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Aug 27, 2021 · 97 tweets · [Richard\\_Autism/status/1431294048543952897](#)



What is not in the DSM-5 autism criteria.

Simply put. Why the \*\*\*\* are the likes of [@PDASociety](#) [@Autism](#) making the stupid decision to view PDA as an anxiety based disorder within the autism spectrum?



I know the logic & reasons why people often view to be an anxiety-based disorder within the autism spectrum. If we can critique Spectrum10k for autism not being an anxiety/ panic disorder. Same point is equally applicable to PDA!

I have had enough of the nonsense around PDA, the seemingly systemic poor quality, research, theory & practice associated with PDA is an ASD. The lack disclosure of conflict interests. The lack of transparency of the PDA Development Group.

The ignoring/ disregarding of typical standards or research & practice. The fact we have [@PDASociety](#) pretending to be an autism stakeholder on basically little to no evidence of worth.

Ignoring established understandings on: autism, demand-avoidance, & disorders, autistic persons research priorities & wishes. All so some autism stakeholders can view PDA as an ASD.

Viewing PDA as an ASD undermines autism, & PDA as a construct. Demand-avoidance is a process, & features suggested to PDA are often associated with trauma. Autism is not caused by trauma, nor is autism a process.

Autistic persons lobbied for subtypes to be removed from the DSM-5 due to how all attempts to divide autism into subtypes have failed & to reduce stigma for ALL autistic persons.

The point about reducing stigma matters, considering the harmful effects of camouflaging on autistic wellbeing & how much of autistic mental health issues are associated with minority stress.

We are meant to be an age of participatory autism research, engaging & respecting autistic persons wishes. We should be respecting the fact we lobbied for the removal autism subtypes.

Anxiety is not an autism symptom. Perhaps, just perhaps Newson was right PDA is not an ASD?

I would suggest research showing PDA is more than autism, or different from autism, supports Newson's statement on the topic.

Essentially, "PDA is an ASD" is a ideological driven political view, that has chosen to ignore established autism understandings, precedents set by good quality research, & the wishes of autistic persons; to create two more types of undeclared COIs.

For what exactly? Because some persons have convinced themselves they know:  
typical research standards  
autism,  
demand-avoidance  
PDA  
disorders  
Better than other persons?

Best bit is, they do not know those things better than other persons, as independent bodies & persons are showing them how they should be viewing and treating PDA, by taking a neutral position & not assuming PDA is an ASD...

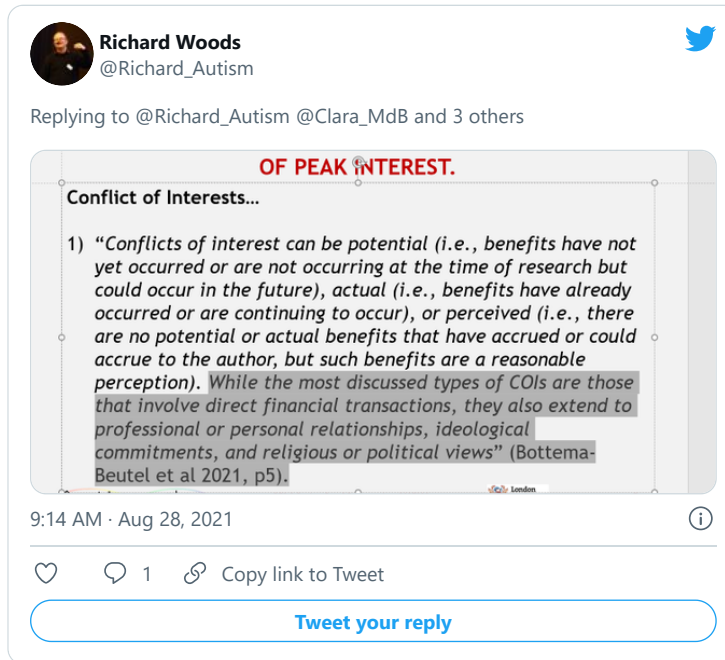
Why there \*\*\*\* are we as a community, stakeholders & autistic persons tolerating this nonsensical notion of "PDA as an ASD"?

