



**Richard Woods** @Richard\_Autism

29 May · 50 tweets · [Richard\\_Autism/status/1398755419108122624](https://twitter.com/Richard_Autism/status/1398755419108122624)



Going reading O'Nions recent work. At least they have referenced one article of mine. Ignored critique of EDA-Q in said article which is bizarre.

[@HappeLab](#)

Sigh, perhaps one day I will view O'Nions work to be equivalent to mine quality, but this is not one those days.

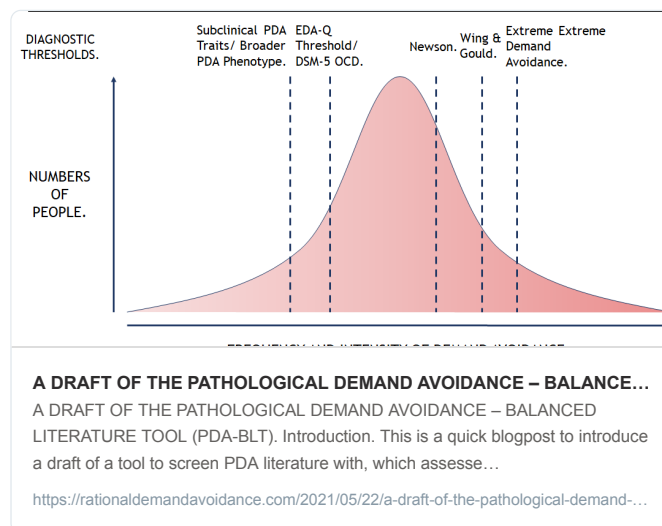


**Extreme Demand Avoidance in Children with Autism Spectrum Disord...**

Extreme/"pathological" demand avoidance (PDA) describes a presentation found in some children on the autism spectrum, characterized by obsessiv

<https://link.springer.com/article/10.1007/s41252-021-00203-z>

[@HappeLab](#) I doubt that article will score well on here, sigh.



Link to article of mine. Screenshot of critique of the EDA-Q.

[https://www.researchgate.net/publication/338650142\\_Commentary\\_Demand\\_Avoidance\\_Phenomena\\_a\\_manifold\\_issue\\_Intolerance\\_of\\_uncertainty\\_and\\_anxiety\\_a](https://www.researchgate.net/publication/338650142_Commentary_Demand_Avoidance_Phenomena_a_manifold_issue_Intolerance_of_uncertainty_and_anxiety_a)

## s explanatory frameworks for extreme demand avoidance in children and adolescents - a commentary on Stuart

population experiences co-occurring anxiety-based disorders, the extreme anxiety levels reported in the DAP literature are plausibly the result of the interaction between autism and a different comorbidity. DAP can be explained by trauma (Woods, 2019a, 2019b).

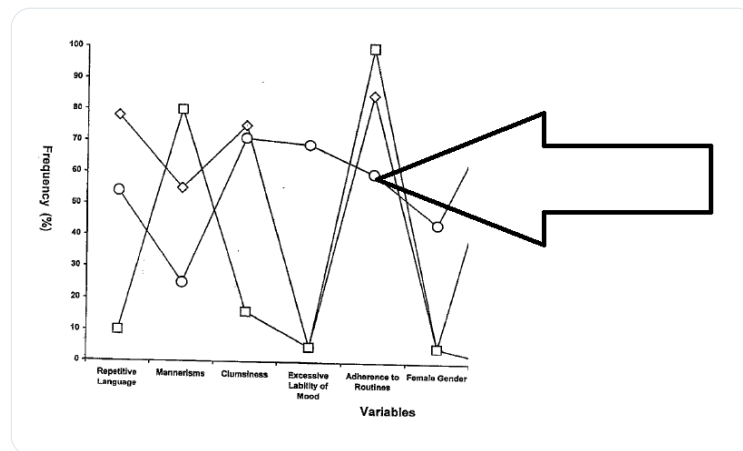
Developmental criteria are unnecessary for a DAP diagnosis as it has many different developmental trajectories (Stuart et al., 2019). Thusly, there are several demand avoidance conditions, akin to the proposed 'autisms', and there is insufficient evidence to favour any of DAP's proposed ontologies over another (Woods, 2019b). Essentially, all has to inform policy and practice in relation to DAP is opinion, including this author. It could therefore be argued that it is inappropriate to include DAP as part of the autism spectrum as it is a false equivalence fallacy.

Stuart et al. (2019) provide a general overview of the DAP literature. There are gaps and difficulties with the extant research and challenges objectively measuring DAP (Woods, 2019a, 2019b). The authors observe that the Extreme Demand Avoidance-Questionnaire (EDA-Q) used in their trial had a ceiling effect and suggest that the anchor points are not very sensitive in capturing variations in behaviour at the more extreme end. A solution would be to change its anchor points from likeness of child to frequency of behaviours (ibid), and other limitations include the following: (a) detecting demand avoidance behaviours in other conditions and false positives; (b) divergent scores between stakeholders; (c) DAP criteria are unstable as there is no consensus this topic (Woods, 2019a, 2019b), and so the tool has not been standardised compared with current diagnostic criteria. For instance, DAP has 10 diagnostic traits (Woods, 2019b), and the EDA-Q was developed before the adoption of 'Sensory Differences' trait and so does not account for it; (d) risk of confirmation bias due to vague questions, behaviours that are not unique and reliance on caregiver reports (Woods, 2019a); and (e) the tool pathologises behaviours that children naturally display when asserting their self-agency in hard times (Moore, in press). Parts of DAP profile are hard to measure, such as 'lacking sense of identity, pride or shame' (Woods,

ford OX4 2DQ, UK and 350 Main St, Malden, MA 02148, USA

Interesting apparently O'Nions is stating that routines and structure might benefit some persons with PDA, yet ignores how this was actually in Newson's original research...

