Richard Woods @Richard_Autism

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There are multiple PDA studies with diagnosed non-autistic persons in, including Newson's, showing clinical need to diagnose PDA outside of autism.

What are the ethical considerations clinician's should be making when deciding to restrict PDA only to autistic persons?

Presently, "PDA Profile of ASD" supporters generally, do not consider if there is a clinical need for PDA in non-autistic persons. They are mainly just going "that does not look like how we think PDA looks like, so it is not PDA". Which is problematic putting it mildly."

Then again "PDA Profile of ASD" supporters also generally ignore that there are multiple cases of non-autistic persons with PDA in the literature (PDA obviously cannot be an ASD if it is seen in non-autistic persons).

To be clear, I go through the various arguments for PDA's clinical need here, & show that most of those arguments are applicable to non-autistic persons with PDA.

I also point out most of the studies with non-autistic persons in here: https://rationaldemandavoidancecom.files.wordpress.com/2021/08/20-june-2021-10-studies-indicating-pda-is-seen-in-non-autistic-persons.pdf

Depending on how one defines PDA, there are multiple non-autistic persons with PDA in Chapter 8 sample of O'Nions thesis.

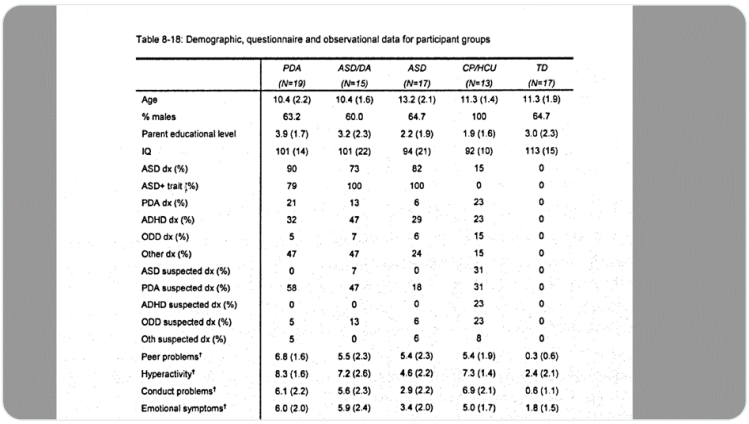
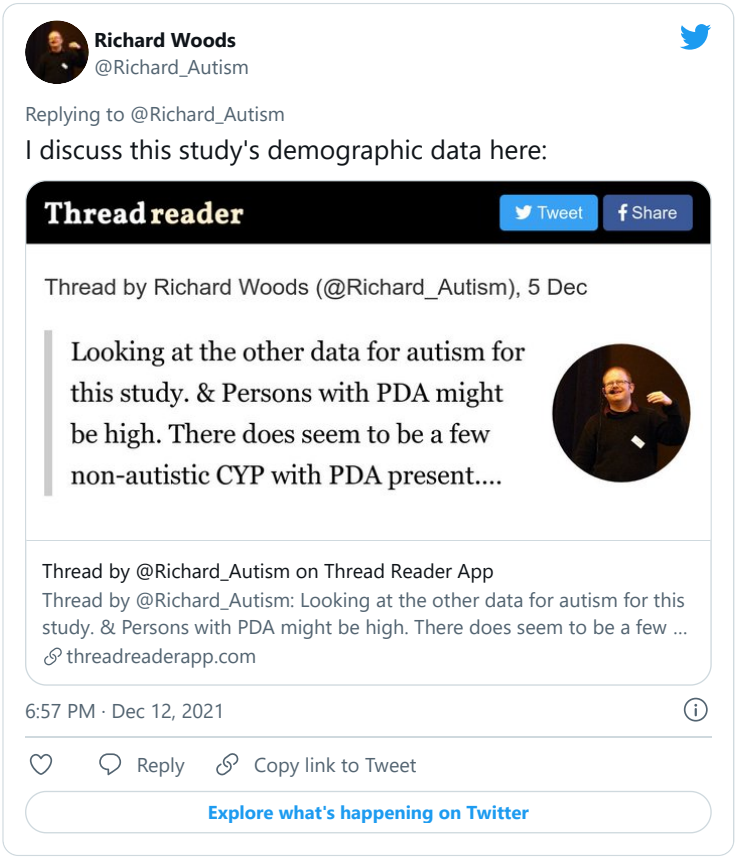


Table 8-18: Demographic, questionnaire and observational data for participant groups