I have calmed down from earlier. I do need to add, due to how poor quality research often has poor quality ethics & vice versa. The poor quality of much PDA research, means there is likely to be systemic poor quality ethics associated with "PDA is an ASD".

My deep concerns & misgivings of the "PDA is an ASD" narrative seem to be valid & warranted.

This is not me "crying wolf", or "lacking expertise". The situation with "PDA as an ASD" is probably as bad I think it is.

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The case that "PDA is an ASD" is ideological commitment & political view are relatively good. One can argue some persons & parties are gaining from it, especially considering the poor quality research. Something ethically dodgy is likely occurring.

Example of an organisation benefitting from "PDA is an ASD". [@PDASociety](#) is working stakeholders to better explain understandings of PDA as an ASD, despite the naff all good quality evidence to support them & NICE/ BPS are not adopting that view...

Indicator quality of my views on PDA.

"I have read quite a lot of your work and it has been an important inspiration for our work on this review." [@ArvidNK](#)

Their systematic validates much/ most of my critique about research's quality/  
<https://journals.sagepub.com/doi/pdf/10.1177/13623613211034382>

We are still awaiting "PDA is an ASD" advocates to properly consider ethics of their position & to provide a compelling case for their position. Which is not surprising considering their general lack of engagement with anything mildly inconvenient.

I mean it is highly damning that I have referenced the first critical PDA article (Garralda, 2003) more times in print than many PDA is an ASD advocates combined!

If you want an indicator of how bad the "PDA is an ASD" position is. I would suggest it is potentially worth looking at the standards of the Health & Care Professions Council.

[@The\\_HCPC](#) "We protect the public by regulating 15 health and care professions in the UK"

Those professions would cover many to most of the key advocates for "PDA is an ASD" narrative.

<https://www.hcpc-uk.org/about-us/who-we-regulate/the-professions/>

Links to its standards, which includes ethics.

HCPC is there to protect the public, just remember that.

<https://www.hcpc-uk.org/about-us/who-we-regulate/the-professions/>

The HCPC regulates Psychologists, Occupational Therapists, and Speech & Language Therapists.

Listing standards which seem relevant to PDA debate. Obviously, I just a lay person on this & commenting on what seems possibly relevant.

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.

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

2.3 You must give service users and carers the information they want or need, in a way they can understand.

3.1 You must keep within your scope of practice by only practising in the areas you have appropriate knowledge, skills and experience for.

9.1 You must make sure that your conduct justifies the public's trust and confidence in you and your profession.

9.3 You must make sure that any promotional activities you are involved in are accurate and are not likely to mislead.

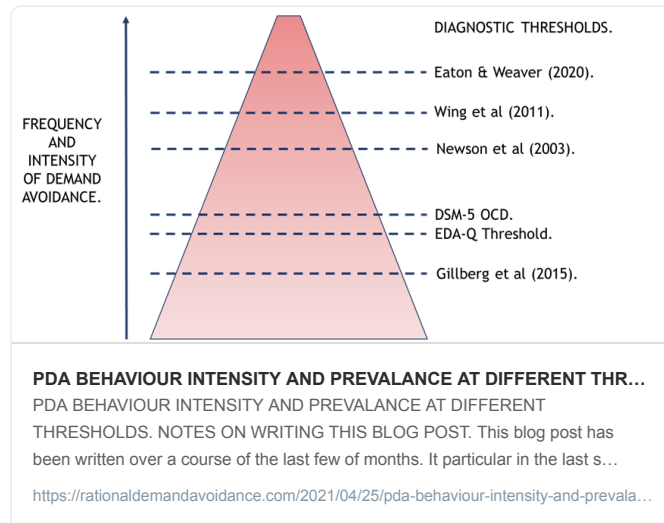
9.4 You must declare issues that might create conflicts of interest and make sure that they do not influence your judgement.

So lets have a look at each on these standards & they might be applicable to "PDA as an ASD".



If you think PDA is clinically needed in autistic persons. Then you should probably be also be viewing PDA as being clinically needed in non-autistic persons.

I discuss much of the arguments for PDA's clinical need here:



I think it is important to point work by O'Nions on this. Particularly here <https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/camh.12287>

"This is in line with other work with children with developmental disabilities, which describes distress, arousal and attempts to physically escape from demand contexts (Lucyshyn et al., 2004)."

