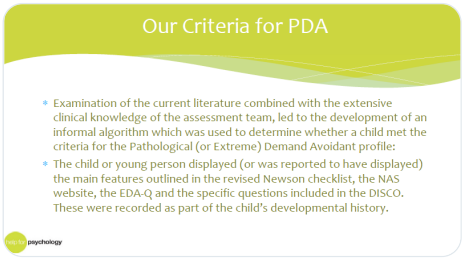
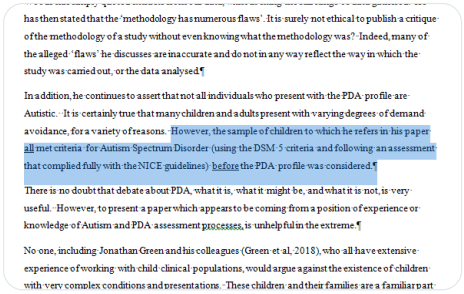
Richard Woods @Richard_Autism

19 Apr 20 • 33 tweets • Richard_Autism/status/1251878076465774592

Thread on weaknesses of Help4Psychology PDA database: https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00003 From public information sources, that indicate it has severe limitations.

The database is constructed by only diagnosing PDA in those the clinic believes are already autistic. Secondly they have a narrow definition of what PDA is. Thirdly, limitations with the tools used:




has then stated that the 'methodology has numerous flaws'. It is surely not ethical to publish a critique of the methodology of a study without even knowing what the methodology was? Indeed, many of the alleged 'flaws' he discusses are inaccurate and do not in any way reflect the way in which the study was carried out, or the data analysed.¶

In addition, he continues to assert that not all individuals who present with the PDA profile are Autistic. It is certainly true that many children and adults present with varying degrees of demand avoidance, for a variety of reasons. However, the sample of children to which he refers in his paper all met criteria for Autism Spectrum Disorder (using the DSM-5 criteria and following an assessment that complied fully with the NICE guidelines) before the PDA profile was considered.¶

There is no doubt that debate about PDA, what it is, what it might be, and what it is not, is very useful. However, to present a paper which appears to be coming from a position of experience or knowledge of Autism and PDA assessment processes, is unhelpful in the extreme.¶

No one, including Jonathan Green and his colleagues (Green et al, 2018), who all have extensive experience of working with child clinical populations, would argue against the existence of children with very complex conditions and presentations. These children and their families are a familiar part

First off, it assumes that PDA can only be found in autistic persons. Others argue PDA is seen outside of autism. For instance:

Commentary: PDA – public display of affection or pathological deman…
Read the full article on doi: 10.1111/jcpp.12149

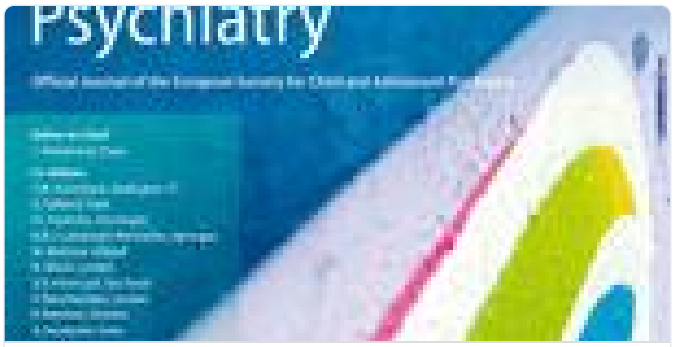
https://onlinelibrary.wiley.com/doi/full/10.1111/jcpp.12275

and can be explained by other conditions than autism:

pathological demand avoidance – Unsafe Spaces
Posts about pathological demand avoidance written by Phil Dore
https://unsafespaces.com/tag/pathological-demand-avoidance/

and
https://thepsychologist.bps.org.uk/volume-29/january-2016/pda-there-another-explanation

There is evidence to support these positions:
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference
Single cases:



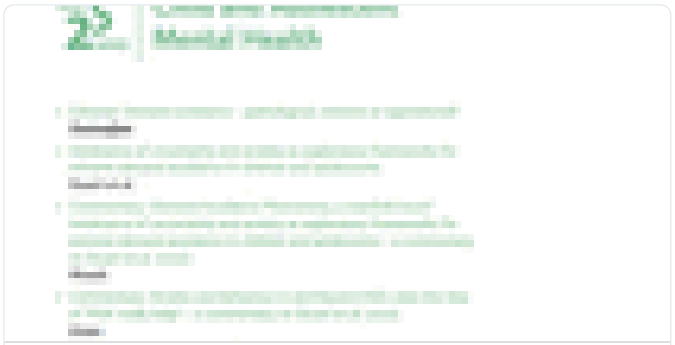
Identifying features of 'pathological demand avoidance' us
The term 'pathological demand avoidance' (PDA) was coined by Elizabeth Newson to describe children within the autism spectrum who exhibit obse
https://link.springer.com/article/10.1007/s00787-015-0740-2

and:

Pathological Demand Avoidance in a population-based cohort of childr…
Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spec…
https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub

And
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

Only diagnosing PDA in autistics assumes 1) Newson was correct PDA was Pervasive Developmental Disorder. Phil Christie is correct that PDA is autism subtype. I cover issues with Christie's assumption here:



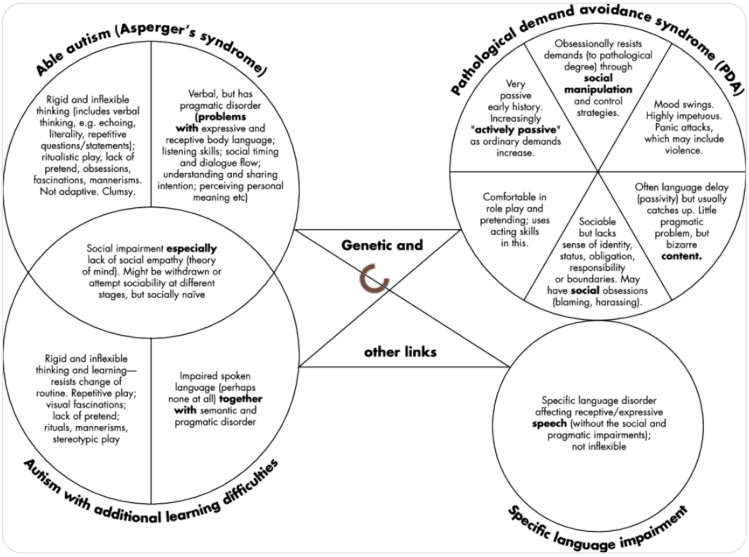
Commentary: Demand Avoidance Phenomena, a manifold issue? Intol…
Read the full article at doi: 10.1111/camh.12336 and response to this commentary at doi: 10.1111/camh.12376

https://onlinelibrary.wiley.com/doi/abs/10.1111/camh.12368

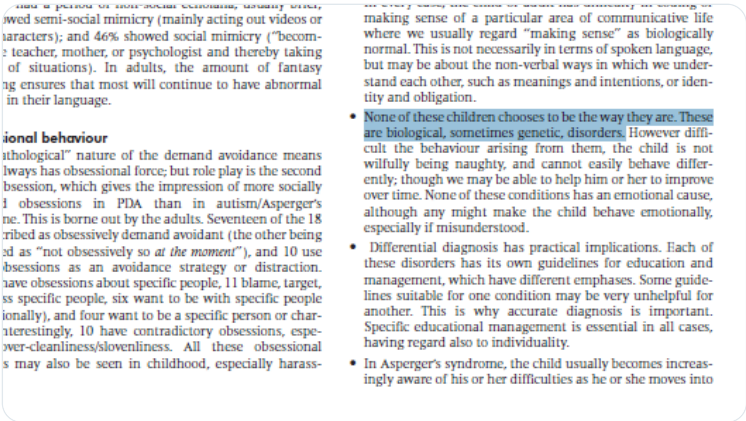
and
https://www.researchgate.net/publication/337403754_Demand_Avoidance_Phenomena_Pathological_Demand_Avoidance_Core_Issues_Attachment_Trauma_Looked_After_Children

Highly likely Newson was incorrect to view PDA as a PDD, she states:
"“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)

This statement is supported by how Newson does not base PDA on the triad of impairment underpins modern autism diagnostic criteria. Nor does she draw PDA overlapping the triad of impairment here:



Worth noting that Newson is incorrect to view Specific Language Impairment as a Pervasive Developmental Disorder. Almost certainly incorrect PDA is 100% genetic/ biological in nature. It is reasonable to assume she her views PDA is a PDD is also a mistake.



...iwed semi-social mimicry (mainly acting out videos or ...aracters); and 46% showed social mimicry ("becom- ...e teacher, mother, or psychologist and thereby taking ... of situations). In adults, the amount of fantasy ...ng ensures that most will continue to have abnormal ... in their language.

