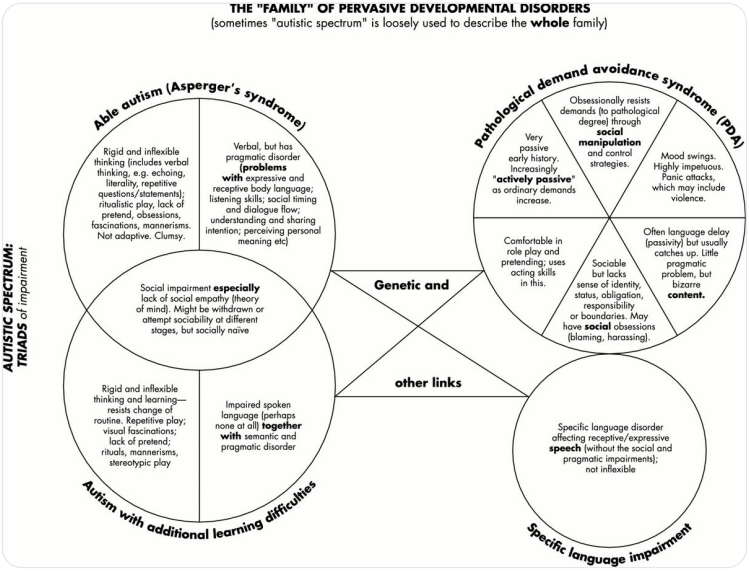
Richard Woods @Richard_Autism

14 Nov • 17 tweets • Richard_Autism/status/1327673982968066050

It is worth pointing out that while Newson did argue that behavioural based approaches, which would include ABA/ PBS are unsuitable for PDA. It is not the same as saying that she thought ABA/ PBS was unsuitable for autism.

First main point is that Newson considered PDA to NOT be autism and to be clinically distinct from autism, i.e. it is not an autism subtype or an autism subgroup.



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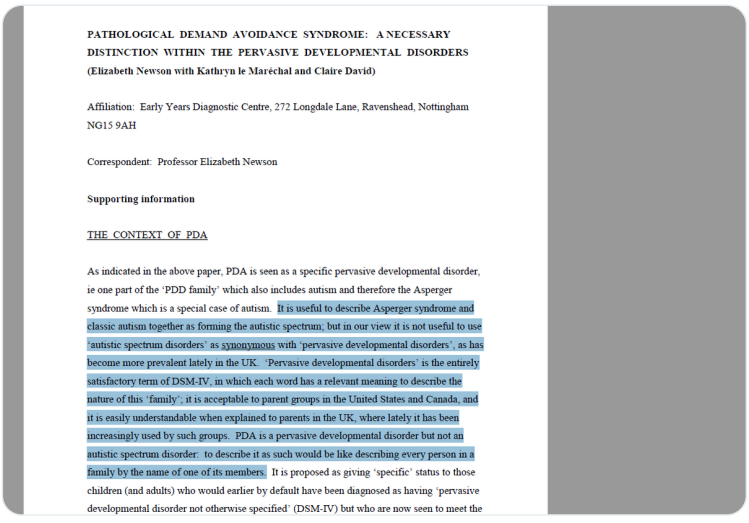

PATHOLOGICAL DEMAND AVOIDANCE SYNDROME: A NECESSARY DISTINCTION WITHIN THE PERVASIVE DEVELOPMENTAL DISORDERS

(Elizabeth Newson with Kathryn le Maréchal and Claire David)

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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