That quote is specifically following talking about demand-avoidance features can be triggered in PDA.

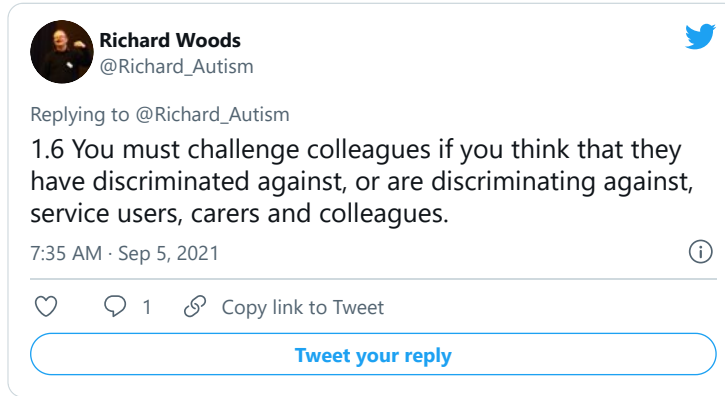
"The ODD label may also encourage automatic use of reinforcement-based approaches, which are the mainstay of parenting interventions for disruptive behaviour disorders in general."

That is O'Nions & Neons arguing PDA is needed to protect persons from receiving reinforcement-based approaches which are commonly used. So logically, non-autistic persons with PDA would also need the same protection.

I would add that SEND system is needs based. So if you think PDA is needed for autistic persons/ CYP, then you are also establishing the need for non-autistic persons/ CYP with PDA.

So with PDA probably being viewed as a disability in UK law, if you treating non-autistic persons/ CYP different to autistic ones, because you think PDA is an ASD. Well you tell me how that looks?

Which then takes us to next standard.



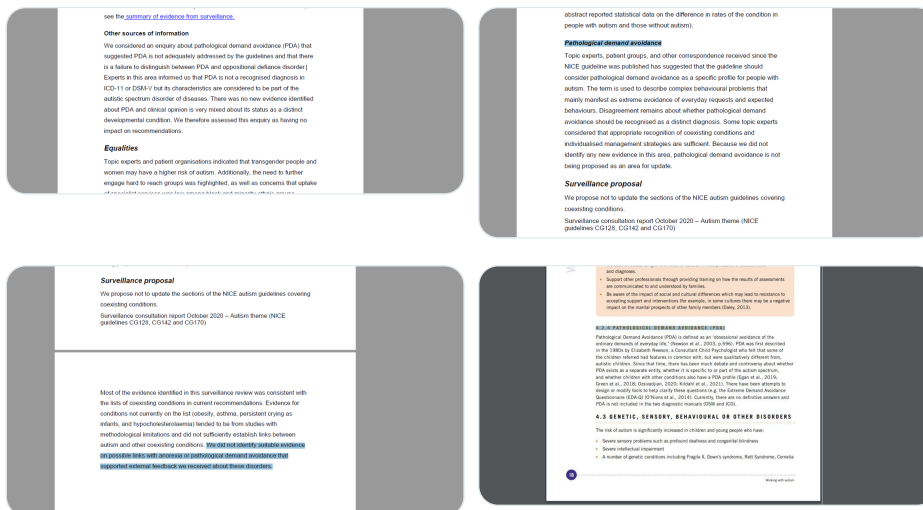
That standard seems self-explanatory on the topic of "PDA as an ASD".

Onto the next standard.



For this one I could go into detail, how many "PDA is an ASD" advocates generally not providing vulnerable persons with all relevant information, such as debates around what PDA could be. How controversial it is. How often it has been challenged.

What I think is the best way to demonstrate what they should be doing is including screenshots of information from @NICEComms & @BPSOfficial on PDA. Shows what an ethical position on PDA should look like.