...ional behaviour

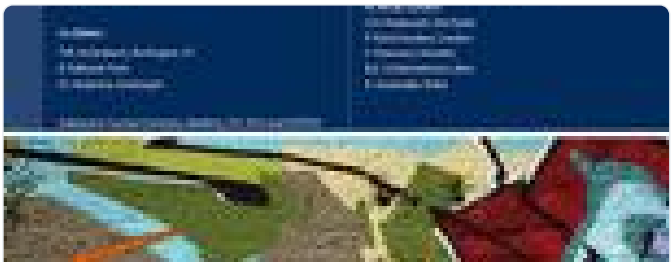
...thological" nature of the demand avoidance means ...lways has obsessional force; but role play is the second ...bsession, which gives the impression of more socially ...l obsessions in PDA than in autism/Asperger's ...ne. This is borne out by the adults. Seventeen of the 18 ...ribed as obsessively demand avoidant (the other being ...d as "not obsessively so *at the moment*"), and 10 use ...bsessions as an avoidance strategy or distraction. ...have obsessions about specific people, 11 blame, target, ...ss specific people, six want to be with specific people ...ionally), and four want to be a specific person or char- ...nterestingly, 10 have contradictory obsessions, espe- ...over-cleanliness/slovenliness. All these obsessional ...s may also be seen in childhood, especially harass-

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 these disorders has its own guidelines for education and management, which have different emphases. Some guidelines suitable for one condition may be very unhelpful for another. This is why accurate diagnosis is important. Specific educational management is essential in all cases, having regard also to individuality.
- In Asperger's syndrome, the child usually becomes increasingly aware of his or her difficulties as he or she moves into

Reason why Newson is almost certainly mistaken about the causes of PDA, is covered here:
https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference
Also mentioned in Norwegian PDA systematic review by @OrmStian

This then leads onto that PDA literature acknowledges it is problematic fitting PDA into the autism spectrum. References:
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
and



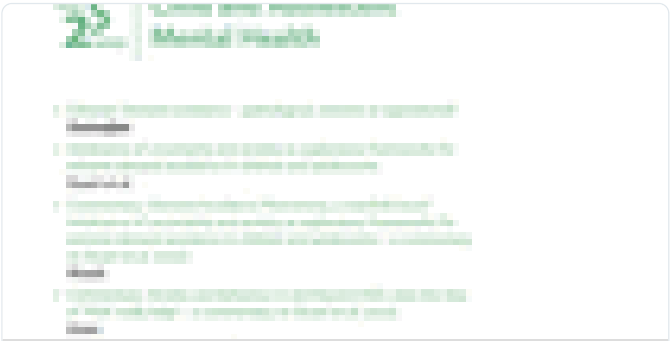
Extreme (“pathological”) demand avoidance in autism: a gen

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexiste

https://link.springer.com/article/10.1007/s00787-014-0647-3

Historically it has been acknowledged it is problematic fitting PDA into the autism spectrum, reasons include: (1) Children with PDA respond better to novelty and spontaneity than autistic persons; (2) PDA's gender ratio is more evenly balanced than the gender ratio of autism. (3) Roleplay and imaginative traits of PDA are either absent or delayed in autism (O'Nions, 2013); (4) Manipulative behaviours attributed to PDA are seen as an exclusionary factor for an autism diagnosis; (5) PDA might be an additional problem for autistic persons, but not caused by autism (Gillberg et al, 2015). Lately, additional issues have emerged, PDA possessing a higher drop off rate of caseness into adulthood compared to autism. PDA's central impairment is high anxiety driven demand avoidance and the extreme anxiety levels attributed to PDA are not associated directly to autism (Woods, 2020a). ¶

I also add further reasons why it is problematic fitting PDA into autism spectrum here:



Commentary: Demand Avoidance Phenomena, a manifold issue? Intol…

Read the full article at doi: 10.1111/camh.12336 and response to this commentary at doi: 10.1111/camh.12376

https://onlinelibrary.wiley.com/doi/abs/10.1111/camh.12368

PDA has higher rates of persons not meeting clinical threshold compared to autism. PDA is: 44% - 89%. Autism is: 0% - 47%.

The figures for autism are from the Autism Dividend Report, page 52, inverted the percentages to make them comparable to PDA.

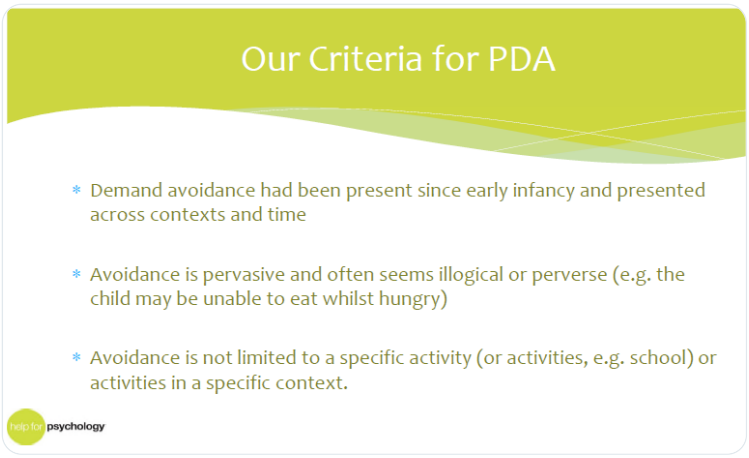
The Autism Dividend report: reaping the rewards of better investment

