

PDA and differential diagnosis

Dr Judy Eaton

Consultant Clinical Psychologist

Research Associate MRC Social Genetic & Developmental
Psychiatry, Kings College London

The background

- * Nearly twenty years ago the NAPC (National Assessment Plan for Children) guidelines were published which were the precursor to the NICE guidelines for the assessment and diagnosis of Autism
- * At this time I helped establish one of the first multi-disciplinary Autism teams in the country
- * During this time (and we were regularly assessing 200+ children per year) we never saw a child with the PDA profile

The background

- * Originally Elizabeth Newson proposed that PDA should be considered as a separate disorder within the Pervasive Developmental disorders
- * She noted that although the children she assessed appeared to meet some of the criteria for Autism, they did not meet all
- * Over the last thirty years, our understanding of what constitutes the broader Autism spectrum has continually developed

The background

- * What Elizabeth Newson did note, however, was the degree of similarity between the children that she saw
- * This led her to develop the initial criteria for Pathological Demand Avoidance.

The background

- * I first came across the PDA profile whilst working in adolescent inpatient services
- * These young people had never been assessed for Autism and had usually been labelled as having an ‘emerging personality disorder’, either emotionally unstable – borderline or antisocial.
- * Most were in an extremely distressed state – engaging in self-harm or behaviour that was deemed ‘challenging’

The background

- * Since 2015 I have been working independently but am regularly commissioned by the NHS to carry out assessments of 'complex' young people – many who do not have Autism and whose difficulties can be better explained by attachment disorder/developmental trauma
- * Like Elizabeth Newson first noted, we have also seen the striking similarity in the presentation of the children we are asked to assess and the ways in which they differ from children with attachment disorders and those with a more easily identifiable diagnosis of Autism
- * We became curious to explore further the concept of Pathological Demand Avoidance

The background

- * I am aware of, and have been closely following the various debates about what PDA is (or is not) and have read and considered the various critical analyses that have been produced which have raised the following questions:
 - * Is PDA a stand alone diagnosis?
 - * Is PDA actually re-branded Autism?
 - * Is PDA an attachment disorder?

The background

- * Autistic academics, such as Damien Milton, have argued that demand avoidance is found frequently in many individuals with Autism, and in those with attachment disorders
- * He also argues (Milton 2013) that most demand avoidance can be described as 'rational' in response to aversive experiences

The background

- * Jonathan Green and his colleagues (Green et al 2018) stated that, in their review of the existing literature, there is currently no evidence to support PDA existing as either a separate diagnosis or syndrome either within or outside of Autism Spectrum Disorder
- * They also felt that PDA traits appear to overlap with Oppositional Defiance Disorder in some autistic children

The background

- * We have speculated whether PDA behaviour might represent a trauma response and an exaggerated 'fight, flight or freeze' response in some children, leading in some cases to dissociation and a catatonic-type presentation
- * We have noted similar behaviour in children who have experienced trauma and/or attachment difficulties
- * However, qualitatively these children present very differently to those with the PDA profile
- * We therefore, decided to objectively collect and analyse the data we collected during the course of our clinical work.

Our sample

- * Our data was collected as a routine part of our clinical assessment work and we acknowledge that our sample is more likely to include children who potentially present with the PDA profile
- * Ethical approval to use this data was received from the Kings College London ethics committee
- * We have examined both quantitative and qualitative data
- * We did not have a specific hypothesis or any pre-conceived expectations about what we would find

Our sample

- * All of the children and young people referred to our clinic were presenting with 'complex and/or challenging behaviour'
- * In many (but not all) cases, it had been suggested that the young people may have Autism/PDA
- * Some (but not all) of the young people had a known history of developmental trauma/attachment difficulties

Our sample

- * All the children and young people were seen over a two year period by the same team, in the same clinic, using the same assessment tools
- * They were a mixture of private referrals and children and young people referred by the local NHS commissioners.

