

“Pathological” / “Extreme” / “Rational” Demand-Avoidance: Reviewing and Refining its Contested Terrain Through an Educational Perspective.

A Frontiers in Education PDA special issue.

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PROFILING MYSELF.

My perspective.

- 1) Is autistic.
- 2) Meets Newson's PDA profile, is not emotionally attached to it.
- 3) Reflect upon "*how their values shape their understanding and construction of autistic people.*" (Botha 2021, p1).
- 4) Agenda is for at least inclusive good quality scientific-method based research & practice.
- 5) My interpretation of PDA & its literature, others may disagree.

PROFILING MYSELF.

Conflicts of interest.

- 1) Developing various PDA tools, e.g., Pathological Demand-Avoidance-Beliefs Scale (PDA-BS).
- 2) Income from delivering training sessions on PDA.
- 3) Reluctantly advocates for it to be diagnosed as a standalone construct.

IN THE BEGINNING.

Background of *Frontiers in Education* PDA Special Issue.

- 1) I, Prof Eddie Chaplin, & Dr Allison Moore are the editors.
- 2) In *Frontiers in Education* journal.
- 3) Frontiers group has clear rules for accepting articles.
- 4) How Newson viewed PDA changed over time.
- 5) No agreement over what PDA is, or what features are associated with PDA.
- 6) Some prematurely viewed PDA as a “*Profile of ASD*” in UK.
- 7) There are ongoing-historical PDA debates.
- 8) What areas should submissions cover.
- 9) Types of submissions editors would welcome.
- 10) Not covering PDA education debates in this video.

IN THE BEGINNING.

Encourage submissions on.

- 1) Systematic & scoping reviews, novel conceptualisations of PDA
- 2) Refinement of proposed ontologies, such as an Attachment Disorder
- 3) Contextualising PDA in historical & current notions of disability
- 4) Questioning underlying assumptions and providing alternative explanations
- 5) Ethical merits for different worldviews of PDA
- 6) Personal perspectives on PDA
- 7) How do PDA strategies compare with other approaches used with SEND persons and wider pedagogies

LET'S TALK.

Main PDA Discourse.

- 1) Called “*Pathological Demand Avoidance*” or “*Extreme Demand Avoidance*”.
- 2) Originally a Pervasive Developmental Disorder.
- 3) A rare autism profile/ subgroup/ subtype.
- 4) Has unique strategies that are different to autism.

AVOIDING DEMANDS OF ORDINARY RESEARCH.

PDA in the UK.

- 1) Some clinicians have been diagnosing PDA as a “*Profile of ASD*”, e.g., (PDA Society 2022).
- 2) Research PDA via their own autism understandings.
- 3) Caregivers are highly motivated to take part in research (O’Nions et al 2016b).
- 4) “*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).
- 5) UK PDA interest has risen sharply over last 10 years & it way outstrips its research base (O’Nions & Eaton 2021).
- 6) Due to campaigning efforts persons can be on the look-out for PDA & is a potential source of bias (Woods 2020).

AVOIDING DEMANDS OF ORDINARY RESEARCH.

Broader academic & clinical situation with PDA.

- 1) PDA is controversial (Falk 2020; Fidler & Christie 2019; Green et al 2018b; O’Nions et al 2014; Schneider et al 2022).
- 2) Independent reputable parties recently concluded no good quality evidence to suggest what PDA is, or what features are associated with it. Divergent opinion was treated equally (Berney et al 2020; Howlin et al 2021; Kildahl et al 2021; NICE 2021).
- 3) PDA 3 other schools of thought (Woods 2021):
 - Rebranded autism.
 - PDA is a pseudo-syndrome/ pseudo-Disorder.
 - PDA is a common mental Disorder.

UNCOMFORTABLE PRETENCE.

NICE Position on PDA.

- 1) Three NICE autism guidelines.
- 2) PDA only mentioned in CG128, diagnosing autism in CYP...
- 3) *“Pathological demand avoidance (PDA) has been described as a particular subgroup of autism with passive early onset, obsessive behaviours which are often person focussed with superficial social skills in whom the most striking feature is refusal to comply (excessive demand avoidance) even to events which the child enjoys. This oppositional behaviour can also be described as ODD. (emphasis added by speaker)” (NICE 2021b, pp.288-289).*

UNCOMFORTABLE PRETENCE.

NICE's Review of PDA.

