



Richard Woods @Richard_Autism

Sep 17 · 116 tweets · [Richard_Autism/status/1571235940324020228](#)

This seems a reasonable critique of a recent paper by Kinderman (whose work I generally hold in high regard).

Why am I mentioning this?

Obviously, to critique something PDA related.



Link to the article co-authored by Kinderman. Study Linguistic analysis of online articles and blogs, debating fundamental issues of psychiatric diagnoses online; so some materials were pro, against, & mixed in position towards use of psychiatric diagnoses.

Link to article mentioned above:

<https://www.tandfonline.com/doi/full/10.1080/09638237.2021.2022631?cookieSet=1#.Yx7MFwUiPPI.twitter>

Why I am mentioning this? The article could have used representative sampling to select public materials to form data set of the data analysis. One could view the selection strategy as a weakness by biasing its results to fit the aim of the study.

So Richard you are mentioning to rant again about how only researching/ diagnosing PDA in suspected autistic persons biases PDA knowledge base & its clinical populations? No, this is not the reason for this short thread.

I am doing it to point out a reason why I refer to the guidance produced by PDA Society in February is a highly partisan research report.

Link to said research report.

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

The point is just asking a bunch people of people, who share a similar/ same view on PDA to produce "guidance" on PDA is going to produce a non-representative & biased report. This is one of the critiques I make 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>

"All the contributors have extensive experience of working with and supporting PDA individuals, and were invited to contribute because either they had recently published on the topic or had long-standing professional contact with the PDA Society."

p1, or the PDA Society report.

"This guidance, therefore, is based on the contributors' considerable clinical experience and expertise and represents their consensus view of current practice and understanding." PDA Society Report p1

Image showing that 11 out of the 12 contributors to PDA Society's Report have a conflict of interest from being in independent/ private practice. Information for the table is seen in page 26-27 of the PDA Society Report.

Table 1: PDA Society Clinicians views Research Report Contributors private practice status.

Number.	Contributor.	Private Practice.	Independent Practice.
1	Phil Christie	No	Yes
2	Gloria Dura-Vila	Yes	No
3	Judy Eaton	Yes	No
4	Allison Hart	No	Yes
5	Libby Hill	No	Yes
6	Keith Howie	No	Yes
7	Ann Ozsivadjian	No	Yes
8	Georgie Siggers	No	Yes
9	Pat Smith	No	No
10	Lisa Summerhill	Yes	No
11	Vicki Wingrove	Yes	No
12	Julia Woollatt.	Yes	No
13	Phil Christie	No	Yes

Richard how do you know this PDA Society research report is biased? I can refer to messages/ emails from others complaining about it. Also PDA literature widely acknowledges that PDA is controversial & contested. Many have written challenging position advocated by PDA Society.

Arguable most well known example.

Pathological Demand Avoidance: symptoms but not a syndrome

Pathological (or extreme) demand avoidance is a term sometimes applied to complex behaviours in children within—or beyond—autism spectrum disorder. The use of pathological demand avoidance as a diagn...

[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)

Recent systematic review

<https://journals.sagepub.com/doi/full/10.1177/13623613211034382>

We know PDA is controversial & contested due to positions of @NICEComms & @repsych towards PDA.

Images show NICE's comments on PDA in recent review of evidence & consultation. Also NICE comments of PDA in its only guidelines for autism which mention PDA, which view PDA as ODD.

Operational defiant disorder (ODD)

Operational behaviour is common in children with ASD.

Children with ODD may show limited empathy or concern for others including lack of remorse.

in ODD

- The child usually understands that that behaviour is unacceptable, even unacceptable for his parent with it.
- The behaviour often has a deliberate quality.
- The child often has clear benefits for the child.
- When children are motivated to alter their behaviour they may do so.
- Should be able to show evidence of social communication.

Assessment of the quality of communication and social interaction in situations when the child is rejecting himself and not trying to avoid demands

Operational behaviours are developmentally normal at times. ODD may coexist in autism as a separate disorder. The operational defiant behaviours in autism are likely to be due to a lack of the sensitivity, sensory sensitivities and anxiety, in ODD, such behaviour is likely to be due to a feeling of being overwhelmed with angry, upset feeling and feeling threatened.

Pathological demand avoidance (PDA) has been described as a particular subgroup of autism with passive early onset, obsessive behaviours which are

see the [summary of evidence from surveillance](#).

Other sources of information

We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiant disorder. Experts in this area informed us that PDA is not a recognised diagnosis in ICD-11 or DSM-V but its characteristics are considered to be part of the autistic spectrum disorder of disorders. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. We therefore assessed this enquiry as having no impact on recommendations.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake of surveillance evidence could have various barriers, such as access, literacy, numeracy.

Appendix K – Differential diagnosis advice for healthcare professionals

Key presenting features that may overlap with autism	Main features to differentiate from autism	Assessments or investigations to differentiate from autism	Special notes / diagnostic pitfalls
	<ul style="list-style-type: none">• understanding competence so that he/she will have some awareness of the impact of their behaviour• Does not usually show stereotyped or repetitive behaviour <p>The child with autism:</p> <ul style="list-style-type: none">• May have little if any awareness of		<ul style="list-style-type: none">• often person focused with superficial social skills in whom the most striking feature is what is usually excessive demand avoidance) even to events which the child enjoys. This oppositional behaviour can also be described as ODD.

abstract reported statistical data on the difference in rates of the condition in people with autism and those without autism).

Pathological demand avoidance

Topic experts, patient groups, and other correspondence received since the NICE guideline was published has suggested that the guideline should consider pathological demand avoidance as a specific profile for people with autism. The term is used to describe complex behavioural problems that mainly manifest as extreme avoidance of everyday requests and expected behaviours. Disagreement remains about whether pathological demand avoidance should be recognised as a distinct diagnosis. Some topic experts considered that appropriate recognition of coexisting conditions and individualised management strategies are sufficient. Because we did not identify any new evidence in this area, pathological demand avoidance is not being proposed as an area for update.

