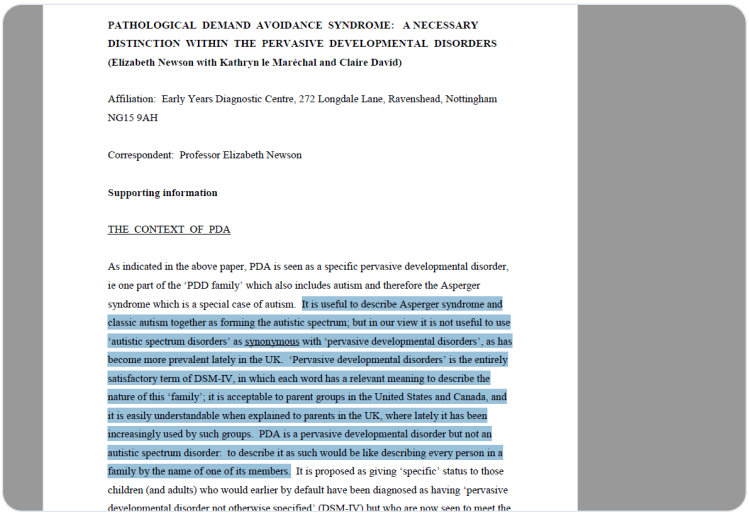
Richard Woods @Richard_Autism

23 Nov • 37 tweets • Richard_Autism/status/1330932049893584897

After much musing, this afternoon. I think a thread on partly why any credible or reputable autism expert should say PDA is NOT autism is probably warranted.

It centers on Newson's work; it is simply can NOT be used to argue PDA is autism. She does not draw PDA overlapping autism. Saying PDA has a different cause of social communication issues to autism.

First point, Newson said this herself, that PDA is not autism and including not rebranded autism (particularly Aspergers).
https://adc.bmj.com/content/archdischild/88/7/595.full.pdf?with-ds=yes



PATHOLOGICAL DEMAND AVOIDANCE SYNDROME: A NECESSARY DISTINCTION WITHIN THE PERVASIVE DEVELOPMENTAL DISORDERS
(Elizabeth Newson with Kathryn le Maréchal and Claire David)

Affiliation: Early Years Diagnostic Centre, 272 Longdale Lane, Ravenshead, Nottingham NG15 9AH

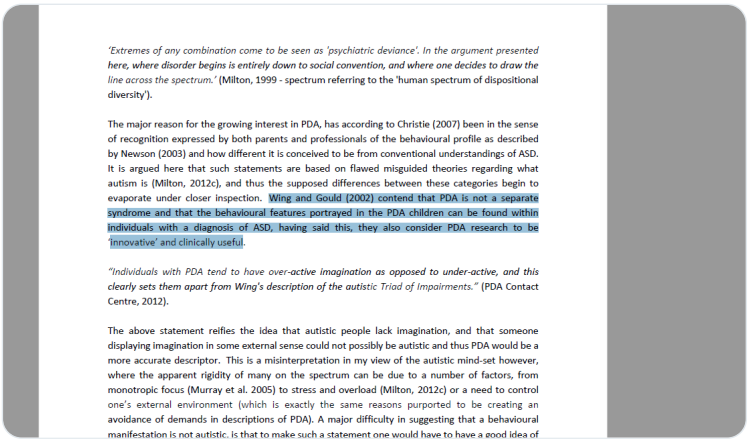
Correspondent: Professor Elizabeth Newson

Supporting information

THE CONTEXT OF PDA

As indicated in the above paper, PDA is seen as a specific pervasive developmental disorder, ie one part of the 'PDD family' which also includes autism and therefore the Asperger syndrome which is a special case of autism. It is 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

This feels like a response to Wing & Gould's comments in 2002, about PDA lacking specificity and it is not a syndrome.
https://kar.kent.ac.uk/62694/431/Natures%20answer%20to%20over%20conformity.pdf



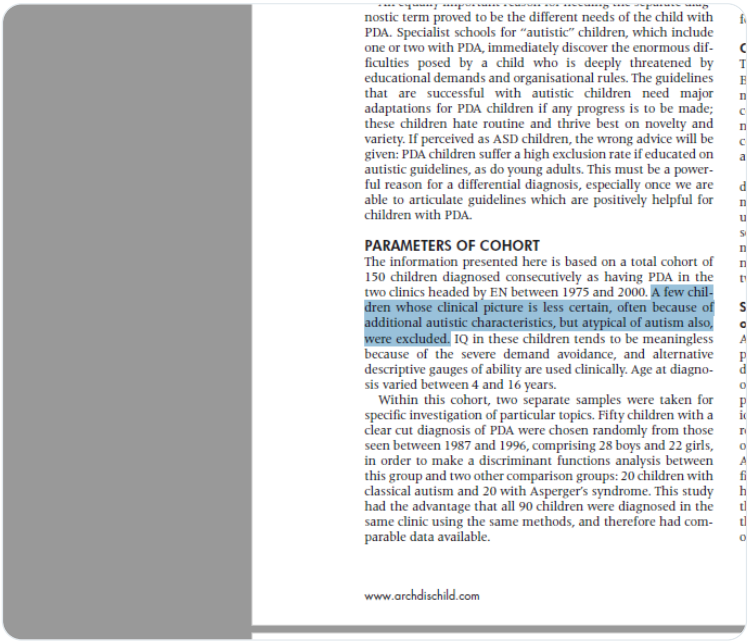
'Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum.' (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').

