

What if “*PDA Profile of ASD*” advocates are confusing non-autism features with autism?

Mr. Richard Woods.

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# 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.

# PROFILING MYSELF.

## My perspective.

- 1) Diagnosed as autistic in 2012.
- 2) Meets Newson's PDA profile, is not emotionally attached to it.
- 3) Presently, no-longer basing identity on diagnostic categories.
- 4) Favours a transdiagnostic approach & we should be aspiring to stop utilising Disorder based constructs in the future.
- 5) Agenda is for at least inclusive good quality scientific-method based research & practice.
- 6) PhD is investigating PDA & part of CADS at LSBU.
- 7) My interpretation of PDA & its literature, others may disagree.

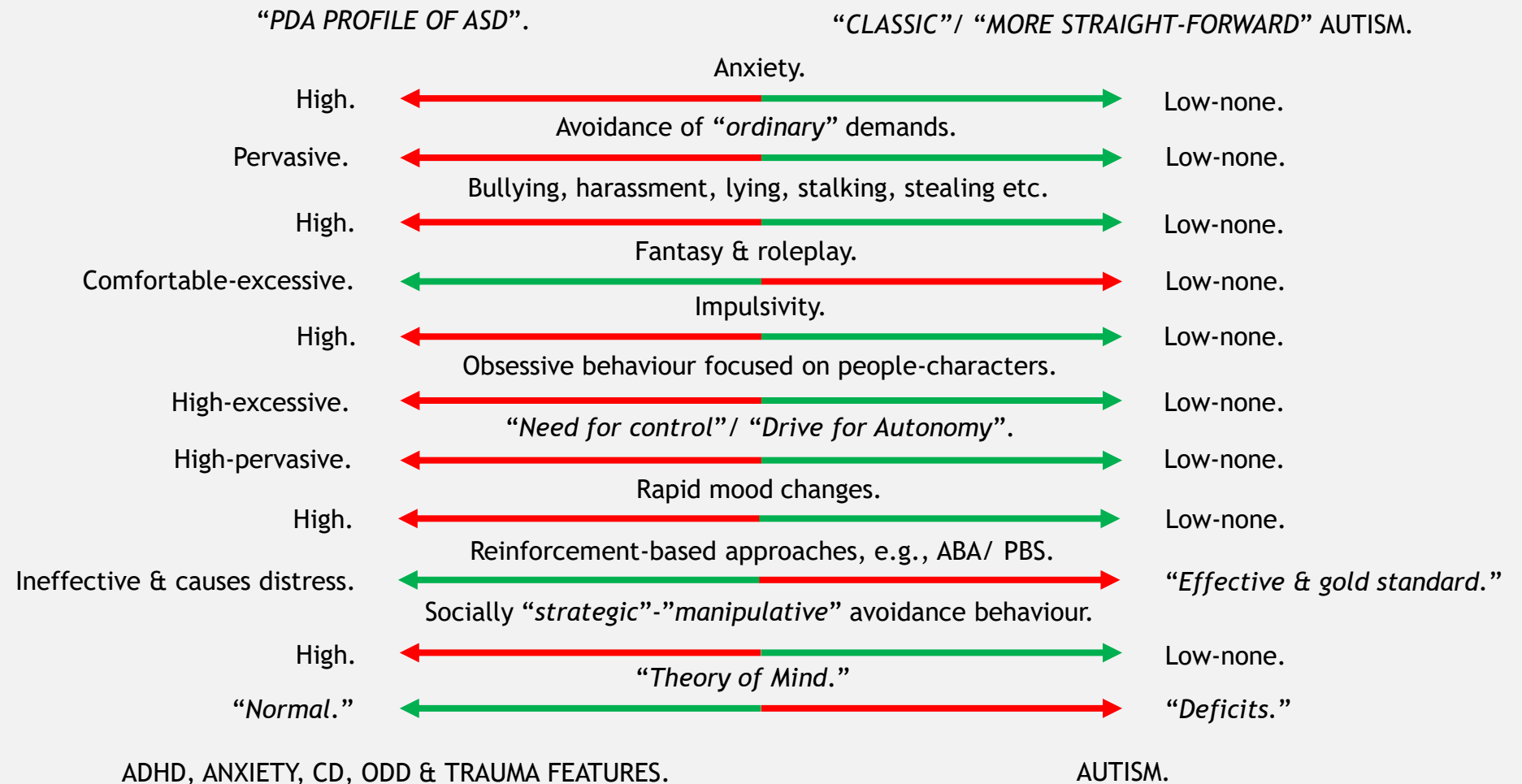
# IN THE BEGINNING.

## Introduction.

- 1) PDA models.
- 2) PDA's controversial status.
- 3) Typical standards.
- 4) Reasons to consider if non-autism features are confused in PDA.
- 5) PDA & autism subtypes literature.
- 6) PDA & fallacies.
- 7) Conclusion.