The other key point is that Newson argued that PDA was needed as it has distinct

educational approaches and needs from autism. She placed substantial emphasis on this point:
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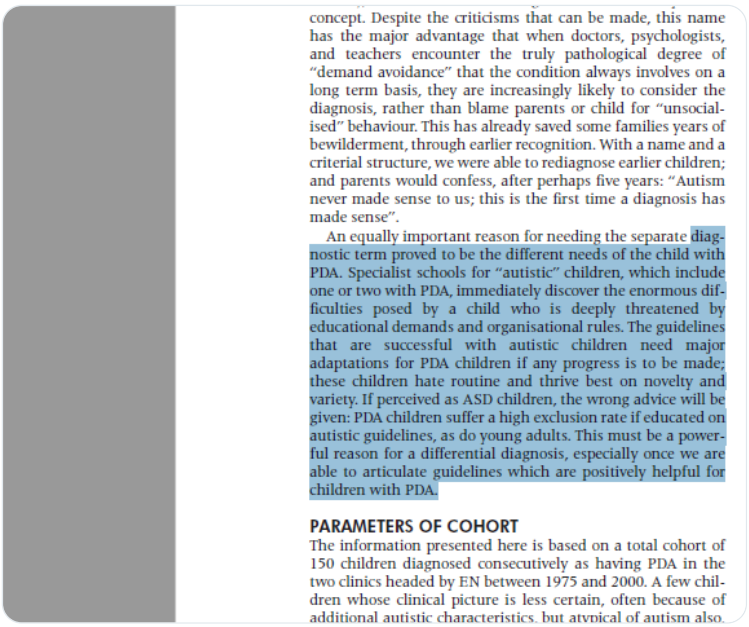


concept. Despite the criticisms that can be made, this name has the major advantage that when doctors, psychologists, and teachers encounter the truly pathological degree of "demand avoidance" that the condition always involves on a long term basis, they are increasingly likely to consider the diagnosis, 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".

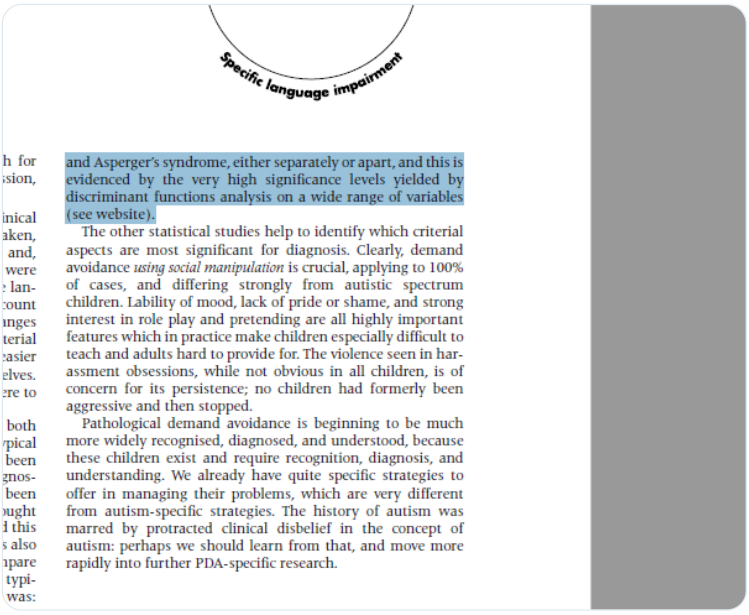
An equally important reason for needing the separate diagnostic term proved to be the different needs of the child with PDA. Specialist schools for "autistic" children, which include one or two with PDA, immediately discover the enormous difficulties posed by a child who is deeply threatened by educational 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

"“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.

Newson on how PDA needs to be significantly different to autism.



and Asperger's syndrome, either separately or apart, and this is evidenced by the very high significance levels yielded by discriminant functions analysis on a wide range of variables (see website).

The other statistical studies help to identify which criterial aspects are most significant for diagnosis. Clearly, demand avoidance *using social manipulation* is crucial, applying to 100% of cases, and differing strongly from autistic spectrum children. Lability of mood, lack of pride or shame, and strong interest in role play and pretending are all highly important features which in practice make children especially difficult to teach and adults hard to provide for. The violence seen in harassment obsessions, while not obvious in all children, is of concern for its persistence; no children had formerly been aggressive and then stopped.

Pathological demand avoidance is beginning to be much more widely recognised, diagnosed, and understood, because these children exist and require recognition, diagnosis, and understanding. We already have quite specific strategies to offer in managing their problems, which are very different from autism-specific strategies. The history of autism was marred by protracted clinical disbelief in the concept of autism: perhaps we should learn from that, and move more rapidly into further PDA-specific research.