The major reason for the growing interest in PDA, has according to Christie (2007) been in the sense of recognition expressed by both parents and professionals of the behavioural profile as described by Newson (2003) and how different it is conceived to be from conventional understandings of ASD. It is argued here that such statements are based on flawed misguided theories regarding what autism is (Milton, 2012c), and thus the supposed differences between these categories begin to evaporate under closer inspection. Wing and Gould (2002) contend that PDA is not a separate syndrome and that the behavioural features portrayed in the PDA children can be found within individuals with a diagnosis of ASD, having said this, they also consider PDA research to be 'innovative' and clinically useful.

"Individuals with PDA tend to have over-active imagination as opposed to under-active, and this clearly sets them apart from Wing's description of the autistic Triad of Impairments." (PDA Contact Centre, 2012).

The above statement reifies the idea that autistic people lack imagination, and that someone displaying imagination in some external sense could not possibly be autistic and thus PDA would be a more accurate descriptor. This is a misinterpretation in my view of the autistic mind-set however, where the apparent rigidity of many on the spectrum can be due to a number of factors, from monotropic focus (Murray et al. 2005) to stress and overload (Milton, 2012c) or a need to control one's external environment (which is exactly the same reasons purported to be creating an avoidance of demands in descriptions of PDA). A major difficulty in suggesting that a behavioural manifestation is not autistic, is that to make such a statement one would have to have a good idea of

There are other facts to support this. Newson removed those who displayed autism features from her sample.



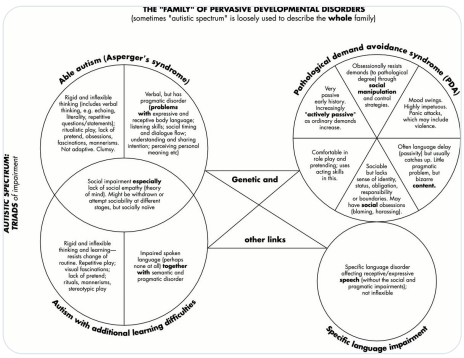
nostic term proved to be the different needs of the child with PDA. Specialist schools for "autistic" children, which include one or two with PDA, immediately discover the enormous difficulties posed by a child who is deeply threatened by educational demands and organisational rules. The guidelines that 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.

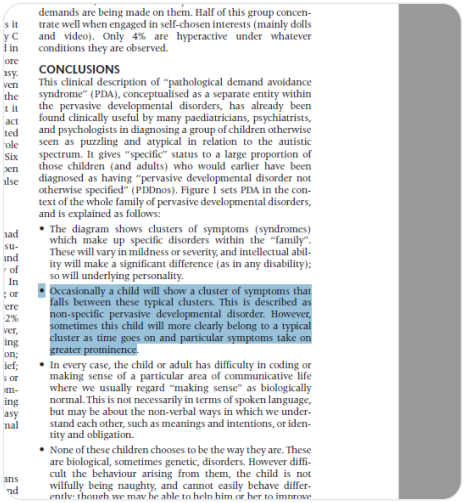
PARAMETERS OF COHORT

The information presented here is based on a total cohort of 150 children diagnosed consecutively as having PDA in the two clinics headed by EN between 1975 and 2000. A few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded. IQ in these children tends to be meaningless because of the severe demand avoidance, and alternative descriptive gauges of ability are used clinically. Age at diagnosis varied between 4 and 16 years.

Within this cohort, two separate samples were taken for specific investigation of particular topics. Fifty children with a clear cut diagnosis of PDA were chosen randomly from those seen between 1987 and 1996, comprising 28 boys and 22 girls, in order to make a discriminant functions analysis between this group and two other comparison groups: 20 children with classical autism and 20 with Asperger's syndrome. This study had the advantage that all 90 children were diagnosed in the same clinic using the same methods, and therefore had comparable data available.

Newson added Specific Language Impairment to her definition for Pervasive Developmental Disorders. How persons with PDD-NOS can transition into any of these 4 syndromes, including non-autistic persons transitioning into PDA.





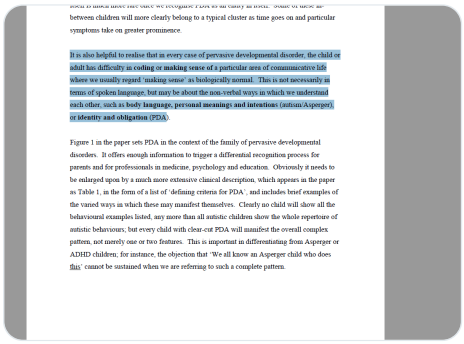
demands are being made on them. Half of this group concentrate well when engaged in self-chosen interests (mainly dolls and video). Only 4% are hyperactive under whatever conditions they are observed.

