Richard Woods @Richard_Autism

Jul 26 • 54 tweets • Richard_Autism/status/1551955837136035842

"Sometimes this is asked alongside an existing autism spectrum disorder diagnosis, but can also be asked as an alternative to such a diagnosis or as an explanation for behavioural difficulties in children without any developmental disorder." Green et al 2018a, p456

This is a quote talking about requests to diagnose PDA in Green et al (2018a) review of PDA. Link below to the article.

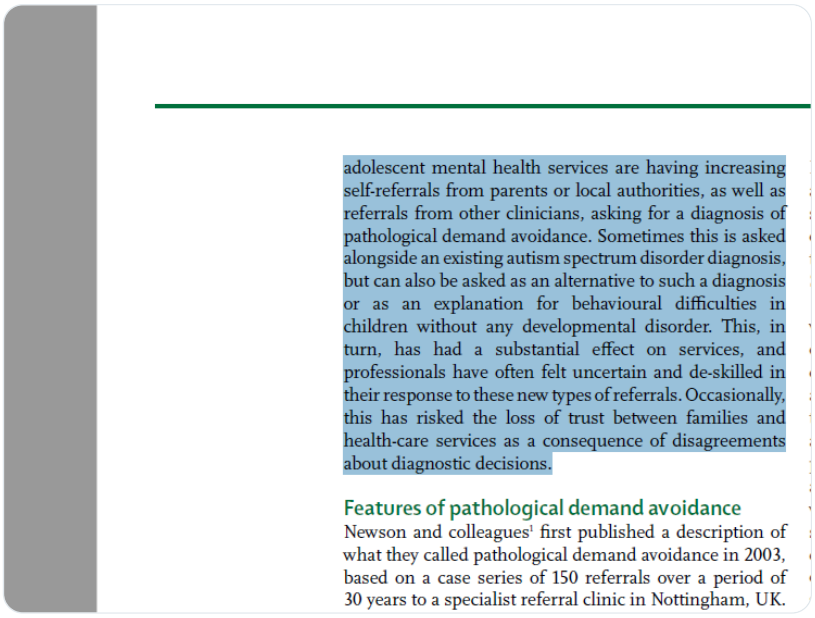
Pathological Demand Avoidance: symptoms but not a syndrome

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

So why I am I mentioning this? It is from multiple authors from clinics across the UK. The authors are: Jonathan Green, Michael Absoud, Victoria Grahame, Osman Malik, Emily Simonoff, Ann Le Couteur, Gillian Baird.

Image of the previous quote by Green et al (2018a) talking about how PDA is diagnosed in clinical settings. Obviously, this quote is reflective of multiple clinics experiences, due to authors backgrounds.


adolescent mental health services are having increasing self-referrals from parents or local authorities, as well as referrals from other clinicians, asking for a diagnosis of pathological demand avoidance. Sometimes this is asked alongside an existing autism spectrum disorder diagnosis, but can also be asked as an alternative to such a diagnosis or as an explanation for behavioural difficulties in children without any developmental disorder. This, in turn, has had a substantial effect on services, and professionals have often felt uncertain and de-skilled in their response to these new types of referrals. Occasionally, this has risked the loss of trust between families and health-care services as a consequence of disagreements about diagnostic decisions.

Features of pathological demand avoidance

Newson and colleagues[1] first published a description of what they called pathological demand avoidance in 2003, based on a case series of 150 referrals over a period of 30 years to a specialist referral clinic in Nottingham, UK.

