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Nov 5, 2021 · 39 tweets · [Richard_Autism/status/1456689498683756552](#)



The more I reflect on the current fiasco over Owen Paterson. More it is reflective over my concerns of those pushing "PDA Profile of ASD", & their apparent disregard for typical research & practice norms.



While there is a difference in the case of the Tories were trying to erode typical standards, in my view key parties pushing "PDA Profile of ASD" seem to disregard broader typical standards, while accepting poor quality standards associated with autism.

This should not be the case. PDA is so "new" & recent in terms of interest, since about 2010, that it should be a beacon of what good quality research & practice looks like.

There is not really an excuse for PDA to have such low standards. As James O'Brien points out that how "Brexit" is used to justify slipping standards by the Tories, their is a "clinical need" for PDA is argued to do similarly for PDA.

Arguing there is a "clinical need" for PDA is not good enough, the debates around PDA's clinical need are contested, & often applicable for non-autistic persons with PDA. Also likes of [@NICEComms](#) & [@BPSOfficial](#) do not buy that argument, they want evidence.

No, having X thousands persons on social media groups is not scientific evidence. Guess who also has hundreds/ thousands of supporters - flat earthers/ anti vaccers. Not that I saying "PDA Profile of ASD" supporters are akin to those groups.

I am not even sure why some "PDA Profile of ASD" supporters view X thousands of persons being members of such social media groups, count as evidence for their perspective.

Perhaps, a mutual "lightbulb" moment, that would be easy to do due to generic nature of PDA & that PDA strategies replicate good practice. This is something I talk about here:

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

The PDA literature acknowledges it is highly contested & controversial, I do not see how apparently not following typical research & practice standards helps PDA. It should just make it more controversial.

There is not really any excuse, if for example they have a conflict of interest they should disclose it. They should be aiming for highest possible standards, such as PDA strategies need RCTs so they can be included in Cochrane Reviews etc etc.

I discuss some of these things here:

osf.io/3w86h/

I am pretty done on this one. I am saying things, hoping that others can empathise my perspective, & passion for why PDA should be held to typical standards on research & practice.

Autistic persons & those with PDA deserve better than what we have with PDA. There is no excuse for why some vulnerable persons should be misled to the point they are doing internalised ableism against those who critique PDA, like me or [@milton_damian](#).



If independent parties who seem not to be benefitting from "PDA Profile of ASD" narrative are taking a neutral position on PDA, & treating divergent opinions equally, which we know they seem to be doing. This is how we should be treating PDA.

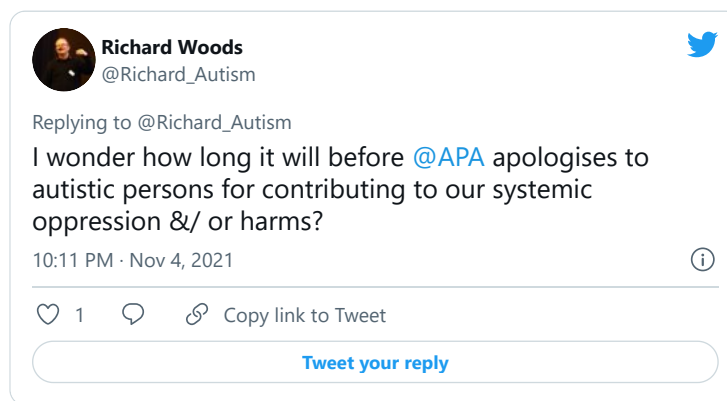
So internalised ableism is when an oppressed group adopts and expresses discourses linked to ableism. This is something I discuss here:

https://www.researchgate.net/publication/325181432_Rational_Pathological_Demand_Avoidance_what_it_is_not_what_it_could_be_what_it_does

Autistic persons are an oppressed population demographic, mainly through the use of pathologising, medical model discourse & ideology. This is something @DrMBotha discusses here:

<https://www.frontiersin.org/articles/10.3389/fpsyg.2021.727542/full>

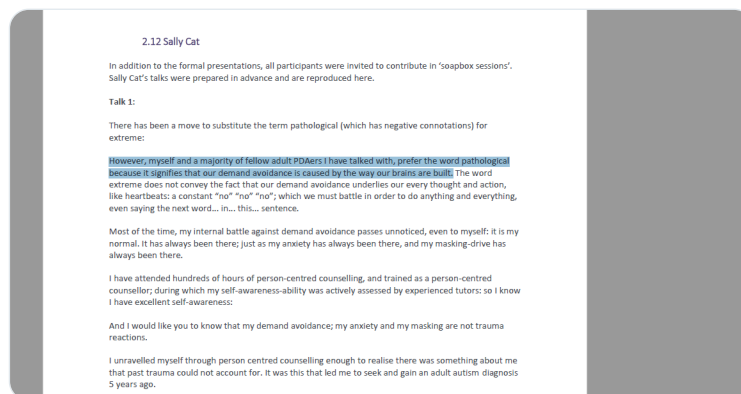
It is why I have tweeted this, due to how @APA has contributed to the harms autistic persons face.



Yet, some autistic persons seem happy & content to adopt & emotionally attach to the "PDA Profile of ASD" narrative, including the "Pathological" descriptor.

Screenshot is from page 13:

<https://www.pdasociety.org.uk/wp-content/uploads/2019/09/Research-Meeting-Report.pdf>



This is despite how PDA appears to pathologise a person's self-agency, especially when a person is distressed & contravening non-autistic norms.

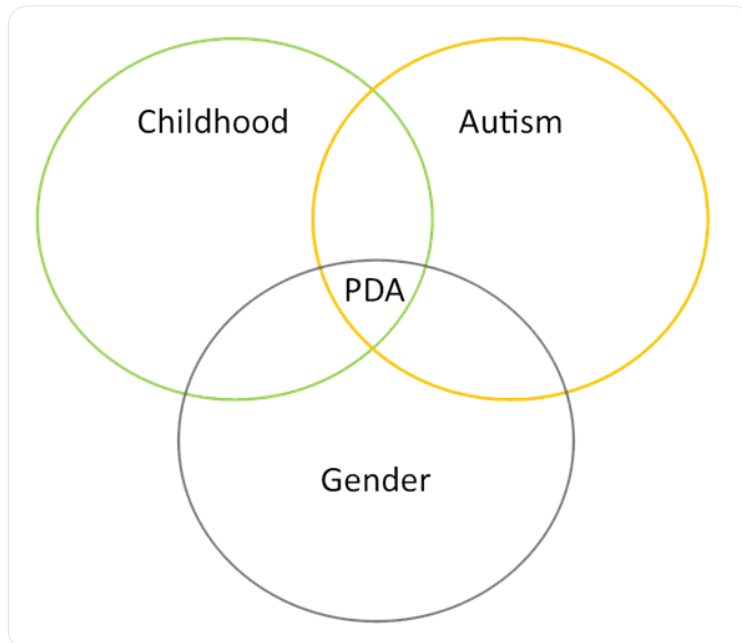
How PDA pathologises a person for contravening non-autistic social norms is set out by @Allison66746425 here.



Pathological demand avoidance: What and who are being pathologise...

The term 'pathological demand avoidance' was first coined in 1983. In recent years, diagnostic tools have emerged to enable practitioners to identify, name and ...

<https://journals.sagepub.com/doi/full/10.1177/2043610619890070>



[@milton_damian](#) argues it here:

<https://kar.kent.ac.uk/62694/431/Natures%20answer%20to%20over%20conformity.pdf>

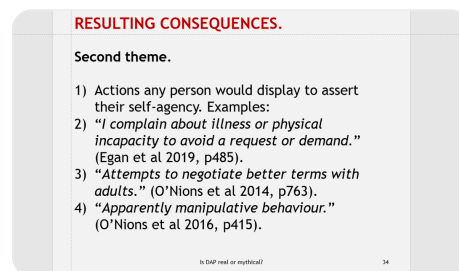
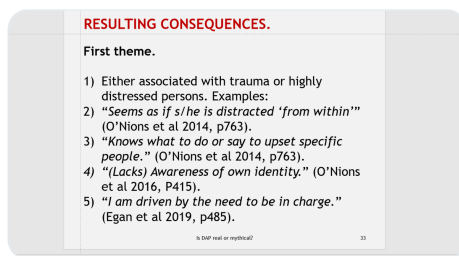
& I build on this here:



I further develop this argument here, with a content analysis of items in PDA diagnostic & screening tools, which shows PDA tends to pathologise features representative of distress & persons asserting their self-agency.

https://www.researchgate.net/publication/340279248_Is_the_concept_of_Demand_Avoidance_Phenomena_Pathological_Demand_Avoidance_real_or_mythical

Images showing some of the items from PDA tools, that they represent either distress or a person expressing their self-agency.



Internalised ableism is a process, its not something has. 1st step of it is multiple persons of an oppressed group internalising discourse used to oppress them, in this medical model version of PDA, that its features are routed to issues within the person.

The next step is that those who have internalised the oppressive discourse then remit it internally within the oppressed group. Thus attacking those who disagree with them. These images literally internalised ableism in action on "PDA profile of ASD".



The thing is though those vulnerable persons who are doing the internalised ableism, probably are unlikely to understand this due to how invested they are in the "PDA Profile of ASD". Probably will not recognise PDA is being used to oppress autistic persons.

I have some sympathy for the vulnerable persons doing the internalised ableism. It is also a significant fact as to why I am so critical of the influential "PDA Profile of ASD" proponents who are not portraying balanced & accurate information on PDA.

It is highly unlikely those who attacking persons who critique "PDA Profile of ASD" would so invested in it, it was widely acknowledged in the PDA literature, it is severely contested, there are many different views on PDA. It might not be a form of autism

As Monique says here, what is said about autism in literature ends up in broader culture. Same principle applies to PDA.

<https://www.frontiersin.org/articles/10.3389/fpsyg.2021.727542/full>

& this is something I argue here:

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

Those like [@PDASociety](#) & [@Autism](#) have an ethical responsibility to provide balanced & accurate information on PDA. 1) so vulnerable persons do not become invested in PDA ahead of its evidence base & so should not be offended when PDA is inevitably critiqued.

2) So the likes of me & [@milton_damian](#) should not have be subjected to crap like this. Just because we reasonably critiqued PDA, which as something highly contested & controversial, PDA is going to critiqued.



As I pointed out here, if one considers broader context of nature of PDA, its generic features, problems with its tools, multiple contradictory behaviour profiles, general mental health issues autistic persons experience from how poorly society treats us...

... 1) bunch of autistic persons would identify with PDA. 2) internalised ableism would result from that, is predictable from advocating for "PDA Profile of ASD" beyond its evidence base & ignoring the consistent robust challenges to that outlook.

This has gone off on a tangent to some extent. My point if typical standards were adopted with PDA over last decade, equally respecting divergent opinion...

... I highly doubt so many autistic persons would identify with PDA, "PDA Profile of ASD" being a "cultural-bound concept" to the UK, & internalised ableism would have occurred to anywhere near the extent it has.

Low & behold, I back again to critiquing the conduct of members of the PDA Development Group/ those otherwise significantly involved in pushing "PDA Profile of ASD" agenda.

I will stop here. I did not intend for this thread to be anywhere near as long as it is.

Before anyone complains, I have been arguing for a balanced & accurate portrayal of PDA to happen for at least 30 months...

https://www.researchgate.net/publication/332727790_An_Updated_Interest_Based_Account_Monotropism_theory_a_Demand_Avoidance_Phenomenon_discussion

A STATE OF MATTER.

Why this matters.

- 1) Ethically, a balanced perspective should be presented (Brooks et al 2014; Dawson 2004; Rutter & Pickles 2016; Waltz 2007).
- 2) Ramifications of community of practice can lead to sources of confirmation bias (Milton 2017a).
- 3) Undermines literature's epistemic integrity (Milton et al 2018).

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

Thank you in advance.