Richard Woods @Richard_Autism

22 May • 135 tweets • Richard_Autism/status/1395996293613375492

You know it is dodgy viewing PDA to be an ASD, when even its supposedly "leading" experts acknowledge interest in PDA has outstripped its research...

Although, I am wondering how reputable they are as information sources. Sigh.

"In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic."

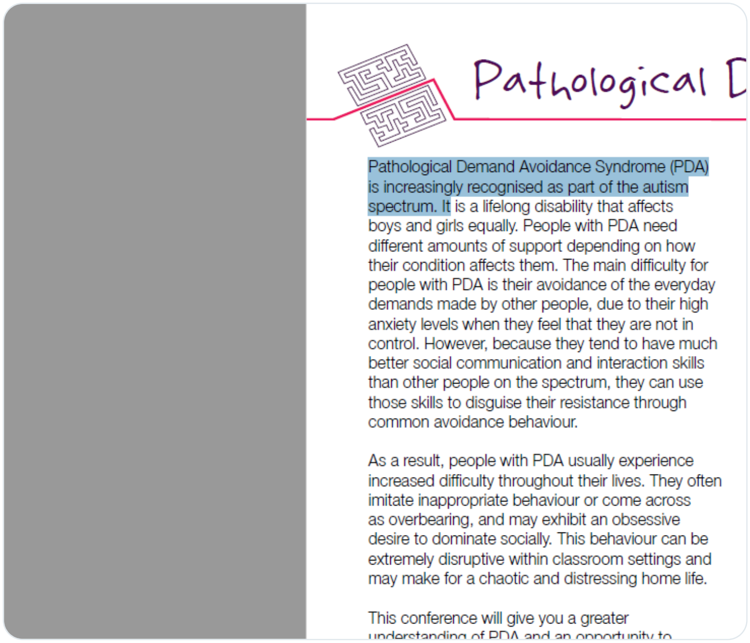
Considering: researchers & clinicians ethically should not predispose one outlook over another; conflicting views on PDA & divergent research results on PDA, which undermine PDA is an ASD. "Dodgy" viewing PDA as an ASD is bit of an understatement.

Which then begs the question, why are "leading" PDA experts viewing PDA to be an ASD?

Perhaps this indicates why:

"Research-based evidence such as this is critical in supporting the clinical understandings about PDA that have developed" (Christie et al, 2011, p186).

Bare in mind the book argues PDA is as an ASD, the research agenda that quote is commenting on views PDA as an ASD. The conference research agenda views PDA as an ASD.



Pathological D

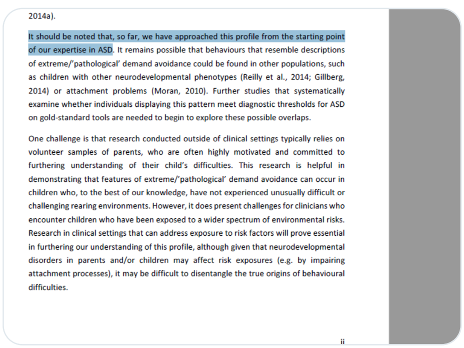
Pathological Demand Avoidance Syndrome (PDA) is increasingly recognised as part of the autism spectrum. It is a lifelong disability that affects boys and girls equally. People with PDA need different amounts of support depending on how their condition affects them. The main difficulty for people with PDA is their avoidance of the everyday demands made by other people, due to their high anxiety levels when they feel that they are not in control. However, because they tend to have much better social communication and interaction skills than other people on the spectrum, they can use those skills to disguise their resistance through common avoidance behaviour.

As a result, people with PDA usually experience increased difficulty throughout their lives. They often imitate inappropriate behaviour or come across as overbearing, and may exhibit an obsessive desire to dominate socially. This behaviour can be extremely disruptive within classroom settings and may make for a chaotic and distressing home life.

This conference will give you a greater understanding of PDA and an opportunity to

The subsequent outlook the researchers took viewed PDA as an ASD.
repository.tavistockandportman.ac.uk/2165/

While attempting to make PDA a "meaningful subgroup of autism".
https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149



2014a).

It should be noted that, so far, we have approached this profile from the starting point of our expertise in ASD. It remains possible that behaviours that resemble descriptions of extreme/'pathological' demand avoidance could be found in other populations, such as children with other neurodevelopmental phenotypes (Reilly et al., 2014; Gillberg, 2014) or attachment problems (Moran, 2010). Further studies that systematically examine whether individuals displaying this pattern meet diagnostic thresholds for ASD on gold-standard tools are needed to begin to explore these possible overlaps.

One challenge is that research conducted outside of clinical settings typically relies on volunteer samples of parents, who are often highly motivated and committed to furthering understanding of their child's difficulties. This research is helpful in demonstrating that features of extreme/'pathological' demand avoidance can occur in children who, to the best of our knowledge, have not experienced unusually difficult or challenging rearing environments. However, it does present challenges for clinicians who encounter children who have been exposed to a wider spectrum of environmental risks. Research in clinical settings that can address exposure to risk factors will prove essential in furthering our understanding of this profile, although given that neurodevelopmental disorders in parents and/or children may affect risk exposures (e.g. by impairing attachment processes), it may be difficult to disentangle the true origins of behavioural difficulties.

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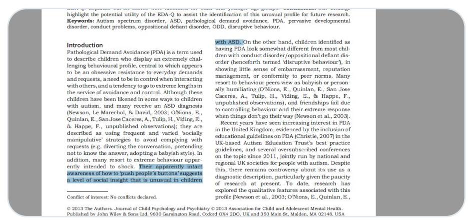

highlight the potential utility of the EDA-Q to assist the identification of this unusual profile for future research.
Keywords: Autism spectrum disorder, ASD, pathological demand avoidance, PDA, pervasive developmental disorder, conduct problems, oppositional defiant disorder, ODD, disruptive behaviour.

Introduction

Pathological Demand Avoidance (PDA) is a term used to describe children who display an extremely challenging behavioural profile, central to which appears to be an obsessive resistance to everyday demands and requests, a need to be in control when interacting with others, and a tendency to go to extreme lengths in the service of avoidance and control. Although these children have been likened in some ways to children with autism, and many receive an ASD diagnosis (Newson, Le Marechal, & David, 2003; O'Nions, E., Quinlan, E., San Jose Caceres, A., Tulip, H., Viding, E., & Happe, F., unpublished observations); they are described as using frequent and varied 'socially manipulative' strategies to avoid complying with requests (e.g. diverting the conversation, pretending not to know the answer, adopting a babyish style). In addition, many resort to extreme behaviour apparently intended to shock. Their apparently intact awareness of how to 'push people's buttons' suggests a level of social insight that is unusual in children with ASD. On the other hand, children identified as having PDA look somewhat different from most children with conduct disorder/oppositional defiant disorder (henceforth termed 'disruptive behaviour'), in showing little sense of embarrassment, reputation management, or conformity to peer norms. Many resort to behaviour peers view as babyish or personally humiliating (O'Nions, E., Quinlan, E., San Jose Caceres, A., Tulip, H., Viding, E., & Happe, F., unpublished observations), and friendships fail due to controlling behaviour and their extreme response when things don't go their way (Newson et al., 2003).

Recent years have seen increasing interest in PDA in the United Kingdom, evidenced by the inclusion of educational guidelines on PDA (Christie, 2007) in the UK-based Autism Education Trust's best practice guidelines, and several oversubscribed conferences on the topic since 2011, jointly run by national and regional UK societies for people with autism. Despite this, there remains controversy about its use as a diagnostic description, particularly given the paucity of research at present. To date, research has explored the qualitative features associated with this profile (Newson et al., 2003; O'Nions, E., Quinlan, E.,

Conflict of interest: No conflicts declared.

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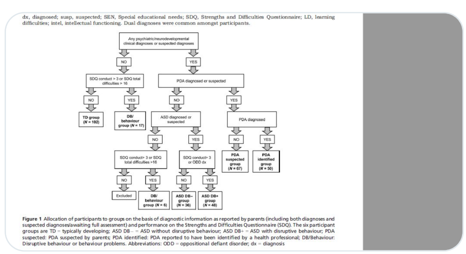
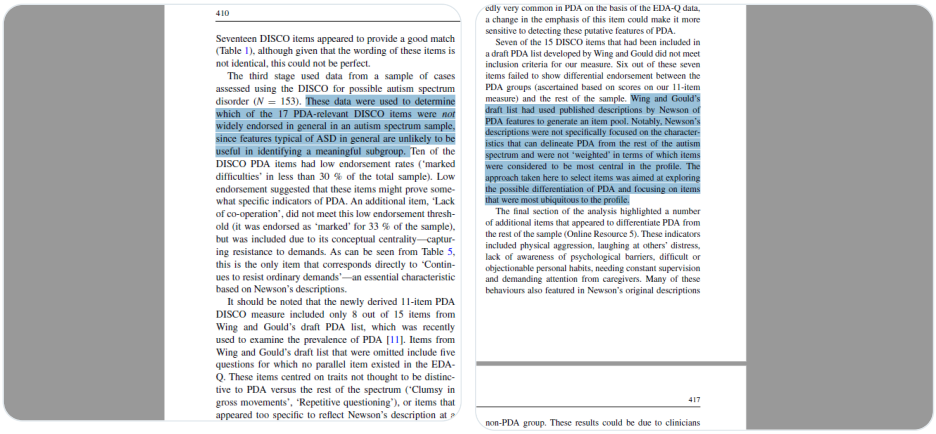


Figure 1 Allocation of participants to groups on the basis of diagnostic information as reported by parents (including both diagnoses and suspected diagnoses/awaiting full assessment) and performance on the Strengths and Difficulties Questionnaire (SDQ). The six participant groups are TD = typically developing; ASD DB– = ASD without disruptive behaviour; ASD DB+ = ASD with disruptive behaviour; PDA suspected: PDA suspected by parents; PDA identified: PDA reported to have been identified by a health professional; DB/Behaviour: Disruptive behaviour or behaviour problems. Abbreviations: ODD = oppositional defiant disorder; dx = diagnosis

And here:
https://link.springer.com/content/pdf/10.1007/s00787-015-0740-2.pdf



410

Seventeen DISCO items appeared to provide a good match (Table 1), although given that the wording of these items is not identical, this could not be perfect.

The third stage used data from a sample of cases assessed using the DISCO for possible autism spectrum disorder ($N = 153$). These data were used to determine which of the 17 PDA-relevant DISCO items were *not* widely endorsed in general in an autism spectrum sample, since features typical of ASD in general are unlikely to be useful in identifying a meaningful subgroup. Ten of the DISCO PDA items had low endorsement rates ('marked difficulties' in less than 30 % of the total sample). Low endorsement suggested that these items might prove somewhat specific indicators of PDA. An additional item, 'Lack of co-operation', did not meet this low endorsement threshold (it was endorsed as 'marked' for 33 % of the sample), but was included due to its conceptual centrality—capturing resistance to demands. As can be seen from Table 5, this is the only item that corresponds directly to 'Continues to resist ordinary demands'—an essential characteristic based on Newson's descriptions.

It should be noted that the newly derived 11-item PDA DISCO measure included only 8 out of 15 items from Wing and Gould's draft PDA list, which was recently used to examine the prevalence of PDA [11]. Items from Wing and Gould's draft list that were omitted include five questions for which no parallel item existed in the EDA-Q. These items centred on traits not thought to be distinctive to PDA versus the rest of the spectrum ('Clumsy in gross movements', 'Repetitive questioning'), or items that appeared too specific to reflect Newson's description at p

edly very common in PDA on the basis of the EDA-Q data, a change in the emphasis of this item could make it more sensitive to detecting these putative features of PDA.

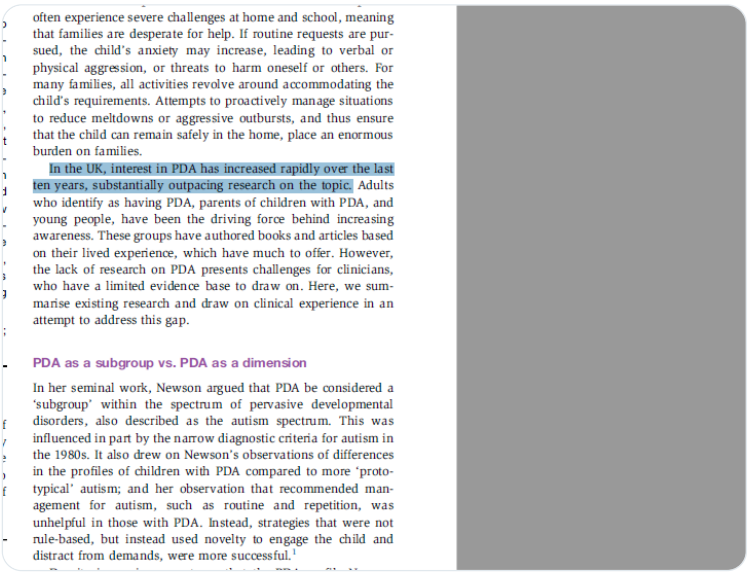
Seven of the 15 DISCO items that had been included in a draft PDA list developed by Wing and Gould did not meet inclusion criteria for our measure. Six out of these seven items failed to show differential endorsement between the PDA groups (ascertained based on scores on our 11-item measure) and the 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, lack of awareness of psychological barriers, difficult or objectionable personal habits, needing constant supervision and demanding attention from caregivers. Many of these behaviours also featured in Newson's original descriptions

417

non-PDA group. These results could be due to clinicians

Screenshot and link for first quote.
https://linkinghub.elsevier.com/retrieve/pii/S1751722220301566



often experience severe challenges at home and school, meaning that families are desperate for help. If routine requests are pursued, the child's anxiety may increase, leading to verbal or physical aggression, or threats to harm oneself or others. For many families, all activities revolve around accommodating the child's requirements. Attempts to proactively manage situations to reduce meltdowns or aggressive outbursts, and thus ensure that the child can remain safely in the home, place an enormous burden on families.

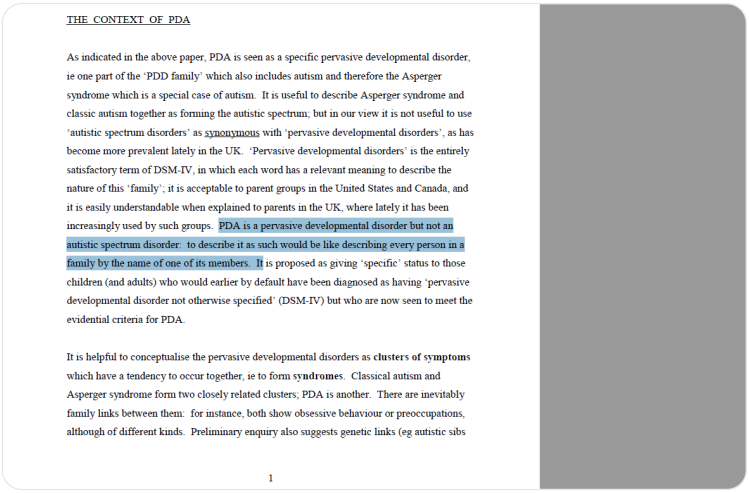
In the UK, interest in PDA has increased rapidly over the last ten years, substantially outpacing research on the topic. Adults who identify as having PDA, parents of children with PDA, and young people, have been the driving force behind increasing awareness. These groups have authored books and articles based on their lived experience, which have much to offer. However, the lack of research on PDA presents challenges for clinicians, who have a limited evidence base to draw on. Here, we summarise existing research and draw on clinical experience in an attempt to address this gap.

PDA as a subgroup vs. PDA as a dimension

In her seminal work, Newson argued that PDA be considered a 'subgroup' within the spectrum of pervasive developmental disorders, also described as the autism spectrum. This was influenced in part by the narrow diagnostic criteria for autism in the 1980s. It also drew on Newson's observations of differences in the profiles of children with PDA compared to more 'prototypical' autism; and her observation that recommended management for autism, such as routine and repetition, was unhelpful in those with PDA. Instead, strategies that were not rule-based, but instead used novelty to engage the child and distract from demands, were more successful.[1]

To contrast the decision to view PDA as an ASD in 2011, if one considers the debates surrounding PDA in the literature in its first 5 articles published before 2010.

Newson's first article in 1983 viewed PDA to not be autism. This was her consistent view throughout her research, including in 2003.
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes



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 useful 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.

It is helpful to conceptualise the pervasive developmental disorders as **clusters of symptoms** which have a tendency to occur together, ie to form **syndromes**. Classical autism and Asperger syndrome form two closely related clusters; PDA is another. There are inevitably family links between them: for instance, both show obsessive behaviour or preoccupations, although of different kinds. Preliminary enquiry also suggests genetic links (eg autistic sibs

1

This is an addition to other acts & comments of Newson, like never basing PDA on the Triad of Impairment & excluding those who had autism features from her database.