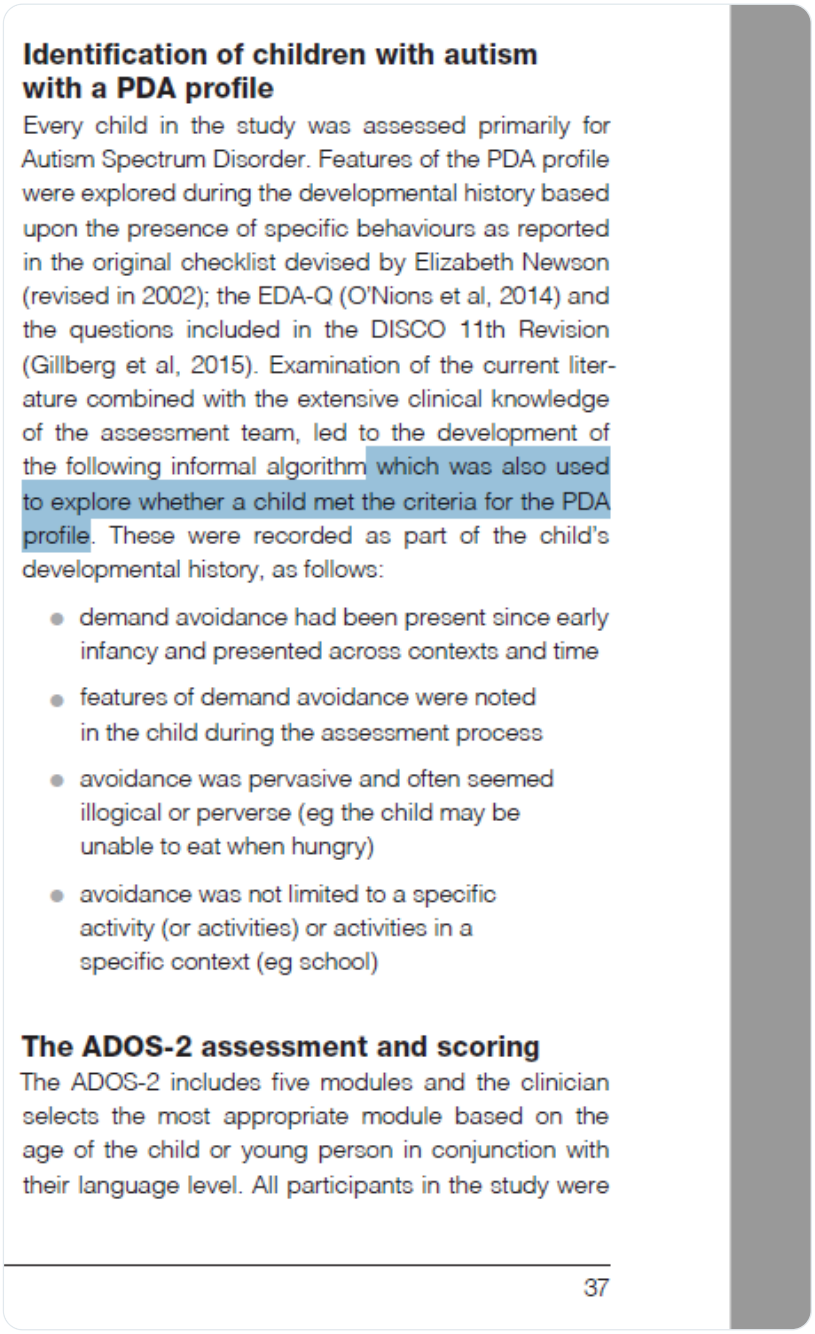
Why am I mentioning this?

"Examination of the current literature combined with the extensive clinical knowledge of the assessment team, led to the development of the following informal algorithm..." Eaton & Weaver 2020, p37.

Algorithm referred to was used to by Help4Psychology to diagnose PDA in those they suspect being autistic. I use suspect deliberately, as I am not confident all those persons with PDA are autistic due to potentially conflating non-autism PDA features with autism...

... The point is I am not confident if Help4Psychology says a person with PDA is autistic due to person meeting DSM-5 autism criteria, or because person presents PDA features & the clinic views PDA as being a form of autism...

Image with the quote from Eaton & Weaver (2020), p37.



Identification of children with autism with a PDA profile

Every child in the study was assessed primarily for Autism Spectrum Disorder. Features of the PDA profile were explored during the developmental history based upon the presence of specific behaviours as reported in the original checklist devised by Elizabeth Newson (revised in 2002); the EDA-Q (O'Nions et al, 2014) and the questions included in the DISCO 11th Revision (Gillberg et al, 2015). Examination of the current literature combined with the extensive clinical knowledge of the assessment team, led to the development of the following informal algorithm which was also used to explore whether a child met the criteria for the PDA profile. These were recorded as part of the child's developmental history, as follows:

- demand avoidance had been present since early infancy and presented across contexts and time
- features of demand avoidance were noted in the child during the assessment process
- avoidance was pervasive and often seemed illogical or perverse (eg the child may be unable to eat when hungry)
- avoidance was not limited to a specific activity (or activities) or activities in a specific context (eg school)

The ADOS-2 assessment and scoring

The ADOS-2 includes five modules and the clinician selects the most appropriate module based on the age of the child or young person in conjunction with their language level. All participants in the study were

37

Link to Eaton & Weaver 2020.
https://www.ingentaconnect.com/contentone/bild/gap/2020/00000021/00000002/art00005

Why am I mentioning Green et al (2018a) quote on how PDA presumably diagnosed in broader clinical practice than Help4Psychology, a single clinic at the time of research in Eaton & Weaver 2020?