<https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/PDA-discriminant-functions-analysis.pdf>



There seems to be a concerted effort to argue there might be a collider bias in Newson's research, instead of actually checking Newson's research statistics for if there could be a collider bias.

@HappeLab We know if there is a collider bias, then it could only be present in between 25% - 33% of Newson's cohort: Bulk of Newson's cohort was recruited after expansion of autism spectrum to include Aspergers. This is just sloppy.

#### WHAT THE LITERATURE AND RICHARD WOODS SAY ABOUT NEWSO...

WHAT THE LITERATURE AND RICHARD WOODS SAY ABOUT NEWSO ET AL (2003). This is a living document, I update as I reflect upon Newson's work more and with more is said about it in the literature....

<https://rationaldemandavoidance.com/2020/10/17/what-the-literature-and-richard-wood...>

[@HappelLab](#) It also does not consider other reasons for differences between PDA and autism, that are results of Newsons methodology; also more pertinently that it is demonstrably true PDA is not autism.

[@HappelLab](#) Article ignores conflict of interest present in the Being Misunderstood report, due to those who consulted on the report. Also ignores other literature, which argues growth in PDA is driven by non-autistic stakeholders & activities like conferences.

cases in this sample. One possibility is that the items incorporated in our PDA measure might disproportionately focus on the more outwardly challenging, as opposed to passive, behaviours described in PDA. The latter have been reported to be more common in females with ASD [19]. Despite this, we found no significant differences between genders for scores on the 11-item DISCO PDA measure across this sample. Analyses in larger samples using case report and diagnostic information on PDA are needed to examine whether items tapping passive forms of demand avoidance (e.g. selective mutism) warrant inclusion in a PDA measure.

#### Strengths and limitations

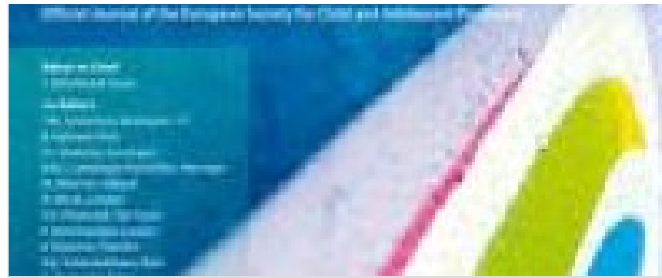
One of the strengths of the current study was that the data used were collected in 2010 or earlier: for the most part prior to the large peak in interest in PDA and the series of annual conferences on the topic held in the UK. As such, it is likely that clinicians were not particularly 'on the lookout' for PDA features in their cases. This meant that it was possible to get an honest and unbiased picture of the features of PDA in this sample.

Limitations of the present study include that the representativeness of the sample as a group undergoing assessments for social and communication disorders is unknown. As such, these results do not provide information about the prevalence of PDA features, or how they compare to a population cohort of those with autism. However, these data remain useful as a large sample of cases undergoing assessment for possible social and communication disorder.

Further limitations include the fact that cases not specifically suspected of social communication disorders were not included, and that none of the cases was comprehensively clinically reviewed by experienced clinicians for the purpose of making or refuting a clinical diagnosis of PDA. For a minority of participants, diagnostic information with respect to autism spectrum disorders was also unavailable. The cutoffs selected here were made pragmatically to ensure that a sufficient number of PDA features were present in the cases included in the PDA groups. However, these data do not provide information on the degree of day to day functional impairment these difficulties produced.

Screenshot if from here:



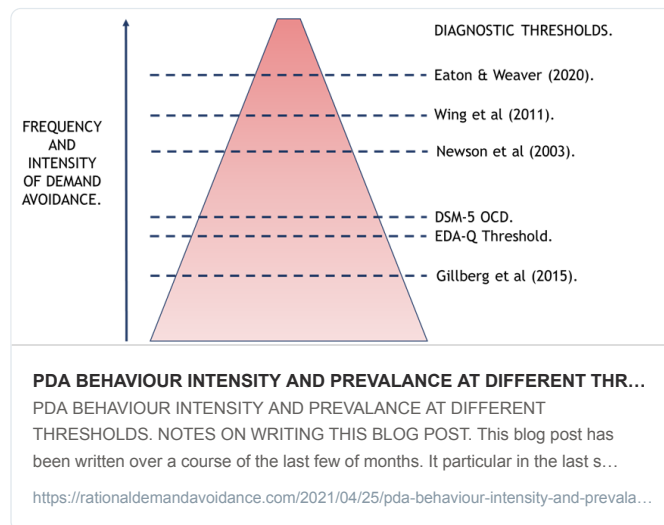


#### Identifying features of 'pathological demand avoidance' using the Diag...

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obse

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

@HappeLab It also ignores how Help4Psychology seem to have created their own PDA definitions, which are NOT representative of literature:



@HappeLab There is also no review of the use of the EDA-Q in PDA research and therefore no discussion of just HOW important the EDA-Q is to knowledge base on PDA. Likewise, no discussion on how often EDA-Q is used in diagnosing PDA.

@HappeLab This seems to be a poor quality article that come to expect from Liz O'Nions and others on PDA.