	PDA (N=19)	ASD/DA (N=15)	ASD (N=17)	CP/HCU (N=13)	TD (N=17)
Age	10.4 (2.2)	10.4 (1.6)	13.2 (2.1)	11.3 (1.4)	11.3 (1.9)
% males	63.2	60.0	64.7	100	64.7
Parent educational level	3.9 (1.7)	3.2 (2.3)	2.2 (1.9)	1.9 (1.6)	3.0 (2.3)
IQ	101 (14)	101 (22)	94 (21)	92 (10)	113 (15)
ASD dx (%)	90	73	82	15	0
ASD+ trait ¦(%)	79	100	100	0	0
PDA dx (%)	21	13	6	23	0
ADHD dx (%)	32	47	29	23	0
ODD dx (%)	5	7	6	15	0
Other dx (%)	47	47	24	15	0
ASD suspected dx (%)	0	7	0	31	0
PDA suspected dx (%)	58	47	18	31	0
ADHD suspected dx (%)	0	0	0	23	0
ODD suspected dx (%)	5	13	6	23	0
Oth suspected dx (%)	5	0	6	8	0
Peer problems†	6.8 (1.6)	5.5 (2.3)	5.4 (2.3)	5.4 (1.9)	0.3 (0.6)
Hyperactivity†	8.3 (1.6)	7.2 (2.6)	4.6 (2.2)	7.3 (1.4)	2.4 (2.1)
Conduct problems†	6.1 (2.2)	5.6 (2.3)	2.9 (2.2)	6.9 (2.1)	0.6 (1.1)
Emotional symptoms†	6.0 (2.0)	5.9 (2.4)	3.4 (2.0)	5.0 (1.7)	1.8 (1.5)

I discuss this study's demographic data here:



There is a non-autistic person diagnosed with PDA here:

This has been recognised as being non-autistic by the Kildahl et al (2021) systematic review.

Screenshot of page 2171 with above case study being acknowledged as non-autistic. Link to the systematic review.
https://journals.sagepub.com/doi/pdf/10.1177/13623613211034382

This matters, as it shows that we are working with DSM-5 autism criteria. That as a person is autistic due to CURRENT autism understandings, not because some persons view PDA to be part of the autism spectrum.

"it is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5."
Eaton & Weaver (2020, p34).

There is a similar statement in Soppitt (2021) about how not all of Newson's cohort do not meet DSM-5 autism criteria. Comments in Newson et al (2003), Christie (2007), & Christie et al (2012), also view not all of Newson's cohort as being autistic.

"few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded." (Newson et al, 2003, p596).

"most of the children referred were complex and anomalous in their developmental profile and many reminded the referring professionals of children with autism or Asperger's syndrome. At the same time, though, they were often seen as atypical in some way."
Christie 2007, p3

"though, they were often seen as atypical in some way. Many of these children came away from the clinic with a diagnostic assessment report that described them, in various ways, as being 'atypically autistic'."
Christie 2007, p3.

In addition to how not all of those being assessed at the clinic were autistic, even by a residual diagnosis, like PPD-NOS (atypical autism in this case).

Newson was consistent, that PDA is not part of the autism spectrum too.

I have spoken plenty of times about how there are non-autistic persons with PDA in the literature, so I do not wish to go on about that.

I would like to know what are the norms for choosing to prioritise their own views on PDA over other persons?

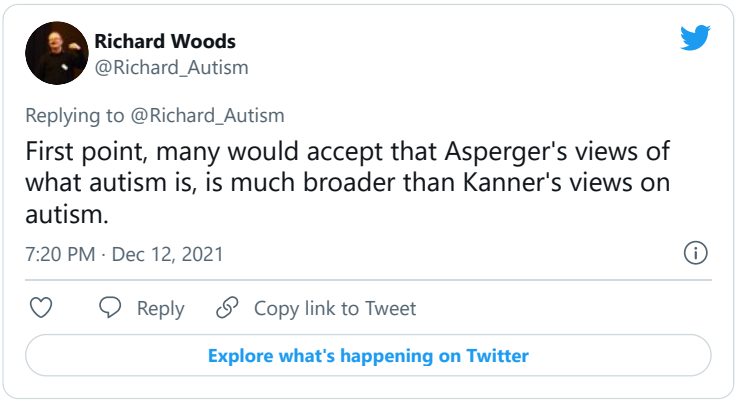
First point to make is that many key "PDA Profile of ASD" advocates are autism specialists, & simply lack the experience to say what PDA looks like in the general population.

