



Richard Woods @Richard_Autism

1 Jun 20 · 28 tweets · [Richard_Autism/status/1267430454052913156](#)



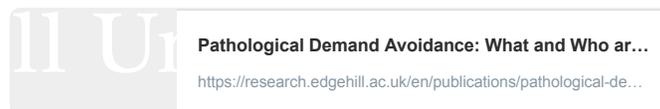
Thread.

During a talk with Harry Thompson & [@Stigmaphrenia_1](#) I have been asked by [@PDAParenting](#) what evidence base would I accept for PDA? After reflecting on it, I can clarify it some more.

Before I start I do meet Newson's PDA profile. I place my autism diagnosis above meeting PDA criteria. Nor do I wish to have a PDA diagnosis due to the threat to my self-agency:



&



First, like many autistic persons or neurodiversity supporters I would mainly like good quality scientific method based research, that also has a robust ethics base and is inclusive of all perspectives on PDA:





Critical Autism Studies
 Critical autism studies; Emancipatory autism studies; Transformative autism studies
 (Woods et al. 2018) Introduction Critical Autism Studies (CAS) is the only autistic-led community of practice,...

https://link.springer.com/referenceworkentry/10.1007%2F978-1-4614-6435-8_102297-1

This is as historically autism has had poor quality ethics and poor quality research base:

https://www.sentex.ca/~nexus23/naa_aba.html

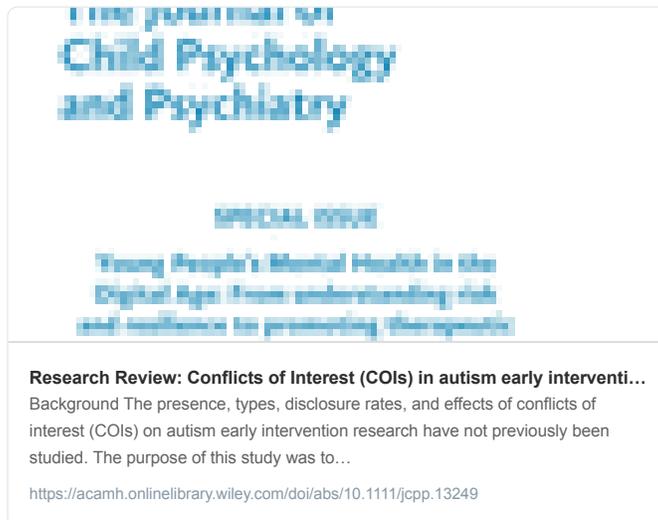
&



The relationship of ethics to quality: a particular case of research in au...
 (2007). The relationship of ethics to quality: a particular case of research in autism. International Journal of Research & Method in Education: Vol. 30, Quality in Educational Research, pp. 353-361.

<https://www.tandfonline.com/doi/abs/10.1080/17437270701614840>

&



Research Review: Conflicts of Interest (COIs) in autism early interventi...
 Background The presence, types, disclosure rates, and effects of conflicts of interest (COIs) on autism early intervention research have not previously been studied. The purpose of this study was to...

<https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.13249>

We are also meant to be in an emancipatory age of autism research:



Volume 35 Number 4 May 2020

Autism: a new introduction to psychological theory and current debate

(2020). Autism: a new introduction to psychological theory and current debate. Disability & Society: Vol. 35, No. 4, pp. 688-690.

<https://www.tandfonline.com/doi/full/10.1080/09687599.2019.1636564>

&

<https://www.openaccessautism.org/index.php/app/article/view/29>

I have written about what kind of evidence base I think PDA requires, my views have not substantially changed on this topic. My views are generally informed by “norms” in wider literature. Mainly good quality scientific method based research is required.