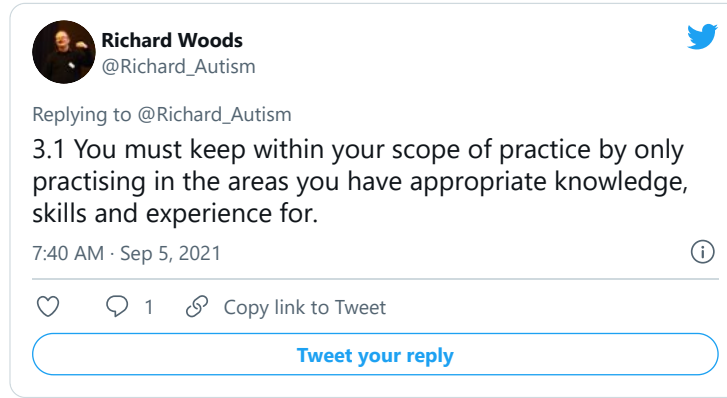
Links to NICE's document.

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

BPS's document.

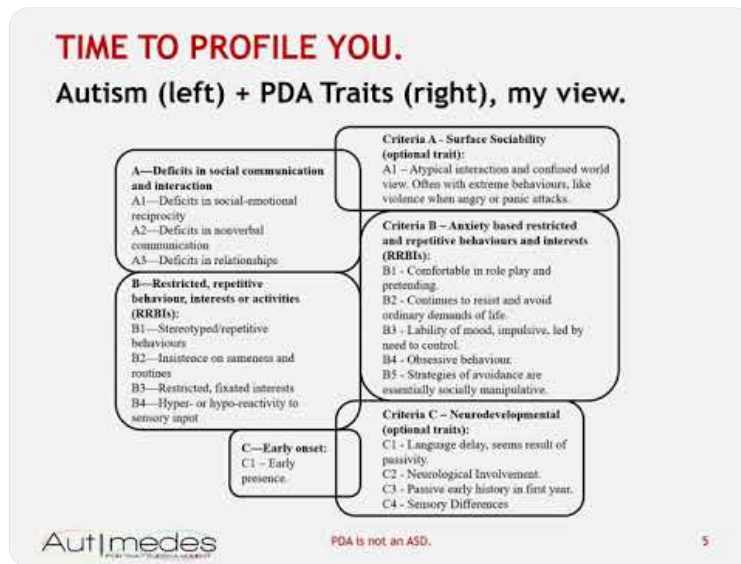
<https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Working%20with%20autism%20-%20best%20practice%20guidelines%20for%20psychologists.pdf>

This takes us nicely onto the next standards.



Much can be said here on this topic.

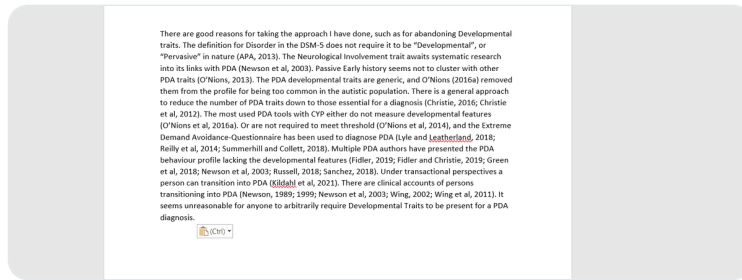
For the first one, you tell me if a certain "PDA is an ASD" "expert" has the appropriate knowledge to challenge Chris Gillberg on how common PDA is & it potentially being a new type of disorder?



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

Then a certain private clinic having the "appropriate knowledge, skills and experience for." arbitrarily deciding PDA has developmental features. While ignoring a substantial amount from the literature & how BPS & NICE treating all experts views equally.

Screenshot of reasons why it is problematic viewing PDA as having developmental features.

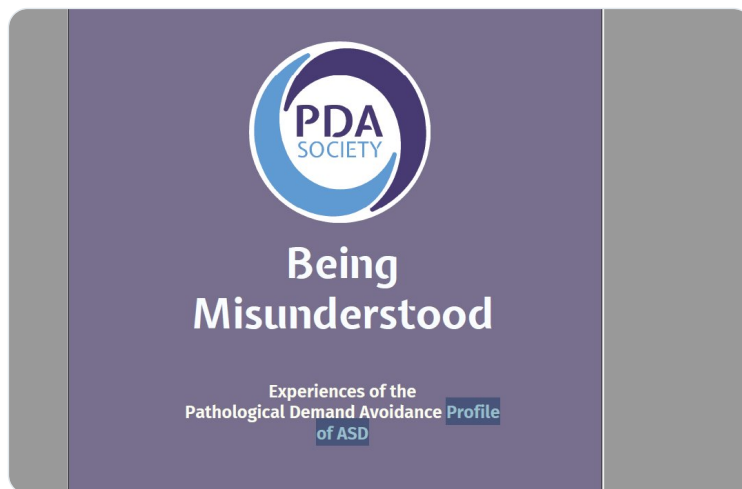


As stated at the top of this thread autism is not an anxiety disorder, or a panic disorder. Do "PDA as an ASD" advocates have the "appropriate knowledge, skills and experience for" claiming autism has a major anxiety component?

