



# **Being Misunderstood**

## **Eastern England 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 Eastern England. 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 Eastern England

### 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 60 families from Eastern England.

### 1. Diagnoses

Answer Options	Eastern	National
Yes, given what I feel is a correct diagnosis	37%	32%
Yes, but I feel it is incomplete	18%	22%
Yes, but not one I agree with	0%	3%
Still waiting for a formal diagnosis	18%	14%
Not requested / been offered a formal diagnosis	5%	7%
Other... (shown below)	22%	23%

- 1 *Had private diagnosis for ASD as we'd been on a waiting list for NHS ADOS for over a year - had DISCO & ADOS privately but not specific PDA*
- 2 *Suffolk & Norfolk Health Trusts do not recognise PDA as a condition and despite years of problems my Grandson is still not diagnosed. In Suffolk, Mental Health and Behavioural problems are separate units and therefore I feel that we have been "bounced around" despite repeated requests for help*
- 3 *Being assessed now at an in-patient unit*
- 4 *Was given a woolly diagnosis of sensory processing issues, high level of demand avoidance & need for control, social immaturity and "a number of ASD traits, but not sufficient for a formal diagnosis".*
- 5 *Requested from local authorities over two years ago and still waiting, only an informal diagnosis of autism made whilst still at secondary school but no formal diagnosis or recognition of PDA. PDA and how to cope fits 100%, standard autism with reliance on structure and routine is of no help whatsoever*
- 6 *Waiting to get appointment with CAMHS, looking to get diagnosed.*
- 7 *CAMH refuses to accept it exists*
- 8 *They don't diagnose PDA in Colchester, Essex*
- 9 *The area in which I live refuse to accept PDA as an independent diagnosis. A referral out of area was refused.*
- 10 *Only found out last year no will understand don't think we will ever get help but we now she has PDA*

11 *Had to pay - still ongoing problems - special school is not equipped for him - only the quiet environment*

12 *Yes, but only stating very high demand avoidance as part of ASD. Trying to change this to ASD with PDA as the PDA is most dominant!*

13 *Applying for private assessment*

## 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	Eastern	National
Need to feel in control	92%	96%
Challenging behaviour	92%	89%
Sensory issues	85%	81%
Difficulty with daily routine eg morning / bed...	83%	78%
Severe anxiety	83%	81%

## 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	Eastern	National
Yes, all the time	47%	41%
Regularly	25%	25%
Sometimes	15%	15%
Occasionally	8%	10%
Never	5%	8%

## 4. Involvement of local services

87% of families had involvement from local services, often multiple services, over the past 2 years. This included over half (56%) 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 ineffectiveness of services.

Answer Options	Eastern	National
Completely	2%	1%
Very	3%	4%
Moderately	7%	13%
Slightly	14%	24%
Not at all	64%	45%
Not applicable	10%	12%

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

Answer Options	Eastern	National
Very satisfied	5%	3%
Fairly satisfied	18%	14%
Neither satisfied nor dissatisfied	8%	15%
Fairly dissatisfied	15%	19%
Very dissatisfied	54%	48%

Some explained their experiences of local services.

- 1 *I became so depressed with school & NHS not supporting me and my son's behaviour being put down to bad parenting that I paid privately for a PDA assessment. It got to the point I needed to know if it was him or me with a problem, and if I had damaged him in some way. The assessment lady said to me "if I could do one thing for you it would be to take away all the guilt you are holding. Nothing you could have done would have made a difference". From that point, I stopped trying to make him into a normal child.*
- 2 *Attended a CAMHS 12 week course 4 years ago and was blamed for my daughter's anxiety and she didn't feel understood.*
- 3 *No one will help us.*
- 4 *We are self-taught about PDA after an experienced CBT therapist saw xxx. Information gathered from PDA.org, ASD websites & studies / books. GP very dismissive. We are appalled at the lack of support by the NHS & NHS refusal to recognise private diagnoses. Lack of clear pathway & understanding within NHS (going around in circles, no knowledge of PDA, passing the buck by NHS individual teams due to lack of understanding).*
- 5 *Nothing via local services. Fought for CCG funding for out-of-area referral to Lorna Wing Centre who diagnosed and provided recommendations for support.*
- 7 *His Private diagnosis is NOT accepted and waiting on a complete reassessment by NHS*
- 9 *I am an Occupational therapist the only knowledge I have is what I have learned as a professional.*
- 10 *We've had no help from local services (and not for lack of trying!). The only thing we have found useful is a local charity called ADD-vance which helped us enormously in the early days. Ironically, they receive no funding from the Local Authority and are reliant solely on donations yet they are our best 'local service' - all the local health professionals recommend them!*
- 11 *Local services are practically non-existent (Herts)*
- 12 *not making any difference. My son in school 1.5 hrs a day since October 2018. It is a waiting game to get EHCP completed and await PRU placement. he is only 6!*
- 14 *We don't get any help apart from family support worker. We only get help we can afford privately.*
- 16 *We have had no involvement from professionals other than for diagnosis. We have learnt all we can and adapted our lives to support our son as much as possible.*
- 18 *Getting a diagnosis at the ENC was key - helping me to learn what I needed to do and how I needed to change in order to help my son - also in giving me the determination to fight for what I believed was right for him in school.*