The most comprehensive survey of current autism practice ever undertaken in the UK

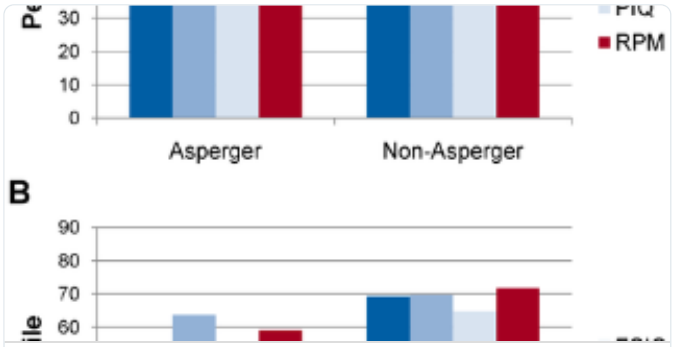
http://nationalautismproject.org.uk/the-autism-dividend

An example of how Grahame et al (2020) have misrepresented my work.

Help4Psychology's 3 additional definitions for PDA. I cover issues with these definitions here:
https://www.researchgate.net/publication/340279248_Is_the_concept_of_Demand_Avoidance_Phenomena_Pathological_Demand_Avoidance_real_or_mythical
If anxiety is causing this demand avoidance; the anxiety would be obsessive in nature& the demand avoidance would be compulsive in nature.

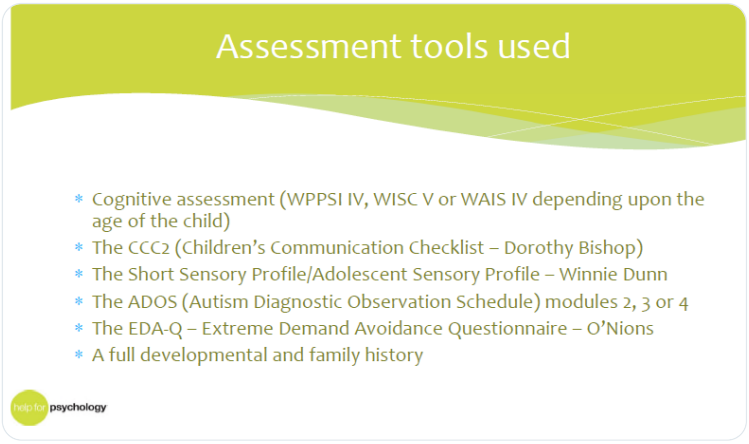


Help4Psychology uses Wechsler Intelligence Scales to measure intelligence. The best tool for measuring autistic intelligence is Raven's Progressive Matrices.



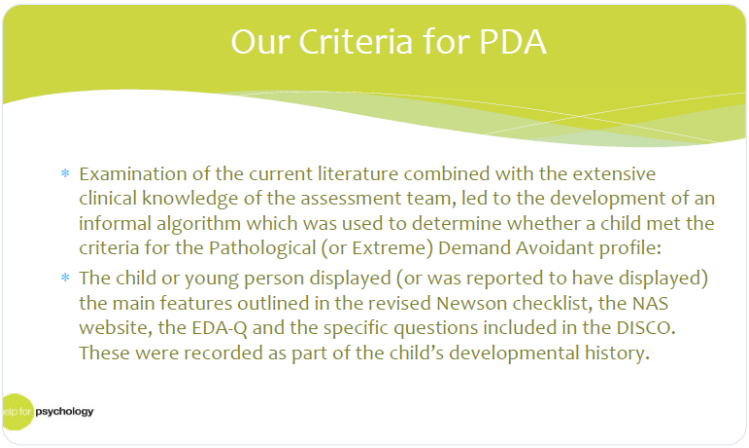
The Level and Nature of Autistic Intelligence II: What about Asperger S...
A distinctively uneven profile of intelligence is a feature of the autistic spectrum. Within the spectrum, Asperger individuals differ from autistics in their early speech development and in being le…

https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0025372

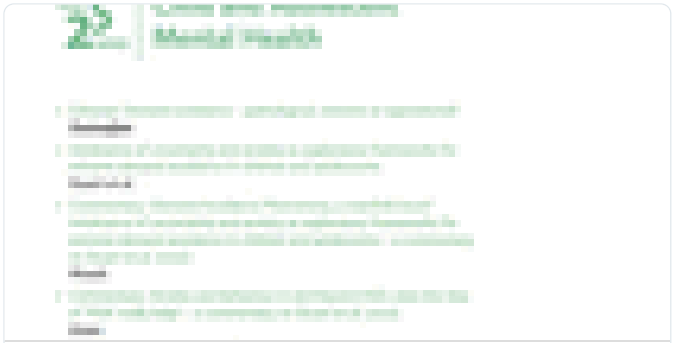


It must be said the ADOS (Autism Diagnostic Observation Schedule) is not designed to assist any clinician/ researcher in to assessing/ identifying features of PDA. I have clarified that with ADOS publisher.

