



Richard Woods @Richard_Autism

Jul 28, 2021 · 58 tweets · [Richard_Autism/status/1420279789932400640](#)



[@ndhumanoid](#) I am unsure it is necessarily twaddle.

Those who identify/ or are diagnosed with PDA often do experience substantial issues around stress caused by aversive demands & do need be supported.

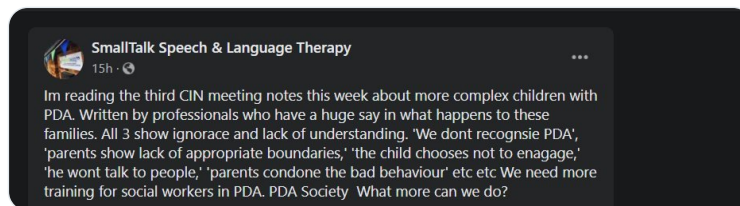
[@ndhumanoid](#) Simply because the evidence base is small & poor quality does not mean it is "twaddle". It does mean anyone advocating for PDA needs to making claims in line with the current evidence base, & update their practice to reflect evidence base.

[@ndhumanoid](#) I.e., stop claiming PDA is anything specific to autism, and start being more inclusive about PDA with non-autistic persons. Or at least what I would do.

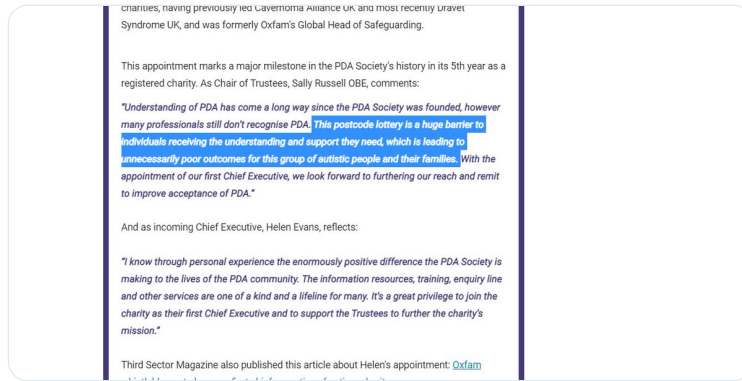
The results should be seen as a warning to those who have built a career on notion "PDA is an ASD".

[@ndhumanoid](#) The results are an opportunity for the "PDA is an ASD" community to show it is genuinely open minded and reform itself, to hold itself to the highest possible standards. Although, based on its response to past critique, it will stay dogmatic.

[@ndhumanoid](#) Here is one indicator the "PDA is an ASD" will not reform itself, or at least the difficulties to it reforming itself. Note the assumptions that they know what PDA is and looks like.



[@ndhumanoid](#) Second indicator of the "PDA is an ASD" community will not reform itself, goes to the [@PDASociety](#). Examples from its recent newsletter.



[@ndhumanoid](#) [@PDASociety](#) "This postcode lottery is a huge barrier to individuals receiving the understanding and support they need, which is leading to unnecessarily poor outcomes for this group of autistic people and their families."

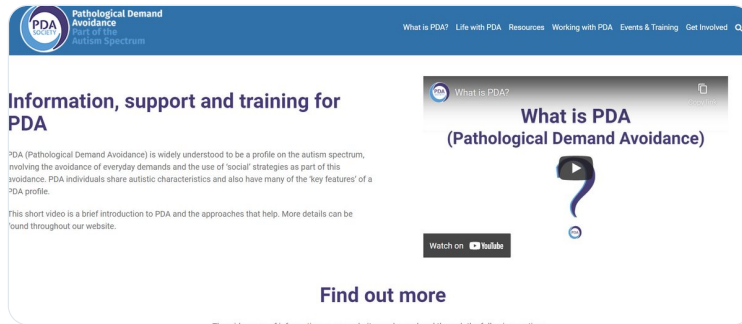
[@ndhumanoid](#) [@PDASociety](#) Again, what is it that is exactly being understood? What evidence is there that PDA leads to persons receiving better outcomes than those not receiving a diagnosis? From my understanding it is not from here:



