Richard Woods @Richard_Autism
15 Jul 20 • 31 tweets • Richard_Autism/status/1283351293826945027

Something that has been bothering me today and is making me cry. It is the conduct of @sallyrssll via her role as a @PDASociety trustee in relation to my research.

Over last several months she has done various things such as 1)Told me that the clinical descriptions by @DrJudes03 is not a behaviour profile.

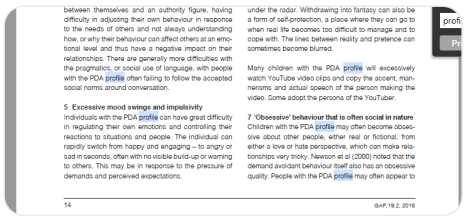
2) Tried to interfere in my research by insisting an unvalidated semi-structured interview created by Liz O'Nions and Fracesca Happe cannot be used to diagnose PDA in non-autistic persons as it is against the wishes of Elizabeth Newson.

Specifically saying a checklist would be against Newson's wishes.

In relation to the first one. It is from this article here:
https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00003
The criteria presented by @DrJudes03 are:
Early history
Resisting and avoiding the ordinary demands
Using social strategies as part of the avoidance

Appearing sociable on the surface
Excessive mood swings and impulsivity
Being comfortable in role play and pretence –
sometimes to an extreme extent
"Obsessive' behaviour that is often social in nature
Sensory differences

Judy Eaton does describe PDA as a profile. One would note that these 8 key features are similar to Elizabeth Newson's. There are some differences, a major one being the inclusion of "Sensory Difference". @DrJudes03 also assumed PDA is an ASD.


between themselves and an authority figure, having difficulty in adjusting their own behaviour in response to the needs of others and not always understanding how, or why their behaviour can affect others at an emotional level and thus have a negative impact on their relationships. There are generally more difficulties with the pragmatics, or social use of language, with people with the PDA profile often failing to follow the accepted social norms around conversation.

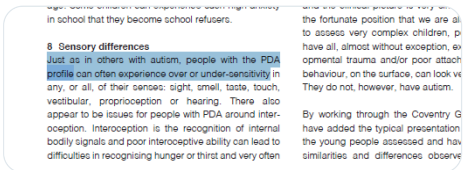
5 Excessive mood swings and impulsivity
Individuals with the PDA profile can have great difficulty in regulating their own emotions and controlling their reactions to situations and people. The individual can rapidly switch from happy and engaging – to angry or sad in seconds, often with no visible build-up or warning to others. This may be in response to the pressure of demands and perceived expectations.

under the radar. Withdrawing into fantasy can also be a form of self-protection, a place where they can go to when real life becomes too difficult to manage and to cope with. The lines between reality and pretence can sometimes become blurred.

Many children with the PDA profile will excessively watch YouTube video clips and copy the accent, mannerisms and actual speech of the person making the video. Some adopt the persona of the YouTuber.

7 'Obsessive' behaviour that is often social in nature
Children with the PDA profile may often become obsessive about other people, either real or fictional, from either a love or hate perspective, which can make relationships very tricky. Newson et al (2000) noted that the demand avoidant behaviour itself also has an obsessive quality. People with the PDA profile may often appear to

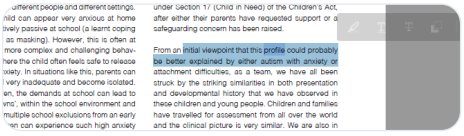
14 GAP.19.2. 2018


in school that they become school refusers.

8 Sensory differences
Just as in others with autism, people with the PDA profile can often experience over or under-sensitivity in any, or all, of their senses: sight, smell, taste, touch, vestibular, proprioception or hearing. There also appear to be issues for people with PDA around interoception. Interoception is the recognition of internal bodily signals and poor interoceptive ability can lead to difficulties in recognising hunger or thirst and very often

the fortunate position that we are al
to assess very complex children, p
have all, almost without exception, e
opmental trauma and/or poor attach
behaviour, on the surface, can look ve
They do not, however, have autism.