@HappeLab Another example of sloppy literature review, is discussing how behaviours seen in PDA do not respond well to reinforcement-based approaches, is described in recent work. Newson et al reported that praise, reward & punishment as ineffective, page 597

identity, these behaviors may also reflect camouflage/masking, described by some autistic people as a means to avoid unwanted social attention (e.g., Livingston et al., 2019).

Children described as having PDA showed extreme lability of mood, including sudden changes from loving to aggressive behavior, impulsivity, obsessions, passivity during infancy, and neurological "soft signs" such as motor clumsiness (Newson et al., 2003). They were as often girls as boys (Newson et al., 2003). Recent work has suggested other co-occurring features, including attempts to control situations and others' activities using coercive strategies (e.g., threats), elaborate excuses, sabotaging, and extreme aggression (Eaton & Weaver, 2020; O'Nions et al., 2018a, b). These behaviors are reportedly resistant to traditional reward and consequence-based strategies (Eaton & Weaver, 2020).

Newson et al. (2003) reported the findings of a discriminant functions analysis for a sample recruited between 1975 and 2000. This analysis identified fewer "typical" autism features (e.g., difficulties with eye contact, lack of symbolic play, stereotypical motor mannerisms, etc.) in those with PDA compared to those with more typical autism/Asperger presentations. Strategies effective for children with "typical" autism, such as routine and repetition, were reportedly unhelpful for the demand avoidant group, who resisted the imposition of adult control. Instead, the demand avoidant group were said to benefit from strategies that were not rule based, such as using novelty to distract from perceived demands (Newson

@Happelab

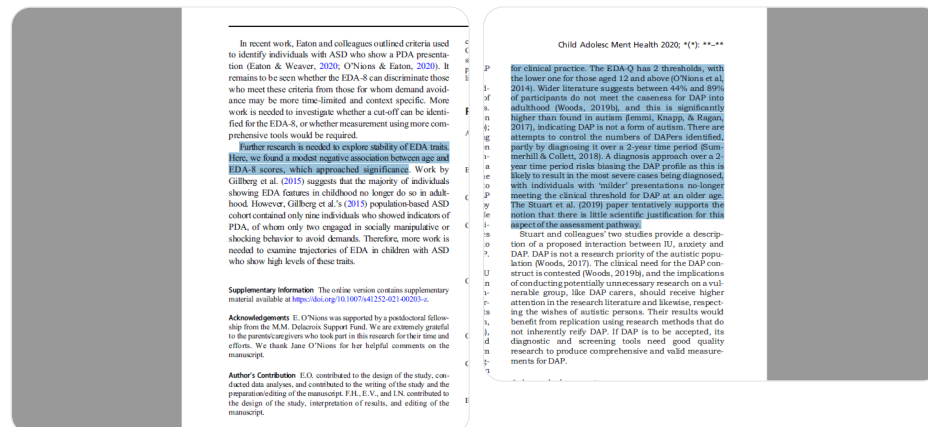
"Praise, reward, reproof, and punishment ineffective; behavioural approaches fail."

Newson et al (2003, p597).

<https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes>

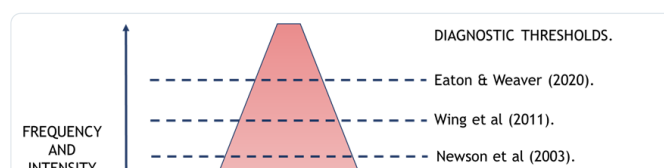
@Happelab There are good reasons why I question if O'Nions is a reputable information on PDA. Latest article is not doing much to ease my concerns.

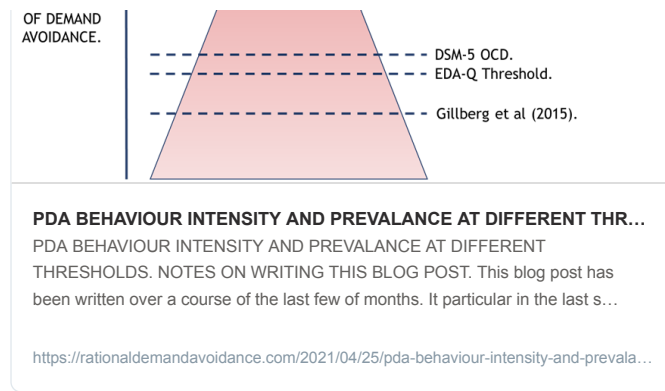
Interesting that it seems to be another study that shows that PDA behaviours decrease with age. Then refer to Gillberg et al (2015). Again, I discuss this the article of mine I reference & I discuss implications of it.



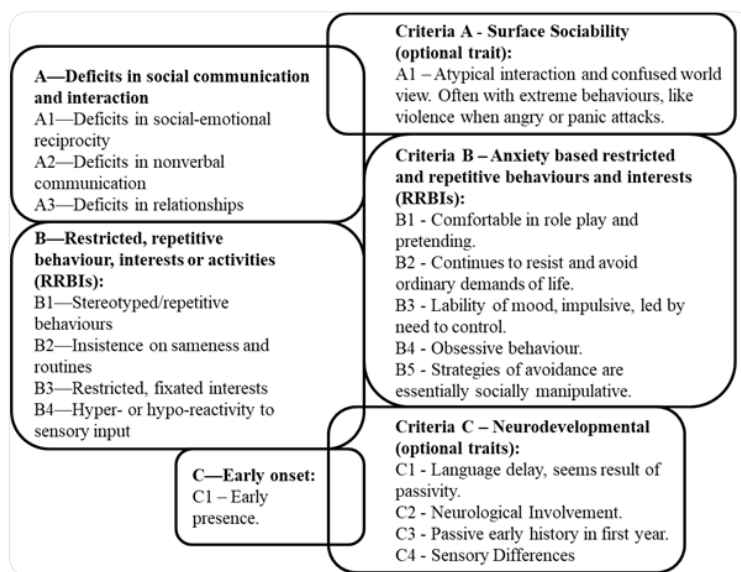
@Happelab It does seem a reasonable statement that this article by you & others would have benefitted from more engagement with Woods (2020).