CONCLUSIONS

This clinical description of "pathological demand avoidance syndrome" (PDA), conceptualised as a separate entity within the pervasive developmental disorders, has already been found clinically useful by many paediatricians, psychiatrists, and psychologists in diagnosing a group of children otherwise seen as puzzling and atypical in relation to the autistic spectrum. It gives "specific" status to a large proportion of those children (and adults) who would earlier have been diagnosed as having "pervasive developmental disorder not otherwise specified" (PDDnos). Figure 1 sets PDA in the context of the whole family of pervasive developmental disorders, and is explained as follows:

- The diagram shows clusters of symptoms (syndromes) which make up specific disorders within the "family". These will vary in mildness or severity, and intellectual ability will make a significant difference (as in any disability); so will underlying personality.
- Occasionally a child will show a cluster of symptoms that falls between these typical clusters. This is described as non-specific pervasive developmental disorder. However, sometimes this child will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.
- In every case, 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 meanings and intentions, or identity and obligation.
- None of these children chooses to be the way they are. These are biological, sometimes genetic, disorders. However difficult the behaviour arising from them, the child is not wilfully being naughty, and cannot easily behave differently, though we may be able to help him or her to improve

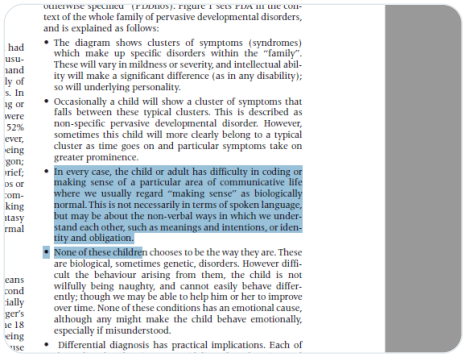
Newson said that all persons with a PDD needed coding issues, which is not needed as problems understanding other's communication would be under "Pervasive" definition.



between children will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.

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

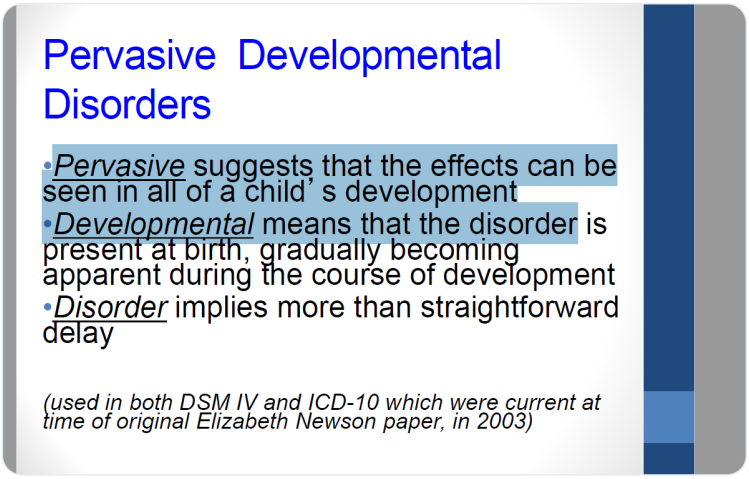
Figure 1 in the paper sets PDA in the context of the family of pervasive developmental disorders. It offers enough information to trigger a differential recognition process for parents and for professionals in medicine, psychology and education. Obviously it needs to be enlarged upon by a much more extensive 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.



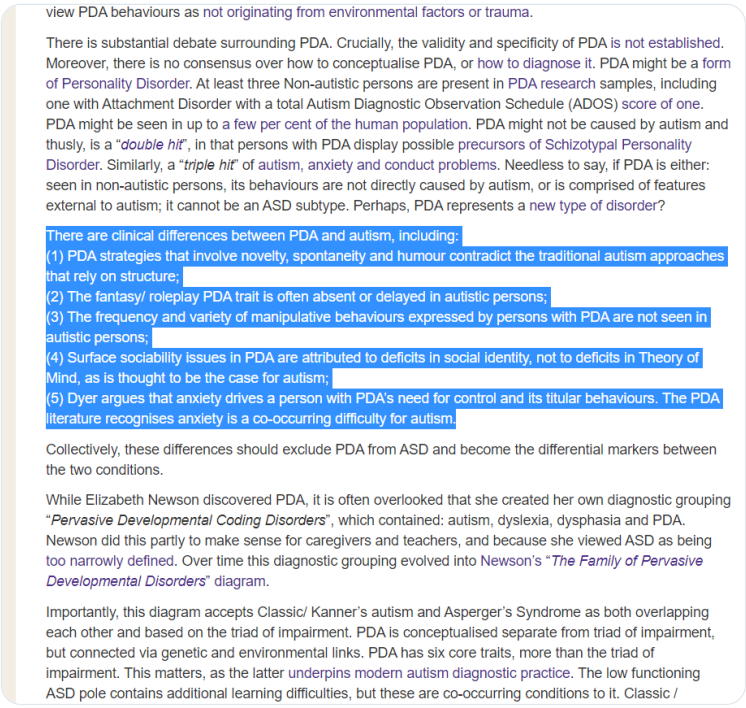
text of the whole family of pervasive developmental disorders, and is explained as follows:

- The diagram shows clusters of symptoms (syndromes) which make up specific disorders within the "family". These will vary in mildness or severity, and intellectual ability will make a significant difference (as in any disability); so will underlying personality.
- Occasionally a child will show a cluster of symptoms that falls between these typical clusters. This is described as non-specific pervasive developmental disorder. However, sometimes this child will more clearly belong to a typical cluster as time goes on and particular symptoms take on greater prominence.
- In every case, 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 meanings and intentions, or identity and obligation;
- None of these children chooses to be the way they are. These are biological, sometimes genetic, disorders. However difficult the behaviour arising from them, the child is not wilfully being naughty, and cannot easily behave differently; though we may be able to help him or her to improve over time. None of these conditions has an emotional cause, although any might make the child behave emotionally, especially if misunderstood.
- Differential diagnosis has practical implications. Each of

Definitions for "Pervasive" that Newson used were from DMS-4. Christie provides it in his conference talks.