By working through the Coventry G
have added the typical presentation
the young people assessed and hav
similarities and differences observe


different people and different settings.
hild can appear very anxious at home
ively passive at school (a learnt coping
as masking). However, this is often at
more complex and challenging behav-
here the child often feels safe to release
xiety. In situations like this, parents can
very inadequate and become isolated.
en, the demands at school can lead to
ns', within the school environment and
multiple school exclusions from an early
n can experience such high anxiety

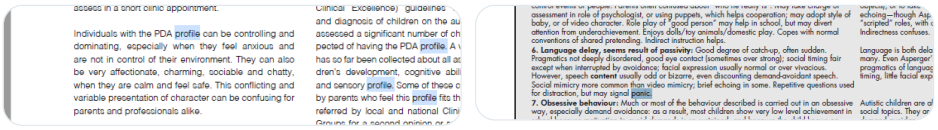
under Section 17 (Child in Need) of the Children's Act,
after either their parents have requested support or a
safeguarding concern has been raised.

From an initial viewpoint that this profile could probably
be better explained by either autism with anxiety or
attachment difficulties, as a team, we have all been
struck by the striking similarities in both presentation
and developmental history that we have observed in
these children and young people. Children and families
have travelled for assessment from all over the world
and the clinical picture is very similar. We are also in

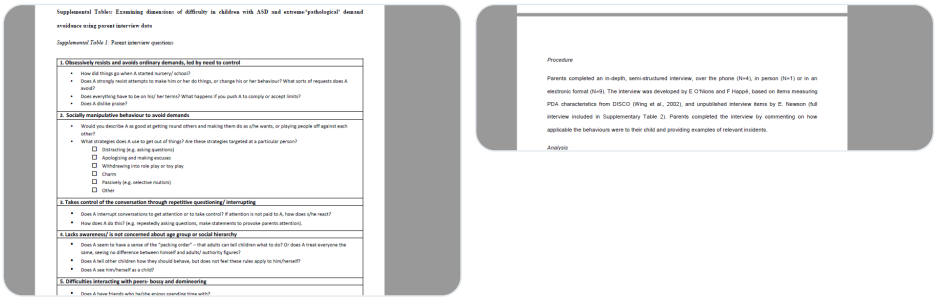
The descriptions by @DrJudes03 are similar in nature to those by Elizabeth Newson:

https://adc.bmj.com/content/archdischild/88/7/595.full.pdf

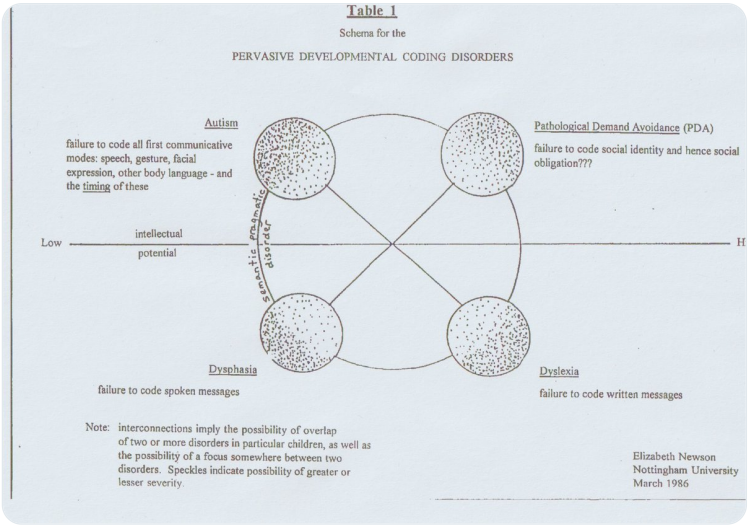
My point here is that the "Key Features" of PDA described by Judy Eaton is a behaviour profile in its own right.



