



Richard Woods @Richard_Autism

22 May · 84 tweets · [Richard_Autism/status/1395996293613375492](https://twitter.com/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 [

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

repository.tavistockandportman.ac.uk/2165/

<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 understanding the understating of the child's disorder. This research is helpful in demonstrating that features of 'extreme' pathological developmental disturbance 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.

highlight the potential utility of the EDA-Q to assist the identification of this unusual profile for future research

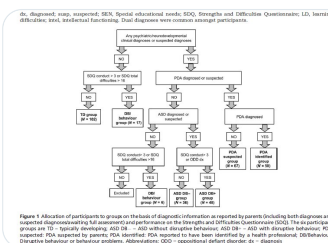
Introduction

Pathological Demand Avoidance (PDA) is a term used to describe children who display an extremely challenging behaviour profile, central to which appears to be an obsessive resistance to everyday demands, requests, and instructions. Children with PDA are often described as having 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 (Gillberg, Marshall, & David, 2001; Gillberg, Eklund, & Quinlan, 2001; Gillberg, Gillberg, & Gillberg, 2001; Gillberg & Hagep, 1997), unpublished observations, and they are described as using frequent and varied 'social manipulative' strategies to avoid complying with requests in the form of the conversation, persistence in the face of refusal, and the use of extreme demands, in addition, many resort to extreme behaviour apparently intended to shock the person they apparently intend to 'push people's buttons' suggest

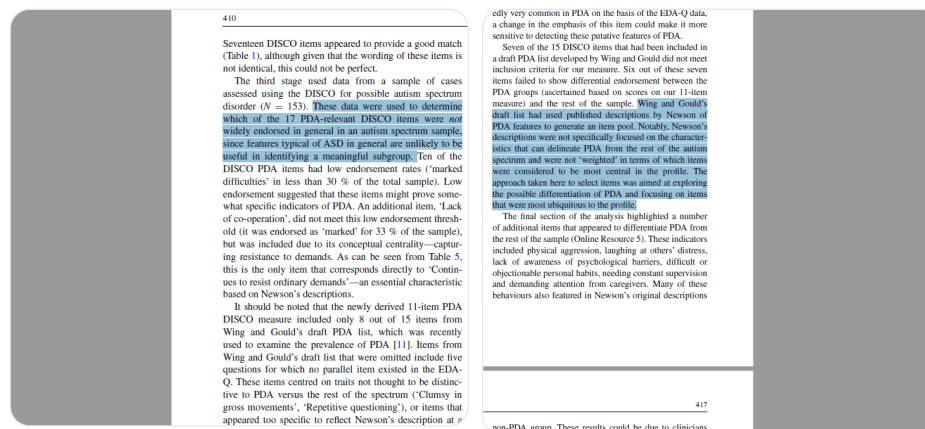
Notes on PDAs: On the other hand, children identified as having PDAs lack another difference from most children with conduct disorder (oppositional defiant disorder) (formerly termed 'disruptive behaviour'), in showing little sense of embarrassment, reputation management, or conformity to peer norms. More research is needed to explore this as uniquely or personally important to children with PDAs (see, for example, Cacioppo, A., Tulp, M., Voling, K., & Huppe, F., unpublished observations), and friendships fall due to controlling behaviour and their extreme responses when things don't go their way (Stevenson et al., 2003). However, the term PDA is not used in the DSM-IV in the United Kingdom, evidenced by the inclusion of educational guidelines on PDA (Charman, 2007) in the UK-based Autism Education Trust's best practice in schools (2008), and several non-accredited conferences in the UK in 2008, such as the 10th annual conference of 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 the

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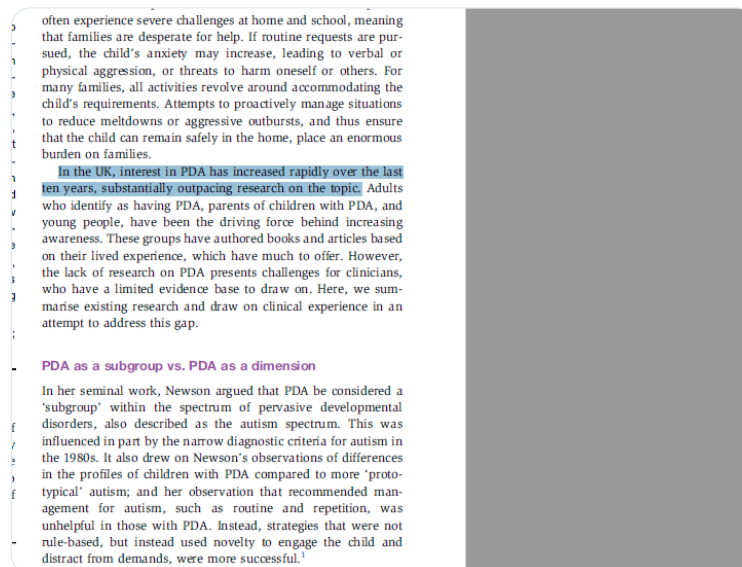