Issues using tools not as designed. EDA-Q is a research tool, it is not designed to be used to make a diagnosis of PDA. Although it is used in this capacity in PDA literature:



The EDA-Q is also noted for having a number of drawbacks which I discuss here:



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https://onlinelibrary.wiley.com/doi/abs/10.1111/camh.12368

For links where EDA-Q is used to diagnose PDA:
https://www.ingentaconnect.com/contentone/bild/gap/2018/00000019/00000002/art00005
and

Pathological Demand Avoidance in a population-based cohort of childr…
Childhood epilepsy is associated with a range of neurobehavioural comorbidities including Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spec…

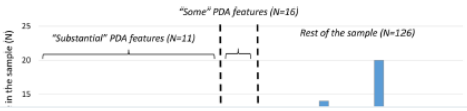
https://www.sciencedirect.com/science/article/abs/pii/S0891422214003461?via%3Dihub

There are also issues with using the 11 validated PDA questions in a developmental history. Again these questions are not designed to be used in that manner. The 11 validated PDA questions are designed to be used with full DISCO.

Behaviour in public places	**21.6**	**29.4**	**49**	**0**
Difficulties with other people	**16.3**	**14.4**	**67.3**	**2**
Repetitive acting out roles*	**15**	**11.8**	**20.3**	**52.9**
Fantasising, lying, cheating, stealing*	**13.7**	**17**	**67.3**	**2**
Inappropriate sociability (rapid, inexplicable changes from loving to aggression)*	**13.1**	**18.3**	**46.4**	**22.2**
Using age peers as mechanical aids, bossy and domineering*	**7.8**	**10.5**	**80.4**	**1.3**
Socially shocking behaviour*	**7.8**	**7.2**	**84.3**	**0.7**
Harassment of others	**7.2**	**10.5**	**80.4**	**2**

Items that were included in Wing and Gould's draft 15-item PDA list are designated with an asterisk. Items are sorted from most to least commonly rated as 'marked difficulties' within the sample ($N = 153$). The 11 DISCO PDA items deemed most useful in identifying PDA are shown in bold. Two items included in this list had specific scoring rules. 'Repetitive acting out roles' was only scored in the clear presence of some degree of apparent imaginative activities (rated across two separate DISCO items), and was un-rateable for over 50 % of the sample. 'Inappropriate sociability (rapid, inexplicable changes from loving to aggression)' was only rateable in the presence of interactions with peers, coded in a separate item

Fig. 1 Distribution of total scores on the 11-item DISCO PDA measure (possible range of scores: 0–22; the lower the score, the more severe is the impairment)



Again these 11 DISCO PDA items have a number issues attached them. Mainly that they were validated with arbitrary thresholds, so these questions are essentially unvalidated. https://www.researchgate.net/publication/337403754_Demand_Avoidance_Phenomena_Pathological_Demand_Avoidance_Core_Issues_Attachment_Trauma_Looked_After_Children

The 11 "validated" PDA DISCO questions only assess for 6 PDA diagnostic traits. As they are essentially unvalidated, one would be better using the 15 unvalidated PDA items that assess 8 PDA diagnostic traits.

In spite of the almost complete lack of scientific study the condition, there has been considerable dispute and bate as to whether or not PDA should be regarded as a riant of autism spectrum disorders (ASDs). The resistce typical of PDA (which could be construed as resistce to change/insistence on sameness), the obsessive haviour, some of the social impairment problems, the guage delay and the "neurological involvement" are also typical/common in ASD. However, the apparently cially manipulative behaviour is not characteristic of SD, and is, in fact, by some, considered to be an exclunary criterion for a diagnosis of ASD. Wing et al. [18] ggested that PDA might be a "double hit", that PDA is an ditional problem in ASD but not due to ASD. Related to s, in another study, it was shown in a small group of boys th ASD who also had psychopathic tendencies [12].

There has been no previous study of the prevalence of DA in the general population. We recently conducted a al population study of ASD in the Faroe Islands [6]. that study we covered all the symptoms of PDA in an erview with a parent of individuals suspected of suffing from ASD. We therefore decided that these data ould provide a good opportunity to get a handle on the evalence of PDA (or, at least, PDA symptoms) in the neral population of individuals with a diagnosis of SD.

