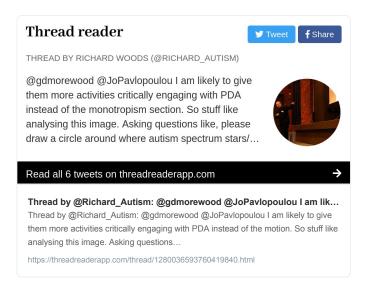


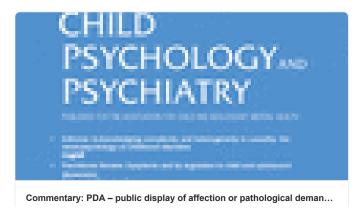
<u>@cassie_davies</u> That means absolutely nothing
<u>@cassie_davies</u> it assumes Newson's original views on
PDA are not seen in other conditions. Her research
sample is biased by the referrals to her clinic. Is plausible
PDA is seen in other conditions.

<u>@cassie davies</u> That means absolutely nothing <u>@cassie davies</u> it assumes Newson's original views on PDA are not seen in other conditions. Her research sample is biased by the referrals to her clinic. Is plausible PDA is seen in other conditions.

<u>@cassie_davies</u> Newson also created her own diagnostic grouping for PDA in 1989 / 1996 that evolved into her "Autistic Family" figure in 2003. If you analyse it, it is clear PDA is not autism & never has been:

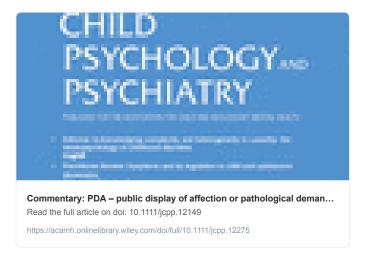


<u>@cassie_davies @GillbergCentre</u> view that PDA maybe a new type of disorder is what best fits the literature at the moment. Also PDA is not part of the autism spectrum:

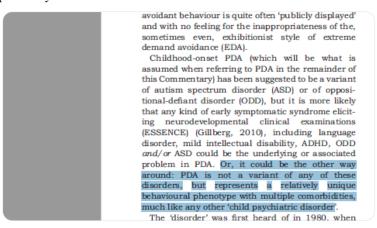


<u>@cassie_davies @GillbergCentre</u> It explains everything from the (supposed) different strategies, to Ellie Bishop's results of no association between PDA traits and Theory of Mind.

<u>@cassie_davies @GillbergCentre</u> When you consider it <u>@GillbergCentre</u> is correct PDA is a new type of disorder:



I will explain why.



<u>@cassie_davies @GillbergCentre</u> Newson created a new diagnostic grouping in 1989 & used it in 1996, called "Pervasive Developmental Coding Disorders". She did for a couple of reasons including viewing autism as being too narrowly defined:

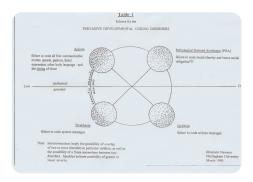
https://www.autismeastmidlands.org.uk/wp-

content/uploads/2016/10/Pathological-Demand-Avoidance-Syndrome.pdf

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https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-a-statistical-update.pdf





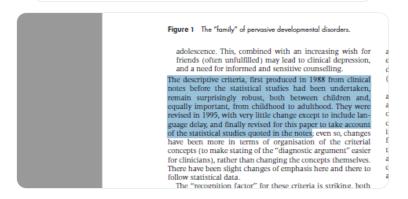
<u>@cassie_davies @GillbergCentre</u> Newson spent 15 years developing PDA behaviour profile, 1988 - 2003.



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...

http://adc.bmj.com/content/88/7/595



<u>@cassie_davies @GillbergCentre</u> Also Newson never systematically investigated features of autism as part of her PDA research:

 $\label{lem:http://www.pdaresource.com/files/An%20examination%20of%20the%20behaviour al%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf$



<u>@cassie_davies @GillbergCentre</u> "Clearly, "hanging together as an entity" is not enough

if that entity is not significantly different from both autism and Asperger's syndrome, either separately or apart" Newson et al 2003, p599.