@Happelab I emailed O'Nions a copy of this blog post to comment on, during mid March 2021, a month before this was accepted. It is possible that they had time to read it.

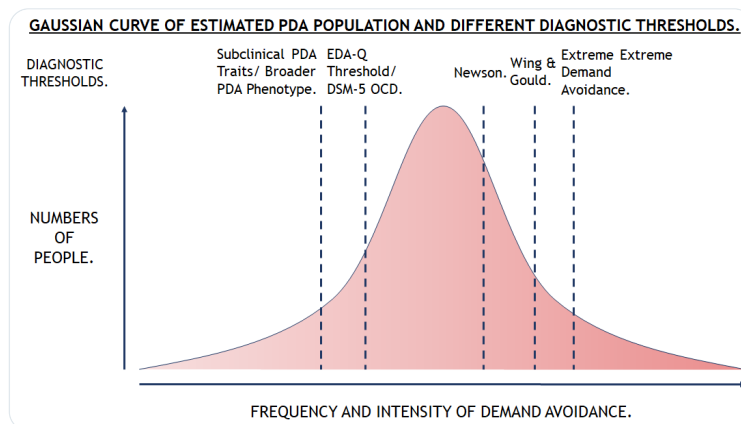




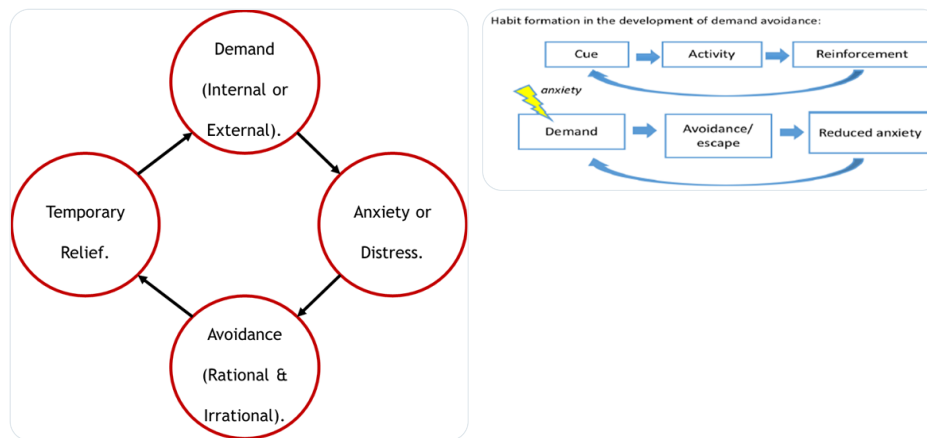
[@Happelab](#) I also think some of Gillberg et al (2015) high drop off rate of those meeting caseness for PDA is due to their diagnostic threshold being low, the core PDA traits (as I define them) do not need to be present to meet Gillberg et al (2015) threshold.



[@Happelab](#) I refer to Gillberg et al (2015) threshold as "Subclinical PDA Traits/ Broader PDA Phenotype".



[@Happelab](#) Point is that if Gillberg et al (2015) are diagnosing persons who do contain most features of the Demand Management Cycle, which is informed by some of O'Nions research. It is unlikely PDA behaviours would be developed & maintained as a CYP matures.



@HappeLab Thus explaining why it why Gillberg et al (2015) decrease so much in their sample.

I notice mention of "strategic" or "manipulative" social demand avoidance behaviours. This is a plus point.

Current view is that both descriptors can be applied, potentially changing with context.

Glad targeting behaviours with intent was mentioned.

The HSQ may be a useful tool for exploring the types of activities that trigger avoidance or behavior that challenges. This measure was identified as having favorable measurement properties compared to other measures of behavior problems in young children with autism (McConachie et al., 2015). Items in the HSQ (described in-depth in Chowdhury et al., 2016, Table 2) could be helpful in identifying particular triggers of avoidance and understanding how it impacts daily life. However, some parents in the current sample anecdotally reported that the HSQ was difficult to complete because they do not usually use "instructions, commands, or rules" for fear of triggering behavior that challenges.

Clinical accounts of PDA highlight a range of concerns, only some of which are covered in the EDA-8 and other measures described here. Omissions include attempts to control others' activities, which in some children may include coercive behavior. Other reported challenges include blaming or targeting others, sabotage, and difficulty taking responsibility (Eaton & Weaver, 2020; Newson et al., 2003; O'Nions et al., 2018a, b). Parental accounts suggest that these behaviors can have a very significant impact, making them important targets for measurement and intervention.

### Limitations and Future Research Directions

Limitations of the present study include the lack of clinical data (e.g., gold-standard diagnostic instruments), reliance on informant report of diagnoses, reliance on a single method of data collection (i.e., questionnaires), and a single informant (one parent/caregiver). Further multimethod investigation is needed in a sample who have received standardized clinical assessments. We note that a similar pattern of results was reported by Chowdhury et al. (2016) with respect to links between the HSQ and other measures in a clinic-based ASD sample. Although common rater-bias could have inflated the strength of detected relations, we were able to detect differential links across measures, suggesting that this did not compromise the findings.