<https://link.springer.com/content/pdf/10.1007/s00787-015-0740-2.pdf>



Screenshot and link for first quote.

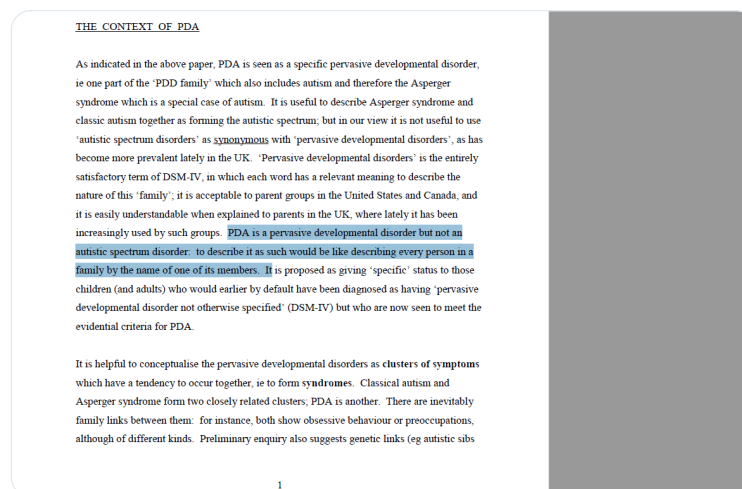
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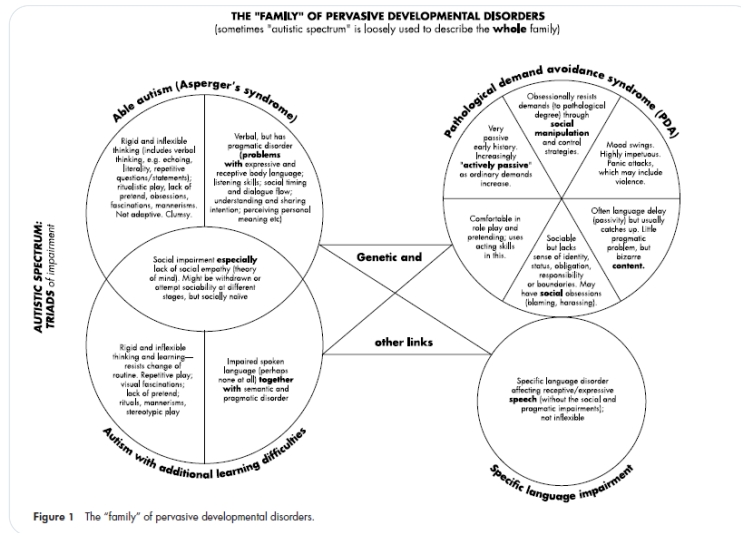
To contrast the decision to view PDA as an ASD in 2011, if one considers the debates surrounding PDA in the literature in its first 5 articles published before 2010.

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>



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.



"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.

DISORDER IN CHILDHOOD

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>

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, pride and shame) would be specially difficult to identify reliably. Others are suggestive 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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- (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.