We know PDA is does not conform to accepted autism understandings. I point out these reasons here:
https://thepsychologist.bps.org.uk/pda-new-type-disorder#:~:text=PDA%20might%20be%20a%20form,cent%20of%20the%20human%20population
&
https://rationaldemandavoidancecom.files.wordpress.com/2020/07/19th-april-2020-help4psychology-research-limitations.pdf



view PDA behaviours as not originating from environmental factors or trauma.

There is substantial debate surrounding PDA. Crucially, the validity and specificity of PDA is not established. Moreover, there is no consensus over how to conceptualise PDA, or how to diagnose it. PDA might be a form of Personality Disorder. At least three Non-autistic persons are present in PDA research samples, including one with Attachment Disorder with a total Autism Diagnostic Observation Schedule (ADOS) score of one. PDA might be seen in up to a few per cent of the human population. PDA might not be caused by autism and thusly, is a "*double hit*", in that persons with PDA display possible precursors of Schizotypal Personality Disorder. Similarly, a "*triple hit*" of autism, anxiety and conduct problems. Needless to say, if PDA is either: seen in non-autistic persons, its behaviours are not directly caused by autism, or is comprised of features external to autism; it cannot be an ASD subtype. Perhaps, PDA represents a new type of disorder?

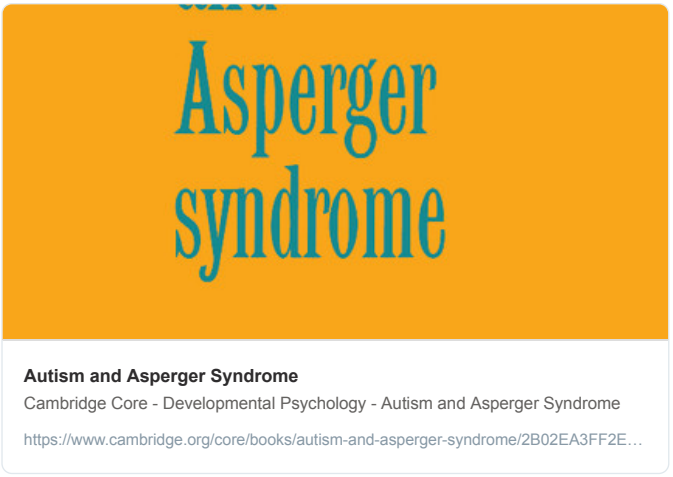
There are clinical differences between PDA and autism, including:
(1) PDA strategies that involve novelty, spontaneity and humour contradict the traditional autism approaches that rely on structure;
(2) The fantasy/ roleplay PDA trait is often absent or delayed in autistic persons;
(3) The frequency and variety of manipulative behaviours expressed by persons with PDA are not seen in autistic persons;
(4) Surface sociability issues in PDA are attributed to deficits in social identity, not to deficits in Theory of Mind, as is thought to be the case for autism;
(5) Dyer argues that anxiety drives a person with PDA's need for control and its titular behaviours. The PDA literature recognises anxiety is a co-occurring difficulty for autism.

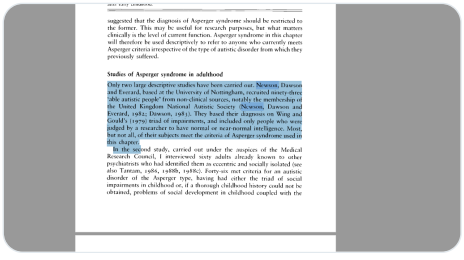
Collectively, these differences should exclude PDA from ASD and become the differential markers between the two conditions.

While Elizabeth Newson discovered PDA, it is often overlooked that she created her own diagnostic grouping "*Pervasive Developmental Coding Disorders*", which contained: autism, dyslexia, dysphasia and PDA. Newson did this partly to make sense for caregivers and teachers, and because she viewed ASD as being too narrowly defined. Over time this diagnostic grouping evolved into Newson's "*The Family of Pervasive Developmental Disorders*" diagram.

Importantly, this diagram accepts Classic/ Kanner's autism and Asperger's Syndrome as both overlapping each other and based on the triad of impairment. PDA is conceptualised separate from triad of impairment, but connected via genetic and environmental links. PDA has six core traits, more than the triad of impairment. This matters, as the latter underpins modern autism diagnostic practice. The low functioning ASD pole contains additional learning difficulties, but these are co-occurring conditions to it. Classic /

Likewise, Newson never based PDA on the Triad of Impairment that underpins modern autism criteria. Newson knew about the Triad of Impairment and used it to diagnose autism before created PDA behaviour profile.





suggested that the diagnosis of Asperger syndrome should be restricted to the former. This may be useful for research purposes, but what matters clinically is the level of current function. Asperger syndrome in this chapter will therefore be used descriptively to refer to anyone who currently meets Asperger criteria irrespective of the type of autistic disorder from which they previously suffered.