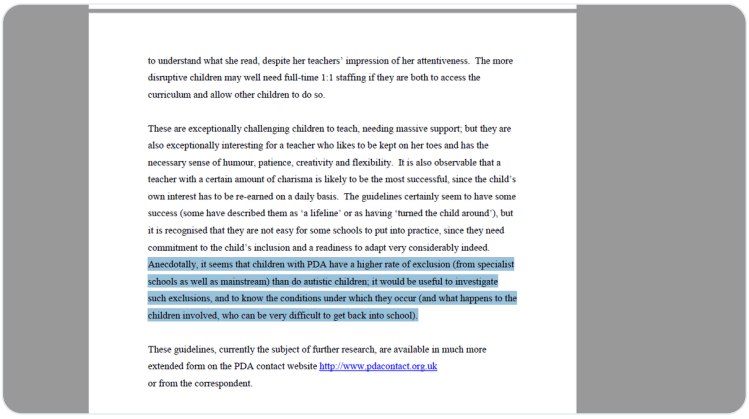
"Praise, reward, reproof, and punishment ineffective; behavioural approaches fail.

Teachers need great variety of strategies, not rule based: novelty helps.

Indirect instruction helps.

Repetitive questions used for distraction, but may signal panic." p597

In the supplementary notes Newson provides 2 sides on educational differences between autism & PDA, makes some observations, such as PDA has higher exclusion rates than autism.

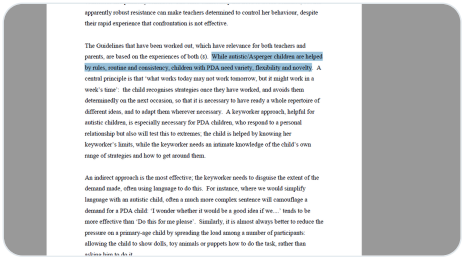


to understand what she read, despite her teachers' impression of her attentiveness. The more disruptive children may well need full-time 1:1 staffing if they are both to access the curriculum and allow other children to do so.

These are exceptionally challenging children to teach, needing massive support; but they are also exceptionally interesting for a teacher who likes to be kept on her toes and has the necessary sense of humour, patience, creativity and flexibility. It is also observable that a teacher with a certain amount of charisma is likely to be the most successful, since the child's own interest has to be re-earned on a daily basis. The guidelines certainly seem to have some success (some have described them as 'a lifeline' or as having 'turned the child around'), but it is recognised that they are not easy for some schools to put into practice, since they need commitment to the child's inclusion and a readiness to adapt very considerably indeed. Anecdotally, it seems that children with PDA have a higher rate of exclusion (from specialist schools as well as mainstream) than do autistic children; it would be useful to investigate such exclusions, and to know the conditions under which they occur (and what happens to the children involved, who can be very difficult to get back into school).

These guidelines, currently the subject of further research, are available in much more extended form on the PDA contact website http://www.pdacontact.org.uk or from the correspondent.

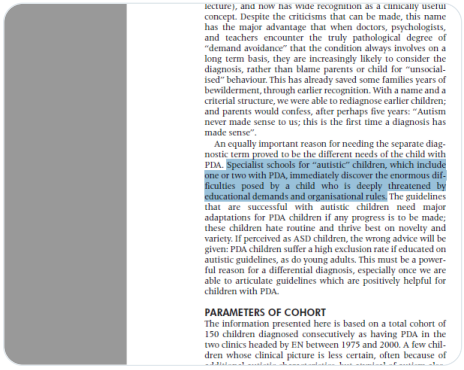
How autistic CYP benefit from structure, routine & rules; contrasts to how PDA requires, almost the opposite approach is mentioned. Worth pointing out that Newson notes the impact a child with PDA can have in a class of autistic pupils.



apparently robust resistance can make teachers determined to control her behaviour, despite their rapid experience that confrontation is not effective.