Surveillance proposal

We propose not to update the sections of the NICE autism guidelines covering coexisting conditions.

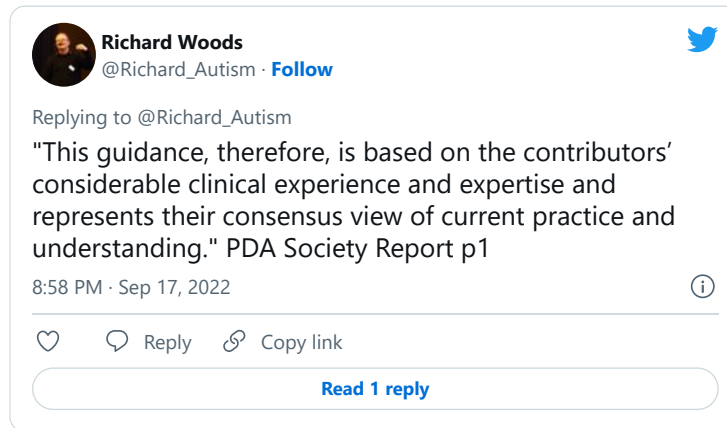
Surveillance consultation report October 2020 – Autism theme (NICE guidelines CG128, CG142 and CG170)

Most of the evidence identified in this surveillance review was consistent with the lists of coexisting conditions in current recommendations. Evidence for conditions not currently on the list (obesity, asthma, persistent crying as infants, and hypochlosterolaemia) tended to be from studies with methodological limitations and did not sufficiently establish links between autism and other coexisting conditions. **We did not identify suitable evidence to provide links with anxiety or pathological demand avoidance that supported earlier feedback we received about these disorders.**

Link to @NICEComms review of PDA evidence & equally respecting divergent opinions on PDA which includes that PDA is not distinct Disorder/ Syndrome, but represents features belonging to accepted things.

<https://www.nice.org.uk/guidance/cg128/documents/surveillance-review-proposal>

So how did the PDA Society achieve consensus amongst those contributing to the research report?



They only asked those who view PDA to be part of the autism spectrum & most of those 12 contributing clinicians careers/ incomes are at least partially dependent on supporting that outlook. Is a conflict on interest present for these 12 persons contributing to this report?

Table 1: PDA Society Clinicians views Research Report Contributors private practice status.

Number.	Contributor.	Private Practice.	Independent Practice.
1	Phil Christie	No	Yes
2	Gloria Dura-Vila	Yes	No
3	Judy Eaton	Yes	No
4	Alison Hart	No	Yes
5	Libby Hill	No	Yes
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7	Ann Ozsivadjian	No	Yes
8	Georgie Siggers	No	Yes
9	Pat Smith	No	No
10	Lisa Summerhill	Yes	No
11	Vicki Wingrove	Yes	No
12	Julia Woollatt.	Yes	No
13	Phil Christie	No	Yes

"...there has been some over-identification by other practitioners." p1.

I.e., claiming some clinicians have diagnosed PDA, when PDA is not present in a person.

Point of the research report by PDA Society, is to control how to approach PDA in clinical practice.

Considering there is such large variation in clinical practice in PDA across UK, it is more than plausible that the 12 clinicians contributing to this report & PDA Society are mistaken, that actually PDA presents differently to how it is presented in the research report!...

"Identification of PDA across the country is variable. There are some services and professionals who do not recognise PDA as a diagnostic term." PDA Society report, p1.

This is my point, with there being such large variation in practice & clinical opinion. Only way to gain consensus between contributing clinicians is to bias the sample of contributing clinicians. We know participants were invited by PDA society to contribute towards the report!

Is this approach ethical, or robust?

I would say, probably not, no!

How can we tell it is probably unethical & un-robust approach?

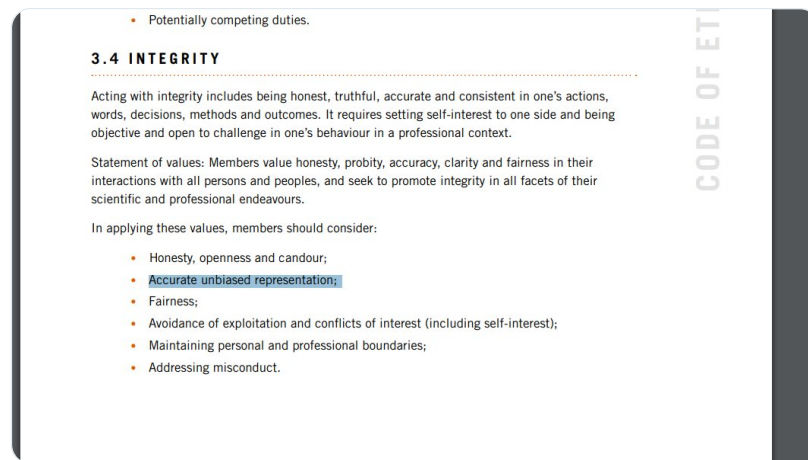
Say I produced a research report claiming to be guidance on how to assess PDA, by only inviting those who think PDA is a pseudo-syndrome, i.e., not a distinct thing. What would be response by PDA Society & others be?

They would probably say said report is biased, as it is not an accurate reflection of PDA, as you have not invited pro "PDA Profile of ASD" supporting clinicians to contribute towards it.

If you want another indicator that such a biased approach to PDA is problematic, one could check code of conduct & ethics by @BPSOfficial. Link to it below:

<https://cms.bps.org.uk/sites/default/files/2022-06/BPS%20Code%20of%20Ethics%20and%20Conduct.pdf>

Image of from page 7 of @BPSOfficial code of ethics & conduct, it shows section on integrity.



"It requires setting self-interest to one side and being objective and open to challenge in one's behaviour in a professional context....

members should consider...

Accurate unbiased representation...

