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Jan 17, 2022 · 64 tweets · [Richard_Autism/status/1483215046805184515](https://twitter.com/Richard_Autism/status/1483215046805184515)

Well, just seen the PDA Society 5 year strategy. We will know if they are being serious if they are being inclusive to non-autistic persons with PDA. Also if actively include me in their research based activities. If not they are being being serious on those topics.

There are some slightly concerning comments in there. Also some positive ones, some less derogatory terms for PDA traits. E.g. p3.

"Having active imaginations, liking fantasy, role-play and pretence."

The wording is interesting, as originally comfortable in roleplay & pretence was viewed as a coping mechanism from Newson's work. It is also how I am viewing it as part of a transactional stress approach to PDA.

Saying they have "active imaginations" is a sign of looping effects of PDA, probably due to the bias of how PDA has taken route among the UK autism community.



Pathological demand avoidance: my thoughts on looping effects and c...

(2017). Pathological demand avoidance: my thoughts on looping effects and commodification of autism. *Disability & Society*: Vol. 32, No. 5, pp. 753-758.

<https://www.tandfonline.com/doi/full/10.1080/09687599.2017.1308705#:~:text=Looping...>

This takes me on to some of the concerning aspects of the strategy:

"The PDA Society is run by the PDA community for the PDA community." p12.

Simply put, there should be no PDA community considering the contested & controversial nature of PDA, i.e., there should be PDA "bubble"

Considering how there is a bubble around the notion of "PDA Profile of ASD", it would suggest the charity exists to further this controversial, contested & extreme (when compared to other views on PDA) outlook over what PDA is.

As I set out the bubble around "PDA Profile of ASD" should not exist. Although, I accept they might argue PDA should be viewed as an ASD globally.

https://www.researchgate.net/publication/355427579_Demand-Avoidance_Phenomena_Pathological_Extreme_Demand_Avoidance_As_a_biopower_identity

"More research is needed before everyone can agree on what PDA is, what helps and its inclusion in the diagnostic manuals" p6.

Simply put if the charity is serious about this sentence, it would be engaging with someone whose PhD is directly related to that...

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

"Research needs to involve PDA individuals and the people who support them because PDA can't be properly understood without listening to the PDA community's lived experiences." P6.

I concur it does need to involve those with PDA, under Equality Act that applies to non-autistic persons with PDA & those who choose not to be part of that community like myself & @milton_damian. PDA is meant to be a disability, it is not a religion...

... just being part of that community does not give its members extra rights over persons with PDA.

Worth restating this PDA is NOT A RELIGION, it is meant to be a disability under the Equality act.

Goal of the PDA Society:

"Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed" p6.

Simply put if the charity is serious about this, it needs to invite me due to my systematic review, which is holding PDA to typical standards such as declarations of conflicts of interests.

https://www.crd.york.ac.uk/prospERO/display_record.php?RecordID=278548

Obvious point about only focusing on the "community's lived experiences", it risks biasing PDA research to only a certain outlook, & ideas of what PDA might be. It also would support my notion "PDA Profile of ASD" is a self-validation exercise.

The focus on "community's lived experiences" undermines the goal of high quality research, as the bias from recruiting samples from the community is a factor why there is no good quality evidence to suggest what PDA is...

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

I would also point out that the "PDA community" members are human, & so are as biased as anyone else on the topic of PDA. One can view it as claims making similar to ABA supporters that they are positioning themselves as only "authority" on what PDA is.

I discuss how pushing for "PDA Profile of ASD" can bias PDA research here:

https://www.researchgate.net/publication/338650142_Commentary_Demand_Avoidance_Phenomena_a_manifold_issue_Intolerance_of_uncertainty_and_anxiety_a_s_explanatory_frameworks_for_extreme_demand_avoidance_in_children_and_adolescents_-_a_commentary_on_Stuar

I point out that "PDA Profile of ASD" supporters are as biased anyone else on PDA here:

https://www.researchgate.net/publication/357033261_Demand-Avoidance_Phenomena_PathologicalExtreme_Demand_Avoidance_what_are_the_implications_of_it_being_a_biopower_identity

"We'll support an Autism and Complex Need Special Interest Group for professionals to share what they are doing." p7.

