

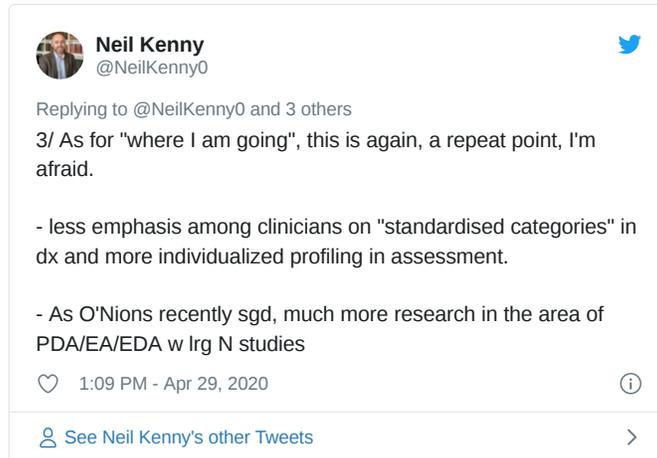


**Richard Woods** @Richard\_Autism

1 May 20 · 34 tweets · [Richard\\_Autism/status/1256195843901841409](#)



Thread on why I do not think this position is credible to argue heterogeneity of autism is an excuse to support PDA.



Yes autism is a very diverse and heterogeneous construct, with many comorbidities present and autistic persons possessing spiky-skills profile. Most people will accept this.

I will post links to these things, if requested.

How heterogeneity of autism means the DSM5 autism criteria are unsuitable for autism, is more complicated than is portrayed. For one, the reasons set out previously are factors why it is impossible to subtype autism.



Due to how **\*ALL\*** attempts to subtype autism have failed, autism subtypes were removed from the DSM5. Categorical autism profiles cannot be reliably identified.

[https://www.jaacap.org/article/S0890-8567\(11\)00268-1/fulltext](https://www.jaacap.org/article/S0890-8567(11)00268-1/fulltext)

and

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3683251/pdf/wps0012-0092.pdf>

Also the DSM5 moved away from category based diagnosis as it acknowledged it does not represent lived experience. Moved to a dimensional approach using many different specifiers.

Through using such specifiers it should be possible to access appropriate support by

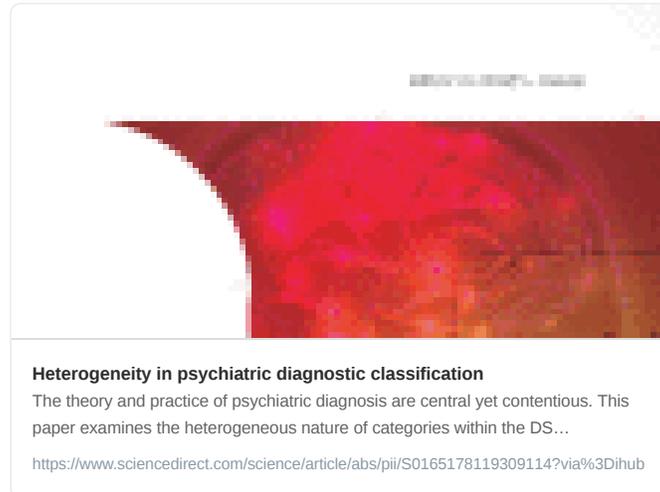
presenting persons strengths & weaknesses. Thus representing previous subtypes:

[https://www.jaacap.org/article/S0890-8567\(11\)00268-1/fulltext](https://www.jaacap.org/article/S0890-8567(11)00268-1/fulltext)

and

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3683251/pdf/wps0012-0092.pdf>

The sheer different amount of different combinations in the DSM5 through the use of specifiers (thousands upon thousands), is one of its main concerns about it.



So there are many different combinations an autistic person can be given.

The diagnostic threshold for autism is political act. Even if people do not meet dx for autism, they should be able to access support through new "Not otherwise specified" dx of Social Communication Disorder:

[https://www.jaacap.org/article/S0890-8567\(11\)00268-1/fulltext](https://www.jaacap.org/article/S0890-8567(11)00268-1/fulltext)

However there does seem to problems with how the DSM5 autism criteria are being used in practice. For one Social Communication Disorders does not seem be used much, reflecting in lack of academic interest:



This matters as SCD is there to mop-up those not meeting threshold for autism dx. We know that DSM5 autism criteria struggle to diagnose those who do not meet autism stereotypes (Aspergers/ PDD-NOS dx).



**How well are DSM-5 diagnostic criteria for ASD represented in standard**

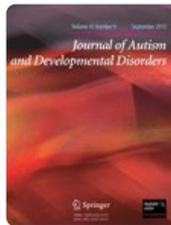
Five years after the publication of DSM-5 in 2013, three widely used diagnostic instruments have published algorithms designed to represent its (sub-)crite

<https://link.springer.com/article/10.1007/s00787-020-01481-z>

I think the average statistic numbers of autistic persons not getting a dx under DSM5 criteria vs DSM4 is about 33% (Need to check Attwood, 2015).

