



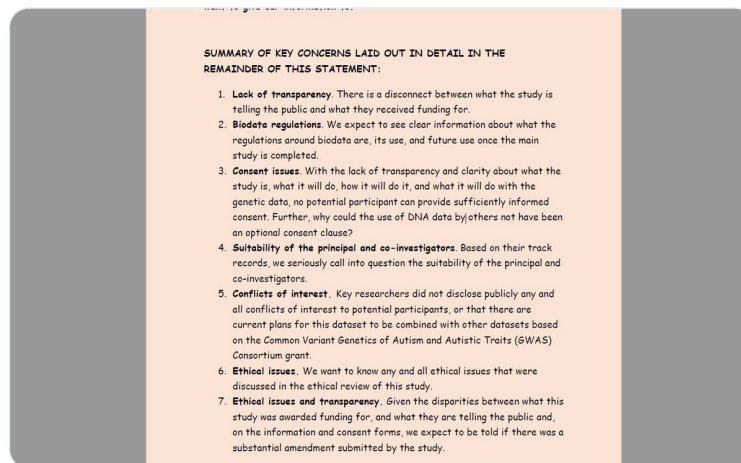
Richard Woods @Richard_Autism

Nov 26, 2021 · 70 tweets · [Richard_Autism/status/1464150578486026241](#)

[@egstirling](#) [@Autism](#) Interesting response. I will respond properly later. Short answer to me doing "personal attacks". The nature of such critique is essentially the same as valid concerns of ABA/ PBS supporters often not disclosing COIs & misleading the public.

[@egstirling](#) [@Autism](#) Also mirrors aspects of concerns BoycottSpectrum10K have for Spectrum10K. On transparency; ethics; conflict of interests; following typical norms on research & practice.

[@egstirling](#) [@Autism](#) Screenshot of summary of concerns BoycottSpectrum10K have for that Spectrum10K.



[@egstirling](#) [@Autism](#) It must also be stressed that three independent reputable parties have looked at PDA & have taken a different approach to it, which equally respects divergent opinions on PDA, i.e., do not assume PDA is a "Profile of ASD".

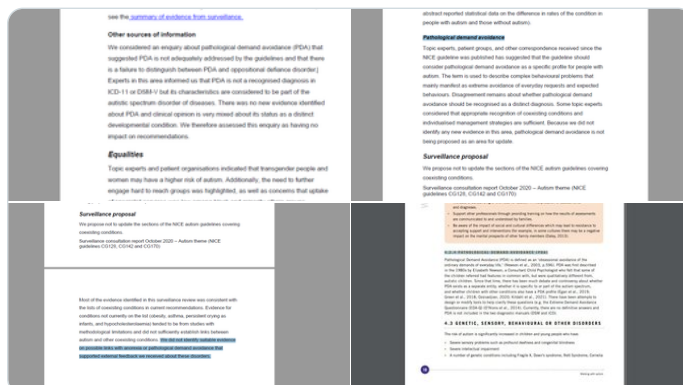
[@egstirling](#) [@Autism](#)



Richard Woods
@Richard_Autism



Replying to @Richard_Autism



8:01 AM · Sep 5, 2021



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Richard Woods
@RichardAutism



Replying to @Richard Autism

Links to NICE's document.
[nice.org.uk/guidance/cg128...](https://www.nice.org.uk/guidance/cg128)

BPS's document.
[bps.org.uk/sites/www.bps.org.uk...](https://bps.org.uk/sites/www.bps.org.uk/files/2019-06/2019-06-11%20BPS%20Statement%20on%20the%20UK%20Government%20White%20Paper%20on%20Brexit%20-%20Final.pdf)

8:02 AM · Sep 5, 2021



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[@egstirling](#) [@Autism](#) Link to recent systematic review which did not assume PDA is a "Profile of ASD" & did observe PDA is seen in non-autistic persons. Authors also noted issues caused by sample recruitment through pro "PDA Profile of ASD" settings.



[@egstirling](#) [@Autism](#) So while might view my comments as "personal attacks", they are not really any different to other valid concerns by autistic persons & our allies have with other problematic research & practices in autism studies.

[@egstirling](#) [@Autism](#) "I'm curious as to why you feel PDA society etc are being deliberately misleading, by working with the information that they have."

I will respond in full later to this.

[@egstirling](#) [@Autism](#) Those reputable independent parties include [@NICEComms](#), which obviously is not a good look for any party to take an approach which is substantially different to NICE.

