Richard Woods @Richard_Autism

21 Sep • 19 tweets • Richard_Autism/status/1308136299212279808

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety Newson did not systematically assess for autism features because she was trying to show PDA was different to autism, to warrant PDA being a "thing". She originally conceptualised it as a new type of disorder. Spent 15 years researching that behaviour profile.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety This is all public information, just a lot of it is unpublished materials. 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
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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

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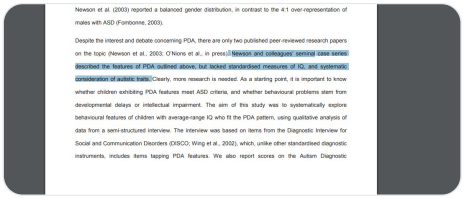
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-a-statistical-update.pdf



Newson et al. (2003) reported a balanced gender distribution, in contrast to the 4:1 over-representation of males with ASD (Fombonne, 2003).

Despite the interest and debate concerning PDA, there are only two published peer-reviewed research papers on the topic (Newson et al., 2003; O'Nions et al., in press). Newson and colleagues' seminal case series described the features of PDA outlined above, but lacked standardised measures of IQ, and systematic consideration of autistic traits. Clearly, more research is needed. As a starting point, it is important to know whether children exhibiting PDA features meet ASD criteria, and whether behavioural problems stem from developmental delays or intellectual impairment. The aim of this study was to systematically explore behavioural features of children with average-range IQ who fit the PDA pattern, using qualitative analysis of data from a semi-structured interview. The interview was based on items from the Diagnostic Interview for Social and Communication Disorders (DISCO; Wing et al., 2002), which, unlike other standardised diagnostic instruments, includes items tapping PDA features. We also report scores on the Autism Diagnostic

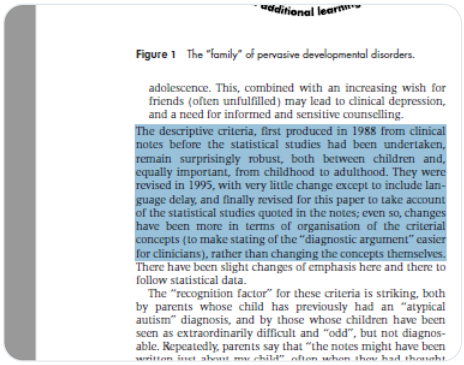
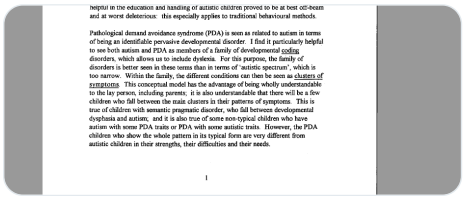


Figure 1 The "family" of pervasive developmental disorders.

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 for clinicians), rather than changing the concepts themselves. 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 autism" diagnosis, and by those whose children have been seen as extraordinarily difficult and "odd", but not diagnosable. Repeatedly, parents say that "the notes might have been



helpful in the education and handling of autistic children proved to be at best off-beam and at worst deleterious: this especially applies to traditional behavioural methods.

Pathological demand avoidance syndrome (PDA) is seen as related to autism in terms of being an identifiable pervasive developmental disorder. I find it particularly helpful to see both autism and PDA as members of a family of developmental coding disorders, which allows us to include dyslexia. For this purpose, the family of disorders is better seen in these terms than in terms of 'autistic spectrum', which is too narrow. Within the family, the different conditions can then be seen as clusters of symptoms. This conceptual model has the advantage of being wholly understandable to the lay person, including parents; it is also understandable that there will be a few children who fall between the main clusters in their patterns of symptoms. This is true of children with semantic pragmatic disorder, who fall between developmental dysphasia and autism; and it is also true of some non-typical children who have autism with some PDA traits or PDA with some autistic traits. However, the PDA children who show the whole pattern in its typical form are very different from autistic children in their strengths, their difficulties and their needs.