- 1) *“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-V 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.”* (NICE 2021a, p10).
- 2) *“We did not identify suitable evidence on possible links with anorexia or pathological demand avoidance that supported external feedback we received about these disorders.”* (NICE 2021a, p48).

UNCOMFORTABLE PRETENCE.

NICE's Review of PDA continued.

- 1) *“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.” (NICE 2021a, p47).*

UNCOMFORTABLE PRETENCE.

RCP PDA definition:

1) *“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....”*

UNCOMFORTABLE PRETENCE.

RCP PDA definition continued:

- 1) *“...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.” (Berney et al 2020, pp.30-31).*

UNCOMFORTABLE PRETENCE.

BPS Position on PDA.

- 1) *“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).” (Howlin et al 2021, p18).*

UNPASSIVE EARLY HISTORY.

Newson's consistent views on PDA not being autism.

- 1) *"...I believe this referral pattern is significant in having brought so many of these children to my notice, because they tend to remind people of autism. However, I am very clear these children are not autistic children."* (Newson 1983, p3).
- 2) *"A few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded."* (Newson et al 2003, p596).
- 3) *"Clearly, "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).
- 4) *"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."* (Newson et al 2003 Supplementary Notes p1).
- 5) There are other examples in Newson's scholarship to support this position.

CIRCLE WARS.

Quotes of PDA as a “Rebranded Autism” outlook.

- 1) *“For example, Wing and Gould (2002) feel that PDA is not a separate syndrome and that the individual behavioural features portrayed in the constellation described as PDA can be found within individuals with an autistic spectrum disorder. They agree, however, that ‘recognition of this subgroup with special problems is innovative and clinically valuable’.”* (Christie 2007, p5).
- 2) *“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.”* (Milton 2017, p32).
- 3) *“Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism.”* (Christie 2007, p3).

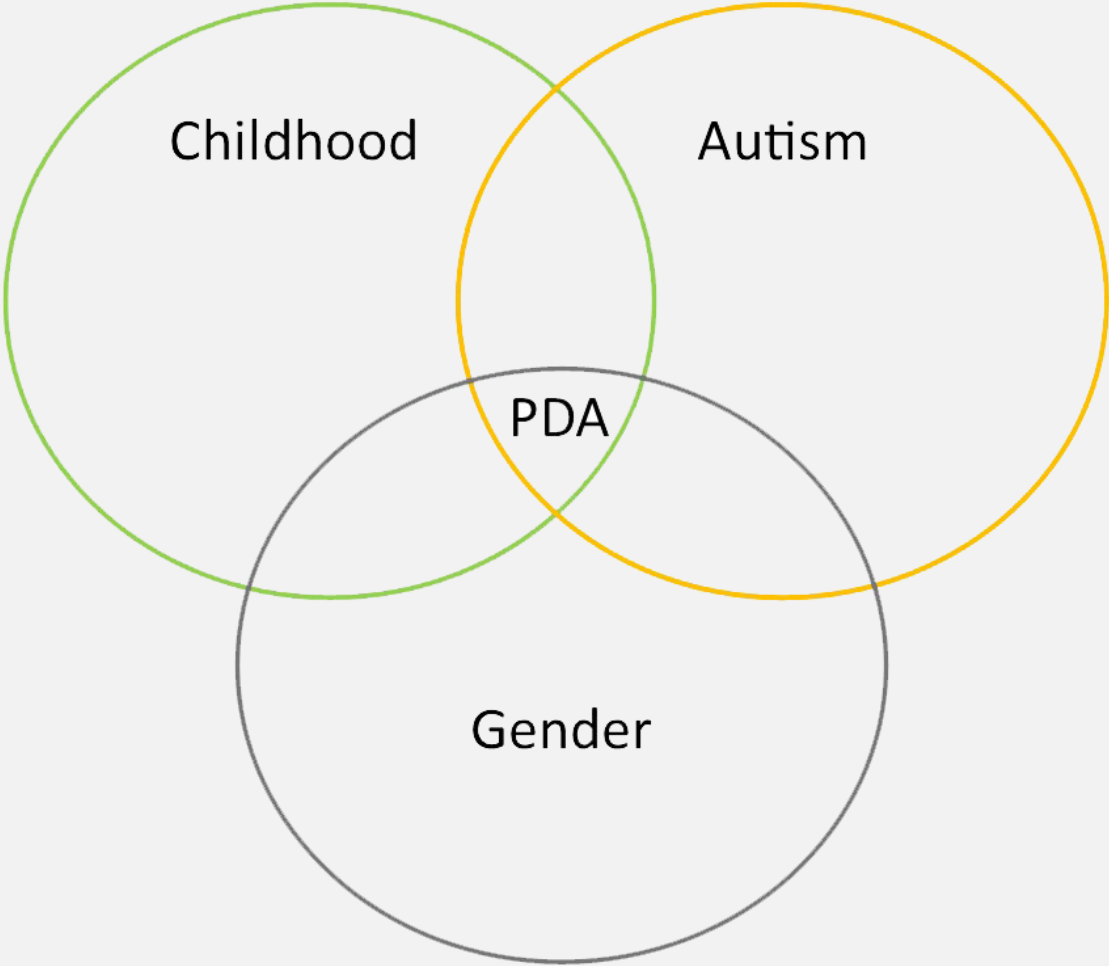
CIRCLE WARS.