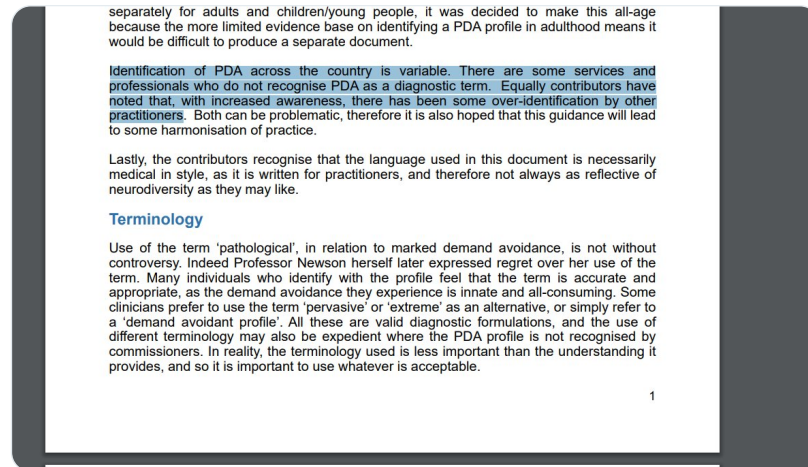
Avoidance of exploitation and conflicts of interest (including self-interest)p7

One could question if the above points have been practiced by PDA Society & the contributing 12 clinicians to its research report.

That brings me full circle in why I retweeted a tweet about sample selection & how it biases research is relevant & that my critique of PDA Society's research report is reasonable.

"Identification of PDA across the country is variable. There are some services and professionals who do not recognise PDA as a diagnostic term. Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners" p1.

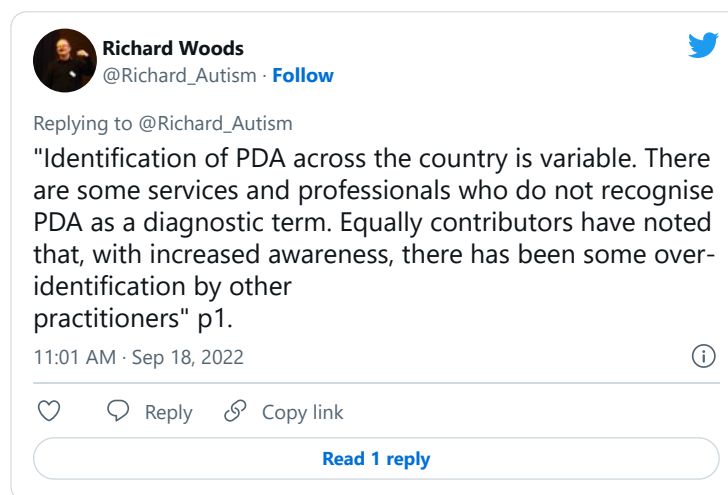
Below is image of from page 1 of PDA Society's research report, which is pretending to be guidance. Highlighted text is the above quote.



Worth noting the quoted text goes on to state the research report is hoped will lead to harmonisation, i.e., to control clinical practice on PDA (as stated previously in the thread)...

... Why am I continuing this thread?


The below quote, the report admits its contributors views on PDA are not representative of broader practice, as there is huge variation in clinical practice to PDA & its contributors view PDA to be over identified.



Fact this report's portrayal of PDA is not representative of broader clinical practice, one cannot take it seriously, partly as its methodology seems to be done to conduct aim of controlling clinical practice on PDA towards a particular outlook. Which is unethical & not robust.

It does beg the question: Why have these 12 clinicians chosen to contribute to this research report & acknowledge their portrayal of PDA is not representative of broader clinical practice?

Perhaps, below tweet gives us an answer.

 **Richard Woods**
@Richard_Autism · Follow

Replying to @Richard_Autism

They only asked those who view PDA to be part of the autism spectrum & most of those 12 contributing clinicians careers/incomes are at least partially dependent on supporting that outlook. Is a conflict on interest present for these 12 persons contributing to this report?

Table 1. PDA Society Clinicians view Research Report Contributors private practice status.

Number	Contributor	Private Practice	Independent Practice
1	Paul Christie	No	Yes
2	Glenn Dunsford	Yes	No
3	Andy Wilson	Yes	No
4	Allyson Pratt	No	Yes
5	Lizzy Hill	No	Yes
6	Keith Brown	No	Yes
7	Alan Marshall-Jones	No	Yes
8	George Siggins	No	Yes
9	Paul Smith	No	No
10	Una Summerhill	Yes	No
11	Nick Wingrove	Yes	No
12	John Woodcock	Yes	No
13	Paul Christie	No	Yes

Fact that portrayal of PDA in the research report is not representative of broader clinical practice means it is plausible to likely that contributing clinicians perspectives on PDA are mistaken, at least in some aspects of what PDA is & its associated features!

Yet, we are meant to accept & believe that PDA Society & those behind this research report are the only persons who understand PDA & know what PDA is; as purpose of report is to control clinical practice surrounding PDA.

Which seems nonsensical proposition. Sigh.



Obviously, implication of this, is that other research of PDA which adopts a similar position to this research report is going to be non-representative of broader clinical practice & same/ similar issues...

I suppose this kind of things happens when a community of practice prematurely forms around a concept, develops its own ideology & terminology. Which is something I critiqued about pro "PDA is an ASD" etc position, 3 years ago here:

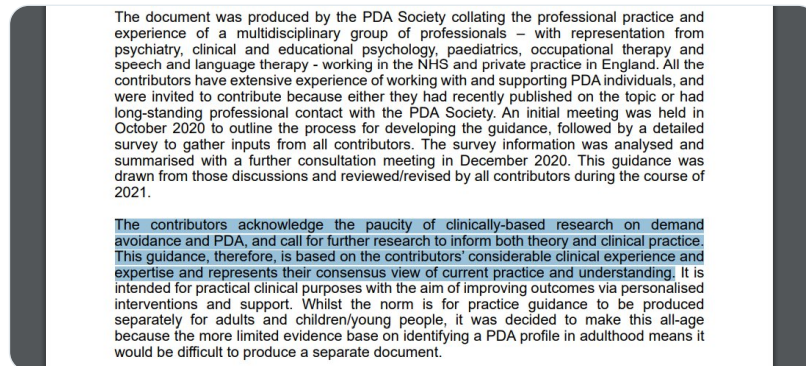
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

"This guidance, therefore, is based on the contributors' considerable clinical experience and expertise and represents their consensus view of current practice and understanding." PDA Society, p1.