Studies of Asperger syndrome in adulthood

Only two large descriptive studies have been carried out. Newson, Dawson and Everard, based at the University of Nottingham, recruited ninety-three 'able autistic people' from non-clinical sources, notably the membership of the United Kingdom National Autistic Society (Newson, Dawson and Everard, 1982; Dowson, 1983). They based their diagnosis on Wing and Gould's (1979) triad of impairments, and included only people who were judged by a researcher to have normal or near-normal intelligence. Most, but not all, of their subjects meet the criteria of Asperger syndrome used in this chapter.

In the second study, carried out under the auspices of the Medical Research Council, I interviewed sixty adults already known to other psychiatrists who had identified them as eccentric and socially isolated (see also Tantam, 1988, 1988). Forty-six met criteria for an autistic disorder of the Asperger type, having had either the triad of social impairments in childhood or, if a thorough childhood history could not be obtained, problems of social development in childhood coupled with the

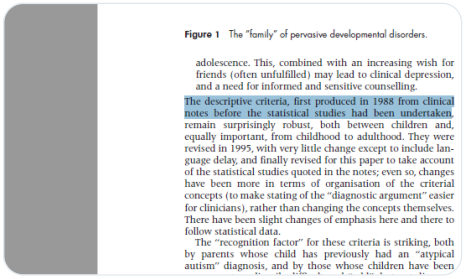


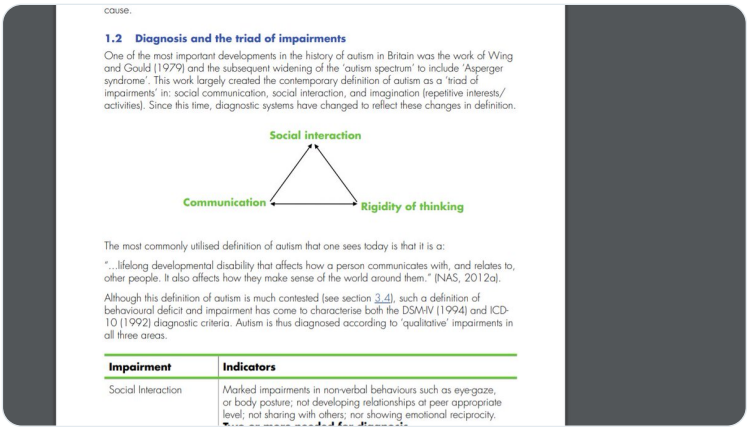
Figure 1 The "family" of pervasive developmental disorders.

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

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

The "recognition factor" for these criteria is striking, both by parents whose child has previously had an "atypical autism" diagnosis, and by those whose children have been

Reference for the triad of impairment.
https://www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1_So-what-exactly-is-autism.pdf



cause.

1.2 Diagnosis and the triad of impairments

One of the most important developments in the history of autism in Britain was the work of Wing and Gould (1979) and the subsequent widening of the 'autism spectrum' to include 'Asperger syndrome'. This work largely created the contemporary definition of autism as a 'triad of impairments' in: social communication, social interaction, and imagination (repetitive interests/ activities). Since this time, diagnostic systems have changed to reflect these changes in definition.

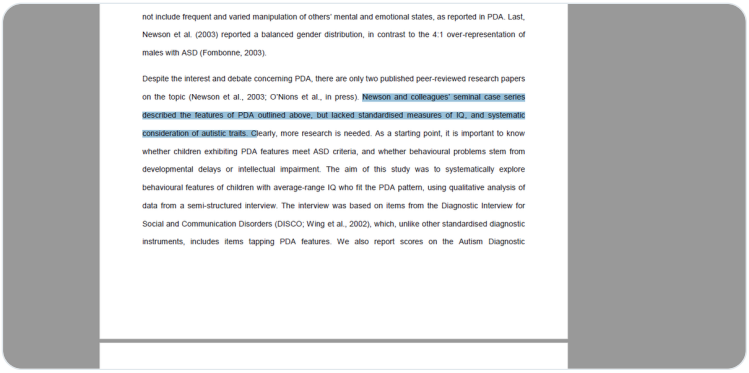
The most commonly utilised definition of autism that one sees today is that it is a:

"...lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them." (NAS, 2012a).

Although this definition of autism is much contested (see section 3.4), such a definition of behavioural deficit and impairment has come to characterise both the DSM-IV (1994) and ICD-10 (1992) diagnostic criteria. Autism is thus diagnosed according to 'qualitative' impairments in all three areas.

Impairment	Indicators
Social Interaction	Marked impairments in non-verbal behaviours such as eye-gaze, or body posture; not developing relationships at peer appropriate level; not sharing with others; nor showing emotional reciprocity.

