



# **Being Misunderstood**

## **North East, Yorkshire and Humberside 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 East, Yorkshire and Humberside. 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 North East, Yorkshire and Humberside

## 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 112 families from the North East, Yorkshire and Humberside (NEYH).

## 1. Diagnoses

Answer Options	NEYH	National
Yes, given what I feel is a correct diagnosis	32%	32%
Yes, but I feel it is incomplete	17%	22%
Yes, but not one I agree with	4%	3%
Still waiting for a formal diagnosis	19%	14%
Not requested / been offered a formal diagnosis	7%	7%
Other... (shown below)	21%	23%

1 *Have official diagnosis but had to pay privately*

2 *Yes, but it is officially ASC "with PDA traits". Also recognised as having ADHD, but not officially diagnosed.*

3 *Not recognised as a separate diagnosis in my area*

4 *we have an asd with pda profile diagnosis now but collected quite a few others incorrectly historically*

5 *Been diagnosed as sensory overload but being referred for ASD assessment.*

6 *Diagnosed asd but because pda not recognised Northumberland it is on his care plan he shows many traits*

7 *They wouldn't diagnose PDA as he hasn't got the relevant autistic traits!*

8 *Would like a diagnosis but they local authority does not fund pda assessments*

9 *Got close to a diagnosis but she wouldn't carry on seeing the professionals*

10 *Not diagnosed, consulted with psychologist and psychologist agreed that child met the criteria for further assessments (ASD) but child refused further assessment.*

11 *ASD diagnosis but when observed for EHCP the educational psychologist agreed that he has strong pda traits*

12 *told lots of autistic traits but too many strengths for autistic diagnosis told behaviour best fits into pda*

13 *Still trying to convince CAMHS to carry out assessment - they say he clearly has anxiety and some ASD traits.*

- 14 *We have Aspergers diagnosis with demand avoidant traits from camhs*
- 15 *Asd diagnosis with pda traits as local area do not diagnose pda*
- 16 *Diagnosis of ASD only. High functioning/Aspergers/PDA not taken into account*
- 17 *Given 'atypical ASD with demand avoidance'. Hoping for a PDA diagnosis next review.*
- 18 *Not able to get a diagnosis as he refuses to comply.*

## 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	NEYH	National
Need to feel in control	95%	96%
Challenging behaviour	90%	89%
Sensory Issues	81%	91%
Severe Anxiety	80%	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	NEYH	National
Yes, all the time	34%	41%
Regularly	31%	25%
Sometimes	17%	15%
Occasionally	8%	10%
Never	9%	8%

## 4. Involvement of local services

87% of families had involvement from local services, often multiple services, over the past 2 years. This included 69% 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 general ineffectiveness of services.

Answer Options	NEYH	National
Completely	1%	1%
Very	3%	4%
Moderately	14%	13%
Slightly	19%	24%
Not at all	55%	45%
Not applicable	8%	12%

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

Answer Options	NEYH	National
Very satisfied	1%	3%
Fairly satisfied	14%	14%
Neither satisfied nor dissatisfied	18%	15%
Fairly dissatisfied	18%	19%
Very dissatisfied	49%	48%

Some explained their experiences of local services.

- 1 *Attends a weekly group ran by prevention which although it is not specifically for ASD it provides really good support for my child for her to have someone to talk and also support for us as a family.*

*Otherwise we get no help and CAMHS refused to assess*

- 2 *ADHD meds reviews are the only semi-regular involvement with camhs. Family support worker admits she's out of her depth. No help with asd issues other than through voluntary sector. Intensive mental health team refuse to get involved in my son's care even after 2 suicide attempts. Can't get an EHCP. Been forced into home ed which isn't helping his mental health or academic achievements. Starting OT this week but at same camhs that don't recognise PDA.*

- 3 *Basic workshop in asd then left to get on with it, no follow up, told it's up to Education services to support.*

- 4 *Everyone has relied on us to advise them, no consistent input to help him*

- 5 *Seeing the psychotherapist at CAMHS seems to be good for him*

- 6 *I learned myself how to deal with autism and pda not one person has gave me any information or suggestions just school meetings over behaviour and my other child is a star pupil so they know now its not my parenting i believe i also have undiagnosed pda at 31 but doncaster services are ridiculous ive had respite stay due to a meltdown from lack of help from services*