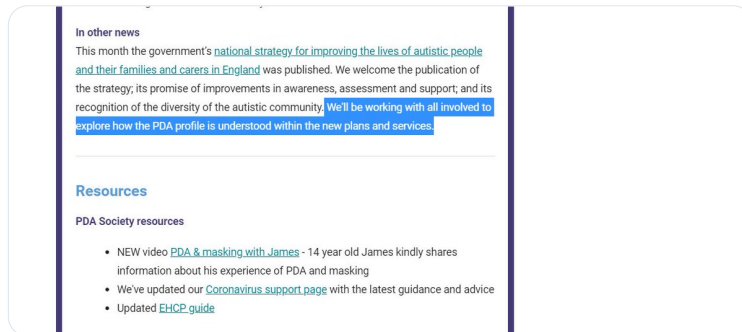
[@ndhumanoid](#) [@PDASociety](#) Lack of consideration by the [@PDASociety](#) that there is a postcode lottery for a reason, mainly due to the lack of good quality evidence to suggest what PDA is and is not.

[@ndhumanoid](#) [@PDASociety](#) "With the appointment of our first Chief Executive, we look forward to furthering our reach and remit to improve acceptance of PDA."

[@ndhumanoid](#) [@PDASociety](#) So furthering their reach and remit to improve PDA as a form of autism, despite lacking the evidence to say PDA is a distinct anything. Anyone seeing the problem with the [@PDASociety](#) here?



[@ndhumanoid](#) [@PDASociety](#)



[@ndhumanoid](#) [@PDASociety](#) "We'll be working with all involved to explore how the PDA profile is understood within the new plans and services."

[@ndhumanoid](#) [@PDASociety](#) In relation to 2021 England autism strategy, which seems not to mention PDA. Begs the question why are they working with anyone to help understand PDA?

[@ndhumanoid](#) [@PDASociety](#) Again worth mentioning [@PDASociety](#) is portraying itself as an autism stakeholder even though PDA lacks evidence to suggest it is a distinct anything, & there are non-autistic persons with PDA in the research base...

[@ndhumanoid](#) [@PDASociety](#) I think this is for the second example on how the "PDA is an ASD" community will not reform itself.

Yes, this will be running thread, updated with examples.

[@ndhumanoid](#) [@PDASociety](#) Third example the "PDA is an ASD" community is unlikely to reform itself comes from a responses to a post of mine highlighting the issues with PDA, responding to "Are there any autistics here who view PDA as an inappropriate label?" on facebook.

[@ndhumanoid](#) [@PDASociety](#) I could pick many different examples but I am going to go this one:

"Richard does not believe in PDA but chooses to chase a trauma model."

So apparently, one needs to believe "PDA is an ASD" for them to be OK with you.

[@ndhumanoid](#) [@PDASociety](#) Such examples highlight the problems faced with PDA research, when there is a community that has essentially already decided what PDA is. Dogma, much?

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

Thank you in advance.

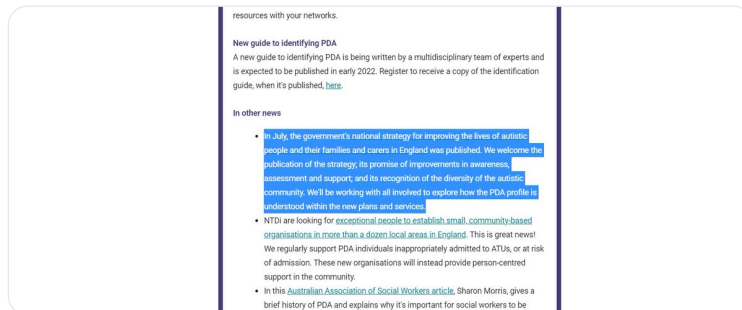
[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) Fourth example that "PDA is an ASD" community will not reform itself to hold PDA and itself to the highest possible standards is this "PDA test for adults".

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) Fifth example goes to [@PDASociety](#) for being a repeat offender. This time for its recent newsletter. First for not even mentioning recent systematic review, or the position of [@BPSOfficial](#) , or [@NICEComms](#)

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) Sixth example goes to [@thepdaspace](#) [#PDASpace](#) for not updating its PDA information to an ethical position. Essentially the reasons why the [@PDASociety](#) are at example number 5, are applicable to PDASpace.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Seventh example goes back to [@PDASociety](#) for viewing PDA as a form of autism. Likewise pretending to be an autism stakeholder by " We'll be working with all involved to explore how the PDA profile is understood within the new plans and services."

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Screenshot from its October newsletter on the topic.

