



Diagnosis of Pathological Demand Avoidance Syndrome

The views of professionals

July 2016

Executive Summary

This report describes the findings of a survey of 52 professionals who diagnose and support those with Autistic Spectrum Disorders (ASD).

Increasing numbers of young people are being identified as having great difficulties with 'demand avoidance' in addition to having other autistic traits, and many families come to the PDA Society to look for information and advice on Pathological Demand Avoidance (PDA). In addition, greater numbers of professionals have been requesting training to ensure they identify those with PDA correctly and provide appropriate support.

The PDA Society conducted a snapshot survey of those who work with, assess and diagnose children and young people with ASD in order to find out about their attitude to the diagnosis of PDA and their current state of knowledge.

The survey showed that:

1. Around half of those responsible for diagnosis would identify PDA (often as a sub-type of ASD).
2. When both diagnosing and giving advice around two thirds of respondents felt constrained by lack of awareness of PDA amongst their colleagues locally and a lack of national recognition.
3. The majority (two thirds) had only come across a small number of children that exhibited extreme demand avoidance, so personal experience was relatively limited. This is to be expected as PDA is relatively rare.
4. Of those surveyed, knowledge of specific strategies appeared to be limited, with around 40% failing to identify the need for flexibility and almost three-quarters suggesting that clear boundaries and routines would be most helpful.
5. Many explained that the lag in published research is a problem, but more than two thirds were also unaware of the latest research in the area.

Families of children and young people who are eventually diagnosed as having PDA talk about the difficulties of finding individual practitioners with sufficient knowledge of the condition. This is important, not for reasons of diagnosis itself, but because when usual ASD strategies are used, these young people fail to progress whereas with the correct advice a significant difference can be made.

Although the survey was limited, it gives a useful indication of the views of those working in the field, including clearly demonstrating the lack of consensus on PDA. As experience of this rare condition develops, it is to be expected that the professional debates will continue and that further training and knowledge sharing will be helpful. This survey highlights the need for professionals to have:

- greater awareness of the latest research;
- case studies which illustrate the similarities and differences with others on the autistic spectrum, and the experiences of colleagues locally;
- better explanations of management strategies and how they differ from those employed for others with ASD;
- tools to help families better understand their child's condition, for cases where PDA is not identified as well as where it is.

Survey Results

The online survey was completed by 52 practitioners from across the UK, including specialist outreach teachers, clinical psychologists and community paediatricians. It was conducted online during May 2016 and individuals working within Child Development Centres were invited to complete it through emailed contact and other professionals through autism networks.

1. Knowledge of PDA

Answer Options	Response Percent
Good / up to date	33.3%
I have some knowledge	41.2%
I have limited knowledge	19.6%
I don't know very much	5.9%

A third said their knowledge was good and up-to-date.

2. Assessment and Diagnosis of ASD

When asked about their role more than a quarter diagnosed children and young people with ASD and the majority used the ADOS assessment tool most frequently in their work.

Answer Options	Response Percent
Assess only	5.8%
Assess and diagnose	26.9%
I refer on individuals, although don't assess and diagnose myself	23.1%
I work with ASD individuals, but don't refer on, assess or diagnose	44.2%

Of those whose role is diagnosis, half said they would diagnose PDA or ASD sub-group PDA, a further 18% explained they would include extreme demand avoidance in a profile description, leaving around a third who do not currently diagnose PDA.

3. Experience

Respondents were asked whether they had come across individuals exhibiting extreme demand avoidance, and only a third suggested that they had seen 'quite a few'.

Answer Options	Response Percent
No	1.9%
Possibly	13.5%
Yes, one or two	51.9%
Yes, quite a few	32.7%

4. Use of specific advice

Those surveyed were asked whether they gave different advice or support compared with others with ASD if they had worked with children with extreme demand avoidance.

Answer Options	Response Percent
Not really	11.4%
Sometimes	59.1%
Always	29.5%

Of those who gave advice to families, fewer than a third said that it would *always* be different to that given to other children.

Half of those surveyed also provided comments.

Some focussed on the fact that usual approaches were not found to be effective.

'the usual advice for ASD doesn't seem to work and needs adapting'

struggle to give advice as usual strategies for ASD don't work eg visual structure

While some highlighted the importance of individual profiling

I would always hope to give advice/support which is specific to the young person

Each child needs an individual plan according to their needs. As most advice regarding ASD is helpful it doesn't always work with children presenting PDA characteristics.