19 *I have had to research everything about PDA, including going on training courses that I can't afford. There is no help out there, you have to accept it or constantly fight to be heard!! (Which is tough when you are a single parent)*

## 5. The challenges

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

1 *Not getting blamed for poor parenting. Lack of support from NHS and schools. No respite as you can't tell by looking at him he has a disability.*

2 *Family and friends don't understand the challenges we face of a daily basis. Our lives are led by our PDA child and everything we do has to be negotiated. If we do manage to get somewhere we often have to come back very soon. Exhausting working with our daughter and school and anyone else as I'm also diagnosed PDA'er!*

3 *The effect on his younger brother who, I feel, never gets the attention he deserves.*

4 *Being accused of fabricating / CP concerns*

5 *The physical violence and destructive behaviour resulting in a complete breakdown in relationships between siblings*

6 *Challenging behaviour that did not fit any form of autism so unaware he was autistic early on and then after informal diagnosis still confused as how to manage anxiety melt downs. Life revolves around what he can and is willing to do and although older and less anxious I am still waiting for a meltdown to occur.*

7 *My son was forced out of education at 7 years old, after 3-4 years of being on a part time timetable. Mostly only managing an hour or two if at all. Local Authority didn't care and ultimately forced me to home educate. They put down elective home education which I fought, won independent complaint which they ignored and I'm still fighting for support 4 years after he was forced out.*

8 *Violence and aggression at home, resulting in some permanent injuries. Severe bullying of her older sister. Very volatile behaviour, very closed in and yet desperate to be accepted and loved but can't show it. Dealing with extreme non-compliance. Complete lack of respect for parents, me as mother especially. Other's reactions and understanding or judgement. Being made to feel a really bad parent by my daughter's junior school. I could go on....*

*Seeing my incredibly talented daughter, especially in music, not cope with demands of practicing and not believing in her own ability with no confidence.*

*Coping with the onset of epilepsy 18 months ago and the impact of her of being out of control, losing her memory and the side effects of medication, and watching her suddenly not coping with life after a hugely positive first year at secondary school.*

9 *No knowing what she had PDA, biggest challenge not knowing what mood she be in day from day.*

10 *Teaching my husband who also has PDA to understand how to deal with our PDA child and not set off a meltdown plus battling with Local Authority & Head teachers/untrained Senco to get my son the correct school support*

11 *Seeing my daughter sad, confused and angry. Seeing the guilt she feels after a meltdown that she can't control and feeling so helpless and guilty because maybe there's something you could have done differently. The lack of respite, schooling and support.*

*Them saying for 9 years it was parenting even though I have 3 other very well behaved happy children until finally a paediatrician realised how well she can mask. Not being able to attend my own health appointments.*

*Being held prisoner in the house. The violence. My youngest son temporarily having to move out with his dad as it was unsafe to live here. Banging my head against a brick wall when no-one would listen. Separating from my partner for 2 years out of our 10 year relationship as i had nothing left to give to anyone as my daughter needed me 24/7, due to lack of respite and school placement.*

*The endless meetings and phone calls and paperwork that get you nowhere. All the empty promises from the local authority. The sheer exhaustion. Being isolated and having no friends. Wondering how you will get through another day battered and bruised and emotionally drained, let alone another 10 years.*

*Looking at all the other parents living normal lives and going on family days out, having happy relationships with their children. Being judged and stared at. Standing in the playground with everyone talking about you and your child because their children are scared of your child yet the local authority don't agree with you that they should be in specialist provision and threaten to fine you daily if you don't send them in so there's nothing you can do about it.*

*Wishing those rare moments when things have gone right and you've judged their moods and demand capability correctly and your child laughs and is happy happened more often. Crying when they don't happen more. Questioning every word that comes out of my mouth to make sure I've worded it correctly to avoid a meltdown.*