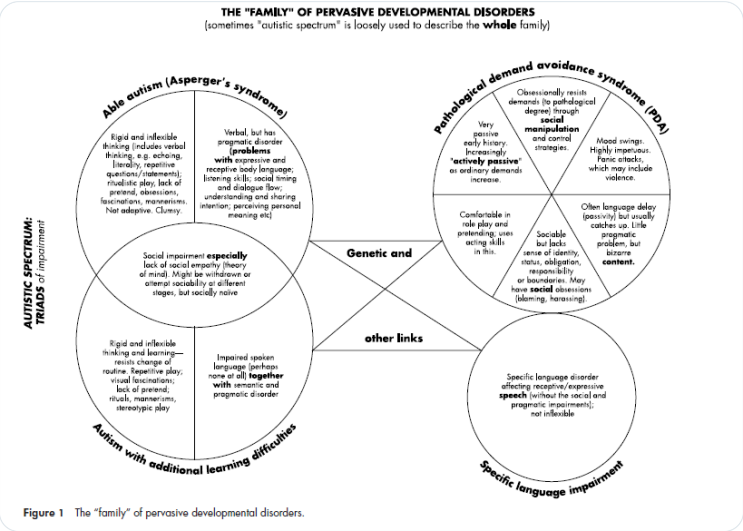


Figure 1 The "family" of pervasive developmental disorders.

"A few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded." (Newson et al, 2003, p596).

"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).

Bear in mind that both Garralda, and Wing & Gould comment on Newson's research saying PDA has no specific features & it remains to be seen if PDA is a distinct Disorder.

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…

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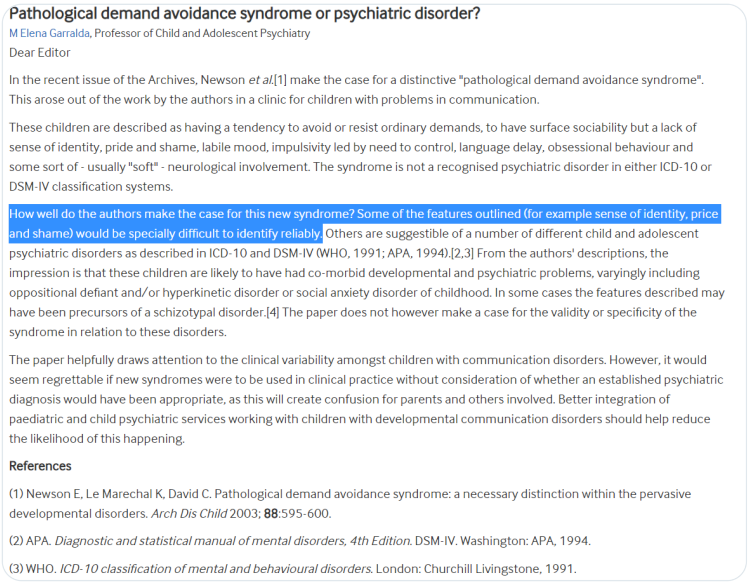


Pathological demand avoidance syndrome or psychiatric disorder?

M Elena Garralda, Professor of Child and Adolescent Psychiatry

Dear Editor

In the recent issue of the Archives, Newson *et al.*[1] make the case for a distinctive "pathological demand avoidance syndrome". This arose out of the work by the authors in a clinic for children with problems in communication.

These children are described as having a tendency to avoid or resist ordinary demands, to have surface sociability but a lack of sense of identity, pride and shame, labile mood, impulsivity led by need to control, language delay, obsessional behaviour and some sort of - usually "soft" - neurological involvement. The syndrome is not a recognised psychiatric disorder in either ICD-10 or DSM-IV classification systems.

How well do the authors make the case for this new syndrome? Some of the features outlined (for example sense of identity, price and shame) would be specially difficult to identify reliably. Others are suggestible of a number of different child and adolescent psychiatric disorders as described in ICD-10 and DSM-IV (WHO, 1991; APA, 1994).[2,3] From the authors' descriptions, the impression is that these children are likely to have had co-morbid developmental and psychiatric problems, varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood. In some cases the features described may have been precursors of a schizotypal disorder.[4] The paper does not however make a case for the validity or specificity of the syndrome in relation to these disorders.

The paper helpfully draws attention to the clinical variability amongst children with communication disorders. However, it would seem regrettable if new syndromes were to be used in clinical practice without consideration of whether an established psychiatric diagnosis would have been appropriate, as this will create confusion for parents and others involved. Better integration of paediatric and child psychiatric services working with children with developmental communication disorders should help reduce the likelihood of this happening.

References

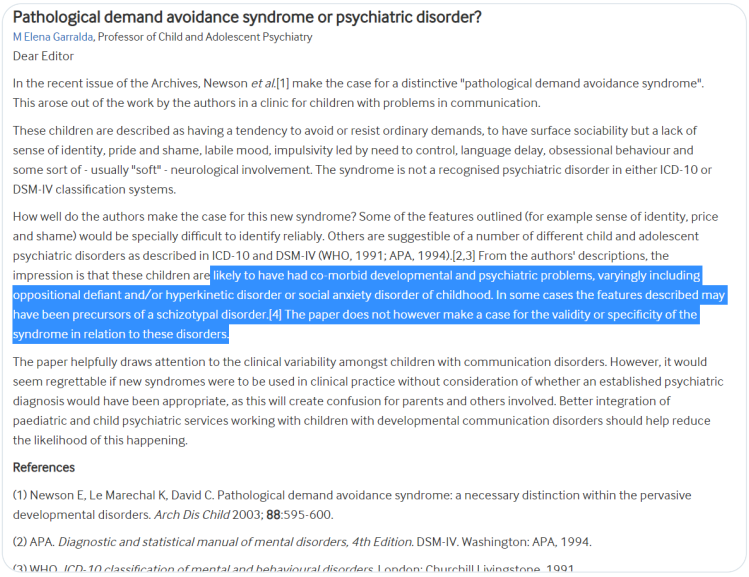
(1) Newson E, Le Marechal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch Dis Child* 2003; **88**:595-600.

(2) APA. *Diagnostic and statistical manual of mental disorders, 4th Edition.* DSM-IV. Washington: APA, 1994.

(3) WHO. *ICD-10 classification of mental and behavioural disorders.* London: Churchill Livingstone, 1991.

Garralda specifically suggests possible presence of:
"likely to have had co-morbid developmental and psychiatric problems,...

"...varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood. In some cases the features described may have been precursors of a schizotypal disorder."



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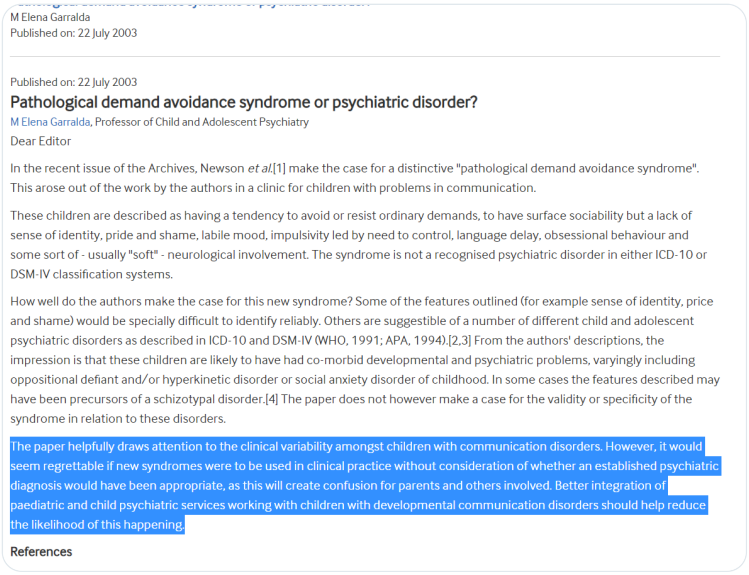
(2) APA. *Diagnostic and statistical manual of mental disorders, 4th Edition.* DSM-IV. Washington: APA, 1994.

(3) WHO. *ICD-10 classification of mental and behavioural disorders.* London: Churchill Livingstone, 1991.

Garralda also challenges the clinical use of PDA.



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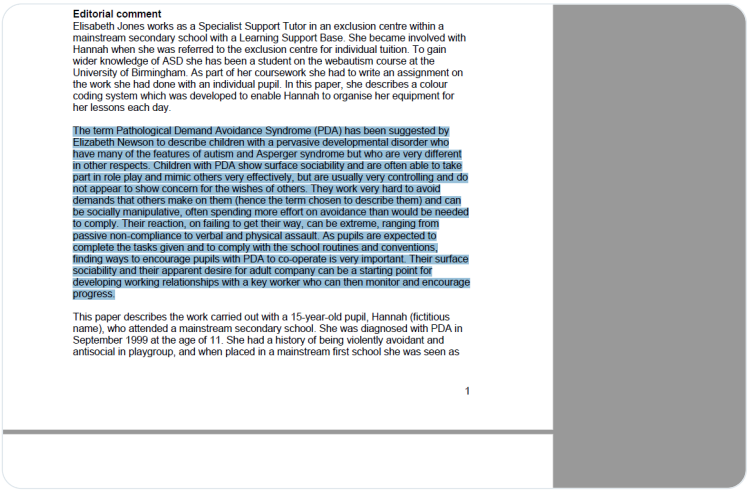
References

Note this paragraph from Jones (2005) case study, it describes the differences of PDA to Autism & Asperger's, that PDA is a Pervasive Developmental Disorder.



Editorial comment

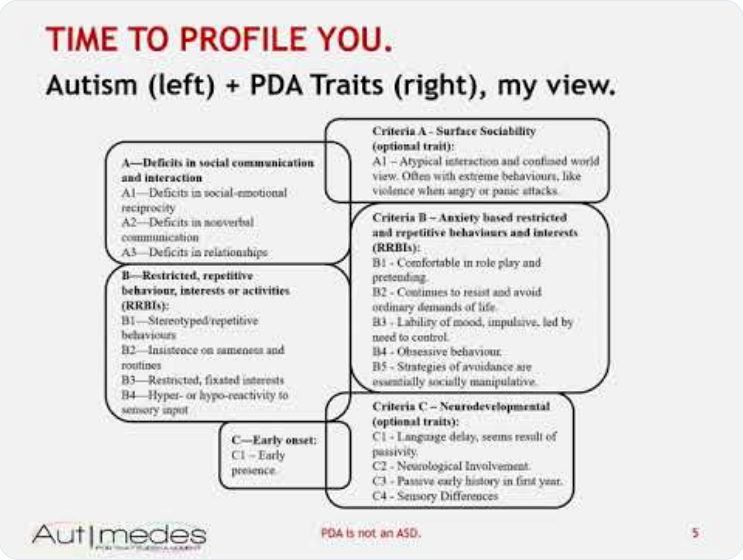
Elisabeth Jones works as a Specialist Support Tutor in an exclusion centre within a mainstream secondary school with a Learning Support Base. She became involved with Hannah when she was referred to the exclusion centre for individual tuition. To gain wider knowledge of ASD she has been a student on the webautism course at the University of Birmingham. As part of her coursework she had to write an assignment on the work she had done with an individual pupil. In this paper, she describes a colour coding system which was developed to enable Hannah to organise her equipment for her lessons each day.

The term Pathological Demand Avoidance Syndrome (PDA) has been suggested by Elizabeth Newson to describe children with a pervasive developmental disorder who have many of the features of autism and Asperger syndrome but who are very different in other respects. Children with PDA show surface sociability and are often able to take part in role play and mimic others very effectively, but are usually very controlling and do not appear to show concern for the wishes of others. They work very hard to avoid demands that others make on them (hence the term chosen to describe them) and can be socially manipulative, often spending more effort on avoidance than would be needed to comply. Their reaction, on failing to get their way, can be extreme, ranging from passive non-compliance to verbal and physical assault. As pupils are expected to complete the tasks given and to comply with the school routines and conventions, finding ways to encourage pupils with PDA to co-operate is very important. Their surface sociability and their apparent desire for adult company can be a starting point for developing working relationships with a key worker who can then monitor and encourage progress.

This paper describes the work carried out with a 15-year-old pupil, Hannah (fictitious name), who attended a mainstream secondary school. She was diagnosed with PDA in September 1999 at the age of 11. She had a history of being violently avoidant and antisocial in playgroup, and when placed in a mainstream first school she was seen as

1

I would point out, that if compares Newson's Pervasive Developmental Disorders Diagnostic grouping to accepted understandings of the diagnostic grouping, they are NOT the same.



https://www.youtube.com/embed/GSIdMzDMC-w

Editorial of Christie (2007) states there is debate if PDA is an form of attachment disorder or personality disorder. Editor also mentions debate if PDA is a separate syndrome or not.
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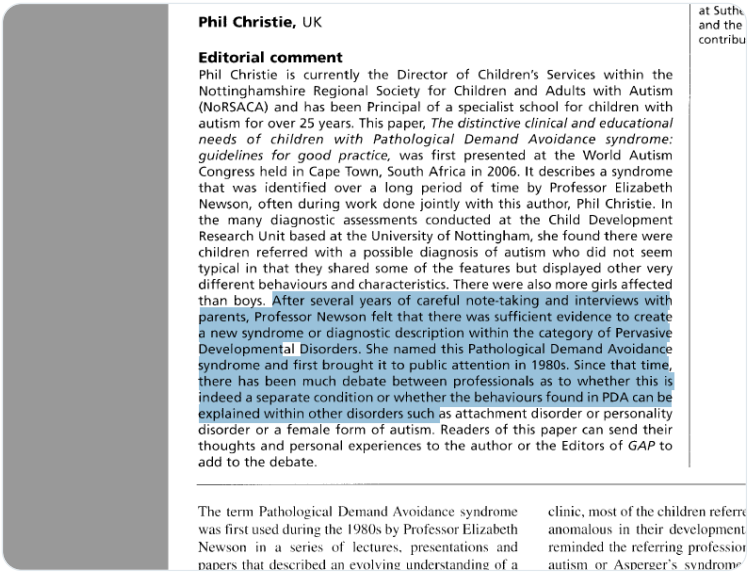


Phil Christie, UK

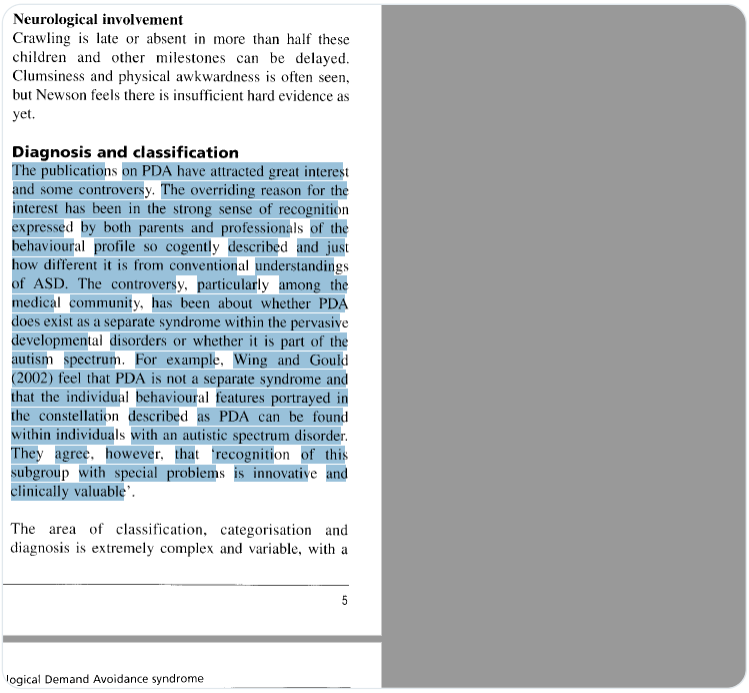
Editorial comment

Phil Christie is currently the Director of Children's Services within the Nottinghamshire Regional Society for Children and Adults with Autism (NoRSACA) and has been Principal of a specialist school for children with autism for over 25 years. This paper, *The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice,* was first presented at the World Autism Congress held in Cape Town, South Africa in 2006. It describes a syndrome that was identified over a long period of time by Professor Elizabeth Newson, often during work done jointly with this author, Phil Christie. In the many diagnostic assessments conducted at the Child Development Research Unit based at the University of Nottingham, she found there were children referred with a possible diagnosis of autism who did not seem typical in that they shared some of the features but displayed other very different behaviours and characteristics. There were also more girls affected than boys. After several years of careful note-taking and interviews with parents, Professor Newson felt that there was sufficient evidence to create a new syndrome or diagnostic description within the category of Pervasive Developmental Disorders. She named this Pathological Demand Avoidance syndrome and first brought it to public attention in 1980s. Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism. Readers of this paper can send their thoughts and personal experiences to the author or the Editors of *GAP* to add to the debate.

The term Pathological Demand Avoidance syndrome was first used during the 1980s by Professor Elizabeth Newson in a series of lectures, presentations and papers that described an evolving understanding of a

clinic, most of the children referr
anomalous in their development
reminded the referring professio
autism or Asperger's syndrom

Christie does discuss some of the controversies around PDA, including Wing & Gould's comments that PDA is not a separate syndrome & its features can be seen in the autistic population.



Neurological involvement

Crawling is late or absent in more than half these children and other milestones can be delayed. Clumsiness and physical awkwardness is often seen, but Newson feels there is insufficient hard evidence as yet.

Diagnosis and classification

The publications on PDA have attracted great interest and some controversy. The overriding reason for the interest has been in the strong sense of recognition expressed by both parents and professionals of the behavioural profile so cogently described and just how different it is from conventional understandings of ASD. The controversy, particularly among the medical community, has been about whether PDA does exist as a separate syndrome within the pervasive developmental disorders or whether it is part of the autism spectrum. For example, Wing and Gould (2002) feel that PDA is not a separate syndrome and that the individual behavioural features portrayed in the constellation described as PDA can be found within individuals with an autistic spectrum disorder. They agree, however, that 'recognition of this subgroup with special problems is innovative and clinically valuable'.

