

<u>@KatyBenson20</u> It is hard to take much from significant swathes of PDA literature. I have learnt to not trust the accuracy or validity of much of what is said by certain "leading" experts on PDA.

- <u>@KatyBenson20</u> My reservations about the quality of much of what is said about PDA, means that the axiology behind my PDA research is different to much of that in currently in PDA literature. Basically, I am skepitcal of anything that assumes "PDA is an ASD".
- <u>@KatyBenson20</u> I can give many examples to justify my skepticism of certain experts scholarship.
- <u>@KatyBenson20</u> About potential harm it can cause, most of it is linked to why PDA is controversial.
- @KatyBenson20 Here is a list of reasons why PDA is controversial.
- <u>@KatyBenson20</u> •The "pathological" descriptor is demeaning and horrible. There is significant dislike of "pathological" descriptor and demand to change PDA's name.
- •PDA lacks consensus on what it is.
- •There is no standardised diagnostic profile or validated tools.
- <u>@KatyBenson20</u> •PDA is not in either main diagnostic manuals.
- •PDA risks undermining validity of clinical based language, as it involves an atypical approach to nosology.
- <u>@KatyBenson20</u> •Ignoring non-autistic persons with PDA and how clinical justifications for PDA are applicable to them.
- •Prematurely forming a community of practice around outlook "PDA is an ASD"; generally missing/ ignoring valid critique of PDA.
- <u>@KatyBenson20</u> •PDA pathologises traits from accepted conditions and thus cannot be a Disorder. Personally, this should only matter to prevent PDA being accepted as something, it is more than e.g., $A + B + C \neq A$.
- @KatyBenson20 •Some features of PDA are hard to reliably measure.
- <u>@KatyBenson20</u> •Lack of cogent accounts and descriptions of PDA, e.g., missing/ignoring non-autistic persons in research samples and still calling PDA an "autism profile". Or deficits in "Pride/ Shame/ Social identity" causing panic attacks. ..
- <u>@KatyBenson20</u> ... These deficits are meant to allow a person to be highly motivated to avoid demands of "ordinary life" (non-autistic life), however now arguing demand

avoidance is compulsive in nature (i.e, not by choice).

- <u>@KatyBenson20</u> •Arguing for this: "To build on developments, insights and increasing recognition of PDA but maintain the integrity of how the condition is understood and the nature of the support that is needed by individuals" (Christie, 2016; 2018; 2019)...
- <u>@KatyBenson20</u> ... With a lack of cogent descriptions and with undermining the integrity of autism, which itself has substantial greater evidence and consensus over what it is, compared to PDA...
- <u>@KatyBenson20</u> ... when PDA contains features of trauma, ADHD and other conditions. Particularly, concerning is associating trauma features with autism, considering legacy of issues of Refrigerator Mother with false FII claims with autism caregivers and autistic persons.
- <u>@KatyBenson20</u> •PDA is viewed as an ASD and is trying to divide autism despite many autistic persons not wanting autism to be subdivided, or in the diagnostic manuals. While PDA is primarily driven by non-autistic stakeholders.
- <u>@KatyBenson20</u> •PDA seems to pathologise a person's self-agency & risks undermining a person's human rights.
- •Poor quality of much of PDA research, circular in nature, with generic features (no feature is PDA specific), or relying on snowball sampling/ caregiver reports
- <u>@KatyBenson20</u> •Signs of many vulnerable persons are supporting "PDA is an ASD" narrative.
- · Lack of disclosure of Conflict of Interests.
- <u>@KatyBenson20</u> •Viewing PDA as an ASD and arguing some autistic persons should be protected from reinforcement-based approaches like ABA/ PBS, while leaving the rest of autistic population to potentially be exposed to ABA/ PBS.
- <u>@KatyBenson20</u> •PDA is a culturally based construct, to the UK
 •PDA is potentially highly stigmatising and is potentially problem:
- •PDA is potentially highly stigmatising and is potentially problematic for autistic persons to escape stigma of autism, as PDA stereotypes are opposite of autism. See the table.



<u>@KatyBenson20</u> •PDA can adversely impact a person's life chances, e.g. who would wish to employ someone who has a "pathological"/ "extreme" aversion to demands? •PDA strategies replicate good practice and comparable strategies are widely practiced.

<u>@KatyBenson20</u> •Comparable approaches to PDA strategies have been practiced for years with autistic persons, independently of any PDA construct. Traditional autism approaches do not work for many autistic persons.

<u>@KatyBenson20</u> •PDA's clinical need has been contested for over two decades.•Lack of adequate engagement with Newson's research.

<u>@KatyBenson20</u> There are some more reasons why PDA is controversial now, than when I first created this list. It is a substantial amount. One should be able see the potential harm PDA can cause...

<u>@KatyBenson20</u> ... For how PDA is mainly driven by non-autistic stakeholders and pushing to divide autism with PDA, contradicts how most autistic persons do not autism in the dx manuals or to be divided-likely undermine cohesion of autistic community & lobbying efforts etc

<u>@KatyBenson20</u> I dread to think what can happen to vulnerable caregivers, if aspects of trauma become associated with autism due to PDA. Already a problem with false FFI claims on autistic caregivers.

<u>@KatyBenson20</u> Likewise, I dread to think what would happen if only a small part of autistic population is becomes "safe" form PBS/ ABA due to a PDA dx.

<u>@KatyBenson20</u> I can refer to literature to back up these controversial aspects of PDA.

<u>@threadreaderapp</u> Please could you unroll?

Thank you in advance?

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