- 7 *see above question. Our experience of local services/support for child mental health has been that it is unhelpful, wasteful, ignorant, and professionally arrogant - in short, disgraceful. I should not have had to diagnose my daughter myself, and then seek professional assessment privately. No health service worth the name should be allowed to refuse to even assess someone with clear health problems.*

- 8 *We eventually got excellent support post private assessments and an ehc plan from a camhs psychotherapist who specialises in anxiety and autism. She taught him about himself. Positives as well as negatives. Got him a psychiatrist and medication. Refused to allow him to avoid her. Created a strong therapeutic relationship. Sort of looked at modified cbt concepts loosely and exposure therapy a bit...My son now says he understands himself and PDA...I think he might have taught her about PDA too as he was clear he was autistic but wasn't sure the asperger boys he knows are on the spectrum...*

- 9 *FAST we're doing some good work with her but closed due to funding. CAHMS have put her on anxiety CBT sessions which have had no benefit.*

10 CAMHS input several years ago was damaging and upsetting to us all. MAST was just pointless. It is all about keeping tabs on the family rather than genuine support or listening.

11 We have had to employ a specialist solicitor 3 times and pay for private diagnoses and reports in order to get respite at school, a special school, respite at home etc.... Camhs are STILL not able to give us the specialist support she needs and we have been trying to get this for her for 8 years.

12 His keyworker at school is very good at supporting my son to develop better coping strategies

13 No one seems to know about or understand pda

14 Stars workshops each month in Leeds have been very good

15 North East Autism Society recognise the PDA profile but mental health services & social services do not.

16 We have not had any help from local services other than the LA with EHCP.

17 On receipt of an autism diagnosis you get put on a waiting list to be seen by the local autism service - normally they observe children in school - i fought for them to visit her at home. 2 visits have made a big difference - she communicated via a Talking Mat on several topics.

I found a private specialist autism counsellor and my daughter can talk to her - she is so far controlling the sessions and will not talk strategies however she has found her voice and is building a trusting relationship.

18 Not had any. Luckily, I'm a primary school teacher and I have adequate training in my professional capacity.

19 CAMHS are not fit for purpose and have let us down 3 times.

The specialist STARS autism team were good. The private psychologist who diagnosed had good understanding of my son but didn't tell me anything I didn't already know.

20 more or less told to carry on as i am have done a lot of research myself

21 CAMHS are worse than useless. Clearly I wasn't listened to as the report stated my daughter's behaviour improved when I was stricter in fact I had said the opposite that her behaviour improved with a more flexible approach. He also asked my daughter repeatedly to 'draw her anger' what would it look like. She could not understand what was being asked of her and I felt this would be quite telling for someone who understands ASD. No mention of her difficulties in doing this in the useless report either.

Was told by another CAMHS professional that PDA doesn't exist, 'you can group any behaviours and call it something if you want '.

22 Not had much support to be honest, it was clinical Psychologist who mentioned my daughter scored high in demand avoidance

23 He's in a school on advice from Phil Christie, doing so much better than he was but still not great.

24 No, because I know far more about PDA than they do. They have tried their best though.

25 We were referred to CAMHS for potential eating disorder, self harm and violent/challenging behaviour (VCB) at parental request via GP

We had 3 initial screener appointments, 1 with our daughter. We were then discharged. Partly

*because our child made it clear they did not want to 'engage' with CAMHS*

*There was no mention of support for the self harm or VCB. They did not refer us to eating disorder clinic because the treatment for anorexia was enforced eating 6 meals a day which wouldn't work for PDA (private diagnosis).*

*We were discharged with NO help support or advice for either problem and left to cope alone.*

*School SENCo does not believe in PDA and accused us of having her diagnosed 'on my say so' (because that's how a private ASD assessment works of course!). SENCo provided no help or support within school for our daughter, even after our autism outreach service had been involved. The autism outreach service gave us permission for our daughter to start school slightly late each day, which did help. When Social Care (who also had no clue about ASD or PDA) became involved, school blamed us for not being able to get her to school, even though her attendance was massively improved after being allowed to start school 20 mins late.*