"Examination of the current literature combined with the extensive clinical knowledge of the assessment team," Eaton & Weaver 2020, p37.

Key part is with extensive clinical knowledge of the assessment team.

I.e., Help4Psychology assumed they know better than other clinicians on how PDA was diagnosed & what PDA is to create their algorithm. Yet the perspective of Green et al (2018) is not mentioned or discussed in Eaton & Weaver (2020). I wonder why?

Also Eaton & Weaver (2020) claim they examined the literature, which does have plenty of cases of PDA being diagnosed as a standalone diagnosis.

I present this information of examples of PDA being diagnosed as a standalone diagnosis here:
https://www.researchgate.net/publication/351071989_Is_Pathological_Demand_Avoidance_a_meaningful_subgroup_of_autism

At least 150 examples in Newson et al (2003), as they excluded cases which had autism features from their database.

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

Around 100 of 375 caregiver reported PDA diagnoses of large scale 2018 survey in the UK.

The Being Misunderstood Report views PDA as an ASD Profile.
https://www.pdasociety.org.uk/wp-content/uploads/2019/08/BeingMisunderstood.pdf

EDA-Q validation study, contained 50 diagnosed CYP with PDA, it is unknown if any these individuals had an autism diagnosis. Research was conducted before widespread adoption of dual "ASD + PDA Traits"
diagnosis, many of these 50 are unlikely to have an autism diagnosis.

Link to that study.
https://acamh.onlinelibrary.wiley.com/doi/abs/10.1111/jcpp.12149

Logic for O'Nions et al (2014a) also applies to O'Nions et al (2014b), the examination of PDA behaviour profile study with 25 CYP diagnosed with PDA.
https://journals.sagepub.com/doi/full/10.1177/1362361313481861

I go into detail on how it is unlikely all of those 25 CYP diagnosed with PDA in the above are autistic in this thread below:
https://rationaldemandavoidancecom.files.wordpress.com/2021/08/20-june-2021-10-studies-indicating-pda-is-seen-in-non-autistic-persons.pdf

At least 9 PDA case studies have PDA diagnosed as a standalone entity.

These 9 examples are spread across multiple studies, so need to share articles on tweet at a time. First 4 cases in Reilly et al 2014.
https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub

This has one, I also argue this one is likely non-autistic, but that is a tangent.
https://www.emerald.com/insight/content/doi/10.1108/JIDOB-07-2016-0013/full/html

There is an earlier case study from 2005 published in Good Autism Practice, which does not have a link to it. Here is one from 2011.
https://www.ingentaconnect.com/contentone/bild/gap/2011/00000012/00000002/art00007

Last case study from Good Autism Practice, is Harvey (2012).
https://www.ingentaconnect.com/contentone/bild/gap/2012/00000013/00000001/art00002

Final case study of diagnosing PDA as a standalone diagnosis is Eaton & Banting 2012. Diagnosed PDA as a standalone condition that is within the autism spectrum.
https://www.emerald.com/insight/content/doi/10.1108/20420921211305891/full/html

I forgot to also state PDA while being diagnosed as a standalone entity, was viewed as being part of the autism spectrum here.

Where am I going with this?
Are there sufficient examples to suggest PDA can be diagnosed as a standalone entity, separate from autism? Well yes.
Is this supported by review paper of clinical practice broader than Help4Psychology? Yes.

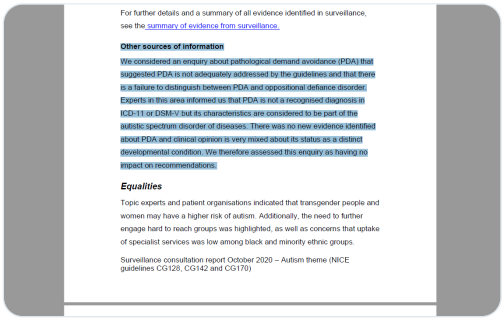
What does this mean for Eaton & Weaver (2020) studies?
It tells us that their definitions are not representative of how PDA may present in its full breadth (spectrum nature), as Help4Psychology PDA definitions & clinical practice are not fully representative.

I.e., Eaton & Weaver (2020) are biased & cannot generalised into broader clinical practice.

Should Eaton & Weaver 2020 assumed their "extensive clinical knowledge of the assessment team" was sufficient to over rule divergent opinions on what PDA presents like. I.e., should Help4Psychology have assumed their opinions allows them to create a PDA algorithm?