So this reports to represent a community of practice, of these invited contributors (& supporting clinicians mentioned in the report) on PDA. Which is not representative of broader clinical practice of PDA & has prematurely formed due to next quote.

"The contributors acknowledge the paucity of clinically-based research on demand avoidance and PDA, and call for further research to inform both theory and clinical practice."
PDA Society p1.

Image below, shows highlighted text of the last 2 quotes.



And yet some would argue I am the problem here in relation to PDA. I am the one who is meant to be arrogant etc.

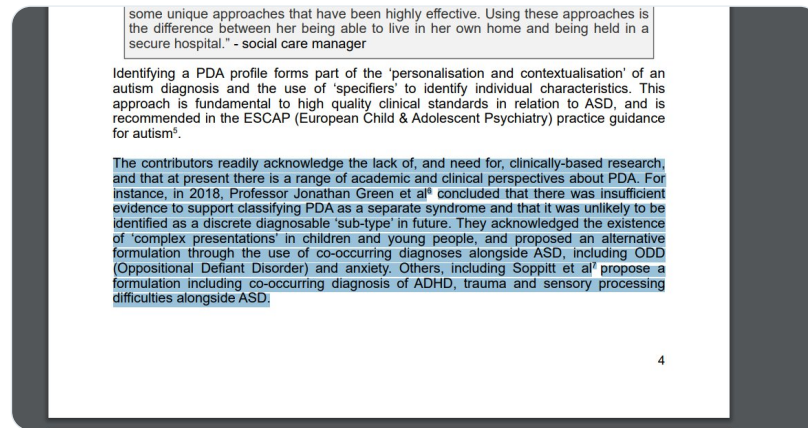
Below image is a defamatory meme by SallyCat.



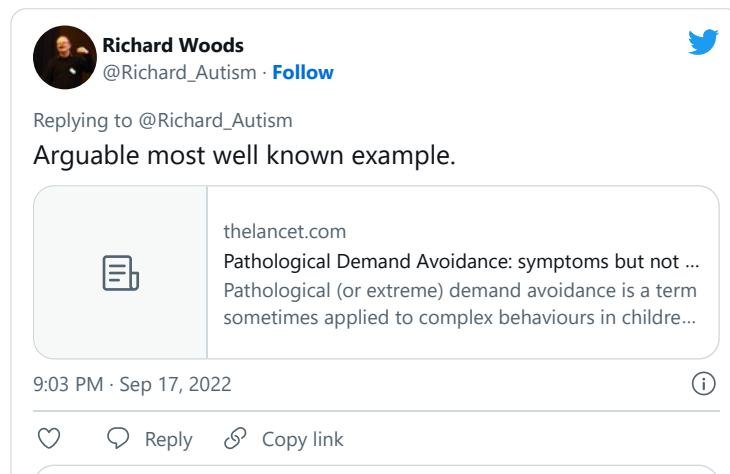
I will go onto to underscore the point that PDA Society's research report which pretends to be clinical guidance on PDA admits its contributors views are not representative of broader clinical practice on PDA.

"The contributors readily acknowledge... that at present there is a range of academic and clinical perspectives about PDA... in 2018, Professor Jonathan Green et al6 concluded that there was insufficient evidence to support classifying PDA as a separate syndrome..."PDA Society p4

Below screenshot is of the above quote, the text is highlighted in full, from the last paragraph on page 4 of the research report by PDA Society 2022.



I have previously referred to Green et al (2018a) in the thread, see below:



I will stop here, because I do not want wish to restate points previously made in the thread. Point is, the research report by PDA Society, which pretends to be clinical guidance, is highly biased. Seems to be unethical & not robust. Hence, cannot be taken seriously.

I do wish to add a final point, after further reflecting upon it.

While PDA's clinical need is contested, e.g.,

"we have much common cause with O'Nions and colleagues ... However, we do not think that achieving these goals requires use of additional unvalidated clinical terms" Green et al (2018b).

Link below to article of Green et al (2018b).



Is one accepts there is a clinical need for PDA, then surely one would also accept clinical need for PDA to be diagnosed at lower diagnosed thresholds.

"Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners" PDA Society p1.

I.e., that PDA Society report claims PDA has been over identified, presumably because others have used different diagnostic thresholds

We know there are different behaviour profiles, different clinical accounts & diagnostic thresholds used for PDA; as this is a limitation of its research base

<https://journals.sagepub.com/doi/full/10.1177/13623613211034382>

There are examples of persons being diagnosed with PDA using Extreme Demand Avoidance-Questionnaire (which is not designed to be used this way), such as in these 4 case studies:

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

Examples of at least 3 non-pervasive diagnoses of PDA as seen in page p176 of O'Nions (2013). Image shows table of participants characteristics for study in chapter 8 of the O'Nions PhD thesis.

