

Evidence for Professional Consideration of Demand Avoidance in Autism Assessments

The following evidence has been drawn together to demonstrate that, while different viewpoints exist, clinicians who choose to use terminology to indicate a PDA profile are not doing so in opposition to current medical guidance and thinking. It also illustrates the increasing evidence that the driver for the use of terminology is the impact on improving outcomes.

1. The trait of 'demand avoidance' within ASD assessments

- 'Demand Avoidance' is listed as a sign or symptom to be considered in an assessment in NICE Guidance (Appendix 3) Good quality assessments should look for the symptom and if present, determine its impact on the individual.
- *"The DSM-5 revisions include [...] the recognition of associated features that support an autism spectrum disorder diagnosis, and the identification of concurrent problems and disorders. [...] This recognition should mean that problematic behaviours, such as extreme demand avoidance and emotional dysregulation, will be included in diagnostic formulations and inform the development of comprehensive child and family intervention programmes"*.
Lancet Child and Adolescent Health

[https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(18\)30044-0/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30044-0/fulltext)

Prof. Green argues that, at the time of writing, there was a lack of evidence to identify PDA as a distinct sub-group, but nevertheless concludes that demand avoidance should be included in diagnostic formulations.

2. The PDA profile (the cluster of traits which includes extreme demand avoidance, emotional dysregulation, and the use of 'social strategies' in avoidance)

2.1 Government Position

The DHSC does not take a position on matters of clinical debate, but does recognise that there is a valid debate on the PDA profile, and highlights the need for specific support for individuals.

Extract from published ministerial statement

"...When assessing how best to meet these needs, professionals should do so without needing a diagnostic label. The lack of consensus on the status of the PDA profile should not be a reason to fail to identify and consider how best to meet the support needs of an individual. It is essential that health, education and social care providers work together to recognise that as young people's needs vary, there must be effective and responsive support for those needs."

<https://www.pdasociety.org.uk/resources/dhsc-statement-on-pda/>

Autism Strategy Review

The Government announcement included the following information:

"The review will inform the new joint adults and children autism strategy to be published in autumn 2019.

The review looks at:

- *joining up health, care and education services to address autistic children's needs holistically*
- *developing diagnostic services to diagnose autism earlier, in line with clinical guidance*
- *improving the transition between children and adult services so that no young people miss out, and ending inappropriate reliance on inpatient hospital care*
- *improving understanding of autism and all its profiles, including recently identified forms such as pathological demand avoidance (PDA)"*

<https://www.gov.uk/government/news/government-review-to-improve-the-lives-of-autistic-children>

2.2 Latest research

- Analysis of data from a clinical population of more than 150 children seen by a Norwich clinic has shown significant differences in diagnostic assessment scores on ADOS between the PDA profile and others with ASD (awaiting publication)
PDA Research Meeting, 2019

Dr Eaton is a Research Associate at King's College London and lead clinician at 'Help for Psychology'. She is author of the book "A Guide to Mental Health Issues in Girls and Young Women on the Autism Spectrum"

- **Child Behaviour and Parenting Strategies Research Summary, October 2019**

Section on the 'PDA Debate' includes:

"...It is clear that learning about PDA has helped many families to better understand their child by realising that problem behaviour can reflect anxiety and overwhelm. It has also helped parents move forward using recommended strategies designed to address avoidance in the context of anxiety. However, the concept of PDA has also triggered disagreements, particularly between parents and clinicians, who can have conflicting goals when it comes to clinical diagnoses.

In some cases, these have undermined parents' confidence and fostered their sense of isolation. Much of the disagreement has centred on whether PDA represents a separate subgroup and should be seen as a diagnosis in its own right.

However, if we make a slight shift in our focus from the issue of diagnosis towards focusing on behaviours that are described in PDA and the mechanisms behind them, much conflict is avoided and more attention given to the critical issue: what can be done to help the child? Even if we think about PDA more loosely as a continuum of behaviours that can occur in ASD, the concept can still be very helpful.

In particular, there are many similarities between behaviours described in PDA and other avoidance patterns that sometimes occur in ASD, such as avoidance of foods (avoidant restrictive food intake disorder), where the child will only eat certain foods considered 'safe', or avoidance of speaking (selective mutism). In all three, the factors mentioned earlier (particularly anxiety and sensitivity to environmental triggers) are thought to play an important role, and as such, management strategies are likely to overlap."