Table 1 DISCO-11 items targeting PDA: the DISCO-11 PDA scale

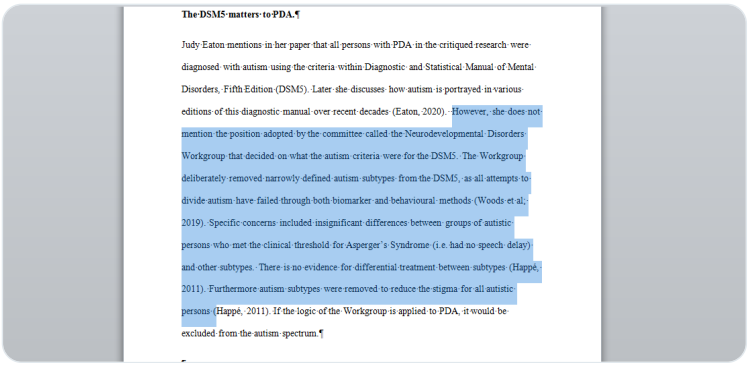
DISCO item and corresponding PDA symptom area	Variable name
Unusually quiet and passive in infancy (1)	UQUIET
Clumsy in gross movements (8)	CCLUMSY
Communicates through doll, puppet, toy animal etc. (5)	CDOLL
Lacks awareness of age group, social hierarchy etc. (3)	CIDENT
Rapid inexplicable changes from loving to aggression (4)	CINAPP
Uses peers as 'mechanical aids'; bossy and domineering (3) and (4)	CPEERAD
Repetitive role play—lives the part, not usual pretence (5) and (7)	CTROL
Hands seem limp and weak for unwelcome tasks (8)	CNOHAND
Repetitive questioning (7)	QUESREP
Obsessed with a person, real or fiction (7)	PERS
Blames others for own misdeeds (3)	BLAME
Harasses another person—may like or dislike them (3) and (7)	HARAS
Socially manipulative behaviour to avoid demands (2)	MANBEH
Socially shocking behaviour with deliberate intent (2) and (3)	SHOCK
Lies, cheats, steals, fantasises, causing distress to others (3) and (7)	LYING

Figures in brackets—(1) through (8)—refer to the eight defining characteristics of Newson's PDA

There are also problems basing PDA definitions off the PDA literature when it is acting as a community of practice, this matters as PDA literature has not really discussed issues around subtyping autism: https://www.researchgate.net/publication/337146735_Demand_avoidance_phenomena_circularity_integrity_and_validity_-_a_commentary_on_the_2018_National_Autistic_Society_PDA_Conference

There is not really an excuse for this @HappeLab has been involved in PDA research, has written about the issues of subtyping autism and was involved in developing DSM5 autism criteria: https://jaacap.org/article/S0890-8567(11)00268-1/fulltext

It should really not have taken me to discuss the Neurodevelopmental Disorders Workgroup's logic behind removing subtypes to get into the PDA literature, it should have been done by @HappeLab



The DSM5 matters to PDA.

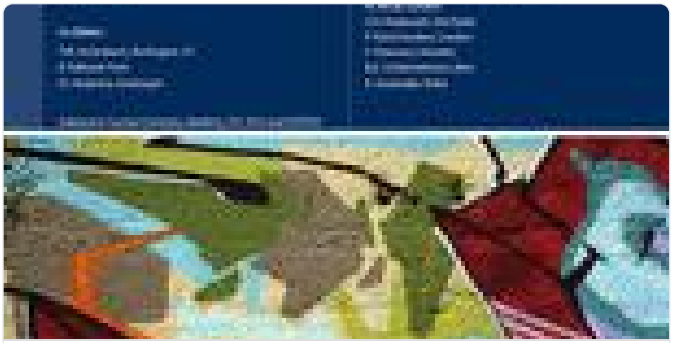
Judy Eaton mentions in her paper that all persons with PDA in the critiqued research were diagnosed with autism using the criteria within Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM5). Later she discusses how autism is portrayed in various editions of this diagnostic manual over recent decades (Eaton, 2020). However, she does not mention the position adopted by the committee called the Neurodevelopmental Disorders Workgroup that decided on what the autism criteria were for the DSM5. The Workgroup deliberately removed narrowly defined autism subtypes from the DSM5, as all attempts to divide autism have failed through both biomarker and behavioural methods (Woods et al., 2019). Specific concerns included insignificant differences between groups of autistic persons who met the clinical threshold for Asperger's Syndrome (i.e. had no speech delay) and other subtypes. There is no evidence for differential treatment between subtypes (Happé, 2011). Furthermore autism subtypes were removed to reduce the stigma for all autistic persons (Happé, 2011). If the logic of the Workgroup is applied to PDA, it would be excluded from the autism spectrum.