<u>@cassie_davies @GillbergCentre</u> Reference for previous link is:

"O'NIONS, E., QUINLAN, E., SAN JOSE CACERES, A., TULIP, H., VIDING, E. & HAPPÉ, F. (submitted) Pathological Demand Avoidance (PDA): an examination of the behavioural features using a semi-structured interview."

<u>@cassie_davies @GillbergCentre</u> Makes sense as "Austistic" Disorder & Aspergers are compared to PDA diagnostic criteria. Newson does not mention triad of impairment except in 2003 except in the "Autistic Family" Figure 1.

<u>@cassie_davies @GillbergCentre</u> Tells us that Newson spent 15 years developing PDA behaviour profile on assumptions 1) Significantly different to autism. 2) Is not autism. As PDA belonged to a new diagnostic grouping.

<u>@cassie_davies @GillbergCentre</u> Does raise awkward questions as to why some persons are saying PDA is part of the autism spectrum, when it clearly never was.

<u>@cassie_davies @GillbergCentre</u> Also PDA literature acknowledeges Newson took a different approach to identifying PDA to O'Nions et al (2016), who aimed to make PDA a "meaningful subgroup":



Identifying features of 'pathological demand avoidance' us

The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obsessive resistance to everyday demands and...

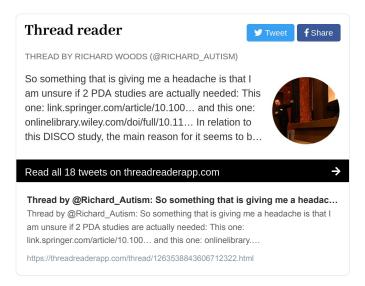
https://link.springer.com/article/10.1007/s00787-015-0740-2

sensitive to detecting these putative features of PDA.

Seven of the 15 DISCO items that had been included in a draft PDA list developed by Wing and Gould did not meet inclusion criteria for our measure. Six out of these seven items failed to show differential endorsement between the

inclusion criteria for our measure. Six out of these seven items failed to show differential endorsement between the PDA groups (ascertained based on scores on our 11-item measure) and the rest of the sample. Wing and Gould's draft list had used published descriptions by Newson of PDA features to generate an item pool. Notably, Newson's descriptions were not specifically focused on the characteristics that can delineate PDA from the rest of the autism spectrum and were not 'weighted' in terms of which items were considered to be most central in the profile. The approach taken here to select items was aimed at exploring the possible differentiation of PDA and focusing on items that were most ubiquitous to the profile.

The final section of the analysis highlighted a number of additional items that appeared to differentiate PDA from the rest of the sample (Online Resource 5). These indicators PDA an autism subtype and their approach was different Newson's. One could even argue that O'Nions et al (2016) was not needed:



<u>@cassie_davies @GillbergCentre</u> Also that Newson did not establish the specificity of PDA, or its validity. Newson showed that PDA is different to "autistic disorder" & Aspergers.



<u>@cassie_davies @GillbergCentre</u> Newson's 2003 paper is a review of her 3 research studies, most/ all of the research was concluded before 2002. So Wing's quote from 2002 is applicable.

<u>@cassie_davies @GillbergCentre</u> "Elizabeth Newson described a behaviour pattern she called "Pathological Demand Avoidance Syndrome" (PDA). Among other features, the children concerned use many strategies to avoid responding to demands...

<u>@cassie_davies @GillbergCentre</u> ... They also seem to find reward in upsetting other people. Children with any type of autistic disorder can show these behaviours so the idea that PDA is a separate syndrome remains unproven"

<u>@cassie_davies @GillbergCentre</u> Wing, Lorna. (2002). The Autistic Spectrum: The Updated Edition. Constable & Robinson Limited, London. Page 30.

<u>@cassie_davies @GillbergCentre</u> Newson's research to establish PDA, is akin to comparing Reactive Attachment Disorder (RAD) & Disinhibited Social Engagement Disorder (DSED) to PDA.

<u>@cassie_davies @GillbergCentre</u> RAD & DSED are 2 types of attachment disorder, but simply comparing PDA to DSED & RAD does not make PDA an attachment disorder; all that has been done is showing PDA is different to DSED & RAD.

<u>@cassie_davies</u> <u>@GillbergCentre</u> Similarly, saying PDA belongs to the Attachment Disorders diagnostic grouping does not make PDA an attachment disorder. For PDA to be an attachment disorder it would need to conform to accepted understandings of attachment disorders.