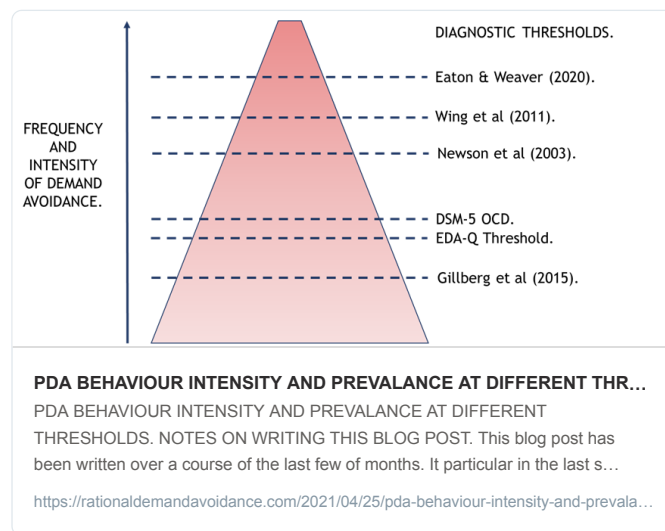
175

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	8	23	9
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)
Total behavioural difficulties [†]	27.2 (3.8)	24.2 (6.4)	16.4 (5.9)	24.6 (4.6)	5.2 (3.1)
Pro-social [†]	4.0 (1.9)	4.6 (2.6)	5.7 (1.9)	3.7 (1.8)	8.9 (1.3)
EDA-Q SV score [†]	8.6 (1.6)	7.2 (2.3)	3.4 (2.5)	6.7 (1.4)	0.6 (1.1)
PDA specific obs.	7.8 (3.2)	2.5 (2.4)	0.8 (1.1)	2.2 (2.2)	0.3 (0.8)
PDA trait measure	16.5 (3.3)	9.7 (1.1)	4.1 (2.7)	8.8 (2.1)	1.1 (1.2)
ASD specific obs.	10.3 (4.4)	11.8 (3.8)	11.2 (4.4)	4.9 (2.3)	3.1 (2.8)
ASD trait measure	17.1 (5.3)	17.3 (4.0)	16.5 (5.1)	10.3 (1.3)	3.4 (2.7)

“A “manipulative child” in the 1970s might get the label of Pathological Demand Avoidance Syndrome in the 2000s.” (Goodley 2011, p10).

We know there is a variety in PDA diagnostic thresholds, as set out here:



Typical use of strategies/ treatments in psychiatric disorders is that they are issues/ symptoms specific, i.e., not tied to a particular diagnosis/ construct. I give evidence to back this up.

One would expect those advocating for PDA to be used in clinical practice, such as those behind PDA Society's research report, to accept the clinical need for PDA at lower diagnostic thresholds so that its strategies should be used as broadly as possible.

A good reason for this, is early use of PDA strategies/ i.e., something similar to Low Arousal Approach as practiced by [@studioIII](#) should help to reduce stress/ distress of those showing demand-avoidance features & therefore presenting highly distressed/ traumatised states...

Lets be clear about this, those contributing the PDA Society's research report chose to adopt a high diagnostic threshold for their portrayal of PDA. How do we know this? Because they are claiming others over identifying PDA...

It is a CHOICE, which has been made by those behind PDA Society research report to have adopt a high diagnostic threshold for PDA.

"The goal of this document is to... to distinguish PDA from other presentations of marked demand voidance;" PDA Society 2022 p1.

As those behind the PDA Society's research report seem to think that PDA is different to other forms of marked demand avoidance.

This is a highly risky position to adopt considering multiple studies indicating PDA can be viewed as characteristics belonging to accepted conditions/ difficulties, or PDA is not distinct diagnostic entity/ syndrome/ disorder/ way of being human.

I will return to the point again. So apparently, we are meant to accept the position & claims made by those behind the PDA Society research report, like only how PDA as presented by them has a clinical need, despite others taken a broader approach to identifying PDA...

Position of those behind the PDA Society's research report is not reflective of broader clinical practice, or opinion & evidence on PDA. Additionally, PDA is highly controversial...

... Absurdity of the position portrayed in PDA Society's research report should be obvious to anyone critically engaging with it.

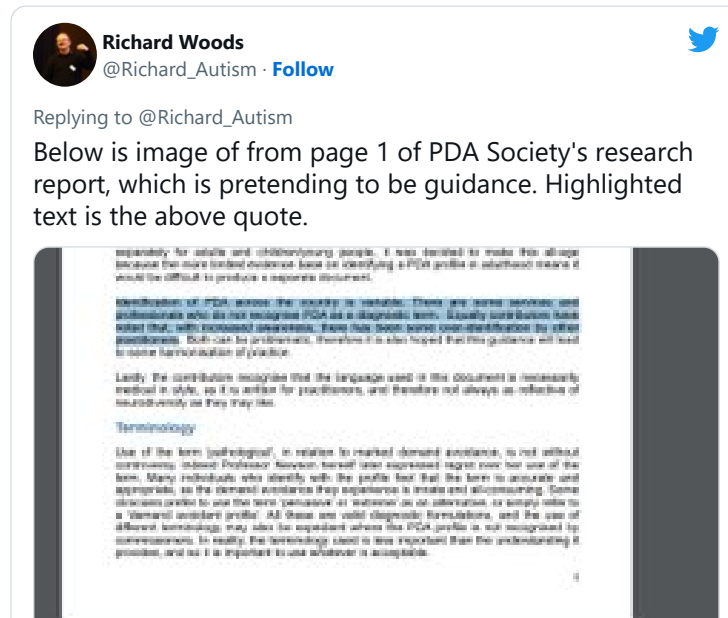
It is not me being emotional about PDA. My concerns are at least generally reasonable & legitimate.

I wish to underscore the point about evidence for clinical need for PDA. Before doing that, it is worth pointing that PDA's clinical need is contested both in literature & clinical practice, as it is not diagnosed universally across the UK.

Likewise, PDA is not included in the two main diagnostic manuals.