The area of classification, categorisation and diagnosis is extremely complex and variable, with a

5

logical Demand Avoidance syndrome

Christie also mentions "'recognition of this subgroup with special problems is innovative and clinically valuable'."

Garralda (2003) made similar comment:
"The paper helpfully draws attention to the clinical variability amongst children with communication disorders."

Crucially, Christie acknowledges PDA does not conform to autism understandings"
"behavioural profile so cogently described and just
how different it is from conventional understandings
of ASD." p5.

Although Christie, is incorrect on Newson's accounts being cogent. Like, how do deficits in social identity/ pride/ shame cause panic attacks? Also many of the features in "Surface Sociability" trait are RRBIs, like panic attacks.

Worth mentioning in Christie et al (2011) it does mention some features of PDA make it problematic fitting into autism, like manipulative social demand avoidance behaviours. p12.

Suppose we go into 2011 a bit. Gould, with Ashton-Smith definitively views PDA to be an autism subgroup, & questions if it is a female form of autism.

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 an accompanying additional diagnosis or, in some cases, misdiagnosis. Kopp et al (2010) have developed a revised version of the autism screening tool, the Autism Spectrum Screening Questionnaire (ASSQ) which is aimed at identifying girls with previously undiagnosed autism. The revised ASSQ consists of certain items which aim to separate girls from boys on the autism spectrum, examples are, '*interacts mostly with younger children*', '*has a different voice or speech*' and '*avoids demands*'. What appears to us as most significant is the high level of demand avoidance in the girls compared with the boys. There is a subgroup within the autism spectrum referred to as Pathological Demand Avoidance (PDA). The individuals are described as more likely to be female, to resist demands obsessively, to be socially manipulative, to have normal eye contact, to show excessive lability of mood and to show social mimicry and role play (Christie et al, 2011; Newson et al, 2003). Could it be that the PDA pattern of behaviour is the female presentation of autism or are there other female presentations of autism within the spectrum? Girls are more likely to refuse demands passively than boys, who do so actively and are seen as defiant, rather than avoidant. The core features of Asperger syndrome in the current international classification systems should be revised to take into account the female presentation of the disorder.

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"Dr Gould pointed out that features of PDA can be found in children and young people across the autism spectrum, but where they cluster they represent the PDA profile" p187.

Matching assertions in Gould & Ashton-Smith (2011), & partly comments made with Wing

Wing also comments on PDA in on page 30 in her 2002 book, that features of PDA can be seen throughout entire autistic population & so remains to be seen if PDA is a Disorder (syndrome).

Wing previously briefly describes Newson's 1983 work, in a paragraph of others attempting to create a syndrome and goes onto to comment ALL clinical accounts described in previous paragraph are not specific to those "syndromes". Frith 1991, pp 106-107).

1970; O'Gorman, 1970; Creak, 1961, 1964).

Other authors attempted to identify specific syndromes. De Sanctis (1906, 1908) applied the terms 'dementia precocissima' and 'dementia precocissima catatonica' to conditions characterised by social and cognitive deterioration and stereotyped behaviour following a varying period of normal development. Heller (translated by Hulse, 1954) described similar conditions for which the term 'dementia infantilis' was used. Some of the children these authors wrote about died within a few years following the regression, but, in others, their condition stabilised at a low level of function. In these, the clinical pictures were strongly reminiscent of severe autism associated with severe retardation. Earl (1934) wrote a vivid account of a group of adolescents and adults who functioned as severely or profoundly mentally retarded with no speech or self-care but with some motor skills, who were indifferent to people and absorbed in repetitive, stereotyped movements of fingers, limbs and body. He referred to this clinical picture as the 'primitive catatonic psychosis of idiocy'. Mahler (1952) described a group of children with abnormal social relationships, especially 'empty clinging' to adults, echolalia and repetitive speech on bizarre themes, to which she gave the name 'symbiotic psychosis'. Newson (1983) wrote about children with what she called the 'demand avoidance syndrome' with some features reminiscent of Mahler's group. They had repetitive speech and play, accurately mimicking people, inappropriate social interaction and a marked tendency to react to any demand from others by tactics of avoidance, which appeared to be manipulative, although in fact they lacked real social skills.

The patterns of impairment described above tend to be associated with moderate, severe or profound mental retardation. Social and communication problems with odd behaviour can also be found among those with borderline or normal intelligence. Weintraub and Mesulam (1983) described adults with a clinical picture similar to that of Asperger's syndrome, although they did not mention circumscribed interests. They referred to this picture as 'developmental learning disabilities of the right hemisphere'. Rourke *et al.* (1986) wrote of 'central processing difficulties' in a group of children with abnormalities of social behaviour, repetitive speech and specific learning problems affecting arithmetic and visuo-spatial skills. Sparrow *et al.* (1986) reported follow-up findings on 'atypical' children who had odd social interaction, were awkward and clumsy in motor skills and, while not typically autistic nor fitting all aspects of Asperger's syndrome, nevertheless had features of both conditions. The same or similar clinical pictures can be found among children and adults given different psychiatric diagnoses. As already discussed, 'schizoid' and 'schizotypal' personality disorders are relevant examples.

The literature on language disorders includes accounts of children whose speech and behaviour is remarkably like that found in children with autism or Asperger's syndrome. Blank, Gessner and Esposito (1979) considered this type of speech problem to be 'a marked discrepancy between the conceptual and the social-interpersonal aspects of verbal behaviour' which is precisely the problem identified by Asperger in his group of children. Rapin and Allen (1983) coined the term 'semantic–pragmatic disorder' for a problem affecting language and behaviour, the features of which closely resemble – in fact, are virtually identical with – Asperger's syndrome. More recently, Rapin (1987) has modified her views. She now suggests that autism and semantic–pragmatic disorder are not mutually exclusive diagnoses, but are terms describing impairments of different aspects of psychological function (sociability and communication respectively) and can and do occur together.

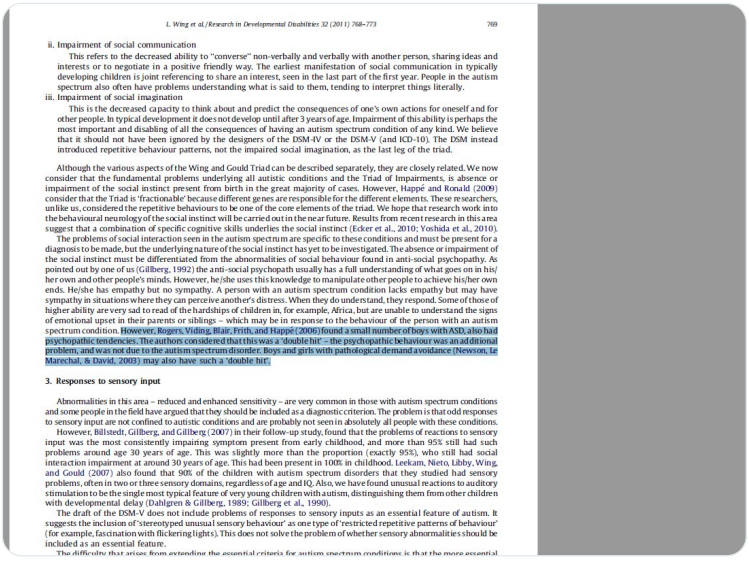
Creating order out of chaos

Also worth mentioning in 2011, Wing, Gould & Gillberg question if PDA may not be caused by autism (p769).

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?via%3Dihub



L. Wing et al. / Research in Developmental Disabilities 32 (2011) 768–773 769

ii. Impairment of social communication

This refers to the decreased ability to "converse" non-verbally and verbally with another person, sharing ideas and interests or to negotiate in a positive friendly way. The earliest manifestation of social communication in typically developing children is joint referencing to share an interest, seen in the last part of the first year. People in the autism spectrum also often have problems understanding what is said to them, tending to interpret things literally.

iii. Impairment of social imagination

This is the decreased capacity to think about and predict the consequences of one's own actions for oneself and for other people. In typical development it does not develop until after 3 years of age. Impairment of this ability is perhaps the most important and disabling of all the consequences of having an autism spectrum condition of any kind. We believe that it should not have been ignored by the designers of the DSM-IV or the DSM-V (and ICD-10). The DSM instead introduced repetitive behaviour patterns, not the impaired social imagination, as the last leg of the triad.

Although the various aspects of the Wing and Gould Triad can be described separately, they are closely related. We now consider that the fundamental problems underlying all autistic conditions and the Triad of Impairments, is absence or impairment of the social instinct present from birth in the great majority of cases. However, Happé and Ronald (2009) consider that the Triad is 'fractionable' because different genes are responsible for the different elements. These researchers, unlike us, considered the repetitive behaviours to be one of the core elements of the triad. We hope that research work into the behavioural neurology of the social instinct will be carried out in the near future. Results from recent research in this area suggest that a combination of specific cognitive skills underlies the social instinct (Ecker et al., 2010; Yoshida et al., 2010).

The problems of social interaction seen in the autism spectrum are specific to these conditions and must be present for a diagnosis to be made, but the underlying nature of the social instinct has yet to be investigated. The absence or impairment of the social instinct must be differentiated from the abnormalities of social behaviour found in anti-social psychopathy. As pointed out by one of us (Gillberg, 1992) the anti-social psychopath usually has a full understanding of what goes on in his/her own and other people's minds. However, he/she uses this knowledge to manipulate other people to achieve his/her own ends. He/she has empathy but no sympathy. A person with an autism spectrum condition lacks empathy but may have sympathy in situations where they can perceive another's distress. When they do understand, they respond. Some of those of higher ability are very sad to read of the hardships of children in, for example, Africa, but are unable to understand the signs of emotional upset in their parents or siblings – which may be in response to the behaviour of the person with an autism spectrum condition. However, Rogers, Viding, Blair, Frith, and Happé (2006) found a small number of boys with ASD, also had psychopathic tendencies. The authors considered that this was a 'double hit' – the psychopathic behaviour was an additional problem, and was not due to the autism spectrum disorder. Boys and girls with pathological demand avoidance (Newson, Le Marechal, & David, 2003) may also have such a 'double hit'.

3. Responses to sensory input

Abnormalities in this area – reduced and enhanced sensitivity – are very common in those with autism spectrum conditions and some people in the field have argued that they should be included as a diagnostic criterion. The problem is that odd responses to sensory input are not confined to autistic conditions and are probably not seen in absolutely all people with these conditions.

However, Billstedt, Gillberg, and Gillberg (2007) in their follow-up study, found that the problems of reactions to sensory input was the most consistently impairing symptom present from early childhood, and more than 95% still had such problems around age 30 years of age. This was slightly more than the proportion (exactly 95%), who still had social interaction impairment at around 30 years of age. This had been present in 100% in childhood. Leekam, Nieto, Libby, Wing, and Gould (2007) also found that 90% of the children with autism spectrum disorders that they studied had sensory problems, often in two or three sensory domains, regardless of age and IQ. Also, we have found unusual reactions to auditory stimulation to be the single most typical feature of very young children with autism, distinguishing them from other children with developmental delay (Dahlgren & Gillberg, 1989; Gillberg et al., 1990).

The draft of the DSM-V does not include problems of responses to sensory inputs as an essential feature of autism. It suggests the inclusion of 'stereotyped unusual sensory behaviour' as one type of 'restricted repetitive patterns of behaviour' (for example, fascination with flickering lights). This does not solve the problem of whether sensory abnormalities should be included as an essential feature.

The difficulty that arises from extending the essential criteria for autism spectrum conditions is that the more essential

Final point before concluding. Newson's sample contained non-autistic persons in, as not all of them would have received an accepted autism diagnosis, this is reflected in comments in Newson et al (2003) & Christie (2007).

More recently it is accepted that some of Newson's cohort would not meet criteria for a DSM-5 autism diagnosis.

"most of the children referred were complex and anomalous in their developmental profile and many reminded the referring professionals of children with autism or Asperger's syndrome." (Christie, 2007, p7).

"We, like others, were diagnosing these children as having atypical autism (stating in what way it was atypical);" (Newson et al, 2003, p595).

That not all of referrals for PDA diagnosis would have received a diagnosis of Asperger's/ Autistic Disorder is also mentioned on page 11 of Christie et al (2011).

Must also be said Christie in 2007, then with others in 2011 argues PDA should be viewed as an ASD & a prolongued debate on what PDA is a distraction from diagnosing PDA to help persons.

The reasons why I am covering debates over what PDA is in 2011 and earlier to set

how "odd" it is that anyone would pursue a research agenda that views PDA as an ASD from that contested position.

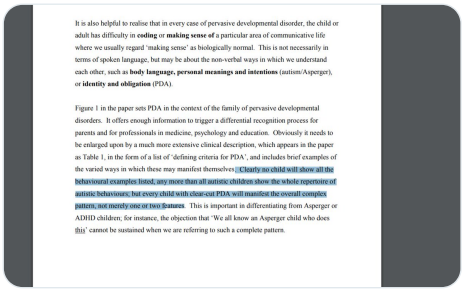
First point, is neither Christie, or Gould in 2011 can say definitively PDA is autism. Newson's research, 2 case studies & their clinical opinion is NOT sufficient to view PDA as a form of autism.

Newson's research only really shows that PDA is different to autism, but she seems to take steps to ensure that would happen, like not basing PDA on triad of impairment & excluding those with autism features.

Not to mention that Newson's cohort has non-autistic persons in it & she argued they ALL required PDA educational strategies, praise/ reward/ punishments do not work with PDA.

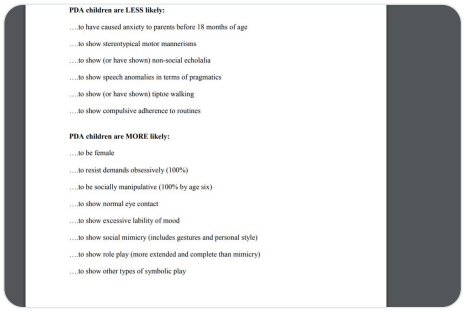
Moreover, later literature acknowledges there is no consensus over what PDA looks like, or how to assess for it. So no-one can be sure definitively what the features are required for a PDA diagnosis.

Yet, Newson does detail her clinical threshold.
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes



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 disorders. It offers enough information to trigger a differential recognition process for parents and for professionals in medicine, psychology and education. Obviously it needs to be enlarged upon by a much more extensive clinical description, which appears in the paper as Table 1, in the form of a list of 'defining criteria for PDA', and includes brief examples of the varied ways in which these may manifest themselves. Clearly no child will show all the behavioural examples listed, any more than all autistic children show the whole repertoire of autistic behaviours; but every child with clear-cut PDA will manifest the overall complex pattern, not merely one or two features. This is important in differentiating from Asperger or ADHD children, for instance, the objection that 'We all know an Asperger child who does this' cannot be sustained when we are referring to such a complete pattern.



PDA children are LESS likely:

- ….to have caused anxiety to parents before 18 months of age
- ….to show stereotypical motor mannerisms
- ….to show (or have shown) non-social echolalia
- ….to show speech anomalies in terms of pragmatics
- ….to show (or have shown) tiptoe walking
- ….to show compulsive adherence to routines

PDA children are MORE likely:

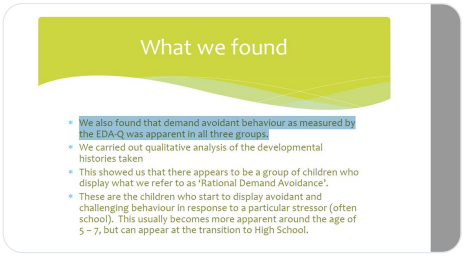
- ….to be female
- ….to resist demands obsessively (100%)
- ….to be socially manipulative (100% by age six)
- ….to show normal eye contact
- ….to show excessive lability of mood
- ….to show social mimicry (includes gestures and personal style)
- ….to show role play (more extended and complete than mimicry)
- ….to show other types of symbolic play

Despite Newson detailing her diagnostic threshold, no-one seems to have attempted to replicate it. Considering the acknowledged difficulties in comparing PDA diagnoses due to lack of agreed diagnostic criteria & validated tools…

… It is likely from the perspective of those making critique PDA might be a form of Personality Disorder/ Attachment etc, that their views are equally valid as Christie's/ Gould's etc.

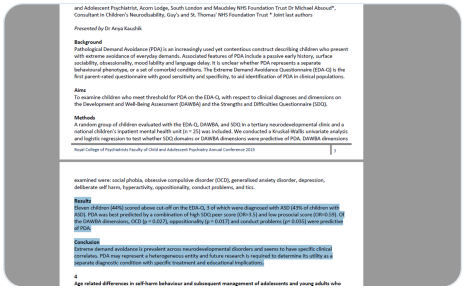
Likewise, with Garrald's comments about PDA might contain features of ADHD seems to be valid, see Green et al (2018) & Egan et al (2020).

We also know that the EDA-Q, which Christie was involved with designing, detects PDA in non-autistic persons, including those with attachment issues/ aversive childhoods.