# ROLEPLAYING A “PROFILE OF ASD”.

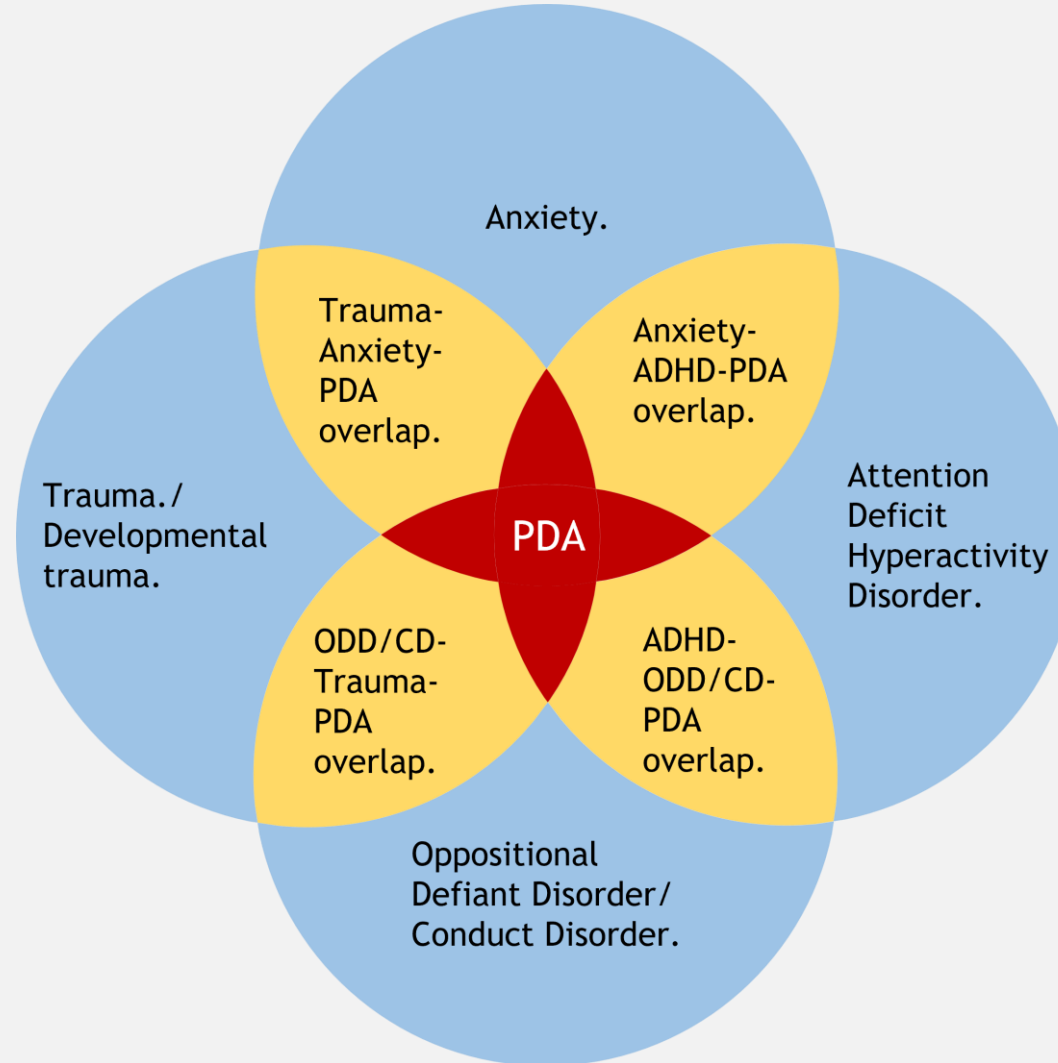
## “PATHOLOGICAL DEMAND-AVOIDANCE (PDA) PROFILE OF ASD” CONSTELLATION OF TRAITS WITHIN AUTISM SPECTRUM.



Please do not reify this diagram. Based on RW interpretations of “PDA Profile of ASD” clinical literature, diagnostic & screening tools.

# CIRCLE WARS?

“PDA Profile of ASD” as co-occurring difficulties.



# SPITTING IMAGES OR SPLITTING IMAGES?

## Combining different PDA.

- 1) Co-occurring categories can unpredictably interact.
- 2) Making some features more intense, while other characteristics less intense.
- 3) Sometimes creating novel features, that can be more intense than features associated with original categories; creating novel categories (Petrolini & Vincente 2022).

