



Being Misunderstood

Northern Ireland 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 Northern Ireland. 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 Northern Ireland

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 15 families from Northern Ireland.

1. Diagnoses

Answer Options	NI	National
Yes, given what I feel is a correct diagnosis	20%	32%
Yes, but I feel it is incomplete	27%	22%
Yes, but not one I agree with	0%	3%
Still waiting for a formal diagnosis	13%	14%
Not requested / been offered a formal diagnosis	7%	7%
Other... (Shown below)	33%	23%

1 *1 diagnosis private. Other 2 pending private*

2 *No - she has been assessed but classic autism ruled out. No assessment for PDA is available.*

3 *Can't get her to go to Doctor*

4 *Had a diagnosis of spd and dyspraxia. Pursuing pda diagnosis*

5 *Diagnosed ASD number of years ago. Consultant refused to diagnose PDA as, in their words, "It doesn't exist, it's just all ASD".*

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 6 concerns** were in line with the national picture:

Answer Options	NI	National
Need to feel in control	100%	96%
Severe Anxiety	93%	81%
Low Self Esteem	87%	73%
Challenging behaviour	73%	89%
Sensory Issues	73%	91%
Problems Sleeping	73%	66%

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	NI	National
Yes, all the time	33%	41%
Regularly	20%	25%
Sometimes	20%	15%
Occasionally	7%	10%
Never	20%	8%

4. Involvement of local services

53% of families had involvement from local services, often multiple services, over the past 2 years. This included two thirds (75%) 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	NI	National
Completely	0%	1%
Very	0%	4%
Moderately	0%	13%
Slightly	11%	24%
Not at all	47%	45%
Not applicable	42%	12%

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

Answer Options	NI	National
Very satisfied	0%	3%
Fairly satisfied	14%	14%
Neither satisfied nor dissatisfied	28%	15%
Fairly dissatisfied	14%	19%
Very dissatisfied	42%	48%

Some explained their experiences of local services;

- 1 *All my own research & part of PDA support group through private clinic*
- 2 *I don't have support*
- 3 *No help given*
- 4 *haven't had any support*
- 5 *He is too complicated for anyone we have ever saw and is discharged*

5. The Challenges

All 15 people described the challenges they faced.

- 1 *Stigma & vilified as a bad parent*
- 2 *School refusal and lack of understanding by professionals*
- 3 *Finding support*
- 4 *unpredictability of the condition and the effects on family life*
- 5 *Completely changing my ideas of how to parent. Ignoring the unhelpful advice re: discipline etc.*
- 6 *Worry as he has such a small life*
- 7 *I don't know how to help her. She refuses help. She is on a downward spiral and has stopped speaking to me*
- 8 *School expulsion after 45 days suspension over 4 months.*
- 9 *Daily issues. No let up. Doubting myself - is it my fault? Very emotional*
- 10 *she just looks like a bad child and our relationship is struggling*
- 11 *Constant argument. Constant manipulation to obtain desired outcome*
- 12 *The violence*
- 13 *I have health problems myself and its constant pressure with avoidance behaviour. Limits what we do as a family. No one understands. When asking for help you get sent to parenting classes which are of no relevance to PDA. If you refuse you are deemed the problem.*
- 14 *Lack of understanding from professionals. Seeing avoidant behaviours as just a grumpy, out of control teen. Parental skill blaming culture.*
- 15 *Child's distress, getting people to understand, isolation, fear of the future*

Conclusions

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

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 across the UK 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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