This is concerning as it suggests that the charity has already decided that PDA is part of the autism spectrum, despite the substantially contested, controversial & extreme position of "PDA Profile of ASD" (relative to other views of what PDA could be).

The obvious problem with this view that PDA is a "Profile of ASD", is that other views on what PDA is can be researched too...

Can PDA be viewed as an Attachment Disorder, or a Personality Disorder? E.g., conceptualising PDA as an attachment disorder & testing its validity!

Simply put "PDA community" is not the only one who can play "spin the Disorder" bottle with PDA.

A short introduction into outlooks of PDA can be found here:

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

The charity is aware of my PhD research plans. So its response to them, to both holding PDA to typical research standards & equally respecting ALL persons with PDA's rights. Charity's response will be very interesting & tell us about how reputable the organisation is.

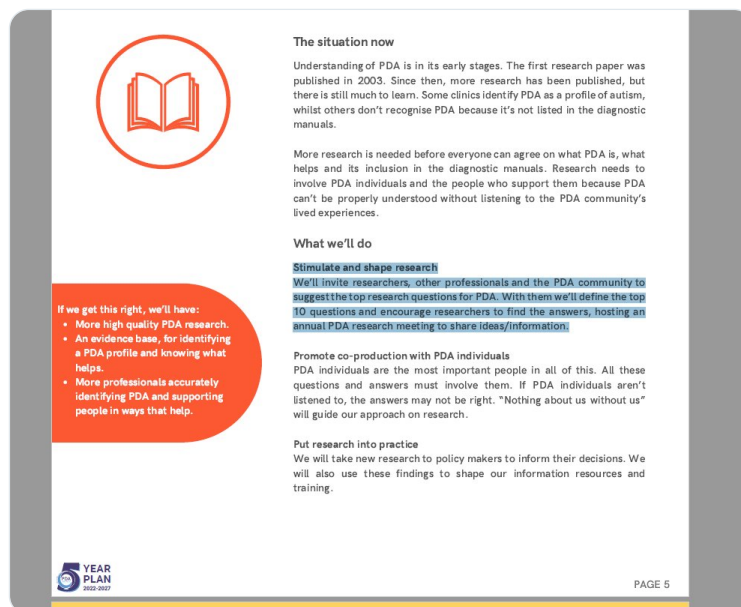
Lets put this way the charity should want PDA being held to typical research standards, like conflicts of interests being disclosed. It should want me to conduct my entire planned research agenda, as it should make PDA less controversial.

Well, I guess the charity's five year strategy can be viewed as evidence there is an agenda to make PDA accepted as part of the autism spectrum. Who would have thought that (rhetorical)?

So I need to go into an example of how the charity seems to have tied itself in knots relating to PDA & its bias towards favouring the PDA community.

"We'll invite researchers, other professionals and the PDA community to suggest the top research questions for PDA. With them we'll define the top 10 questions and encourage researchers to find the answers, hosting an annual PDA research meeting to share ideas/information." p6

I have highlighted the text in the below screenshot:



"Some clinics identify PDA as a profile of autism, whilst others don't recognise PDA because it's not listed in the diagnostic manuals." p6