Newson never systematically assessed her PDA cases for autism features, or for autism itself. As said previously, she excluded those who showed autism features. This is kind of the opposite of screening her sample for autism.
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

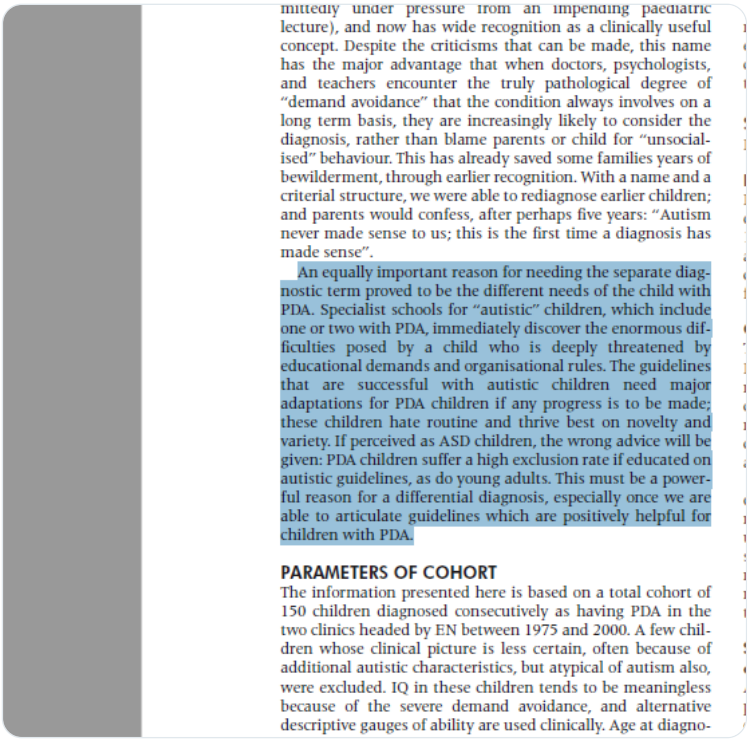


not include frequent and varied manipulation of others' mental and emotional states, as reported in PDA. Last, Newson et al. (2003) reported a balanced gender distribution, in contrast to the 4:1 over-representation of males with ASD (Fombonne, 2003).

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

We know those who would often be referred for a PDA diagnosis do not conform to autism stereotypes and would be unlikely to receive a diagnosis under DSM-5 criteria.
https://rationaldemandavoidancecom.files.wordpress.com/2020/08/01-august-2020-how-effetive-is-pda-at-helping-autistic-persons-receive-a-diagnosis-if-they-do-not-conform-to-autism-stereotypes.pdf

Newson was not trying to make PDA part of autism. She was trying to show that PDA was substantially different to autism and it is why PDA is needed within PDDs.



mittedly 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

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

"“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).

My point to all this is that there are multiple good grounds to think that PDA is NOT autism, from Newson’s research. Importantly, that it appears that Newson included some non-autistic persons in her database.

There is NO way to sure/ confident ALL her cases were autistic. Hence, we can NOT assume PDA is autism.

This means that assumptions and logic based on Newson’s work that PDA is autism fall-down very quickly as they are simply wrong. This should be obvious to any credible or reputable autism expert.

This ignores other reasons as to why PDA is not autism, such as it appears a self-validation exercise to assume PDA is autism.
https://rationaldemandavoidancecom.files.wordpress.com/2020/08/03-august-2020-pda-as-a-self-validation-exercise.pdf

Some would argue that we should favour the opinions of clinicians and practitioners who espouse the view PDA is an ASD, due to how often they interact with certain persons, who might conform to some interpretations of PDA.

The weakness here is that there is no consensus over what PDA looks like. That a PDA dx is not an indicator if a person has PDA or not.

Furthermore, it is just as possible that an equivalent expert with a different background and working experiences’ opinions on PDA are just as valid as any autism specialists are. We just do not know due to a lack of research.

Newson created her own diagnostic grouping, meaning PDA pretty much end up anyway by creating another new one.
https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Pathological-Demand-Avoidance-a-statistical-update.pdf

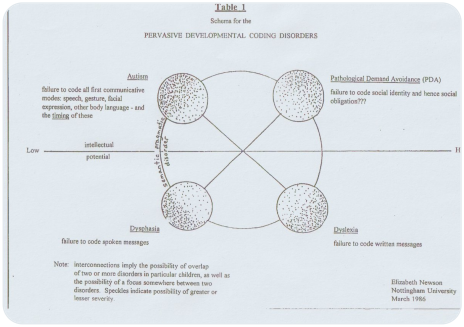
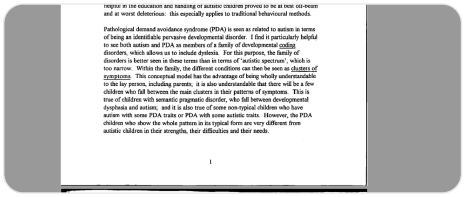