<u>@cassie_davies @GillbergCentre</u> Newson does did not establish PDA was a distinct entity. Nor, did she establish PDA conformed to accepted autism understandings. Newson's conceptualisation of PDA makes it problematic fitting it into autism.

@cassie davies @GillbergCentre Links:

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

&





<u>@cassie_davies</u> <u>@GillbergCentre</u> Also Newson's research has a selection bias by its samples being drawn from referrals to a clinic specialising in "Coding" Disorders; persons who have problems processing/ making sense of some aspects of communication.

<u>@cassie_davies @GillbergCentre</u> My point here is that while Newson's research is weak, she did not establish it as an autism profile. She did view PDA as a being different and separate from autism. Worth noting PDA was diagnosed separately from autism by ENC until 2015.

<u>@cassie_davies @GillbergCentre</u> Which underlies the differences in approach to PDA between Newson and O'Nions et al (2016).

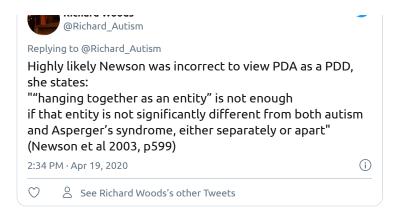
<u>@cassie_davies @GillbergCentre</u> Simply put there needs to be more justification for saying PDA is an ASD than it being arbitrarily called a Pervasive Developmental Disorder based on Newson's work. Especially as there is considerable debate around what PDA could be.

<u>@cassie_davies @GillbergCentre</u> Also Newson did not investigate the IQ of her sample.

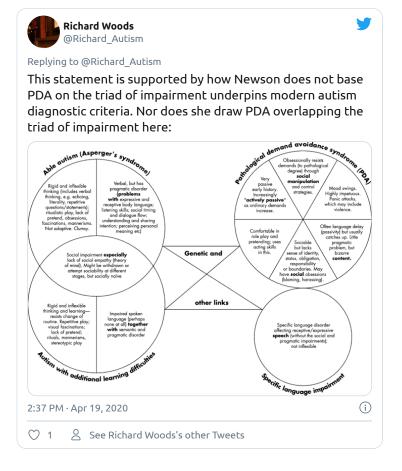
There are other issues with Newson's work, around certain assumptions.



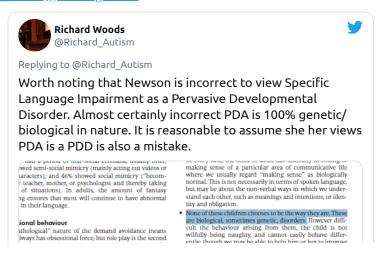




@cassie_davies @GillbergCentre



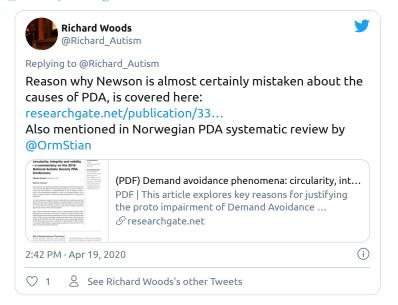
@cassie davies @GillbergCentre



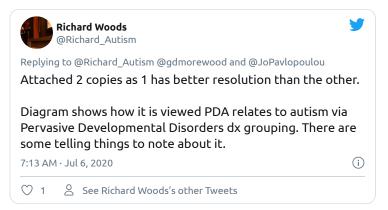
bosession, which gives the impression of more socially 1 obsessions in PDA than in autism/Asperger's ne. This is borne out by the adults. Seventeen of the 18 ribed as obsessively demand avoidant (the other being das "not obsessively so at the moment"), and 10 use bosessions as an avoidance strategy or distraction, have obsessions about specific people, 11 blame, target, so specific people, six want to be with specific people in a proposition of the distribution of the secondary, and four want to be a specific person or characteristingly, 10 have contradictory obsessions, espever-cleanliness/slovenliness. All these obsessional is may also be seen in childhood, especially harass
2:40 PM·Apr 19, 2020