Getting onto last few pieces of critique of Help4Psychology PDA database.

This is a weak one, but it includes significantly less PDAers than Newson's research:
Less DAPers than Newson had: 111 vs 150.

The database ideally needed to use a tool designed to diagnose PDA as a standalone construct, independent of autism; i.e. Elizabeth Newson's own semi-structured interview: 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

Finally, one would expect that if @GillbergCentre conducted the study, diagnosing it in non-autistic persons, they would see many more PDAers including non-autistic ones:



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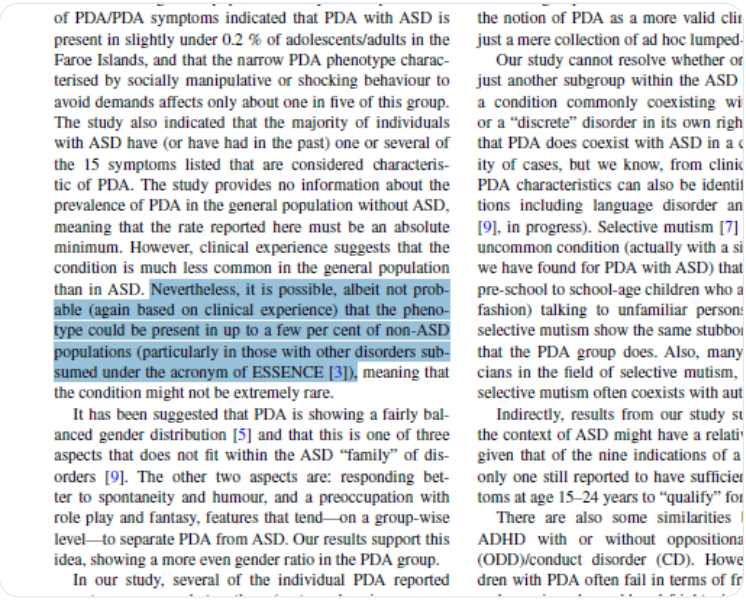


of PDA/PDA symptoms indicated that PDA with ASD is present in slightly under 0.2 % of adolescents/adults in the Faroe Islands, and that the narrow PDA phenotype characterised by socially manipulative or shocking behaviour to avoid demands affects only about one in five of this group. The study also indicated that the majority of individuals with ASD have (or have had in the past) one or several of the 15 symptoms listed that are considered characteristic of PDA. The study provides no information about the prevalence of PDA in the general population without ASD, meaning that the rate reported here must be an absolute minimum. However, clinical experience suggests that the condition is much less common in the general population than in ASD. Nevertheless, it is possible, albeit not probable (again based on clinical experience) that the phenotype could be present in up to a few per cent of non-ASD populations (particularly in those with other disorders subsumed under the acronym of ESSENCE [3]), meaning that the condition might not be extremely rare.

It has been suggested that PDA is showing a fairly balanced gender distribution [5] and that this is one of three aspects that does not fit within the ASD "family" of disorders [9]. The other two aspects are: responding better to spontaneity and humour, and a preoccupation with role play and fantasy, features that tend—on a group-wise level—to separate PDA from ASD. Our results support this idea, showing a more even gender ratio in the PDA group.

In our study, several of the individual PDA reported

the notion of PDA as a more valid cli
just a mere collection of ad hoc lumped-

Our study cannot resolve whether or
just another subgroup within the ASD
a condition commonly coexisting wi
or a "discrete" disorder in its own righ
that PDA does coexist with ASD in a
ity of cases, but we know, from clinic
PDA characteristics can also be identif
tions including language disorder an
[9], in progress). Selective mutism [7]
uncommon condition (actually with a si
we have found for PDA with ASD) that
pre-school to school-age children who a
fashion) talking to unfamiliar persons
selective mutism show the same stubbo
that the PDA group does. Also, many
cians in the field of selective mutism,
selective mutism often coexists with aut

Indirectly, results from our study s
the context of ASD might have a relati
given that of the nine indications of a
only one still reported to have sufficie
toms at age 15–24 years to "qualify" for

There are also some similarities
ADHD with or without oppositiona
(ODD)/conduct disorder (CD). Howe
dren with PDA often fail in terms of fr