@HappeLab cannot say I am impressed with this apparent "obsession" with researching PDA in autism & fallacious axiom that PDA is an ASD.

@HappeLab There seem to be an issue of selective referencing. No mention of EDA-Q detecting PDA in non-autistic persons. Presumably, you & others would say PDA is an ASD, EDA-Q was detecting autistic persons, because it was detecting PDA. Or "false positives"

[@Happe](#) This research by yourself, O'Nions & others is about refining EDA-Q's ability to detect PDA in autistic CYPs, so there is a COI in not reporting the EDA-Q detects PDA in non-autistic persons; as it is a lot harder to justify this research's rationale.

Child ASD severity		
Social interaction <sup>b</sup>	.01	.06
Social communication <sup>b</sup>	-.03	.05
RRBs <sup>a,b</sup>	.13	.12
SCQ total score <sup>b</sup>	.07	.13*

Bonferroni-adjusted  $p$  value = .0007 (68 comparisons). Results surviving Bonferroni correction: \* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$  uncorrected

<sup>a</sup> Spearman's rank correlation coefficients calculated

<sup>b</sup> Data available for Sample 2 only ( $n = 233$ )

*Inflexible Non-compliance* and each of the measures expected to show divergence (Table S5). We found that coefficients were similar, with the following exceptions: *SDQ Conduct Problems* was more strongly related to *EDA-8* than it was to both *Demand Specific Non-compliance* and *Socially Inflexible Non-compliance*, and *EDI Dysphoria* was more strongly related to *EDI Reactivity* than it was to *EDA-8*.

### Discussion

The aim of the present study was to conduct psychometric analysis to refine the EDA-Q using data from parents/caregivers of children reported to have an ASD diagnosis. The goal was to identify whether one or more dimensions best described EDA-Q items in an ASD sample, and to drop items that were not sufficiently discriminating, or which behaved differently with respect to quantifying EDA dependent on the child's age, gender, ability level, or independence in daily living activities.

In line with previous analyses, we found that 23 of the 26 EDA-Q items loaded significantly onto a single underlying component (O'Nions, Christie, et al., 2014a). IRT analysis

Springer

[@HappeLab](#) It begs the question, why not also do this research for PDA in non-autistic persons? Oh, PDA is seen in non-autistic persons, PDA cannot be autism. Means one cannot assume PDA is autism. So it is easier to not mention it and avoid such issues.

[@HappeLab](#) Links to where EDA-Q has detected PDA in non-autistic persons.

# Developmental Disabilities

**Pathological Demand Avoidance in a population-based cohort of children...**

Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spec...

<https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub>

&  
<https://www.pdasociety.org.uk/wp-content/uploads/2019/09/Research-Meeting-Report.pdf>  
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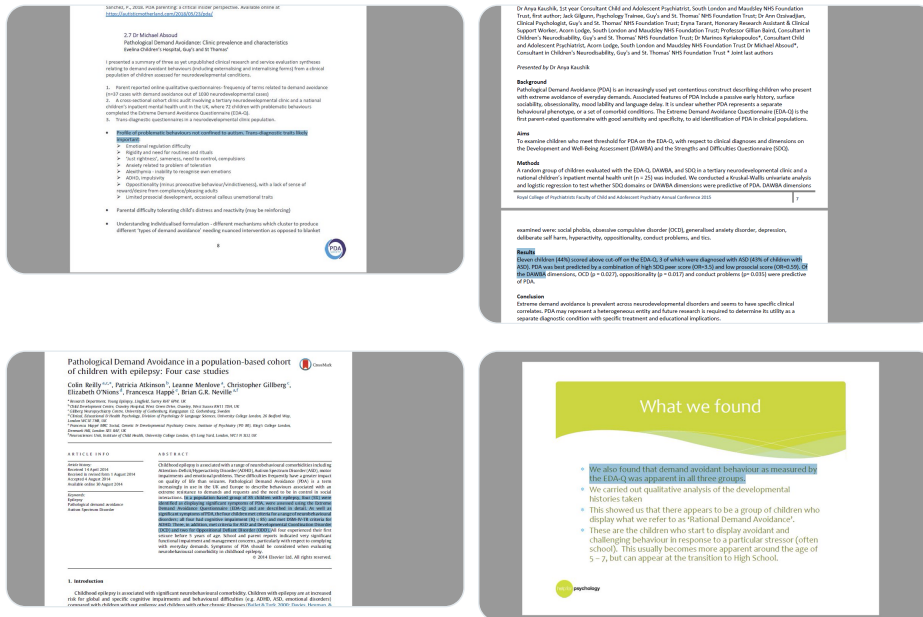




## Pathological demand avoidance (PDA) 2018 presentations

pda conference 2018

<https://www.autism.org.uk/what-we-do/professional-development/past-conferences/pd...>



[@Happelab](#) unless O'Nions has referenced Garralda in their PhD thesis, it would appear that she has not yet referenced their article in print...



## Pathological demand avoidance syndrome: a necessary distinction wit...

A proposal is made to recognise pathological demand avoidance syndrome (PDA) as a separate entity within the pervasive developmental disorders, instead of being classed under “pervasive developmental...

<https://adc.bmj.com/content/88/7/595.responses#pathological-demand-avoidance-syn...>

Chowdhury, M., Aman, M. G., Scullin, L., Swiezy, N., Arnold, L. E., Lecavalier, L., Johnson, C., Handen, B., Stigler, K., Baur, K., Sukhodolsky, D., & McDougle, C. J. (2010). The home situations questionnaire-PDD version: factor structure and psychometric properties. *Journal of Intellectual Disability Research*, 54(3), 281-291. <https://doi.org/10.1111/j.1365-2788.2010.01259.x>.