Quotes of PDA as a “*Rebranded Autism*” outlook continued.

- 1) *“Could it be that the PDA pattern of behaviour is the female presentation of autism or are there other female presentations of autism within the spectrum?”* (Gould & Ashton-Smith 2011, p37).
- 2) *“...PDA represents the medicalising and pathologising of behaviours that from an outsider perspective seem to be differentiated from what is deemed capable by autistic people, but could be seen as the behaviours of an autistic person who has gained a modicum of normative social skills and is simply asserting their agency...”* (Milton 2017, p37).
- 3) *“Currently, there does not seem to be clear rationale to make EDA a separate sub-division of autism, given the removal of clinical subtypes such as Asperger’s syndrome from the DSM-5 (Green et al., 2018). However, anecdotally, clinicians who recognise EDA report that they find a clear distinction between autism and EDA (e.g. Eaton et al., 2018). In practice, it seems that clinicians are identifying a difference between the two which does not seem to be translating into research.”* (White et al 2022, p7).

CIRCLE WARS.

Rebranded autism (Moore 2019).



A HIDDEN IMPAIRMENT?

PDA is not a real Disorder/ syndrome, that its features are attributed to accepted difficulties & Disorders.

- 1) *“Others are suggestible of a number of different child and adolescent psychiatric disorders as described in ICD-10 and DSM-IV (WHO, 1991; APA, 1994).[2,3] From the authors' descriptions, the impression is that these children are likely to have had co-morbid developmental and psychiatric problems, varyingly including oppositional defiant and/or hyperkinetic disorder or social anxiety disorder of childhood. In some cases the features described may have been precursors of a schizotypal disorder.” (Garralda 2003).*
- 2) *“However, Rogers, Viding, Blair, Frith, and Happe’ (2006) found a small number of boys with ASD, also had psychopathic tendencies. The authors considered that this was a ‘double hit’ - the psychopathic behaviour was an additional problem, and was not due to the autism spectrum disorder. Boys and girls with pathological demand avoidance (Newson, Le Marechal, & David, 2003) may also have such a ‘double hit’.” (Wing et al 2011, p769).*

A HIDDEN IMPAIRMENT?