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

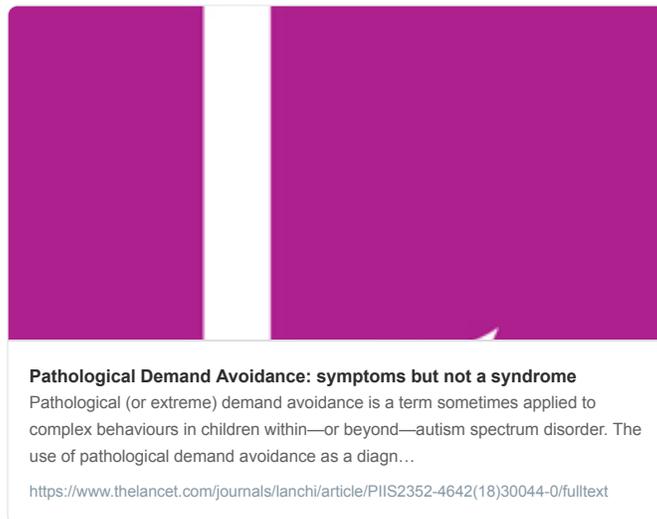
And

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

Pertinently, much of the research into PDA view it as an autism subtype and this is not scientific as researches have prior ideas beliefs about what it could be:

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

Despite lacking evidence suggesting PDA is a separate construct/ diagnosis.



That PDA literature acknowledges PDA might not be caused by autism:





The Measurement of Adult Pathological Demand Avoidance Traits

Pathological ("extreme") demand avoidance (PDA) involves obsessively avoiding routine demands and extreme emotional variability. It is clinically linked to autism spectrum disorder...

<https://link.springer.com/article/10.1007/s10803-018-3722-7>

&



Autism spectrum disorders in the DSM-V: Better or worse than the DS...

The DSM-V-committee has recently published proposed diagnostic criteria for autism spectrum disorders. We examine these criteria in some detail. We be...

<https://www.sciencedirect.com/science/article/abs/pii/S0891422210002647>

&

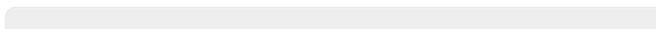


Mapping the educational experiences of children with pathological de...

'Pathological demand avoidance' (PDA) describes a pattern of difficulties increasingly recognised as forming part of the autistic spectrum. Although clinical reports suggest that children with PDA ar...

<https://onlinelibrary.wiley.com/doi/abs/10.1111/1471-3802.12081>

Crucially, it is being argued PDA is seen in non-autistic persons and there is some evidence to support this:



(PDF) Pathological Demand Avoidance and the DSM-5: a rebuttal to Ju...
 PDF | My article "Demand avoidance phenomena: circularity, integrity and validity – a commentary on the 2018 National Autistic Society PDA Conference."... | Find, read and cite all the research you n...
https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidanc...

The arguments about rights to a diagnosis are equally applicable to non-autistic PDAers.

making a positive difference to many persons' lives.

*te its
 ciety as part
 ntroversial.
 ntological'.
 myself
 oful name
 re anxiety
 s better."*

The clinical need for PDA has been contested for almost two decades (Garraida, 2003; Green et al, 2018; Malik and Baird, 2018). In addition some argue PDA is also found in non-autistic people and is not confined to autistic persons (Egan, 2019; Gillberg, 2014; Malik and Baird, 2018; McElroy, 2016). This is supported by individual cases of non-autistic persons in PDA research samples (O'Nions et al, 2015; O'Nions et al, 2016; Reilly et al, 2014), in addition to other empirical evidence set

Certain situations, PDA would require higher evidence levels. Such as PDA research and diagnostic tools require valid and accurate measurements:

22 | **Mental Health**

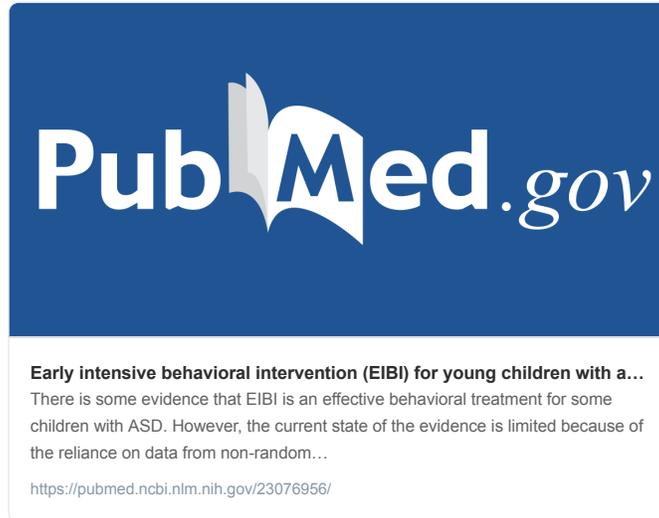
Commentary: Demand Avoidance Phenomena, a manifold issue? Intol...
 Read the full article at doi: 10.1111/camh.12336 and response to this commentary at doi: 10.1111/camh.12376
<https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/camh.12368>