# SPITTING IMAGES OR SPLITTING IMAGES?

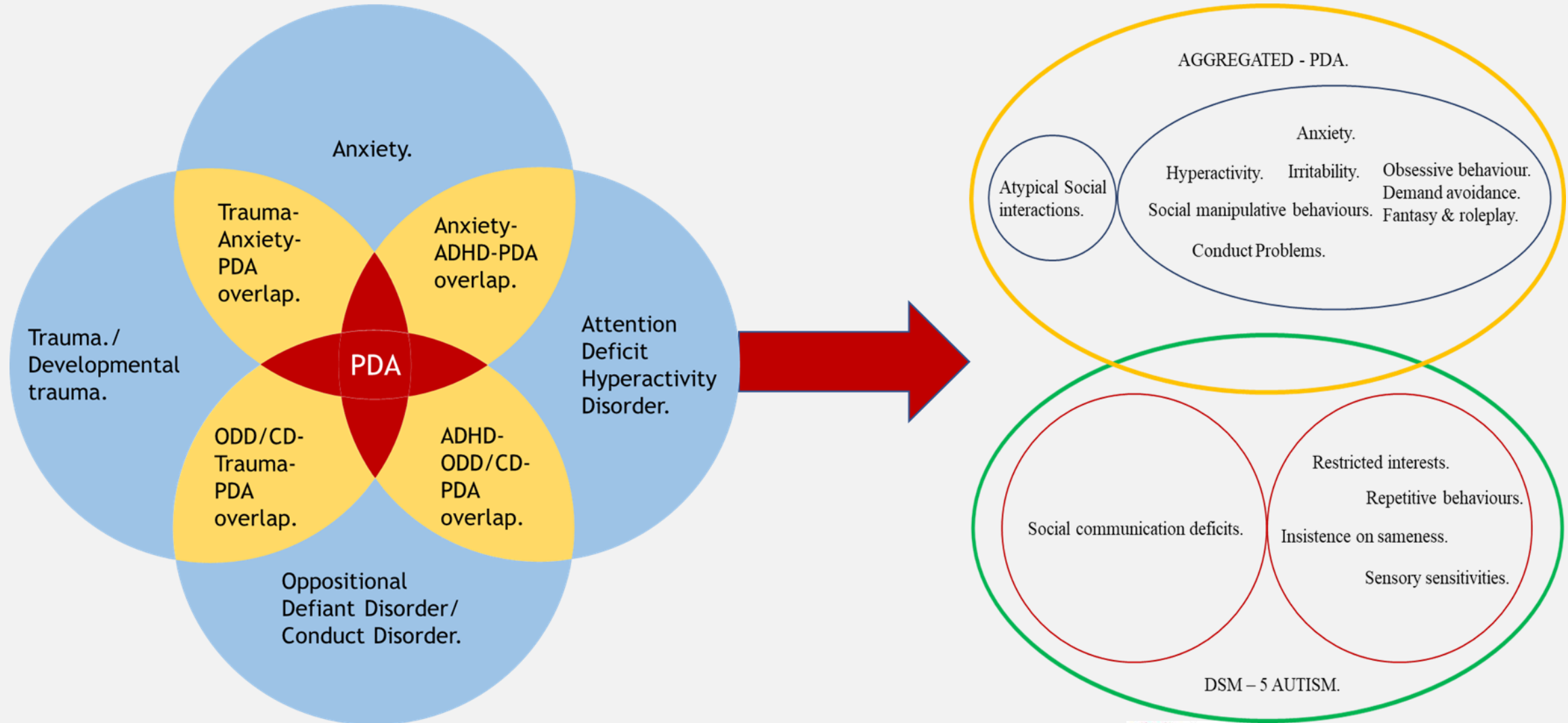
## Combining different PDA.

- 1) Co-occurring difficulties often present differently in autistics, compared to non-autistics (Kildahl et al 2021).
- 2) PDA maybe result of such unpredictable interactions between competing co-occurring conditions.
- 3) PDA likely presents differently in non-autistic persons.
- 4) Assuming PDA is a “Profile of ASD” &/ or basing PDA clinical descriptions from suspected autistic populations is unlikely to be representative of PDA in non-autistic populations...



# SPITTING IMAGES OR SPLITTING IMAGES?

## Co-occurring difficulties interacting might create PDA?



# AVOIDING DEMANDS OF ORDINARY RESEARCH.

## PDA in the UK.

- 1) Research PDA via their autism understandings.
- 2) Caregivers are highly motivated to take part in research (O’Nions et al 2016b).
- 3) *“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).
- 4) UK PDA interest has risen sharply over last 10 years & it way outstrips its research base (O’Nions & Eaton 2021).
- 5) 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.

Should there be a bubble on “*PDA Profile of ASD*”? - NO!

- 1) PDA is controversial (Falk 2020; Fidler & Christie 2019; Green et al 2018b; O’Nions et al 2014a; O’Nions et al 2014b; O’Nions et al 2016b).
- 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; Mols & Danckaerts 2022; NICE 2021).
- 3) Robustly challenged for almost 2 decades (Garralda 2003; Green et al 2018a; Green et al 2018b; Green 2020; Malik & Baird 2018; McElroy 2016; Milton 2017; Moore 2020; Wing 2002; Wing & Gould 2002; Woods 2017; Woods 2019; Woods 2020).