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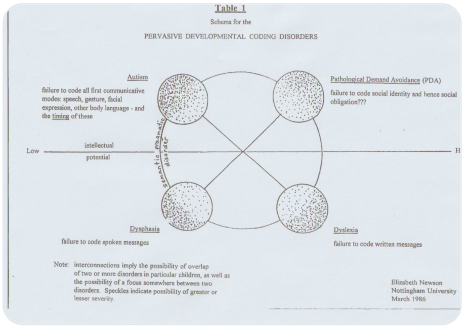


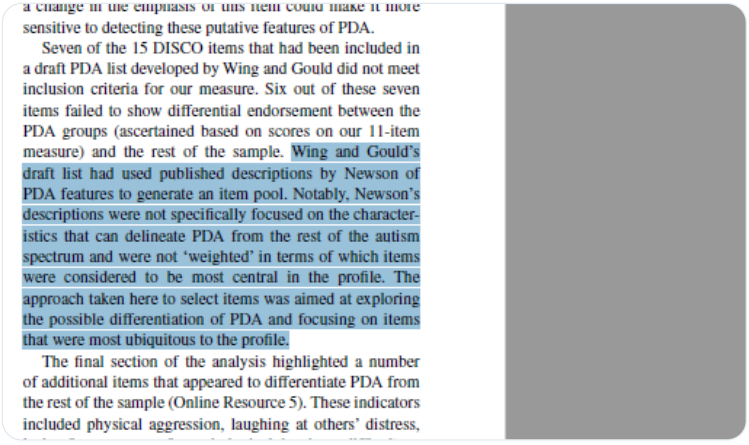
@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety "Clearly, "hanging together as an entity" is not enough if that entity is not significantly different from both autism and Asperger's syndrome, either separately or apart" Newson et al, 2003, p599.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety Newson was not trying to make PDA an autism subgroup, but was trying to show PDA was different to autism. Her research has a seletion bias, it is really poor quality generally.

Identifying features of 'pathological demand avoidance' using the Diag…
The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obse

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

You really need to read this:
https://thepsychologist.bps.org.uk/pda-new-type-disorder


a change in the emphasis of this item could make it more 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 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 included physical aggression, laughing at others' distress,

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety These reasons are one reason why I struggle to take anyone seriously who insists PDA is an autism subgroup, because it does not represent what Newson did, or was trying to do. It is the PDA development group who are trying to make PDA an autism subgroup.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety I am pretty certain Newson would have been perfectly happy to have PDA diagnosed outside of autism, considering she consistently did things to help other stakeholders. Take note @sallyrssll

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll I started reading Newson's 2003 article supplementary notes to see if "surface sociability" trait is mandatory for a PDA dx. It is not, at least in Faroe Islands paper.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll Back to these side notes. I have just broken down in tears & hysterics. One Newson seems to have a broader conceptualisation of PDDs, that is broader than autism. I.e. my critique of her "The “family” of pervasive developmental disorders." is valid.

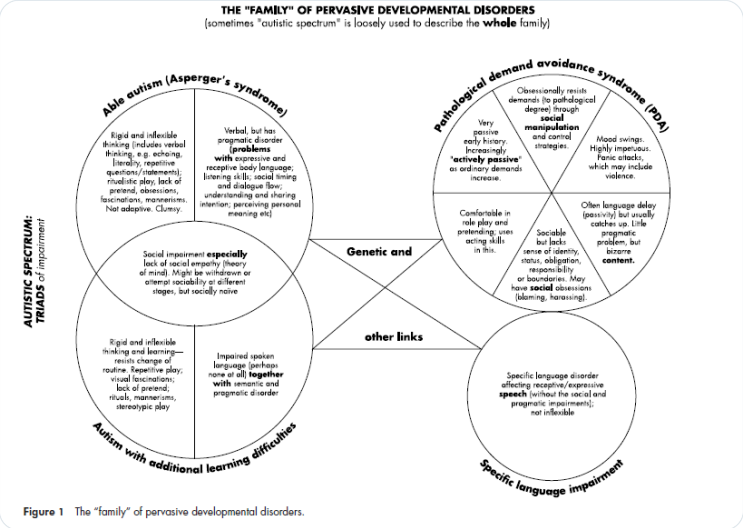
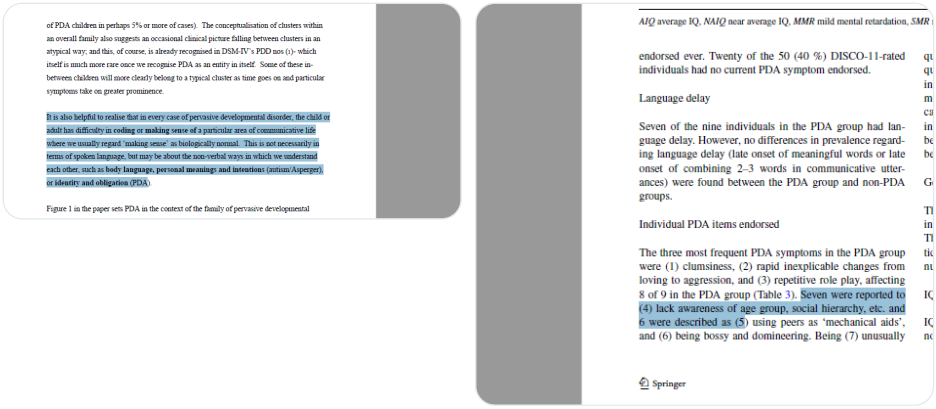


