



Richard Woods @Richard_Autism

Nov 26, 2021 · 53 tweets · [Richard_Autism/status/1464379294566735872](https://twitter.com/Richard_Autism/status/1464379294566735872)

This is an excellent article by [@KristenBott](#) & [@Noahsasson](#).

For me I am slightly speechless at how many of its points, can be applied to assuming PDA is a "Profile of ASD"... I guess in many ways it is predictable. Sigh.



Noah Sasson
@Noahsasson



Studies of "autistic traits" in the general population are increasingly prevalent. In this letter to the editor, [@KristenBott](#) and I discuss why these studies don't necessarily extend to autism and urge caution & clarity in how they're framed & interpreted.



Studies of autistic traits in the general population are not studies of autism. Studies of autistic traits in the general population are becoming increasingly prevalent. In this letter to the editor, we caution researchers...
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2:11 PM · Nov 26, 2021



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To be clear this article is important to PDA debate, if one considers what it means to various PDA studies.

First thing to point out, autistic traits is not the same thing as the diagnostic entity of autism. That features & experience of autistic persons, is not the same of autistic traits in the general population.

"Autistic traits differ from autism both quantitatively, as emphasized in trait studies, and qualitatively." (Sasson & Bottema-Boutel 2021, p1).

So autistic traits are also not specific to autism, & seen in many other conditions/ demographics.

Nick Chown does provides an excellent critique of autistic traits here:

<https://www.openaccessautism.org/index.php/app/article/view/19>

Before I discuss other implications for Sasson & Bottema-Beutel paper relates to PDA research, I need to point out that situation between PDA traits & PDA dx.

There is much greater overlap between PDA traits & PDA as a diagnostic entity, compared to autistic traits & autism.

For autistic traits, as a concept are often assessed for using questionnaires like the Autism Quotient. For PDA, most of our knowledge of it is linked to the Extreme Demand Avoidance-Questionnaire.

That the EDA-Q has been used to diagnose persons with PDA, including at least one non-autistic person.

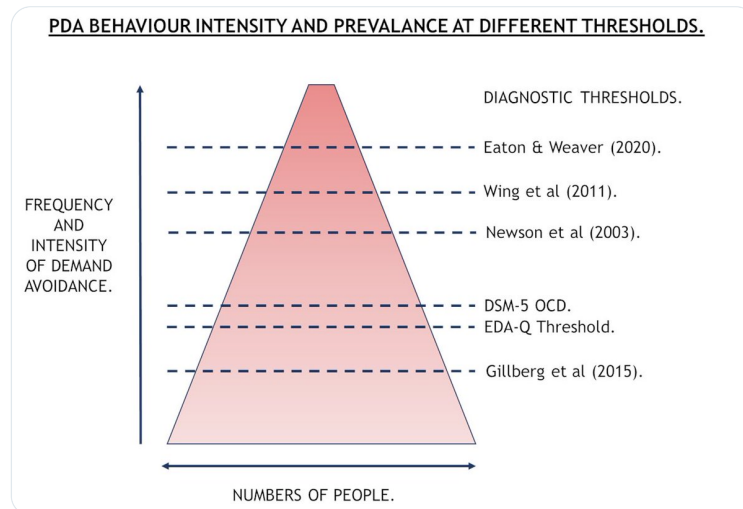
Screenshots showing why the EDA-Q is important to our limited understanding of PDA. Slides are from this conference talk:

https://www.researchgate.net/publication/353348556_Demand_Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_is_it_a_Disorder_at_a_lower_diagnostic_threshold

AVOIDING VARIANCE.	
EDA-Q is important.	
1) A 26-item observer rated screening tool designed for use with autistic CYP with DAP traits (O’Nions et al 2014a).	
2) Validation study contained non-autistic CYP...	
3) EDA-Q threshold is not pervasive or developmental (Woods 2021).	
4) Most/ much DAP clinical needs arguments applicable lower diagnostic thresholds (Woods 2021).	
5) EDA-Q commonly used in DAP diagnoses (Lyle & Leatherland 2018; Reilly et al 2014; Summerhill & Collett 2018).	