Do "PDA as an AS" advocates have the "appropriate knowledge, skills and experience for." claiming autism can be divided/ subtyped, considering consensus, evidence & political reasons against that outlook (eg to reduce stigma for all autistic persons)?

Do "PDA as an ASD" advocates have the "appropriate knowledge, skills and experience for." claiming to be "authoritative" on PDA, considering they claim PDA is a "Profile", while [@NICEComms](#) views it to be a Disorder?

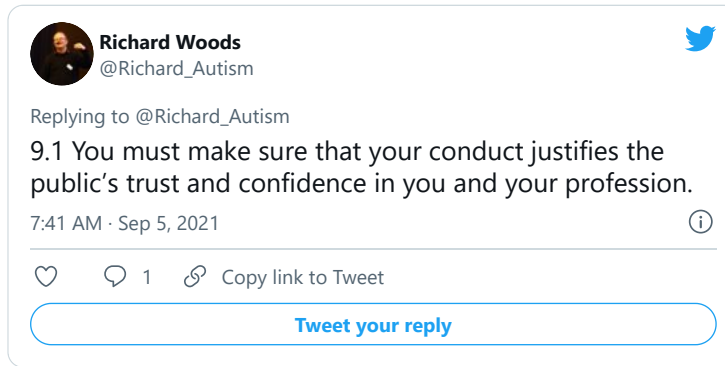
So screenshot of [@PDASociety](#) Being misunderstood report, in which it's front cover states PDA is a "Profile of ASD".



"We did not identify suitable evidence on possible links with anorexia or pathological demand avoidance that supported external feedback we received about these disorders." (NICE 2021, p48, see link given earlier).

I will leave this here, and move onto the next standard.





I am not going to say as much as about this I could say.

I think it is worth pointing that we [@PDASociety](#) pretending to be an autism stakeholder. Working with various parties to better increase understanding on PDA on little to no evidence of any worth.

Certain clinicians have been supporting the [@PDASociety](#) in its campaigning efforts to get PDA recognised as an ASD. For instance:

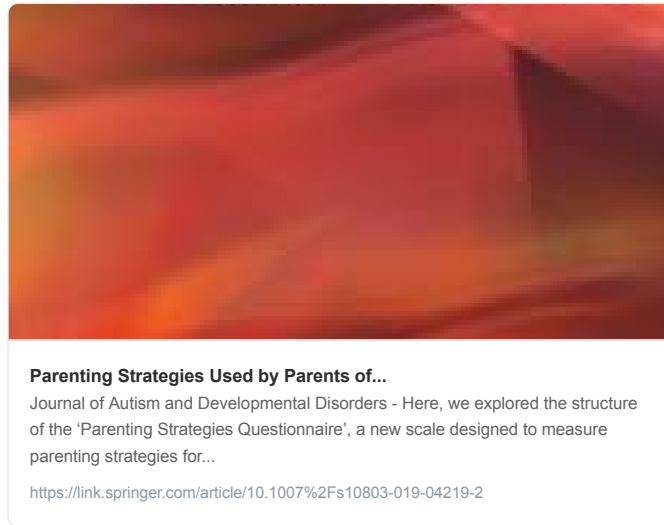
<https://www.pdasociety.org.uk/wp-content/uploads/2019/08/BeingMisunderstood.pdf>

Bear in mind the PDA literature is clear clinicians have been a driving force in pushing the "PDA is an ASD" narrative. So it is not only those in the above link.

"clinicians are increasingly using the term to describe children who fit the profile." (O'Nions et al 2016 p8).



“interest in the concept of PDA largely centres on the UK, it is at present a culture-bound concept” (O’Nions et al 2020, p398).



