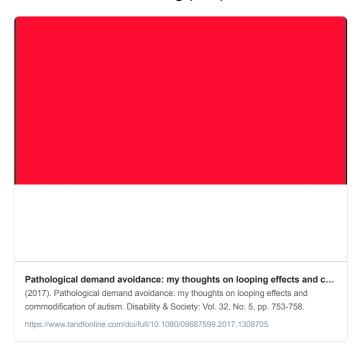


I see <u>@AutismEducatio1</u> has published a biased interpretation of PDA, with language which suggests there will be evidence that PDA will be recognised as an ASD. Perhaps, it is worth reminding people of this article.



I will post a link and screenshot of the relevant paragraph later today.

On on the plus side, one of the undisclosed COIs I have complained about is Christie's involvement with the AET. So hopefully that will be in print soon. Another was Gould's involvement with NAS, due NAS's COI on PDA.

The other undisclosed COIs, include:

- Not referring to working relationships, like with the PDA Society.
- Development of various tools (which often view PDA to be ASD).
- -Viewing PDA to be an ASD, like an assumption.
- Judy Eaton earning income derived from PDA and autism related activities.
- Happe being on the Neurodevelopmental Disorders Workgroup.

There is public evidence for all of these.

There seems to be a common approach to COIs, of if in doubt disclose it. Response will be interesting to them.

When you consider some the of the COis, they can appear substantial, to the point where it might have impacted how article is percieved at peer review/ publication.

Link to the <u>@AutismEducatio1</u> document. https://www.autismeducationtrust.org.uk/sites/default/files/2021-09/GAP_report%20-%20mainReport_I-S.pdf

Screenshot of page 13 where it discusses PDA and autism subgroups.

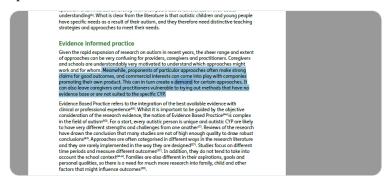


"As yet, there is insufficient evidence and PDA has not met criteria for clinical validity for acceptance in either DSM 5 or ICD 11." Page 13.

Is rather bold assumptions there.

If <u>@AutismEducatio1</u> feels it is appropriate to discuss issues dividing autism before discussing PDA, it does raise questions why certain PDA authors with pertinent knowledge on dividing autism, have not written about it their PDA scholarship?

It does matter, page 14 of the AET document is telling. First paragraph of evidence informed practice.



"Meanwhile, proponents of particular approaches often make strong claims for good outcomes, and commercial interests can come into play with companies promoting their own product. This can in turn create a demand for certain approaches." p14.

Has someone written about such a thing about PDA before, while yes they have here:



It must be noted that it applies to individuals with commercial interests. Like guess who is on @AutismEducatio1?

Phil Christie who seems to have "commercial interests" on PDA.

Link to <a>@AutismEducatio1 board members:



Autism Education Trust

Discover The AET Board. 10 Board Members who govern the AET, determining strategy, protecting values and both supporting, and holding staff accountable.

https://www.autismeducationtrust.org.uk/about/aet-board

Phil Christie

A consultant child psychologist, and former director of an autism specific school, working as part of autism associates.



Phil Christie is a Consultant Child Psychologist and specialist adviser working on an independent basis, or with colleagues as part of Autism Associates. Phil was Director of Children's Services and Principal of Sutherland House School and the Elizabeth Newson Centre for more than 30 years. The Elizabeth Newson Centre provided diagnostic assessments of children from all over the UK and has a particular specialism in Pathological Demand Avoidance syndrome.

Phil is an Associate Editor of 'Good Autism Practice' and previously undertook the same role for 'Autism: International Journal of

Research and Practice'. He was elected as Chair of the advisory council for the Autism Education Trust and is now Vice Chair of the programme board.

Phil has been involved in conferences, training sessions and presentations on a range of topics related to the autism spectrum across the UK and internationally. He has been extensively involved in leading training events around PDA for schools and other organisations providing for children with complex presentations on the autism spectrum.

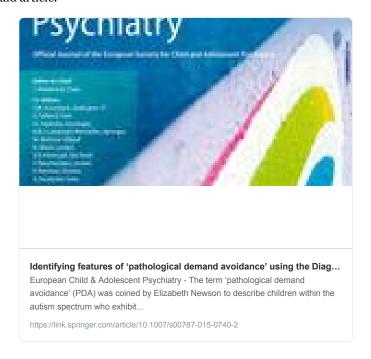
"Phil has been involved in conferences, training sessions and presentations on a range of topics related to the autism spectrum across the UK and internationally...

... He has been extensively involved in leading training events around PDA for schools and other organisations providing for children with complex presentations on the autism spectrum."

To quote an article Christie co-authored:

"Phil Christie receives payment for training and consultancy from voluntary and statutory bodies."

Link to said article.



Now it should be noted it seems to be typical practice that persons disclose their conflicts on an interest. @COPE has an interesting case study here.