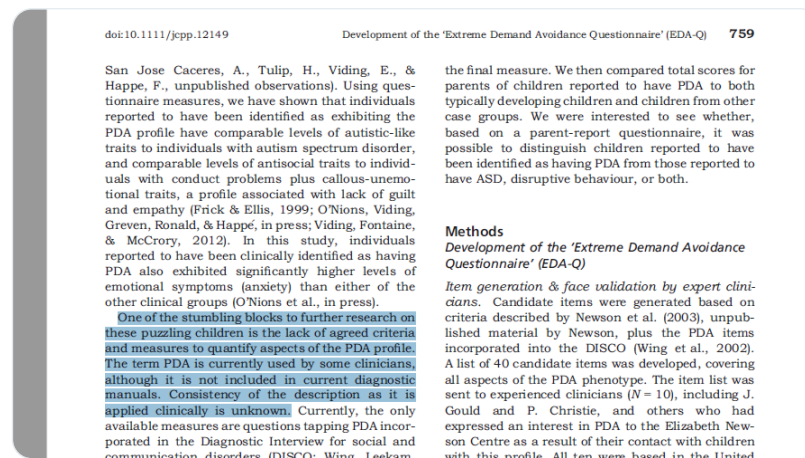
First point, if one accepts clinical need for PDA, one should accept that any diagnosis of PDA, irrespective of diagnostic threshold is evidence for its clinical need. Simple reason is if there is no clinical need for PDA to be diagnosed, clinician should not be making the PDA dx

As pointing out in below tweet there is a huge variety of approaches to diagnoses PDA in clinical practice.



This has been recognised in PDA literature since at least 2013, e.g., see O'Nions et al (2014a, p759).

Below images a highlighted text noting lack of consensus over how to approach PDA in O'Nions et al (2014a).



Link to O'Nions et al (2014a) article

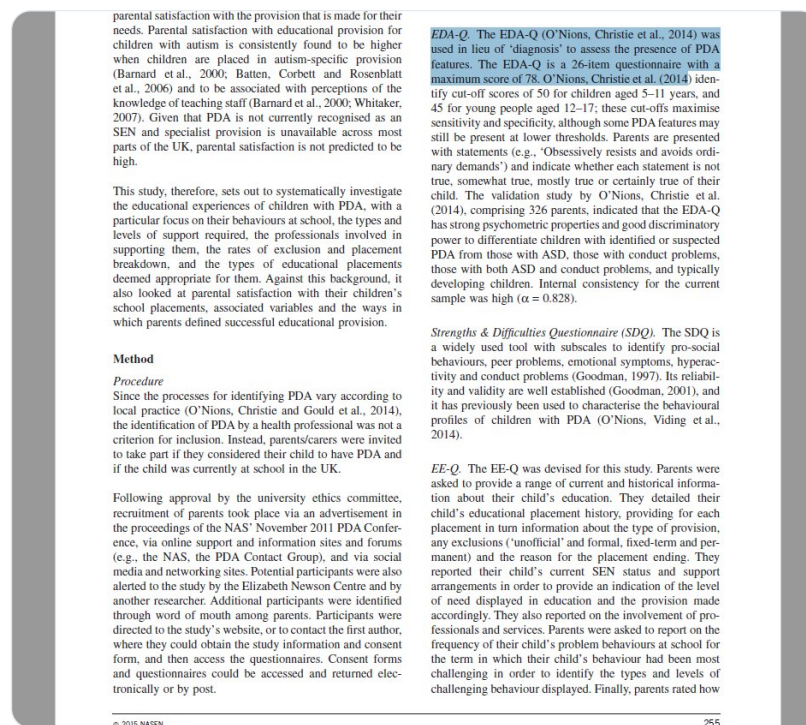
<https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149>

The large heterogeneity towards diagnosing PDA was an important factor for Langton & Gore (2016) to not trust PDA diagnoses as an indicator for PDA in their studies, one which can be used to indicate clinical need for PDA.

"Procedure

Since the processes for identifying PDA vary according to local practice (O'Nions, Christie and Gould et al., 2014), the identification of PDA by a health professional was not a criterion for inclusion." Langton & Gore, 2016, p255.

Below is image of p255 of Langton & Gore (2016) article which is mapping educational experiences. Highlighted text is use of the EDA-Q screening tool. Image also includes section where above quote is from.



Link to Langton & Gore (2016) article

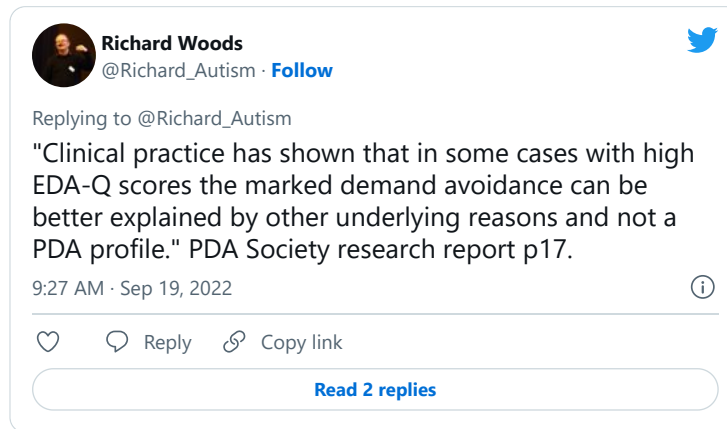
<https://nasenjournals.onlinelibrary.wiley.com/doi/abs/10.1111/1471-3802.12081>

Now the EDA-Q (Extreme Demand Avoidance-Questionnaire) is important to our limited research knowledge on PDA, as most studies involve the EDA-Q, at least in some capacity.

So one would expect that those who accept PDA's clinical need would be sticking close to EDA-Q's cut-off threshold to be sure of generalising limited PDA knowledge.

"Clinical practice has shown that in some cases with high EDA-Q scores the marked demand avoidance can be better explained by other underlying reasons and not a PDA profile." PDA Society research report p17.

This is a bold claim made about the EDA-Q, by those behind the PDA Society's research report. Especially considering their portrayal of PDA is not representative of broader opinion, clinical practice & general importance of EDA-Q to our PDA knowledge.



What they are essentially claiming is that their clinical experience has shown that EDA-Q has much false positive identification, i.e., many persons meeting cut-off on EDA-Q do not have PDA.

