

Jun 24 · 59 tweets · Richard Autism/status/1540259111727775744

[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)

online March 22, 2018 [http://dx.doi.org/10.1016/S2352-4642\(18\)30044-0](http://dx.doi.org/10.1016/S2352-4642(18)30044-0)

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A more recent example is by Schneider et al (2020), which indicated PDA is not a distinct Disorder/ Syndrome/ diagnostic entity



"Unlike psychiatric comorbidities and adaptive behaviour, PDA was not discriminating. Our results are therefore in agreement with the authors who questioned the validity of PDA as a distinct entity [41]." Schnieder et al (2022, p8).

Just two recent examples of those with divergent views investigating PDA.

If you want an example of someone who thinks "PDA Profile of ASD" supporters have special rights on PDA, look to SallyCat, or the PDA Society (latter with its recent survey).

"What the analysis shows is that, first, neither science nor people with the diagnosis hold a monopoly over the use of language." Werkhoven et al (2021, p5).

Link to article below.

It argues that no stakeholder group has a monopoly over a Disorder/ syndrome.

<https://onlinelibrary.wiley.com/doi/full/10.1111/dmcn.15177>

More pertinently, in the UK academics have legal rights to conduct their research unimpeded due to Academic Freedom. Which means even if "PDA Profile of ASD" supporters wanted other researchers to only research their PDA, it means diddly squat.

Especially, when legal threshold for being disabled by demand-avoidance is the same of other things, it is the threshold set by the Equality Act. That disability threshold is lower than some "PDA Profile of ASD" supporters threshold for PDA.

"You're disabled under the Equality Act 2010 if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities."...

"What 'substantial' and 'long-term' mean

'substantial' is more than minor or trivial, eg it takes much longer than it usually would to complete a daily task like getting dressed"...

... long-term' means 12 months or more, eg a breathing condition that develops as a result of a lung infection".

Link to government's definition for disability:



Considering that when independent parties look at PDA, they all seem to take the same approach of wanting good quality evidence & equally respecting divergent opinion. It tells us what an ethical approach to PDA looks like.

The point here is there is NO consensus over what PDA looks like, or what features are associated with PDA. That topic expert opinion & research results are conflicted over what might be.

I provide a brief introduction to position of independent reviews of PDA here & the various ongoing-historical debates here:



<https://www.youtube.com/embed/5yyUXxGmenw>

I go into great detail about the different schools of thoughts of PDA 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

Yet, a short overview of the different worldviews on PDA is below:

https://www.researchgate.net/publication/354386742_Pathological_demand_avoidance_PDA_Its_four_schools_of_thought

Where am I going with this thread? Simple, I going to argue it will be research which establishes what PDA is & what features are associated with PDA. That it is problematic to prematurely favour anyone outlook on PDA over another...

So, have some prematurely prioritised a particular outlook on PDA? Well yes, PDA Society & those with who are invested in the "PDA Profile of ASD" outlook have done this

Where have they done this? One blatant example is in this research report which is pretending to be clinical guidance on PDA.

<https://www.pdasociety.org.uk/wp-content/uploads/2022/01/Identifying-Assessing-a-PDA-profile-Practice-Guidance.pdf>

I go into extensive depth on why the above research report which is pretending to be clinical guidance is problematic here:

<https://rationaldemandavoidancecom.files.wordpress.com/2022/05/02-february-2022-reflections-on-pda-society-research-report-portraying-pro-pda-profile-of-asd-supporting-clinicians.pdf>

Should the PDA Society & those who put the names to this research report pretending to be clinical guidance been so definitive on PDA? No, it is ethically problematic them acting in the way they have.

How do we know that, as multiple independent parties have all equally respected divergent opinions, these include the likes of [@NICEComms](#) [@rcpsych](#) [@BPSOfficial](#)

I literally quote

National Institute for Health and Care Excellence

Royal College of Psychiatrists

British Psychological Society

reviews of PDA below in the below slides for ease of reference.

https://www.researchgate.net/publication/361101822_Pathological_Extreme_Rational_Demand-Avoidance_Reviewing_and_Refining_its_Contested_Terrain_Through_an_Educational_Perspective_-_A_Frontiers_in_Education_PDA_special_issue

I will quote the recent Dutch systematic review on PDA.