Figure 1 The "family" of pervasive developmental disorders.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll Also note that Faroe Islands paper did not view manipulative demand avoidance as essential for a PDA dx. Some would challenge if Gillberg et al dx PDA.

Extreme ("pathological") demand avoidance in autism: a general popu…
Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexiste

https://link.springer.com/article/10.1007/s00787-014-0647-3



of PDA children in perhaps 5% or more of cases). The conceptualisation of clusters within an overall family also suggests an occasional clinical picture falling between clusters in an atypical way; and this, of course, is already recognised in DSM-IV's PDD nos (-) which itself is much more rare once we recognise PDA as an entity in itself. Some of these in-between children will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.

It is also helpful to realise that in every case of pervasive developmental disorder, the child or adult has difficulty in coding or making sense of a particular area of communicative life where we usually regard 'making sense' as biologically normal. This is not necessarily in terms of spoken language, but may be about the non-verbal ways in which we understand each other, such as body language, personal meanings and intentions (autism/Asperger), or identity and obligation (PDA).

Figure 1 in the paper sets PDA in the context of the family of pervasive developmental

AIQ average IQ, *NAIQ* near average IQ, *MMR* mild mental retardation, *SMR*

endorsed ever. Twenty of the 50 (40 %) DISCO-11-rated individuals had no current PDA symptom endorsed.

Language delay

Seven of the nine individuals in the PDA group had language delay. However, no differences in prevalence regarding language delay (late onset of meaningful words or late onset of combining 2–3 words in communicative utterances) were found between the PDA group and non-PDA groups.

Individual PDA items endorsed

The three most frequent PDA symptoms in the PDA group were (1) clumsiness, (2) rapid inexplicable changes from loving to aggression, and (3) repetitive role play, affecting 8 of 9 in the PDA group (Table 3). Seven were reported to (4) lack awareness of age group, social hierarchy, etc. and 6 were described as (5) using peers as 'mechanical aids', and (6) being bossy and domineering. Being (7) unusually

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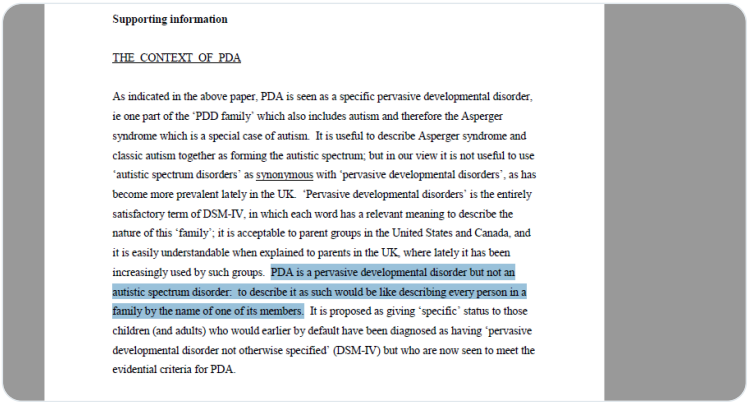
@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll The point about surface sociability not being an essential PDA trait means, if it is not seen in all diagnosed with PDA, one cannot argue PDA must be an autism subtype due to clustering of RRBIs & this surface sociability trait.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll I think this argument is weak anyway as having social communication issues is common in mental health disorders, most do not include them in their dx criteria.

