



Richard Woods @Richard_Autism

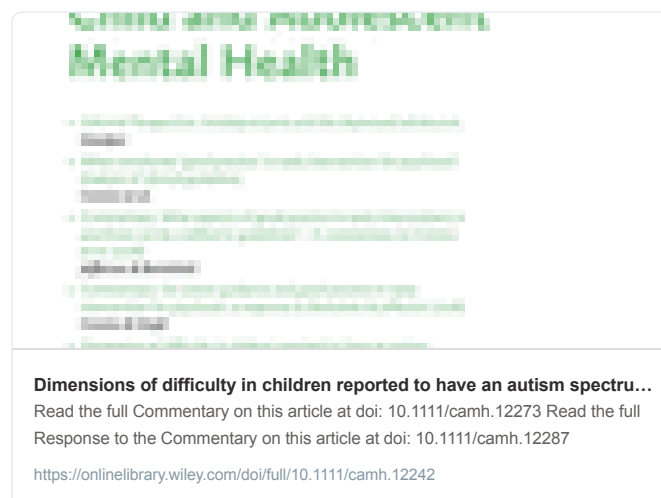
21 May 20 · 18 tweets · [Richard_Autism/status/1263538843606712322](https://twitter.com/Richard_Autism/status/1263538843606712322)



So something that is giving me a headache is that I am unsure if 2 PDA studies are actually needed:
This one:



and this one:



In relation to this DISCO study, the main reason for it seems to be establish it as an autism subtype. They took an approach to *make* a "meaningful subgroup.

The third stage used data from a sample of cases assessed using the DISCO for possible autism spectrum disorder ($N = 153$). These data were used to determine which of the 17 PDA-relevant DISCO items were *not* widely endorsed in general in an autism spectrum sample, since features typical of ASD in general are unlikely to be useful in identifying a meaningful subgroup. Ten of the DISCO PDA items had low endorsement rates ('marked difficulties' in less than 30 % of the total sample). Low endorsement suggested that these items might prove somewhat specific indicators of PDA. An additional item, 'Lack of co-operation', did not meet this low endorsement threshold (it was endorsed as 'marked' for 33 % of the sample), but was included due to its conceptual centrality—capturing resistance to demands. As can be seen from Table 5, this is the only item that corresponds directly to 'Continues to resist ordinary demands'—an essential characteristic

They admit their approach is different Newson's and they make some observations I am not entirely sure is accurate of Newson's work:

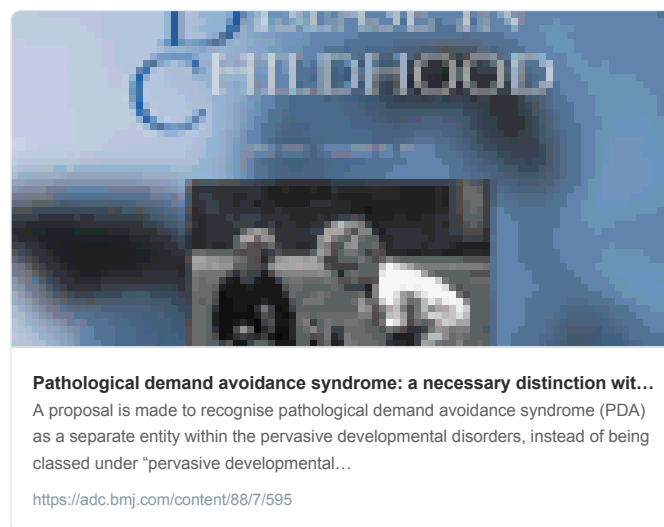
...ing at others' distress, lack of awareness of psychological barriers, difficult or objectionable personal habits, needing constant supervision and caregivers (all at $p = 0.001$ or lower) and number of other emotional symptoms both in those with PDA and those without PDA of the sample.

was to identify interview items that would make it possible to distinguish between the two groups, avoiding items tapping into features common across the autism spectrum. The study focused on identifying items by (a) existing results suggesting commonly observed in individuals with PDA and (b) new data reported here assessed using the DISCO, which was to be relatively unusual in the sample.

inclusion criteria for our measure. Six out of these seven items failed to show differential endorsement between the PDA groups (ascertained based on scores on our 11-item measure) and the rest of the sample. Wing and Gould's draft list had used published descriptions by Newson of PDA features to generate an item pool. Notably, Newson's descriptions were not specifically focused on the characteristics that can delineate PDA from the rest of the autism spectrum and were not 'weighted' in terms of which items were considered to be most central in the profile. The approach taken here to select items was aimed at exploring the possible differentiation of PDA and focusing on items that were most ubiquitous to the profile.