What we found

- We also found that demand avoidant behaviour as measured by the EDA-Q was apparent in all three groups.
- We carried out qualitative analysis of the developmental histories taken
- This showed us that there appears to be a group of children who display what we refer to as 'Rational Demand Avoidance'.
- These are the children who start to display avoidant and challenging behaviour in response to a particular stressor (often school). This usually becomes more apparent around the age of 5 – 7, but can appear at the transition to High School.



and Adolescent Psychiatrist, Acorn Lodge, South London and Maudsley NHS Foundation Trust Dr Michael Absoud[1], Consultant in Children's Neurodisability, Guy's and St. Thomas' NHS Foundation Trust * Joint last authors

Presented by Dr Anya Kaushik

Background
Pathological Demand Avoidance (PDA) is an increasingly used yet contentious construct describing children who present with extreme avoidance of everyday demands. Associated features of PDA include a passive early history, surface sociability, obsessionality, mood lability and language delay. It is unclear whether PDA represents a separate behavioural phenotype, or a set of comorbid conditions. The Extreme Demand Avoidance Questionnaire (EDA-Q) is the first parent-rated questionnaire with good sensitivity and specificity, to aid identification of PDA in clinical populations.

Aims
To examine children who meet threshold for PDA on the EDA-Q, with respect to clinical diagnoses and dimensions on the Development and Well-Being Assessment (DAWBA) and the Strengths and Difficulties Questionnaire (SDQ).

Methods
A random group of children evaluated with the EDA-Q, DAWBA, and SDQ in a tertiary neurodevelopmental clinic and a national children's inpatient mental health unit (n = 25) was included. We conducted a Kruskal-Wallis univariate analysis and logistic regression to test whether SDQ domains or DAWBA dimensions were predictive of PDA. DAWBA dimensions

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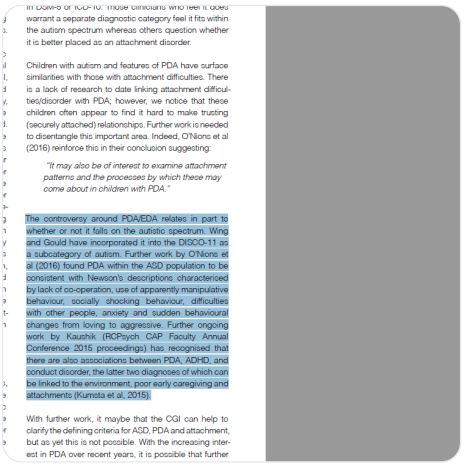
examined were: social phobia, obsessive compulsive disorder (OCD), generalised anxiety disorder, depression, deliberate self harm, hyperactivity, oppositionality, conduct problems, and tics.

Results
Eleven children (44%) scored above cut-off on the EDA-Q, 3 of which were diagnosed with ASD (43% of children with ASD). PDA was best predicted by a combination of high SDQ peer score (OR=3.1) and low prosocial score (OR=0.59). Of the DAWBA dimensions, OCD (p = 0.027), oppositionality (p = 0.017) and conduct problems (p= 0.035) were predictive of PDA.

Conclusions
Extreme demand avoidance is prevalent across neurodevelopmental disorders and seems to have specific clinical correlates. PDA may represent a heterogeneous entity and future research is required to determine its utility as a separate diagnostic condition with specific treatment and educational implications.

4
Age related differences in self-harm behaviour and subsequent management of adolescents and young adults who



warrant a separate diagnostic category feel it fits within the autism spectrum whereas others question whether it is better placed as an attachment disorder.

Children with autism and features of PDA have surface similarities with those with attachment difficulties. There is a lack of research to date linking attachment difficulties/disorder with PDA; however, we notice that these children often appear to find it hard to make trusting (securely attached) relationships. Further work is needed to disentangle this important area. Indeed, O'Nions et al (2016) reinforce this in their conclusion suggesting:

> *"It may also be of interest to examine attachment patterns and the processes by which these may come about in children with PDA."*

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 can be linked to the environment, poor early caregiving and attachments (Kumsta et al, 2015).

With further work, it maybe that the CGI can help to clarify the defining criteria for ASD, PDA and attachment, but as yet this is not possible. With the increasing interest in PDA over recent years, it is possible that further

Links to two of the other screenshots. Kaushik et al (2015) is not available anymore publicly from my knowledge, so I tend to reference in Flackhill et al (2017).
https://www.ingentaconnect.com/contentone/bild/gap/2017/00000018/00000001/art00009
&

"High SDQ conduct and hyperactivity scores plus a clinical diagnosis of anxiety were highly predictive of scores above the pathological demand avoidance threshold on the EDA-Q" (Green et al, 2018, p461-462).

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…

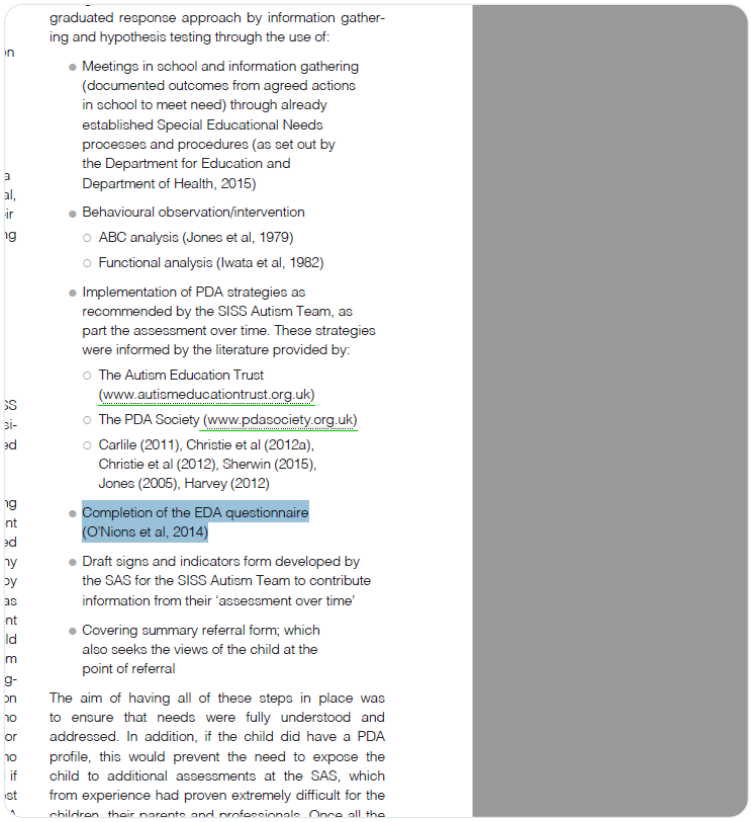
https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(18)30044-0/fulltext

"This research indicates that, for community adult populations, self-reported individual differences in ADHD, emotional instability, and antagonism appear to better predict PDA than ASD."

Individual differences, ADHD, adult pathological demand avoidance, a…
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?via%3Dihub

The EDA-Q is used as part of the assessment process for many CYP with PDA. For instance, it is part of the assessment pathway of Summerhill & Collett (2018, p29). https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00004



graduated response approach by information gathering and hypothesis testing through the use of:

- Meetings in school and information gathering (documented outcomes from agreed actions in school to meet need) through already established Special Educational Needs processes and procedures (as set out by the Department for Education and Department of Health, 2015)
- Behavioural observation/intervention
  - ABC analysis (Jones et al, 1979)
  - Functional analysis (Iwata et al, 1982)
- Implementation of PDA strategies as recommended by the SISS Autism Team, as part the assessment over time. These strategies were informed by the literature provided by:
  - The Autism Education Trust (www.autismeducationtrust.org.uk)
  - The PDA Society (www.pdasociety.org.uk)
  - Carlile (2011), Christie et al (2012a), Christie et al (2012), Sherwin (2015), Jones (2005), Harvey (2012)
- Completion of the EDA questionnaire (O'Nions et al, 2014)
- Draft signs and indicators form developed by the SAS for the SISS Autism Team to contribute information from their 'assessment over time'
- Covering summary referral form; which also seeks the views of the child at the point of referral

The aim of having all of these steps in place was to ensure that needs were fully understood and addressed. In addition, if the child did have a PDA profile, this would prevent the need to expose the child to additional assessments at the SAS, which from experience had proven extremely difficult for the children, their parents and professionals. Once all the

The point it is, it is hard to dismiss the critique of Garralda when it is being supported by research evidence. The tool which detects those features (while designed to detect PDA in autism), is widely being used in clinical practice.

Which highlights the absurdity of blindly assuming PDA is an ASD, as has been done by some since 2011.

There is NO significant justification for adopting that position 10 years ago.

To sum up PDA debate 10 years ago:
- PDA definitively is an ASD.
- PDA is not ASD (Newson's view).
- PDA is not Disorder (Syndrome).
- PDA does not conform to accepted autism understandings.
- PDA is not clinically useful.
- PDA is clinically useful.

- PDA may be a form of Attachment Disorder.
- PDA may be a form of Personality Disorder.
- PDA may NOT be caused by autism.
- PDA might contain features of non-autism constructs, like ADHD/ ODD/ certain anxiety disorders.

- CYP with PDA may have precursors for Sychozotypal Personality.
- Newson's cohort included non-autistic persons. All her research really does is show PDA is different to Asperger's & Autistic Disorder.

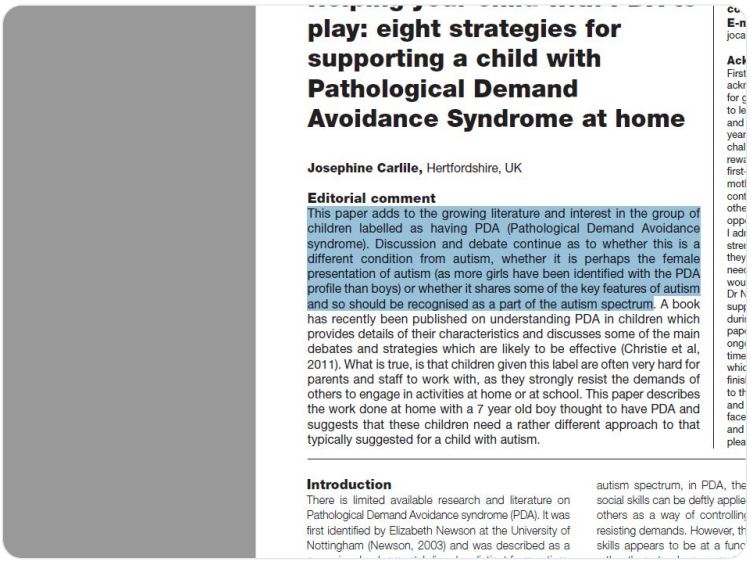
Despite this, some people have blindly assumed PDA is an ASD & pursued an

evidence base to support that outlook. To the point now that interest in UK for PDA does NOT reflect its evidence base...

That is a damning for those involved in pursuing this agenda and outlook.

It is damning as they should not be favouring the outlook PDA is an ASD to the extent they have done, they should be taking a balanced approach to PDA, that does not predispose PDA to be an ASD.

I am in process of drafting a tool to screen PDA literature for balance & figured I should check rest of extant literature in 2011, only other article is Carlile 2011. See Editorial.
https://www.ingentaconnect.com/contentone/bild/gap/2011/00000012/00000002/art00007



play: eight strategies for supporting a child with Pathological Demand Avoidance Syndrome at home

Josephine Carlile, Hertfordshire, UK

Editorial comment

This paper adds to the growing literature and interest in the group of children labelled as having PDA (Pathological Demand Avoidance syndrome). Discussion and debate continue as to whether this is a different condition from autism, whether it is perhaps the female presentation of autism (as more girls have been identified with the PDA profile than boys) or whether it shares some of the key features of autism and so should be recognised as a part of the autism spectrum. A book has recently been published on understanding PDA in children which provides details of their characteristics and discusses some of the main debates and strategies which are likely to be effective (Christie et al, 2011). What is true, is that children given this label are often very hard for parents and staff to work with, as they strongly resist the demands of others to engage in activities at home or at school. This paper describes the work done at home with a 7 year old boy thought to have PDA and suggests that these children need a rather different approach to that typically suggested for a child with autism.

Introduction

There is limited available research and literature on Pathological Demand Avoidance syndrome (PDA). It was first identified by Elizabeth Newson at the University of Nottingham (Newson, 2003) and was described as a

For the record, from my knowledge only other article was Carlile (2011) case study.

"Discussion and debate continue as to whether this is a different condition from autism, Whether it is perhaps the female presentation of autism (as more girls have been identified with the PDA profile than boys)...

... or whether it shares some of the key features of autism and so should be recognised as a part of the autism spectrum." p51

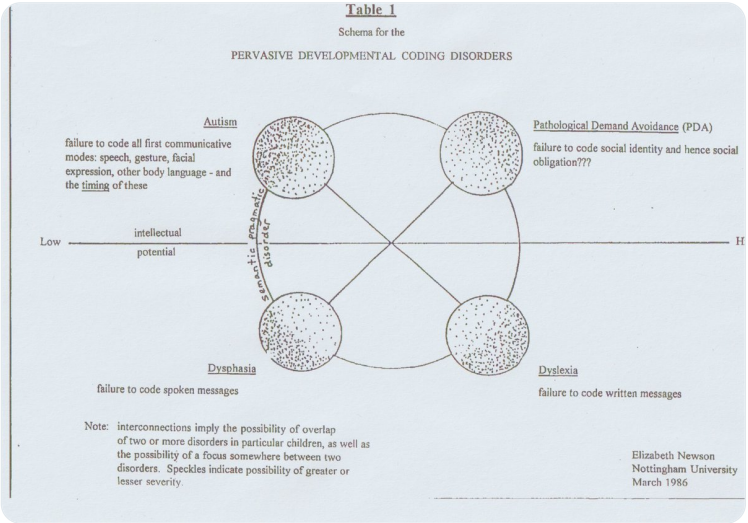
Also page 51 "There is limited available research and literature on Pathological Demand Avoidance syndrome (PDA)."

This establishes is that it premature (putting it mildly) to view PDA as an ASD in 2011. Note the part about debates if PDA is autism or not.

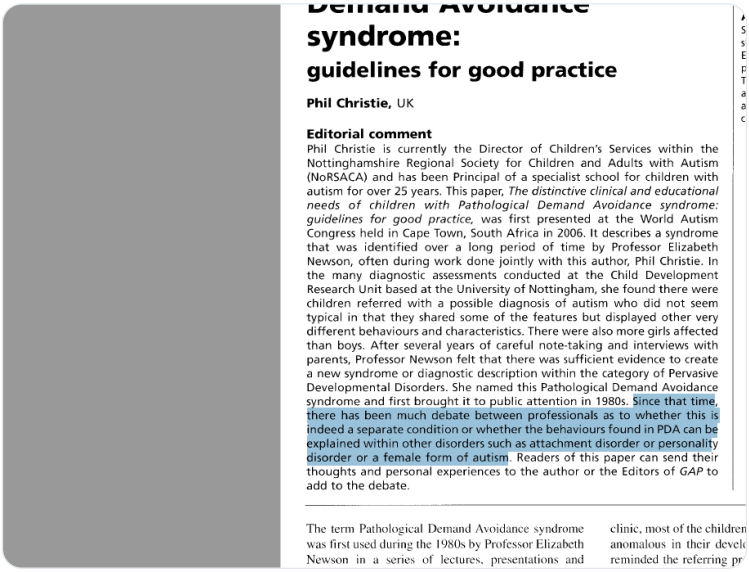
I am adding this to it, as it as I am basing the items of key points that were extant in the PDA literature in 2011. Which seems a reasonable place to base items on, considering it is from this point it appears an agenda to view PDA as an ASD starts.

Other draft items include PDA being distinct from autism.
PDA has limited or no ToM deficits.
PDA was originally a Pervasive Developmental Coding Disorder.

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



That PDA might be a form of female autism, that is mentioned above, and I also think it is in the editorial of Christie (2007).



syndrome:

guidelines for good practice

Phil Christie, UK

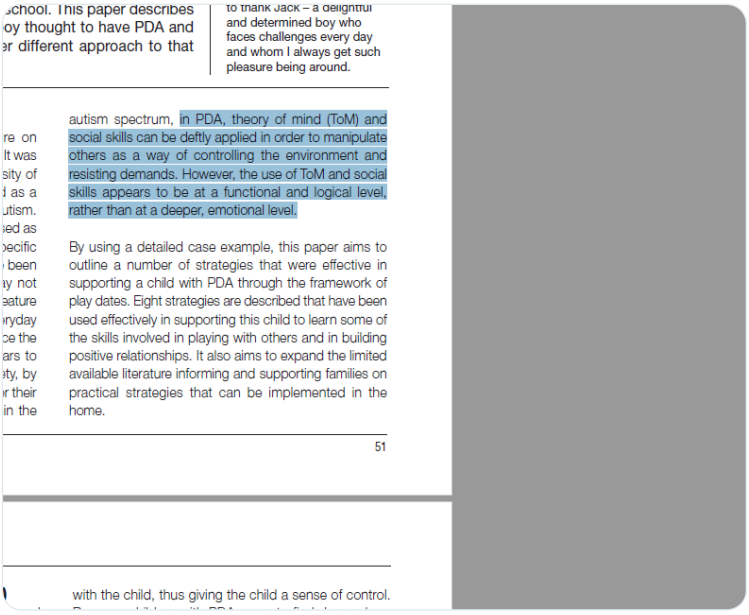
Editorial comment

Phil Christie is currently the Director of Children's Services within the Nottinghamshire Regional Society for Children and Adults with Autism (NoRSACA) and has been Principal of a specialist school for children with autism for over 25 years. This paper, *The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice,* was first presented at the World Autism Congress held in Cape Town, South Africa in 2006. It describes a syndrome that was identified over a long period of time by Professor Elizabeth Newson, often during work done jointly with this author, Phil Christie. In the many diagnostic assessments conducted at the Child Development Research Unit based at the University of Nottingham, she found there were children referred with a possible diagnosis of autism who did not seem typical in that they shared some of the features but displayed other very different behaviours and characteristics. There were also more girls affected than boys. After several years of careful note-taking and interviews with parents, Professor Newson felt that there was sufficient evidence to create a new syndrome or diagnostic description within the category of Pervasive Developmental Disorders. She named this Pathological Demand Avoidance syndrome and first brought it to public attention in 1980s. Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism. Readers of this paper can send their thoughts and personal experiences to the author or the Editors of *GAP* to add to the debate.