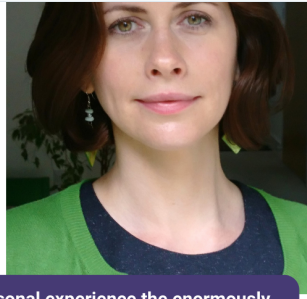


[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Screenshot of their website stating PDA is part of the spectrum.

Link here:

first Chief Executive, Helen Evans

Helen joins as an openly autistic woman with a personal connection to PDA, and a passion for neurodiversity. She brings a wealth of experience running neurological charities.



"I know through personal experience the enormously positive difference the PDA Society is making to the

The PDA Society announces appointment of its first Chief Executive

The PDA Society is delighted to announce the appointment of its first Chief Executive, Helen Evans. Helen joins as an openly autistic woman with a personal connection to PDA, and a passion for neu...

<https://www.pdasociety.org.uk/the-pda-society-announces-appointment-of-its-first-chief...>

The screenshot shows the PDA Society website's resources page. The header includes the PDA Society logo and navigation links: 'What is PDA?', 'Life with PDA', 'Resources', 'Working with PDA', 'Events & Training', and 'Get Involved'. The main content area is titled 'Resource Categories' and lists various categories with their respective counts: 'All stars - most used' (16), 'Books' (54), 'Case Studies' (32), 'Editable Tools' (10), 'Good Practice & Insight' (44), 'International' (20), 'Research' (43), and 'Studies & Commentaries' (13). A featured article titled 'Individual differences, ADHD, Adult Pathological Demand Avoidance and delinquency' is highlighted, with a description and a download icon.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) At least the newsletter includes a link to recent systematic review, but predictably does not discuss importance of the systematic, that charity lacks evidence to say PDA is a form autism & thus undermines its efforts to work with other organisations.

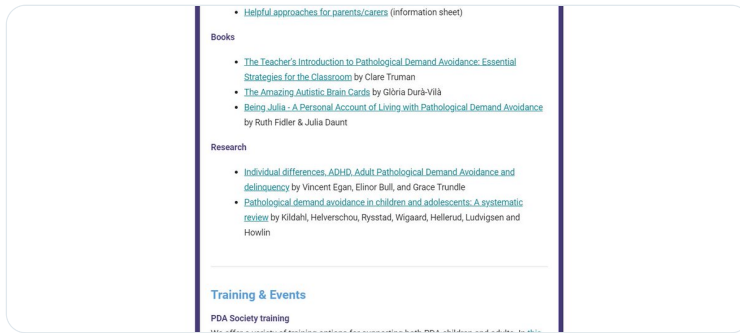
[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Link to Kilhahl et al (2021) systematic review on its website.



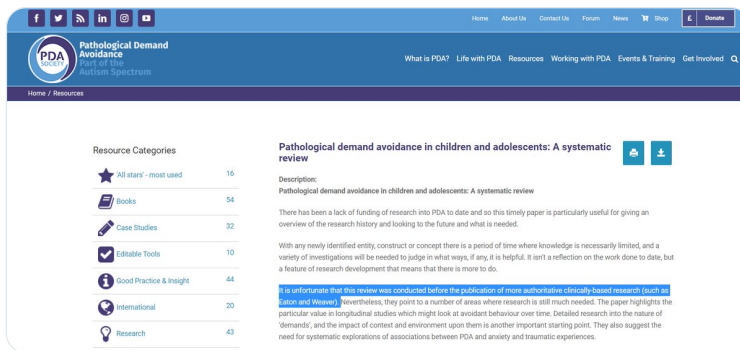
Pathological demand avoidance in children and adolescents: A syste...

Pathological demand avoidance in children and adolescents: A systematic review
There has been a lack of funding of research into PDA to date and so this timely paper is particularly useful for giv...

<https://www.pdasociety.org.uk/resources/pathological-demand-avoidance-in-children-a...>



[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Screenshot of the PDA Society's page on the systematic review. Highlighting their claim Eaton & Weaver is " more authoritative clinically-based research".



[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Considering that study appears highly biased, & informed by clinicians experience, & not broader literature. Also its highly circular nature, & possible conflation of anxiety based RRBIs with autism social communications issues.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Claim "more authoritative clinically-based research (such as Eaton and Weaver)." is problematic putting it mildly. From what I can tell a more accurate description is that research is self-validating pseudoscience, done to support outlook PDA is an ASD.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Important to note Kildahl et al (2021) did not view PDA as a form of autism, acknowledged there were non-autistic persons with PDA in the literature, which contradicts position adopted in Eaton & Weaver (as they only dx PDA in autism).