## 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 diagnosed ASD (Aspergers) with PDA strategies, I'm 50 with undiagnosed ASD/PDA, my recently bereaved Dad is 82 and also undiagnosed ASD/PDA. Since my Mum died last year and I've got to know my Dad better, it's very clear that he had spent 60 years being shielded by my Mum! I would be really interested to get all 3 of us PDA assessed to see what the pattern is. On talking to my Dad, his Dad was also very similar and his Dad. So, if any research is being done please let me know - my Dad is old but extremely independent and capable and it would be good not to lose the chance of 3 generations being looked at! Thanks*

2 *I am completing this survey on behalf of my Daughter & Grandson. There is huge frustration at a lack of diagnosis (whatever it may be) which would lead to correct management. Problems were first noticed at Primary School and nearly 10 years on, despite jumping through many hoops and endless requests. The difficulties have increased with age and are close to an intolerable level.*

3 *Even with PDA support and provision written into EHCP school ignore it, don't see it as necessary or misunderstand it. Also the general background of sensory/social overwhelm can be too much even though son has own workspace and 1:1.*

*But difficulty complying with traditional learning combined with historical allegations of fabricating/CP concerns plus vindictive LA mean they are likely to hound us if attempt elective*



*HE (which in any case is not what my son wants, he likes school)*

*So we have half school and half autonomous learning at home and in community written in section 1*

*The LA haven't provided any of the sensory equipment or swimming provision it says will be paid for by personal budget.*

*The school ignore the EHCP and me and speak with our son directly asking him leading questions and twisting what he says to suit as a strategy to undermine me. I am continually threatened with prosecution to intimidate me and currently have a case being investigated by the Ombudsman and a formal complaint about to go in front of a governors panel at school.*

*I am unable to work and my husband has had to dramatically reduce his hours to be able to collect our son from school in the car as I don't drive and he can't cope with the walk home.*

*My husband and I both have physical health consequences as well as continuous high stress levels and exhaustion. We are unsupported. We are older parents.*

4 *I wish this was more known and not confused with ODD*

5 *The rollercoaster of PDA.*

*The Ups - The amazing energy when something excites and motivates and engages.*

*The Straights - When there is calm, they're focused and level and mostly on either some Ipad or Xbox or computer or watching their favourite You Tuber or tedious amounts of Minecraft!*

*The Downs - They are quick, impulsive and explosive. The firework that misfires, static electricity, kinetic energy refusing to go back into its bottle.*

*The Experience - It's never dull, it pushes you to your limits physically and emotionally. Questioning is this my journey? Is this the best our life can be?*

*The Overall Review and Rating - He is my child, my beloved son, the babe I carried and the boy I wish so much for, my love for all the peaks and troughs is regardless, but that's not the same as do I always like my child? No I don't, the times he spits in my face, or he bites me so hard he draws blood. The times I'm surrounded by broken glass, another TV smashed or how broken he makes me feel. Those times are just moments in a journey that encompass so much more. I will NOT give up! I WILL be his best advocate. My funny, at times loving and so full of crazy ideas little man.*

*I KNOW my child and wherever this rollercoaster takes us I am on the ride, I have to confess I'm not sure many people would pay to join me on this same ride.....*

*But I know there are plenty out there riding the same ride with more ups and downs. Thankfully for Social Media we are able to share our journeys, offer cyber support and form networks that help us think that we, are a little less crazy than we thought.*

*By the way the "Ride" is called PDA Pathological Demand Avoidance. And whilst it may not be the ride of choice for everyone it DOES need promoting, awareness for those on it and living with it. In life Rollercoasters encourage screams, right now together we need to raise our voices and share the Challenges of having a child living with PDA*

*Get PDA accepted by consultants and professionals and all schools and politicians.*

*How would I rate this ride? Challenging. But if you can hold on for the downs whilst keeping your calm, the ups will always energise you for what is to come. Hold on tight, take a breath and keep moving forward.*