Particularly thinking of the likes of Christie here. His background seems to be substantially less diverse than Gillerg's for example. Gillberg suggests PDA is seen quite commonly & in different constructs.

Another point to make is that most Disorders are spectrum, heterogenous in nature, and often have features which overlap other Disorders in the DSM-5. This is quite clearly stated in the front of the DSM-5. So PDA can still be PDA at lower diagnostic thresholds...

We also know from autism literature it is problematic reifying one particular outlook of a Disorder, in this case the construct of ASD, over another. There multiple reasons why.

First point, many would accept that Asperger's views of what autism is, is much broader than Kanner's views on autism.



Second one is that a clinician's opinion can bias who they diagnose with autism to begin with. We know that a clinician's bias can be a barrier to diagnosing autism in females.

Link to systematic review to barriers diagnosing autism in females.

Barriers to Autism Spectrum Disorder Diagnosis for Young Women an…
Review Journal of Autism and Developmental Disorders - There is increased recognition that women and girls with autism spectrum disorders (ASD) are underserved by the clinical criteria and...

https://link.springer.com/article/10.1007/s40489-020-00225-8

Worth restating this quote by Eaton on the topic.
“Professionals and teams working with children need to become aware of the ways in which girls can mask their difficulties, and need to move away from using the DSM as a ‘bible’...

... Stating that someone does not fulfil criteria, when these criteria are based on upon a ‘male’ presentation of a disorder, is short sighted in the extreme.” (Eaton, 2017, page 176).

One can make a similar statement about not diagnosing PDA in non-autistic persons due to basing PDA diagnostic criteria on autistic presentations of PDA. Again must be said PDA probably presents differently in autistic persons, when seen in non-autistic persons.

"A study by Lord and colleagues8 showed that 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." Happe 2011, p541.

I.e., a clinician's (broader clinic's) bias, impacts which specific subtype a person was diagnosed with under DSM-4.

We also know from autism history, that understandings of autism has become much broader, in how autism presents, but all autistic persons do tend to need support in some form. So that autism prevalence rates have risen substantially.

Link to where I argue this in a conference talk.
https://www.researchgate.net/publication/353348556_Demand_Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_is_it_a_Disorder_at_a_lower_diagnostic_threshold

So we know that there are cases of non-autistic persons with PDA in the PDA literature. That there are good reasons from DSM-5 & autism literature to think it is probbaly silly to view PDA as only presenting a particular way, i.e., how it may presents in autistic persons.

Which takes me back to:

What are the ethical considerations clinician's should be making when deciding to restrict PDA only to autistic persons?

From what I can tell they are good grounds ethically, legally & clinical need arguments to diagnose PDA in non-autistic persons.

There are also seems to be good arguments from a knowledge & understanding perspective to diagnose PDA in non-autistic persons.

I am genuinely interested to know if there is anything I am missing on this.

What should clinicians be ethically considering before deciding to restrict PDA only to autistic persons?

@threadreaderapp Please could you unroll?

Thank you in advance.

To put this into context, "PDA Profile of ASD" supporters obviously accept the clinical need for PDA, as they are advocating for it to be diagnosed in autistic persons.

This is where it gets potentially dodgy as the SEND system is needs based. Multiple studies have examples of PDA being diagnosed in non-autistic persons, as shown above. Generally, practicing clinicians are not meant to discriminate.

It is worth restating the standards of regulator for practicing psychologists, occupational therapists & speech and language therapists standards is clear; they must NOT discriminate & challenge discrimination where they find it.

From @The_HCPC standards.
Challenge discrimination

1.5 You must not discriminate against service users, carers or colleagues by allowing your personal views to affect your professional relationships or the care, treatment or other services that you provide.

From @The_HCPC
1.6 You must challenge colleagues if you think that they have discriminated against, or are discriminating against, service users, carers and colleagues.

Link to @The_HCPC standards.
https://www.hcpc-uk.org/standards/standards-of-conduct-performance-and-ethics/

Link again to where I show most of the clinical need arguments are applicable to non-autistic persons with PDA.

When you consider such things, it probably is no wonder that generally "PDA Profile of ASD" supporters do not consider if there is a clinical need for PDA outside of autism. One might suspect they might not like the potential answer.

@threadreaderapp please can you unroll again?

Thank you again.

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