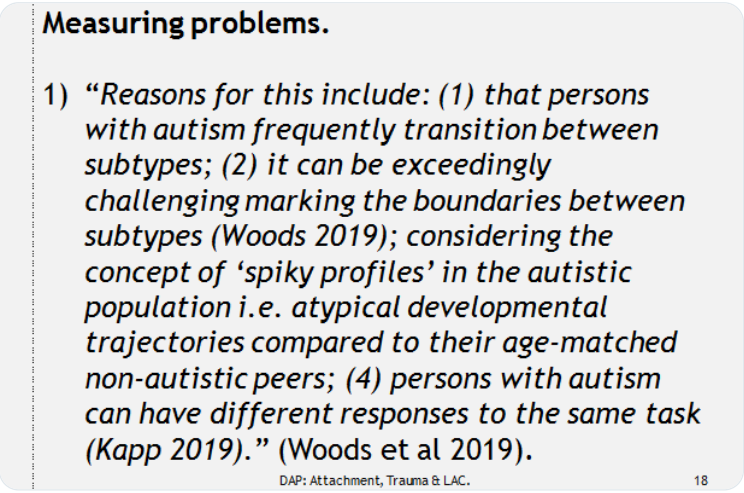
I think that is all the critique and limitations I know of going by public sources.

Until such times that Help4Psychology PDA research results are replicated or not replicated independly using Newson's diagnostic tool and diagnosing in non-autistic persons; their PDA database needs to be treated with caution.
Over to @DrJudes03

For reasons why it is difficult to subtype/ divide autism can be found here:

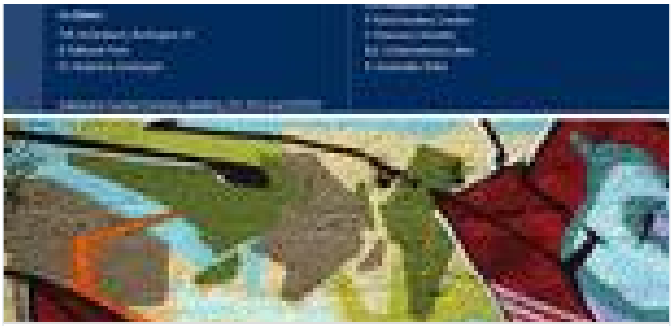
Empathy and a Personalised Approach in Autism

https://link.springer.com/article/10.1007%2Fs10803-019-04287-4



If people need a better image of Newson's "Autistic Family" diagram.

Also 15 unvalidated DISCO PDA items, also need the full DISCO as questions to assess for delayed speech development are in full DISCO.



Extreme (“pathological”) demand avoidance in autism: a gen

Research into Pathological Demand Avoidance (PDA), which has been suggested to be a subgroup within the Autism Spectrum Disorder (ASD), is almost nonexiste

https://link.springer.com/article/10.1007/s00787-014-0647-3

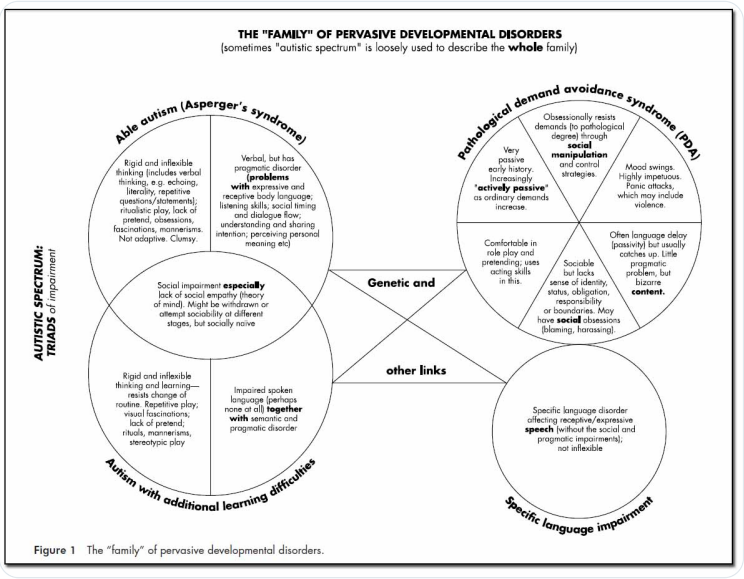


Figure 1 The “family” of pervasive developmental disorders.

Articles by Langton and Frederickson are also important as they are clear, no consensus over how to diagnose PDA means researchers cannot rely on a PDA dx as an indicator has PDA or not:

Parents’ experiences of professionals’ involvement for children with e…

(2018). Parents’ experiences of professionals’ involvement for children with extreme demand avoidance. International Journal of Developmental Disabilities: Vol. 64, No. 1, pp. 16-24.

https://www.tandfonline.com/doi/abs/10.1080/20473869.2016.1204743?journalCode=y…

Obviously means that no-one can rely on any PDA dx as an accurate identifier if a person has PDA or not. Raises questions over accuracy of Help4Psychology's definitions are reflective of

all PDAers?

@threadreaderapp please unroll

Thank you to @sofadog for this.

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