- 7 *It is frustrating that my child's emotional outbursts were regulated until CAMHS insisted that the risperidone be removed. She says that she would rather live 5 years less and be happy than without risperidone! No one listens....*
- 8 *Life is tough but I have made the bestest friends from shared experiences. There is nothing like finding someone else who shares your experiences. We can even laugh about the difficulties we experience!!*
- 9 *PDA can be managed if you understand the condition so the more publicity and recognition the better...keep up the good work you are doing.*
- 10 *I've been told Norfolk (where I am) is behind and therefore doesn't yet recognise PDA as a thing yet so I will have to wait or go private for diagnosis*
- 11 *I am interested to learn more about pads to help my daughter and make other people aware of it.*
- 12 *Much more support is needed for this condition and recognition. Disgusted by CAMH pushing us out the door practically after he left education. I dread to think what happens in a crisis with him suppose I have to cope. Can't claim PIP for him as he won't cope with interview etc. no income to help whatsoever as no tax credit available after he quit his apprentice course due to a bullying boss. Job application waste of time too as only 17.*
- Nobody wants him and yet he's so clever and funny and knows how to behave in public but not given a chance with his low exam results due to his anxiety.*
- 13 *We, parents of PDA children need more help from professionals. Our children need more help as well. Children with mental health issues need more help!*
- 14 *I long for much greater understanding and acceptance of PDA among medical and educational personnel. For support and help with the family and support for the individual. Living with daily violence is so hard and has had a major effect on my health and family relationships.*
- 15 *Think most know it as it's on my blog ;)*
- 16 *I have only come across PDA recently as I avoided labels - I sent the profile out to my son's advocate, social worker and my close family for their opinion and it was a clear unanimous of my son fitting this profile.*
- I have other children including another ASD - the lack of support and understanding we have endured as made all our lives unbearable at times with my son going into care at 16( absolutely awful ) I cannot stress enough the impact this has had on all our lives and I am writing a book detailing the many experiences so parents do not give up ( we are all our kids have ) and to bring into the public domain how much of this is a societal issue , an issue that can be worked with and solved ( I'm also setting up a project for those on the spectrum - to get them into work and redo what education couldn't and offer them a life, hope and a way forward )*
- The criminal justice system is a joke and do is care ( won't go into education and that was special*
- School settings ) we did what we could do to change things but it could have gone so much further hence my book and project*
- These young people have so much to give and deserve so much better as we as parents and Carers*
- 17 *Got no money to go private, can't talk to any one we just bad mum and dad.*

18 *I am one of three trustees who run SENSational Families. We try and help support parents in Norfolk who have a child with a disability.*

*I hear all the time about how many people are suffering due to their child having PDA. Norfolk refuses to recognise it and therefore there is no support. Way too many children are being excluded from school and way too many are school refusing due to no understanding at school. My son school refused for 6 months.*

*We paid and went privately and where very lucky to see xxx. We are now paying to see someone else privately due to the fact that Charlie's anxiety is massively effecting his life and he isn't managing to access school fully (4 mornings a week and that's at a specialist ASD school). We cannot see point one or CAMHS because they won't see us. So many children and their families are being let down.*

*Keep fighting and doing what you are doing!!!!*

19 *I wish we could understand why he does what he does more. What is going on in his brain. What fires or doesn't to cause the reactions and explosive behaviour.*

20 *Although told my son presents as PDA not diagnosed just on ASD spectrum which covers PDA*

21 *I run a small group to support families with a child with PDA. It is extremely sad that there are so many families that are struggling with extreme behaviour and it is not recognised by professionals*

*Since using different strategies we have regained some balance at home alongside an appropriate school. Life if difficult but better than it was.*

*It is essential that the profile is recognised as it's vital for the child and carers to know what their difficulties are*

22 *The experience we have had with schools, authorities, other parents has left us both scarred, my son was unbelieved, (as was I) mistreated, and totally unsupported. Yes, he joined a few circle round the table - small groups and very little 121 - but not for long! It has left me seriously depressed and made my son's anxiety 100 times worse. It's a constant draining battle AGAINST THE AUTHORITIES - It's a nightmare you can't escape from!!!*

23 *We have been treated extremely bad over the three years of getting a diagnosis, we have had lost paperwork so had to start from beginning, a year later, new paediatrician threatens my daughter with police for hitting so made her hate "Humans".*

*I was told that my daughter should be loved not labelled. We have been spoken down to, I have been judged and blamed. I am totally disgusted that we have had to go through this to get the correct help for my daughter to have a positive future. Although my daughter had other diagnosed conditions since she was six, we were never told that we could have been helped financially (DLA) so have struggled on our own.*

*Things have got to change, not only more services but they must be more willing to share their information so people like ourselves have an easier time getting diagnosed and the correct help. I feel angry and bitter about the whole process, I feel that the NHS stole three years of quality family time from us and we can never get it back!!!*

24 *The Facebook support group has been an absolute life saver for us. It has made us realise that we were experiencing more than the health professionals and teachers were making out. It has given us the strength to continue to give our daughter the skills to manage life, even if she doesn't get support in the future.*

## Conclusions

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

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 largely 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.

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### 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](http://www.pdasociety.org.uk)

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