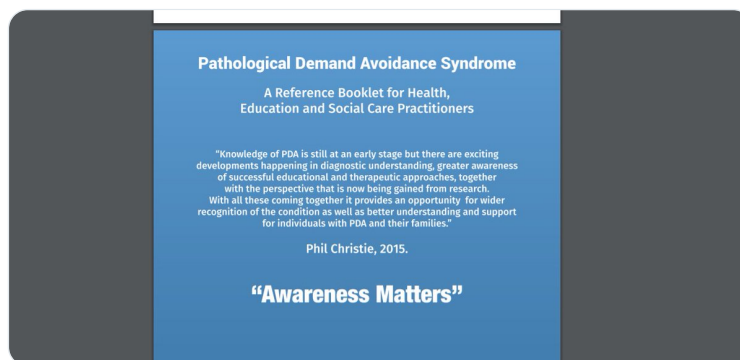
So that is a "culture-bound concept" (the article views PDA to be an ASD) on little to no evidence of worth...

On that note I will move onto the next standard.

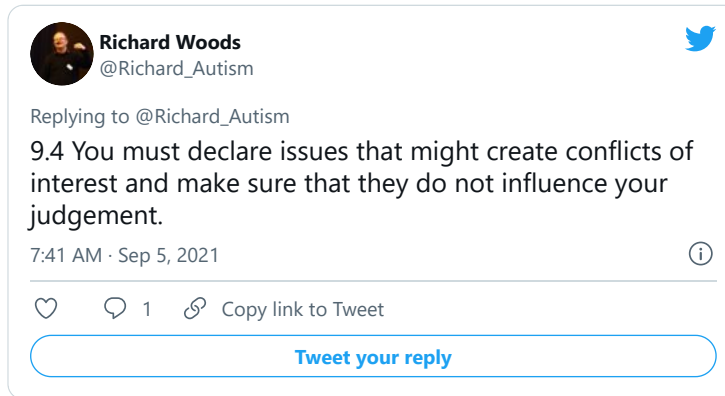


For this one I am going to take a screenshot from here:

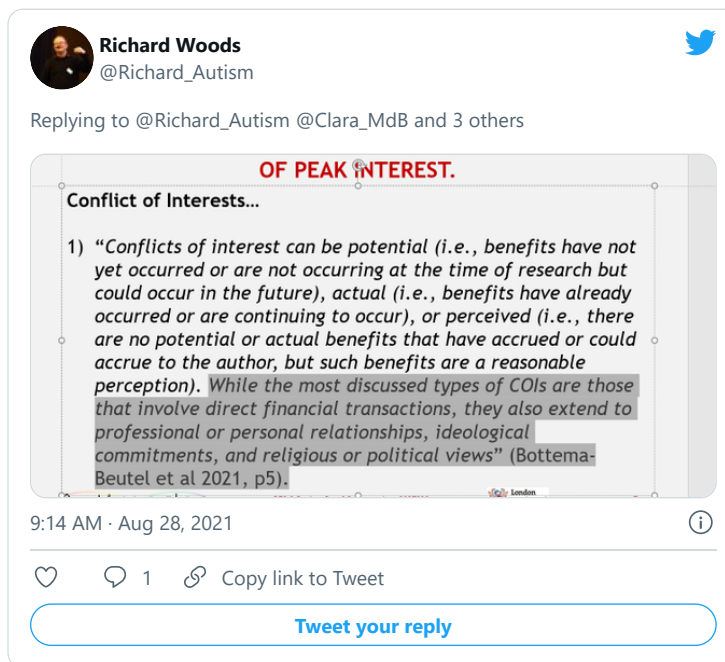
<http://www.pdaresource.com/files/pda-awareness-matters-booklet.pdf>



Moving onto the last standard.



I think I have already covered this one in detail in the thread. I am not going to retweet or restate those points. I think it is important to note, that I think these standards are often inter related.



Retweeting to give an example of an important COI. So The PDA Development Group is a committee whose activities are not public knowledge or who is exactly on there. [@PDASociety](#) describes its work as "authoritative and helpful summary".

PDA Development Group has produced various "guidelines" for use with "PDA as an ASD".

# PDA

## Development

### **Education Provision and Support – Guidance**

Children and Young People with PDA: Guidelines for Educational Provision and Support This guidance was prepared by the PDA Development Group and published in December 2019. It provides and...