Chowdhury, M., Aman, M. G., Lecavalier, L., Smith, T., Johnson, C., Swiezy, N., McCracken, J. T., King, B., McDougle, C. J., Baur, K., Deng, Y., & Scullin, L. (2016). Factor structure and psychometric properties of the revised home situations questionnaire for autism spectrum disorder: the home situations questionnaire-autism spectrum disorder. *Autism*, 20(5), 528-537. <https://doi.org/10.1177/1462361315593941>.

Christie, P., Duncan, M., Healy, Z., & Fidler, R. (2012). *Understanding pathological demand avoidance syndrome in children*. Jessica Kingsley Publishers.

Cole, S. R., Platt, R. W., Schisterman, E. F., Chu, H., Westreich, D., Richardson, D., & Poole, C. (2010). Illustrating bias due to conditioning on a collider. *International Journal of Epidemiology*, 39(2), 417-420. <https://doi.org/10.1093/ije/dyp334>.

Eaton, J., & Banting, R. (2013). Adult diagnosis of pathological demand avoidance – subsequent care planning. *Journal of Learning Disabilities and Offending Behaviour*, 3(3), 150-157. <https://doi.org/10.1108/20420921211305891>.

Eaton, J., & Weaver, K. (2020). An exploration of the pathological (or extreme) demand avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and their developmental histories. *Good Autism Practice (GAP)*, 21(2), 33-51(19).

Embretson, S., & Reise, S. (2000). *Item response theory for psychologists*. Lawrence Erlbaum Associates.

Gillberg, C., Gillberg, I. C., Thompson, L., Biskupsto, R., & Billstedt, E. (2015). Extreme ("pathological") demand avoidance in autism: a general population study in the Faroe Islands. *European Child & Adolescent Psychiatry*, 24(8), 979-984. <https://doi.org/10.1007/s00787-014-0647-3>.

Goodman, R. (1997). The strengths and difficulties questionnaire: a research note. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 38(5), 581-586. <http://www.ncbi.nlm.nih.gov/pubmed/9255702>.

Gore Langton, E., & Frederickson, N. (2016). Mapping the educational experiences of children with pathological demand avoidance. *Journal of Research in Special Educational Needs*, 16(4), 254-263. <https://doi.org/10.1111/1471-3802.12081>.

Green, J., Absoud, M., Grahe, V., Malik, O., Simonoff, E., Le Couteur, A., & Baird, G. (2018). Pathological demand avoidance: symptoms but not a syndrome. *The Lancet Child & Adolescent Health*, 2(6), 455-464. [https://doi.org/10.1016/S2352-4642\(18\)30044-0](https://doi.org/10.1016/S2352-4642(18)30044-0).

@HappeLab An obvious place to cite Garralda (2003) would have been here, with those disagreeing with PDA. Then again, considering the article is juxtaposing disagreement against caregivers & those with lived experience of PDA.

2020; PDA Society, 2019). A survey of nearly 1500 respondents conducted by the UK PDA Society revealed that, for many parents, adopting "PDA strategies," including indirect and non-confrontational approaches to making demands, had been helpful. Survey respondents reported that 70% of 969 young people were unable to tolerate their school environment or were home educated, highlighting substantial unmet need (PDA Society, 2019).

Despite enthusiasm from parents and those with lived experience, the concept of PDA has sparked disagreement and debate (Green et al., 2018; Malik & Baird, 2018; Woods, 2020). It has been argued that PDA should be viewed as a collection of symptoms rather than a syndrome (Green et al., 2018). However, there is emerging consensus that some children with ASD do present with a behavioral profile resembling PDA, evidenced by work from several independent groups (Eaton & Banting, 2013; Eaton & Weaver, 2020; Gillberg et al., 2015; Green et al., 2018; O'Nions et al., 2018a, b; Stuart et al., 2019), and international scholars who report that some children with ASD find routine demands aversive and may react to pressure to comply with avoidance and behavior that challenges (e.g., Agazzi et al., 2013; Lucyshyn et al., 2004, 2007).

The difficulties experienced by young people and their families provide a clear imperative for further investigation of extreme demand avoidance (EDA) in children with ASD. Previously, the "Extreme Demand Avoidance Questionnaire" (EDA-Q) was developed to quantify traits described in accounts of PDA based on informant reports (O'Nions, Christie, et al., 2014a). Items drew on descriptive accounts of PDA (Newson et al., 2003), unpublished materials authored by Newson, and relevant items from the Diagnostic Interview for Social and Communication Disorders (DISCO) (Leekam et al., 2002). Items were reviewed by clinical experts. The pool of EDA-Q items was then refined by dropping items that failed to differentiate "PDA" and "non-PDA" groups, based on parental reports of their child's behaviors and whether they

@HappeLab Citing Garralda (2003) then undermines this juxtaposition as it is disagreement with PDA before growth in interest in PDA... Also seems to no mention of Wing's consistent critique of PDA over two decades either...

@HappeLab Likewise a lack of coverage with why PDA has been controversial before growth in interest in PDA.

@HappeLab Seems observation of "cherry picking" / "selective referencing" is valid.

Not the first either in articles by yourself, O'Nions & others, I might point out.