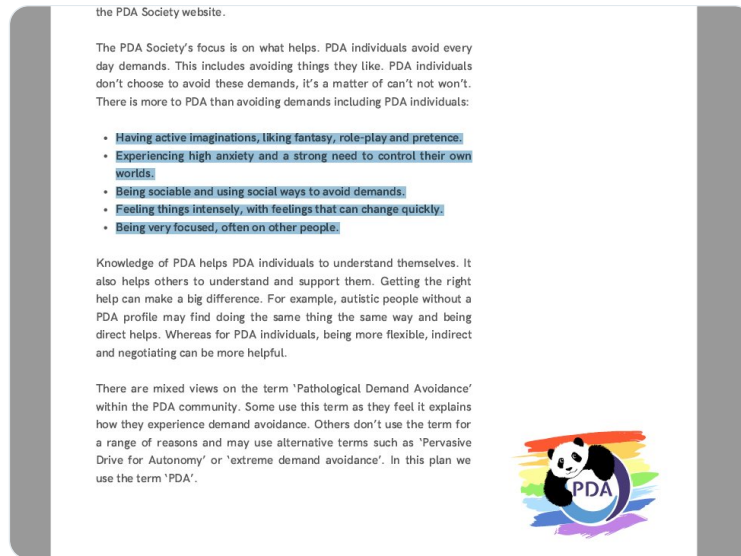
"Since 2003 there's been more research and PDA is now widely thought to be a profile of autism. However, not everyone agrees, and more research is needed" P3

"This includes avoiding things they like. PDA individuals don't choose to avoid these demands, it's a matter of can't not won't." P3

This is simply a bold claim considering some view PDA as being a common mental Disorder. My PhD research should help to clarify if it is or not.

It supports my view that the charity has already decided upon what PDA looks like.

Below image shows other features which charity says those with PDA have.



I support the general neutral language used in those traits. Also good to see PDA must not be from early infancy, which raises questions about certain PDA studies which the charity claims as "more authoritative".

I am being positive about how these traits are listed.

The point I am making is that charity is aware there is much divergent opinion on PDA, although it seems to be (conveniently) ignoring debates around PDA is seen in non-autistic persons.

How is this an example of the charity tying itself up in knots? Simple, it is favouring the PDA community & outlook PDA is an ASD, despite divergent opinion, the extreme, controversial & contested nature of the charity's own position on PDA...

... While having this:

"Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed, informing policy and practice, with improved outcomes for PDA individuals." p6.

It is widely acknowledged in the literature, both "PDA Profile of ASD" supporting academics, & those who with divergent opinion, than sourcing research from the community is a potential source bias to PDA research.

And this:

"Researchers are required to be open minded, to avoid research "designed to support a preconceived notion or belief" (Chown et al, 2019, p1)...

... Ethically, researchers need to attempt falsification of their hypothesis as part of the scientific method that is involved in most research (Milton, 2016; Rutter and Pickles, 2016)." Woods 2019 p36.

It seems rather hasty & premature to suggest putting forward a top 10 research priorities on PDA, when research into PDA is still on going & said research priorities will probably exclude PDA persons who are not part of the community, or not autistic.

Any such top 10 PDA research priorities based on the PDA community, presently is likely to be biased in favour of "PDA Profile of ASD".

Also by actively favouring "PDA Community" is likely to further bias PDA research, undermining the quality of said research produced on the topic. There are reasons why I am having to address the risk of bias caused by PDA community in my PhD research!

I am actively being encouraged by my PhD supervisors, like [@milton_damian](#) to be inclusive of those who are not part of the PDA community, partly due to the bias presented from the PDA community.

Some examples of where in the literature sourcing research from the PDA community creates a potential source of bias.

"We sampled only cooperative families who were willing to engage with research, who had some degree of knowledge of extreme/'pathological' demand avoidance. Their particular experiences could had impacted their construal of their child's difficulties." O'Nions et al 2018a, p226.

"A further consideration is that, in the present study, participants were a community-based sample recruited from online sources (e.g., parent support groups, social network groups)..." O'Nions et al 2021a, p32.

Screenshot is on an entire paragraph by O'Nions et al 2021a talking about risk of bias created due to sourcing research from PDA community.