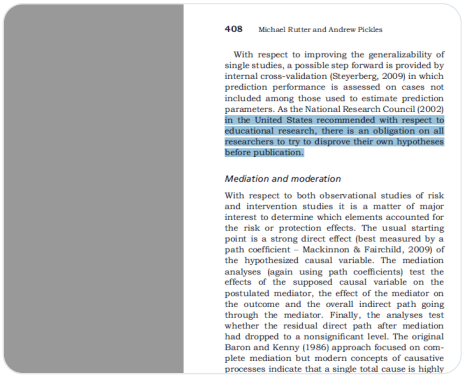
Table 1
Schema for the
PERVASIVE DEVELOPMENTAL CODING DISORDERS
Autism
failure to code all first communicative modes: speech, gesture, facial expression, other body language - and the timing of these
Pathological Demand Avoidance (PDA)
failure to code social identity and hence social obligation???
Low
intellectual potential
Dysphasia
failure to code spoken messages
Dyslexia
failure to code written messages
Note: Interconnections imply the possibility of overlap of two or more disorders in particular children, as well as the possibility of a focus somewhere between two disorders. Speckles indicate possibility of greater or lesser severity.
Elizabeth Newson
Nottingham University
March 1986


Pathological demand avoidance syndrome (PDA) is seen as related to autism in terms of being an identifiable pervasive developmental disorder. I find it particularly helpful to see both autism and PDA as members of a family of developmental coding disorders, which allows us to include dyslexia. For this purpose, the family of disorders is better seen in three 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.

To those who say PDA must be autism as it was Pervasive Developmental Disorder. Newson's version is different to the accepted one. It lacks Rett's Syndrome & Childhood Disintegrative Disorder.

I would also refer you back onto how Newson also required persons with a Pervasive Developmental Disorder to also have "Coding" issues; she is still thinking in terms of her "Pervasive Developmental Coding Disorders" diagnostic grouping.

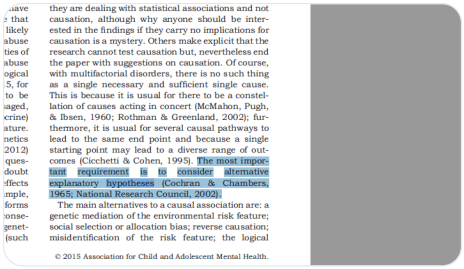
Back to the original point of the thread. Ethically, researchers should be trying to falsify hypotheses and challenge their views. We should be conducting scientific method-based research.
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference


408 Michael Rutter and Andrew Pickles

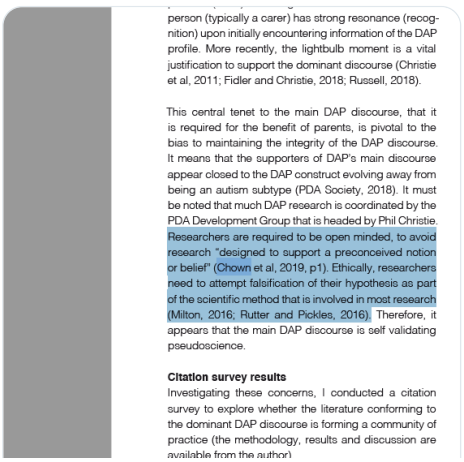
With respect to improving the generalizability of single studies, a possible step forward is provided by internal cross-validation (Steyerberg, 2009) in which prediction performance is assessed on cases not included among those used to estimate prediction parameters. As the National Research Council (2002) in the United States recommended with respect to educational research, there is an obligation on all researchers to try to disprove their own hypotheses before publication.

Mediation and moderation

With respect to both observational studies of risk and intervention studies it is a matter of major interest to determine which elements accounted for the risk or protection effects. The usual starting point is a strong direct effect (best measured by a path coefficient – Mackinnon & Fairchild, 2009) of the hypothesized causal variable. The mediation analyses (again using path coefficients) test the effects of the supposed causal variable on the postulated mediator, the effect of the mediator on the outcome and the overall indirect path going through the mediator. Finally, the analyses test whether the residual direct path after mediation had dropped to a nonsignificant level. The original Baron and Kenny (1986) approach focused on complete mediation but modern concepts of causative processes indicate that a single total cause is highly


they are dealing with statistical associations and not causation, although why anyone should be interested in the findings if they carry no implications for causation is a mystery. Others make explicit that the research cannot test causation but, nevertheless end the paper with suggestions on causation. Of course, with multifactorial disorders, there is no such thing as a single necessary and sufficient single cause. This is because it is usual for there to be a constellation of causes acting in concert (McMahon, Pugh, & Ibsen, 1960; Rothman & Greenland, 2002); furthermore, it is usual for several causal pathways to lead to the same end point and because a single starting point may lead to a diverse range of outcomes (Cicchetti & Cohen, 1995). The most important requirement is to consider alternative explanatory hypotheses (Cochran & Chambers, 1965; National Research Council, 2002).

The main alternatives to a causal association are: a genetic mediation of the environmental risk feature; social selection or allocation bias; reverse causation; misidentification of the risk feature; the logical


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)

ALL autism researchers have an obligation to improve the standards of common poor-quality autism research (which many PDA studies fall into).
https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13315

Such sources of COI may be encouraged by universities, which—the evidence suggests—do not encourage their accurate reporting. We might then ask, more generally, to what extent inadequate standards in autism intervention research are enabled by the actions or inactions of universities.