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Also positions adopted by NICE & BPS that lack of evidence to say what PDA is, or linking it to autism. Equally treating divergent opinions on the topic. Obviously, if one respects opinion PDA is seen outside of autism.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) One cannot say PDA is part of the autism spectrum.


Simply not good enough by a charity pretending to be an autism stakeholder, which is

meant to be "working with all involved to explore how the PDA profile is understood within the new plans and services."

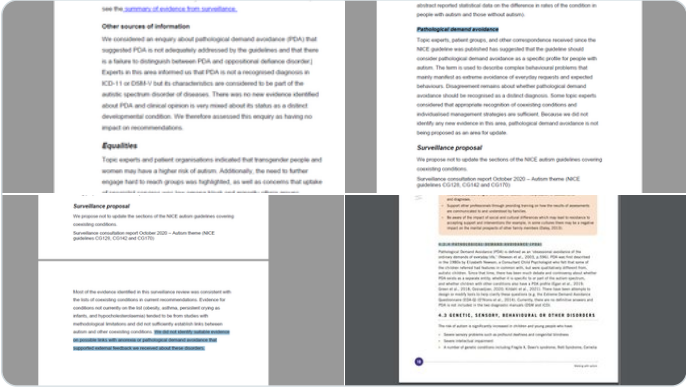
[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) If I was working with the PDA Society, I would such information to be readily available & presented if reputable independent groups took a substantially position to it.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Not to mention if I was a vulnerable person looking for information on PDA.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#)

 **Richard Woods**
@Richard_Autism

Replying to @Richard_Autism




8:01 AM · Sep 5, 2021

1 Copy link to Tweet

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[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#)

 **Richard Woods**
@Richard_Autism

Replying to @Richard_Autism

Links to NICE's document.
nice.org.uk/guidance/cg128...

BPS's document.
bps.org.uk/sites/www.bps...

8:02 AM · Sep 5, 2021

1 Copy link to Tweet

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[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) That is it for this example of "PDA as an ASD" proponents being dogmatic on the topic.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Example on why Eaton & Weaver is not "more authoritative clinically-based research". The paper acknowledges that not ALL of Newson's cohort meet DSM-5 autism criteria.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) "... it is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5." (Eaton & Weaver 2021, p34).

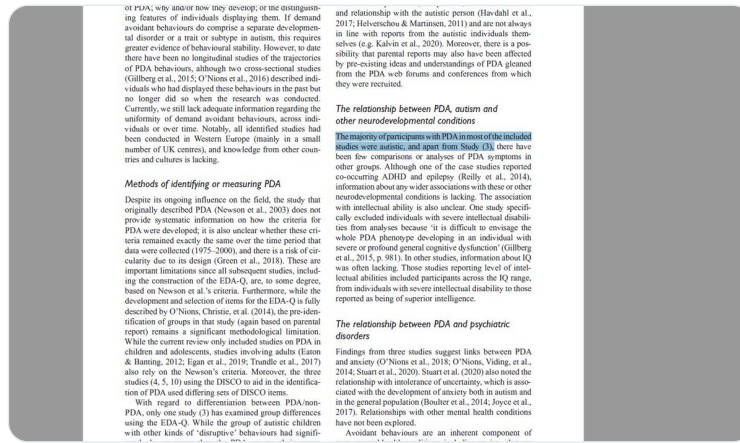
[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Screenshot of the above quoted text.



[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) If not ALL of all Newson's cohort are autistic, then there are some non-autistic persons in Newson's research who are NOT autistic. Kildahl et al 2021 noted non-autistic persons in PDA samples.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) "The majority of participants with PDA in most of the included studies were autistic, and apart from Study (3)" (Kildahl et al 2021, p10).

See below screenshot.



[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Kildahl et al (2021) also described issues with PDA research from biased recruitment methods for many of its samples, that it is possible for same participants to be recruited in multiple samples.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) Just because most samples have a high number of autistic persons in it, does not mean that PDA is a form of autism. Jumping to that conclusion, is an example of texas sharpshooter fallacy [@KatyBenson20](#) suggested on the topic.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) This issue is also compounded because PDA probably presents slightly differently in non-autistic persons, as autism & co-occurring conditions frequently simultaneously interacts with each other.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) Combine these issues with the fact that Eaton & Weaver (2020) only diagnoses PDA in autistic persons, & not as a standalone diagnosis, undermines the utility of that research; it is difficult to describe it as "more authoritative clinically-based research".