[@egstirling](#) [@Autism](#) [@NICEComms](#) It is potentially hugely problematic for PDA Society to working with government under 2021 England Autism Strategy, when PDA itself is not mentioned in that Autism Strategy, & how there is little to no good quality evidence to support charities views on PDA.

[@egstirling](#) [@Autism](#) [@NICEComms](#) As I said I will respond in full to your other point later.

[@egstirling](#) [@Autism](#) [@NICEComms](#) For one I have issues with "working with the information that they have." part you state. I would argue they are taking a fallacious, discriminatory approach to PDA & autism, which do NOT conform to DSM-5 autism criteria or NICE autism guidelines.

[@egstirling](#) [@Autism](#) [@NICEComms](#) There biggest issue is that they are assuming PDA is only seen in autistic persons, which ignores many studies & expert opinion PDA is seen in non-autistic persons.

[@egstirling](#) [@Autism](#) [@NICEComms](#) Including in Newson's own PDA research, which she was clear PDA is NOT an ASD & it would be a mistake to view it as such.

[@egstirling](#) [@Autism](#) [@NICEComms](#) So this leads to issues where PDA is mainly researched in entirely (or suspected) autistic population samples etc. Which leads to persons going well PDA is only seen in autistic persons rah rah rah.

[@egstirling](#) [@Autism](#) [@NICEComms](#) Including going well PDA looks different to other conditions seen in autistic persons so it must be part of the autism spectrum. Blah blah.

[@egstirling](#) [@Autism](#) [@NICEComms](#) Problem is co-occurring issues tend to present differently in non-autistic persons vs autistic persons. PDA probably looks different, with different causal mechanisms in autistic persons vs non-autistic persons. Yet, THIS IS TO BE EXPECTED & IS PERFECTLY FINE

[@egstirling](#) [@Autism](#) [@NICEComms](#) If one accepts divergent opinion on PDA, with accepted autism & nature of Disorder understandings; PDA should be common heterogeneous Spectrum Disorder seen inside & outside of autism.

[@egstirling](#) [@Autism](#) [@NICEComms](#) I am still awaiting to see how PDA Society & others think that supposedly being an anxiety based Disorder conforms to accepted autism understandings. When it is widely recognised anxiety based disorders are not part of autism spectrum.

[@egstirling](#) [@Autism](#) [@NICEComms](#) I find it highly arrogant to believe that just because X thousand persons are stating PDA is seen in autistic persons, means that PDA MUST be a "Profile of ASD", that divergent opinions on PDA, accepted understandings of autism & Disorders are mistaken.

[@egstirling](#) [@Autism](#) [@NICEComms](#) Newson was clear on her throughout her work PDA is not ASD, if anything went out of her way to ensure PDA could not be viewed as an ASD. Which detail here:

https://www.researchgate.net/publication/351071989_Is_Pathological_Demand_Avoidance_a_meaningful_subgroup_of_autism

[@egstirling](#) [@Autism](#) [@NICEComms](#) More importantly PDA has consistently been controversial & highly contested within the academic literature since 2002. At present there are 4 main schools of thought on PDA, as described in this 800 word essay.

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

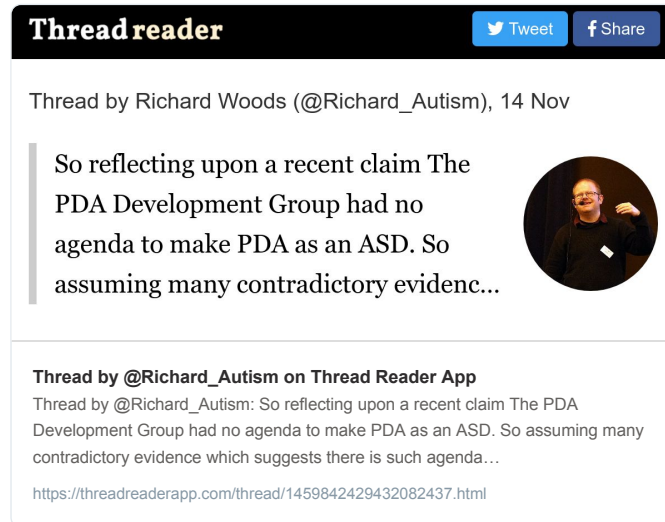
[@egstirling](#) [@Autism](#) [@NICEComms](#) I describe the history of different debates on PDA here:

https://www.researchgate.net/publication/356109997_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_Its_four_schools_of_thought_and_how_you_may_conceptualise_it

[@egstirling](#) [@Autism](#) [@NICEComms](#) There seems to be an agenda to make PDA be accepted as a "Profile of ASD" since 2011. Which PDA Society denies, yet there is a good case view this agenda as existing.