The final section of the analysis highlighted a number of additional items that appeared to differentiate PDA from the rest of the sample (Online Resource 5). These indicators included physical aggression, laughing at others' distress, lack of awareness of psychological barriers, difficult or objectionable personal habits, needing constant supervision and demanding attention from caregivers. Many of these behaviours also featured in Newson's original descriptions

First: is that Newson did seem to favour certain diagnostic traits. She said there was not enough evidence for "Neurological Involvement". Moreover, she the other 8 diagnostic traits are included in her famous "autistic family" diagram



This DISCO paper seems to focus on differentiating PDA from rest of autism. Yet, Newson is quite clear that she thinks her results indicated her PDA criteria are significantly different to classic autism & Aspergers.

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and Asperger's syndrome, either separately or apart, and this is evidenced by the very high significance levels yielded by discriminant functions analysis on a wide range of variables (see website).

The other statistical studies help to identify which criterial aspects are most significant for diagnosis. Clearly, demand avoidance *using social manipulation* is crucial, applying to 100% of cases, and differing strongly from autistic spectrum children. Liability of mood, lack of pride or shame, and strong interest in role play and pretending are all highly important

Which is so. Newson did not base PDA on triad of impairment. Nor could she, she did not systematically assess autism features. She compared autism & Aspergers to PDA, i.e. investigating if PDA is different to them, not if PDA is a PDD.

<http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf>

males with ASD (Fombonne, 2003).

Despite the interest and debate concerning PDA, there are only two published peer-reviewed research papers on the topic (Newson et al., 2003; O'Nions et al., in press). **Newson and colleagues' seminal case series described the features of PDA outlined above, but lacked standardised measures of IQ, and systematic consideration of autistic traits.** Clearly, more research is needed. As a starting point, it is important to know whether children exhibiting PDA features meet ASD criteria, and whether behavioural problems stem from developmental delays or intellectual impairment. The aim of this study was to systematically explore

Pertinently, Newson was clear on how robust she thought her diagnostic criteria were:

Figure 1 The "family" of pervasive developmental disorders.

adolescence. This, combined with an increasing wish for friends (often unfulfilled) may lead to clinical depression, and a need for informed and sensitive counselling.

The descriptive criteria, first produced in 1988 from clinical notes before the statistical studies had been undertaken, remain surprisingly robust, both between children and equally important, from childhood to adulthood. They were revised in 1995, with very little change except to include language delay, and finally revised for this paper to take account of the statistical studies quoted in the notes; even so, changes have been more in terms of organisation of the criterial concepts (to make stating of the "diagnostic argument" easier for clinicians), rather than changing the concepts themselves. There have been slight changes of emphasis here and there to follow statistical data.

The "recognition factor" for these criteria is striking, both

and Asperger evidenced by discriminant (see website).

The other s aspects are n avoidance *usi* of cases, an children. Labi interest in rol features whic teach and adu assessment obse concern for i aggressive an Pathologica

Also quite important is that the original 15 PDA items for the DISCO were used in a population study, i.e. it can differentiate between autistic persons.

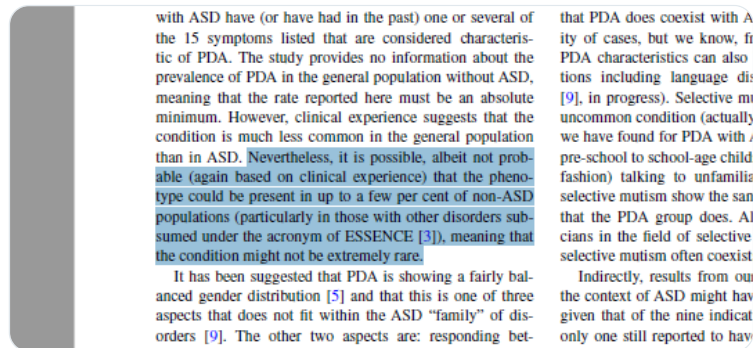


Extreme ("pathological") demand avoidance in autism: a gen

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexistent in spite of the frequent reference to...