- 26 *I've had to do all my own research on how to cope the pda page has been massive help so have learned some good strategies to help but always ticking time bomb with my son have to give him choice about everything so he feels in control the control thing is really hard to deal with*
- 27 *I have had to learn to manage my son on my own as people seem to like to repeat everything they have read in a book*
- 28 *We are paying for private support that is specific for demand avoidance issues.*
- 29 *I understand my child completely it's s getting the help he needs that is the problem*
- 30 *I have had to research entirely independently of any professional involvement as school had decided it was a parenting issue and weren't able to consider any other possibility and camhs had their hands tied by my daughters 'unwillingness' to engage with any therapies*
- 31 *I have found everything out through asking a clinical psychologist friend and extensive research. Our strategies are very much made up by us.*
- 32 *Any PDA support / information has been from contact between the PDA Society and their support groups, and us as parents. Google / Facebook have been more useful than so called healthcare & education professionals.*
- 33 *Help from paediatrician has been very supportive, also had cygnet and sensory courses ect those have been most beneficial and OT to some extent around sensory issues but feel she didn't understand / believe the pda side and didn't get true reflection of my child's struggles*
- 34 *Not applicable as had to go private as all services kept saying was my child is very complex*
- 35 *Whilst the Clinical Psychologist was very helpful and listened, putting the right strategies in place, she felt she knew about the same amount as I did, and was learning along the way herself.*
- 36 *Our local services do not formally recognise PDA, although their staff ask many questions about demand avoidance issues, but then focus on other elements including attachment issues and poor parenting.*
- 37 *Child refused to go or to talk to them*

## 5. The Challenges

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

- 1 *No one understands*
- 2 *It never stops, you are constantly walking on egg shells and trying to determine and avoid any potential next issues or problems, like having a 2 year old toddler for 13 year. However the more recent violence towards me now he's big makes me very fearful and anxiety higher than normal.*
- 3 *It has taken away any sense of enjoyment of being a parent even to my other children without PDA. Our family lives under a cloud. Suicide attempts, running away, police involvement, arguments, stress, feeling let down and feeling at breaking point, have become normal. It is exhausting and depressing with little light at the end of the tunnel.*
- 4 *Seeing them struggle and others being blind to it.*
- 5 *Learning how to rephrase demands to make them not seem like a demand. Not coping well when she was younger.*
- 6 *My whole life has changed. I am stressed constantly and no longer have any patience or tolerance for anybody other than my children. My marriage has broke down and I have no friends. I don't even get any support from my family*
- 7 *Lack of awareness by others. People judging and thinking your child is naughty. Lack of understanding by professionals. No adequate training available. No schools specifically for children with PDA. Lack of support for parents & siblings. Everyday in our house is a challenge.*
- 8 *Dealing with the violence; and watching our child be so unhappy and feeling unable to help*
- 9 *Local Authority and schools, getting them to see that it wasn't bad parenting. Others judging us and our daughter.*
- 10 *CAMHS don't accept it exists do can't offer the appropriate advice understanding or strategies that best support, flexible, indirect/suggestive approaches to demands and ways to deal with reducing anxiety. The biggest help has been autism and PDA Facebook groups and activities. My son is violent and verbally very challenging at times it impact on normal family activities for us all. Lack of regular respite has been an issue we had to fight to get it and it is not a huge amount. I am fed up of this life it is a daily struggle and I feel sorry for my other child. My marriage is ruined by the stress of living with our son and we are both on anti depressants. When he was 6 I felt suicidal as no one understood what we were going through and I started to self harm by scratching my arms.*
- 11 *Everyday Life. Ensuring he is happy and safe. Supporting him when he experiences little difficulties through talking daily with our 'private talks'. Helping him with his learning everyday to ensure he stays in mainstream school and achieves his full potential. Not losing our sense of humour along the way.*
- 12 *Accessing the right education setting that understands the complex profile, keeping relationships together under the strain*
- 13 *Identifying what is wrong with her, with no idea for 4 years, nobody willing to assess her (and indeed CAMHS cancelling an appointment with a consultant), and nobody providing meaningful support.*
- 14 *Arguing and fighting for help and for someone to accept pda exists*