The term Pathological Demand Avoidance syndrome was first used during the 1980s by Professor Elizabeth Newson in a series of lectures, presentations and

clinic, most of the children anomalous in their develo reminded the referring pr

The ToM issues point matters, especially as the social demand avoidance is meant to be sophisticated, which contradicts later interpretations by some "leading" PDA experts. Newson & Christie et al (2011) also make similar comments to Carlile (2011).



chool. This paper describes
oy thought to have PDA and
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to thank Jack – a delightful and determined boy who faces challenges every day and whom I always get such pleasure being around.

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autism spectrum, in PDA, theory of mind (ToM) and social skills can be deftly applied in order to manipulate others as a way of controlling the environment and resisting demands. However, the use of ToM and social skills appears to be at a functional and logical level, rather than at a deeper, emotional level.

By using a detailed case example, this paper aims to outline a number of strategies that were effective in supporting a child with PDA through the framework of play dates. Eight strategies are described that have been used effectively in supporting this child to learn some of the skills involved in playing with others and in building positive relationships. It also aims to expand the limited available literature informing and supporting families on practical strategies that can be implemented in the home.

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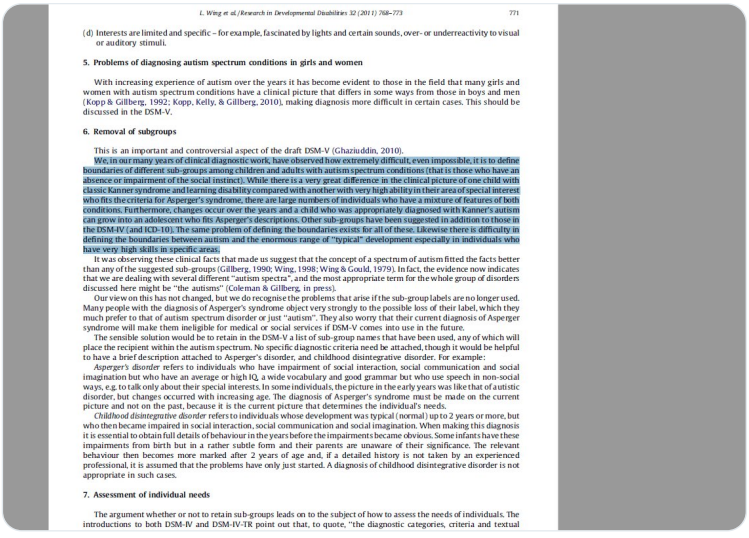
with the child, thus giving the child a sense of control.

The other final draft item is that persons can transition into PDA, this point is mentioned consistently by Newson, from 1989 to 2003. Wing makes same observation in 2002 & 2011, latter one with Gould & Gillberg.

The above point matters as it directly contradicts Christie's frequent conference presentation point that PDA has to be Developmental in nature.

"However, sometimes this child will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence" (Newson et al, 2003, p598).
Screen shot p771, link previously in thread.
Link Newson 1999
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/The-family-of-pervasive-development-disorders.pdf



L. Wing et al. / Research in Developmental Disabilities 32 (2011) 768–773 771

(d) Interests are limited and specific – for example, fascinated by lights and certain sounds, over- or underreactivity to visual or auditory stimuli.

5. Problems of diagnosing autism spectrum conditions in girls and women

With increasing experience of autism over the years it has become evident to those in the field that many girls and women with autism spectrum conditions have a clinical picture that differs in some ways from those in boys and men (Kopp & Gillberg, 1992; Kopp, Kelly, & Gillberg, 2010), making diagnosis more difficult in certain cases. This should be discussed in the DSM-V.

6. Removal of subgroups

This is an important and controversial aspect of the draft DSM-V (Ghaziuddin, 2010).

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 (that is those who have an absence or impairment of the social instinct). While there is a very great difference in the clinical picture of one child with classic Kanner syndrome and learning disability compared with another with very high ability in their area of special interest who fits the criteria for Asperger's syndrome, there are large numbers of individuals who have a mixture of features of both conditions. Furthermore, changes occur over the years and a child who was appropriately diagnosed with Kanner's autism can grow into an adolescent who fits Asperger's descriptions. 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. Likewise there is difficulty in defining the boundaries between autism and the enormous range of "typical" development especially in individuals who have very high skills in specific areas.

It was observing these clinical facts that made us suggest that the concept of a spectrum of autism fitted the facts better than any of the suggested sub-groups (Gillberg, 1990; Wing, 1998; Wing & Gould, 1979). In fact, the evidence now indicates that we are dealing with several different "autism spectra", and the most appropriate term for the whole group of disorders discussed here might be "the autisms" (Coleman & Gillberg, in press).

Our view on this has not changed, but we do recognise the problems that arise if the sub-group labels are no longer used. Many people with the diagnosis of Asperger's syndrome object very strongly to the possible loss of their label, which they much prefer to that of autism spectrum disorder or just "autism". They also worry that their current diagnosis of Asperger syndrome will make them ineligible for medical or social services if DSM-V comes into use in the future.

The sensible solution would be to retain in the DSM-V a list of sub-group names that have been used, any of which will place the recipient within the autism spectrum. No specific diagnostic criteria need be attached, though it would be helpful to have a brief description attached to Asperger's disorder, and childhood disintegrative disorder. For example:

Asperger's disorder refers to individuals who have impairment of social interaction, social communication and social imagination but who have an average or high IQ, a wide vocabulary and good grammar but who use speech in non-social ways, e.g. to talk only about their special interests. In some individuals, the picture in the early years was like that of autistic disorder, but changes occurred with increasing age. The diagnosis of Asperger's syndrome must be made on the current picture and not on the past, because it is the current picture that determines the individual's needs.

Childhood disintegrative disorder refers to individuals whose development was typical (normal) up to 2 years or more, but who then became impaired in social interaction, social communication and social imagination. When making this diagnosis it is essential to obtain full details of behaviour in the years before the impairments became obvious. Some infants have these impairments from birth but in a rather subtle form and their parents are unaware of their significance. The relevant behaviour then becomes more marked after 2 years of age and, if a detailed history is not taken by an experienced professional, it is assumed that the problems have only just started. A diagnosis of childhood disintegrative disorder is not appropriate in such cases.

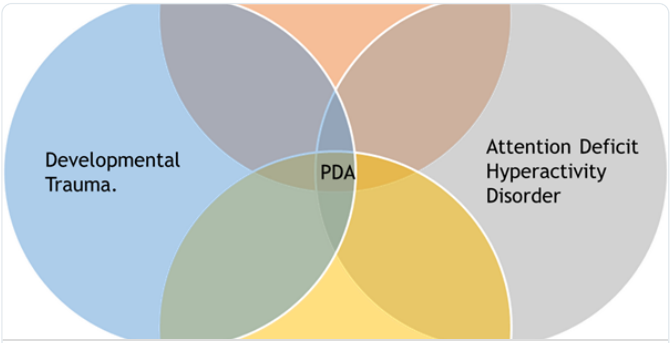
7. Assessment of individual needs

The argument whether or not to retain sub-groups leads on to the subject of how to assess the needs of individuals. The introductions to both DSM-IV and DSM-IV-TR point out that, to quote, "the diagnostic categories, criteria and textual

I am also including an item on PDA meant to have different strategies compared to traditional autism ones, as this point is frequently made in the literature, even though I think point is highly debatable. It seems fair to include it.

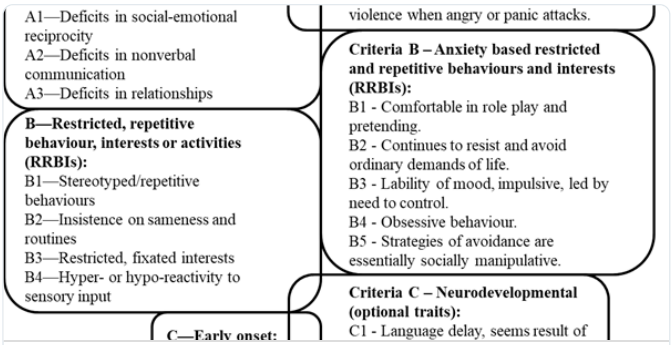
I will post the draft tool on my blog later, I need to quite a bit of work drafting the tool first.

This thread details where the items are from and the rationale with the tool, which also is justified in the blog post:



A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BELIEFS S…
A DRAFT OF THE PATHOLOGICAL DEMAND AVOIDANCE – BELIEFS SCALE (PDA-BS). Introduction. This blog post is an expanded debate entry I have started on Researchgate about a tool to assess a person's beli…
https://rationaldemandavoidance.com/2021/04/30/a-draft-of-the-pathological-demand-…

List of PDA articles, I checked was from here.


A1—Deficits in social-emotional reciprocity
A2—Deficits in nonverbal communication
A3—Deficits in relationships

B—Restricted, repetitive behaviour, interests or activities (RRBIs):
B1—Stereotyped/repetitive behaviours
B2—Insistence on sameness and routines
B3—Restricted, fixated interests
B4—Hyper- or hypo-reactivity to sensory input

violence when angry or panic attacks.

Criteria B – Anxiety based restricted and repetitive behaviours and interests (RRBIs):
B1 - Comfortable in role play and pretending.
B2 - Continues to resist and avoid ordinary demands of life.
B3 - Lability of mood, impulsive, led by need to control.
B4 - Obsessive behaviour.
B5 - Strategies of avoidance are essentially socially manipulative.

Criteria C – Neurodevelopmental (optional traits):
C1 - Language delay, seems result of

28th OF APRIL 2021 UPDATE TO THE LIST OF DEMAND AVOIDANCE P…
28th OF APRIL 2021 UPDATE TO THE LIST OF DEMAND AVOIDANCE PHENOMEMA ARTICLES & CHAPTERS. Introduction. This is a quick update to the list articles and book chapters currently extant on Demand A…
https://rationaldemandavoidance.com/2021/04/28/28th-of-april-2021-update-to-the-list-…

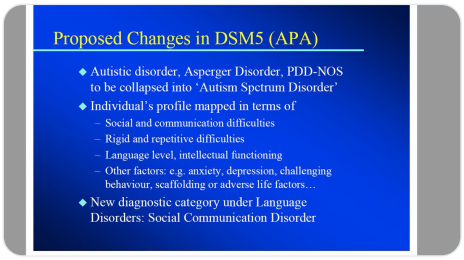
There was another link I wished to add to this thread, but I have currently forgetten it. I will add if/ when I recall it.

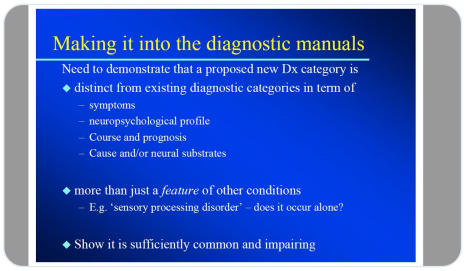
I was going to say, that I checked other sources outside those articles, such as three books which have in been drawn upon in this thread.

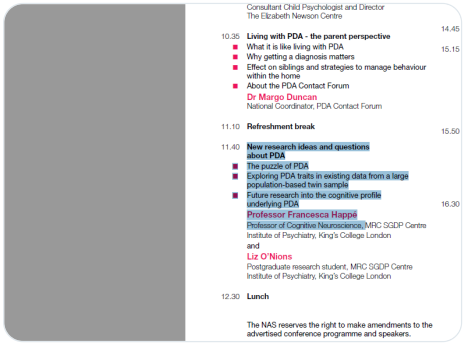
Reasons why I doubt PDA has separate strategies for autism can be found here: https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

Saying this I could also cite Happe (2011), as she was involved in setting up that PDA is an ASD research agenda & co-authored various articles.

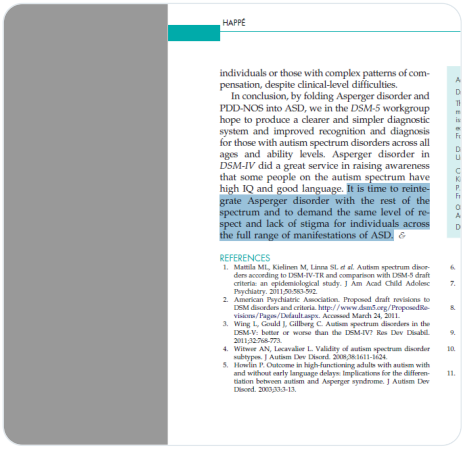
It is relevant, if you are trying to make PDA an ASD subtype/ subgroup/ profile, it is reasonable to discuss reasons why subtypes were removed from the DSM-5. Happe discusses this in the original research agenda conference slides. Slides 16 + 17.







Specifically, including items lack of evidence of differential treatment between subtypes. Subtypes were removed to reduce stigma for all autistics. Lack significant differences between autism subtypes.
https://www.jaacap.org/article/S0890-8567(11)00268-1/fulltext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individuals or those with complex patterns of compensation, despite clinical-level difficulties.

In conclusion, by folding Asperger disorder and PDD-NOS into ASD, we in the *DSM-5* workgroup hope to produce a clearer and simpler diagnostic system and improved recognition and diagnosis for those with autism spectrum disorders across all ages and ability levels. Asperger disorder in *DSM-IV* did a great service in raising awareness that some people on the autism spectrum have high IQ and good language. 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.

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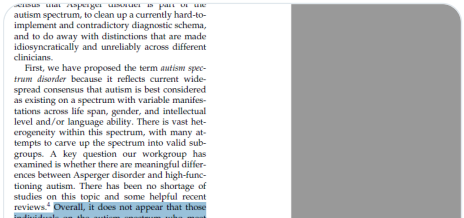
2. American Psychiatric Association. Proposed draft revisions to DSM disorders and criteria. http://www.dsm5.org/ProposedRevisions/Pages/Default.aspx. Accessed March 24, 2011.
3. Wing L, Gould J, Gillberg C. Autism spectrum disorders in the DSM-V: better or worse than the DSM-IV? Res Dev Disabil. 2011;32:768-773.
4. Witwer AN, Lecavalier L. Validity of autism spectrum disorder subtypes. J Autism Dev Disord. 2008;38:1611-1624.
5. Howlin P. Outcome in high-functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. J Autism Dev Disord. 2003;33:3-13.


autism spectrum, to clean up a currently hard-to-implement and contradictory diagnostic schema, and to do away with distinctions that are made idiosyncratically and unreliably across different clinicians.

First, we have proposed the term *autism spectrum disorder* because it reflects current widespread consensus that autism is best considered as existing on a spectrum with variable manifestations across life span, gender, and intellectual level and/or language ability. There is vast heterogeneity within this spectrum, with many attempts to carve up the spectrum into valid subgroups. A key question our workgroup has examined is whether there are meaningful differences between Asperger disorder and high-functioning autism. There has been no shortage of studies on this topic and some helpful recent reviews.[4] 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, if one compares groups of equivalent current developmental level or IQ. Some studies have shown that the outcome of these two groups is very similar in adolescence and adulthood.[5] 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. Taken together,

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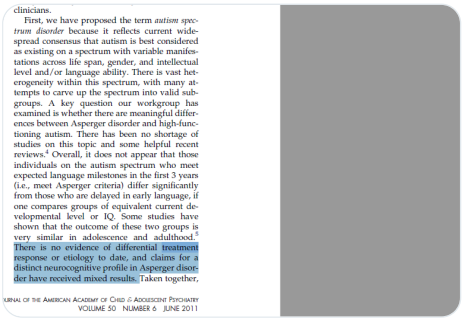
clinicians.