I think answer to this question is a no. Why do I say that? Arbiters of clinical practice, NICE, BPS & RCP have not prioritised Help4Psychology PDA definitions/ views when recently reviewing PDA in clinical guidelines. I wonder why (rhetorical)?

Images are from pages 10 + 47 of @NICEComms review of evidence for autism.



For further details and a summary of all evidence identified in surveillance, see the summary of evidence from surveillance.

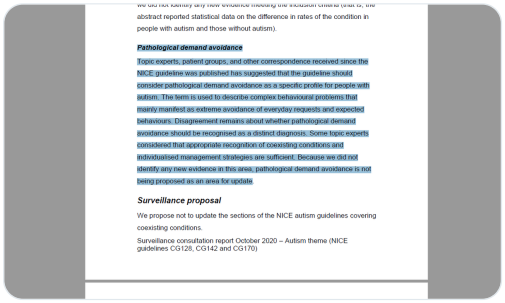
Other sources of information

We considered an enquiry about pathological demand avoidance (PDA) that suggested PDA is not adequately addressed by the guidelines and that there is a failure to distinguish between PDA and oppositional defiance disorder. Experts in this area informed us that PDA is not a recognised diagnosis in ICD-11 or DSM-5/-TR but its characteristics are considered to be part of the autistic spectrum disorder of diseases. There was no new evidence identified about PDA and clinical opinion is very mixed about its status as a distinct developmental condition. We therefore assessed this enquiry as having no impact on recommendations.

Equalities

Topic experts and patient organisations indicated that transgender people and women may have a higher risk of autism. Additionally, the need to further engage hard to reach groups was highlighted, as well as concerns that uptake of specialist services was low among black and minority ethnic groups.

Surveillance consultation report October 2020 – Autism theme (NICE guidelines CG128, CG142 and CG170)



abstract reported statistical data on the difference in rates of the condition in people with autism and those without autism).

Pathological demand avoidance

Topic experts, patient groups, and other correspondence received since the NICE guideline was published has suggested that the guideline should consider pathological demand avoidance as a specific profile for people with autism. The term is used to describe complex behavioural problems that mainly manifest as extreme avoidance of everyday requests and expected behaviours. Disagreement remains about whether pathological demand avoidance should be recognised as a distinct diagnosis. Some topic experts considered that appropriate recognition of coexisting conditions and individualised management strategies are sufficient. Because we did not identify any new evidence in this area, pathological demand avoidance is not being proposed as an area for update.

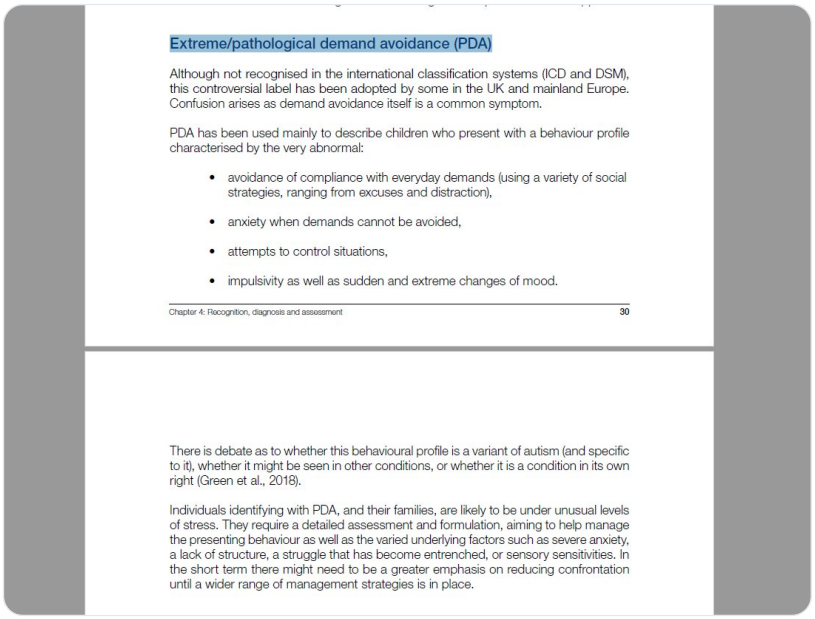
Surveillance proposal

We propose not to update the sections of the NICE autism guidelines covering coexisting conditions.

Surveillance consultation report October 2020 – Autism theme (NICE guidelines CG128, CG142 and CG170)

Link to NICE's review.
https://www.nice.org.uk/guidance/cg128/documents/surveillance-review-proposal

Image from pages 30-31 of @rcpsych guidance for autism, where it discusses PDA. Interestingly this describes PDA as not having social communication issues.