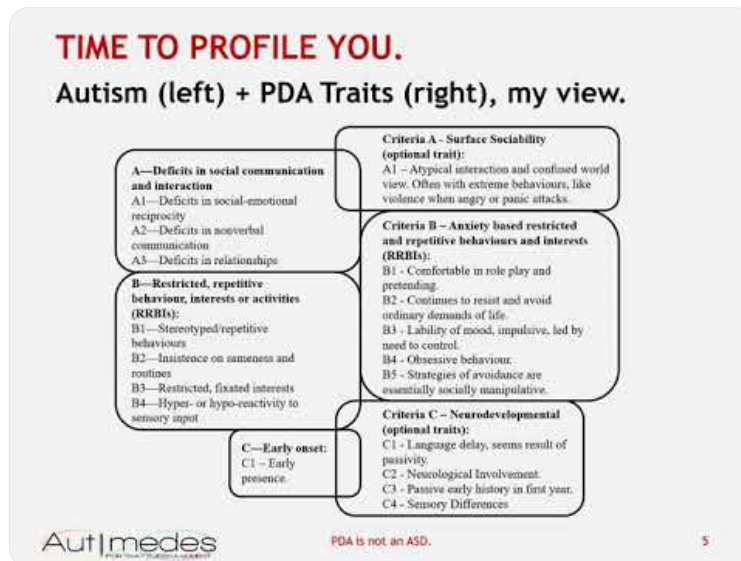
[osf.io/8sbvw/](https://osf.io/8sbvw/)

[@Happelab](#) At least this latest article, substantiates my point the reviewer of this submission of mine was talking male bovine excrement, as O'Nions does view PDA to be autism in their latest article.

[@Happelab](#) "Across the broader autism spectrum as we now know it," p2.

I have no idea what you & others are specifically referring to here?

There is NO agreed definition of what broader autism spectrum is & discuss this here:



<https://www.youtube.com/embed/GSIdMzDMC-w>

[@Happelab](#) This article of yours and others, seems to support my view that a prematurely formed a community of practice surrounding fallacious assumption "PDA is an ASD", and that such research is a self-validation exercise.

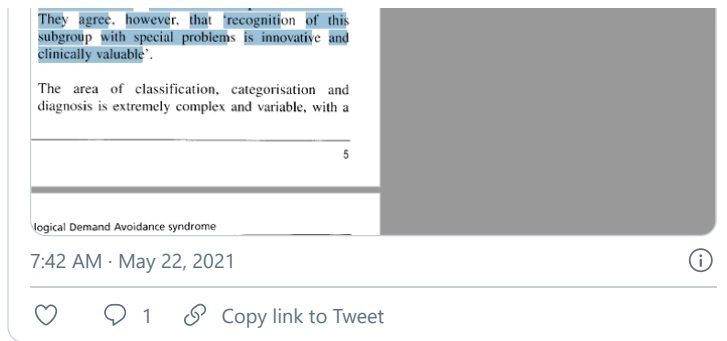
 **Richard Woods**  
@Richard\_Autism

Replying to @Richard\_Autism

Christie does discuss some of the controversies around PDA, including Wing & Gould's comments that PDA is not a separate syndrome & its features can be seen in the autistic population.

**Neurological involvement**  
Crawling is late or absent in more than half these children and other milestones can be delayed. Clumsiness and physical awkwardness is often seen, but Newson feels there is insufficient hard evidence as yet.

**Diagnosis and classification**  
The publications on PDA have attracted great interest and some controversy. The overriding reason for the interest has been in the strong sense of recognition expressed by both parents and professionals of the behavioural profile so cogently described and just how different it is from conventional understandings of ASD. The controversy, particularly among the medical community, has been about whether PDA does exist as a separate syndrome within the pervasive developmental disorders or whether it is part of the autism spectrum. For example, Wing and Gould (2002) feel that PDA is not a separate syndrome and that the individual behavioural features portrayed in the constellation described as PDA can be found within individuals with an autistic spectrum disorder.



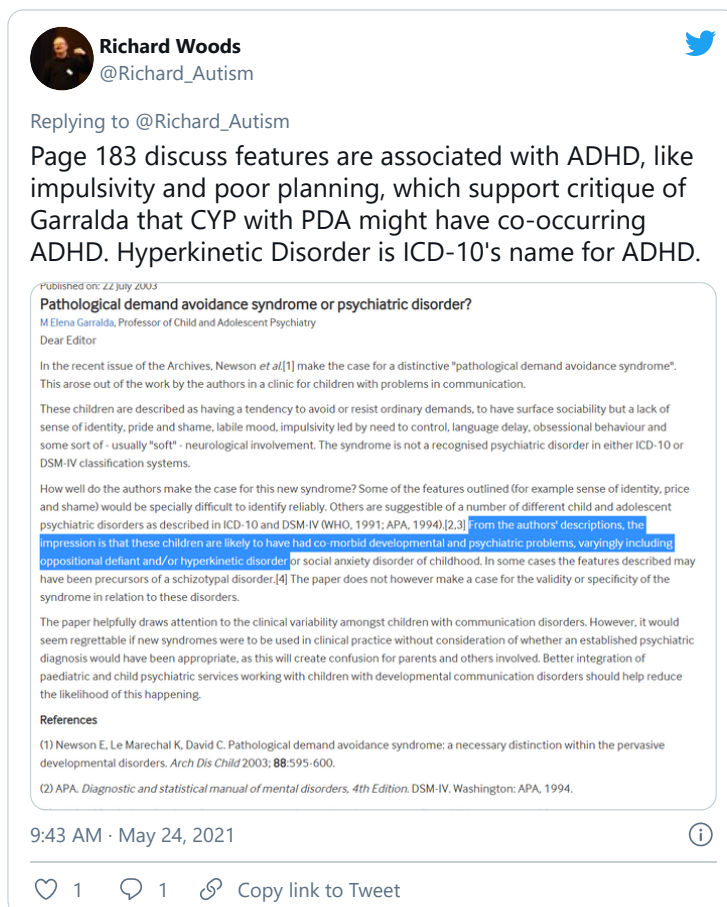
[@HappeLab](#) previous tweet contains a screenshot of where Christie (2007) discusses PDA's controversies, Wing and Gould's views on PDA.

