



Being Misunderstood

Wales 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 Wales. 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 Wales

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 40 families from Wales.

1. Diagnoses

Answer Options	Wales	National
Yes, given what I feel is a correct diagnosis	25%	32%
Yes, but I feel it is incomplete	30%	22%
Yes, but not one I agree with	0%	3%
Still waiting for a formal diagnosis	20%	14%
Not requested / been offered a formal diagnosis	7.50%	7%
Other... (shown below)	17.50%	23%

- 1 Went Private
- 2 Asked CAMHS for a diagnosis, they refused
- 3 ASD with demand avoidance traits
- 4 Not severe enough for Educational psychologists to do the initial assessment
- 5 Was dx GDD at 2 have fought and fought to get ASD assessment and she's 10 in Nov and clearly not got GDD now
- 6 Private dx of PDA as the ASD dx did not get the correct support
- 7 No. CAMHS and Ed Psych have stated their agreement with PDA but local health Board ASD team refuse to assess.

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	Wales	National
Need to feel in control	98%	96%
Challenging behaviour	88%	89%
Severe Anxiety	93%	81%
Sensory Issues	80%	91%
Difficulty with daily routine e.g. morning / bed	80%	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	Wales	National
Yes, all the time	46%	41%
Regularly	33%	25%
Sometimes	18%	15%
Occasionally	0%	10%
Never	3%	8%

4. Involvement of Local Services

83% of families had involvement from local services, often multiple services, over the past 2 years. This included almost two thirds (64%) 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 almost complete ineffectiveness of services.

Answer Options	Wales	National
Completely	0%	1%
Very	0%	4%
Moderately	10%	13%
Slightly	13%	24%
Not at all	55%	45%
Not applicable	23%	12%

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

Answer Options	Wales	National
Very satisfied	0%	3%
Fairly satisfied	8%	14%
Neither satisfied nor dissatisfied	13%	15%
Fairly dissatisfied	16%	19%
Very dissatisfied	62%	48%

Some explained their experiences of local services.

- 1 *I've done all my own research and educated the majority of them. They are aware of PDA but struggle to get what it means in practice to support someone who has it*
- 2 *CAHMS have only seen him due to the anxiety will not look or read up about pda so no understanding. Going to end with CAHMS as we can only access 2 service at a time.*
- 3 *SSD and CAMHS support has made little or no difference. In terms of outcomes, they have compounded matters. There is a complete lack of awareness/understanding by both agencies of PDA.*
- 4 *The O.T. was just an hour of demands and I really do not want to take my son back but feel If I don't I will told I am 'refusing help'.*

- 5 I'm self-taught and am teacher those who have contact with my daughter.
- 6 Our son is adopted and this is clearly an inherited condition. It has been a very long rocky road for us and him. I have fought for him every inch of the way but having been thrown out of college due to violent bullying behaviour he ran off to spend a weekend with his girlfriend and her mother who live on benefit and we have not seen him since apart from a weekend visit in July. We only hear from him if he wants money. (He receives a small DWP benefit weekly). Shortly after he left I became seriously ill with kidney disease(Nephrososis) and have been receiving Chemo and steroid treatment ever since. It is my belief that the difficulties that we have experienced over the years particularly recently have contributed to my ill health.
- 7 As she is so compliant in school and rarely spoke nobody was to bothered as she caused them no problems until he went into the sencos class the senco saw things immediately and gathered evidence for me to pass on other an ASD assessment
- 8 CAMHS told me that PDA does not exist so I had to pay £1000 for a private assessment, which found that she does indeed have PDA.
- 9 Apart from a book for newly diagnosed children (we had been waiting for 3 1/2 years by that point) we have been offered no services or support.
- 10 I have received absolutely no help

5. The Challenges

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

- 1 How our son is unable to engage with school and finds it difficult to join in with family activities etc. Whilst in school he displayed self-injurious behaviour which was heart breaking.
- 2 Getting health authorities to help. We are still at square one after 5 years.
- 3 Existing as a separate entity... I have lost myself in the all-consuming task of supporting and caring for him. Trying to maintain good mental emotional physical and spiritual health whilst having demands imposed on you is a challenge that I initially couldn't master. Getting support is an equal challenge a day is further draining on your resources
- 4 Isolated, No support from family / friends as moved For husbands work. Problems with sibling no support
- 5 Getting services to understand Autism/recognise PDA and the chronic underlying anxiety that affects an individual's every waking hour and impact on their daily functioning.
- 6 Seeing my son suffer mentally because he couldn't fit in with 'normal society'
- 7 Other people's judgements and ignorant opinions
- 8 Getting strangers (currently employers), to understand my daughter has a condition that affects her and requires additional support, despite her looking and being able to communicate perfectly normally.