Some have argued that standard autistic person does not exist due to autism's heterogeneity. Obvious response to this, is that it blatant does if people are being denied a dx if they do not meet stereotypes.

This is also an issue for those who often camouflage.



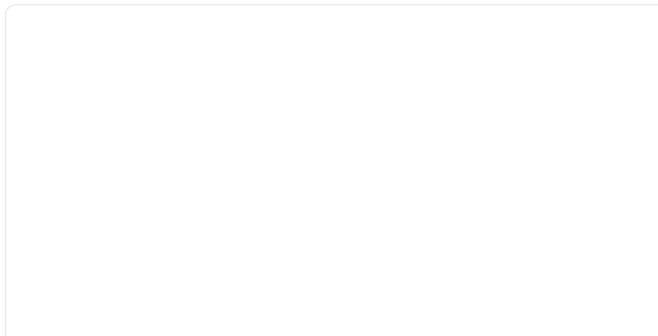
**Empathy and a Personalised Approach in Autism**

<https://link.springer.com/article/10.1007/s10803-019-04287-4>

There is a problem in wider medical community of clinicians have a narrow, stereotypical view of autistic people. I will dig out the reference for this if requested.

So it is logical that there will be some barriers to accessing support due to narrow autism understandings, but this can be countered by better quality autism training.

It is argued that the various comorbids that autistic persons often present is a barrier to accessing support. What is overlooked here is that many of these comorbids are associated to trauma/ aversive childhood experiences:



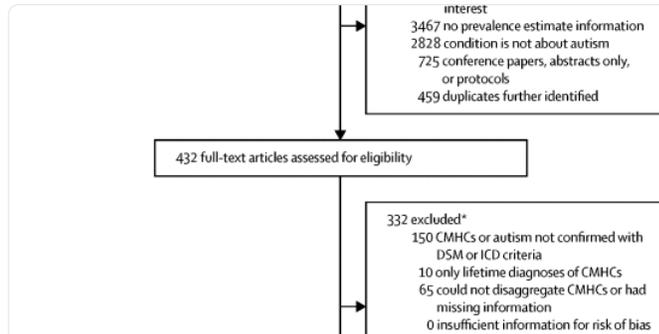
**17th OF MARCH 2020 BLOG POST: UPDATING MY CURRENT THOUGH...**

17th OF MARCH 2020 BLOG POST: UPDATING MY CURRENT THOUGHTS ON THE MEDICAL NATURE OF DEMAND AVOIDANCE PHENOMENA. Introduction.

This blog post discusses three different topics that explain som...

<https://rationaldemandavoidance.com/2020/03/17/17th-of-march-blog-post-updating-m...>

We know that many autistic pupils will develop mental health issues, or autism symptoms become worse when we are distressed.

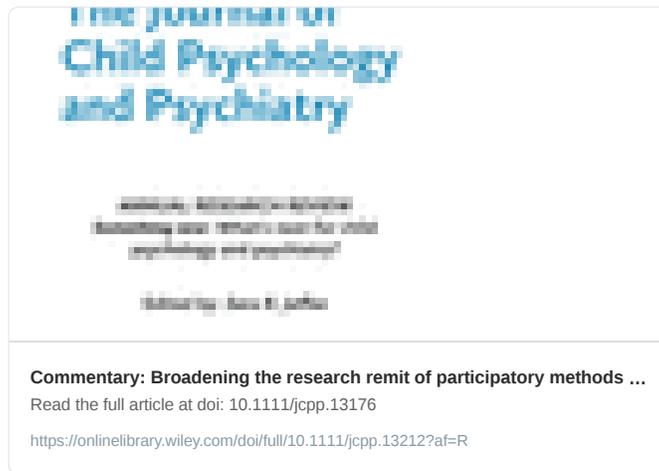


#### Prevalence of co-occurring mental health diagnoses in the autism pop...

Co-occurring mental health conditions are more prevalent in the autism population than in the general population. Careful assessment of mental health is an essential component of care for all people ...

[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(19\)30289-5/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(19)30289-5/fulltext)

and



#### Commentary: Broadening the research remit of participatory methods ...

Read the full article at doi: 10.1111/jcpp.13176

<https://onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13212?af=R>

and

[https://www.researchgate.net/publication/332727790\\_An\\_Updated\\_Interest\\_Based\\_Account\\_Monotropism\\_theory\\_a\\_Demand\\_Avoidance\\_Phenomenon\\_discussion](https://www.researchgate.net/publication/332727790_An_Updated_Interest_Based_Account_Monotropism_theory_a_Demand_Avoidance_Phenomenon_discussion)

I can provide more references if needed.