PDA strategies need Randomised Control Trials:

Empathy and a Personalised Approach in Autism
<https://link.springer.com/article/10.1007%2Fs10803-019-04287-4>

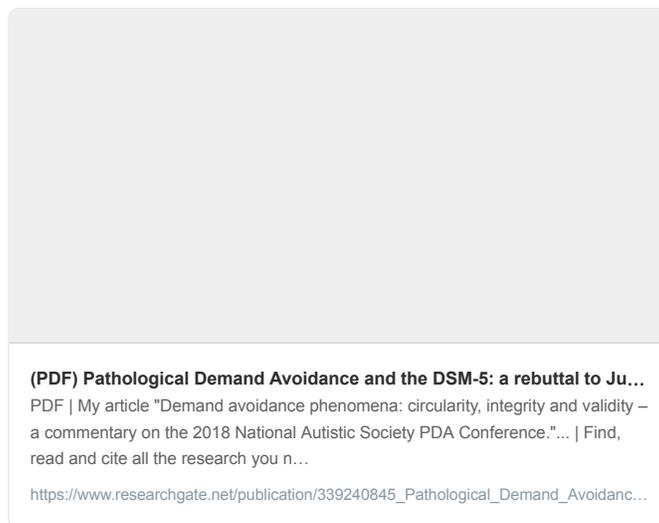


This is as if PDA approaches do not have RCTs they will not be included in high quality systematic reviews. Some autism strategies have these issues of needing RCTs, such as those of Applied Behaviour Analysis:



Crucially, there is no evidence of differential treatment between subtypes:
[https://jaacap.org/article/So890-8567\(11\)00268-1/fulltext](https://jaacap.org/article/So890-8567(11)00268-1/fulltext)

So this will require high quality evidence to overturn. Likewise that all previous attempts to divide autism have failed:



So this will also need large amounts of good quality evidence to contradict.

A specific example is replicating and if possible deeming the results of this study as

essentially false in nature:

high school			
<9th grade	0.1	0.0-1.1	0.4
ADOS diagnostic classification, ^b			
% of probands			
Autism	87.8	79.4-95.9	5.1
Autism spectrum	12.2	4.1-20.6	5.1
ADOS module, ^b % of probands			
1	16.9	8.0-26.6	5.1
2	23.0	15.9-31.4	5.1
3	57.1	48.3-67.9	6.7
4	3.0	0.0-6.5	2.1
ADI-R diagnostic classification			

A Multisite Study of the Clinical Diagnosis of Different Autism Spectru...
Context Best-estimate clinical diagnoses of specific autism spectrum disorders (autistic disorder, pervasive developmental disorder—not otherwise specified, and Asperger syndrome) have been used as t...
<https://jamanetwork.com/journals/jamapsychiatry/fullarticle/1107413>

Using methods that views PDA as a standalone construct/ diagnosis:

(PDF) Pathological Demand Avoidance and the DSM-5: a rebuttal to Ju...
PDF | My article "Demand avoidance phenomena: circularity, integrity and validity – a commentary on the 2018 National Autistic Society PDA Conference."... | Find, read and cite all the research you n...
https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidanc...

cannot be as the research is in some ways similar for use diagnostic profiles and on when making a diagnosis.

greater consensus over what current understanding of autism that are well established, such as a co-occurring condition (Happé 2019; Woods, 2020). w autistic people tend to display behaviours and Interests (RRBIs) as for them. Contrarily, RRBIs are ive thoughts that is accepted not autism. These fixed points have and Statistical Manual of Mental (DSM-5) criteria but these are search continues. Such bounda g from PDA. It is inappropriate to pices of PDA to autism.