The second point is a bit more complicated. The semi-structured interview in question is this one:
https://acamh.onlinelibrary.wiley.com/action/downloadSupplement?doi=10.1111%2Fcamh.12242&file=camh12242-sup-0001-Supinfo.pdf
Was created by Liz O'Nions and @HappeLab for O'Nions PhD research:
http://www.pdaresource.com/files/An%20examination%20of%20the%20behavioural%20features%20associated%20with%20PDA%20using%20a%20semi-structured%20interview%20-%20Dr%20E%20O'Nions.pdf

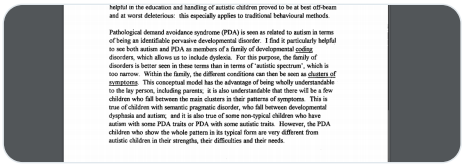


Newson created her own diagnostic grouping “Pervasive Developmental Coding Disorders in 1989.As she thought autism was too narrowly defined:
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-Syndrome.pdf
&
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-a-statistical-update.pdf



Newson wanted a diagnostic grouping that can benefit lay persons, including carers.

This diagnostic grouping eventually evolved into the "Autistic Family" diagram.



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

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

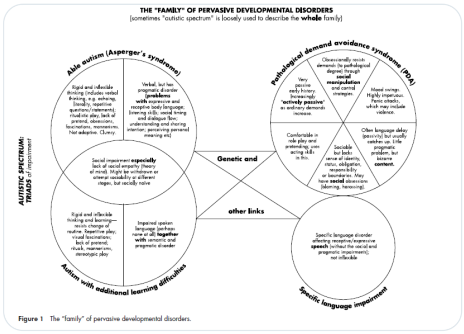
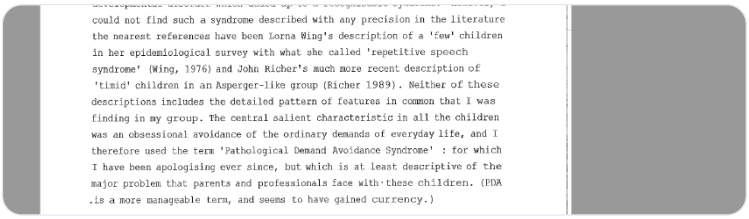


Figure 1 The "family" of pervasive developmental disorders.

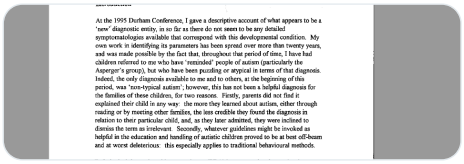
Newson has consistently shown over 15 years worth PDA scholarship, from 1989 to 2003 that mental disorder constructs should mainly benefit lay persons like caregivers, teachers and professionals. I show how she did this.

Side point, but important did had consistently apologised for calling PDA, "Pathological" Demand Avoidance: https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-Syndrome.pdf

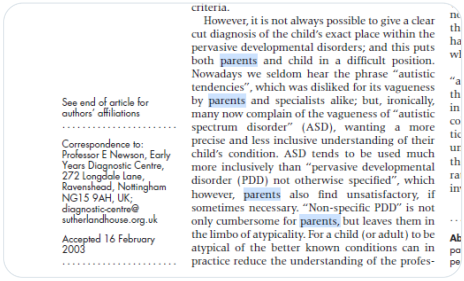


could not find such a syndrome described with any precision in the literature the nearest references have been Lorna Wing's description of a 'few' children in her epidemiological survey with what she called 'repetitive speech syndrome' (Wing, 1976) and John Richer's much more recent description of 'timid' children in an Asperger-like group (Richer 1989). Neither of these descriptions includes the detailed pattern of features in common that I was finding in my group. The central salient characteristic in all the children was an obsessional avoidance of the ordinary demands of everyday life, and I therefore used the term 'Pathological Demand Avoidance Syndrome' : for which I have been apologising ever since, but which is at least descriptive of the major problem that parents and professionals face with these children. (PDA is a more manageable term, and seems to have gained currency.)