So the position of those behind PDA Society's research report, is at least seems dismissive of evidence by Langton & Gore (2016) for PDA's clinical need, with its evidence based on the EDA-Q.

Next research piece which is might be used to indicate PDA's clinical need for PDA, is Truman et al (2021), link to it below.

<https://www.tandfonline.com/doi/full/10.1080/13603116.2021.1916108?cookieSet=1>

This study looked at educational experiences of autistic children, in 4 groups, including one with diagnoses of PDA & a second of suspected PDA using the EDA-Q.

"Results demonstrated that there were few group differences in terms of the frequency of failed school placements and exclusions...There were no significant differences in school exclusions, but the fact that these occurred across all groups is of concern." Truman et al 2021, 11

Now that is problematic, as it indicates that a PDA diagnosis is not making difference to improving educational experiences for those diagnosed with PDA.

One could go even further & to suggest that if PDA is needed due to its supposed unique strategies, then PDA diagnoses should be given to most of those in Truman et al (2021) sample, due to how bad generally autistic children are experiencing UK education system.

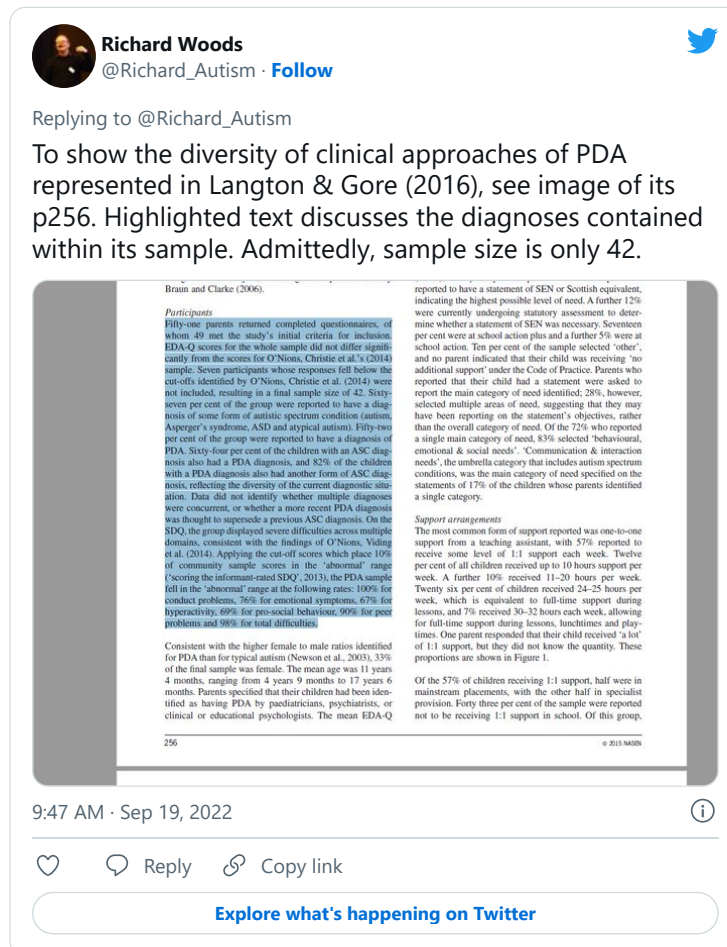
A key point to be made is that both Truman et al (2021) & Langton & Gore (2016) studies used a mix of snowball sampling & recruiting participants from places where persons are likely to have preconceived ideas of PDA.

This is a limitation to both studies, as Kildahl et al (2021) noted about Langton & Gore (2016), but Truman et al (2021) was not included it this systematic review's data set.

<https://journals.sagepub.com/doi/full/10.1177/13623613211034382>

Most importantly, the recruitment method for both studies means that the PDA diagnoses would be have been from multiple clinics & i.e., so should be considered somewhat representative of diversity of clinical approaches towards PDA.

So neither of these two studies can be used to argue for clinical need of only exclusively diagnosing PDA as portrayed in PDA Society's research report.



Now last piece of evidence I am going to refer, which if one accepts clinical need for PDA, is PDA Society's own Being Misunderstood Report (Russell, 2018).

This evidence is meant to be used by advocates to lobby local organisations to recognise PDA, i.e., is meant to be indicative of PDA's clinical need.

Link to PDA Society's Being Misunderstood Report (Russell, 2018).

<https://www.pdasociety.org.uk/wp-content/uploads/2019/08/BeingMisunderstood.pdf>

"The survey was placed online and promoted through the PDA Society website and social media networks for two weeks in March 2018... The sample size is significant with 1,445" Russell, (2018, p2).

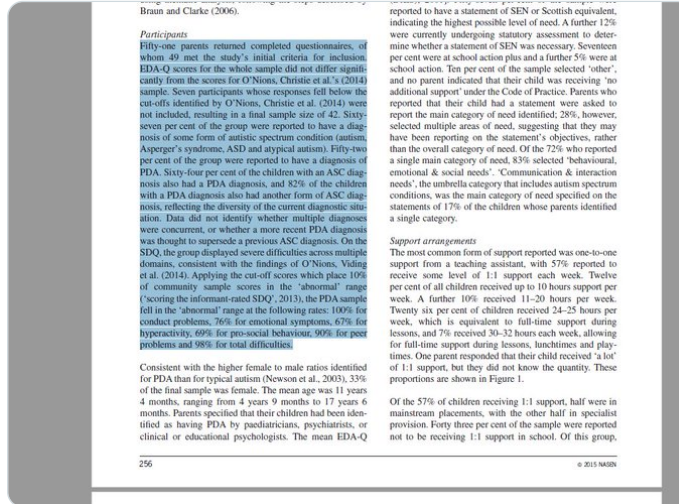


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To show the diversity of clinical approaches of PDA represented in Langton & Gore (2016), see image of its p256. Highlighted text discusses the diagnoses contained within its sample. Admittedly, sample size is only 42.