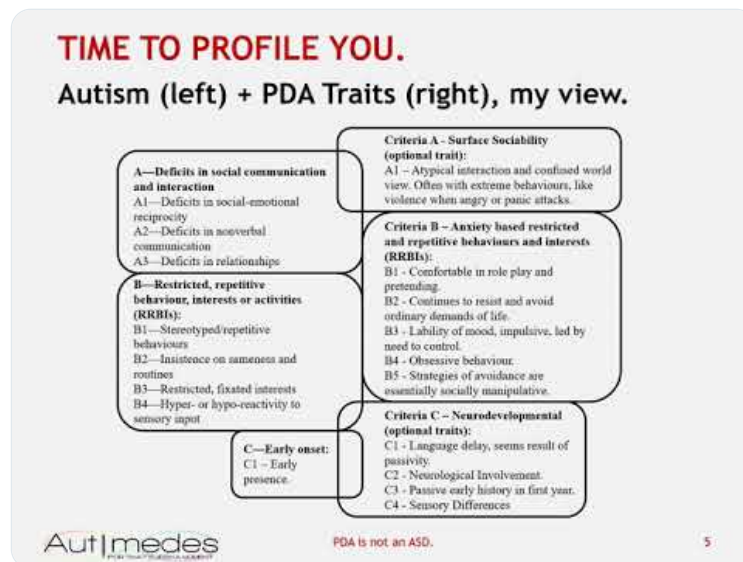
Editorial comment

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

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.

<https://www.ingentaconnect.com/contentone/bild/gap/2007/00000008/00000001/art00002>

	<p>Phil Christie, UK</p> <p>Editorial comment</p> <p>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, <i>The distinctive clinical and educational needs of children with Pathological Demand Avoidance syndrome: guidelines for good practice</i>, 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.</p>	<p>at Suth, and the contribu</p>
<p>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</p>		<p>clinic, most of the children referred anomalous in their development reminded the referring professor autism or Asperger's syndrome</p>

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

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

Garraida (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.

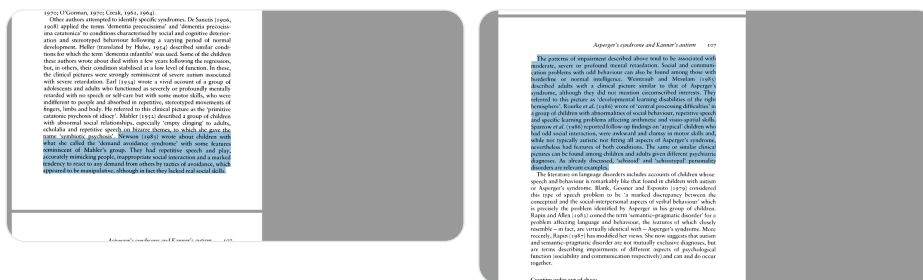
37

"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.

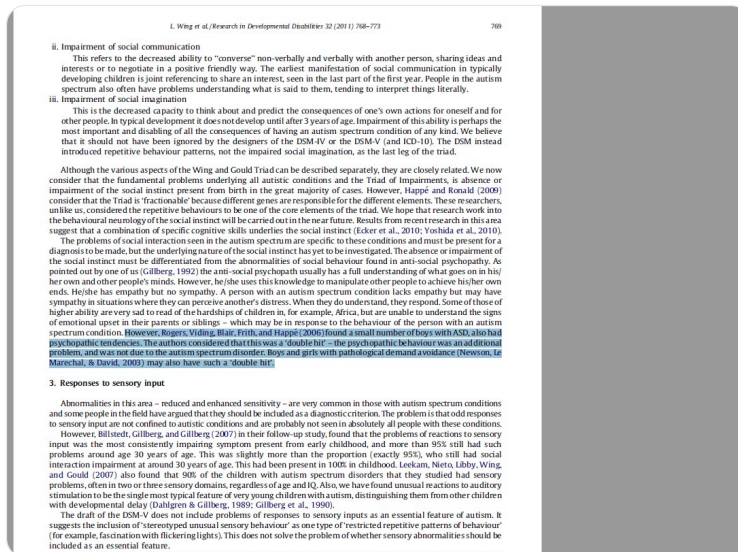
Matching assertions in Gould & Ashton-Smith (2011), & partly comments made with Wing

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).



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



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 prolonged 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.

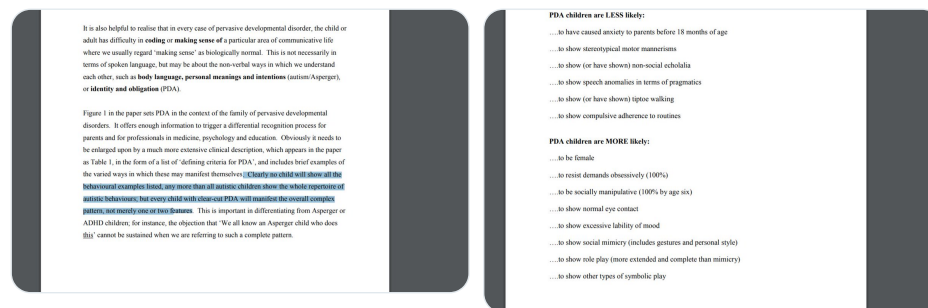
Newson's research only really shows that PDA is different to autism, but she seems to take steps to ensure that would happen, like not basing PDA on triad of impairment & excluding those with autism features.