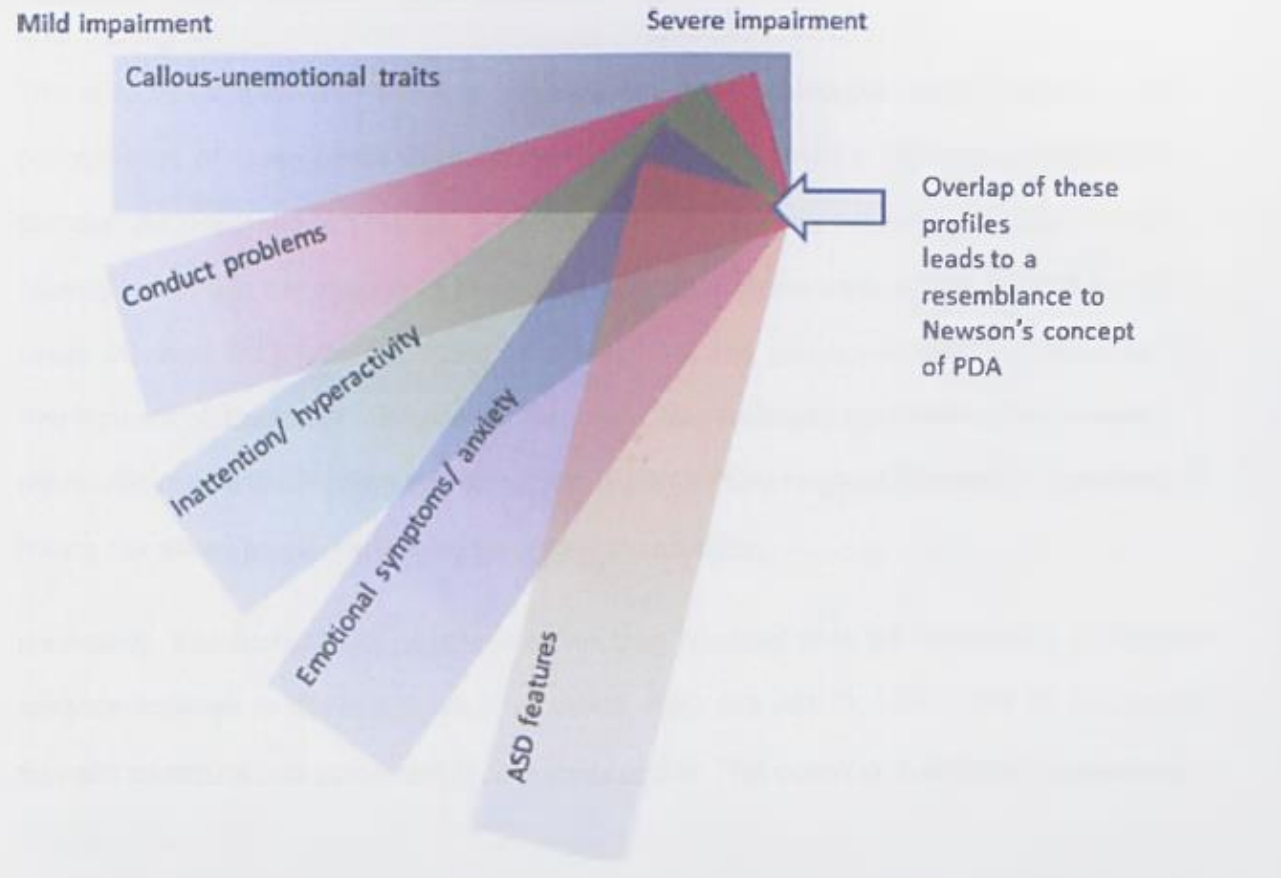
PDA is not a real Disorder/ syndrome, that its features are attributed to accepted difficulties & Disorders continued.

- 1) *“Nevertheless, the use of the term highlights an important known range of co-occurring difficulties for many children with autism spectrum disorder that can substantially affect families. We explore how these difficulties can best be understood through understanding of social, sensory, and cognitive sensitivities in autism spectrum disorder, identification of frequently occurring comorbid conditions, and assessment of how these problems interact within the child’s social environment.”* (Green et al 2018a, p455).
- 2) *“Our results are therefore in agreement with the authors who questioned the validity of PDA as a distinct entity [41]”* (Schneider et al 2022, p8).

SPIKY PROFILE.

