Richard Woods @Richard_Autism

Aug 14, 2021 · 58 tweets · Richard_Autism/status/1426442753538465794

@judehea I have quite clear views on how I think PDA should be viewed. I have an essay on this submitted, awaiting to receive feedback.

@judehea The issue is that no-one can really be sure of what looks like, & thus exactly what it is. I try to give a comprehensive over view on the topic, from different outlooks. While also being clear that PDA is blatantly not an ASD.

@judehea Recent systematic review.
“Problems concerning definition and measurement in the reviewed studies currently limit any conclusions regarding the uniformity or stability of the behaviours described, or the characteristics of individuals displaying them.” (p1).

@judehea “evidence that PDA is either a separate disorder or constitutes a stable subtype or trait in autistic individuals is currently lacking.” (Kildahl et al 2021, p12).

@judehea This is compounded by small evidence base, general lack of consideration of alternative explanations in PDA research, & other issues like testing assumptions; PDA is meant to be anxiety-based, but hardly any anxiety specific tools used in its research.

@judehea Despite this
Researched PDA via their autism understandings (O’Nions et al 2016b).
“interest in the concept of PDA largely centres on the UK, it is at present a culture-bound concept” (O’Nions et al 2020, p398).

@judehea UK PDA interest has risen sharply over last 10 years & it way outstrips its research base (O’Nions & Eaton 2021).
Due to campaigning efforts persons can be on the look-out for PDA & is a potential source of bias (Woods 2020).

@judehea The potential bias from campaigning for PDA as an ASD is that bad, someone recently (mistakenly) said this about me:
“Richard does not believe in PDA but chooses to chase a trauma model.”

@judehea That quote is symptomatic of what appears to be pervasive bias on the topic. Seemingly high risk of bias in snowball sampling was enough for me to be advised not to use snowball sampling in my PhD...

@judehea The most fundamental issue is that how PDA has been pursued over last decade is unethical & unscientific, it has largely been about validating the single perspective PDA is an ASD.

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@judehea I am approaching PDA from "typical" research norms; good quality inclusive scientific-method based, theory, research & practice.

@judehea 4 schools of thought on PDA.

Common mental health disorder (Gillberg 2014).
Rare autism subtype (Christie 2007).
Rebranded autism (Milton 2017).
Symptoms from interaction between autism & co-occurring conditions (Green et al 2018)..

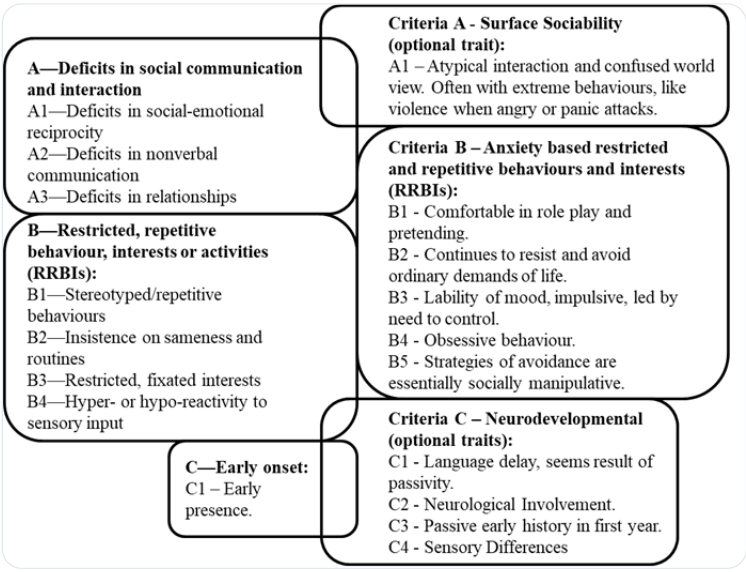
@judehea Which I detail how they evolved in the literature below:
https://www.researchgate.net/publication/351071989_Is_Pathological_Demand_Avoidance_a_meaningful_subgroup_of_autism

@judehea Even with these different schools of thought there are variations of it. So it debated if PDA is a form of attachment disorder, or a personality disorder.
https://thepsychologist.bps.org.uk/volume-29/january-2016/pda-there-another-explanation

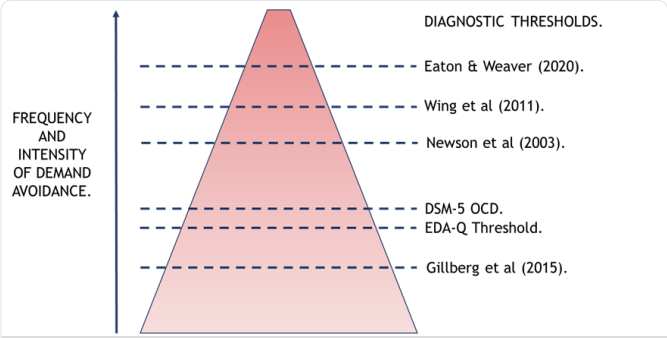
@judehea 5 Different Behaviour Profiles.