How PDA is needed as other constructs were not helpful for parents and PDA is.



At the 1995 Durham Conference, I gave a descriptive account of what appears to be a "new" diagnostic entity, in so far as there do not seem to be any detailed symptomatologies available that correspond with this developmental condition. My own work in identifying its parameters has been spread over more than twenty years, and was made possible by the fact that, throughout that period of time, I have had children referred to me who have 'reminded' people of autism (particularly the Asperger's group), but who have been puzzling or atypical in terms of that diagnosis. Indeed, the only diagnosis available to me and to others, at the beginning of this period, was 'non-typical autism'; however, this has not been a helpful diagnosis for the families of these children, for two reasons. Firstly, parents did not find it explained their child in any way the more they learned about autism, either through reading or by meeting other families, the less credible they found the diagnosis in relation to their particular child, and, as they later admitted, they were inclined to dismiss the term as irrelevant. Secondly, whatever guidelines might be invoked as helpful in the education and handling of autistic children proved to be at best off-beam and at worst deleterious: this especially applies to traditional behavioural methods.



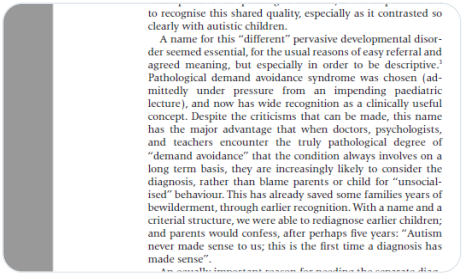
criteria.

However, it is not always possible to give a clear cut diagnosis of the child's exact place within the pervasive developmental disorders; and this puts both parents and child in a difficult position. Nowadays we seldom hear the phrase "autistic tendencies", which was disliked for its vagueness by parents and specialists alike; but, ironically, many now complain of the vagueness of "autistic spectrum disorder" (ASD), wanting a more precise and less inclusive understanding of their child's condition. ASD tends to be used much more inclusively than "pervasive developmental disorder (PDD) not otherwise specified", which however, parents also find unsatisfactory, if sometimes necessary. "Non-specific PDD" is not only cumbersome for parents, but leaves them in the limbo of atypicality. For a child (or adult) to be atypical of the better known conditions can in practice reduce the understanding of the profes-

See end of article for authors' affiliations

Correspondence to: Professor E Newson, Early Years Diagnostic Centre, 272 Longdale Lane, Ravenshead, Nottingham NG15 9AH, UK; diagnostic-centre@sutherlandhouse.org.uk

Accepted 16 February 2003

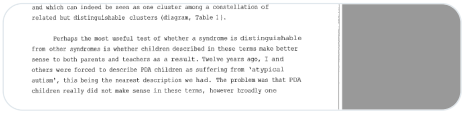


to recognise this shared quality, especially as it contrasted so clearly with autistic children.

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".

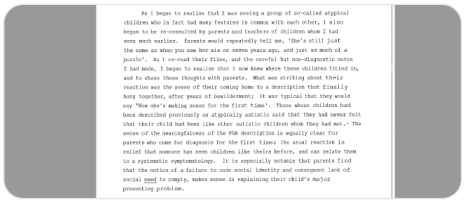
Here is Newson saying suggesting perhaps the best test for distinguishing a syndrome from other ones, if persons identified with it make better sense to teachers/ caregivers.

Newson also knew she was reifying PDA when creating its behaviour profile.



and which can indeed be seen as one cluster among a constellation of related but distinguishable clusters (diagram, Table 1).