AVOIDING VARIANCE.	
EDA-Q is important.	
1) EDA-Q is involved in most DAP research (Bishop 2018; Brede et al 2017; Eaton 2018; Egan et al 2019; Goodman 2018; Green et al 2018; Langton & Frederickson 2016a; Langton & Frederickson 2016b; Lyle & Leatherland 2018; Moore 2020; O’Nions et al 2014a, O’Nions 2015; O’Nions et al 2016; O’Nions et al 2018a; O’Nions et al 2021; Reilly et al, 2014; Stuart et al, 2020; Tollerfield et al 2021; Truman et al 2021; Woods 2019b).	
2) Unwise to substantially deviate from its threshold.	

I do need to be clear there is no consensus over what PDA is, or what it looks like, and this extends to there being multiple diagnostic thresholds for PDA in print.



The EDA-Q threshold is close to the threshold to when features become pathological in nature in DSM-5.

Screenshot is from previous conference talk.

AVOIDING VARIANCE.

When does DAP become "Pathological Demand Avoidance"?

- 1) DAP presents as a continuum in human population.
- 2) Fluid & transient over lifespan & diverse situations.
- 3) *"the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning."* (APA 2013, p21).
- 4) *"...start to display avoidant behaviour and challenging behaviour in response to a particular stressor..."* (Eaton 2018, p20).
- 5) Around EDA-Q threshold and/ or *"problematic demand avoidance"* (O'Nions et al 2018b).

So one could view PDA traits as being akin to PDA as a diagnostic entity, a comparable assumption cannot be made for autistic traits with autism.

"researchers must be careful about framing and interpreting findings about autistic traits as extending to autism for several reasons." (Sasson & Bottema-Beutel 2021, p1).

This is important with PDA, considering the literature acknowledges those with PDA can interact atypically with autism measures.

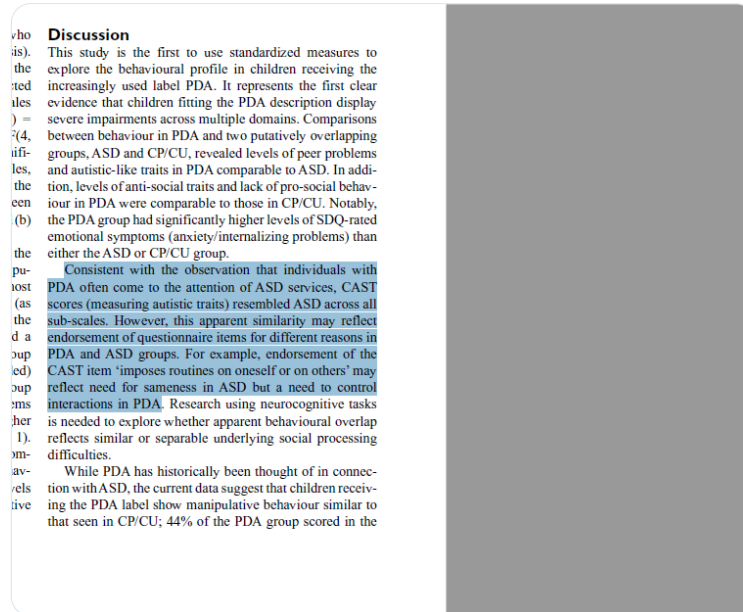
It means one cannot be automatically assume a person meeting cut-off on autism or autistic traits tests, is autistic. Likewise, that any associations between autistic traits/ autism & PDA means PDA is a form of autism.

"traits are also not unique to autism. They often are found at high levels in non-autistic people with anxiety," (Sasson & Bottema-Beutel 2021, p2).

Note the part about autistic traits often found in those with anxiety, & anxiety is meant to be fundamental impairment with PDA.