# ROLEPLAYING ANOTHER AUTISM SCANDAL?

## Warnings from autism history.

- 1) Autism often has poor quality theory, research, & practice.
- 2) Many cases of bold claims leading to perverse adverse ramifications, e.g.,:
  - Refrigerator mother.
  - Vaccines causes autism.
  - Theory of Mind deficits.
  - Empathy deficits.
  - Extreme Male Brain.
- 3) Autism stakeholders need to adhere to typical ethical standards.

# MEETING DEMANDS OF ORDINARY RESEARCH.

## MQ case study in researchers acting to prevent harm.

- 1) Researchers have a responsibility to minimise & avoid causing harm.
- 2) Significant community interest in Monotropism.
- 3) 700+ autistics in initial MQ validation study (Garau et al 2023).

# OF PEAK INTEREST?



 nd\_psych DrJoey - Autistic Psych

**New Autism assessment - The Monotropism Questionnaire. LINK [→](https://osf.io/4wru2...)**

261.4K Likes, TikTok video from DrJoey - Autistic Psych (@nd\_psych): "New Autism assess..."

2.7M views |

🎵 original sound - DrJoey - Autistic Psych



 audhdfeelings Sam ✨ AuDHD ∞ PDA 🧠

**#autismassement #monotropism #autism #adhd #audhd  
#selfdiagnosis #latediagnosis #neurodivergent #autismawareness...**

61.3K Likes, 1.1K Comments. TikTok video from Sam ✨ AuDHD ∞ PDA 🧠 (@audhdfeelings):...

564.6K views |

🎵 original sound - Sam ✨ AuDHD ∞ PDA 🧠

# MEETING DEMANDS OF ORDINARY RESEARCH.

MQ case study in researchers acting to prevent harm.

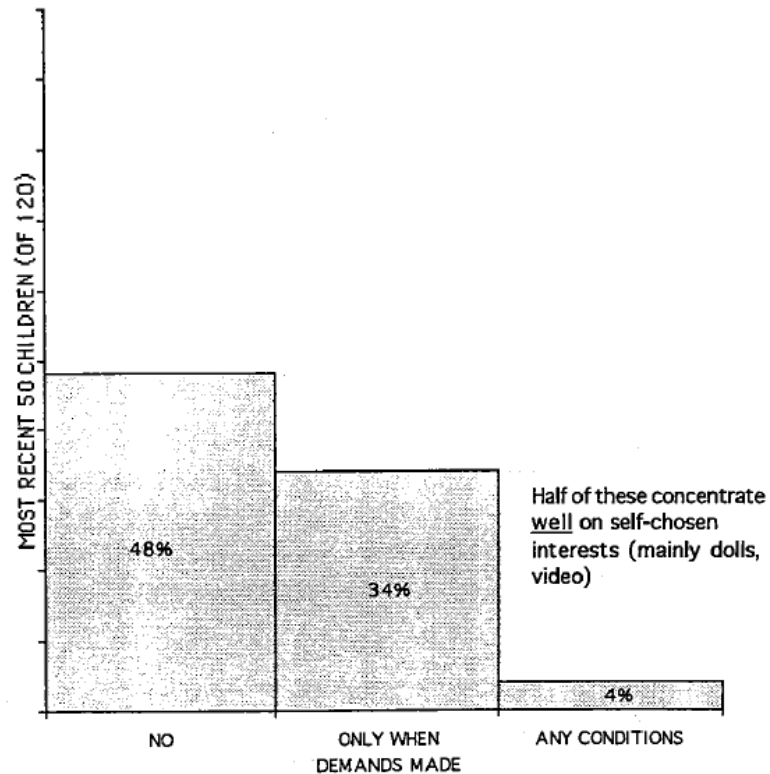
- 1) MQ went viral as an autism self-assessment test.
- 2) Debate if Monotropism is seen in non-autistics (Woods 2020).
- 3) MQ may not be representative of non-white autistics.
- 4) Assesses a version of Monotropism, not autism (Garau et al 2023).
- 5) Thankfully, co-authors acted swiftly to prevent potential erroneous reification of MQ.
- 6) Indicates responsibility for potential harm from reification of PDA as a “*Profile of ASD*” is with those advocating for “*PDA Profile of ASD*”.

# ROLEPLAYING A DIAGNOSTIC CATEGORY?

Table 14

Pathological Demand Avoidance Syndrome :

**FLITTING**  
**(is this ADD?)**



Newson 1996, p20.



# ROLEPLAYING A DIAGNOSTIC CATEGORY?

## Consistent doubts of constituent nature.

- 1) Newson's descriptions indicate co-occurring difficulties, e.g., ADHD, anxiety disorder of childhood, ODD (Garralda 2003).
- 2) Maybe a “*double-hit*”, potentially caused by psychopathic tendencies, instead of autism (Wing et al 2011).
- 3) Questions how well do co-occurring difficulties, like ADHD, SAD & ODD describe the component features of PDA? (Green et al 2018a).

# ROLEPLAYING A DIAGNOSTIC CATEGORY?

Examples of studies indicating is a pseudo-syndrome.