From my understanding of this DISCO paper, the original 15 PDA DISCO items were never fully used to assess the Lorna Wing Centre database, so we do not know how they compare to these 11 "validated" items (they are not validated as used arbitrary thresholds).

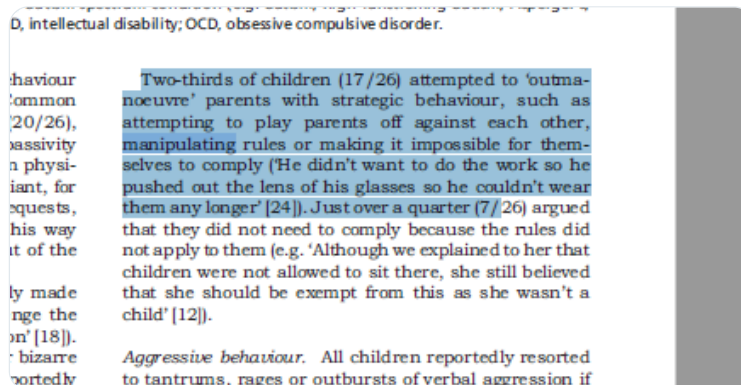
Also the entire study assumes PDA is an autism subtype. At least the Faroe Islands paper does not make this assumption. There simply is not the evidence in 2015 to say PDA is only found in autism.



The second study. My issue here, is that seems to be a replication study from some research from O'Nions PhD. They tried to get it published for some reason it was not: <http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf>

Now what bothers me is that, as Dimensions of Difficulty, uses the same tool to do very similar research to the unpublished one. The results are very similar main difference is second study says some behaviours are "socially strategic".

It is important to note that the second study also notes that some behaviours are manipulative. The previous study views the behaviours as manipulative, not socially strategic. Both studies have similar authors. O'Nions, Happe, Viding & Quinlan.



Which raises questions why they thought they needed to conduct, what is effectively a replication study? Why they have come out with slight different results?

Bare in mind, both:



Identifying features of 'pathological demand avoidance' us

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obsessive resistance to everyday demands and...

<https://link.springer.com/article/10.1007/s00787-015-0740-2>

and:



Dimensions of difficulty in children reported to have an autism spectru...

Read the full Commentary on this article at doi: 10.1111/camh.12273 Read the full Response to the Commentary on this article at doi: 10.1111/camh.12287

<https://onlinelibrary.wiley.com/doi/full/10.1111/camh.12242>

Both do things to make PDA conform closer to autism. I cover this elsewhere:

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THREAD BY RICHARD WOODS (@RICHARD_AUTISM)

Thread: So tonight I have been trying to figure out why the wording for DISCO items is different between @ONionsLiz and @GillbergCentre PDA research. Yes, I emailed them to clarify why. Links to respective PDA DISCO articles:...

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Thread by @Richard_Autism: Thread: So tonight I have been trying to ...

Thread by @Richard_Autism: Thread: So tonight I have been trying to figure out why the wording for DISCO items is different between @ONionsLirgCentre PDA research. Yes, I emailed them to clarify why....

<https://threadreaderapp.com/thread/1261049980929933313.html>

So what I can tell, there are at least 2 PDA studies that arguably did not need happen and are both effected by confirmation bias. This is why it is giving me a headache.

Surely, it can not be as bad as it seems?

Can I also add there is simply not the evidence today to say that PDA is only found in autistic persons.

Importantly, O'Nions has gone from saying it is problematic fitting PDA into autism spectrum:



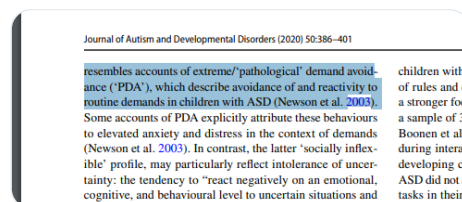
and:

<http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf>

To saying PDA is part of autism spectrum:



Change can be viewed as confirmation bias.