First, we have proposed the term *autism spectrum disorder* because it reflects current widespread consensus that autism is best considered as existing on a spectrum with variable manifestations across life span, gender, and intellectual level and/or language ability. There is vast heterogeneity within this spectrum, with many attempts to carve up the spectrum into valid subgroups. A key question our workgroup has examined is whether there are meaningful differences between Asperger disorder and high-functioning autism. There has been no shortage of studies on this topic and some helpful recent reviews.[4] 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, if one compares groups of equivalent current developmental level or IQ. Some studies have shown that the outcome of these two groups is very similar in adolescence and adulthood.[5] 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. Taken together,

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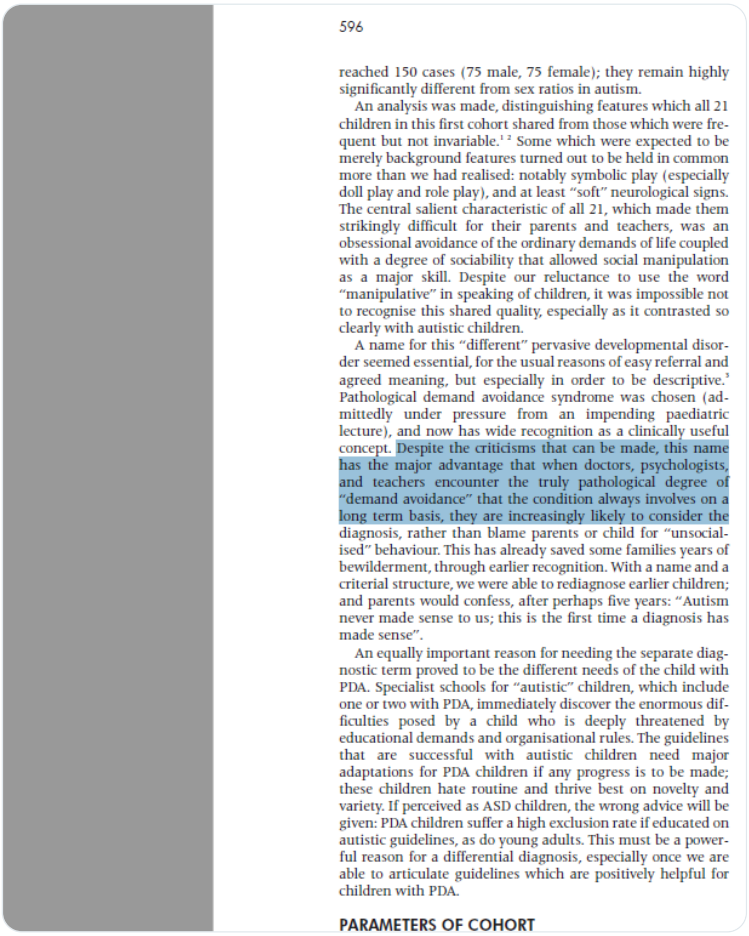
VOLUME 50 NUMBER 6 JUNE 2011

I have added an item to reflect that "Pathological" descriptor is controversial. Newson indirectly acknowledges this in her 2003 article & states she dislikes the name in her

1983 article.



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reached 150 cases (75 male, 75 female); they remain highly significantly different from sex ratios in autism.

An analysis was made, distinguishing features which all 21 children in this first cohort shared from those which were frequent but not invariable.[1 2] Some which were expected to be merely background features turned out to be held in common more than we had realised: notably symbolic play (especially doll play and role play), and at least "soft" neurological signs. The central salient characteristic of all 21, which made them strikingly difficult for their parents and teachers, was an obsessional avoidance of the ordinary demands of life coupled with a degree of sociability that allowed social manipulation as a major skill. Despite our reluctance to use the word "manipulative" in speaking of children, it was impossible not to recognise this shared quality, especially as it contrasted so clearly with autistic children.

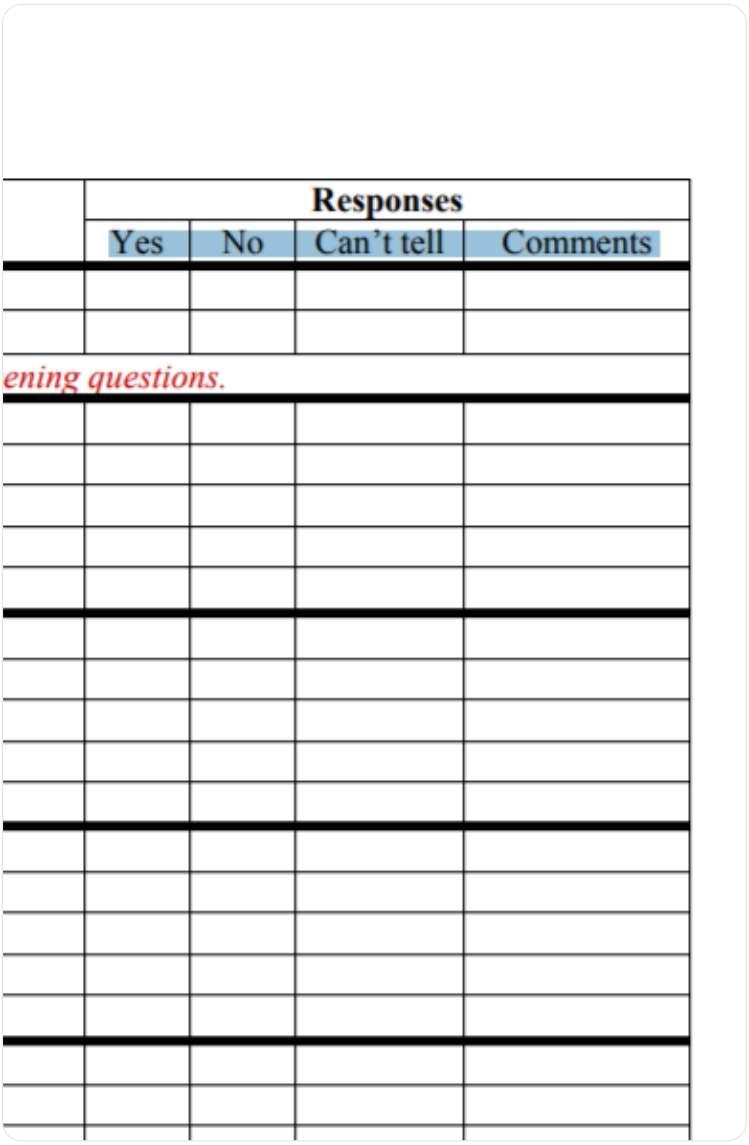
A name for this "different" pervasive developmental disorder seemed essential, for the usual reasons of easy referral and agreed meaning, but especially in order to be descriptive.[3] Pathological demand avoidance syndrome was chosen (admittedly under pressure from an impending paediatric lecture), and now has wide recognition as a clinically useful concept. Despite the criticisms that can be made, this name has the major advantage that when doctors, psychologists, and teachers encounter the truly pathological degree of "demand avoidance" that the condition always involves on a long term basis, they are increasingly likely to consider the diagnosis, rather than blame parents or child for "unsocialised" behaviour. This has already saved some families years of bewilderment, through earlier recognition. With a name and a criterial structure, we were able to rediagnose earlier children; and parents would confess, after perhaps five years: "Autism never made sense to us; this is the first time a diagnosis has made sense".

An equally important reason for needing the separate diagnostic term proved to be the different needs of the child with PDA. Specialist schools for "autistic" children, which include one or two with PDA, immediately discover the enormous difficulties posed by a child who is deeply threatened by educational demands and organisational rules. The guidelines that are successful with autistic children need major adaptations for PDA children if any progress is to be made; these children hate routine and thrive best on novelty and variety. If perceived as ASD children, the wrong advice will be given: PDA children suffer a high exclusion rate if educated on autistic guidelines, as do young adults. This must be a powerful reason for a differential diagnosis, especially once we are able to articulate guidelines which are positively helpful for children with PDA.

PARAMETERS OF COHORT

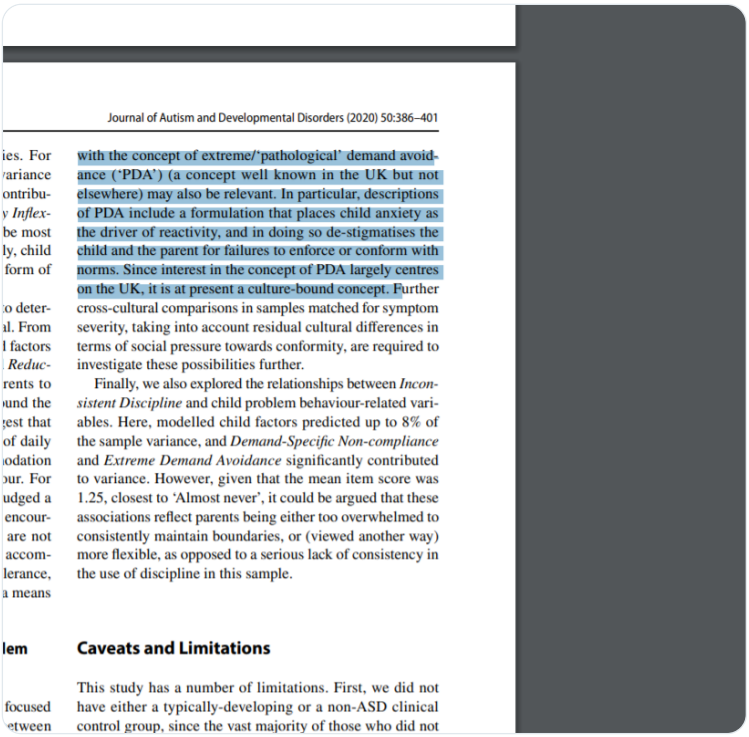
I am also trying to group the items in a way that is easy for people to use them, when screening PDA literature. So items based on Newson's work are placed together. Likewise, issues with PDA being an ASD are grouped together etc.

I have basically copied the responses section to the Mixed Methods Appraisal Tool (MMAT), as this is the type information one should be seeking if investigating PDA literature's balance of perspectives.
http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf



	Responses			
	Yes	No	Can't tell	Comments
ening questions.				

It is actually worse than I thought. Certain "leading" PDA experts have also admitted PDA is a cultural based entity
https://link.springer.com/content/pdf/10.1007/s10803-019-04219-2.pdf



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with the concept of extreme/'pathological' demand avoidance ('PDA') (a concept well known in the UK but not elsewhere) may also be relevant. In particular, descriptions of PDA include a formulation that places child anxiety as the driver of reactivity, and in doing so de-stigmatises the child and the parent for failures to enforce or conform with norms. Since interest in the concept of PDA largely centres on the UK, it is at present a culture-bound concept. Further cross-cultural comparisons in samples matched for symptom severity, taking into account residual cultural differences in terms of social pressure towards conformity, are required to investigate these possibilities further.

Finally, we also explored the relationships between *Inconsistent Discipline* and child problem behaviour-related variables. Here, modelled child factors predicted up to 8% of the sample variance, and *Demand-Specific Non-compliance* and *Extreme Demand Avoidance* significantly contributed to variance. However, given that the mean item score was 1.25, closest to 'Almost never', it could be argued that these associations reflect parents being either too overwhelmed to consistently maintain boundaries, or (viewed another way) more flexible, as opposed to a serious lack of consistency in the use of discipline in this sample.

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Caveats and Limitations

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This study has a number of limitations. First, we did not have either a typically-developing or a non-ASD clinical control group, since the vast majority of those who did not

"Since interest in the concept of PDA largely centres
on the UK, it is at present a culture-bound concept." (O'Nions et al 2020, p398).

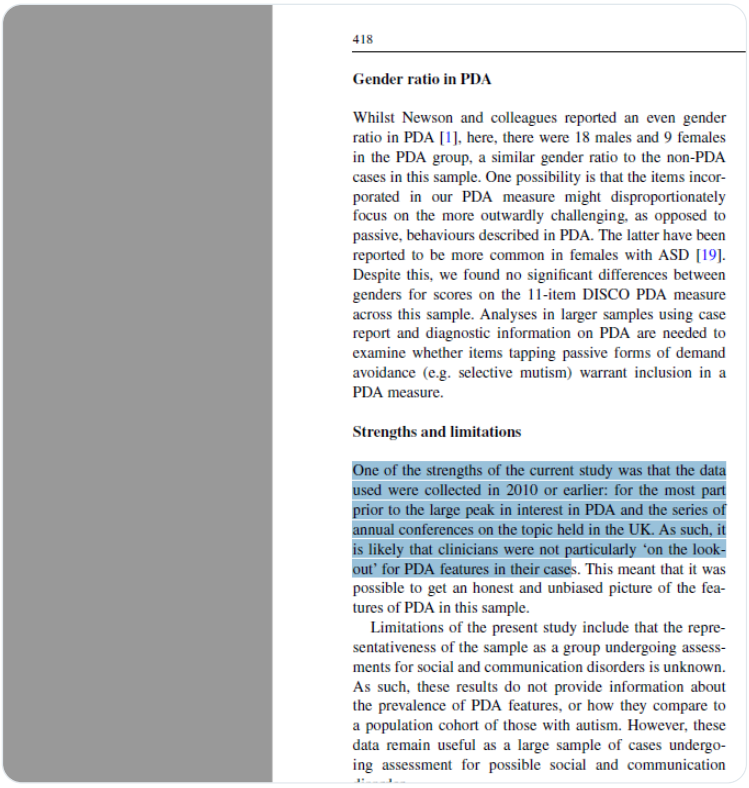
What this means is that some people erroneously viewed PDA as an ASD, decided to pursue a research agenda PDA is an ASD. Subsequently interest in PDA has outstripped PDA research & PDA has become a culturally bound concept...

Likewise, "leading" PDA experts have acknowledged that persons can be on the look out for PDA. Which it seems fair to say some of them appear to be on the lookout for PDA to be an ASD. Furthermore, they they approach is shortsighted in the extreme.

"As such, it is likely that clinicians were not particularly 'on the lookout' for PDA features in their cases." (O'Nions et al, 2016, p418).

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



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Gender ratio in PDA

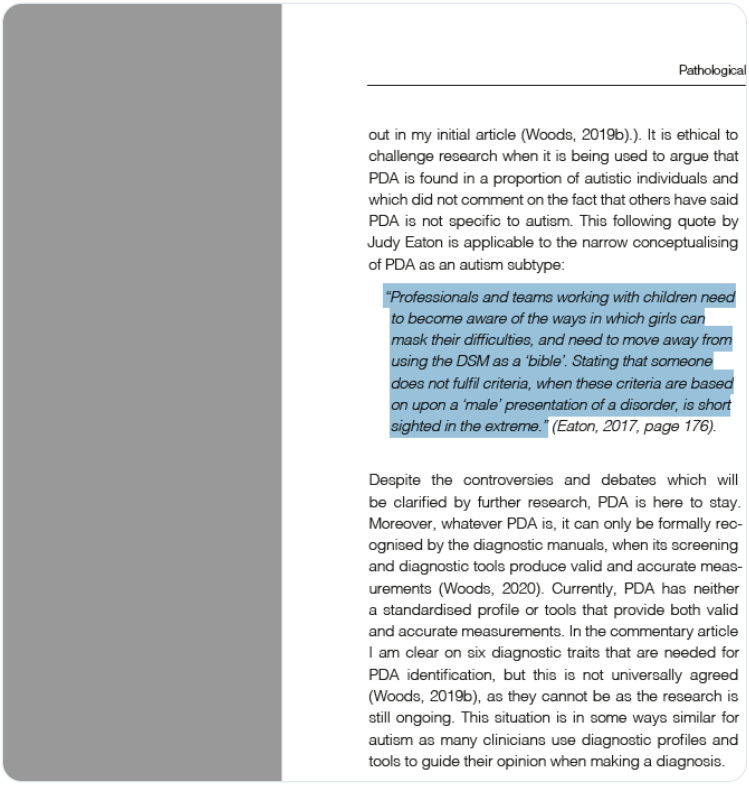
Whilst Newson and colleagues reported an even gender ratio in PDA [1], here, there were 18 males and 9 females in the PDA group, a similar gender ratio to the non-PDA cases in this sample. One possibility is that the items incorporated in our PDA measure might disproportionately focus on the more outwardly challenging, as opposed to passive, behaviours described in PDA. The latter have been reported to be more common in females with ASD [19]. Despite this, we found no significant differences between genders for scores on the 11-item DISCO PDA measure across this sample. Analyses in larger samples using case report and diagnostic information on PDA are needed to examine whether items tapping passive forms of demand avoidance (e.g. selective mutism) warrant inclusion in a PDA measure.

Strengths and limitations

One of the strengths of the current study was that the data used were collected in 2010 or earlier: for the most part prior to the large peak in interest in PDA and the series of annual conferences on the topic held in the UK. As such, it is likely that clinicians were not particularly 'on the lookout' for PDA features in their cases. This meant that it was possible to get an honest and unbiased picture of the features of PDA in this sample.