"Given that the validity of PDA is not yet sufficiently substantiated, guidelines for clinical practice hard to pass on. There is currently no consensus on diagnosing or treating PDA." English translation of D. MOLS, M. DANCKAERTS (2022).

"A valid definition and delineation regarding PDA is critical to conduct further research to other domains of validity." From Mols & Danckaerts (2022, p16 - English Abstract).

Is prematurely prioritising one outlook on PDA over another going to achieve a valid definition for PDA?

Being blunt... NO!!!!

Yet, why are the actions of the PDA Society & the clinicians who put the names to this research report pretending to be clinical guidelines unwise & ethically problematic?

<https://www.pdasociety.org.uk/wp-content/uploads/2022/01/Identifying-Assessing-a-PDA-profile-Practice-Guidance.pdf>

"The lack of research into symptom clustering means that the description of the concept of PDA still has little empirical basis and is currently mainly based is on clinical impressions of experts...

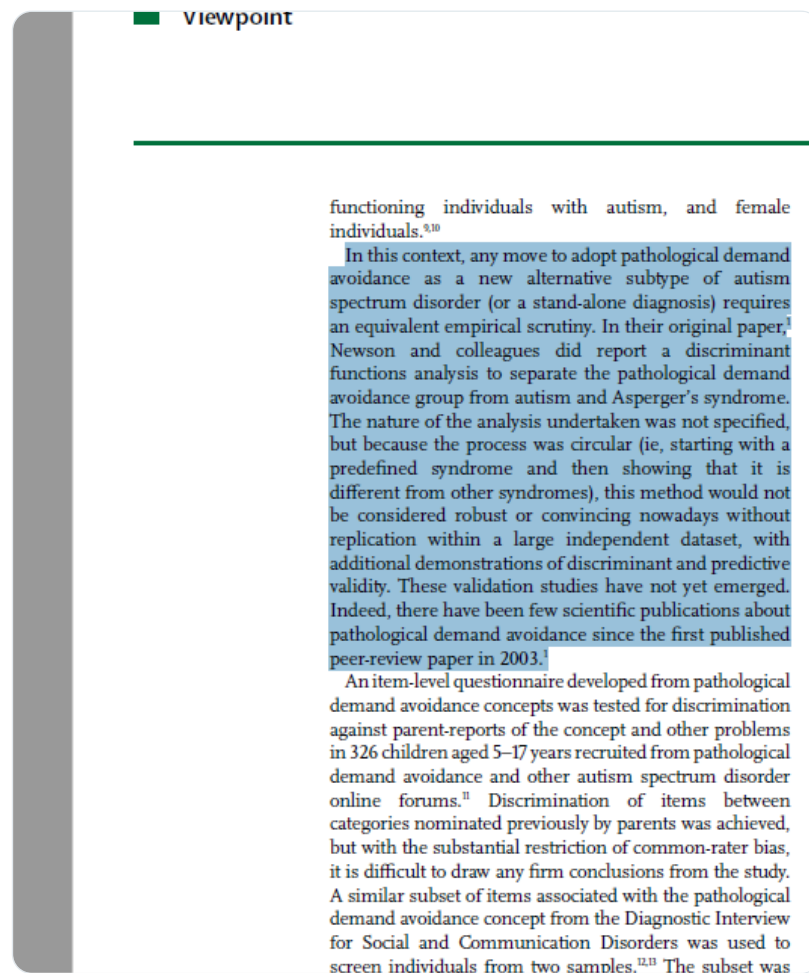
... The high recognition factor that Newson cites as evidence of strong coherence of PDA as an entity is subject to expectation and confirmation bias"

Mols & Danckaerts (2022 - English translation).

I.e. Relying upon clinical opinion is a circular process & is open to bias...

"At first, cluster analytic studies about the symptoms need to be conducted." From Mols & Danckaerts (2022, p16 - English Abstract).

Green et al (2018a, p458) makes a similar point to the Dutch systematic review.



Now this where I bring all this critique together. Yes, "PDA Profile of ASD" supporters could conduct studies to support their views on PDA & try to get PDA recognised as a "Profile of ASD"...

... Yet, at the same time those who disagree with PDA being a "Profile of ASD" can also conduct their studies to get PDA recognised as a Disorder/ separate diagnosis/ Syndrome as something different to "PDA Profile of ASD"...