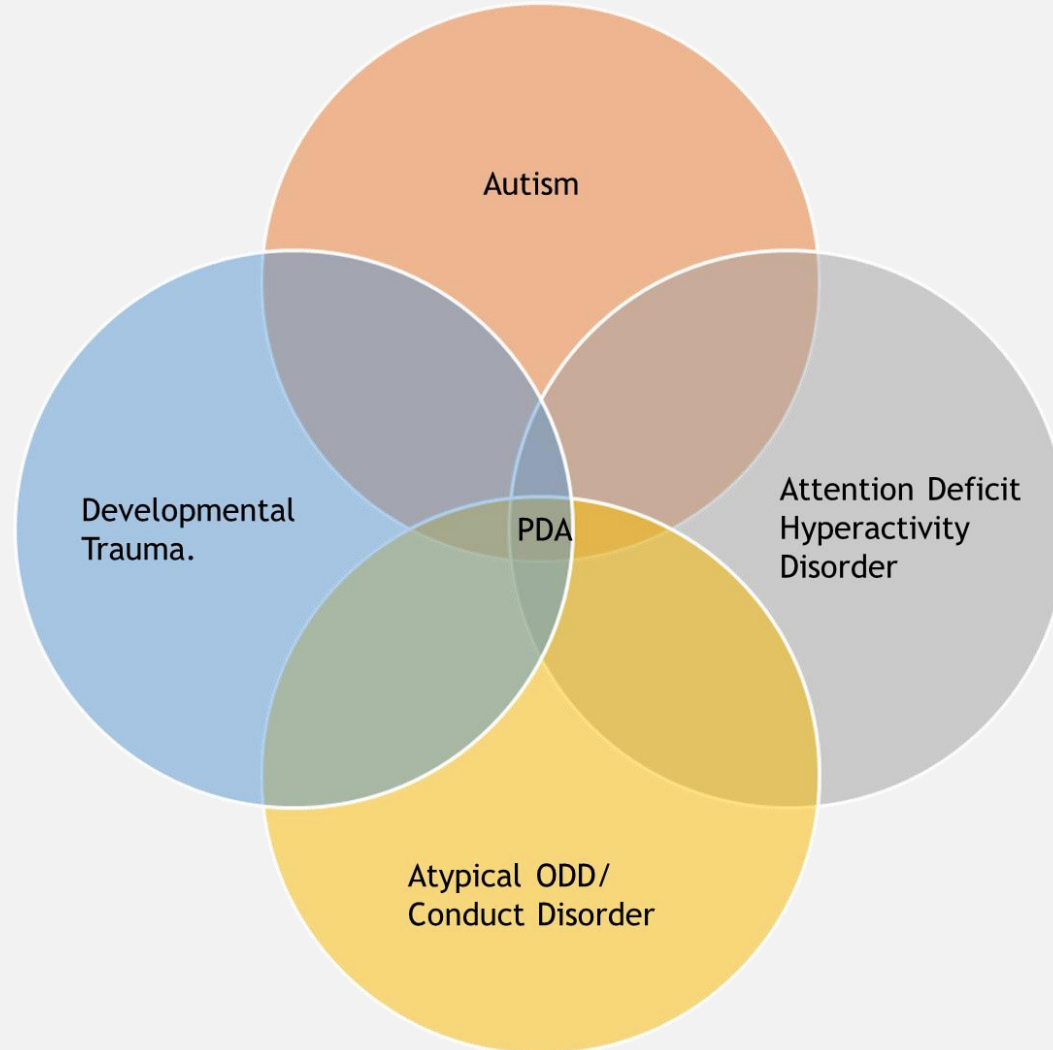
How accepted constructs may relate to PDA (O’Nions 2013, p93).

Figure 4-1: Schematic representation of dimensions of neuro-developmental and behavioural disorders in the general population that share features with PDA.



CIRCLE WARS.

Soppitt (2021, p299) PDA & its components diagram (my version).



A KLING-ON?

PDA as a form of Attachment Disorder.

- 1) *“Since that time, there has been much debate between professionals as to whether this is indeed a separate condition or whether the behaviours found in PDA can be explained within other disorders such as attachment disorder or personality disorder or a female form of autism.” (Christie 2007, p3).*
- 2) *“PDA describes a child who is primarily led by a need to avoid demands and control situations, struggles with social communication and relationships. However, these exact same characteristics could equally be used to describe a child with disordered attachment (NICE, 2015). Furthermore, research has shown that children with a diagnosed attachment disorder may be as impaired as autistic children in their social relatedness and language skills (Sadiq, et al., 2012), and one study found that the symptoms of ASD and attachment disorder can be comorbid (Giltaij, et al., 2015). Therefore, given that PDA is currently considered a form of ASD, it is fair to assume that a similar overlap in symptoms may exist between PDA and attachment disorders.” (McElroy 2016).*

A KLING-ON?

PDA as a form of Attachment Disorder continued.

- 1) *“Resistance to the inclusion of PDA into the DSM being predicated on it being a false identification of a form of attachment disorder rather than having a neurological basis (PDA Contact Centre, 2012).” (Milton 2017, p30).*
- 2) *“...There is simply not enough evidence to support a claim such as this, especially when there are similar traits associated with both developmental and attachment disorders. It is more than possible that autistic people can be traumatised by social relationships and by negating such factors as ever having a causative association with avoidance behaviours could be potentially negligent...” (Milton 2017, p33).*
- 3) *“Those clinicians who feel it does warrant a separate diagnostic category feel it fits within the autism spectrum whereas others question whether it is better placed as an attachment disorder.” (Flackhill et al 2017, p65).*

THEY ARE BREEDING LIKE RABBITS.

