provision for my son leaving me no choice but to begin proceedings to go to SEN tribunal.*
- I think it is disgusting that instead of helping and supporting the so-called professionals constantly place obstacles in the way making it more difficult for us to achieve a normal life.*
- 27 *We have had some really awful experiences with education provision. This has resulted in our very bright 16 year old daughter receiving virtually NO secondary education at all.*
- 28 *At the moment we are coping without help your Web site has given me more help than understanding and I have adapted my parenting which is working I just hope she carries on coping at school*
- 29 *I would like to know more about PDA in siblings of those with autism. I think it is fairly common among families I know even if the child with PDA is not thought to have autism.*
- 30 *People being so judgemental with expectations make life very difficult. My son has had so many negative experiences he refuses to go out & is a recluse at 9 years old with no friends. Health Professionals refuse to acknowledge his diagnosis & no help or support is offered. This affects child & family, with isolation & breakdown of relationships.*
- 31 *If I had one wish it would be that the rest of the world could see the fear in my grandsons eyes when he is fighting them instead of seeing a naughty lad. I wish they would open their eyes and see his strengths and beauty.*
- 32 *My daughter had been the ultimate masker in primary school and then in high school the mask slipped and fell off. Her mental health spiralled and her ability to hold it all in vanished. Having had to get to crisis point every time before we were offered the next level of support. I had to fight of ECHP and specialist provision. I read up attended conferences and training courses to access a greater understand of my daughters needs as i was her voice and her advocate. It's not been easy but the specialist school have been amazing in building up her trust and self-esteem up again, slowly I'm getting my amazing daughter back again. The PDA society has been a life line literally thank you.*

Conclusions

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

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

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

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

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

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

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

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

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

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

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

About the PDA Society

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

www.pdasociety.org.uk

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