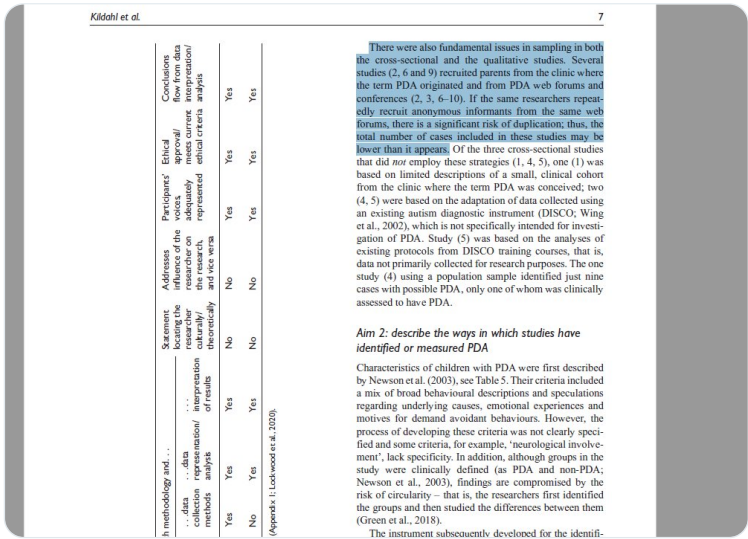
"parents of children with ASD who had reported their child to have PDA were recruited through several streams, these parents had some knowledge of PDA...

... If parents identify with the PDA construct strongly then does that bias parental description and interpretation of child behaviours?" Malik & Baird 2018, p388.

"There were also fundamental issues in sampling in both the cross-sectional and the qualitative studies. Several studies (2, 6 and 9) recruited parents from the clinic where the term PDA originated and from PDA web forums and conferences (2, 3, 6–10)...

... If the same researchers repeatedly recruit anonymous informants from the same web forums, there is a significant risk of duplication; thus, the total number of cases included in these studies may be lower than it appears." Kildahl et al 2021, p7.

Screenshot from @ArvidNK systematic review on PDA noting problems created by sourcing PDA research from PDA community.



It must also be said I have spoken about the problems of limiting PDA research to a particular outlook of it here, as it risks biasing clinical understandings of PDA.

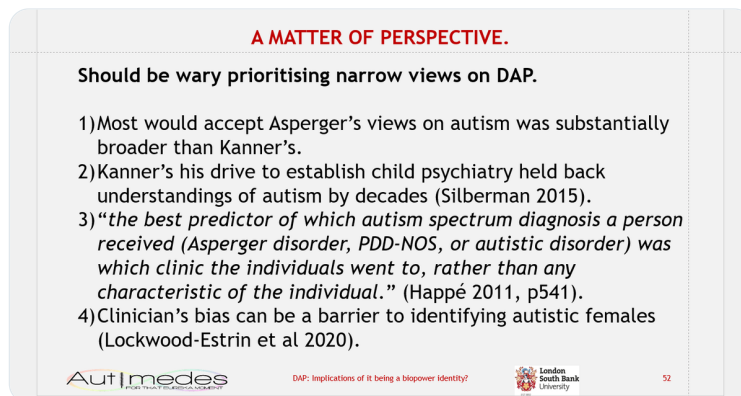
Screenshot where I discuss issues created by potentially biasing PDA to only those with "severe" presentations here (Woods 2020a, 69)



I also discuss problems created from taking narrow views on autism in this talk from last December. I also note some examples from autism literature which suggest it is unwise taking a narrow view on PDA.

https://www.researchgate.net/publication/357033261_Demand-Avoidance_Phenomena_PathologicalExtreme_Demand_Avoidance_what_are_the_implications_of_it_being_a_biopower_identity

Screenshot of the examples from autism literature on why we should be wary taking narrow views on PDA.



It must also be noted that academics in the UK are protected by academic freedom, which means they are protected against things like political & commercial pressures on their research. I.e., it is not for the charity to suggest or bias which outlooks are adopted on PDA research!

It should be clear to anyone open minded on the topic, unless the charity's 5 year strategy, at least referring to its goal on PDA research is updated, PDA critics are highly likely to have a field on the topic risk of bias created by it.

Likewise, it should be clear that favouring the PDA community undermines the charity's own promoting high-quality research on PDA.

As I said [@Georgin24661487](#) does appear the charity has tied itself up in knots.

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

Thank you in advance.

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