<https://www.pdasociety.org.uk/resources/education-provision-and-support-guidance/>

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# PDA

## Development

### **Pathological Demand Avoidance: summary sheet**

A one-page explanation of the PDA profile, produced by the PDA Development Group and published in June 2016. It describes the main features and the key approaches to supporting a PDA person. The P...

<https://www.pdasociety.org.uk/resources/pathological-demand-avoidance-summary-sh...>

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Public information denotes that persons from specific organisations are on the PDA Development Group:

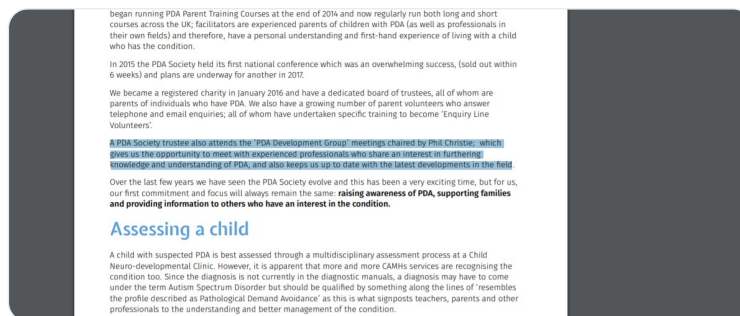
" PDA Development Group comprises a group of clinical and professional experts, and includes representation from the NAS and PDA Society." By [@PDASociety](#)

What good is that information in holding the PDA Development Group to account? It is meant to be producing vital "guidelines" (which are not recognised by NICE). Surely there should be transparency, for accountability & oversight? Who exactly is involved?

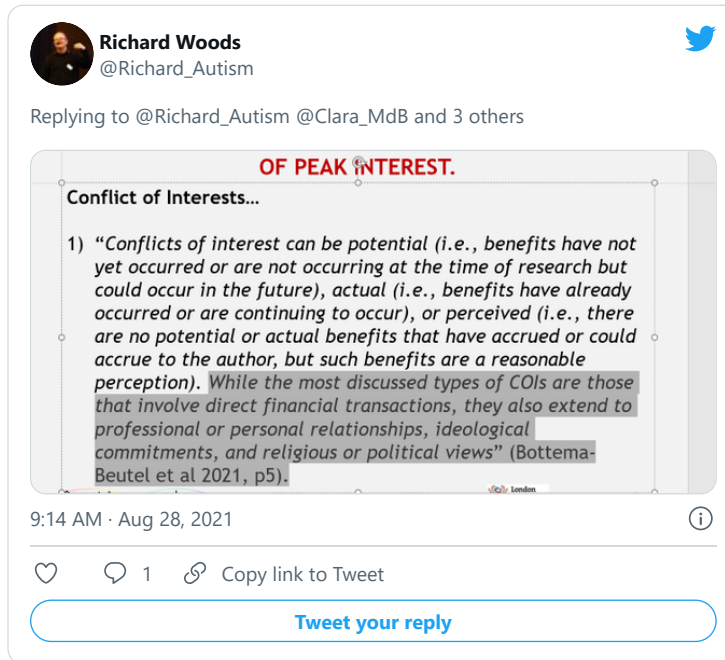
"A PDA Society trustee also attends the 'PDA Development Group' meetings chaired by Phil Christie;" (PDA Society 2016, p12).

<http://www.pdaresource.com/files/pda-awareness-matters-booklet.pdf>

Screenshot of the text, mentioning Phil Christie is on the PDA Development Group.



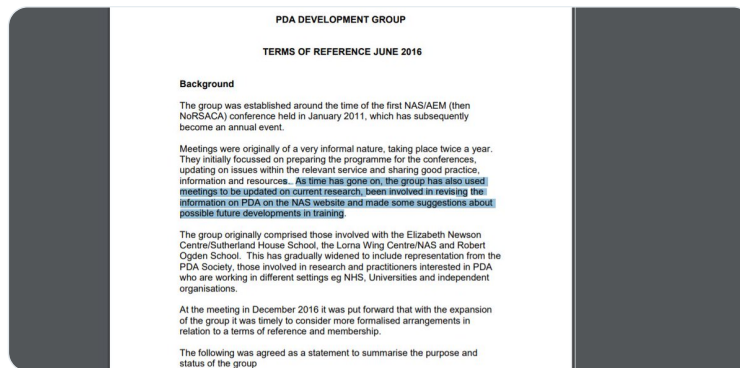
So we have at least one known member of the PDA Development Group. Is this often acknowledged in Christie's PDA scholarship as a conflict of interest? I will let you guess that the answer to that one.