Extreme/pathological demand avoidance (PDA)

Although not recognised in the international classification systems (ICD and DSM), this controversial label has been adopted by some in the UK and mainland Europe. Confusion arises as demand avoidance itself is a common symptom.

PDA has been used mainly to describe children who present with a behaviour profile characterised by the very abnormal:

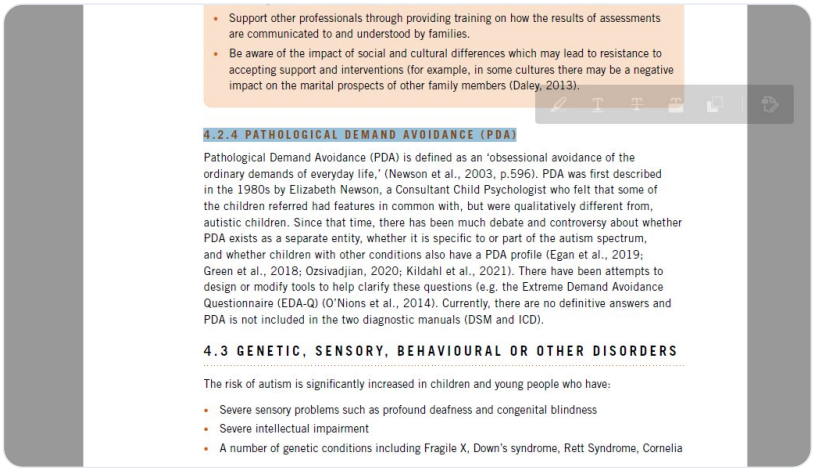
- avoidance of compliance with everyday demands (using a variety of social strategies, ranging from excuses and distraction),
- anxiety when demands cannot be avoided,
- attempts to control situations,
- impulsivity as well as sudden and extreme changes of mood.

There is debate as to whether this behavioural profile is a variant of autism (and specific to it), whether it might be seen in other conditions, or whether it is a condition in its own right (Green et al., 2018).

Individuals identifying with PDA, and their families, are likely to be under unusual levels of stress. They require a detailed assessment and formulation, aiming to help manage the presenting behaviour as well as the varied underlying factors such as severe anxiety, a lack of structure, a struggle that has become entrenched, or sensory sensitivities. In the short term there might need to be a greater emphasis on reducing confrontation until a wider range of management strategies is in place.

Link to RCP's guidance on autism is below
https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr228.pdf?sfvrsn=c64e10e3_2

Image is from page 18 of @BPSOfficial guidance on working with autistic persons, where it discusses PDA.



- Support other professionals through providing training on how the results of assessments are communicated to and understood by families.
- Be aware of the impact of social and cultural differences which may lead to resistance to accepting support and interventions (for example, in some cultures there may be a negative impact on the marital prospects of other family members (Daley, 2013).

4.2.4 PATHOLOGICAL DEMAND AVOIDANCE (PDA)

Pathological Demand Avoidance (PDA) is defined as an 'obsessional avoidance of the ordinary demands of everyday life,' (Newson et al., 2003, p.596). PDA was first described in the 1980s by Elizabeth Newson, a Consultant Child Psychologist who felt that some of the children referred had features in common with, but were qualitatively different from, autistic children. Since that time, there has been much debate and controversy about whether PDA exists as a separate entity, whether it is specific to or part of the autism spectrum, and whether children with other conditions also have a PDA profile (Egan et al., 2019; Green et al., 2018; Ozsivadjian, 2020; Kildahl et al., 2021). There have been attempts to design or modify tools to help clarify these questions (e.g. the Extreme Demand Avoidance Questionnaire (EDA-Q) (O'Nions et al., 2014). Currently, there are no definitive answers and PDA is not included in the two diagnostic manuals (DSM and ICD).

4.3 GENETIC, SENSORY, BEHAVIOURAL OR OTHER DISORDERS

The risk of autism is significantly increased in children and young people who have:

- Severe sensory problems such as profound deafness and congenital blindness
- Severe intellectual impairment
- A number of genetic conditions including Fragile X, Down's syndrome, Rett Syndrome, Cornelia

Now, these documents are from 2020 - 2021, mainly after Eaton & Weaver (2020) was published. This does not reduce the validity of my point that Help4Psychology should not have assumed their opinions are enough to create a PDA algorithm/ assume they know better than others on PDA.

PDA has been controversial since at least 2002 & challenged in the literature since that time. Help4Psychology is aware of the limited & poor quality evidence base for PDA at the time of conducting research in Eaton & Weaver (2020).