Perhaps the most useful test of whether a syndrome is distinguishable from other syndromes is whether children described in these terms make better sense to both parents and teachers as a result. Twelve years ago, I and others were forced to describe PDA children as suffering from 'atypical autism', this being the nearest description we had. The problem was that PDA children really did not make sense in these terms, however broadly one



As I began to realise that I was seeing a group of so-called atypical children who in fact had many features in common with each other, I also began to be re-consulted by parents and teachers of children whom I had seen much earlier. Parents would repeatedly tell me, 'She's still just the same as when you saw her six or seven years ago, and just as much of a puzzle'. As I re-read their files, and the careful but non-diagnostic notes I had made, I began to realise that I now knew where these children fitted in, and to share these thoughts with parents. What was striking about their reaction was the sense of their coming home to a description that finally hung together, after years of bewilderment: it was typical that they would say 'Now she's making sense for the first time'. Those whose children had been described previously as atypically autistic said that they had never felt that their child had been like other autistic children whom they had met.– The sense of the meaningfulness of the PDA description is equally clear for parents who come for diagnosis for the first time; the usual reaction is relief that someone has seen children like theirs before, and can relate them to a systematic symptomatology. It is especially notable that parents find that the notion of a failure to code social identity and consequent lack of social need to comply, makes sense in explaining their child's major presenting problem.

– 4 –

seen that the headings differ from those in Table 2 only in the way the data is arranged and conceptualised: in fact the consistency of this pattern as it has emerged has been unexpected, but also reassures one that the definition of the data into an identifiable syndrome is indeed justified.

We can now enlarge on each defining feature in turn, drawing now on thirty-six children in illustration.

Newson et al (2003, p599) state:

"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"

This is supported by how PDA is drawn separately and away from accepted autism subtypes in her "Autistic Family" figure.

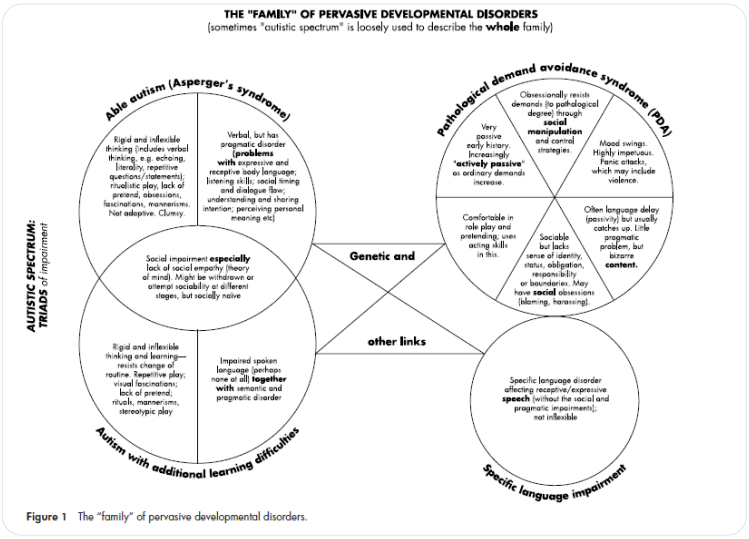


Figure 1 The "family" of pervasive developmental disorders.

Must be noted accepted subtypes are based on triad of impairment and drawn overlapping each other. This is not the case for PDA. Also PDA is based on deficits in social identity, while autism has deficits in ToM.

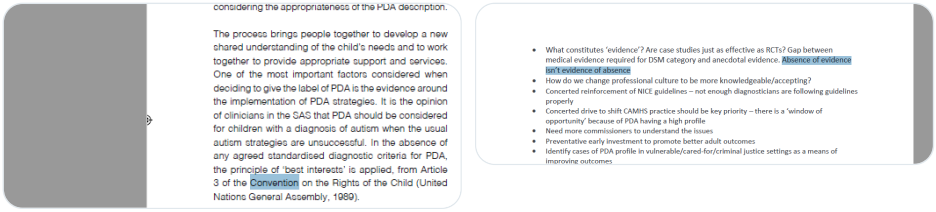
Newson's clinic specialised in "coding" disorders, where persons struggle to process aspects of communication or just not make sense of it. Newson's clinic also based in one City, Nottingham. It is possible she research is affected by sampling bias.