Can "PDA Profile of ASD" supporters stop research by those who disagree with "PDA Profile of ASD"? No...

Is particularly wise to think that "PDA Profile of ASD" is the only valid way to conceptualise PDA?

I would suggest the literature would say that is clear NO.

Why do I say literature indicates it is unwise to view "PDA Profile of ASD" is only valid way to conceptualise PDA?

Simple answer is that topic expert opinion on what PDA is, is substantially mixed & research evidence on what PDA is conflicted.

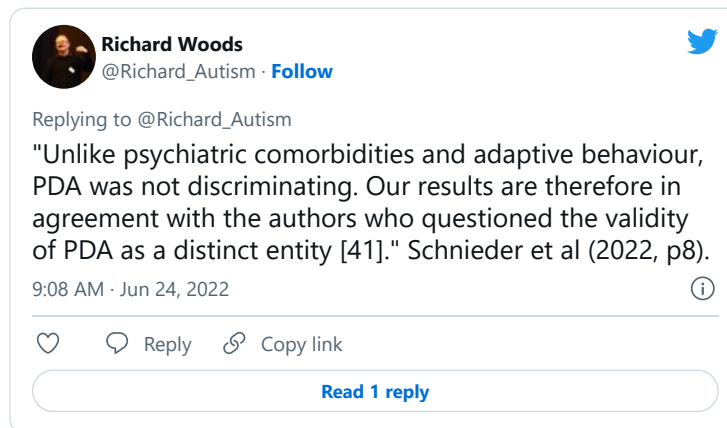
Some studies indicate a connection between PDA & autism, others do not. Many studies indicate PDA is seen in non-autistic persons.

"In the literature, the findings on the positioning of the PDA concept remain divided and remain unclear whether ASD is a necessary predisposition."

Mols & Danckaerts (2022 - English translation).

Link to Dutch systematic review before I forget

<https://tvgg.be/nl/proefschriften/diagnostische-validiteit-van-het-concept-pathological-demand-avoidance-een-systematische-literatuurreview>



Case for PDA being seen in non-autistic persons.

AN OLD ROLEPLAY.

Good case DAP is seen in non-autistic persons.

- 1) Studies DAP is seen outside of autism (Absoud 2019; Eaton 2018; Egan et al 2019; Flackhill et al 2017; Newson et al 2003; O’Nions 2013; O’Nions et al 2014a; O’Nions et al 2014b; O’Nions et al 2015; O’Nions et al 2016a; Reilly et al 2014).
- 2) Studies probably contain non-autistic persons (Stuart et al 2020; Trundle et al 2017).
- 3) Experts DAP is seen outside of autism (Green et al 2018a; Schneider et al 2022; Woods 2020b).
- 4) Advocates for DAP is part of autism spectrum (Thompson 2019).
- 5) “DAP Profile of ASD” supporters likewise discriminating against non-autistic persons with DAP.

Autimedes

DAP: An ethical case study.

London South Bank University

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I set out reasons in the PDA literature why it is problematic viewing PDA as a form of autism here & how PDA can interact atypically with autism tools.

<https://rationaldemandavoidancecom.files.wordpress.com/2022/05/02-february-2022-reflections-on-pda-society-research-report-portraying-pro-pda-profile-of-asd-supporting-clinicians.pdf>

Modern understandings of autism model demand-avoidance with a transactional with environment stressors (internal & external). I.e., demand-avoidance is not due to deficits located within the person.

DROPPING THE MASK.

For whom, is DAP a “complex” matter to?

- 1) “Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).” (APA 2013, p50).
- 2) Modern autism understandings take a transactional stress approach to demand-avoidance (McQuaid et al 2022), i.e., demand-avoidance is not due to deficits located within the person.
- 3) Is DAP a “complex”/ confusing matter to “DAP Profile of ASD” supporters?

AutImedes DAP: An ethical case study. London South Bank University 18

Richard Woods
@Richard_Autism · Follow

Replying to @Richard_Autism

An example of one view on the broadening of autism as a construct, shows it has been static since the DSM-5, from Lombardo & Mandelli (2022).