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>

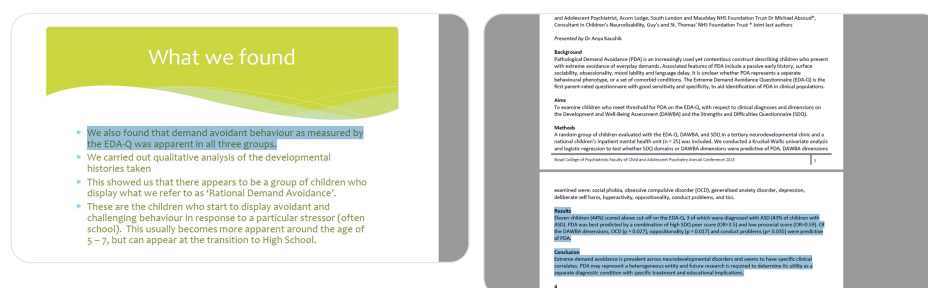


Despite Newson detailing her diagnostic threshold, no-one seems to have attempted to replicate it. Considering the acknowledged difficulties in comparing PDA diagnoses due to lack of agreed diagnostic criteria & validated tools...

... 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.



IT COULD BE THAT THOSE CHILDREN WHO NEED IT, DON'T
 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 difficul-
 ties/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'Hara 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 DSM-5 as
 a subcategory of autism. Further work by O'Hara et al
 (2016) found PDA within the ASD population to be
 consistent with Newson's description: 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 may be 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 inter-
 est 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](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."

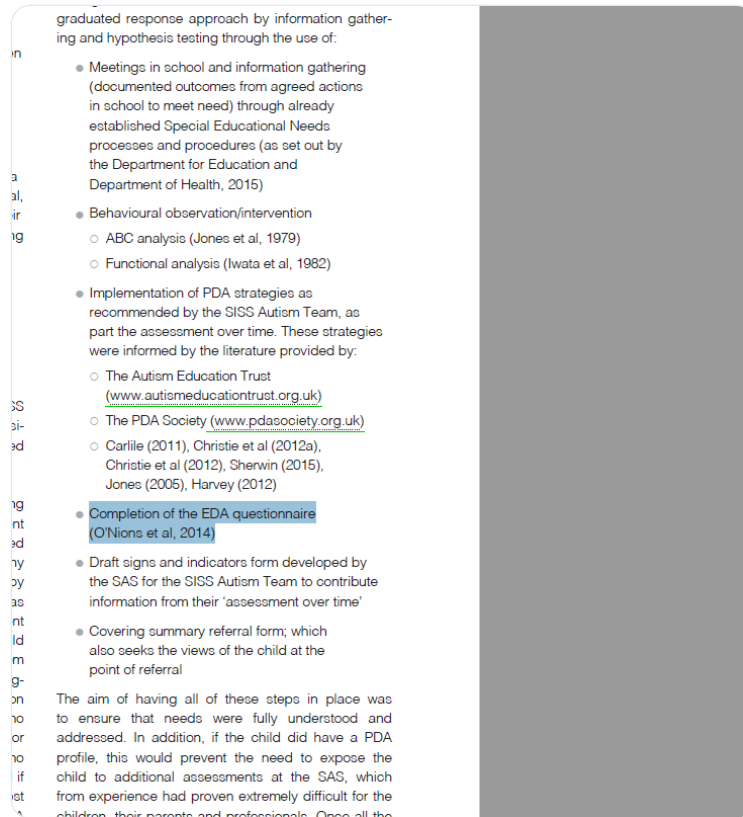
in Developmental Disabilities

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>



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>



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.