- 1) “*Triple hit*” of autism, conduct problems & (assumed) anxiety. (O’Nions et al 2014b).
- 2) PDA features predicted by anxiety, conduct problems & hyperactivity (Green et al 2018a).
- 3) PDA features predicted by attention issues, antagonism & lower emotional stability (Egan et al 2020).
- 4) “*Unlike psychiatric comorbidities and adaptive behaviour, PDA was not discriminating. Our results are therefore in agreement with the authors who questioned the validity of PDA as a distinct entity.*” (Schneider et al 2022, p8).
- 5)  $A + B + C \neq A$ , PDA cannot be something it is more than.

# ROLEPLAYING A DIAGNOSTIC CATEGORY?

Richard Woods

Table 6.1 Questions and sub-questions from PDA diagnostic and screening tools that contain manipulative behaviours and denote intent

Question or sub-question.	Tool and reference.
Good at getting round others and making them do as s/he wants.	EDA-Q (O'Nions et al., 2014a).
I blame or target a particular person/persons.	EDA-QA (Egan et al., 2019).
Does A harass other people? (e.g. writing threatening letters, making verbal threats, stalking, untrue accusations of sexual abuse).	Revised PDA DISCO questions (O'Nions et al., 2016).
Does A frequently tease, bully, refuse to take turns, make trouble.	Revised PDA DISCO questions (O'Nions et al., 2016).
Socially shocking behaviour with deliberate intent	Original PDA DISCO questions (Gillberg et al., 2015).
Lies, cheats, steals, fantasises, causing distress to others.	Original PDA DISCO questions (Gillberg et al., 2015).
Would you describe A as good at getting round others and making them do as s/he wants, or playing people off against each other?	O'Nions and Happé semi-structured interview (O'Nions et al., 2015, 2018).
What strategies does A use to get out of things? Are these strategies targeted at a particular person?	O'Nions and Happé semi-structured interview (O'Nions et al., 2015, 2018).
<ul style="list-style-type: none"> <li>• Distracting (e.g. asking questions)</li> <li>• Apologising and making excuses</li> <li>• Withdrawing into role play or toy play</li> <li>• Charm</li> <li>• Passively (e.g. selective mutism)</li> <li>• Other</li> </ul>	
Does A ever threaten to hurt him/herself, or do things to hurt him/herself?	O'Nions and Happé semi-structured interview (O'Nions et al., 2015, 2018).
Is this behaviour impulsive, or does A do it on purpose to show s/he is in control, cause distress or get attention?	

Woods 2022, p70.

# ROLEPLAYING A DIAGNOSTIC CATEGORY?

Recurring doubts over PDA causing confusion.

- 1) PDA's use will create confusion for caregivers & others involved (including clinicians) (Garralda 2003).
- 2) Risk to clinical language's validity & turning nosology upside down & recipe for clinical and research confusion (Green et al 2018b).

# ROLEPLAYING A DIAGNOSTIC CATEGORY?

## Other pertinent factors to consider.

- 1) General failure to take account of alternative explanations for behaviours.
- 2) Sourcing participants from places knowledgeable in “*PDA Profile of ASD*” is a risk of bias (Kildahl et al 2021).
- 3) Clear risk that non-autism features could be confused with autism due to “*PDA Profile of ASD*”.
- 4) This possibility should already be actively considered!