subtype an autistic person was diagnosea with, was the individual clinic they attended (Fletcher-Watson and Happé 2019; Happé, 2011; Happé and Frith, 2020). These results would need to be deemed false for autism subtypes to become widely accepted again. Particularly using similar conceptualisations of autism subtypes as discrete diagnoses, the dual Autism + PDA diagnosis would not be valid for such research as it pathologises more characteristics than a traditional autism diagnosis (Moore, 2020). Research investigating differences between High Functioning Autism and Asperger's Syndrome either found no differences between the groups or any differences resulting from circular practices, such as the diagnostic methods to identify each subtype (Happé and Frith, 2020). Any future replication studies need to ensure that any difference between PDA and other subtypes is not from circular methods. Such research sets part of the evidence base required for PDA being established as an autism subtype.

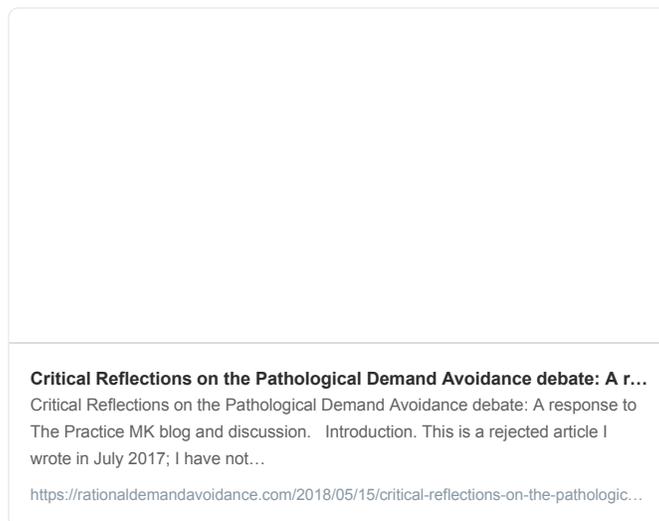
This evidence threshold is higher than that suggested by the PDA Development Group which includes NAS/ PDA Society Judy Eaton and Phil Christie. There is a

research agenda to get PDA recognised in main diagnostic manuals (Christie et al, 2011, p182).

Their base is attempting to make PDA an autism subtype:



Often only researching PDA in mainly suspected autistic population samples:



&

<https://www.ingentaconnect.com/contentone/bild/gap/2019/00000020/00000002/art00005>

&

Preconceived ideas

<https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00003>

Christie has argued at the 2018 & 2019² NAS PDA conferences that 2 main diagnostic manuals do not recognise differences between clinicians and researchers, manuals places more reliance on reliability than validity.

i.e. does not matter who uses a diagnosis like autism/ ADHD/ ODD etc and for what purpose.

I suspect this priming audience for PDA does not need good quality scientific method research base, i.e. can make PDA an autism subtype. Which explains why PDA Development Group's members are frequently saying PDA is part of the autism spectrum.

PDA Development Group research has changes in descriptions that make PDA conform more to autism understandings, such as moving away from "manipulative" to "socially strategic".



Pathological demand avoidance syndrome: a necessary distinction wit...
A proposal is made to recognise pathological demand avoidance syndrome (PDA) as a separate entity within the pervasive developmental disorders, instead of being classed under "pervasive developmental..."
<https://adc.bmj.com/content/88/7/595>

&

<http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf>

&



Dimensions of difficulty in children reported to have an autism spectru...
Read the full Commentary on this article at doi: 10.1111/camh.12273 Read the full Response to the Commentary on this article at doi: 10.1111/camh.12287
<https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/camh.12242>

I discuss this issue in more topic here:

Thread reader Tweet Share

THREAD BY RICHARD WOODS (@RICHARD_AUTISM)

Thread: So tonight I have been trying to figure out why the wording for DISCO items is different between

...why the wording for DISCO items is different between @ONionsLiz and @GillbergCentre PDA research. Yes, I emailed them to clarify why. Links to respective PDA DISCO articles:...