Back to Newson's notes.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll This is Newson herself saying PDA is NOT autism, but is a PDD due to her broader conceptualisation of it.
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes
Supports my view Newson was trying to PDA is different is autism, not to make it an autism subgroup.



Supporting information

THE CONTEXT OF PDA

As indicated in the above paper, PDA is seen as a specific pervasive developmental disorder, ie one part of the 'PDD family' which also includes autism and therefore the Asperger syndrome which is a special case of autism. It is usefil to describe Asperger syndrome and classic autism together as forming the autistic spectrum; but in our view it is not useful to use 'autistic spectrum disorders' as synonymous with 'pervasive developmental disorders', as has become more prevalent lately in the UK. 'Pervasive developmental disorders' is the entirely satisfactory term of DSM-IV, in which each word has a relevant meaning to describe the nature of this 'family'; it is acceptable to parent groups in the United States and Canada, and it is easily understandable when explained to parents in the UK, where lately it has been increasingly used by such groups. PDA is a pervasive developmental disorder but not an autistic spectrum disorder: to describe it as such would be like describing every person in a family by the name of one of its members. It is proposed as giving 'specific' status to those children (and adults) who would earlier by default have been diagnosed as having 'pervasive developmental disorder not otherwise specified' (DSM-IV) but who are now seen to meet the evidential criteria for PDA.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll I am crying tears of joy at this. It means despite everything I have been put through by the PDA supporters. The name calling, doubting me, complaints @SallyRussll interfering in my research.

It means I am right on PDA.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll "PDA is a pervasive developmental disorder but not an autistic spectrum disorder: to describe it as such would be like describing every person in a family by the name of one of its members."

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll Quote is important as it is fallacious to assume PDA is an autism subgroup, i.e. Christie cannot say PDA is an ASD due to it being a PDD.

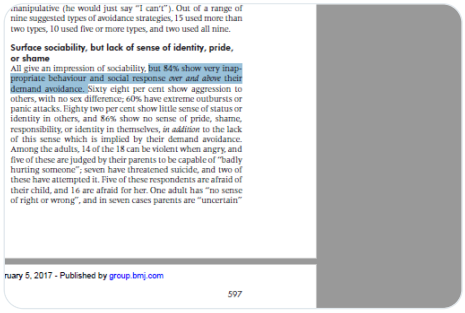
It also means as PDA is not autism, it would have changed diagnostic groups if it had been included in the DSM-5.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll It means that majority of PDA research, lobbying & campaigning for the last 10 years is based on mistaken belief.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll Actually checked Newson et al (2003) for stats on surface

sociability prevalence among sample. Short answer, it is not a universal trait in Newson's research. Which means one cannot use it to argue PDA is an ASD.

@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll Basically around one in sixth of Newson's sample did not have surface sociability traits.
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf


manipulative (he would just say "I can't"). Out of a range of nine suggested types of avoidance strategies, 15 used more than two types, 10 used five or more types, and two used all nine.

Surface sociability, but lack of sense of identity, pride, or shame

All give an impression of sociability, but 84% show very inappropriate behaviour and social response *over and above* their demand avoidance. Sixty eight per cent show aggression to others, with no sex difference; 60% have extreme outbursts or panic attacks. Eighty two per cent show little sense of status or identity in others, and 86% show no sense of pride, shame, responsibility, or identity in themselves, *in addition* to the lack of this sense which is implied by their demand avoidance. Among the adults, 14 of the 18 can be violent when angry, and five of these are judged by their parents to be capable of "badly hurting someone"; seven have threatened suicide, and two of these have attempted it. Five of these respondents are afraid of their child, and 16 are afraid for her. One adult has "no sense of right or wrong", and in seven cases parents are "uncertain"

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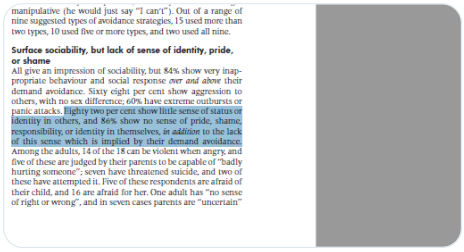
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@tinkerbellbites @milton_damian @martinbeecher @GillLoomesQuinn @PDASociety @sallyrssll I think this is enough for this thread. @threadreaderapp please could you unroll ?

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