- 9 Repeating myself to try and get my child understood and coping with society who often see a naughty rude child that doesn't get disciplined.
- 10 Getting people - families, friends, school and medical to listen and understand that pda can and does exist. That firmer parenting won't improve the child's behaviour or compliance - in fact it reduces trust and makes things worse
- 11 Constantly being used as punch-bag or victim of abusive language, with no respite, but being told he's not disabled enough to qualify for support or PDA doesn't exist as not in the DSM
- 12 Keeping him and everyone around him safe

Final comments

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

- 1 I begged SSD for support from when my son was 13 -15. They refused on the grounds he did not have a Learning Disability and there were no Child Protection issues. It was only some 2 years later when I got to having suicidal thoughts that my youngest son's school put in a referral with my consent.

I'm sad to say once SSD became involved, matters deteriorated rapidly. They did not treat us as a family in need of support, but focused on my elder son's wishes only...who refused to engage with any support. They told me I was overtly negative about him...I was simply exhausted; struggling to work full-time, single parent with no family support. They encouraged my son to live with paternal grandparents when he was 16, who discouraged him from having any contact with me for 5 months. Paternal grandparents found they could not look after him and SSD contacted me and suggested my son move back in with me. He did so, but by that time his aggression and demand avoidance had escalated. He refused to accept any boundaries and became physically aggressive to the point that Police had to be called. PGP's could not look after him and neither could I without support. He went to live in supported lodgings with a family who had little understanding or training in Autism. They were de-registered because of financial irregularities and so my son had to move to another supported lodgings but this was even worse. Again, they had no knowledge of Autism, were overtly negative about him and were unable to understand that his refusal to leave the house or go to college, employment or training was anxiety-related. Despite my continued pleas for intensive support by specialist workers (ASD/PDA trained) it fell on deaf ears.

This placement broke down after just 6 months and my son moved back home briefly but I knew that for my younger son's well-being and my sanity, this could not be long-term unless there was intensive support package including respite from SSD. The fact that my son refuses all offers of support complicates matters, but this is his automatic default. SSD fail to recognise this and simply told me he's 18; he has a choice how to live his life. CAMHS told me the same thing, when my son refused support from Adult services failing to recognise the pathology of his behaviour is anxiety-driven and therefore will naturally avoid ALL demands placed on him.

I feel bereft, that our family has broken down. I feel powerless that now my son is 18 he can choose to live in any way he can. However, I do not believe he is making informed choices. He is simply taking the path of least resistance/fewer demands. This is not how I had envisaged our life. I feel devastated for my son with PDA, my younger son who has lost his older brother and for me as a Mum. All I ever wanted was support to keep our family together; to enhance his and our quality of life. He was subject of a Social Service Care & Support Plan, along with a Care & treatment Plan. These are meant to be holistic support packages. Instead, they were piece-meal,

fragmented processes, nothing but a tick box exercise. I feel in terms of post-diagnostic support, having an Autism label has not benefited my son. I work in CAMHS (albeit in another region) and know only too well that psychiatrists/psychologists even nurses attribute all behaviours to one's Autism. If a child or young person had anxiety to the extent my son has without having a label of Autism, they would be subject to involvement via a community intensive therapy team. Children and Young People are being failed simply because they have an Autism label and everything is put down to this! I'm so sad.

- 2 Due to his ability to mask so few people see that we face so many difficulties including family
I find that very isolating and lonely

Also I reached out to a friend who told me stop telling people he was ASD and all young boys are demand avoidant.