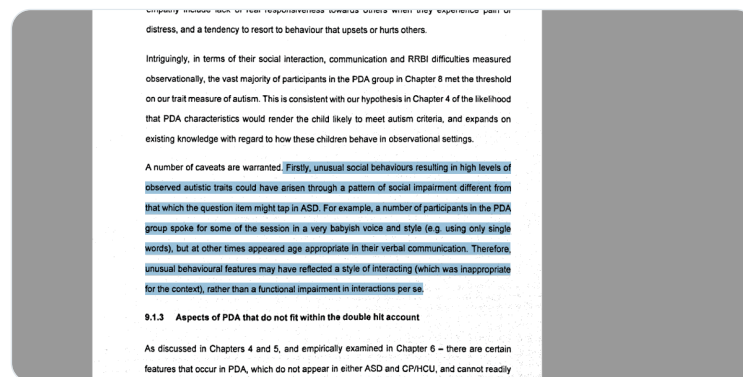
It matters considering with a transactional perspective, stress driven demand-avoidance actions can cause a person to have social interaction issues & consequently issues understanding others.

An example of how those with PDA can interact atypically with autistic traits measure. From O'Nions et al (2014b, 541).



Those with PDA can interact atypically with autism tests, such as their communication style might even be impaired.

From O'Nions (2013 p198).

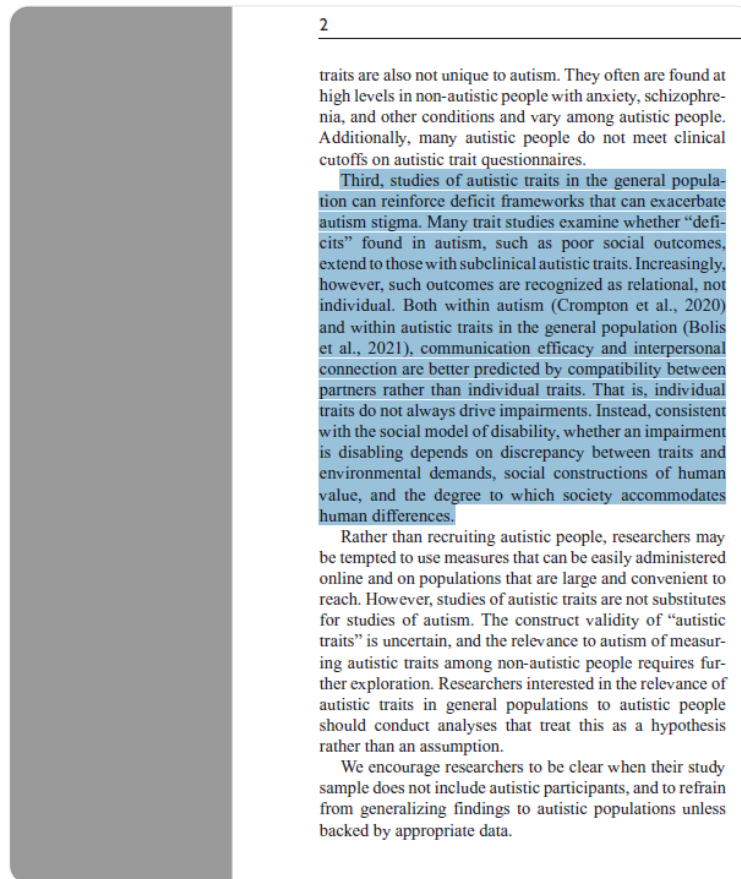


"First, the autism spectrum does not extend indefinitely, and everybody is not "a little bit autistic."" (Sasson & Bottema-Beutel 2021, p1).

The above quote is there to point out, that the autism spectrum is not indefinite. There is a cut-off point, and one reasonably question if PDA falls within that cut-off point.

This matters, as one critique of Sasson & Bottema-Beutel (2021) is that autistic traits can reify notion that features in autistic persons is due to deficits, despite things like social issues seem to be relational in nature.

See the highlighted paragraph from page 2.



This matters when it is increasingly being argued PDA should be viewed as transactional in a nature, such as by (Fidler & Christie 2019; Green et al 2018; Milton 2017).

Viewing PDA as being caused by deficits located within the individual does not represent modern understandings of autism, or PDA.

Lets be clear about this, "PDA Profile of ASD" conceptualisations are often based on assuming there are some deficits present.