[@egstirling](#) [@Autism](#) [@NICEComms](#) It also seems non-credible that PDA Society would not be aware of consequences of its actions, i.e., that campaigning for & portraying PDA as a "Profile of ASD", it will be contribute to that becoming a "culture-bound concept" to the UK.

[@egstirling](#) [@Autism](#) [@NICEComms](#) Which would mean that the charity has lied to me, which it appears it has done on multiple occasions. For example of where I discuss this.



[@egstirling](#) [@Autism](#) [@NICEComms](#) I am also pretty certain off the top of my head Sally Russell stated in an email that decisions on how to view Disorders like PDA is political; which implies that the charity has made a political choice to view PDA as a "Profile of ASD".

[@egstirling](#) [@Autism](#) [@NICEComms](#) This is despite how contested PDA. The equal rights non-autistic persons with PDA have to research, diagnoses & support.

https://www.researchgate.net/publication/353417488_Rights_of_non-autistic_children_and_young_persons_with_PDA

[@egstirling](#) [@Autism](#) [@NICEComms](#) There are many reasons within the PDA literature, both historically & at present that suggests viewing PDA as a "Profile of ASD" is rather stupid thing to do. For example, for an overview to debates on what PDA is circa 2011:

<https://rationaldemandavoidancecom.files.wordpress.com/2021/05/22-may-2021-oddities-with-creating-pda-is-an-asd-research-agenda-in-2011-2.pdf>

[@egstirling](#) [@Autism](#) [@NICEComms](#) PDA's nature was severely contested in 2011, yet some persons argued PDA was an ASD & researched PDA while assuming an ASD since 2011 (e.g., Happe & O'Nions). O'Nions thesis is incredibly informative on their rationale.

<https://ethos.bl.uk/OrderDetails.do?did=2&uin=uk.bl.ethos.814002>

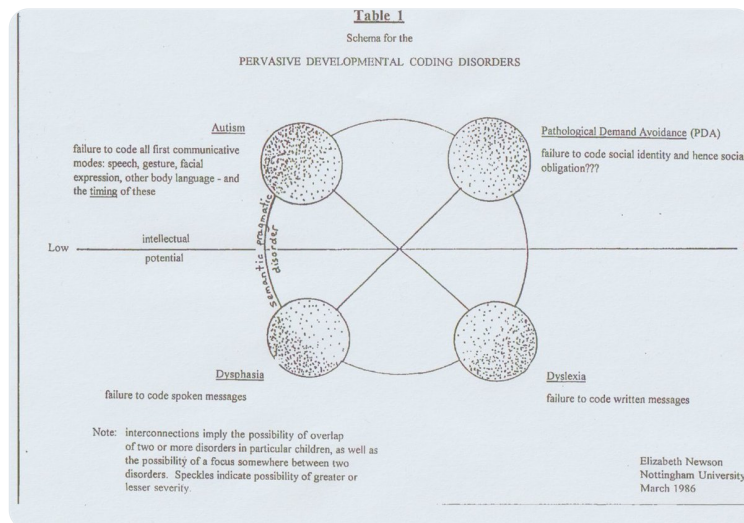
[@egstirling](#) [@Autism](#) [@NICEComms](#) That if today reputable independent parties like [@BPSOfficial](#) & [@NICEComms](#) are not assuming PDA is an ASD, while equally respecting divergent opinions on PDA. Then there is reasonable to expect the PDA Society & others to mirror that approach.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) It matters as out of the four main schools of thought, the only one which seems not valid, is "PDA Profile of ASD". While the other three main schools of thought, essentially require PDA to NOT be a "Profile of ASD".

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) One cannot view PDA as a "Profile of ASD", if assuming PDA is a pseudo-syndrome, that its features are presentative of over Disorders/ conditions. Or a common mental Disorder.