*Sibling copies behaviour and really tough for him as often does not get choices etc.
Hubby and I don't get time together and permanently tired
Would like support without the battle from children services or any one for that matter*

- 3 The hardest thing is that my child doesn't display enough classic autism traits for CAHMS to give him any diagnosis. They have said many traits of autism but not enough to meet the strict criteria to diagnose. They have not discharged him though as they can see something is going on. This leaves families in limbo. They will not discuss PDA.

- 4 Our experience of CAMHS is appalling. It took 3 years of trying to get even seen. They met with us, the parents twice and my son once for 40 minutes then gave the diagnosis and dismissed him from their books. They have since rejected a further referral.

- 5 It has been shocking how various teachers over the years, despite an official diagnosis, refused to believe that our son is autistic. We found out that secret reports had been written about him and ourselves by unprofessional teachers who questioned his diagnosis and stated we were making it up and that we should be parenting him in a practically Victorian manner. This matter had to be taken to the head of the local education authority with the support of the NHS children's disability team but we did not receive any apology or explanation. It caused a huge deterioration in our mental health.

Our son's mental health has been severely affected by the way teachers have treated him in the past. He ran away from school and the teacher in charge of him blatantly lied about the circumstances to save her own job!!

We now have a teacher that listens, has done research, asked for specialist support and respects us and our son. It has made the world of difference to us all but we are all frightened as to what may happen when my son moves to secondary school if teachers behave as shockingly as before.

- 6 I've recently done an interview for BBC Wales live which was aired regarding PDA
- 7 I have 3 boys. 2 diagnosed with Asperger's Syndrome. My youngest not diagnosed. I think he has strong PDA traits.
- 8 I live in the small probably unrealistic hope that all the work, love and tolerance that we and others have invested in our adopted son will one day bear fruit.
- 9 Being the parent of a child with PDA is harder than anyone can imagine. Working full time is virtually impossible. Everything revolves around the PDA child and it puts an unimaginable strain on family life, siblings grow up with compassion and understanding but inevitably they take a back seat unless you have a great deal of support. Unfortunately, I don't have that. My younger



daughter is terrified of her PDA sister when she kicks off because she becomes so narcissistic and confrontational, it is scary to be honest.

- 10 We are in a limbo land. xxx has traits of both PDA and classic autism, so we are constantly changing strategies and goals. We waited for years for assessment, only to be told that they had already given him an official diagnosis despite no assessments!!
- 11 It's the uncertainty of what that Day will be like. I've learnt to take one day at a time.
- 12 I have been exceedingly disappointed in the level of 'information' offered to parents. The prevailing attitudes of the PDA Society that PDA-ers are burdens or less than is appalling. PDA-ers when enabled and empowered are the most interesting, captivating world changers there are. That is the message that parents need to hear. HOPE!!! Where is that? All you talk about is surviving PDA. When you should be enabling and empowering the parents to celebrate their #LittleHumans as gifts to this world.
- 13 I have never experienced autism first hand before, let alone raise a child not only with ASD but with a profile of PDA. It has completely changed me as a person, and in a lot of ways for the better. My expectations in life are more simplified, and I find such joy in the little things watching my son develop. I have entered and been accepted into his unique little world and I am so proud to be there with him. I wish there was more understanding and support available. In the early days before I discovered PDA I genuinely thought it was all in my head and that I was going mad. I went to the doctor for help and explained the struggles I had and she signed me off work - I found out later that she had signed me off with depression with no known origin. This upset me as I had told her the reasons behind my poor mental state - she had never heard of PDA and clearly thought it was in my head. I went through a very low time where counselling wasn't available due to lack of funding, and a doctor that didn't believe my situation. If I hadn't found the PDA society and spoken to a volunteer I don't know where I would be right now. I would love to continue fighting for awareness, to continue learning and to one day help others like I was.
- 14 Paediatrician and OT don't believe in PDA. Children with Disabilities team says doesn't qualify for support. School struggling. We're not coping. Boys not eating or drinking. But no one helps, just taf meetings every few months which offer nothing. Feel like just leaving him at a hospital waiting room and walking away - unless we do something drastic nothing will happen.

Conclusions

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

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 generally 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-focussed.

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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