See Richard Woods's other Tweets

@cassie davies @GillbergCentre



@cassie_davies @GillbergCentre

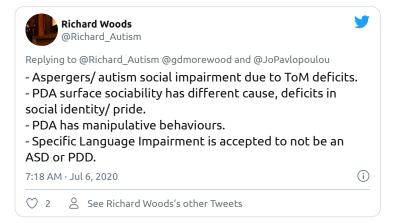


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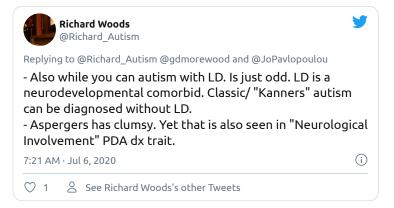




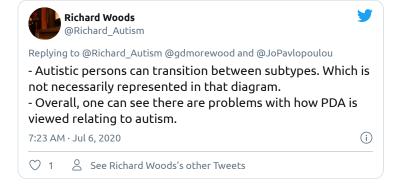
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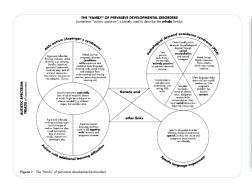
@cassie davies @GillbergCentre

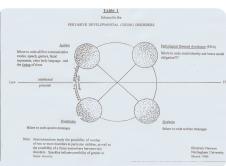


@cassie_davies @GillbergCentre



<u>@cassie_davies @GillbergCentre</u> The point here is it appears Newson was mistaken to say PDA was a Pervasive Developmental Disorder and that PDA is instead a Pervasive Developmental Coding Disorder, but that is not the same thing as an autism profile.





@cassie davies @GillbergCentre It is worth point out that Newson's research did not significantly change the PDA profile from 1989 to 2003. That any changes were more for "diagnostic argument" than changes to her concept of PDA.



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...

http://adc.bmj.com/content/88/7/595

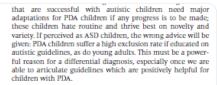


adolescence. This, combined with an increasing wish for friends (often unfulfilled) may lead to clinical depression, and a need for informed and sensitive counselling.

The descriptive criteria, first produced in 1988 from clinical notes before the statistical studies had been undertaken, remain surprisingly robust, both between children and, equally important, from childhood to adulthood. They were revised in 1995, with very little change except to include language delay, and finally revised for this paper to take account of the statistical studies quoted in the notes, even so, changes have been more in terms of organisation of the criterial concepts (to make stating of the "diagnostic argument" easier or clinicians), rather than changing the concepts them There have been slight changes of emphasis here and there to follow statistical data.

The "recognition factor" for these criteria is striking, both by parents whose child has previously had an "atypical

@cassie davies @GillbergCentre Another limitation of Newson's work is that it did not take measurements for IQ. She argued that an IQ test score was not reflective of a CYP with PDA actual ability. Which there might be something to.



PARAMETERS OF COHORT

The information presented here is based on a total cohort of 150 children diagnosed consecutively as having PDA in the two clinics headed by EN between 1975 and 2000. A few chil-dren whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded. IQ in these children tends to be meaningless because of the severe demand avoidance, and alternative descriptive gauges of ability are used clinically. Age at diagno-

sis varied between 4 and 16 years.

Within this cohort, two separate samples were taken for

<u>@cassie_davies @GillbergCentre</u> I think this is the final critique I have of Newson's paper. This is from the Green et al (2018) review:



individuals.9,30 In this context, any move to adopt pathological demand avoidance as a new alternative subtype of autism spectrum disorder (or a stand-alone diagnosis) requires an equivalent empirical scrutiny. In their original paper, Newson and colleagues did report a discriminant functions analysis to separate the pathological demand avoidance group from autism and Asperger's syndrome. The nature of the analysis undertaken was not specified, but because the process was circular (ie, starting with a predefined syndrome and then showing that it is different from other syndromes), this method would not be considered robust or convincing nowadays without replication within a large independent dataset, with additional demonstrations of discriminant and predictive validity. These validation studies have not yet emerged. Indeed, there have been few scientific publications about pathological demand avoidance since the first published peer-review paper in 2003.¹ An item-level questionnai

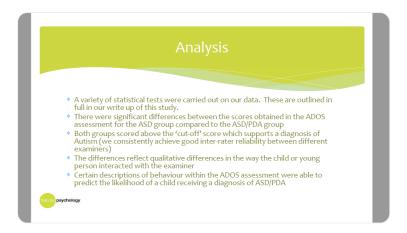
nnaire developed from nathological

<u>@cassie_davies @GillbergCentre</u> One should see Newson's research:

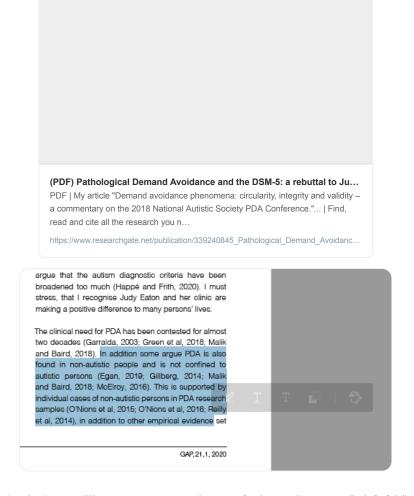
- Is poor quality.
- Did not establish PDA as a syndrome
- Did not establish PDA as an autism "profile".
- Incorrect PDA was a Pervasive Developmental Disorder, but it is a "Pervasive Developmental Coding Disorder".

@cassie davies @GillbergCentre If you plug PDA is a "Pervasive Developmental Coding Disorder" into PDA literature, it explains almost everything. PDA has (supposed) different strategies to autism. Because PDA is a PDCD: https://www.pdasociety.org.uk/wp-content/uploads/2019/07/AET-standards-for-PDA-Phils-GAP-1.pdf

@cassie davies @GillbergCentre You want to know why all other attempts divide autism have failed & @DrJudeso3 is seeing PDA as a distinct entity: Because PDA is a pervasive developmental coding disorder:



<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why is PDA seen in non-autistic persons? Because PDA is a Pervasive Developmental Coding Disorder & not autism:



<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> Why is PDA's seen as "triple hit" of autism, conduct problems. Because PDA is a Pervasive Developmental Coding Disorder & not autism.



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

Debate tends to centre on whether PDA constitutes a syndrome that is specific and distinct from other forms of autistic spectrum disorders, with the possibility that PDA is a 'female' presentation of more typical autism (e.g., Kopp and Gillberg, 2011). Others question whether the PDA phenotype is sufficiently distinct from other conditions, such as oppositional defiance and anxiety disorders (e.g., Garralda, 2003). Most recently, Gillberg (2014) acknowledges that PDA is 'a very real problem' (p. 769), which he suggests occurs across multiple diagnoses, including attention deficit hyperactivity disorder, language disorders and certain chromosomal syndromes. Recent research (O'Nions, Viding and Greven et al., 2014) shows that children with PDA display comparable levels of autistic traits to children with autism spectrum disorders (ASD) and comparable levels of conduct problems to children with conduct disorder. Children with PDA also display higher levels of emotional symptoms than either group. PDA may thus currently be conceptualised as a 'triple hit' of autism, conduct problems and anxiety.

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Triple hit of autism, anxiety and conduct problems.

<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> Why Ellie Bishop found no relation between PDA & ToM, while there is a relation between ToM & features associated with autism. Because PDA is a Pervasive Developmental Coding Disorder & not autism.

https://discovery.ucl.ac.uk/id/eprint/10057038/

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why is precursors to Personality Disorders seen & more closely associated to PDA than autism traits. Because it is a Pervasive Developmental Coding Disorder & not autism.

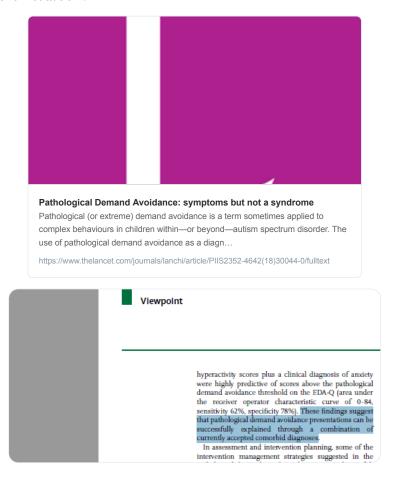


The Measurement of Adult Pathological Demand Avoidance Traits

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

<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> Why can PDA be represented by interaction of accepted comorbids. Because it is a Pervasive Developmental Coding Disorder & not autism.