Newson et al (2003).
O'Nions et al (2016a).
Green et al (2018).
Eaton et al (2018).
Woods (2019).

@judehea Which is why I aggregated them together here:



@judehea Then to cap off the uncertainty on the topic, there are several different diagnostic thresholds on PDA, & there is substantial variation across the threshold for PDA in the literature.



PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THR...

PDA BEHAVIOUR INTENSITY AND PREVALANCE AT DIFFERENT THRESHOLDS. NOTES ON WRITING THIS BLOG POST. This blog post has been written over a course of the last few of months. It particular in the last s…

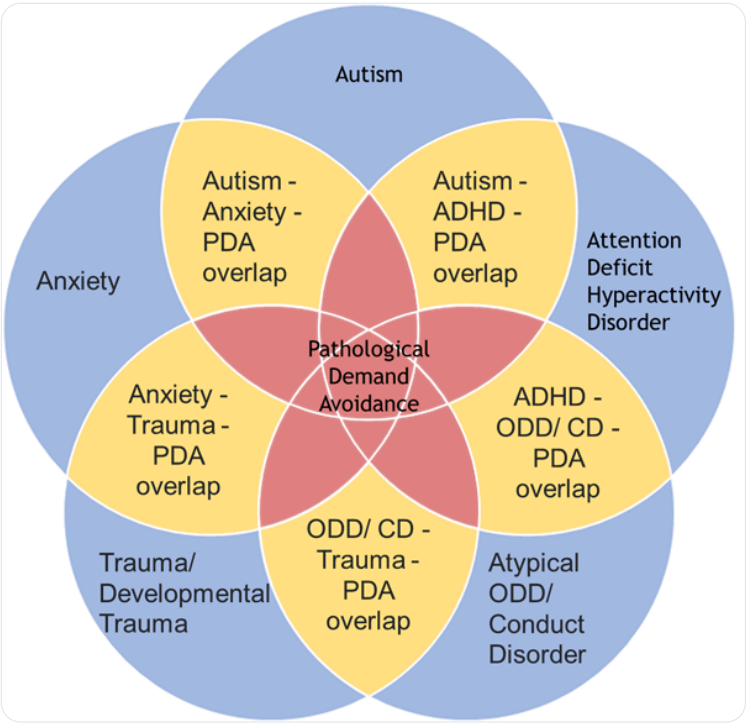
https://rationaldemandavoidance.com/2021/04/25/pda-behaviour-intensity-and-prevala…

@judehea One of the reasons why I am the leading autistic expert on PDA, is that not arrogant enough to assume that only one narrow perspective on PDA is valid; i.e., it is rare autism subtype, has to look a certain way.

@judehea I try to an inclusive approach to PDA that accommodates as many different valid outlooks on PDA as possible.

@judehea So in my view the only school of thought on PDA which is not valid, is that it is a rare autism subtype/ profile/ subgroup/ disorder. I can go into great detail on why there is a strong & valid case for this position.

@judehea So I think that PDA can be viewed as a pseudo syndrome, a collections of symptoms resulting from interaction of autism & various co-occurring conditions. I.e, PDA features can be explained by accepted constructs.



@judehea Inherently PDA seems to pathologise features not associated with autism, which explains why results are indicating it is different from autism, as Newson's view that PDA is separate & independent from autism seem valid.

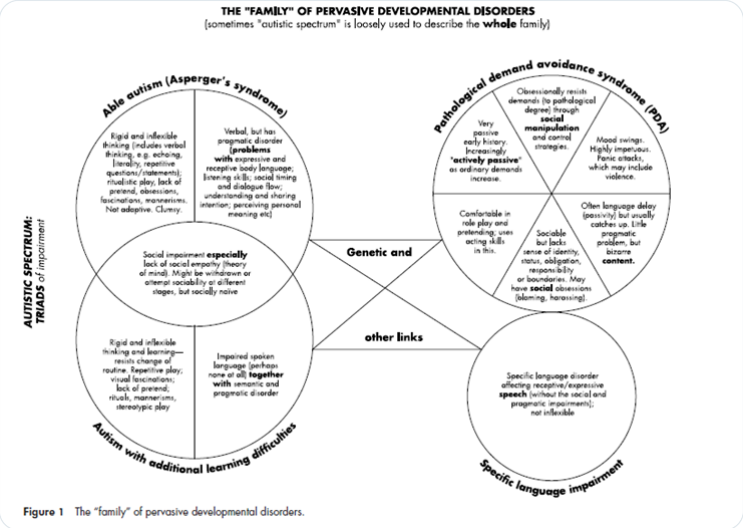
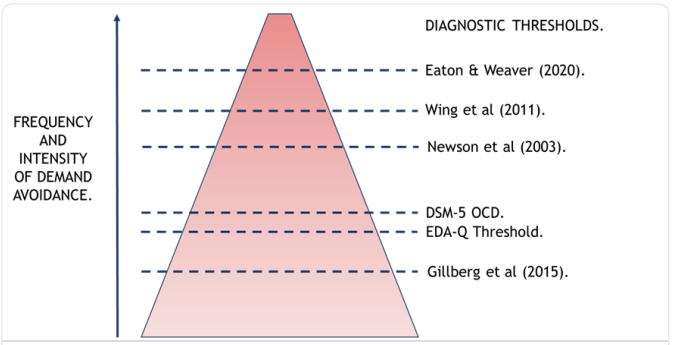