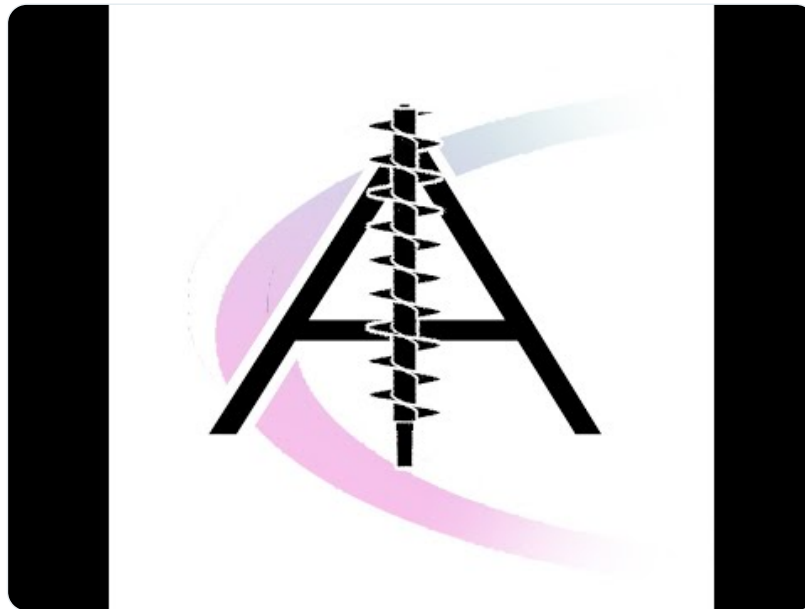
I do not agree with everything in this image.

The diagram illustrates the historical changes in the diagnostic criteria for autism spectrum conditions. It shows a timeline from 1943 to 2018, with key milestones marked by vertical lines. The criteria are categorized into four main groups: Kanner, Asperger, Monothetic, and Polythetic. The Kanner and Asperger criteria are shown as static since the DSM-5. The Monothetic criteria are shown as static since the DSM-III-R. The Polythetic criteria are shown as static since the DSM-5. The diagram also shows the inclusion of Asperger's syndrome in the DSM-5 and the DSM-5's definition of autism as a 'disturbance' that is not better explained by intellectual disability or global developmental delay.

7:01 AM · Jun 20, 2022

Read 1 reply

It is possible to inclusively model PDA with a transactional stress perspective.



<https://www.youtube.com/embed/7cCYoHV4ii8>

I set out reasons here, why it is problematic adopting a narrow perspective on PDA, as a "Profile of ASD", using examples from the autism literature.

A MATTER OF PERSPECTIVE.

Should be wary prioritising narrow views on DAP.

- 1) Most would accept Asperger's views on autism was substantially broader than Kanner's.
- 2) Kanner's his drive to establish child psychiatry held back understandings of autism by decades (Silberman 2015).
- 3) *"the best predictor of which autism spectrum diagnosis a person received (Asperger disorder, PDD-NOS, or autistic disorder) was which clinic the individuals went to, rather than any characteristic of the individual."* (Happé 2011, p541).
- 4) Clinician's bias can be a barrier to identifying autistic females (Lockwood-Estrin et al 2020).

AutImedes DAP: Implications of it being a biopower identity? London South Bank University 52

Another example to be wary of narrow views "PDA Profile of ASD", is a historical one from Psychiatry, when in 1920s it was mistakenly assumed that Epilepsy & Schizophrenia were rarely co-occurring with each other.

There is even a quote from Judy Eaton which is relevant to this debate, see p75 below.

https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DSM-5_a_rebuttal_to_Judy_Eaton

The point is, just because some prematurely believe (for whatever reason) they know what PDA is (PDA Profile of ASD). It is a MASSIVE & DANGEROUS ASSUMPTION to believe that only their views/ beliefs on PDA are valid.

It is NOT an assumption I am making & for many good reasons.

Especially, when others are conducting PDA research & those studies are likely to support divergent outlooks on PDA...

Because "PDA Profile of ASD" are NOT in control of PDA, or have a monopoly on PDA.

Which takes me to why I started this thread. To point out that it is ethical & reasonable to acknowledge where the academic debate is on PDA, the ongoing-historical debates on PDA.

<https://www.frontiersin.org/research-topics/40032/pathological-extreme-rational-demand-avoidance-reviewing-and-refining-its-contested-terrain-through>



<https://www.youtube.com/embed/xFiUWN3y9ho>

[@threadreaderapp](#) please could you unroll?

Thank you in advance.

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