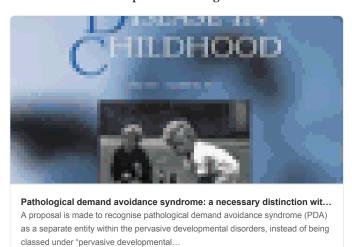


<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why do High attention deficit, antagonism, and low emotional stability predict PDA (and autism does not predict PDA)? Because PDA is a Pervasive Developmental Coding Disorder & no autism.



<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why did above study also see precursors to Personality Disorders, supporting critique of Garralda & Wing et al?

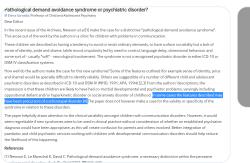
Because PDA is a Pervasive Developmental Coding Disorder & not autism:



https://adc.bmj.com/content/88/7/595.responses

&





<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why is high anxiety driven demand avoidance PDA's central impairment, while anxiety is a recognised comorbid to autism? Because PDA is a Pervasive Developmental Coding Disorder and not autism: https://www.ingentaconnect.com/contentone/bild/gap/2011/00000012/00000001/art00005

'The fact that girls with undiagnosed autism are painstakingly copying some behaviour is not picked up and therefore any social and communication problems they may be having are also overlooked. This sort of mimicking and repressing their autistic behaviour is exhausting, perhaps resulting in the high statistics of women with mental health problems.' (p. 31)

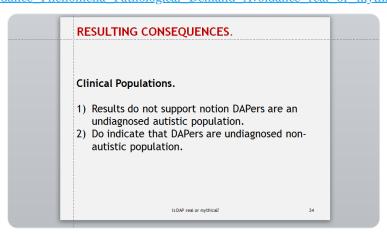
Adults and adolescents seen at The Lorna Wing Centre are usually referred through mental health services. Some of the co-morbid diagnoses are obsessive compulsive disorder, eating disorders, personality disorders, selective mutism, anxiety and depression. Taking an appropriate developmental history often reveals that they are on the autism spectrum with either

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why some research shows associations between PDA, ADHD & Conduct Disorder? Because PDA is Pervasive Developmental Coding Disorder & not autism.

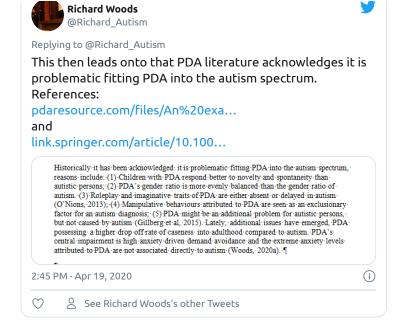
https://www.ingentaconnect.com/contentone/bild/gap/2017/00000018/0000001/art00009

The controversy around PDA/EDA relates in part to whether or not it falls on the autistic spectrum. Wing and Gould have incorporated it into the DISCO-11 as a subcategory of autism. Further work by O'Nions et al (2016) found PDA within the ASD population to be consistent with Newson's descriptions characterised by lack of co-operation, use of apparently manipulative behaviour, socially shocking behaviour, difficulties with other people, anxiety and sudden behavioural changes from loving to aggressive. Further ongoing work by Kaushik (RCPsych CAP Faculty Annual Conference 2015 proceedings) has recognised that there are also associations between PDA, ADHD, and conduct disorder, the latter two diagnoses of which car be linked to the environment, poor early caregiving and attachments (Kumsta et al, 2015).

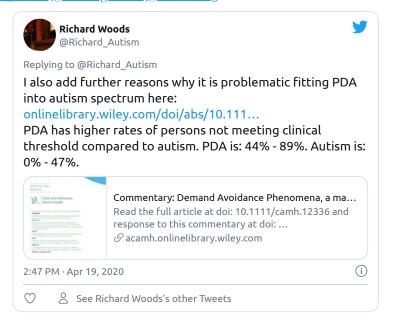
<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> Why does my content analysis of PDA tools suggests there is a population of undiagnosed non-autistic persons with PDA? Because PDA is a Pervasive Developmental Coding Disorder & not autism: https://www.researchgate.net/publication/340279248 Is the concept of Deman d Avoidance Phenomena Pathological Demand Avoidance real or mythical



<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Why are there important clinical differences between PDA & autism? Because it PDA is a Pervasive Developmental Coding Disorder & not autism.