It is more than plausible that PDA is more common that some think it is and less narrow than some believe, i.e. how Asperger’s views on autism were more broader than Kanner’s opinions on autism.

The points about “absence of evidence is not evidence of absence” and arguments around rights to a diagnosis are equally applicable for non-autistic persons with PDA:

https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00004

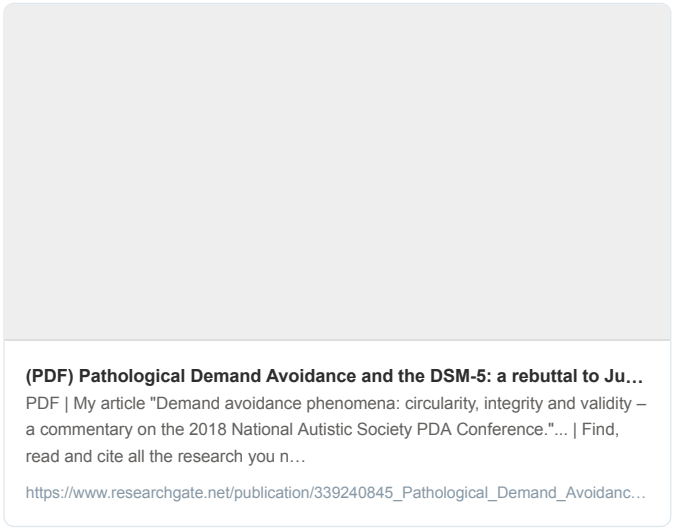
&

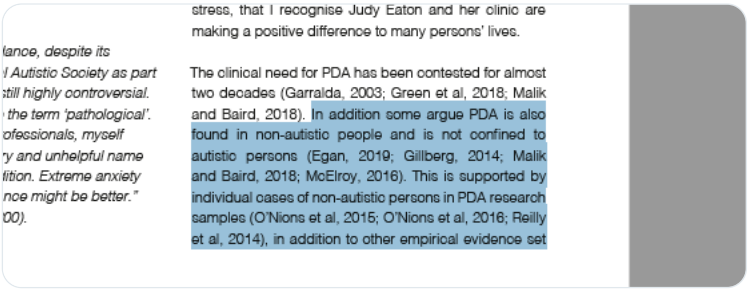

considering the appropriateness of the PDA description.

The process brings people together to develop a new shared understanding of the child's needs and to work together to provide appropriate support and services. One of the most important factors considered when deciding to give the label of PDA is the evidence around the implementation of PDA strategies. It is the opinion of clinicians in the SAS that PDA should be considered for children with a diagnosis of autism when the usual autism strategies are unsuccessful. In the absence of any agreed standardised diagnostic criteria for PDA, the principle of 'best interests' is applied, from Article 3 of the Convention on the Rights of the Child (United Nations General Assembly, 1989).

- What constitutes 'evidence'? Are case studies just as effective as RCTs? Gap between medical evidence required for DSM category and anecdotal evidence. Absence of evidence isn't evidence of absence
- How do we change professional culture to be more knowledgeable/accepting?
- Concerted reinforcement of NICE guidelines – not enough diagnosticians are following guidelines properly
- Concerted drive to shift CAMHS practice should be key priority – there is a 'window of opportunity' because of PDA having a high profile
- Need more commissioners to understand the issues
- Preventative early investment to promote better adult outcomes
- Identify cases of PDA profile in vulnerable/cared-for/criminal justice settings as a means of improving outcomes

The PDA literature does indicate they exist:




lance, despite its
l Autistic Society as part
still highly controversial.
the term 'pathological'.
ofessionals, myself
y and unhelpful name
lition. Extreme anxiety
nce might be better."
00).

stress, that I recognise Judy Eaton and her clinic are making a positive difference to many persons' lives.