Limitations of the present study include that the representativeness of the sample as a group undergoing assessments for social and communication disorders is unknown. As such, these results do not provide information about the prevalence of PDA features, or how they compare to a population cohort of those with autism. However, these data remain useful as a large sample of cases undergoing assessment for possible social and communication

Sortsighted in the extreme quote and it being applicable to viewing PDA as an ASD.
https://www.researchgate.net/publication/339240845_Pathological_Demand_Avoidance_and_the_DSM-5_a_rebuttal_to_Judy_Eaton



Pathological

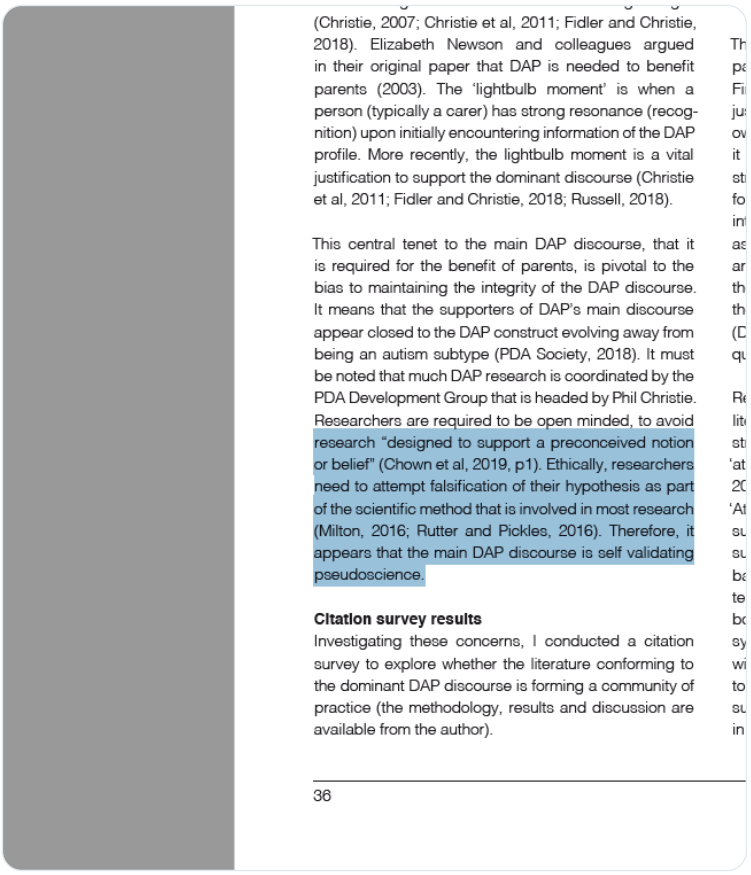
out in my initial article (Woods, 2019b).). It is ethical to challenge research when it is being used to argue that PDA is found in a proportion of autistic individuals and which did not comment on the fact that others have said PDA is not specific to autism. This following quote by Judy Eaton is applicable 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 and diagnostic tools produce valid and accurate measurements (Woods, 2020). Currently, PDA has neither a standardised profile or tools that provide both valid and accurate measurements. In the commentary article I am clear on six diagnostic traits that are needed for PDA identification, but this is not universally agreed (Woods, 2019b), as they cannot be as the research is still ongoing. This situation is in some ways similar for autism as many clinicians use diagnostic profiles and tools to guide their opinion when making a diagnosis.

To be blatantly clear researchers should not be favouring the view PDA is an ASD over its other outlooks on it, as ethically they should be adopting the scientific-method and attempting to falsify hypotheses.

https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference



(Christie, 2007; Christie et al, 2011; Fidler and Christie, 2018). Elizabeth Newson and colleagues argued in their original paper that DAP is needed to benefit parents (2003). The 'lightbulb moment' is when a person (typically a carer) has strong resonance (recognition) upon initially encountering information of the DAP profile. More recently, the lightbulb moment is a vital justification to support the dominant discourse (Christie et al, 2011; Fidler and Christie, 2018; Russell, 2018).

This central tenet to the main DAP discourse, that it is required for the benefit of parents, is pivotal to the bias to maintaining the integrity of the DAP discourse. It means that the supporters of DAP's main discourse appear closed to the DAP construct evolving away from being an autism subtype (PDA Society, 2018). It must be noted that much DAP research is coordinated by the PDA Development Group that is headed by Phil Christie. Researchers are required to be open minded, to avoid research "designed to support a preconceived notion or belief" (Chown et al, 2019, p1). Ethically, researchers need to attempt falsification of their hypothesis as part of the scientific method that is involved in most research (Milton, 2016; Rutter and Pickles, 2016). Therefore, it appears that the main DAP discourse is self validating pseudoscience.

Citation survey results

Investigating these concerns, I conducted a citation survey to explore whether the literature conforming to the dominant DAP discourse is forming a community of practice (the methodology, results and discussion are available from the author).

36

It is an understatement, to say that viewing PDA as an ASD becoming an " culture-bound concept", SHOULD NOT HAVE HAPPENED...

At least there is more than sufficient case to warrant investigating undeclared conflict of interests in PDA literature.

@threadreaderapp please can you unroll?

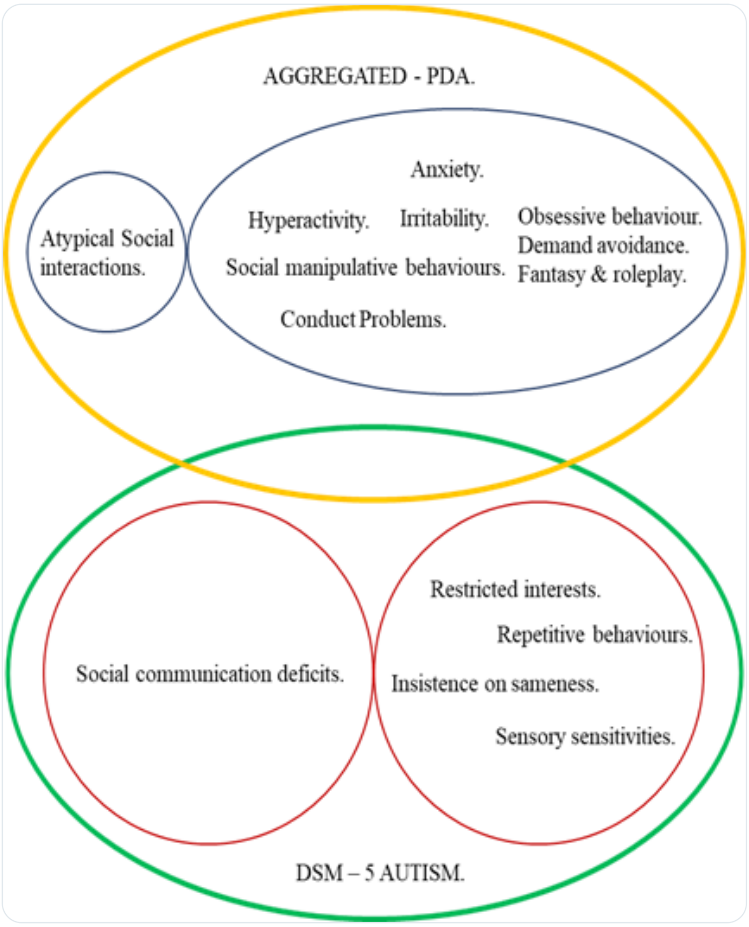
Thank you in advance.

I should add an items to cover results of this, as they are discussed in Christie et al (2011), pp182-184.
https://journals.sagepub.com/doi/pdf/10.1177/1362361313481861

I also think it is worth including an that anxiety is not an autism feature as this is Gould and Ashton-Smith (2011). Maybe an item on PDA demand avoidance being obsessive in nature, as this is how Newson described it.

The point here is that there is sufficient points in 2011 to seriously doubt PDA is autism... Which begs the question why no-one in 2011 bothered to make that leap of logic then?

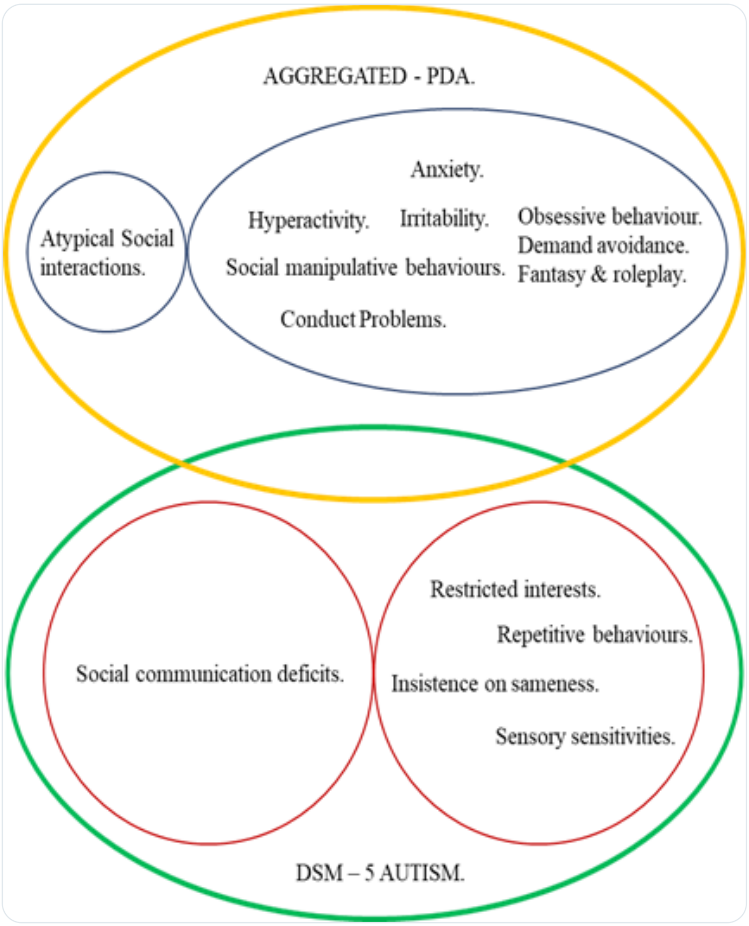
In fact, I think if one was reflective enough, that something similar to this image could have been produced in 2011, suggesting how PDA compares to autism.



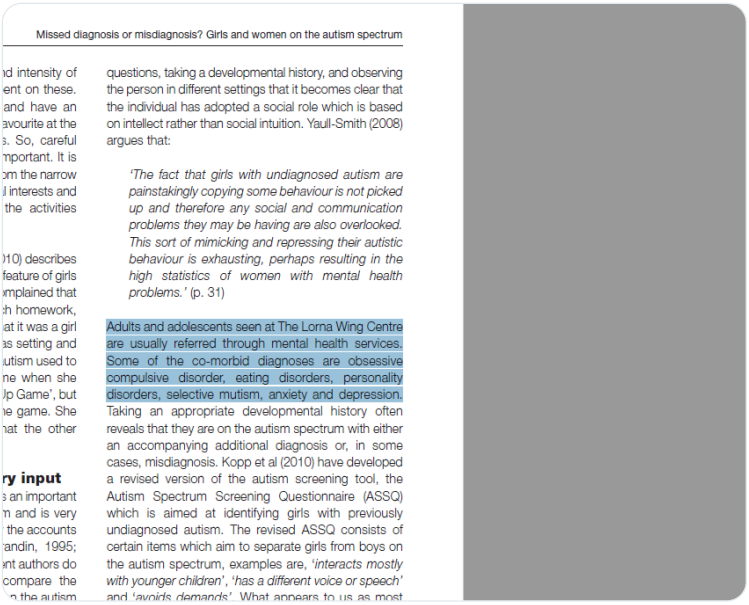
The difference in social communications issues is acknowledged (i.e., no ToM deficits. ADHD features been suggested. Conduct problems have been noted. Anxiety based demand avoidance & anxiety not being an autism.

Demand avoidance is obsessive in nature. Comfortable in roleplay and pretend, social manipulation are noted to counter autism understandings. are also noted.

There is sufficient points in the literature in 2011 to construct something similar to this.



Screen of anxiety being a co-occurring issue in autism, as mentioned in Gould & Ashton-Smith.



Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum

questions, taking a developmental history, and observing the person in different settings that it becomes clear that the individual has adopted a social role which is based on intellect rather than social intuition. Yaull-Smith (2008) argues that:

> *'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 an accompanying additional diagnosis or, in some cases, misdiagnosis. Kopp et al (2010) have developed a revised version of the autism screening tool, the Autism Spectrum Screening Questionnaire (ASSQ) which is aimed at identifying girls with previously undiagnosed autism. The revised ASSQ consists of certain items which aim to separate girls from boys on the autism spectrum, examples are, *'interacts mostly with younger children'*, *'has a different voice or speech'* and *'avoids demands'*. What appears to us as most

Christie et a (2011, p184) refer to PDA having high anxiety levels, within the top two percent of human population. Screenshot of PDA demand avoidance is meant to be linked to high anxiety in Carlile (2011).

Links to Carlile 2011:
https://www.ingentaconnect.com/contentone/bild/gap/2011/00000012/00000002

/art00007

Gould and Ashton-Smith 2011 article:
https://www.ingentaconnect.com/contentone/bild/gap/2011/00000012/00000001/art00005

"whether it shares some of the key features of autism
and so should be recognised as a part of the autism spectrum" Editorial comment. Carlile (2011, p59).

I would say PDA does not have core features of autism...

That Newson seems correct to conceptualise PDA as having more clusters of symptoms, than Autism does...

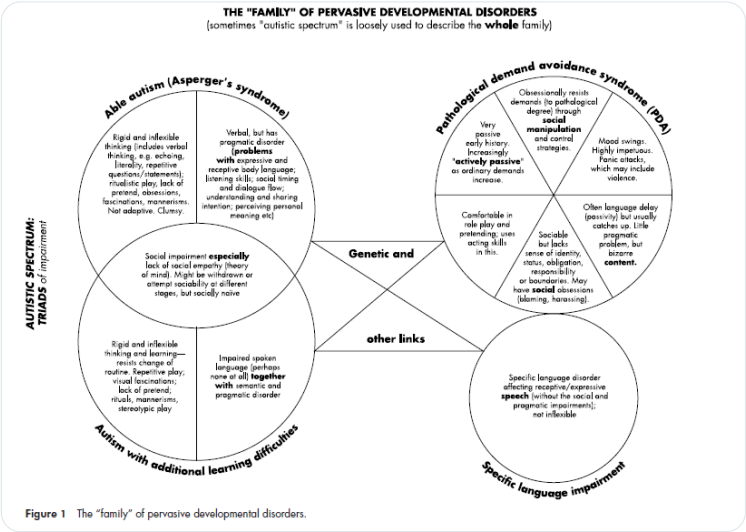


Figure 1 The "family" of pervasive developmental disorders.

Points I need to cover:
O'Nions Masters thesis.
Autistic-like is not equivalent to autism...
Obsessive Behaviour.
Anxiety based behaviour impacting social interactions, can cause chaotic worldview seen in some persons with PDA...

Anxiety driven behaviour impacting social interactions can is seen in anxiety based Disorders, like OCD.
Routines.
Difficulty measuring some PDA features.
Educational Strategies.
Not all of Newson's cohort meet DSM-5 autism criteria.

"Obsessive behaviour: Much or most of the behaviour described is carried out in an obsessive way, especially demand avoidance:" (Newson et al, 2003, p597).
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes

"Praise, reward, reproof, and punishment ineffective; behavioural approaches fail." (Newson et al, 2003, p597). Newson describes educational approaches in

supplementary notes. Christie (2007), & Christie et al (2011) detail educational approaches for PDA.

Likewise, Carlile (2011) suggests different educational approaches are needed for PDA versus "traditional" autism ones. Although, as I mention earlier, I think this statement can validly challenged.

"Some of the features outlined (for example sense of identity, price and shame) would be specially difficult to identify reliably." (Garralda, 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…

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

Published on: 22 July 2003

Pathological demand avoidance syndrome or psychiatric disorder?

M Elena Garralda, Professor of Child and Adolescent Psychiatry

Dear Editor

In the recent issue of the Archives, Newson *et al.*[1] make the case for a distinctive "pathological demand avoidance syndrome". This arose out of the work by the authors in a clinic for children with problems in communication.

These children are described as having a tendency to avoid or resist ordinary demands, to have surface sociability but a lack of sense of identity, pride and shame, labile mood, impulsivity led by need to control, language delay, obsessional behaviour and some sort of - usually "soft" - neurological involvement. The syndrome is not a recognised psychiatric disorder in either ICD-10 or DSM-IV classification systems.

How well do the authors make the case for this new syndrome? Some of the features outlined (for example sense of identity, price and shame) would be specially difficult to identify reliably. Others are suggestible of a number of different child and adolescent psychiatric disorders as described in ICD-10 and DSM-IV (WHO, 1991; APA, 1994).[2,3] From the authors' descriptions, the impression is that these children are likely to have had co-morbid developmental and psychiatric problems, varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood. In some cases the features described may have been precursors of a schizotypal disorder.[4] The paper does not however make a case for the validity or specificity of the syndrome in relation to these disorders.

The paper helpfully draws attention to the clinical variability amongst children with communication disorders. However, it would seem regrettable if new syndromes were to be used in clinical practice without consideration of whether an established psychiatric diagnosis would have been appropriate, as this will create confusion for parents and others involved. Better integration of paediatric and child psychiatric services working with children with developmental communication disorders should help reduce the likelihood of this happening.

References

(1) Newson E, Le Marechal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch Dis Child* 2003; **88**:595-600.

(2) APA. *Diagnostic and statistical manual of mental disorders, 4th Edition*. DSM-IV. Washington: APA, 1994.

Not all of Newson's cohort meeting DSM-5 autism criteria. (Eaton & Weaver, 2020, p34; Soppitt, 2021, p311).

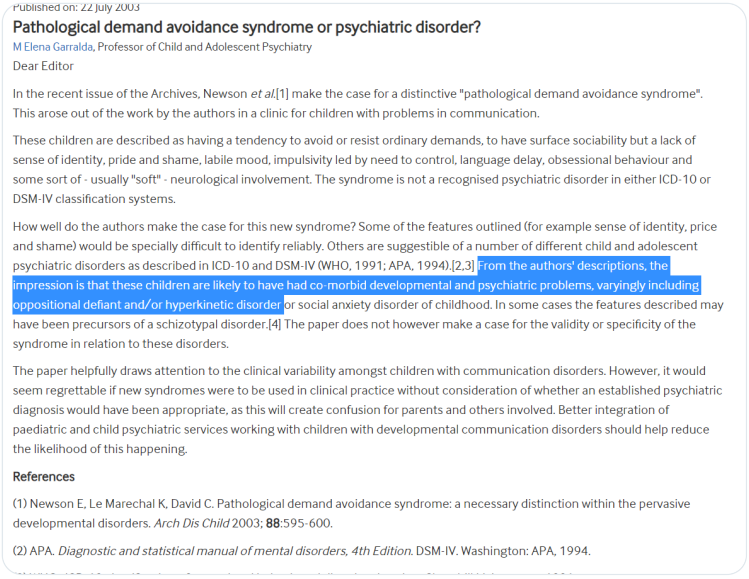
Now onto O'Nions master's research, as discussed in Christie et al (2011, pp182-184).