"most children show very low level achievement in school because motivation to avoid demands is so sustained, and because the child knows no boundaries to avoidance." Newson et al 2003 p597.

For the EDA-Q.

"... for the purposes of avoidance or controlling interactions (6 items); insensitivity to hierarchy/ praise/need to manage reputation (6 items); lack of responsibility (3 items); need for control (2 items)" O'Nions et al 2014a, p759.

Back to Newson et al (2003, p597) for other deficits:


"Surface sociability, but apparent lack of sense of social identity, pride, or shame:"

For deficits in social identity again, this is from a talk by Phil Christie in 2016, in Denmark. Slide 60.


We need to...

- refine our understanding of the *essential* criteria and the core difficulty with social identity
- Better understand areas of 'overlap' and 'co-morbidity' or co-existence
- Reach broader consensus on use criteria and classification in diagnosis
- Develop research tools for use as screening and diagnostic guidelines
- ...future versions of diagnostic manuals

Note the deficits in not complying with others, by excessive need for control here.
This is from the PDA Society's website:



Identifying PDA



Identifying PDA

Identifying PDA The PDA profile of autism can be difficult to identify, and it's not uncommon for it to be missed, misunderstood or misdiagnosed, which can lead to poor outcomes. This page explor...

<https://www.pdasociety.org.uk/what-is-pda-menu/identifying-pda/>

The distinctive features of a PDA profile of autism are:

- **resisting and avoiding the ordinary demands of life** – the key words here are 'ordinary demands', so this might include getting up, getting dressed, eating a meal or washing. Significantly, it includes things that someone might want to do/enjoy. For more info see [What is demand avoidance?](#)
- **using 'social' strategies as part of the avoidance** – this means not just saying no, withdrawing, shutting down or running away, but a variety of avoidance approaches including distraction, making excuses, physical incapacitation, withdrawing into fantasy, procrastination, controlling, reducing meaningful conversation or masking. For more info see [Demand avoidance of the PDA kind](#).
- **appearing sociable, but lacking some understanding** – meaning that individuals may appear more socially 'able' than one might expect (with, for instance, more 'socially accepted' eye contact or conversational skills) but that this may mask underlying differences/difficulties in social interaction (for instance, not seeing any difference between themselves and an authority figure) and communication (for instance, whilst an individual may be very articulate, their understanding of others may not be so robust).
- **experiencing intense emotions and mood swings** – meaning difficulties with emotional regulation, rapid mood swings, impulsiveness and unpredictability.
- **appearing comfortable in role play, pretence & fantasy** – this can sometimes be to an extreme extent with other personas (be that a person or an animal) being adopted for a prolonged period of time. The line between fantasy and reality can sometimes become blurred.
- **focusing intently, often on other people** – with PDA, "repetitive or restrictive interests" are often social in nature, relating to real or fictional people
- **a need for control which is often driven by anxiety or an automatic 'threat response' in the face of demands**

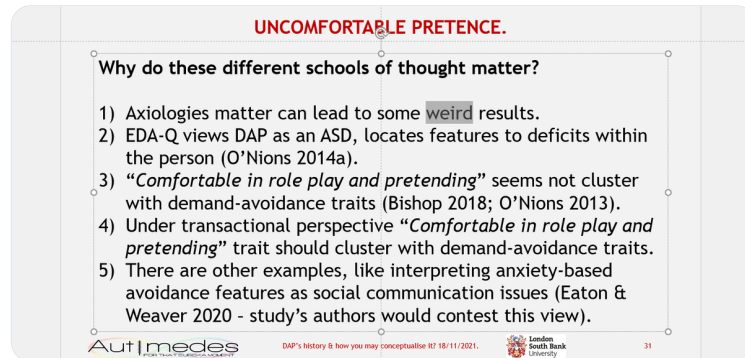
In addition, with PDA, we know that individuals are **unlikely to respond to conventional approaches** in support, parenting or teaching. The response to different approaches is being used as a way to support identification of the PDA profile (for example in the pathway being developed in [Solihull](#)). Helpful approaches for PDA – based on trust, negotiation, collaboration, flexibility and careful use of language – can be found in the [family life](#) and [adult life](#) sections.