9:47 AM · Sep 19, 2022



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The snowball sampling methodology used in Russell (2018) means the Being Misunderstood Report has same issues as Truman et al (2021) & Langton & Gore (2016), in both times of limitation of how participants were recruited & that diversity of PDA clinical practice is represented.

9:54 AM · Sep 19, 2022



Reply



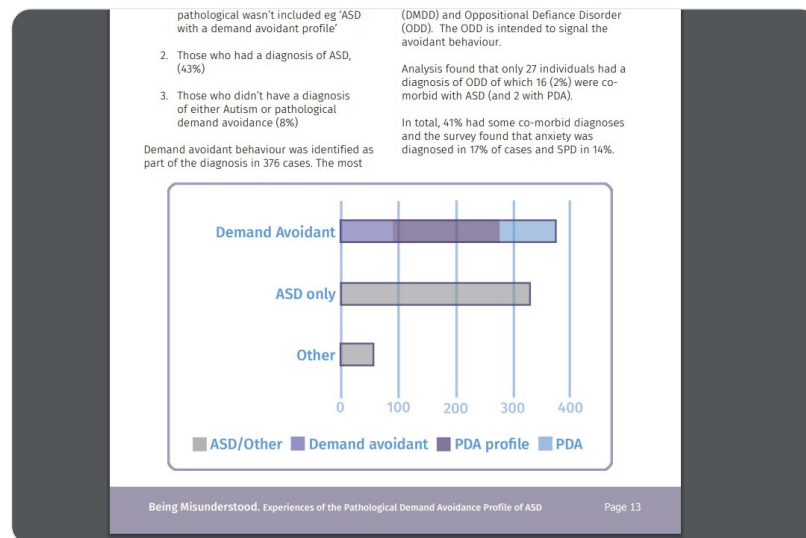
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I need to apologise, I have accidentally added tweets to wrong parts in the thread, so it has accidentally bifurcated & I am trying to make the thread cohesive again.

The diversity of clinical practice to PDA is indicated on page 13, which shows different terminology is used to indicate PDA in clinical practice.



So obviously, Russell (2018) like with Truman et al (2021), & Langton & Gore (2016) cannot be used to argue the clinical need for PDA to be diagnosed exclusively, as presented in the PDA Society's 2022 research report.

There is a huge caveat with these studies & generally with evidence base which might be used to support PDA's clinical need, they are overwhelmingly biased towards PDA in suspected autistic persons.

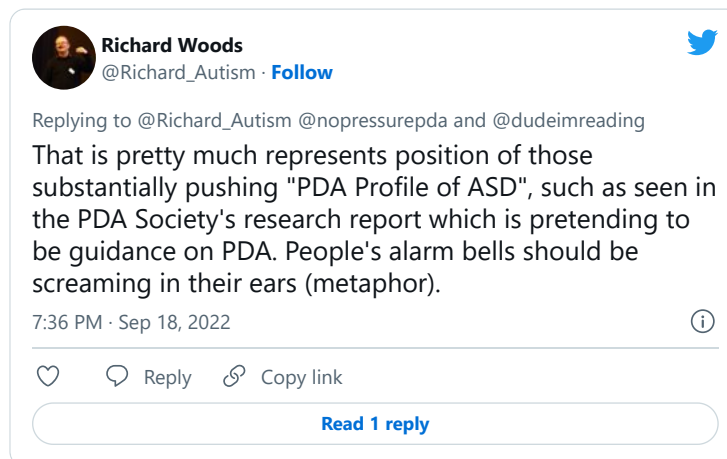
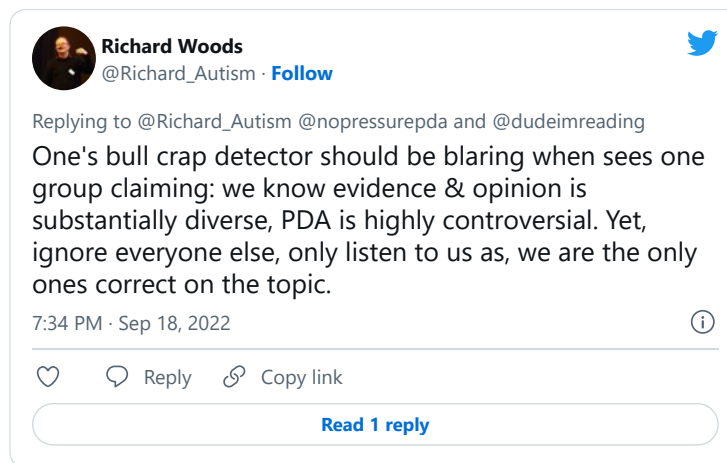
This matters, as besides people claiming PDA is seen in non-autistic persons & some examples of PDA seen in non-autistic persons, including diagnoses of PDA in non-autistic persons; there is little to none specific PDA research into clinical need for PDA in non-autistic persons.

There is simply not the evidence to warrant ONLY diagnosing PDA in suspected autistic persons, as we lack the evidence base to state that difficulties faced by non-autistic persons with PDA is statistically significantly different from PDA in suspected autistic persons.

This goes back to my point about the absurdity of the approach of those behind PDA Society's 2022 research report, in espousing for PDA to be only be accepted in how they portray PDA.

Clinical need for PDA is contested. Evidence base for PDA's clinical need is small-limited in size, contradictory, while supporting a diverse range of clinical thresholds & not large enough to only justify diagnosing PDA in only suspected autistic persons.

Yet, those behind PDA's Society's 2022 research report have produced a document which makes many bold claims, & aim is to control how PDA is approached in clinical practice, to reflect their views on PDA. Which are not representative of broader practice, opinion & evidence.



There are many other good reasons besides those presented in this thread, as to why I do not the PDA Society's 2022 Research Report which is pretending to be clinical guidance seriously. I struggle to how producing such a highly biased report looks good for those behind it.

Link again below to PDA Society's 2022 research report.

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



[@threadreaderapp](#) Please can you unroll this thread.

Thank you in advance, it is very much appreciated.

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