[@HappeLab](#)

"The last ten years have seen a rapid increase in interest in PDA in the UK," (O'Nions et al, 2021, p2).

Sets time period of rise in interest in PDA is discussed in & strong disagreements over it. Article seems not to cover earlier critique.

[@HappeLab](#) not reviewing the literature for research results on the EDA-Q seems to be substantial error. Especially when omitting Garralda (2003), as some of their observations are supported by research with EDA-Q.



@Richard\_Autism

Replying to @Richard\_Autism

"High SDQ conduct and hyperactivity scores plus a clinical diagnosis of anxiety were highly predictive of scores above the pathological demand avoidance threshold on the EDA-Q" (Green et al, 2018, p461-462).



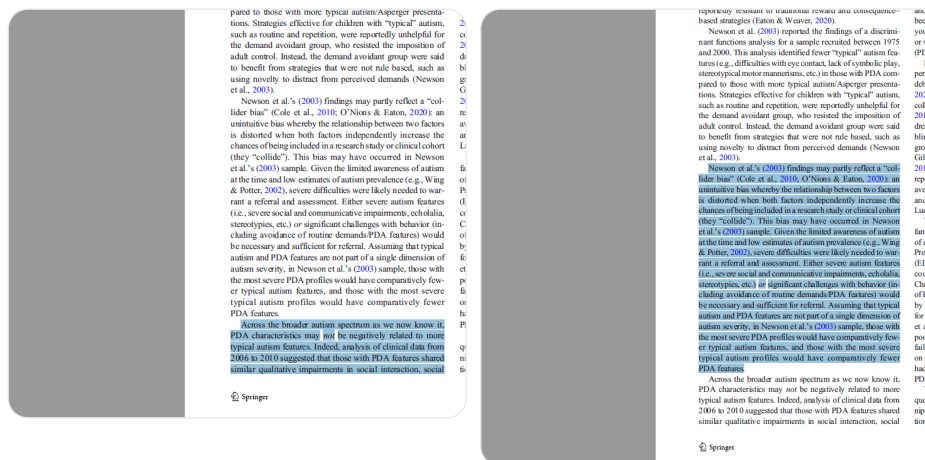
Pathological Demand Avoidance: symptoms but not ...  
Pathological (or extreme) demand avoidance is a term sometimes applied to complex behaviours in childre...  
thelancet.com

8:44 AM · May 22, 2021

1 1 Copy link to Tweet

@HappeLab previous tweets show where at least one of Garralda (2003) observations are supported by research results, with EDA-Q and EDA-QA.

@HappeLab There does seem to be a COI in not discussing such research results & Garralda, as it undermines attempts to try and support the view PDA as an ASD in the article.



@HappeLab If one acknowledges Garralda is correct PDA has features of ADHD, then it contradicts assertions PDA is autism. As PDA cannot be more than its constituent parts.  $A + B + C \neq A$ .



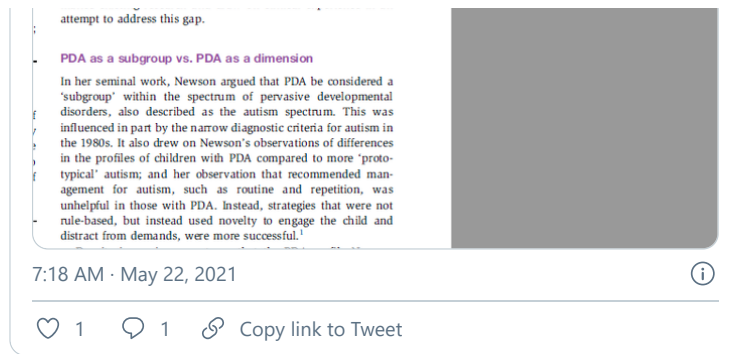
Richard Woods  
@Richard\_Autism

Replying to @Richard\_Autism

Screenshot and link for first quote.  
[linkinghub.elsevier.com/retrieve/pii/S...](https://linkinghub.elsevier.com/retrieve/pii/S...)

often experience severe challenges at home and school, meaning that families are desperate for help. If routine requests are pursued, the child's anxiety may increase, leading to verbal or physical aggression, or threats to harm oneself or others. For many families, all activities revolve around accommodating the child's requirements. Attempts to proactively manage situations to reduce meltdowns or aggressive outbursts, and thus ensure that the child can remain safely in the home, place an enormous burden on families.

In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic. Adults who identify as having PDA, parents of children with PDA, and young people, have been the driving force behind increasing awareness. These groups have authored books and articles based on their lived experience, which have much to offer. However, the lack of research on PDA presents challenges for clinicians, who have a limited evidence base to draw on. Here, we summarise existing research and draw on clinical experience in an



[@HappeLab](#) I would suggest that, perhaps a contributing factor in why growth in PDA has outstripped its research, is because certain "leading experts" (includes more than authors of this article) are not providing balanced & accurate information on PDA?

[@HappeLab](#) It would be substantially harder to justify forming a community of practice, and doing certain research, if one accurately portrays contested nature of PDA & credits certain research results to those who first predicted them.

[@neuroteachers](#) Would you like to do the honours?

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