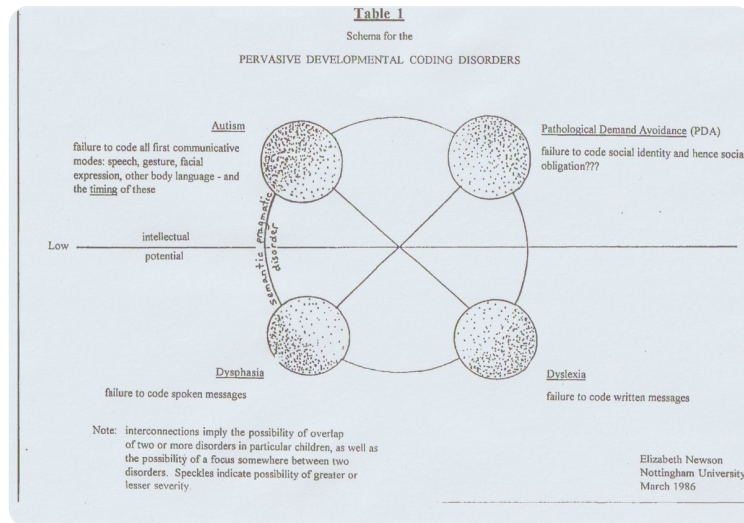
I am adding this to it, as it as I am basing the items of key points that were extant in the PDA literature in 2011. Which seems a reasonable place to base items on, considering it is from this point it appears an agenda to view PDA as an ASD starts.

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).

Demand Avoidance syndrome: guidelines for good practice

Phil Christie, UK

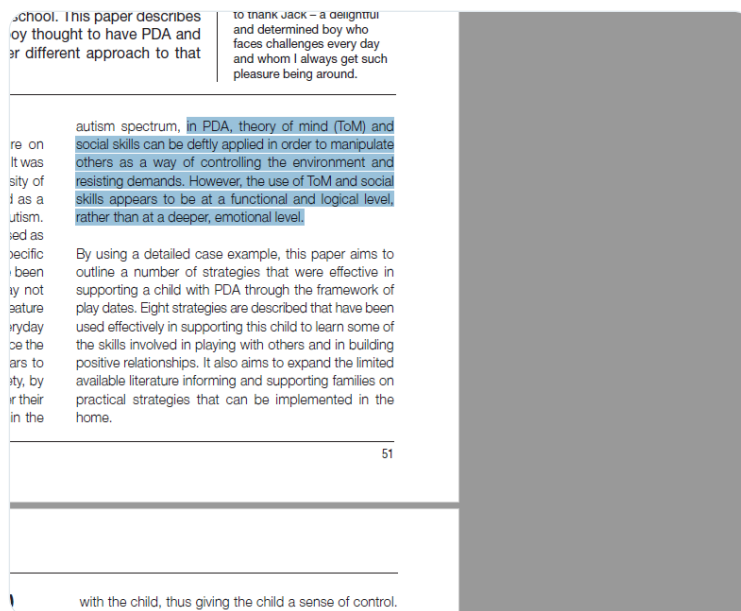
Editorial comment

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 development 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).



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.

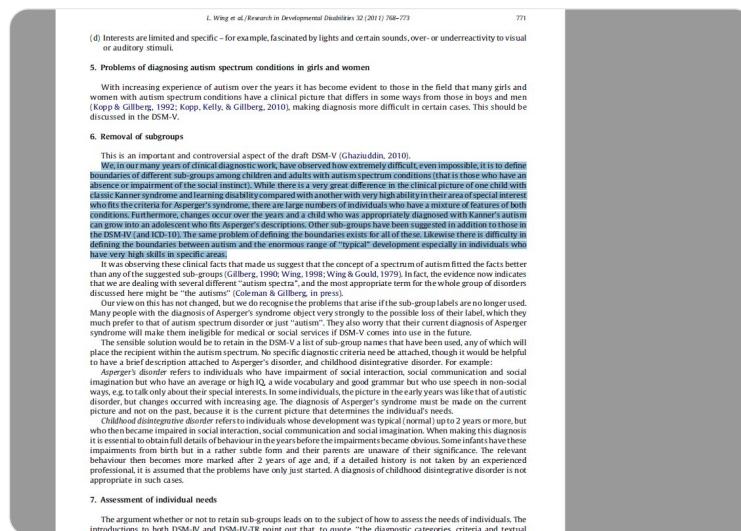
The above point matters as it directly contradicts Christie's frequent conference presentation point that PDA has to be Developmental in nature.