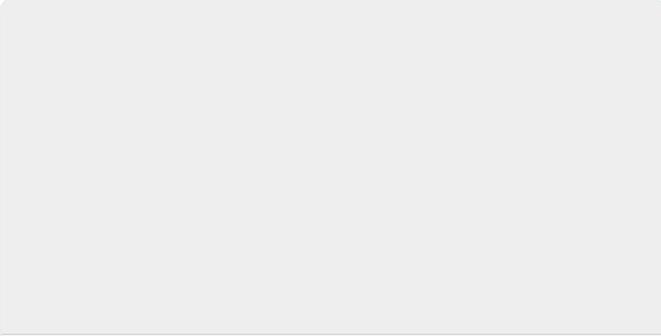


Read all 22 tweets on threadreaderapp.com →

Thread by @Richard_Autism: Thread: So tonight I have been trying to ...
 Thread by @Richard_Autism: Thread: So tonight I have been trying to figure out why the wording for DISCO items is different between @ONionsLirgCentre PDA research. Yes, I emailed them to clarify why....

<https://threadreaderapp.com/thread/1261049980929933313.html>

So PDA Development Group’s PDA research is as comparably biased and flawed as basing autism diagnostic tools and profile on male dominated samples. Which as Judy Eaton herself argues is short sighted.



(PDF) Pathological Demand Avoidance and the DSM-5: a rebuttal to Ju...
 PDF | My article "Demand avoidance phenomena: circularity, integrity and validity – a commentary on the 2018 National Autistic Society PDA Conference."... | Find, read and cite all the research you n...
https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidanc...

...which did not comment on the fact that criteria have been used to define PDA is not specific to autism. This following quote by Judy Eaton is applicable to the narrow conceptualising of PDA as an autism subtype:

"Professionals and teams working with children need to become aware of the ways in which girls can mask their difficulties, and need to move away from using the DSM as a 'bible'. Stating that someone does not fulfil criteria, when these criteria are based on upon a 'male' presentation of a disorder, is short sighted in the extreme." (Eaton, 2017, page 176).

Despite the controversies and debates which will be clarified by further research, PDA is here to stay. Moreover, whatever PDA is, it can only be formally recognised by the diagnostic manuals, when its screening criteria are included in the manuals. This is not the case for PDA. The DSM-5 does not include PDA as a subtype of autism. This is a significant omission. The DSM-5 discusses how autism is defined in the current diagnostic manual over the previous editions. However, she does not mention the committee called the Workgroup that decided on the criteria for the DSM-5. The workgroup's narrow definition of autism has led to all attempts to divide autism into subtypes based on biomarker and behavioral characteristics. Specific concerns include the difference between groups of autism (e.g. high and low functioning) and the threshold for Asperger syndrome (e.g. delay) and other subtypes. Furthermore, differential treatment based on these subtypes is not recommended. Furthermore, autism subtypes are not recognized in the DSM-5. Furthermore, autism subtypes are not recognized in the DSM-5.

This all combines to build a picture that we need new diagnostic and research tools that 1) view PDA independent of autism; 2) are based on Newson’s original clinical descriptions.

The required validation studies for PDA need to be conducted using these unbiased tools:





Pathological Demand Avoidance: symptoms but not a syndrome

Pathological (or extreme) demand avoidance is a term sometimes applied to complex behaviours in children within—or beyond—autism spectrum disorder. The use of pathological demand avoidance as a diagn...

[https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(18\)30044-0/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30044-0/fulltext)

&



Commentary: PDA - what's in a name? Dimensions of difficulty in chil...

Read the full article at doi: 10.1111/camh.12242 Read the Response to this Commentary at doi: 10.1111/camh.12287

<https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/camh.12273>

Concluding ,the evidence base I am suggesting is significantly different and stronger to that being constructed and advocated by the PDA Development Group.

I will end with, surely if you care about the integrity of PDA construct/ diagnosis and those identifying with it, you would also want the higher evidence levels I am suggesting?

...