To quote the link

"Advice:

_ The public has the right to know if there were conflicting interests and that if there was any doubt, it is better to disclose. _ Just because the material is in the public domain does not exonerate an author from declaring such interests."

This approach to disclosing conflicts of interests seem to the standard set my publishers.

For example by <u>@ElsevierConnect</u>
"Full transparency is always the best course of action, and, if in doubt, disclose." p2.

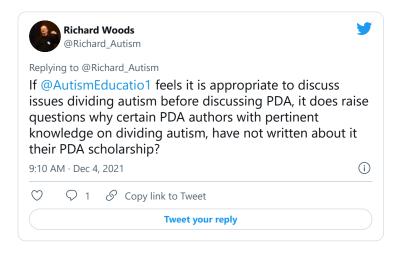
Link below.

https://www.elsevier.com/ data/assets/pdf_file/0007/653884/Competing-Interests-factsheet-March-2019.pdf

Most research journals seem to be members of <u>@COPE</u>. That transparency is best.

Which takes me back to, it is really is not a good look <u>@Autism</u> PDA Society, Phil Christie & Judy Eaton, and other members of the PDA Development Group are yet to respond to these reasonable questions on the topic.





So lets look at one article by proponent "PDA Profile of ASD" supporters, where they should have discussed difficulty dividing autism. Lets go for the EDA-Q development paper.

Link to the article in question.

Yes, its authors include O'Nions, Christie, Happe & Gould. https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

So it seems that Christie was on an <u>@AutismEducatio1</u> board at the time of the article.

"He was elected as Chair of the advisory council for the Autism Education Trust and is now Vice Chair of the programme board."

This matters as the paper mentions <u>@AutismEducatio1</u> republished Christie's 2007 article.

"evidenced by the inclusion of educational guidelines on PDA (Christie, 2007) in the UK-based Autism Education Trust's best practice guidelines" O'Nions et al (2014 p758).

To be clear, all the authors said they had no COIs.

"Conflict of interest: No conflicts declared." O'Nions et al (2014, p758).

Moving onto Gould, they were at the time of the article working for <u>@Autism</u> via the Lorna Wing Centre.

See the contact address for Gould from the article: "The NAS Lorna Wing Centre for Autism, Bromley, Kent, UK" p758.

Gould, like Christie had in print expressed the view PDA is a form of autism, all before the publication of O'Nions et al (2014). So one could view them as having a COI on any research which supports that outlook. I am going off on tangent a bit.

"and several oversubscribed conferences on the topic since 2011, jointly run by national and regional UK societies for people with autism." O'Nions et al (2014, p758).

This quotes matters, as these conferences in the quote are run by guess who?

@Autism

The paper also mentions that there were PDA items in an semi-structured interview, Diagnostic Interview for Social and Communication Disorders (DISCO).

"Currently, the only available measures are questions tapping PDA incorporated in the Diagnostic Interview for social and communication disorders (DISCO; Wing, Leekam, Libby, Gould, & Larcombe, 2002)," O'Nions et al 2014, p759. "Candidate items were generated based on criteria described by Newson et al. (2003), unpublished material by Newson, plus the PDA items incorporated into the DISCO (Wing et al., 2002)."

O'Nions et al (2014, p759).

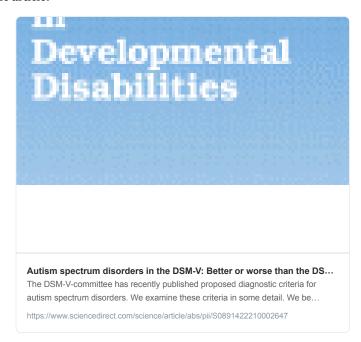
Why do the above 2 quotes matter?

Because <u>@Autism</u>, tends to generate income via PDA related activities, like its PDA conferences, and various training & support packages for the use of DISCO. As discussed below:



Now we are getting into a bit more dodgy ground. So Gould has co-authored a paper which discusses the difficulties in successfully dividing autism, with Wing & Gould in 2011.

Link to the article:



"We, in our many years of clinical diagnostic work, have observed how extremely difficult, even impossible, it is to define boundaries of different sub-groups among children and adults with autism spectrum conditions" Wing et al 2011, p711.

In the article, they discuss how autistic persons often transition between subtypes.

"Other sub-groups have been suggested in addition to those in the DSM-IV (and ICD-10). The same problem of defining the boundaries exists for all of these."

Wing et al 2011, p711.

The article does mention PDA in it.

"Boys and girls with pathological demand avoidance (Newson, Le Marechal, & David, 2003) may also have such a 'double hit'." Wing et al (2011, p769).

Which tells us that Wing et al (2011) thought the problems defining autism subtypes applied to PDA.

The above quote matters, because logic tells you PDA cannot be something it is more than...

Are these factors mentioned in O'Nions et al (2014)?

From what I can tell no. Wing et al (2011) is not cited. Neither is Happe (2011), which I will go onto next.