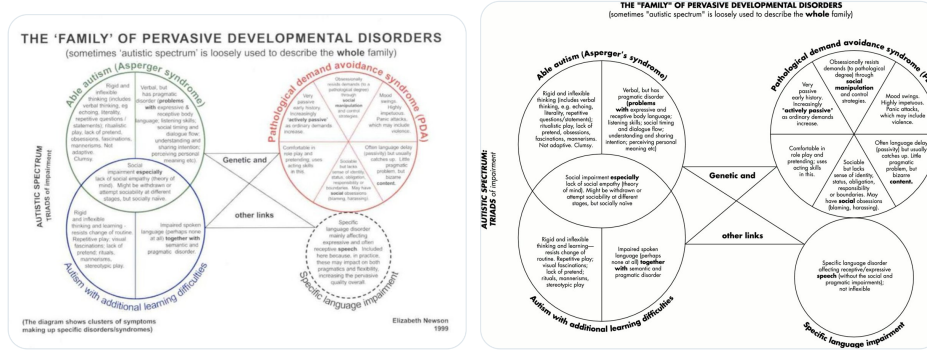
[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) There is evidence & theoretical models which indicate PDA represents a distinct clustering of features which is different to autism, going all the way back before Newson created PDA's first behaviour profile.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) Like how PDA Society & many others ignore how Newson created her own diagnostic grouping to place PDA in 1986, before she created its first behaviour profile in 1988.



[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) Newson's two later diagnostic groupings are revising the original Pervasive Developmental Coding Disorders grouping. Newson's PDD group does not conform to accepted understandings of that diagnostic grouping.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) For PDA Society has in the past used this Newson 1999 image in its materials (colour image), when it should be using Newson et al (2003 p599) image (black & white one).



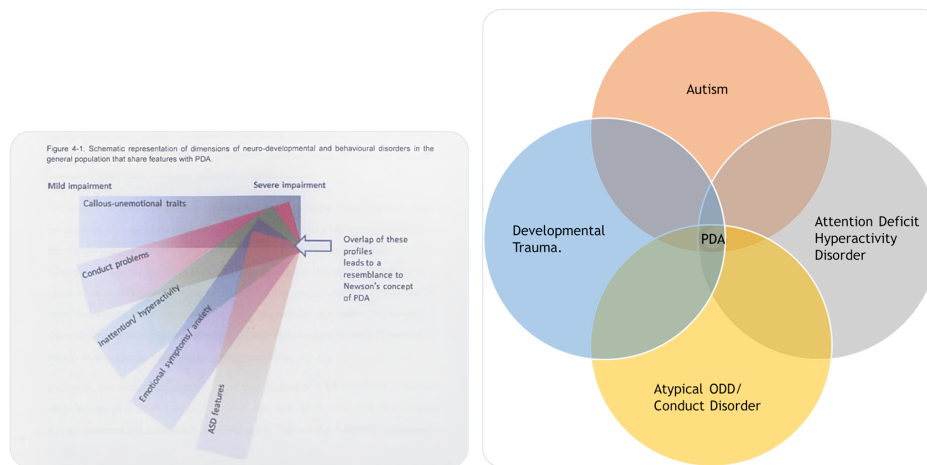
[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) So this is from p10 of PDA Society's 2016 Awareness Matters booklet.



[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) I suspect the charity used that image as Christie tends to use Newson 1999 image in his work, & to argue that as PDA was a PDD, it must now be an ASD. Despite this being a highly fallacious assumption. Charity seems to collaborate a lot with Christie.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) I am just as critical of Christie, I have learnt to double check his claims. I am critical of his lack of referencing divergent opinion & lack of disclosure of conflicts of interest.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) Examples of other theoretical models indicating PDA is distinct clustering of features & thus different to PDA include O'Nions (2013 p93). & Soppitt (2021 p299 - the Venn Diagram one).



[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) Vital consequence of the above diagrams is that PDA cannot be autism, if it contains non-autism features, logic tells you PDA cannot be something it is more than. e.g. $A+B+C \neq A$.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) If the PDA Society was equally respecting divergent opinion on PDA, it basically has to stop saying that it is part of the autism spectrum.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) I have had other issues with the charity, like it refusing to platform divergent opinion, like my own on its website.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) It initially refused to share the Being Misunderstood Report question booklet with me as it is apparently scared of me analysing it. Despite it sharing the question booklet with [@NeilKenny](#) & others.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) At present the charity & others are refusing to answer several reasonable questions, these ones to be specific:



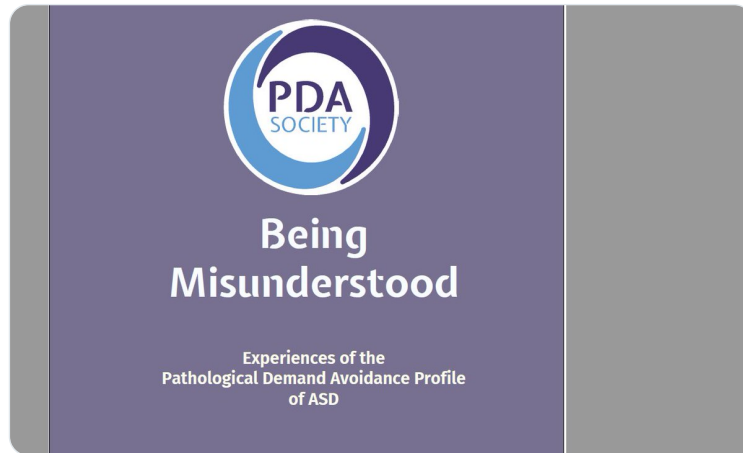
[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) Those questions are reasonable & important. Knowing who was on the PDA Development Group, is vital to know to ensure their involvement in PDA scholarship is not undermining the integrity of said scholarship & PDA research.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) To be clear the charity has since started to platform my work on its website, but they originally refused my requests on the topic.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) This is my point, the charity & other prominent "PDA Profile of ASD" supporters seem to have no issues cherry picking the literature, producing research which intrinsically supports their own views on PDA (which contradicts ethical research norms).

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) E.g, on the research front, their 2018 Being Misunderstood Report, which is meant to be used for lobbying to recognition of PDA as a "Profile of ASD".

Screenshot is of the cover of the Being Misunderstood Report.



[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) The charity has apparently lied to me & is/ was happy not to platform divergent opinion on PDA. Claiming PDA is a "Profile of ASD" on little to no good quality evidence. Not mirroring approach taken by multiple reputable independent parties, like [@NICEComms](#)

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) The charity has means, motive & opportunity to mislead the public. One can state it is clearly benefitting from its position on PDA when it is working with government to support its outlook on PDA, on little to no good quality evidence.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) As an outsider, who is not invested or emotionally attached to the "PDA Profile if ASD" narrative. There seems to be many good reasons to reasonably view the charity (& others) as misleading the public & being unscrupulous to nature of PDA.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) These are the reasons off the top of my head, it is even a considered response after a period of reflection. I might come back to this, if I have time to reflect upon it more & provide more reasons.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) *It is not even a considered response...* Is what I meant to say.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) Bear in mind, my approach to this, is to be dogmatically following an inclusive scientific-method approach to research practice due to being a social model neurodiversity supporter. I intrinsically try to be open minded on things.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) This is reflective in my work on PDA. I have gone from viewing PDA as a "rebranded autism" in 2017:



[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) To PDA is best viewed as being a "pseudo-syndrome" in 2018 - 2019.

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) To more recently viewing it as best described as a new type of (common) disorder.

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

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) Bear in mind, it is reasonable for us to expect the PDA Society to be transparent on divergent opinion on PDA. Who is/ was on the PDA Development Group, & what it did.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) If BoycottSpectrum10K can demand such things of Spectrum10K, then it is reasonable that autism stakeholders & autistic persons demand the same from PDA Society & [@Autism](#) etc.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) An example of how concerns of some ABA supporters not declaring equivalent conflicts of interest is here & they were made to disclose them after a complaint.

<https://link.springer.com/content/pdf/10.1007/s10803-021-05200-8.pdf>

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) So that it is clear from a research perspective the charity should be transparent over who was on the PDA Development Group & what it did.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) Many of the PDA Development Group members should be registered with [@The_HCPC](#), which from my understanding Judy Eaton is. SALT's, registered practicing psychologists & OTs are required to disclose their conflicts of interest.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) [@The_HCPC](#) Link to [@The_HCPC](#) conflicts of interests policy.

<https://www.hcpts-uk.org/globalassets/about-us/who-we-are/partners/policies/hcpc-conflict-of-interest-policy2.pdf>

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) [@The_HCPC](#) There is also the issue of how anxiety is not recognised as an intrinsic feature of autism in DSM-5 autism criteria & NICE autism guidelines. How anxiety based disorders are not accepted to be ASDs, & PDA is meant to be an anxiety based disorder.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) [@The_HCPC](#) So one can argue the charity is asking practitioners to not follow accepted clinical practice. Which is why I keep asking PDA Society to disclose how it thinks viewing PDA as an ASD, conforms to DSM-5 & NICE autism documents.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) [@The_HCPC](#) I will stop here for now. I will add any further points, if I make time to reflect on this topic.

[@egstirling](#) [@Autism](#) [@NICEComms](#) [@BPSOfficial](#) [@NeilKennyo](#) [@The_HCPC](#) [@threadreaderapp](#) please can you unroll?

Thank you in advance.

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