Figure 1 The "family" of pervasive developmental disorders.

@judehea This makes sense as PDA is meant to be an anxiety based construct, & yet it is widely accepted that anxiety is not core feature of autism, but a co-occurring difficulty. PDA seems an independent clustering of features.

@judehea I think PDA is most likely a new type of Disorder.
https://thepsychologist.bps.org.uk/pda-new-type-disorder

@judehea I think PDA should (even only temporarily) be placed within OCD and Related Disorders diagnostic grouping.



@judehea I am interested in the demand-avoidance. Not demand-avoidance plus developmental features, not demand-avoidance plus developmental features plus social communication issues.

@judehea There are many good reasons to only focus on the demand-avoidance aspects of PDA.

@judehea This is from an email I sent with someone this week.

"I am also not specifically looking at PDA's developmental traits. There are good reasons to discard them from the PDA profile.

@judehea The definition for Disorder in the DSM-5 does not require it to be "Developmental", or "Pervasive" in nature. Neurological Involvement trait awaits systematic research into its links with PDA. Passive Early history seems not to cluster with other PDA traits.

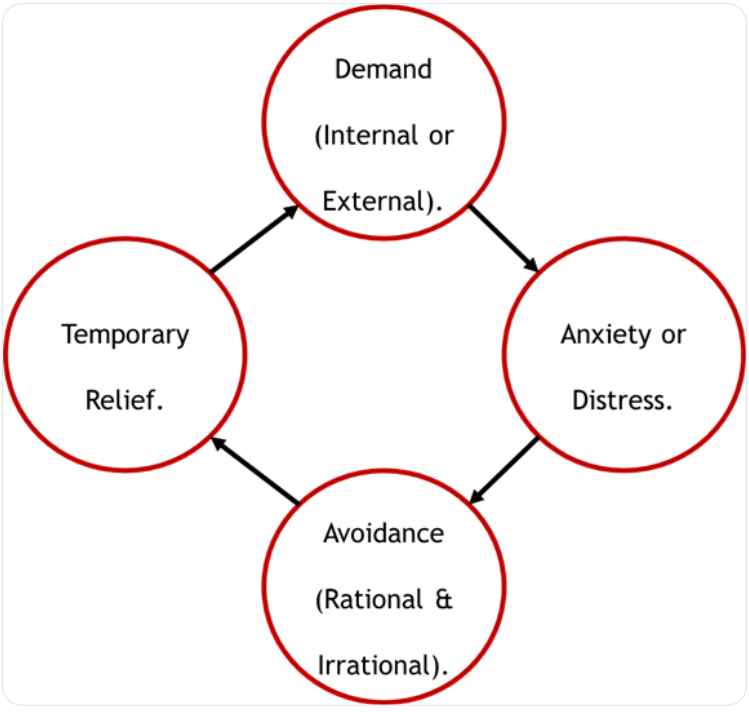
@judehea The PDA developmental traits are generic, and O'Nions (2016) removed them from the profile for being too common in the autistic population. There is a general approach to reduce number of PDA traits down to those essential for a diagnosis.

@judehea The most used PDA tools with CYP either do not measure developmental features or are not required to meet threshold. Multiple PDA authors have presented the PDA behaviour profile lacking the developmental features.

@judehea Under transactional perspectives a person can transition into PDA. There are clinical accounts of persons transition into PDA.

@judehea I am focusing on the core PDA traits, which are linked to the generic negative feedback cycle that seems to develop and maintain PDA features.

@judehea Based on some of O'Nions PDA research, the OCD cycle, broader mental health literature & expert opinion. I created the Demand Management Cycle.