15 Stopping school restraining the child (92 occasions in three months) when displaying anxiety traits.

## 6. Final comments

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

- 1 *There needs to be a national acceptance and not a postcode lottery my LA North Yorkshire still does not accept PDA better care to help manage the mental health effects such as anxiety and accept the serious of it*
- 2 *Camhs will diagnose a limited amount of conditions and provide no therapy at the time of diagnosis. Limited therapy is available when you reach crisis point. Advice and help can vary from reasonable to appalling especially in light of suicidal ideation. Social services have no resources or understanding. Schools are failing these kids and their families. There is nowhere for these kids to go for appropriate help and education. If camhs won't acknowledge PDA, they continue to advise all services to apply strategies that we all know don't work. How counter productive is that?*
- 3 *My knowledge on PDA is from what I've educated myself on through websites & actually living with it. I believe when a child as a formal diagnosis of autism I feel a pda investigation should also be done. Cahms say her pda is part of the autism trait n offer no help, support nothing just kind words to dry my tears. PDA should acknowledged more like autism is.*
- 4 *I feel a bit of a fraud as we don't have any diagnosis of anything at this point, I just know mother has been working.*
- 5 *Local provision and the local authority have let our son down hugely, we have struggled to find a school setting and have had to go out of authority to find this. CAMHS service not fit for purpose and not enough knowledge in the local authority about PDA*
- 6 *My sons been treat like a prisoner in school been attacked by teachers swore at by them because he cant help his anxiety he's been failed by his last school who laughed when i said asd i can't begin to explain half but he's currently involved in assessments but hes down as asd only as of now the senco in his school is failing him badly she refuses pda is a thing and wont listen n will only try autistic strategies this is a better school than the last i dont want to move him again but from nursery hes not been excluded no less than 7x per year at least more some years*
- 7 *The hardest thing for me at the beginning for me in my PDA journey was that CYPS do not recognise PDA and initially having professionals insinuate I was making this up and that I was the cause of her anxiety. I have the classic highly intelligent masking girl with no early indications or delayed development. Her father also didn't believe she had PDA to begin with so I was also battling him, this played a major part in the breakdown of our relationship. PDA needs to be recognised by EVERY health authority. I read the same story on closed Facebook pages over and over again.*  
  
*For me realising my child had PDA was a relief; it meant I wasn't a bad parent and she wasn't a naughty child. Modifying my parenting style and using PDA techniques has made a huge improvement, life is still very difficult but much improved now I know so much about PDA.*
- 8 *It's totally hitting your head against a brick wall - he doesn't tick conventional boxes so is just tossed aside by professionals. I contacted CAHMS again last week after school raising issues - I have yet to receive even an acknowledgement from them.*
- 9 *Thank you to the PDA Society for all you do*

- 10 *I believe if my child had got the proper help when I first requested it we would not have suffered the trauma we have x*
- 11 *thanks for all you do to raise awareness of PDA*
- 12 *My daughter currently goes to a special school for children with moderate learning difficulties and with complex challenging behaviour. She has an EHCP and is currently banded 4/5 which is maximum she can have, we are told. Astonishingly her current teachers at her special school involved their unions and all bar one teacher voted against teaching my daughter because of her extreme behaviours associated with her disability. A disability which was documented and known before they accepted her. There is no other suitable school in the local authority. We are currently at month 6 of a very long battle to get her into an independent special school. We intend to peruse a complaint of disability discrimination regarding the school and hopefully name and shame the school involved.*
- 13 *I just wish the professionals would listen more to parents. We live with our children everyday, the professionals see a snap shot and make judgments upon that. They are more concerned about putting us on parenting courses (which run during the daytime, no good for us that work) and making us feel inadequate. They also forget that girls present differently.*
- 14 *My daughter was accepted for initial testing for asd whilst we lived in west yorkshire (aged 4) however when we moved to east yorks they refused to do this stating they dont usually begin testing until a childs 7yrs*
- 15 *Meaningful advocacy has been missing for my daughter for years. This has impacted on every aspect of her life and meant that people who have never met her, nor understand her have set unrealistic goals for her. She is now broken and her life chances are heavily reduced. As a consequence of permanently being out of school, only one of us can work and this has caused a lot of pressure, debt and worry in supporting our family of 5. Siblings are heavily impacted on.*
- 16 *As my child is a young age (3) it has only been the last couple of months that professionals seem to be taking any notice of anything I tell them. Before this we were told it was parenting and bad behaviour issues and sent on numerous parenting courses with techniques that of course only increased issues, all trainers on the courses after hearing about our daily life and issues agreed that they did not believe it was a behaviour issue. Very soul destroying as a parent being made to think your parenting and actions are to blame for how distressed your young child is and dangerous behaviour such as injuring their siblings. The answer "She's only 2" is the most frustrating phrase I have had to hear over and over again.*
- 17 *With a child who masks well at school would like officials to observe at home regular to see for themselves our way of life and the difficulties we face daily*
- 18 *I think a huge problem is lack of societal understanding. As people are more aware of the word 'autism' it almost seems to be like 'Oh yes I've heard of that' and the real meaning is minimised. P DA looks like a badly parented child. As a carer you give up so much to take on this challenge that carries a stigma not the support you need.*
- 19 *More local courses made available please.*
- 20 *I have no energy left the fight has taken 7 years to diagnosis and we often feel controlled and trapped by his behaviours as the world has to revolve around what he needs. His ADHD adds more complexity to it as I am on guard as he runs off, has no safety awareness, harms members of the public particularly overpowers young children. We face looks and discrimination everywhere we go, we can't sit in a cafe or go in a plane, we can't sit and watch our kids play on holiday as he runs off and we are in high alert about his behaviours. I don't enjoy life anymore and feel my other son has a huge amount to put up with. I am seriously thinking him and is would manage better if he was in a residential school but it fills me with a heart wrenching sadness for him.*