The ethical & quality standards the likes of NICE, BPS & RCP working towards, in addition to broader context of PDA were insignificantly different when NICE/ BPS/ RCP recently reviewed PDA vs when Eaton & Weaver (2020) was published.

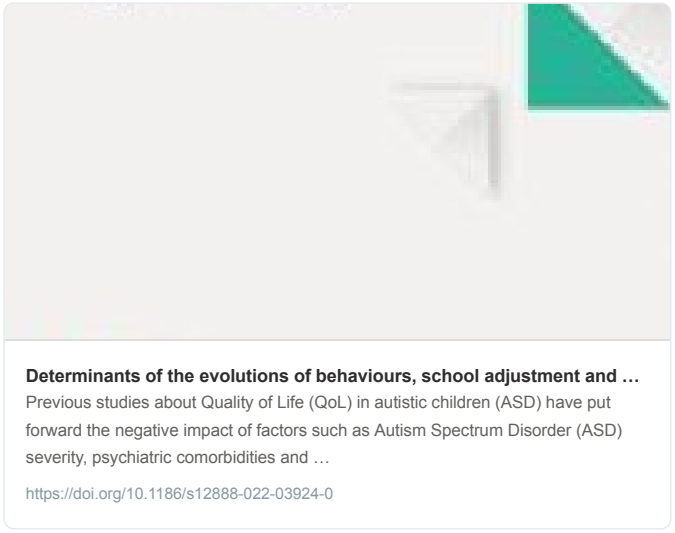
In particular most of the examples in PDA literature of it being diagnosed separately were from before 2016. Green et al (2018a) came out 2 years before Eaton & Weaver (2020)...

... The reasons for equally respecting other clinics & topic experts views on PDA were sufficient before NICE/ BPS/ RCP reviewed PDA in 2020 - 2021. Help4Psychology do not have a good excuse for ignoring it...

... End of the day those who disagree with Help4Psychology have been, are & will continue to conduct PDA research & gaining evidence for their own views, that disagrees with Help4Psychology's views on PDA...

... Help4Psychology believe that only they understand what PDA is, & how PDA should be diagnosed? If so, they are likely to be proven mistaken in the future.

An example of those who disagree with "PDA Profile of ASD" conducting research into PDA & producing results which do not support Help4Psychology outlook on PDA.



Determinants of the evolutions of behaviours, school adjustment and …
Previous studies about Quality of Life (QoL) in autistic children (ASD) have put forward the negative impact of factors such as Autism Spectrum Disorder (ASD) severity, psychiatric comorbidities and …

https://doi.org/10.1186/s12888-022-03924-0

I have accidentally forgotten two more examples of where there are persons diagnosed with PDA as a standalone entity.

Four out of 22 individuals with PDA in a medium scale research into CYP with PDA educational experiences had a solo PDA diagnosis.
https://nasenjournals.onlinelibrary.wiley.com/doi/abs/10.1111/1471-3802.12081

I think the sample in the above is exactly the same as this other study on caregiver experiences of professionals, by the same authors.
https://www.tandfonline.com/doi/abs/10.1080/20473869.2016.1204743?cookieSet=1

There are also three CYP diagnosed with PDA, who are non-autistic in Chapter 8 study in O'Nions PhD thesis.