@cassie davies @GillbergCentre @DrJudeso3



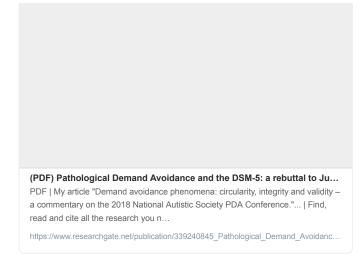
<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> One should get the gist PDA is best explained by being a Pervasive Developmental Coding Disorder & not as an autism profile.

<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> Why does this PDA model has anxiety as obsessive & the demand avoidance as compulsive? Because PDA is a Pervasive Developmental Coding Disorder & not an ASD:

https://lizonions.files.wordpress.com/2019/09/1909childbehaviourparentingstrateg iessummarv.pdf

Model does not explicitly say anxiety is obsessive & anxiety as compulsive

<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> A differential marker between autism & other conditions with RRBI's is the source of RRBI. If source is from fear/ anxiety/ aversion it tends to attributed as non-autism in nature:



&



<u>@cassie_davies</u> <u>@GillbergCentre</u> <u>@DrJudeso3</u> From a literature perspective it is problematic and controversial to say PDA is an autism profile. It is best explained by being a Pervasive Developmental Coding Disorder.

<u>@cassie_davies @GillbergCentre @Dr.Judeso3</u> To further underscore the point. Some argue PDA is an ASD as it has social communication issues & RRBIs. That does not mean PDA is an ASD profile...

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> ... The surface communication issues for PDA are different to autism, surface sociability and not linked to ToM:



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...

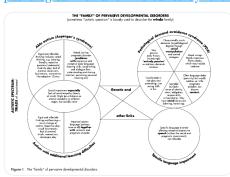
http://adc.bmj.com/content/88/7/595

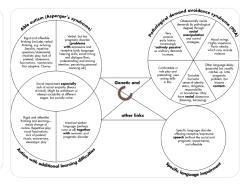
&

https://discovery.ucl.ac.uk/id/eprint/10057038/

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https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Communication-development-of-Children-with-pathological-Demand-Avoidance-Syndrome.pdf





<u>@cassie_davies @GillbergCentre @DrJudeso3</u> ... That the nature of RRBIs in PDA is different in nature to that of autism. It indicates the presence of trauma. E.g. precursors for Personality Disorders suggest presence of trauma.

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://rational demand avoidance.com/2020/03/17/17 th-of-march-blog-post-updating-m... and the state of the control of the



Individual differences, ADHD, adult pathological demand avoidance, a... $% \label{eq:control_eq}$

Pathological Demand Avoidance (PDA) is a developmental disorder involving challenging behaviour clinically linked to Autism Spectrum Disorder (ASD). M...

https://www.sciencedirect.com/science/article/abs/pii/S0891422220301633

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> ... Which tells you 1) PDA is not an autism profile. 2) PDA is a new type of disorder, i.e. a Pervasive Developmental Coding Disorder.

This should be obvious to any credible autism expert/researcher/clinician.

<u>@cassie_davies @GillbergCentre @DrJudeso3</u> Must also be said one can be clinically diagnosed with autism & not actually be autistic; "quasi-autism". Which supports the point PDA having RRBIs & social communication issues does not make it an autism profile:

https://www.ingentaconnect.com/contentone/bild/gap/2017/00000018/0000001/art00000

way of understanding the attachment contributions to a clinical picture will hopefully provide more confidence in establishing co-morbidity and also informing a clinical decision. Such decisions should always trump reliance on diagnostic instruments, which should only inform, as opposed to over-ride, clinical judgement.

Findings from the Romanian orphan studies

The Romanian orphan studies indicate the overlap with attachment disorder and autism. These children showed attachment difficulties and some appeared to have autism, termed 'quasi-autism' as it was not typical (Rutter et al 2001). Such autistic characteristics were not found in a similarly studied sample of typical children in the UK adopted in the first six months of life. The Romanian adoptees were somewhat different from many children with typical autism in the improvement they showed between the ages of 4 and 6 years and the extent of their social approach (Rutter et al 1999).

@cassie_davies @GillbergCentre @DrJudeso3 @FidgetyF_cker



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