*I think about all of this every minute of every day and it makes me want to runaway with my other son and have a better life without him. We need much more help than we have shouted from the roof tops to get. The sad thing was a social worker told me there are no resources for anyone you only got care because you k is the law. I said yes I bloody well do! What a prick!*

21 *We only came across PDA last summer - it was a light bulb moment. We wished we had the information sooner.*

22 *Sheer luck it seems hot us a dx and CAMHS support in Lincolnshire. We actually had the same CAMHS worker for many years, who my daughter engaged with really well*

23 *Personally it took about three years to accept the diagnosis and with lots of reading we came out winning. My child is unique and very special, however not all are in agreement and as a result we keep ourselves to ourselves. Thank you for presenting surveys about PDA to help others.*

24 *How many of us are at home? How many of our children wish to be in school and cannot be because adaptations cannot be met? How many lose their benefit at reassessment because MH issues and demand avoidance is not seen? Where is the career path communicated to those with mental health issues? The NHS service has no sensory qualified OTs therefore sensory if is not complete - private assessments are costly - can the ASC charities work together with the COT to re-instate sensory qualified OTs on the NHS.*

*My daughters agoraphobia has largely been contributed to the sensory issues. It has taken us a long time at home and a lot of research ourselves to help her. Recovery time - she needs a lot of recovery time - why don't health professionals understand the extent of this? I would like to see the PDA society do more to raise the profile. If we have to attend Tribunal I do not think i can do it - I have no funds for private assessments and attendees, I just cannot take it one - this will affect my daughters school place - I used to have a responsible job but my own coping strategies are severely diminished.*

*I have nt mentioned aggression in this survey - sad my daughter was aggressive every day at home throughout primary school and now lashes out infrequently based at home, however she internalises a lot of her anger and it affects her badly. I have been hurt a lot by my daughter and at one point felt I could not cope with her (that was my saddest and lowest point). There was no help. CAMHS sat back as she tried to re-engage with school after a breakdown and watched her slip into a second one - that is when we stopped her going to school - they are the most cold hearted unprofessional service I have ever encountered. Her self harm was seen as superficial. Her lack of eating was overlooked. All through primary when she did not sleep it was overlooked. CAMHS do not understand the sensory differences - they are useless - the NAS Make It Stop video was spot on - CAMHS dismissed her problems as being on the autism spectrum.*

*Primary school badly let her down and reported "she is Ok in school" - her mental health was very poor and she had a breakdown in Y7. She has cut herself off socially and has kept in touch with one single person - her whole life she has been obsessively sociable - this is a big change. Since breakdown she is a very different person and we are supporting her to be her true self.*

25 *I just feel so lost in trying to get support for her. I feel I am massively letting her down.*

26 *My children have been subject to two child protection plans. My eldest son is in residential care for adults with mental health disorders (he is 18 and has AS). My husband and I have separated and I have had to give up working outside the home. The behaviour of my son with (possible) PDA has been a significant factors in this.*

27 *There needs to be support for the family as a whole. I am not talking about the Prevension service who are a waste of time and money.*

28 *I would really welcome a PDA diagnosis in the future. The strategies are so different to ASD and think it would be really helpful for him to have an accurate diagnosis.*

29 *I had to move 450 miles in order to get my son in a suitable school. PDA was not recognised in Cornwall so we went to Norsaca for our diagnosis. It changed our lives.*