Others explained the ways in which their advice was different:

Treat avoidance or refusal as a sign of high anxiety and respond through emphasising reassurance and negotiation

A lot more flexibility and child led learning. Far fewer rules. We only use rules that would be illegal in the community as adults (e.g. no hurting, no stripping) everything else is up for negotiation.

The element of surprise/novelty for those with PDA seems to work whereas other young people with ASD like the opposite, predictable routine.

Less emphasis on 'goals'. Reduction of perceived pressure (including praise). Giving choices for young person to retain some control

Depending on the individual - 3rd party discussions, not directed at the individual. Saying no in a yes way. Giving the notion of control by giving limited choices - however the outcome will be what is required of the individual. Instructions kept to the minimum, and only to 'demand' what is absolutely necessary.

5. The strategies considered

Answer Options	Response Percent
I'm not sure at the moment	7.7%
Reward Charts	15.4%
Praise	30.8%
Routine	42.3%
Visual Cue Cards	34.6%
Simple instructions	59.6%
Limited choices	57.7%
Flexibility	61.5%
Clear boundaries	69.2%

When asked to suggest which strategies were most likely to be helpful, the results demonstrated a general lack of knowledge, even amongst those who had felt their knowledge was good and up-to-date. Close to 4 in 10 of those surveyed didn't identify 'flexibility' as helpful (including a quarter of those who identified themselves as having good knowledge).

The literature suggests that reward charts, direct praise, routine, simple instructions and clear boundaries are unhelpful as long-term strategies, but flexibility, limited choices and use of visual cue cards can all be helpful.

6. Lag in research

Detailed research often lags behind practitioner experience and ideas on management of conditions. This was considered to be a problem in the case of PDA. Comments on the topic were invited, and most people simply agreed it was an issue. A few more detailed comments were also provided by those who felt that PDA was a valuable diagnosis and others who felt it was not.

The comments highlight the tension that can occur when working with a particular child's needs within some professional frameworks.

'Yes, in the sense that the term PDA is increasingly being used families and organisations such as the NAS. However, as an NHS based practitioner I am supposed to refer to the evidence base for best practice and so far the evidence base in PDA is patchy and often rather anecdotal. This can lead to a tension between trying to provide helpful support and advice for families and remaining coherent with best (or good enough) practice. That situation means that an NHS practitioner can seem unhelpful in what they're able to advise or sanction as other, less regulated practitioners are often willing to make rather sweeping claims, and that just increases confusion and distress for families.'

'Kind of. I feel there is research and there is practitioner experience but issues with diagnosis often lead to the wrong diagnosis, therefore the wrong strategies are applied and a child is out of school before any advice can be given.'

‘Yes our assessment team say they will only use diagnostic terms in the recognised classification systems. Personally I prefer the idea of profiling individuals do we understand what their autism means for them.’

There were differing views on the sufficiency of the existing research:

‘The invention of "new" conditions by practitioners is frequently not supported by systematic research.’

‘ think the research is there. Practitioner experience is lagging behind.’

7. Constraints on Diagnosis and Advice

There was a general feeling that diagnosis was held back by a lack of national recognition, and also by the attitude of other professionals locally.

Local authority policy	27.3%
Local authority practice	47.7%
Lack of recognition by other professionals in your area	65.9%
Lack of recognition of PDA nationally	72.7%
Lack of international recognition of PDA	40.9%

Of those surveyed whose role is to diagnose ASD, the figures were similar with three quarters saying they were constrained by lack of recognition of PDA nationally, and 58% reporting that they felt constrained by lack of recognition by other professionals locally.

When it came to advice, the primary concern was ‘other professionals’ with 71% highlighting it as an issue.

Local authority policy	17.1%
Local authority practice	39.0%
Lack of recognition by other professionals in your area	70.7%
Lack of recognition of PDA nationally	56.1%
Lack of international recognition of PDA	29.3%

8. Need for increased awareness

There was an overwhelming call for greater awareness for all those involved in providing care and support to those with autism.

Parents	83.3%
GPs	95.8%
Specialist SEN teachers	87.5%
SEN support workers	87.5%
Clinical Psychologists	87.5%
CAMHS staff generally	87.5%
Community Paediatricians	91.7%
CDC staff generally	75.0%

Social Workers	83.3%
Local authority decision-makers	87.5%

Other comments:

'I think it is only helpful when considered a part of the autism spectrum'

'Educational psychologists'

'I do not think the "diagnosis" serves any useful purpose'

'Speech and Lang therapists, occupational therapists'

'I think that people working with PDA must have a very thorough foundation knowledge on ASD first'

9. Latest research

Liz O'Nions has been conducting research over recent years and has published an 'Extreme Demand Avoidance Questionnaire' (published in the Journal of Child Psychology and Psychiatry in 2014). While not a diagnostic tool, it is being used by practitioners to explore the nature of extreme demand avoidance traits in individuals. Those participating in this survey were asked whether they had come across it, and around two-thirds had not. Of those who had identified themselves as having good knowledge, 40% had not.