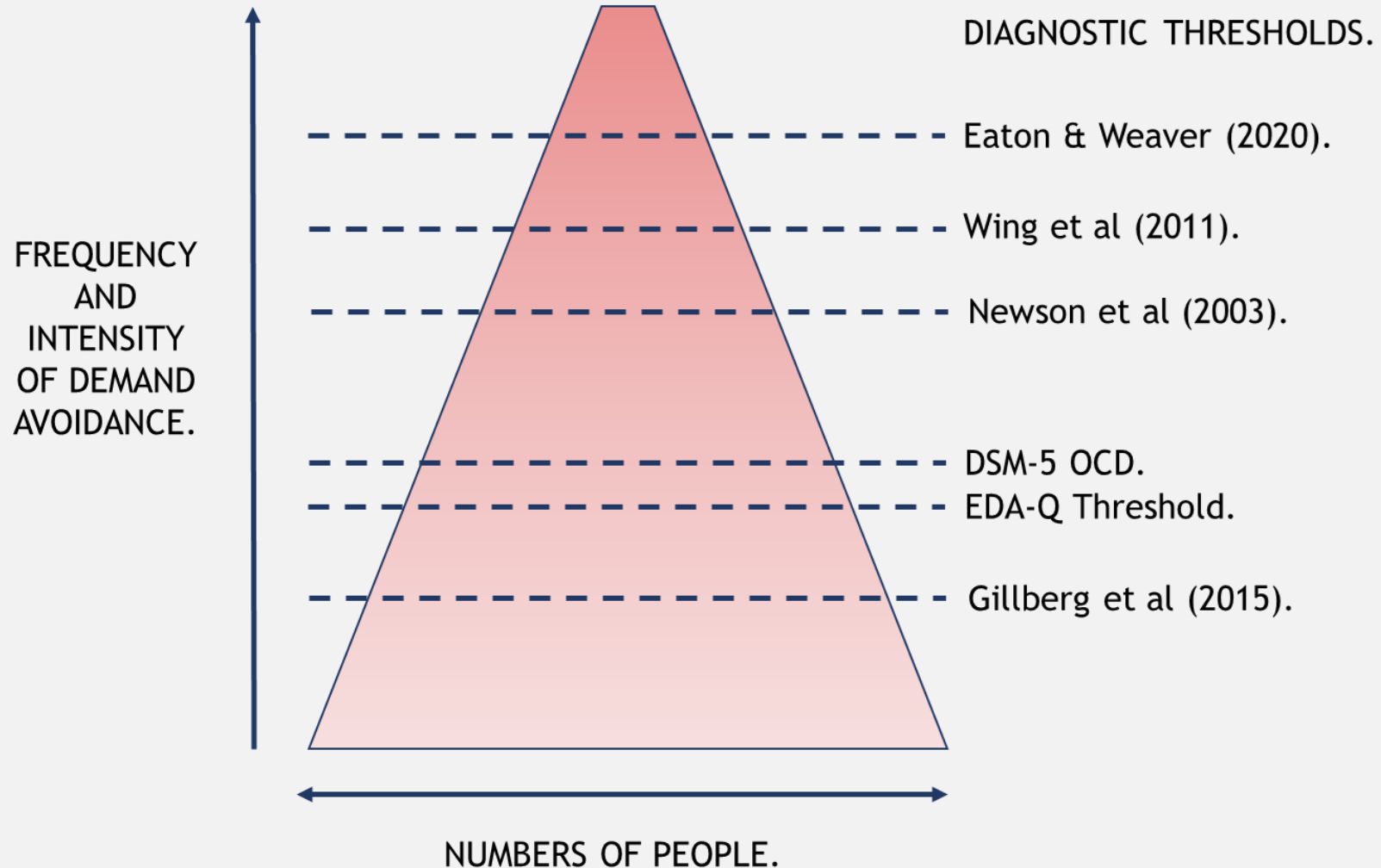
## BOB THE BUILDER'S PROFILE.

Outlook PDA is a separate clustering of features from autism.

- 1) PDA needs to be different to autism (Newson et al 2003).
- 2) *“There is a growing acknowledgement that individuals with PDA have a recognisable pattern of characteristics that are similar to each other and distinct from those of others with more straightforward presentation of autism.”* (Fidler 2019, p100).
- 3) *“PDA is currently best understood as a ‘profile’ (or cluster of traits) on the autism spectrum.”* (PDA Society 2022, p3).
- 4) *“Equally contributors have noted that, with increased awareness, there has been some over-identification by other practitioners.”* (PDA Society 2022, p1)

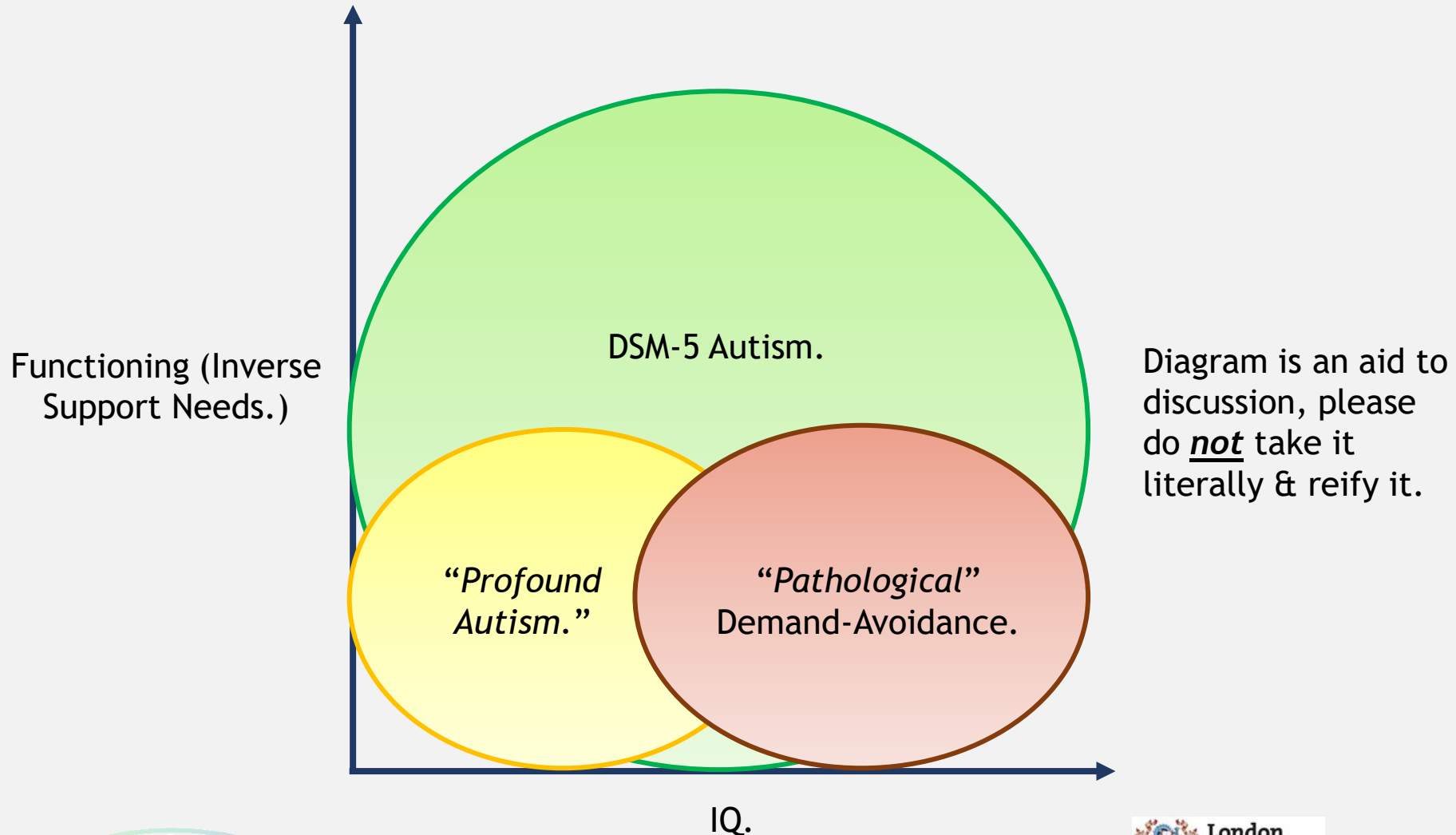
# TIME TO PROFILE YOU.