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) That is only one example why it is problematic to view Eaton & Weaver (2020) as "more authoritative clinically-based research".

I am done this time.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) I also need to add that the fact the PDA Society described Eaton & Weaver as "more authoritative clinically-based research" is highly concerning for multiple reasons.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) I am not happy about these reflections that led to this. The charity described some research which has NOT disclosed any of its conflicts of interests as "more authoritative".

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) So obviously, it is acceptable for "PDA as an ASD"

supporters for it ignore typical research standards & practice of disclosing conflicts of interest.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) Also should be noted the charity does disclose its own conflict of interest, as it has a working relationship with Judy Eaton, at least through the PDA Development Group, both are members of.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) This is not exactly actions of a reputable organisation/ information source for PDA. If I was working with PDA Society or a vulnerable person looking for information on PDA, I would want to know the charity was following typical research & practice standards.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) At the moment that simply cannot be said of the PDA Society.

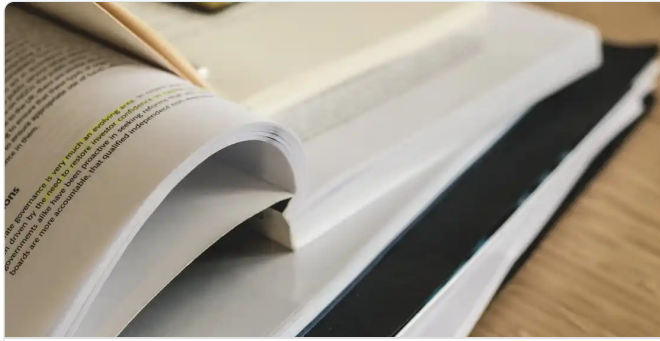
I am disheartened by these reflections, really the PDA Society, & other prominent "PDA as an ASD" supporters should be doing better than this. Such actions are likely to add controversy around PDA.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) This is not a trivial matter. Considering poor quality research standards, tend to be associated with poor quality ethics. We that these are issues with much autism research & practice, especially non disclosure of conflicts of interest.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) There are efforts to raise the standards of autism research & practice both in quality & ethics. Which leading "PDA as an ASD" advocates seem happy to ignore. This upsets me as, autistic persons & those with PDA (autistic or not) deserve better than this.

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICEComms](#) [@thepdaspace](#) [@KatyBenson20](#) Screenshot of where PDA Society describes Eaton & Weaver as "more authoritative clinically-based research (such as Eaton and Weaver)".

Link to the page is below:



Pathological demand avoidance in children and adolescents: A syste...

Pathological demand avoidance in children and adolescents: A systematic review
There has been a lack of funding of research into PDA to date and so this timely paper is particularly useful for giv...

<https://www.pdasociety.org.uk/resources/pathological-demand-avoidance-in-children-a...>

The screenshot shows the website for Pathological Demand Avoidance (PDA), part of the Autism Spectrum. The page features a navigation bar with social media icons and a search bar. Below the navigation, there is a 'Resource Categories' section with a list of categories and their counts:

Resource Category	Count
All stars - most used	16
Books	54
Case Studies	32
Editable Tools	10
Good Practice & Insight	44
International	20
Research	43

The main content area displays a resource titled 'Pathological demand avoidance in children and adolescents: A systematic review'. The description states: 'There has been a lack of funding of research into PDA to date and so this timely paper is particularly useful for giving an overview of the research history and looking to the future and what is needed. With any newly identified entity, construct or concept there is a period of time where knowledge is necessarily limited, and a variety of investigations will be needed to judge in what ways, if any, it is helpful. It isn't a reflection on the work done to date, but a feature of research development that means that there is more to do. He emphasises that this review was conducted before the publication of more authoritative clinically-based research (such as Jason and Mowley) nevertheless, they point to a number of areas where research is still much needed. The paper highlights the particular value in longitudinal studies which might look at avoidant behaviour over time. Detailed research into the nature of 'demands', and the impact of context and environment upon them is another important starting point. They also suggest the need for systematic explorations of associations between PDA and anxiety and traumatic experiences.'

[@ndhumanoid](#) [@PDASociety](#) [@threadreaderapp](#) [@BPSOfficial](#) [@NICComms](#)
[@thepdaspace](#) [@KatyBenson20](#) [@threadreaderapp](#) please can you unroll again?

Thank you in advance.