This matters, on two levels. One because viewing PDA as being caused by deficits located within the individual is leading to some weird research results.

It can also lead to features which should be a coping mechanism to aversive demands, not clustering with other demand-avoidant traits.

Screenshot is from here:

https://www.researchgate.net/publication/356109997_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_It's_four_schools_of_thought_and_how_you_may_conceptualise_it



It can also apparently lead to some clinicians thinking that those with PDA scoring atypically on the ADOS, is evidence that PDA is a form of autism (as clinicians are not considering they are causing demand-avoidance by stressing CYP via the ADOS).

I am referring to this research:

<https://www.ingentaconnect.com/contentone/bild/gap/2020/00000021/00000002/art00005>

"Third, studies of autistic traits in the general population can reinforce deficit frameworks that can exacerbate autism stigma" Sasson & Bottema-Boutel 2021, p2

The above quote takes into the second reason why "PDA Profile of ASD" etc can be problematic from viewing PDA caused by deficits located in the person.

That is because basing PDA on deficits located within the person, can add to stigma experienced by autistic persons. Contrary to a claim on O'Nions & others.

Considering the harmful impact stigma has upon autistic persons, this is not a good thing, without even considering the notion, it ignores modern transactional understandings of social interactions in autistic persons & other humans.

"That is, individual traits do not always drive impairments. Instead, consistent with the social model of disability, whether an impairment is disabling depends on discrepancy between traits...

... and environmental demands, social constructions of human value, and the degree to which society accommodates human differences."

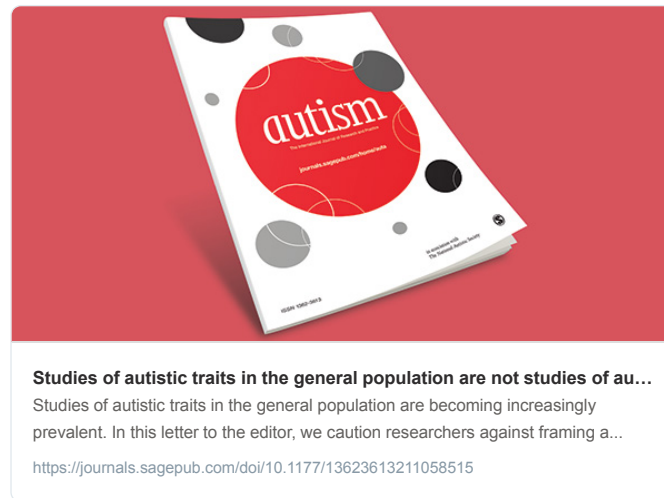
Sasson & Bottema-Beutel 2021, p2.

This quote literal points out that autistic persons are not impaired in social interactions due to deficits, but due to their environment.

At least in social interactions context.

The point is if the demand-avoidance via social avoidance features are impairing due to deficits located within the person, it does not represent modern understandings of autism; how can one reasonably view PDA as a "Profile of ASD"?

Article by [@Noahsasson](#) & [@KristenBott](#) adds to the reasons why it is problematic viewing PDA as a "Profile of ASD" due to various research results. Also on a theoretical level. Adds to ethical problems & controversies surrounding PDA.



In practical terms, it means to be sure a person with PDA is autistic, they probably need an autism diagnosis, which is independent from a PDA assessment, i.e., so that clinicians are not even considering an ASD+PDA dual dx.

Unsure how practical that is though. One might even argue, it requires an autism assessment without the ADOS as PDA seems to act atypically with the ADOS & the ADOS is not designed to assess for PDA features.

So to conclude this short paper. Highlights the problems of assuming PDA is a "Profile of ASD" etc due to those expressing PDA features meeting cut-offs for autism on autism, or autistic traits tools.

That one cannot assume a person with PDA, is autistic due to meeting cut-off on either an autism tool, or autistic traits tool.

On that note. [@threadreaderapp](#) please could you unroll?

Thank you in advance.

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