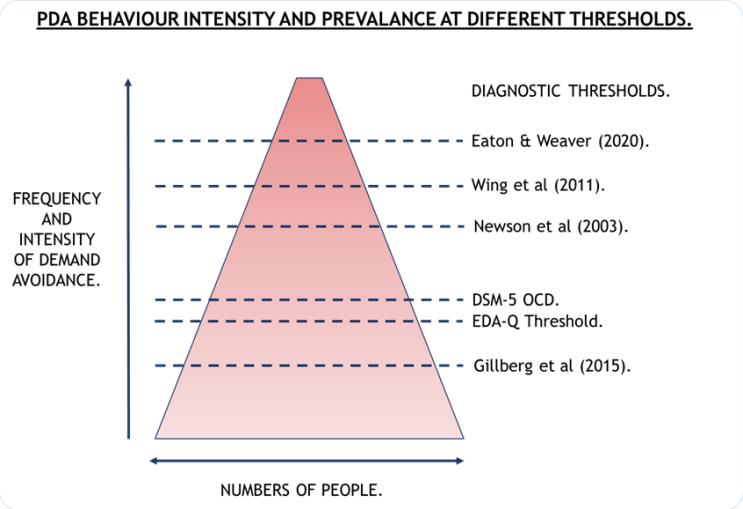
@judehea The Demand Management Cycle seems to underpin the development & maintenance of PDA features. Also reflects how the avoidance features can become "hot-wired", and generalise.

@judehea It is through focusing on the demand-avoidance of PDA, fundamentally taking a transactional outlook which views to be a PDA process, not a collection of "deficits" that are located in the person, why I think PDA should go in OCD & Related Disorders.

@judehea At the same time, I also acknowledge there is likely a good case PDA can go into & disruptive, impulse-control, & conduct disorders.

@judehea My own view, is that PDA seems to be intrinsically about stress management. E.g, this image from PDA Society.

@judehea I need to be clear, I accept that some think PDA is from early infancy, and is pervasive in nature. For me that represents a tiny window of what PDA probably looks like.



@judehea If one views PDA to be a Disorder. The demand-avoidance should become "pathological" at a "non-pervasive" level, so around the EDA-Q, with it presenting in a single context, such as school.

@judehea PDA presents as a continuum in human population.
Fluid & transient over lifespan & diverse situations.
"the disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.“ (APA 2013, p21).

@judehea “...start to display avoidant behaviour and challenging behaviour in response to a particular stressor...” (Eaton 2018, p20).
Around EDA-Q threshold and/ or “problematic demand avoidance” (O’Nions et al 2018b).

@judehea If one accepts the clinical arguments for PDA, then most/ all of them are applicable to PDA in non-autistic persons and to lower diagnostic thresholds.

@judehea There does appear to be many studies with non-autistic persons with PDA in, includes Newsons cohort. Many experts saying PDA is seen in non-autistic persons.

@judehea This gets back to my point, I am not arrogant enough to think that only a narrow outlook (PDA is an ASD) which contradicts established understandings on Disorders & autism is the only valid way to view PDA.

@judehea I respect others opinions and research results that indicate PDA is seen in non-autistic persons, just as much as I accept that Help4Psychology are seeing a particularly narrow version of PDA.

@judehea This is my point, I am trying to take an inclusive approach to it.

@judehea While I think most of the arguments for clinical need for PDA have merit. I also think that two main reasons for PDA being not clinically needed are valid.

@judehea Which is that PDA features can be found in accepted constructs, & PDA can be modelled as a pseudo-syndrome. That PDA strategies, or equivalent approaches are widely practiced independently of PDA.

@judehea Actually the case for PDA being a pseudo-syndrome makes sense as strategies/ treatments, tend to be issues/ symptom specific, not diagnoses/ syndrome specific.

@judehea I only argue that PDA should be diagnosed as a Disorder because I think some persons (mainly those who view PDA to be an ASD) are going to diagnose PDA irrespective of divergent opinion. I am trying to be pragmatic about it.

@judehea Just because PDA overlaps many accepted constructs, it does not prevent it being it's own distinct "thing". Most Disorders in DSM-5 overlap other Disorders in there.

@judehea What PDA cannot be, is something it is more than. Basic logic, so A + B + C ≠ A, e.g., PDA cannot be a form of autism.

@judehea In short, I think PDA can be diagnosed, & at a much lower threshold than some would advocate. Although, I think overall we should be treating PDA with extreme caution, only diagnosing it rarely due to uncertainty over it.

@judehea I also think PDA is being used to control the autistic population, & broader autism community, I will be talking more about this at a PARC event in October. I suspect this is out of scope of your questions.

@judehea Have I answered your questions? Do you have any other questions?

@judehea Actually I need to point out, that if one views PDA to be about stress management, logically its etiology is trauma &/ or aversive childhood experiences.

@judehea @threadreaderapp please could you unroll?

Thank you in advance.