30 *We are now trying to get my 14yr old granddaughter a diagnosis*

31 *CAMHS in Leeds is not fit for purpose when it comes to understanding and supporting children with autism.*

*If I hadn't fought for my son he would just have been considered another naughty child, thankfully I had the support of a good Senco but wasn't enough and he currently not in education although officially still on school roll. There is a lack of provision for academically able children who can't cope with mainstream school.*

32 *It shouldn't be this hard to get support from services and schools, life with PDA is hard enough without unknowledgeable people making it harder.*

*Thank you for all the hard work you do supporting and raising awareness.*

33 *professionals need to understand pda can happen without an autistic diagnosis and there needs to be more leeway with assessments*

34 *Too many 'professionals' fail to recognise parental expertise and experience. Not enough respite or childcare to suit PDA personalities.*

35 *Child missed diagnosis of asd 3 years ago , thought things would get easier if anything got a lot more harder and struggle on ,*

36 *the best thing we ever done was get assessed at the Elizabeth Newson centre!! 10 year of hell before that, however now is a bearable type of hell*

37 *I wish people would stop using the same tired strategies from their "cookbooks" when our child needs a fully individualised approach teaching him the logical and rational basis for the things he has to do.*

38 *We've had ehcp refused twice because she is clever and scraping through her grades and they say school should support her so still fighting for her ehcp she has been massively failed by the education system since year 4 and no one will take accountability for it*

39 *We are exhausted. Despite complaining about lack of support and services to CCG, MP, Leeds City Council, PALS - nothing has been offered our daughter except ADOS waiting list (12 months): restraint training for us and melatonin which she can't/won't take. She has not been able to attend school at all since September 2017. She is unable (due to anxiety) to go to appointments etc and has just been abandoned. We are paying privately for ADOS/PDA assessment at Help 4 Psychology in Norfolk in May. We will then start going down EHCP route. Not that I'm holding my breath...*

40 *PDA is not recognised in kirklees*

41 *I just hope it can be recognised all over the country, and better understanding that it's not bad parenting the child needs control we need to teach a less direct form of parenting and shouldn't be critical to parents who have to parent in such away*

42 *Professionals not listening, taking experiences seriously, feel like were doing this alone, been made to feel like issues are attachment (I'm a health visitor and acutely aware of what this entails) feel like we're living in a black hole with no means of escape most of the time, planning to give up my role as HV as no emotional capacity to deal with issues outside my home.*

*Thank you for listening.*

43 *I think its just so difficult for people to understand what life is like. My daughter masks in most places apart from in the home.*

*The lack of advice/help from professionals has been draining. Its been the support from other parents via facebook that has been the most helpful.*

44 *The whole assessment process is confusing and seems to be designed to steer parents to pay privately as much as it can.*

45 *I would but I honestly don't have time right now. I'm not at conference as I have work and then a wedding that weekend. Too much. Thank you for doing this. Am sure my boy will be well away from the system once anything is done but I love that you guys are trying and those coming behind us will have help and choices xxx*

46 *We've fought at FtT, UT, now at stage 3 social care complaint. LA is biggest barrier. Lack of ed support has huge knock on consequences outside education. We feel isolated, trapped in debt, relationship rocky, both depressed...but saddest thing is our nearly 15yo daughter who has had no secondary education, lost progress, will not achieve any GCSE's now and is suicidal hardly leaving her room. 5 years of fighting to get the right support has left her like this.*

47 *Education & how it still has the ability to exclude children for behaviours related to their disability is a disgrace. Ofsted are indifferent to off rolling SEND kids. DfE are turning a blind eye. Local authorities are routinely failing PDA kids & parents are being left to pick up the pieces.*

48 *A big thank you for the work you do, and especially to the person running the Twitter handle for being kind and supportive.*

49 *Lack of knowledge of PDA is putting children into crisis, leading to schools self diagnosing and causing injury and stress due to over restraint.*

50 *Caring for a child with PDA is completely draining and there is no relief. Simple issues trigger anxiety attacks which results in behavioural meltdowns of the like I have never seen before. Few people in the non-PDA world understand and think you are inventing events.*

## Conclusions

This report illustrates the experiences of those with a PDA profile of ASD who are living in the North East, Yorkshire and Humberside.

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 generally 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)

Registered charity no: 1165038

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