So another co-author of O'Nions et al (2013) was a member of the Neurodevelopmental Disorders Workgroup, & had written about the challenges dividing autism, going onto to explain why the subtypes were removed from the DSM-5. In this case in 2011.

Link to the article by @<u>HappeLab</u> https://www.jaacap.org/article/S0890-8567(11)00268-1/fulltext

"This editorial considers some of these issues from my perspective as a member of the DSM-5 Neurodevelopmental Disorders Workgroup." Happe 2011, p740.

Quote confirms Happe was a member of the Neurodevelopmental Disorders Workgroup.

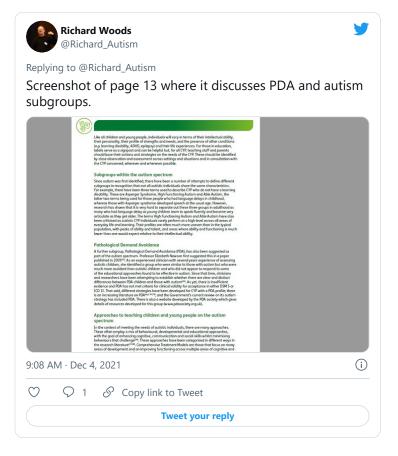
"Overall, it does not appear that those individuals on the autism spectrum who meet expected language milestones in the first 3 years (i.e., meet Asperger criteria) differ significantly from those who are delayed in early language,..." Happe (2011, p740).

"There is no evidence of differential treatment response or etiology to date, and claims for a distinct neurocognitive profile in Asperger disorder have received mixed results." P740.

"the best predictor of which autism spectrum diagnosis a person received (Asperger disorder, PDD-NOS, or autistic disorder) was which clinic the individuals went to, rather than any characteristic of the individual." Happe (2011, p741).

"It is time to reintegrate Asperger disorder with the rest of the spectrum and to demand the same level of respect and lack of stigma for individuals across the full range of manifestations of ASD." Happe (2011, p742).

Likewise, none of these seemingly pertinent points about debates for removing autism subtypes are mentioned in O'Nions et al (2014).



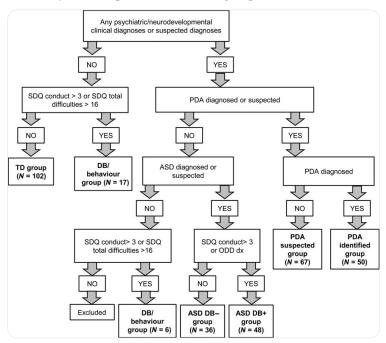
If the <u>@AutismEducatio1</u> can seem fit to discuss autism subtypes, before discussing PDA, then, it surely it is reasonable to expect Happe & Gould to discuss difficulties in successfully dividing autism, in an article which views PDA to be part of the autism spectrum.

"Their apparently intact awareness of how to 'push people's buttons' suggests a level of social insight that is unusual in children with ASD." O'Nions et al (2014, 758).

"Our current interest in researching PDA stems from reports and observations that this behaviour has a different quality (e.g. difficult behaviour in ASD may be to achieve a concrete goal or avoid a specific activity,...

... as opposed to persistent avoidance of any requests to maintain control), and fails to respond to the usual ASD approaches." O'Nions et al 2014, p766.

Image from O'Nions et al (2014, p761). It shows how those suspected with PDA are sourced exclusively from suspected autistic CYP groups.



The point is, the central axiom to O'Nions et al (2014) seems to be that PDA is part of the autism spectrum. Yet, broader debates around difficulties & failings to successfully divide autism WERE NOT MENTIONED by authors who knew about such problems.

One might view the omission of such information as potentially impacting how O'Nions et al (2014) was perceived at peer review, &/ or the editor which processed the submission.

I think there are other COIs in O'Nions et al (2014) than the three mainly discussed in detail. It is worth quoting <u>@AutismEducatio1</u> again about how caregivers are vulnerable to being mislead.

"Meanwhile, proponents of particular approaches often make strong claims for good outcomes, and commercial interests can come into play with companies promoting their own product...

... This can in turn create a demand for certain approaches. It can also leave caregivers and practitioners vulnerable to trying out methods that have no evidence base or are not suited to the specific CYP." AET 2021, p14.

Which is why this article is so important, as such commercial processes, and creation of demand, is applicable to charities, & certain individuals views on PDA. tandfonline.com/loi/cdso20

Sorry this article.



It is exactly, these kind of processes I am discussing in this conference talk. How certain parties with COIs, making strong claims, without strong evidence. Creating demand, which misleads various autism stakeholders.

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

Perhaps, just perhaps, my views on how "PDA Profile of ASD" are being propagated are valid, and those who are principally involved in driving demand for "PDA Profile of ASD" are not as reputable as they claim?



https://www.youtube.com/embed/xFiUWN3y9ho

@threadreaderapp please could you unroll?

Thank you in advance.

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