## Different PDA diagnostic thresholds (Woods 2021).



# CIRCLE WARS.

DSM-5 AUTISM, “PROFOUND AUTISM”, & “PATHOLOGICAL” DEMAND-AVOIDANCE RELATIVE SUPPORT NEEDS COMPARED TO IQ.





# WHO HAS A “PATHOLOGICAL” NEED TO CONTROL WHOM?

Self-advocacy, “*PDA Profile of ASD*” & “*Profound Autism*”.

- 1) “*Profound Autism*” advocates claiming autistic neurodiversity supporters are harassing them (Singer et al 2023).
- 2) Likewise, non-disabled autistic persons cannot advocate for those with “*Profound Autism*” (Singer 2022).
- 3) Ignore preferences of non-disabled autistic persons.
- 4) “*Profound Autism*” & other ableist terms should be used (Singer et al 2023).
- 5) Similar actions taken by “*PDA Profile of ASD*” advocates, to prioritise their outlooks on PDA, as examples shown throughout talk and elsewhere, or another example is in Milton (2022).

# BOB THE BUILDER'S PROFILE.

## Biasing PDA research & descriptions.

- 1) PDA descriptions changed to become autism-like features.
- 2) E.g., Social avoidance behaviours being “*manipulative*”, “*manipulative*” behaviours are not indicative of autism (Woods 2022).
- 3) E.g., “*strategies of avoidance are essentially socially manipulative*” (Newson et al 2003, p597) to “*strategies of avoidance that are essentially ‘socially manipulative’*” (O’Nions et al 2016a, p415), then to “*Uses social strategies as part of avoidance, eg, distracting, giving excuses*” (Green et al 2018a, p457).

# BOB THE BUILDER'S PROFILE.

## Biasing PDA research & descriptions..

- 1) Axiom that “*PDA Profile of ASD*” proponents views on PDA are only valid outlook on PDA.
- 2) Disregarding other topic experts’ views & supporting evidence.

# PROFOUNDLY DISTURBING?

## Subtyping autism & DSM-5.

- 1) All attempts to divide autism have failed (Kapp 2023)
- 2) Its why “*Profound Autism*” constructed from co-occurring ID &/ or language issues (Woods et al 2023).
- 3) Indicates “*PDA Profile of ASD*” features are not-autism.
- 4) DSM-5 replaced autism subtypes with autism & SCD (APA 2013).
- 5) PDA was informally excluded from DSM-5.
- 6) Most autistics do not want autism subtyped.
- 7) Seems SCD is not used much (Kapp & Ne’eman 2019).
- 8) DSM-5 autism criteria not designed to create autism subtypes (Kapp 2023), let alone identify “*PDA Profile of ASD*”...

# MAKING SENSE?

Fallacies seem applicable to “*PDA Profile of ASD*”.

- 1) Begging the question = Assumes PDA is distinct thing and arguing to prove it is a thing.
- 2) No True Scotsman = if PDA descriptions/ diagnoses do not conform to “*PDA Profile of ASD*”, they are not PDA, such as instead are “*Rational Demand Avoidance*”.