<p>absence of a robust evidence base, PDA has not entered the diagnostic manuals, and the concept remains controversial. There is discussion about whether PDA is a syndrome, or describes behaviour seen in a range of disorders. Its relationship with autism has also been debated. Some have argued that PDA is simply a 'high-functioning' ADHD/spectrum syndrome, or a more female-typical presentation of Autism Spectrum Disorder (ASD) (Golan and Baron-Cohen, 2011). [However, several 'descriptions' of PDA have been proposed. PDA do not fit easily within our current concept of ASD. First, unlike those with ASD, children with PDA are reported to respond poorly to routine and predictability, instead preferring spontaneity and novelty. Second, it is pre-occupation with role-play and fantasy it described as characteristic of PDA, but pretend play is typically absent or delayed in ASD (Frith, 1991; Leslie, 1987). Third, descriptions of autism do not include frequent and varied manipulation of others' mental and emotional states, as reported in PDA. Last, Newson et al. states involved a 'balanced gender distribution, in contrast to the 4:1 over representation of males with ASD (primarily males)].</p> <p>Despite the interest and debate surrounding PDA, there are only two published peer-reviewed research papers on the topic (Newson et al., 2003; O'Hara et al., in press). Newson and colleagues' seminal case series described the features of PDA outlined above, but lacked standardised measures of IQ, and systematic</p>	<p>n.d.). Data on SES were calculable for n = 185.</p> <p>Mean age of the children on whom parents/caregivers reported was 11 years 1 month (range 6 years 1 month–16 years 8 months), and the median age band of parent/caregiver respondents was 40–44 years. Other details of the sample are provided in Table 1.</p> <p>Parents with an interest in extreme/ 'pathological' demand avoidance (PDA) were highly represented in the sample, with 116 (52%) mentioning extreme or pathological demand avoidance or demand avoidance behaviour, as part of their child's diagnostic description, a profile that they believed might fit their child, or a concept that had informed their parenting approach. Given the nature of the snowballing recruitment strategy, an even greater proportion of respondents may be familiar with the PDA concept and the associated formulation of avoidance in ASD being associated with anxiety.</p> <p>Measures</p> <p>Measures analysed in the present study are described in detail below. Total scores for conduct and antisocial scores out</p>	<p>score of 0, we recorded its received a score of 0.</p> <p>An exploratory factor analysis of the Positive Parenting subscale (n = 862 parents) revealed four factors (mean = 11.12, SD = 2.49), which we named: (1) 'Parental involvement' (n = 11.12, SD = 2.49), (2) 'Parental control' (n = 11.12, SD = 2.49), (3) 'Parental support' (n = 11.12, SD = 2.49), and (4) 'Parental discipline' (n = 11.12, SD = 2.49). The exploratory factor analysis revealed that the items loaded onto the factors in a way that was consistent with the theoretical framework of the study. The exploratory factor analysis revealed that the items loaded onto the factors in a way that was consistent with the theoretical framework of the study.</p>
<p>ands and requests, use of objects to avoid, and behaviour to avoid, as well as apparent social skills, reflected in peers and lack of social skills. Newson described non-compliance to unpleasant demands to accept suggestions, activities or walk in children with PDA are aggressive or socially manipulative. Newson et al. (2003) described 'manipulative', unlike children with PDA, who are reported to subvert requests by behaviour intended to avoid a sense of responsibility. Newson's participants were children, identifying roles with which they failed and threatening by others that they were not intelligent, the of environment meant</p>	<p>social relating was a prominent feature, potentially reflecting underlying socio-cognitive difficulties (for discussion see Frick and Moffitt, 2010). Other potentially overlapping terms include pervasive refusal syndrome (Taylor et al., 2000), schizoid personality in childhood (Wolff and Barlow, 1979) and 'borderline' states (Weil, 1953).</p> <p>At least three aspects of Newson's description of PDA also do not appear to fit straightforwardly within the autism spectrum. First, children with PDA are described as responding best to spontaneity, humour and unpredictability – very distinct from the structure and repetition as the core of educational strategy with autism (Kunze and Mesibov, 1999). Second, PDA is described as showing a fairly balanced gender distribution (Newson et al., 2003) in contrast to the strong male bias in ASD (Fombonne, 2003). Third, a preoccupation with role play and fantasy, even difficulty telling pretence from reality, is said to be characteristic of PDA, while absent or delayed pretend play is a marker for ASD (Frith et al., 1991; Leslie, 1987).</p> <p>The aim of this study was to compare parent-reported behavioural difficulties in children receiving the PDA label and children with autism or conduct problems and callous/unemotional traits. Children with conduct problems and callous/unemotional traits (CPCU), a specifier for DSM-5 (2013), including a narcissistic manner of anti-social behav-</p>	