"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

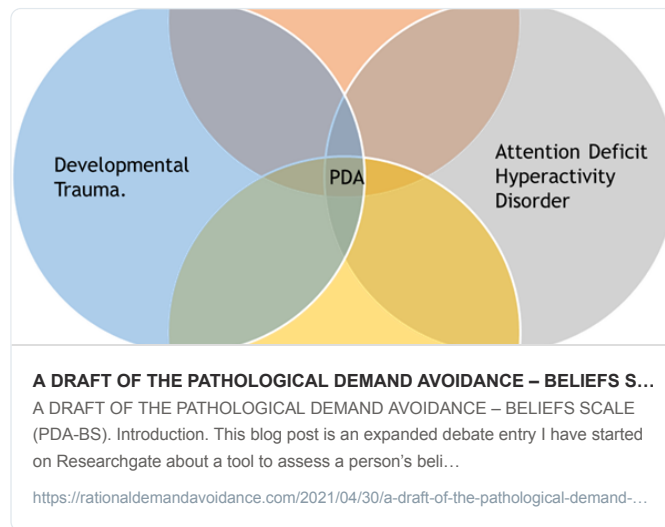
<https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/The-family-of-pervasive-development-disorders.pdf>



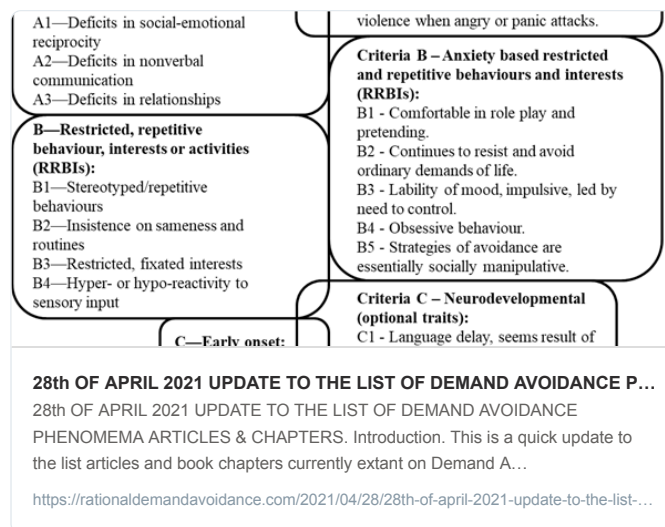
I am also including an item on PDA meant to have different strategies compared to traditional autism ones, as this point is frequently made in the literature, even though I think point is highly debatable. It seems fair to include it.

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:



List of PDA articles, I checked was from here.



There was another link I wished to add to this thread, but I have currently forgotten 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. Happé discusses this in the original research agenda conference slides. Slides 16 + 17.

Proposed Changes in DSM5 (APA)

- Autistic disorder, Asperger Disorder, PDD-NOS to be collapsed into 'Autism Spectrum Disorder'
- Individual's profile mapped in terms of
 - Social and communication difficulties
 - Rigid and repetitive difficulties
 - Language level, intellectual functioning
 - Other factors: e.g. anxiety, depression, challenging behaviour, scaffolding or adverse life factors...
- New diagnostic category under Language Disorders: Social Communication Disorder

Making it into the diagnostic manuals

Need to demonstrate that a proposed new Dx category is

- distinct from existing diagnostic categories in term of
 - symptoms
 - neuropsychological profile
 - Course and prognosis
 - Cause and/or neural substrates
- more than just a *feature* of other conditions
 - E.g. 'sensory processing disorder' – does it occur alone?
- Show it is sufficiently common and impairing

New research ideas and questions about PDA

Overview

- PDA: much concern, little research
- Why research PDA?
- PDA and Autism Spectrum Disorders?
- Does understanding the basis of ASD help us understand PDA?
- What underlies demand avoidance?
- How might PDA make it into the diagnostic manuals?
- Our current research into PDA

Prof. Francesca Happé
francesca.happe@kcl.ac.uk
Elizabeth O'Nions
elizabeth.o'nions@kcl.ac.uk

MRC Social, Genetic and Developmental Psychiatry Centre

KING'S COLLEGE LONDON

Consultant Child Psychologist and Director
The Elizabeth Newson Centre

10.30 **Living with PDA - the parent perspective**

- What it is like living with PDA
- Why getting a diagnosis matters
- Effect on siblings and strategies to manage behaviour within the home
- About the PDA Contact Forum

Dr Mirjam Dumas
National Coordinator, PDA Contact Forum

11.10 **Refreshment break**

11.40 **New research ideas and questions about PDA**

- The puzzle of PDA
- Exploring PDA traits in existing data from a large population-based twin sample
- Future research into the cognitive profile underlying PDA

Professor Francesca Happé
Professor of Cognitive Neuroscience, MRC SGDP Centre
Institute of Psychiatry, King's College London
and
Lia O'Nions
Postgraduate research student, MRC SGDP Centre
Institute of Psychiatry, King's College London

12.30 **Lunch**

The NAS reserves the right to make amendments to the advertised conference programme and speakers.