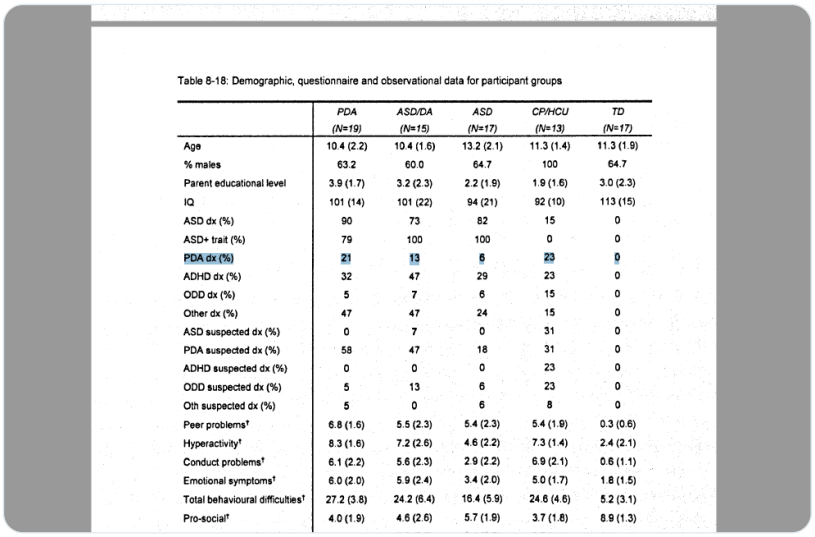
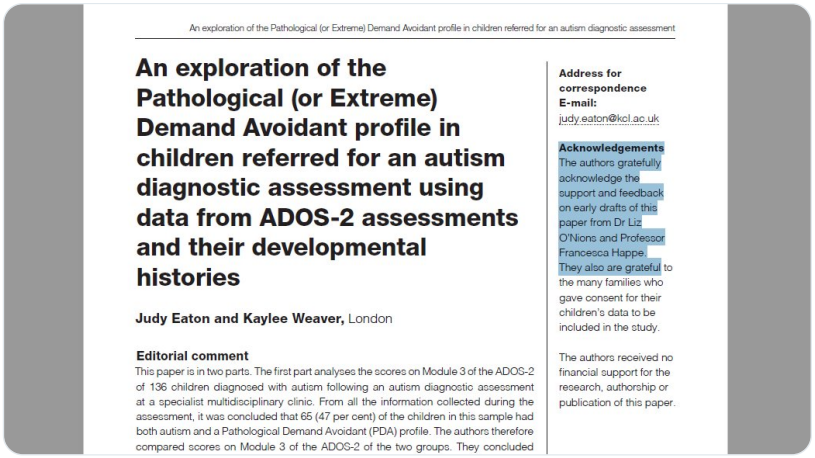


Table 8-18: Demographic, questionnaire and observational data for participant groups

	PDA (N=19)	ASD/DA (N=15)	ASD (N=17)	CP/HCU (N=13)	TD (N=17)
Age	10.4 (2.2)	10.4 (1.6)	13.2 (2.1)	11.3 (1.4)	11.3 (1.9)
% males	63.2	60.0	64.7	100	64.7
Parent educational level	3.9 (1.7)	3.2 (2.3)	2.2 (1.9)	1.9 (1.6)	3.0 (2.3)
IQ	101 (14)	101 (22)	94 (21)	92 (10)	113 (15)
ASD dx (%)	90	73	82	15	0
ASD+ trait (%)	79	100	100	0	0
PDA dx (%)	21	13	6	23	0
ADHD dx (%)	32	47	29	23	0
ODD dx (%)	5	7	6	15	0
Other dx (%)	47	47	24	15	0
ASD suspected dx (%)	0	7	0	31	0
PDA suspected dx (%)	58	47	18	31	0
ADHD suspected dx (%)	0	0	0	23	0
ODD suspected dx (%)	5	13	6	23	0
Oth suspected dx (%)	5	0	6	8	0
Peer problems†	6.8 (1.6)	5.5 (2.3)	5.4 (2.3)	5.4 (1.9)	0.3 (0.6)
Hyperactivity†	8.3 (1.6)	7.2 (2.6)	4.6 (2.2)	7.3 (1.4)	2.4 (2.1)
Conduct problems†	6.1 (2.2)	5.6 (2.3)	2.9 (2.2)	6.9 (2.1)	0.6 (1.1)
Emotional symptoms†	6.0 (2.0)	5.9 (2.4)	3.4 (2.0)	5.0 (1.7)	1.8 (1.5)
Total behavioural difficulties†	27.2 (3.8)	24.2 (6.4)	16.4 (5.9)	24.6 (4.6)	5.2 (3.1)
Pro-social†	4.0 (1.9)	4.6 (2.6)	5.7 (1.9)	3.7 (1.8)	8.9 (1.3)

The thesis was not publicly available at time of Eaton & Weaver (2020) was conducted. Yet, they did have feedback from O'Nions on the manuscript. Maybe unfair to expect Help4Psychology to be aware of these 3 cases at time they conducted their research in Eaton & Weaver (2020).



An exploration of the Pathological (or Extreme) Demand Avoidant profile in children referred for an autism diagnostic assessment using data from ADOS-2 assessments and their developmental histories