The Guidelines that have been worked out, which have relevance for both teachers and parents, are based on the experiences of both (i). While autistic/Asperger children are helped by rules, routine and consistency, children with PDA need variety, flexibility and novelty. A central principle is that 'what works today may not work tomorrow, but it might work in a week's time': the child recognises strategies once they have worked, and avoids them determinedly on the next occasion, so that it is necessary to have ready a whole repertoire of different ideas, and to adapt them wherever necessary. A keyworker approach, helpful for autistic children, is especially necessary for PDA children, who respond to a personal relationship but also will test this to extremes; the child is helped by knowing her keyworker's limits, while the keyworker needs an intimate knowledge of the child's own range of strategies and how to get around them.

An indirect approach is the most effective; the keyworker needs to disguise the extent of the demand made, often using language to do this. For instance, where we would simplify language with an autistic child, often a much more complex sentence will camouflage a demand for a PDA child: 'I wonder whether it would be a good idea if we…' tends to be more effective than 'Do this for me please'. Similarly, it is almost always better to reduce the pressure on a primary-age child by spreading the load among a number of participants: allowing the child to show dolls, toy animals or puppets how to do the task, rather than



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.

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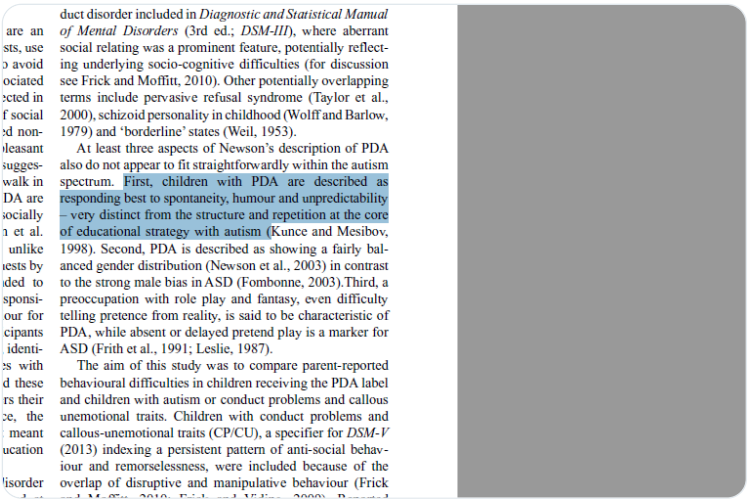
The apparent educational approaches for PDA vs autism is noted as a reason why it is problematic fitting PDA into the autism spectrum.

Pathological demand avoidance: Exploring the behavioural profile - Eli…

'Pathological Demand Avoidance' is a term increasingly used by practitioners in the United Kingdom. It was coined to describe a profile of obsessive resistance ...

https://journals.sagepub.com/doi/10.1177/1362361313481861

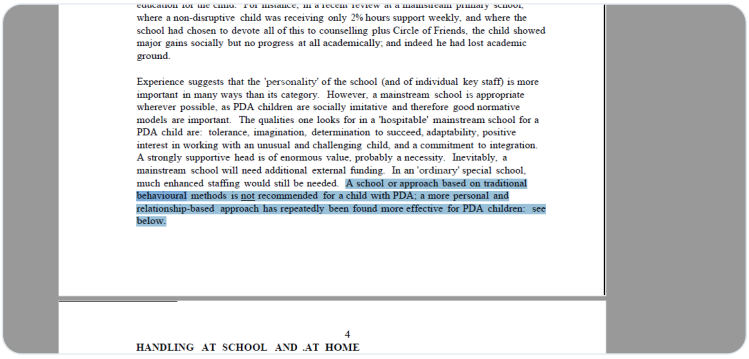


duct disorder included in *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed.; *DSM-III*), where aberrant social relating was a prominent feature, potentially reflecting underlying socio-cognitive difficulties (for discussion see Frick and Moffitt, 2010). Other potentially overlapping terms include pervasive refusal syndrome (Taylor et al., 2000), schizoid personality in childhood (Wolff and Barlow, 1979) and 'borderline' states (Weil, 1953).