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/So890-8567\(11\)00268-1/fulltext](https://www.jaacap.org/article/So890-8567(11)00268-1/fulltext)

HAPPE

individuals or those with complex patterns of compensation, despite clinical-level difficulties.

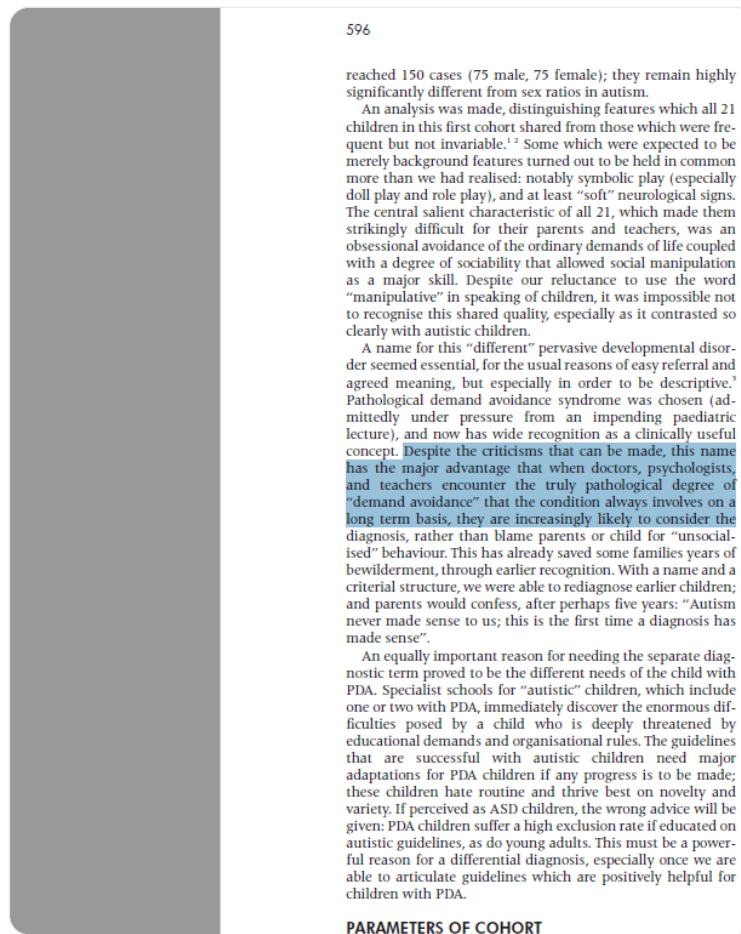
In conclusion, by folding Asperger disorder and PDD-NOS into ASD, we in the DSM-5 workgroup hope to produce a clearer and simpler diagnostic system and improved recognition and diagnosis for those with autism spectrum disorders across all ages and ability levels. Asperger disorder in DSM-IV did a great 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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1. Mantle M, Gillberg M, Liss S, et al. Autism spectrum disorders according to DSM-IV-TR and comparison with DSM-5 draft criteria: an epidemiological study. *J Am Acad Child Adolesc Psychiatry*. 2011;50:580-592.
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. Wang L, Gould J, Gillberg C. Autism spectrum disorders in the DSM-IV: better or worse than the DSM-IV? *Res Dev Disabil*. 2011;35:768-775.
4. Winner AN, Lattin L. Validity of autism spectrum disorder subtypes. *J Autism Dev Disord*. 2009;39:1611-1624.
5. Hendrix 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;33:1-13.
- 6.
- 7.
- 8.
- 9.
- 10.
- 11.

First, we have proposed the term *autism spectrum disorder* because it reflects current wide-spread 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.⁶ Overall, it does not appear that those individuals on the autism spectrum who meet expected language milestones in the first 3 years (i.e., most 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.⁷ 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,

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



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

[illegible]

I think I have covered everything, need to save this and publish a blog post on the draft.

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

Thank you in advance.

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