Newson's cohort contains non-autistic CYP with PDA.

- 1) *"...I believe this referral pattern is significant in having brought so many of these children to my notice, because they tend to remind people of autism. However, I am very clear these children are not autistic children."* (Newson 1983, p3).
- 2) *"A few children whose clinical picture is less certain, often because of additional autistic characteristics, but atypical of autism also, were excluded."* (Newson et al 2003, p596).
- 3) *"...it is likely that many of the original cohort of children assessed by Newson and her team would today meet the diagnostic criteria for Autism Spectrum Disorder using DSM 5."* (Eaton & Weaver 2020, p34).
- 4) *"Given that most of Newson's original PDA sample would now fulfil the broader ASD criteria, where do you stand on its relationship with the autistic continuum?"* (Soppitt 2021, p311).

THEY ARE BREEDING LIKE RABBITS.

Examples of PDA is found in non-autistic persons.

- 1) “A “manipulative child” in the 1970s might get the label of Pathological Demand Avoidance Syndrome in the 2000s.” (Goodley 2011, p10).
- 2) Chapter 5 study has one CYP with diagnosed with Attachment Disorder & ADOS Score of 1 (O’Nions 2013, p226).
- 3) Chapter 8 study has 23% of CYP diagnosed with PDA are non-autistic. (O’Nions 2013, p176).
- 4) “As well as significant symptoms of PDA, the four children met criteria for a range of neurobehavioural disorders; all four had cognitive impairment (IQ < 85) and met DSM-IV-TR criteria for ADHD. Three, in addition, met criteria for ASD...” (Reilly et al 2014, p3236).
- 5) 8 out of 11 (73%) CYP with PDA are non-autistic (Kaushik et al 2015, p8).
- 6) “Pathological (or extreme) demand avoidance is a term sometimes applied to complex behaviours in children within– or beyond–autism spectrum disorder.” (Green et al 2018a, p455).
- 7) 7 out of 24 (29%) CYP with PDA are non-autistic (McFadzen 2020, p27).

AVOIDING VARIANCE.

Submissions should (there are good reasons why I am making this video):

- 1) Recognise there is no agreement over what PDA is.
- 2) Recognise there is no agreement over what features are associated with PDA.
- 3) Recognise PDA is controversial.
- 4) Discuss the different ongoing-historic PDA debates in their own interpretation.
- 5) Situate/ contextualise their research in these ongoing-historic debates.

AUSTERITY MEASURES.

Article Process Charges.

- 1) *Frontiers in Education* does have APCs.
- 2) Expected within 30 days of article acceptance.
- 3) Frontiers group has a fund authors can apply for (editors are not involved with this fund).
- 4) Available through below link:

<https://zendesk.frontiersin.org/hc/en-us/articles/201904402-Do-I-qualify-for-fee-support->

AVOIDING VARIANCE.

Encourage submissions on.

- 1) Systematic & scoping reviews, novel conceptualisations of PDA
- 2) Refinement of proposed ontologies, such as an Attachment Disorder
- 3) Contextualising PDA in historical & current notions of disability
- 4) Questioning underlying assumptions and providing alternative explanations
- 5) Ethical merits for different worldviews of PDA
- 6) Personal perspectives on PDA
- 7) How do PDA strategies compare with other approaches used with SEND persons and wider pedagogies

AVOIDING VARIANCE.

Researchers, clinicians & practitioners need to specify
(Conclusion).

- 1) What school of thought they are basing their axiology upon.
- 2) What certain definition for PDA they use.
- 3) What exact behaviour profile they are using, particularly the wording as different versions have different clinical interpretations.
- 4) What their exact threshold for PDA is.

SAY HELLO TO THANOS FOR ME.

The End Game.

- 1) Contact Details: richardwoodsautism@gmail.com
- 2) Twitter handle:
@Richard_Autism
- 3) My researchgate:
https://www.researchgate.net/profile/Richard_Woods10
- 4) Frontiers in Education special issue topic page:
<https://www.frontiersin.org/research-topics/40032/pathological-extreme-rational-demand-avoidance-reviewing-and-refining-its-contested-terrain-through>

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ARE WE THERE YET?

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