Concerns raised by this unprecedented paper thus extend beyond the level of individual author COIs. Bottema-Beutel et al.'s work tells us to be alert to these issues when conducting, reporting, and evaluating research. Despite perverse incentives, individual researchers and research groups have an obligation to improve the entrenched low standards in autism intervention research. Perpetuating and taking advantage of low standards is anathema to the true purpose of science: to make discoveries that ultimately make people's lives

chiatry published by John Wiley & Sons Ltd on behalf of Association for Child and Adolescent Mental Health

interventions. It has led individuals, organizations, and governments to invest their money, and their reputations, in interventions, training, and certification. Having invested themselves so heavily, they have no incentive to acknowledge, much less encourage, good quality research which may show they have erred. This process has also produced volumes of litigation (with paid expert witnesses, who have COIs) propagating claims that autistics not receiving hyped interventions (whose benefits vs harms are uncertain at best) are incapable of learning and

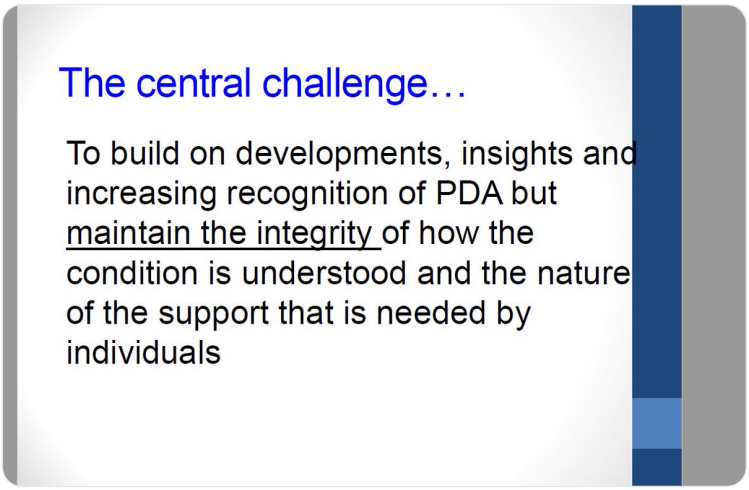
© 2020 The Authors. Journal of Child Psychology and Psychiatry p

better. Knowing and applying the best available standards is essential to the development of an evidence base for early intervention research in autism that we can trust.

Acknowledgements

S.F-W. has published one early autism intervention evaluation study, based on an iPad app, and reporting null results. She included the following Conflict of Interest (COI) statement in the published paper: *The*

It is not scientific to try and maintain the integrity of someone's understandings of something. I.e. It is unethical of Christie to say this.



To me someone saying PDA is an ASD, is like someone saying that ABA is scientific, has good evidence base and helps autistic persons.

Yet, many autistic persons, would recognize such views on ABA to nonsense. Many autism experts challenge the unscientific evidence base of ABA/ PBS; arguing we deserve better.

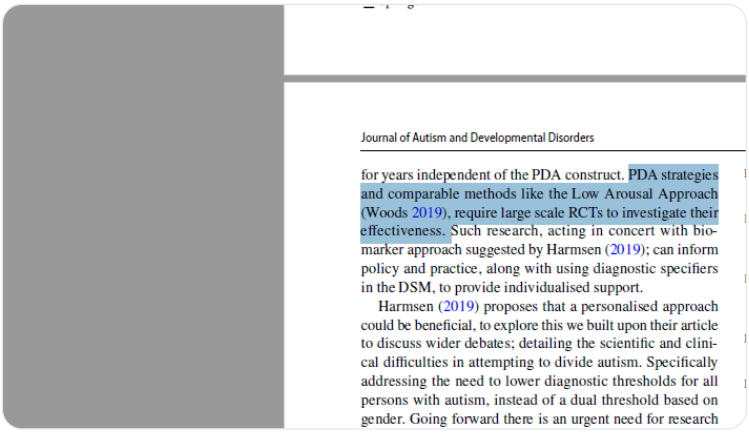
Example, Likes of @ABAControversyUK blocks people who do not listen to case against ABA etc. The situation is no different for PDA in my views.

We know that assuming PDA is an ASD is negatively impacting PDA research.
https://rationaldemandavoidancecom.files.wordpress.com/2020/08/03-august-2020-pda-as-a-self-validation-exercise.pdf

To me it is reasonable not take anyone seriously if they are assuming PDA is autism after they have been presented with at least this information. Especially, if an expert should already know this information about Newson's work.

This is not a maybe/ if/or matter, to me this is a serious topic, about maintaining the

(little) integrity of autism research, policy, and practice. Why else would I argue that level of evidence PDA strategies require are RCTs?


Journal of Autism and Developmental Disorders

for years independent of the PDA construct. PDA strategies and comparable methods like the Low Arousal Approach (Woods 2019), require large scale RCTs to investigate their effectiveness. Such research, acting in concert with biomarker approach suggested by Harmsen (2019); can inform policy and practice, along with using diagnostic specifiers in the DSM, to provide individualised support.

Harmsen (2019) proposes that a personalised approach could be beneficial, to explore this we built upon their article to discuss wider debates; detailing the scientific and clinical difficulties in attempting to divide autism. Specifically addressing the need to lower diagnostic thresholds for all persons with autism, instead of a dual threshold based on gender. Going forward there is an urgent need for research

This transcends people's careers and reputations. This is about trying to help people's lives through good quality scientific-method research and principles.

This is a red line for me, it is primarily through demanding such standards, that autistic lives will be improved.

It is a test of an autism expert's integrity in how they portray PDA.

@threadreaderapp please unroll?

• • •