First point mentions PDA might be a "double-hit" p183, similarly to Wing et al (2011) does, but also adds top 2% of population for parent-rated anxiety p184.

This means PDA can be described as a "triple-hit" of autistic-like features, conduct problems & anxiety in 2011. Issue here is that means PDA cannot be something it is more than. A + B + C ≠ A, i.e., PDA CANNOT be autism.

Even if PDA is a "double-hit", same logic applies, that PDA cannot be autism. This is just indicating a lack of critical engagement by Christie et al (2011), other comments of theirs also suggest a lack or robust engagement which I will cover in a moment.

Page 183 discuss features are associated with ADHD, like impulsivity and poor planning, which support critique of Garralda that CYP with PDA might have co-occurring ADHD. Hyperkinetic Disorder is ICD-10's name for ADHD.



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References

(1) Newson E, Le Marechal K, David C. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Arch Dis Child* 2003; **88**:595-600.

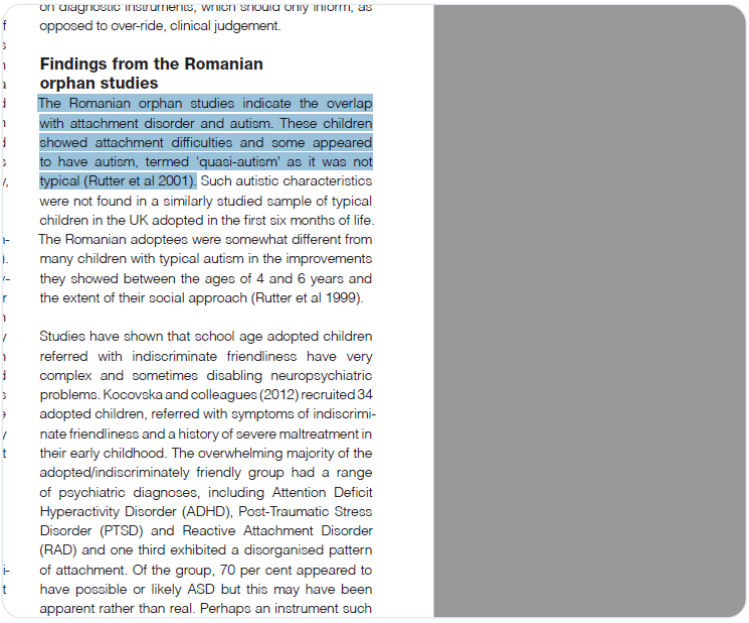
(2) APA. *Diagnostic and statistical manual of mental disorders, 4th Edition.* DSM-IV. Washington: APA, 1994.

Must be said neither Christie (2007), or Christie et al (2011) reference Garralda (2003). So make of that what you will.

Christie et al (2011) mention that persons with PDA scored similarly to autistic CYP on "autistic like traits" and discuss how the scored differently. Mentions PDA tends to have better eye contact than autism.

My issue here is that "autistic like traits" does not make a person autistic, or mean that PDA is a form of autism. It is possible for autistic persons to be misdiagnosed with things like BPD because that dx has social interaction issues.

It is possible for non-autistic persons to be diagnosed with autism, like those with "quasi-autism", due to attachment issues.
https://www.ingentaconnect.com/contentone/bild/gap/2017/00000018/00000001/art00009



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 improvements they showed between the ages of 4 and 6 years and the extent of their social approach (Rutter et al 1999).

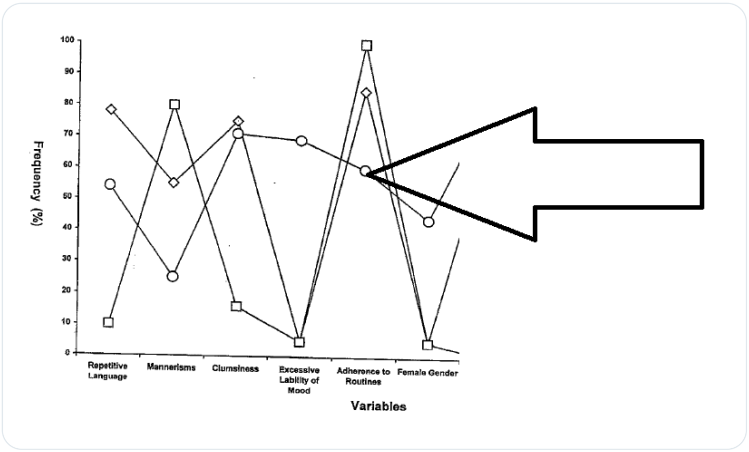
Studies have shown that school age adopted children referred with indiscriminate friendliness have very complex and sometimes disabling neuropsychiatric problems. Kocovska and colleagues (2012) recruited 34 adopted children, referred with symptoms of indiscriminate friendliness and a history of severe maltreatment in their early childhood. The overwhelming majority of the adopted/indiscriminately friendly group had a range of psychiatric diagnoses, including Attention Deficit Hyperactivity Disorder (ADHD), Post-Traumatic Stress Disorder (PTSD) and Reactive Attachment Disorder (RAD) and one third exhibited a disorganised pattern of attachment. Of the group, 70 per cent appeared to have possible or likely ASD but this may have been apparent rather than real. Perhaps an instrument such

Likewise social communication issues and struggling with social interactions are common childhood disorders, and can be found in constructs like, attachment disorders ADHD, ODD and Conduct Disorder; all Disorders which overlap PDA...

It is at least premature to argue that PDA is an ASD based on "autistic like traits". At the worst irresponsible to do so.

Christie et al (2011) p183 also mention how CYP with PDA scored higher than autistic CYP on "imposing routines on themselves and others". This important as it challenges stereotype that those with PDA dislike routines & structure.

This supports research by Elizabeth Newson that 60% of persons with PDA adhered to routines, see page 4 (Newson, 1998).
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/PDA-discriminant-functions-analysis.pdf



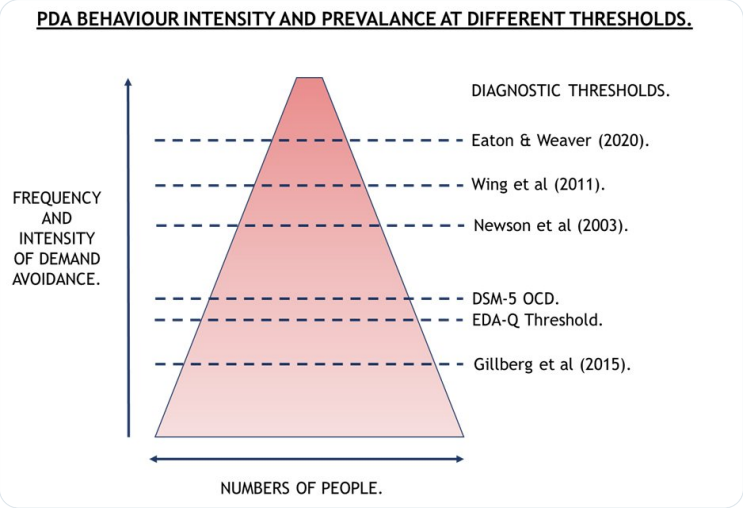
I cover this point in this article.
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

Right, the point about autistic persons being misdiagnosed with BPD. One could argue that those with BPD have "autistic-like traits", if so many autistic persons are being misdiagnosed with it (not that I think anyone should).

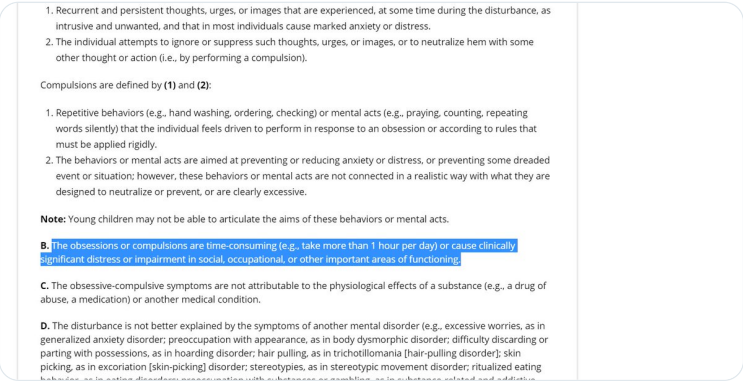
Most Disorders in the DSM-5 contain:
"the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning." (APA, 2013, p21).

It is perfectly reasonable for anxiety driven behaviours to cause social interaction issues, and PDA to NOT be autism.

Considering Eaton & Weaver (2020) are arguing anxiety driven demand avoidance behaviours are impacting ADOS scores, one can easily adopt this position relating to some persons with PDA, at some PDA diagnostic threshold (there are several PDA dx thresholds).



For instance, the line about anxiety driven anxiety behaviours impacting social functioning is present in OCD.
https://www.ocduk.org/ocd/diagnosing-ocd/



1. Recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress.
2. The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize hem with some other thought or action (i.e., by performing a compulsion).

Compulsions are defined by **(1)** and **(2)**:

1. Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.
2. The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

Note: Young children may not be able to articulate the aims of these behaviors or mental acts.

B. The obsessions or compulsions are time-consuming (e.g., take more than 1 hour per day) or cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The obsessive-compulsive symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

D. The disturbance is not better explained by the symptoms of another mental disorder (e.g., excessive worries, as in generalized anxiety disorder; preoccupation with appearance, as in body dysmorphic disorder; difficulty discarding or parting with possessions, as in hoarding disorder; hair pulling, as in trichotillomania [hair-pulling disorder]; skin picking, as in excoriation [skin-picking] disorder; stereotypies, as in stereotypic movement disorder; ritualized eating

I think the final point here, is that if one is consistently expressing anxiety driven behaviours, & it is impacting their social interactions; it is likely to also impact the development of person's worldview & understanding of the world.

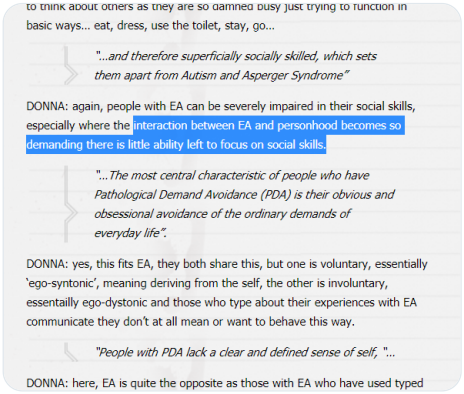
This is point is covered by Donna Williams in 2008. I am not expecting anyone to particularly know of her work in 2011. Yet, if one is taking a transactional approach to

a CYP development, it makes sense.

Exposure Anxiety versus Pathological Demand Avoidance.
Someone wrote to me about the differences between Exposure Anxiety (EA, as written about in the book, Exposure Anxiety; The Invisible Cage) and Pathological Demand Avoidance (PDA). Here are my ref…

https://blog.donnawilliams.net/2008/06/17/exposure-anxiety-versus-pathological-dema…

Donna Williams also makes a good point, that if someone is that anxious most of the time, they will be often be mentally exhausted and little mental energy left to focus on social interactions. Which again, I think is pretty obvious & straightforward.



to think about others as they are so damned busy just trying to function in basic ways... eat, dress, use the toilet, stay, go...

> *"...and therefore superficially socially skilled, which sets them apart from Autism and Asperger Syndrome"*

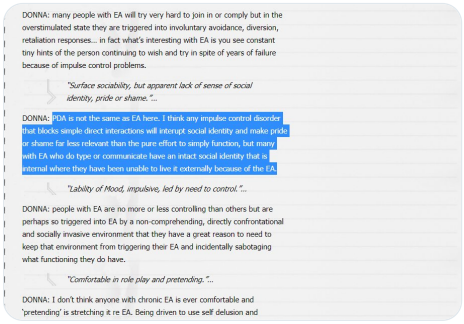
DONNA: again, people with EA can be severely impaired in their social skills, especially where the interaction between EA and personhood becomes so demanding there is little ability left to focus on social skills.

> *"...The most central characteristic of people who have Pathological Demand Avoidance (PDA) is their obvious and obsessional avoidance of the ordinary demands of everyday life".*

DONNA: yes, this fits EA, they both share this, but one is voluntary, essentially 'ego-syntonic', meaning deriving from the self, the other is involuntary, essentailly ego-dystonic and those who type about their experiences with EA communicate they don't at all mean or want to behave this way.

> *"People with PDA lack a clear and defined sense of self, "...*

DONNA: here, EA is quite the opposite as those with EA who have used typed



DONNA: many people with EA will try very hard to join in or comply but in the overstimulated state they are triggered into involuntary avoidance, diversion, retaliation responses... in fact what's interesting with EA is you see constant tiny hints of the person continuing to wish and try in spite of years of failure because of impulse control problems.

> *"Surface sociability, but apparent lack of sense of social identity, pride or shame."...*

DONNA: PDA is not the same as EA here. I think any impulse control disorder that blocks simple direct interactions will interupt social identity and make pride or shame far less relevant than the pure effort to simply function, but many with EA who do type or communicate have an intact social identity that is internal where they have been unable to live it externally because of the EA.

> *"Lability of Mood, impulsive, led by need to control."...*

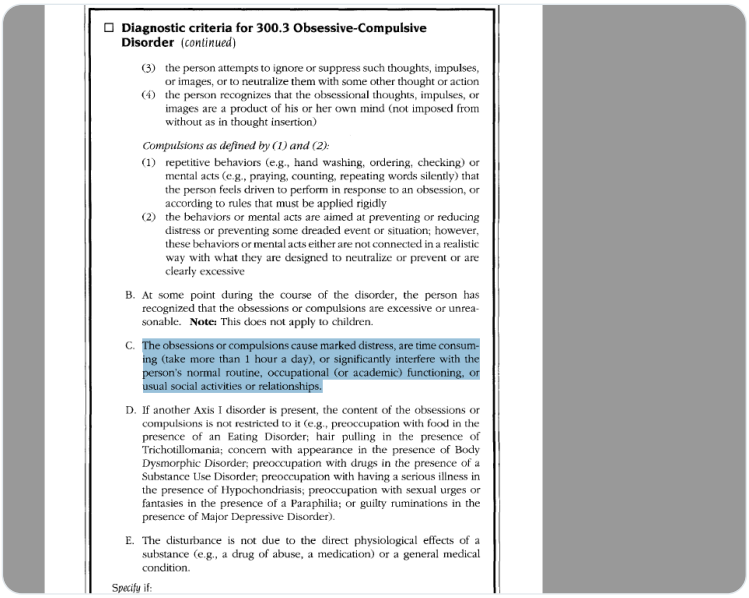
DONNA: people with EA are no more or less controlling than others but are perhaps so triggered into EA by a non-comprehending, directly confrontational and socially invasive environment that they have a great reason to need to keep that environment from triggering their EA and incidentally sabotaging what functioning they do have.

> *"Comfortable in role play and pretending."...*

DONNA: I don't think anyone with chronic EA is ever comfortable and 'pretending' is stretching it re EA. Being driven to use self delusion and

Some might argue I am being harsh for using sentence from DSM-5 Disorders & 2013. Yet, workgroups working on DSM-5 were present in 201, including the one Happe worked on for autism. DSM-5 aimed to have consistency in Disorders across from DSM-4 to DSM-5.

So this information is highly likely to have been publicly available in 2011 and I the point about anxiety driven features impacting social functioning is OCD DSM-4 criteria (APA, 1994, p423).



☐ **Diagnostic criteria for 300.3 Obsessive-Compulsive Disorder** (*continued*)

(3) the person attempts to ignore or suppress such thoughts, impulses, or images, or to neutralize them with some other thought or action
(4) the person recognizes that the obsessional thoughts, impulses, or images are a product of his or her own mind (not imposed from without as in thought insertion)

Compulsions as defined by (1) and (2):

(1) repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
(2) the behaviors or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviors or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent or are clearly excessive

B. At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable. **Note:** This does not apply to children.

C. The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour a day), or significantly interfere with the person's normal routine, occupational (or academic) functioning, or usual social activities or relationships.

D. If another Axis I disorder is present, the content of the obsessions or compulsions is not restricted to it (e.g., preoccupation with food in the presence of an Eating Disorder; hair pulling in the presence of Trichotillomania; concern with appearance in the presence of Body Dysmorphic Disorder; preoccupation with drugs in the presence of a Substance Use Disorder; preoccupation with having a serious illness in the presence of Hypochondriasis; preoccupation with sexual urges or fantasies in the presence of a Paraphilia; or guilty ruminations in the presence of Major Depressive Disorder).

E. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

Specify if:

So the point about anxiety driven behaviours impacting social interactions etc, does not mean PDA is an ASD appears to be valid.

I will add further items to PDA-BLT later. I needed to cover the literature review.

@threadreaderapp please unroll.

Thank you in advance again.

• • •