It is understandably difficult to keep up with all the latest research in a field of interest, especially when conditions are relatively rare. Nevertheless, these results indicate the need for improved knowledge management on this topic.

Answer Options	Response Percent
Yes	28.8%
No	65.4%
Maybe	5.8%

10. Comments on assessment and diagnosis of PDA

Finally those surveyed were invited to add any further comments on their view of the assessment and diagnosis of PDA and what would help them most. 21 respondents chose to do so.

<i>More information is needed for all practitioners</i>
<i>Im struggling with getting other professionals to recognise PDA as a possible explanation for a 4 year old im working with</i>
<i>More peer reviewed research about diagnosis would help. Also greater awareness in the medical sector.</i>

<i>We are offered questionnaires to assess ADHD and ASD but not PDA by Health</i>
<i>Where health services won't diagnose it then they can't use this as an excuse to ignore the behaviours and difficulties the individual faces</i>
<i>For it to be recognised so more appropriate guidance and support for children.</i>
<i>Absolutely no support given from authority or Ed Psych service. Left to sink or swim on our own. Very angry and let down by all 'support' services/professionals. [comment from specialist teacher]</i>
<i>At this time I am prepared to make a diagnosis of ASD, and define a specific profile of PDA. This appears to be coherent with the currently available research on PDA and I feel is helpful in recognising both social communication difficulties and significant demand avoidance.</i>
<i>My concern is that, for the few children I have met who may meet the profile of PDA described by Elizabeth Newson (three in 10 years), I feel their difficulties could be understood in different ways. I accept that some young people present with extreme levels of demand avoidance - however, I would consider this a symptom rather than a diagnosis in its own right. I feel that with an ongoing push towards PDA as a diagnosis, with as yet limited research and subsequently a lack of agreed diagnostic criteria, we potentially ignore the other causes to these sort of challenges. A search on Pubmed for 'Pathological Demand Avoidance' currently returns just seven results.</i>
<i>For myself, and I know for my colleagues, this isn't simply a 'we don't want to recognise this' or 'I don't believe in it'. As practitioners we must work within the best available evidence. There clearly are young people who present with demand avoidance, but there is an impression that a new diagnosis is being pushed without clear evidence. Unfortunately for the National Autistic Society to state they recognise it as part of the autism spectrum without providing additional information or justification is also unhelpful.</i>
<i>Positive experiences, where things have worked well and a youngster has stayed in school</i>
<i>Although I feel it is most helpful to see PDA as part of the spectrum, I understand the value of characterising what we see in PDA. I think my biggest problem is that when PDA is discussed separately to autism, it limits our understanding of the spectrum, and limits the support we can provide for people on the spectrum.</i>
<i>Recognition by other professionals would be most helpful, this is a barrier to our advice/support</i>
<i>I work with adults not children. I shared with only young PDA man I have diagnosed to date everything I could find on PDA in adults (not a lot) and guidelines for children with PDA. PDA for adults info has to improve.</i>
<i>In my view this is a complete waste of time.</i>
<i>More national training for staff to recognise and diagnose</i>

Our clinical experience shows that a group of children with a particular subset of behaviours not responding to usual ASD intervention definitely exists. Whether this is part of the autism spectrum or something else is less important than supporting these children.

For PDA to be recognised by all.

Tools for differential diagnosis

It would help if a decision would be made on getting PDA recognised in local authorities. I am an experienced practitioner who continually battles for support for children with all Learning Difficulties diagnosis recognised or not. I study and collate unbiased evidence to the medical professionals for this not to be recognised as valid. Their assessments have to take place - however lack of time, funding or staff prevents this. Young people wait months/years or sometimes never get the support they need.

Specific training courses on diagnosis/ intervention.

It is always helpful when parents attend the clinic with their own diaries/observations of their child's behaviours and the strategies used to date

Prepared by Sally Russell OBE for the PDA Society, with thanks for all the helpful contributions from the PDA Society Trustees

Visit the PDA Society website for further information and advice.