Judy Eaton and Kaylee Weaver, London

Editorial comment

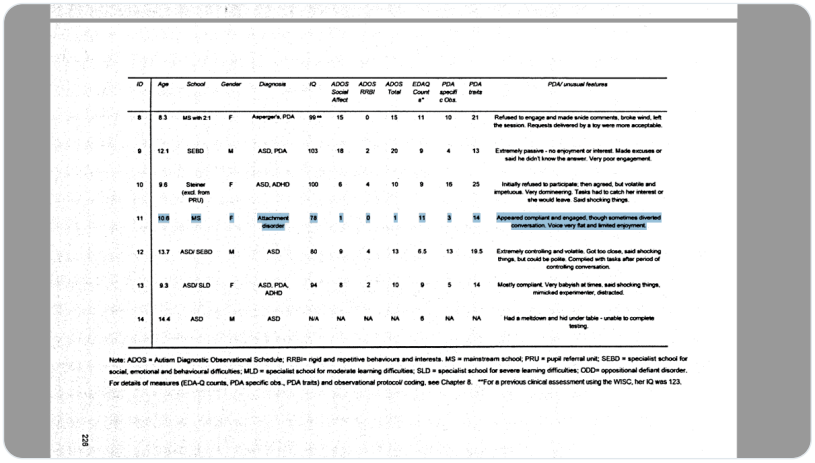
This paper is in two parts. The first part analyses the scores on Module 3 of the ADOS-2 of 136 children diagnosed with autism following an autism diagnostic assessment at a specialist multidisciplinary clinic. From all the information collected during the assessment, it was concluded that 65 (47 per cent) of the children in this sample had both autism and a Pathological Demand Avoidant (PDA) profile. The authors therefore compared scores on Module 3 of the ADOS-2 of the two groups. They concluded

Address for correspondence
E-mail:
judy.eaton@kcl.ac.uk

Acknowledgements
The authors gratefully acknowledge the support and feedback on early drafts of this paper from Dr Liz O'Nions and Professor Francesca Happé. They also are grateful to the many families who gave consent for their children's data to be included in the study.

The authors received no financial support for the research, authorship or publication of this paper.

Also there is an example of case with PDA in attachment disorder & ADOS score of one in O'Nions thesis. Chapter 5 sample. Image from p226. Again might be unreasonable to expect Help4Psychology to be aware of this example when conducting Eaton & Weaver (2020).



ID	Age	School	Gender	Diagnosis	IQ	ADOS Social Affect	ADOS RRBI	ADOS Total	EDAQ Count a*	PDA specif c Obs	PDA traits	PDA/ unusual features
8	8.3	MS with 2:1	F	Asperger's, PDA	99 **	15	0	15	11	10	21	Refused to engage and made snide comments, broke wind, left the session. Requests delivered by a toy were more acceptable.
9	12.1	SEBD	M	ASD, PDA	103	18	2	20	9	4	13	Extremely passive - no enjoyment or interest. Made excuses or said he didn't know the answer. Very poor engagement.
10	9.6	Steiner (exact. from PRU)	F	ASD, ADHD	100	6	4	10	9	16	25	Initially refused to participate, then agreed, but volatile and impetuous. Very domineering. Tasks had to catch her interest or she would leave. Said shocking things.
11	10.6	MS	F	Attachment disorder	78	1	0	1	11	3	14	Appeared compliant and engaged, though sometimes diverted conversation. Voice very flat and limited enjoyment.
12	13.7	ASD/ SEBD	M	ASD	80	9	4	13	6.5	13	19.5	Extremely controlling and volatile. Got too close, said shocking things, but could be polite. Complied with tasks after period of controlling conversation.
13	9.3	ASD/ SLD	F	ASD, PDA, ADHD	94	8	2	10	9	5	14	Mostly compliant. Very babyish at times, said shocking things, mimicked experimenter, distracted.
14	14.4	ASD	M	ASD	N/A	NA	NA	NA	8	NA	NA	Had a meltdown and hid under table - unable to complete testing.

Note: ADOS = Autism Diagnostic Observational Schedule; RRBI= rigid and repetitive behaviours and interests. MS = mainstream school; PRU = pupil referral unit; SEBD = specialist school for social, emotional and behavioural difficulties; MLD = specialist school for moderate learning difficulties; SLD = specialist school for severe learning difficulties; ODD= oppositional defiant disorder. For details of measures (EDA-Q counts, PDA specific obs., PDA traits) and observational protocol coding, see Chapter 8. **For a previous clinical assessment using the WISC, her IQ was 123.

226

Link to O'Nions thesis is below.
https://ethos.bl.uk/OrderDetails.do?did=1&uin=uk.bl.ethos.814002

Point of the above examples PDA can be seen/ diagnosed as a standalone entity to make point against Help4Psychology (Eaton & Weaver 2020), creating their own PDA definitions & algorithm, as previously set out in this thread.

I am done adding to this thread. So I will end it here.

This thread just shows how "wild west" some PDA clinical practice & research is.

On that note, @threadreaderapp please can you unroll?

Thank you in advance.

...