Many autistic pupils show school refusal, mainly due to distress at what they are experiencing at school (regardless of if they are PDA or not).

<https://attwoodandgarnettevents.com/2018/11/29/school-refusal-by-professor-tony-attwood/>

This situation is a key justification for PDA dx pathway.

<https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00004>

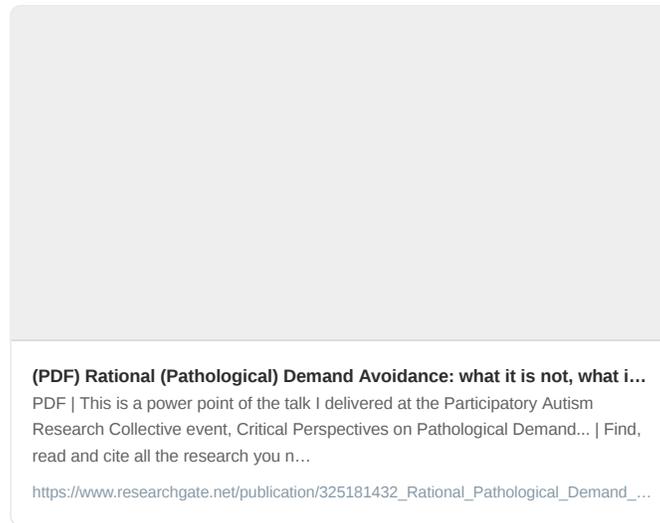
We also know that at least in the UK. Many statistics are showing that autistic persons are being properly supported by wider society:

<https://www.tandfonline.com/doi/pdf/10.1080/09687599.2017.1328157>

[https://www.researchgate.net/publication/337146735\\_Demand\\_avoidance\\_phenomena\\_circularity\\_integrity\\_and\\_validity\\_-\\_a\\_commentary\\_on\\_the\\_2018\\_National\\_Autistic\\_Society\\_PDA\\_Conference](https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference)

[a commentary on the 2018 National Autistic Society PDA Conference](https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference)

Likewise for many disabled persons:



It is likely, if not certain that many of comorbid constructs to autism are created by how society is treating autistic persons, by not properly supporting us. This is not even considering ABA/ PBS debate.

Now there are various possible responses we can do these issues. We could

- create a new disorder and attach it good working strategies, i.e. PDA.
- better support autistic & other SEND persons.
- do better autism training.
- lower autism diagnosis threshold

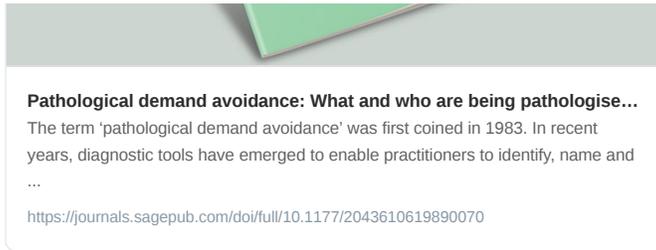
So PDA is one possible option to the problem being presented. It also does nothing to address wider systematic problems of not supporting autistic & SEND persons. There are other issues attached to PDA to.

For one tying PDA to certain strategies to control resource allocation (as suggested by Christie), just increases competition to scarce SEND resources.

Moving away from standardised behaviour profiles risks undermining trust and reputation of the psy-professionals. Social constructs like disorders are based on reliably measuring certain features & these require standardised behaviour profiles.

The fact that PDA does not have a standardised behaviour profile is well documented in its literature. Some argue that caution should be taken with PDA because of this reason:





Also using PDA to paper-over cracks in SEND system, by having carers request PDA as a proxy to good practice strategies is viewed by some as threat to validity of clinical based language (and credibility of their profession):

[https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(18\)30221-9/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30221-9/fulltext)

While yes I accept that how the DSM5 criteria are being operationalised is problematic and something does need to be done to address this:



The DSM5 criteria are not the only factors causing problems to autistic persons support.

As an autism stakeholder, I do not see why we should lower the quality and integrity of an autism diagnosis by diagnosing PDA as part of the autism spectrum.

Many PDA supporters and PDAers, say they know what PDA is and that we should maintain the integrity of PDA construct. The issue is, PDA as a construct has very little integrity to it:

<https://linkinghub.elsevier.com/retrieve/pii/S2352464218300440>

and

<https://www.researchgate.net/project/Understanding-Pathological-Demand-Avoidance-PDA-in-the-context-of-Autism-Spectrum-Disorders-ASD>

So surely these same PDA supporters who accuse me of undermining the (very little) integrity PDA has, will logically understand; why as an autistic person, I am very concerned at the notion of including PDA as autism subtype!

For the record, Attwood, 2015, says numbers of autistics not dx by DSM5 criteria vs DSM4 ranges from 9% - 52%, median of 33%. Page 18.

\*Median\* not medium.

[@DrJudes03](#) I believe you wanted some of these statistics.

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