# MAKING SENSE?

Fallacies seem applicable to “*PDA Profile of ASD*”.

3) Appeal to popularity = Claiming that many hundreds/ thousands of people believe in “*PDA Profile of ASD*”, so it must be a thing.

4) Equivalence = Claiming “*PDA Profile of ASD*” is a different and distinct thing, with its features being different in nature to autism, but “*PDA Profile of ASD*” is a “*Profile of ASD.*”.  $A + B + C \neq A$  is applicable.

# THE “*LIGHT-BULB MOMENT*”?

## “*PDA Profile of ASD*” used to other (from PDA Space, 2023).

practical guidance. You can find out more and how to contact them when you register.

Thank you to our speakers, and thank you too for joining us this year.

### Friday 19th May 2023 | Creating Inclusion

**Cathleen Long and Rachel Gavin:** Fabricated or induced illness - Practice Guide

**Julia Daunt:** Making sense of Sensory Processing Difficulties (SPD)

**Amanda Hind:** Navigating life as a Black mixed-heritage, late-diagnosed autistic woman

**Roanna Brewer:** The PDAers guide to navigating education

**Kay Aldred:** Working with the nervous system to understand and support regulation

**Tori Rist:** How to create an inclusive school

**Dr Theresa Kidd:** PDAers reaching adulthood: Contributing Elements for a Successful Transition

**Laura Hellfeld & Scott:** When Demands Make Eating Hard

**Tigger:** True inclusion in education, peers and staff

**Kristy Forbes:** Tuning into neuroaffirming family culture for PDA

**Kyra Chambers:** Collaborative approaches in mental health care

### Saturday 20th May 2023 | Supporting Inclusion

**Helen Edgar & Viv Dawes:** Autistic Burnout - Supporting children and young people

**Hannah Harris:** Why Collaboration = Yes

**Tracey Chadwick:** Doing EBSA differently

**Catrina Lowry:** The Other 29

**Corrina Wood:** PDA, intolerance of uncertainty and CUES©

**Julia Caro:** Puzzles and contradictions

**Lindsay Guttridge:** How can parents deal with feeling excluded?

**Paula Rice:** True inclusivity doesn't fit in a predefined box

**Christina Keeble:** No I don't need to be more consistent!

**Sally Cat & No Pressure PDA:** PDA and trauma

### Sunday 21st May 2023 | Learning From Inclusion

**David Gray Hammond & Tanya Adkin:** Autism, PDA and addiction

**Dr Naomi Fisher & Heidi Steel:** 4 things that your children need for their learning to SOAR

**Debs Bamford:** Safeguarding with a twist

**Suzan Issa:** PDA and the nervous system

**Asher Jenner:** PDA and inclusion ...why has it been vital to me?

**Kate Denny:** The WARM model

**Riko Ryuki:** PDA vs ADA. The difference between PDA and autistic demand avoidance, and why it matters

**Sally PDA talk:** When I want to be included

**Libby Hill:** Using Poly-vagal theory to explain PDA and selective mutism

**Nicola Reekie:** Feeling Excluded As a Parent

## THE “*LIGHT-BULB MOMENT*”?

Fallacies seem applicable to “*PDA Profile of ASD*”.

5) False dichotomy = “*PDA Profile of ASD*” is “*complex*” / “*perplexing*” versus non-“*Profile of ASD*” autism is “*more straightforward*” / “*classic*”.

6) Texas sharpshooter = Assuming PDA is a “*Profile of ASD*” and then conducting research to support it:

- Assuming PDA features = autism features.
- Only investigating PDA in entirely autistic population samples.
- Designing tools which assume PDA is a “*Profile of ASD*”.
- Recruiting participants from sources which are knowledgeable in “*PDA Profile of ASD*”.



# AVOIDING VARIANCE.

## Concluding comments.

- 1) It is reasonable to consider if accounts of “*PDA Profile of ASD*” confusingly, reattributes non-autism features with autism.
- 2) Plausible, perhaps probable that PDA represents non-autism features.
- 3) This possibility should already be actively considered...
- 4) Responsibility for potential harm from premature reification of “*PDA Profile of ASD*” is from those advocating for “*PDA Profile of ASD*”.
- 5) Adhering to typical standards & be cautious over PDA claims.
- 6) Prioritise integrity of autism & accepted categories over “*PDA Profile of ASD*”.

# ANY QUESTIONS?

## The End Game.

- 1) Contact Details: [richardwoodsautism@gmail.com](mailto:richardwoodsautism@gmail.com)
- 2) Twitter handle:  
@Richard\_Autism
- 3) My researchgate:  
[https://www.researchgate.net/profile/Richard\\_Woods10](https://www.researchgate.net/profile/Richard_Woods10)
- 4) My Youtube channel:  
<https://www.youtube.com/@autimesdes>
- 5) Any questions?

# THE FIRST JOB REFERENCE.

## References.

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