

<u>@SusieBass</u> Being honest, I do not where to begin. The issues with much of PDA narrative is systemic.

As I twitted earlier today are many good reasons for not even viewing PDA as a form of autism. Much/ most of critique of PDA seems valid.

<u>@SusieBass</u> I mean if literature does not justify viewing PDA as an ASD in 2011. The scientific and ethical response, is not to pursue an agenda that tries to create evidence base to view PDA as an ASD. Just so much of it is bonkers.

<u>@SusieBass</u> Example. So say I "emulate" O'Nions PhD research, but: Assume PDA is a form of attachment disorder.

I argue PDA is an attachment disorder.

Approach PDA from understanding of disorder.

Create a tool for PDA with advise from 10 attachment disorder specialists

<u>@SusieBass</u> Only validate new PDA tool on CYP with suspected attachment disorder & not even use a screening tool for attachment disorder.

Do a qualitative study into PDA with persons who conform to my views PDA is an attachment disorder.

<u>@SusieBass</u> Have a sample of 14 CYP, 13 with attachment disorder & 1 with ASD. Acknowledge PDA does not conform to attachment disorder understandings. Yet still argue PDA is a form of attachment disorder.

<u>@SusieBass</u> Then go and base a career on the notion that PDA is a form of attachment disorder.

Bear in mind this seems to be what O'Nions has done, but with viewing PDA as an ASD.

<u>@SusieBass</u> If I did that, most people should be at least raising a curious eye brow.
Yet, most critical reviewers of the literature should be going, that is not science or ethical.

<u>@SusieBass</u> *No*. For my PhD, I am not "emulating" O'Nions PhD research, with trying to make PDA an attachment disorder.

Although, I am tempted to just to make the point...

<u>@SusieBass</u> Some of CYP with PDA/ suspected PDA, in EDA-Q validation study had an autism dx. It is unclear exactly how many were autistic, as only "indicators" of autism were used for those lacking an autism dx. This was at time when PDA was diagnosed as stand alone dx.

- <u>@SusieBass</u> Newson's cohort has some non-autistic persons in it. So it is problematic assuming that all CYP with PDA, even suspected PDA, in that study were autistic.
- <u>@SusieBass</u> Actually, this has been bugging me. I think a case study based on O'Nions career via PDA research is needed to highlight ethical issues with PDA. Thinking about it, might be worth doing another on Christie's various involvement's in "PDA is an ASD" agenda.
- <u>@SusieBass</u> "One challenge is that research conducted outside of clinical settings typically relies on volunteer samples of parents, who are often highly motivated and committed to furthering understanding of their child's difficulties." O'Nions et al (2016b, p2).
- <u>@SusieBass</u> "Parents who had expressed an interest in participating in research through direct contact with the researchers were also invited to participate....
- <u>@SusieBass</u> ... Participants were encouraged to share information with other parents in their networks to facilitate further recruitment" (O'Nions et al 2021. p3).
- <u>@SusieBass</u> "We identified participants where the same respondent may have been included in both Sample 1 and Sample 2 by checking whether there were children with an identical combination of birth year, birth month, and gender in both Samples 1 and 2." (ibid, p4).
- <u>@SusieBass</u> "Second, many of them had a particular interest in the concept of PDA. As such, our sample may overrepresent engaged and motivated parents who adopt more accommodative as opposed to authoritarian approaches." (O'Nions et al, 2020, p399).
- <u>@SusieBass</u> "We sampled only cooperative families who were willing to engage with research, who had some degree of knowledge of extreme/'pathological' demand avoidance." (O'Nions et al 2018, p226).
- <u>@SusieBass</u> These points matter, as it creates a potential source of confirmation bias in the research results. Also particularly concerning, that O'Nions is aware of interest in PDA among caregiver's & actively worked with this in at least two studies.
- <u>@SusieBass</u> "Thirdly, it is recognised that the surge in interest into DAP since before 2010 can lead to persons to be 'on the lookout' for features of DAP (O'Nions et al., 2016). This interest is plausibly driven by social media campaigning by DAP carers...
- <u>@SusieBass</u> ... The sample was sourced through the PDA Society, and their participation in this research, one would assume, indicates their support for the construct...
- <u>@SusieBass</u> ... It is also reasonable to assume that the participants are knowledgeable on DAP. Therefore, this is a credible source of confirmation bias." Woods, 2020, p69).

Yes, I am talking about Stuart et al (2020), but it is applicable to O'Nions research.

<u>@SusieBass</u> "If parents identify with the PDA construct strongly then does that bias parental description and interpretation of child behaviours?" (Malik & Baird 2018, p388).

Commenting on O'Nions et al 2018...

- <u>@SusieBass</u> "Since 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).
- <u>@SusieBass</u> "In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic." (O'Nions and Eaton 2021, p411).
- <u>@SusieBass</u> I am not going to provide the many quotes of when O'Nions has viewed PDA to be an ASD. Probably worth mentioning the time used arbitrary threshold's, that viewed PDA as an ASD subgroup though.
- <u>@SusieBass</u> "17 PDA-relevant DISCO items were not widely endorsed in general in an autism spectrum sample, since features typical of ASD in general are unlikely to be useful in identifying a meaningful subgroup." (O'Nions et al 2016a, p410).
- <u>@SusieBass</u> "Identification of a cutoff is somewhat arbitrary, since scores followed a continuous (albeit skewed) distribution." (O'Nions 2016b, p411).
- <u>@SusieBass</u> "A major criticism of trait theory is that it can be said to have created its own industry." (Milton 2010, p4).
- @SusieBass Worth restating this quote by Grinker.

WHY IS IT ALWAYS ME (AUTISM)? Demand from non-autistic stakeholders. 1) Interest is driven by non-autistic stakeholders (Christie et al 2012; Newson et al 2003). 2) "once a diagnosis takes hold and serves as the hub around which so much wealth, so many people, and activities coalesce, it takes on a life of its own as an authentic, naturalized classification (Hacking 2000). This category, in turn, provides an incentive for manufacturing people with the diagnosis of autism whose presence and needs support this financial infrastructure." (Grinker 2020).

@SusieBass It does seem reasonable to question if O'Nions has acted:

- Benefitted from their actions in their research, while pursuing PDA as an ASD?
- Ethically?
- Scientifically?
- <u>@SusieBass</u> I suspect if a case study is produced on a researcher acting, like O'Nions has done with respect to "PDA as an ASD", but with viewing PDA as a form of attachment disorder; many would inherently see the problems with it.
- <u>@SusieBass</u> Oh before I forget. CYP with PDA are a vulnerable group. So are their caregivers also a vulnerable group.

This is actually a good example to turn into a case study on researcher ethics.

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<u>@SusieBass</u> <u>@threadreaderapp</u> Also O'Nions has had non autistic persons with PDA in multiple research samples and missed/ ignored implications PDA is not an ASD.

While this case study is interesting, is getting rather lamentable.

@SusieBass @threadreaderapp @threadreaderapp please could you unroll?

Thank you again.

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