At least three aspects of Newson's description of PDA also do not appear to fit straightforwardly within the autism spectrum. First, children with PDA are described as responding best to spontaneity, humour and unpredictability – very distinct from the structure and repetition at the core of educational strategy with autism (Kunce and Mesibov, 1998). Second, PDA is described as showing a fairly balanced gender distribution (Newson et al., 2003) in contrast to the strong male bias in ASD (Fombonne, 2003).Third, a preoccupation with role play and fantasy, even difficulty telling pretence from reality, is said to be characteristic of PDA, while absent or delayed pretend play is a marker for ASD (Frith et al., 1991; Leslie, 1987).

The aim of this study was to compare parent-reported behavioural difficulties in children receiving the PDA label and children with autism or conduct problems and callous unemotional traits. Children with conduct problems and callous-unemotional traits (CP/CU), a specifier for *DSM-V* (2013) indexing a persistent pattern of anti-social behaviour and remorselessness, were included because of the overlap of disruptive and manipulative behaviour (Frick

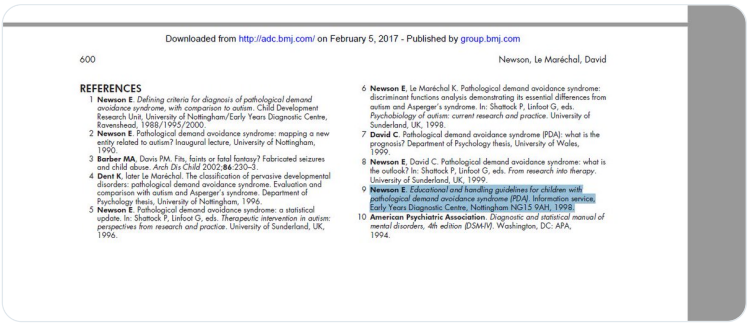
The point about behavioural based approaches on reward and consequences do not work with PDA, while a relationship-based approach (that many autistic persons would advocate today for autistic CYP) is recommended for PDA since 1998 (I think the date is).



where a non-disruptive child was receiving only 2% hours support weekly, and where the school had chosen to devote all of this to counselling plus Circle of Friends, the child showed major gains socially but no progress at all academically; and indeed he had lost academic ground.

Experience suggests that the 'personality' of the school (and of individual key staff) is more important in many ways than its category. However, a mainstream school is appropriate wherever possible, as PDA children are socially imitative and therefore good normative models are important. The qualities one looks for in a 'hospitable' mainstream school for a PDA child are: tolerance, imagination, determination to succeed, adaptability, positive interest in working with an unusual and challenging child, and a commitment to integration. A strongly supportive head is of enormous value, probably a necessity. Inevitably, a mainstream school will need additional external funding. In an 'ordinary' special school, much enhanced staffing would still be needed. A school or approach based on traditional behavioural methods is not recommended for a child with PDA; a more personal and relationship-based approach has repeatedly been found more effective for PDA children: see below.

https://www.autismeastmidlands.org.uk/wp-content/uploads/2016/10/Educational-and-handling-Guidelines.pdf



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So some of you may know that the school Newson clinic is based at, practices PBS. So some argue it is ironic they use PBS when Newson was against such based behavioural approaches.

The problem here is that Newson against the use behavioural approaches for PDA. That Newson thought PDA was clinically distinct from autism, and that PDA is NOT an Autism Spectrum Disorder.

Newson seems to be perfectly fine with behavioural approaches used for autism. The different educational approaches between PDA & autism, were an important

justification for her, for why PDA is needed.

The crux of Newson's PDA research is that PDA is substantially different to autism (including Asperger's), that PDA is not an autism spectrum disorder. PDA has unique educational needs compared to autism. Therefore PDA needs to be diagnosed for such persons.

I do not want to say it, Newson probably would have been fine with PBS/ ABA being used with autism. Her work suggests she would have objected to PBS/ ABA being used for CYP with PDA instead.

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@threadreaderapp Please can you unroll

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