<https://lizonions.files.wordpress.com/2019/09/1909childbehaviourparentingstrategiessummary.pdf>

Dr O’Nions has been working on child behaviour with a focus on PDA, since 2011, and is the most published author on the topic. Currently a researcher at UCL.

Prof Happe, Head of the MRC Centre for Social, Genetic and Developmental Psychiatry, KCL, recently awarded the BPS President’s Award for Distinguished Contributions to Psychological Knowledge.

- Doctorate research including analysis of PDA traits in ASD concluded:

“The distinct behavioural profile of children with ASC and high PDA compared to those with low PDA traits provides support for previous research (e.g. O’Nions et al, 2014) and evidence to support the use of PDA as a clinically relevant and valid label to describe these symptoms as they occur within the autism spectrum.”

Dr. Bishop, UCL

https://discovery.ucl.ac.uk/id/eprint/10057038/8/Bishop_10057038_thesis_id_removed.pdf

2.3 Diagnostic terminology in practice

- There is still debate over how to frame diagnostic formulations, however, the use of terminology to reflect the role of demand avoidance when part of the PDA profile is widespread.

In a survey of nearly 1000 young people suspected of having PDA, parents reported that 768 had been given a diagnosis and of these half included reference to PDA or used identifying terminology.

‘Being Misunderstood’ PDA Society, 2018

<https://www.pdasociety.org.uk/resources/2018-summary/>

- Clinician’s viewpoint

“Whatever name we give to children’s difficulties, it must never reduce their complexity to a meaningless label; it should never put them into a box. On the contrary, it should help them and the adults caring for them to understand their set of talents and difficulties, and to find ways to foster the former and cope with the latter. No two people on the Autism Spectrum with PDA are the same: the ASD assessment has to identify how ASD affects your child and the identification of PDA by a multidisciplinary team of professionals is part of this process. PDA is dimensional and affects people on the autism spectrum in different ways, so there is a need to describe which bits apply to your child and which don’t.

The report following the assessment needs to reflect your child’s unique profile to guide a ‘needs-led’ programme of strategies that is shared by everyone involved in their care.

Identifying PDA is crucial as I’ve been told on many occasions by parents and teachers that the approaches used with children with a more typical presentation of autism often don’t work and can be counterproductive with those with PDA. Conversely, I have been told on many occasions how the application of ‘PDA friendly strategies’ was, quoting a father I worked with, ‘life transforming’ for his daughter and the whole family.

Moreover, developing a detailed description of your child's ASD will help them develop self-awareness, and understanding their PDA symptoms is part of this."

<https://www.myfamilyourneeds.co.uk/pathological-demand-avoidance-autism-diagnosis/>

Dr Dura-Vila, Consultant Adult and Child Psychiatrist and Medical Lead for ASD,
Surrey and Borders NHS Trust
Author of 'Me and My ASD' and 'Me and My PDA'

- Clinician's viewpoint

"We have made the point in earlier publications (Christie 2007, Christie et al, 2012) that the on-going controversy about the use of the term PDA and how it relates to those in the diagnostic classification systems can serve as a distraction and the focus should be on how a diagnostic understanding of an individual to formulate more effective forms of support and management. This view has been supported recently by O'Nions, Happé and Vidings (2016) in their article for the debate issue of the British Psychological Society Division of Educational and Clinical Psychologists (2016). In this paper they conclude the following.

'Children who exhibit this very problematic behavioural profile need to have their difficulties in complying with demands and extreme/controlling behaviour fully addressed in assessments, as it is these behaviours that typically create the most challenge for families and schools. Appropriate description and formulation of the child's difficulties is the starting point for the identification of potential management strategies and appropriate educational support. It is essential that help is provided for these very vulnerable children and their families.'

'Collaborative Approaches to Learning for pupils with PDA. Strategies for Education Professionals' Jessica Kingsley Publishers. 2019
Ruth Fidler and Phil Christie, Autism Associates.

- The PDA Society's statement on diagnostic terminology concludes:

"PDA is not a diagnosis in its own right, however the PDA profile can be identified during an autism assessment and, where appropriate, should be included as a clear signpost to the support strategies that will be helpful. The research to date means that PDA would not be diagnosed as a standalone condition, but that formulations such as 'Autism with a PDA profile' or 'ASD with demand avoidant traits' or similar can be, and are being, used."

<https://www.pdasociety.org.uk/resources/pda-society-statement-about-diagnostic-terminology/>