The clinical need for PDA has been contested for almost two decades (Garralda, 2003; Green et al, 2018; Malik and Baird, 2018). In addition some argue PDA is also found in non-autistic people and is not confined to autistic persons (Egan, 2019; Gillberg, 2014; Malik and Baird, 2018; McElroy, 2016). This is supported by individual cases of non-autistic persons in PDA research samples (O'Nions et al, 2015; O'Nions et al, 2016; Reilly et al, 2014), in addition to other empirical evidence set

It seems:

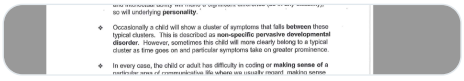
1) One could question @sallyrssll understanding of the PDA literature.
2) Newson would probably be perfectly fine with PDA being dx-ed in non-autistic persons & in any method, if the diagnosis benefitted most caregivers/ teachers/ professionals.

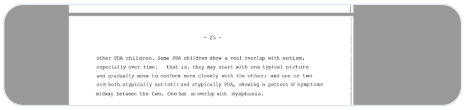
That is why I cried as it seems @sallyrssll interference in my research to stop PDA being diagnosed in non-autistic persons, as it undermines the @PDASociety position PDA is an ASD profile.

Points of clarification. Newson had consistently apologising for calling PDA "Pathological" Demand Avoidance.

Newson created her own diagnostic grouping “Pervasive Developmental Coding Disorders in 1989. As she thought autism was too narrowly defined. There are other reasons discussed above.

@Fidgety_Fucker has anyone told you Newson said people can transition between PDA to autism & vice versa?
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-Syndrome.pdf
&
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/The-family-of-pervasive-development-disorders.pdf

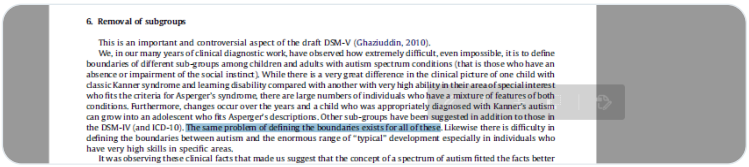




@FidgetyF_cker
Wing has repeatedly stated that autistic persons can transition between subtypes, including here with Gould & Gillberg.

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

Also applicable to PDA. My point is @DrJudes03 Rational Demand Avoidance group seems to be PDA!



6. Removal of subgroups

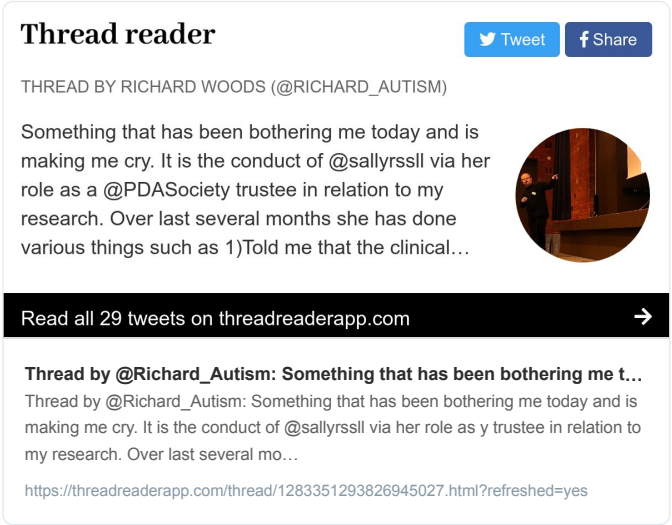
This is an important and controversial aspect of the draft DSM-V (Ghaziuddin, 2010).

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

Sorry meant to tag @FidgetyF_cker instead.

Or in other words @FidgetyF_cker the definitions of PDA you seem to cling to, appear to be: 1) Arbitrary. 2) Wrong!



• • •