Consider the potential implications of the PDA Development Group's actions, what it has done and is trying to do. This is not even considering its historic actions which include setting PDA information on [@Autism](#) website.

Screenshot of what the PDA Development Group did circa around 2016 - 2017.

<https://rationaldemandavoidancecom.files.wordpress.com/2020/08/pda-development-group-tor-july-2016.pdf>



Now if Phil Christie has a COI for being a member of the PDA Development Group. Then surely its other members do, or is this wishful thinking?

If all members of the PDA Development Group have a conflict of interest. We do not know who these members are, & said members are not disclosing said COI in their PDA scholarship. One it undermines the integrity of PDA literature & resources.

Potentially more pertinently are members of PDA Development Group "must declare issues that might create conflicts of interest and make sure that they do not influence your judgement."?

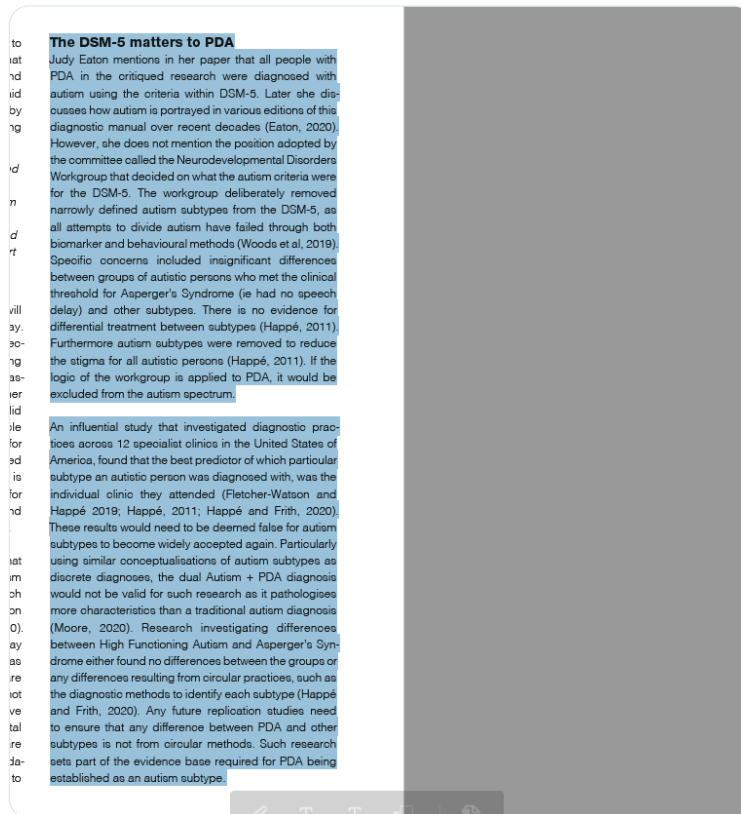
On that note I stop these musings.

I think it should be obvious to most reasonable persons that viewing "PDA as an ASD" is highly problematic from an ethical perspective.

I am just going to add a links to where I discuss issues with subtyping autism, including that subtypes were removed to reduce stigma for all autistic persons.

Here:

[https://www.researchgate.net/publication/339240845\\_Pathological\\_Demand\\_Avoidance\\_and\\_the\\_DSM-5\\_a\\_rebuttal\\_to\\_Judy\\_Eaton](https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DSM-5_a_rebuttal_to_Judy_Eaton)



And here:

[https://www.researchgate.net/publication/337171306\\_Empathy\\_and\\_a\\_Personalised\\_Approach\\_in\\_Autism](https://www.researchgate.net/publication/337171306_Empathy_and_a_Personalised_Approach_in_Autism)

Screenshot, first three paragraphs after introduction are relevant.



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

Thank you again in advance?