Our sample

- * Gender

- * Females – 150

- * Males – 201

- * Age range

- * <5 - 43

- * 6 – 10 171

- * 11 – 17 101

- * Over 17 35

Assessment tools used

- * Cognitive assessment (WPPSI IV, WISC V or WAIS IV depending upon age)
- * The CCC2 (Children's Communication Checklist – Dorothy Bishop)
- * The Short Sensory Profile/Adolescent Sensory Profile – Winnie Dunn
- * The ADOS – Autism Diagnostic Observation Schedule (Modules 2, 3 or 4)
- * The EDA-Q (Extreme Demand Avoidance Questionnaire – O'Nions)
- * In addition, a full detailed developmental history was taken for every child

What we found

- * Using the original criteria for PDA outlined by Elizabeth Newson, the questions in the DISCO (Diagnostic Interview for Social and Communication Disorders, Wing and Gould) and the DSM 5 criteria for Autism Spectrum Disorders we made the following clinical diagnoses as part of our assessments

What we found

- * Autism Spectrum Disorder (those children who met DSM 5 criteria for Autism)
- * Autism Spectrum Disorder with the PDA profile
- * Other (those children who presented with a range of challenging/emotionally dysregulated behaviour but who did not meet criteria for Autism)

What we found

Total number of children = 351

Total diagnosed with Autism and PDA profile	= 111
Total diagnosed with Autism	= 145
Total diagnosed as Other	= 95

Number of girls with Autism and PDA profile	= 55
Number of boys with Autism and PDA profile	= 56

Number of girls with Autism	= 58
Number of boys with Autism	= 87

Number of girls with Other	= 37
Number of boys with Other	= 58

What we found

- * A whole range of statistical tests were used on the data we collected which revealed a number of interesting findings which we plan to write up for review and publication.
- * Very briefly though we found that there was evidence to support that Autism with the PDA profile was significantly different from those children in our 'Other' (non-Autistic) category and similar at many levels to the Autistic group.

What we found

- * We also found that demand avoidant behaviour as measured by the EDA-Q was apparent in all three groups.
- * We carried out qualitative analysis of the developmental histories taken
- * This showed us that there appears to be a group of children who display what we refer to as 'Rational Demand Avoidance'.
- * These are the children who start to display avoidant and challenging behaviour in response to a particular stressor (often school). This usually becomes more apparent around the age of 5 – 7, but can appear at the transition to High School.

What we found

- * We also found a number of children in our 'Other' category who also displayed challenging behaviour. However, this tended to be either an attachment behaviour (seeking attention in order to validate that you are being 'held in mind' by another person) or intentional oppositional behaviour (flouting rules or disruptive behaviour in the classroom)
- * This was qualitatively and quantitatively very different from the pervasive, extreme and 'pathological' avoidance behaviour of the Autism and PDA group.

What we found

- * This type of behaviour starts from a very early age and affects all aspects of the child's life, even the ability to carry out tasks and activities that the child wants and enjoys.

What does this mean?

- * We strongly believe that there are a group of children and young people with Autism who appear to be 'hardwired' to present with particular challenges
- * There are a number of theories which could account for this which need further exploration
- * These include sensory differences, leading to trauma responses to particular situations and Monotropism (the tendency to be single minded and focused upon one particular thing)

What does this mean?

- * What is clear is that children with this profile do have Autism
- * PDA is not a form of attachment disorder, neither is it caused by bad parenting
- * We feel that it urgently needs acknowledging at the very least as a recognised descriptor for children who present with remarkably similar challenges

What does this mean

- * There are so many families and young people who are struggling because of a lack of awareness/recognition of the PDA profile
- * Families who are turned away from diagnostic services
- * Families who are (unnecessarily) sent on inappropriate parenting courses
- * Families who are subject to social care investigations and constantly worry that their child might be taken away

What does this mean?

- * And finally, there are the young people like Bethany – the 17 year old girl who has spent 22 months in and out of a seclusion suite in an ATU, because over the years there has been misunderstanding of her condition, her behaviour and how to manage these.
- * Bethany is not the only young person in this situation.
- * Regardless of what we call it, how and why it develops, the PDA profile should be routinely explored for any child presenting with challenging and difficult behaviours and used as part of a multi-disciplinary formulation.

Thank you

- * I would like to give a massive 'thank you' to Katie Duncan and Kaylee Weaver, our amazing Assistant Psychologists who have spent many hundreds of hours entering thousands of pieces of data, often in their own time. This would not have been possible without them.
- * This research was carried out in conjunction with Kings College London, but no external funding was used.