

The likely adverse effects of “*Profound Autism*” and “*PDA Profile of ASD*” discourses.

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) 2012 autistic attribution, now “*post-autistic identity*”!
- 2) Meets Newson’s PDA profile, is not emotionally attached to it.
- 3) No-longer basing identity on diagnostic categories.
- 4) Favours a transdiagnostic approach & we should be stop utilising Disorder based constructs in the future.
- 5) PhD is investigating PDA & part of CADS at LSBU.

# PROFILING MYSELF.

## My perspective.

- 1) *Frontiers in Education* PDA special issue project lead.
- 2) Peer review PDA manuscripts.
- 3) Equally respects divergent views & evidence to critically synthesise appropriate interpretations on PDA.
- 4) My interpretation of PDA & its literature, others may disagree.

# IN THE BEGINNING.

## Introduction.

- 1) *“Profound Autism” & “PDA Profile of ASD”*.
- 2) Subgroup terminology.
- 3) Logical fallacies.
- 4) Arguments for & against subgroups.
- 5) Issues with *“Profound Autism” & “PDA Profile of ASD”*.
- 6) Reflective questions.
- 7) **Trigger warning, preventable deaths, slides: 30-38.**

# FOOD FOR THOUGHT.

## Is this person autistic?

- Have a unique talent e.g., role play.
- Preference for stability in e.g., best friend or routines.
- Sensory sensitivities e.g., finds certain sounds painful.
- Likes to have friends.
- Perfectionism e.g., needs their work to be perfect.
- Avoidance of eye contact.
- Has high anxiety.
- Restricted range of interests.
- Social awkwardness.
- Had language delay e.g., only spoke after 4 years old.

# AN OLD ROLEPLAY.

## Autism history.

- 1) Autism used to be a form of CS (Silberman 2015).
- 2) 1966 prevalence rates 1 in 2500, now ~ 1 in 100.
- 3) Autism becomes a spectrum (Happé & Frith 2020).
- 4) DSM4: PDD-NOS was the most commonly subtype.
- 5) ASD Level One to Level Three (APA 2013).
- 6) “*High Functioning Autism*”, equivalent to Asperger’s.
- 7) Now accepted indistinguishable clinical differences & strategies between autism subtypes (Woods 2020b).
- 8) Subtypes excluded to reduce stigma (Happé 2011).

# PROFOUNDLY DISTURBING?

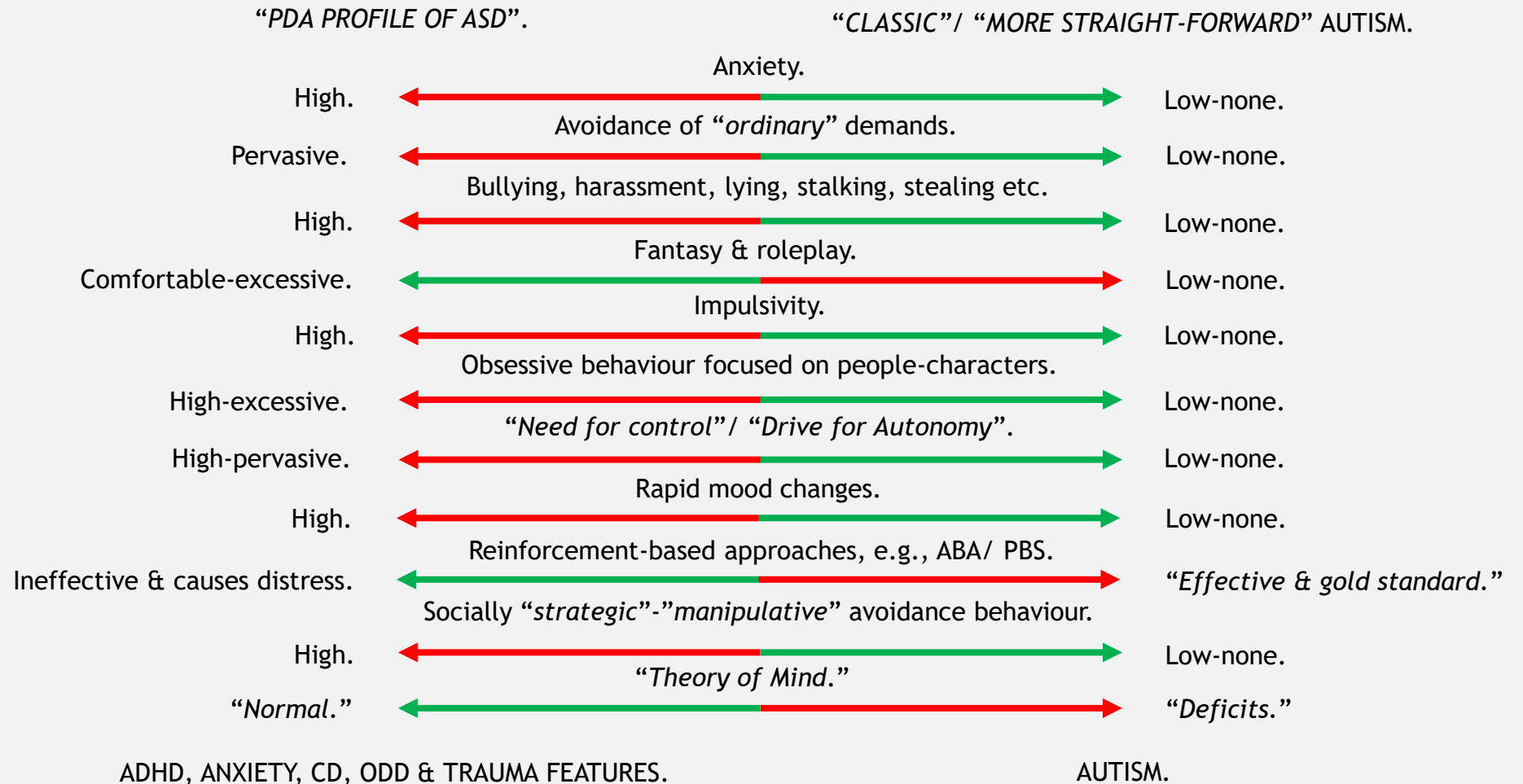
## “*Profound Autism*” definitions.

- 1) ID &/or language impairment (Lord et al 2021).
- 2) “*Severe*” *autism* added (Waizbard-Bartov et al 2023a).
- 3) Broadened to severe & challenging behaviours including self-injury, aggression and irritability (ASF 2022).
- 4) Need 24/7 support & cannot advocate for themselves.
- 5) “*Non-Profound Autism*” is for those autism is expressed less in (Hughes & Maenner 2023).
- 6) Using other co-occurring issues, e.g., anxiety, to create subtypes (Waizbard-Bartov et al 2023b).



# ROLEPLAYING A “PROFILE OF ASD”.

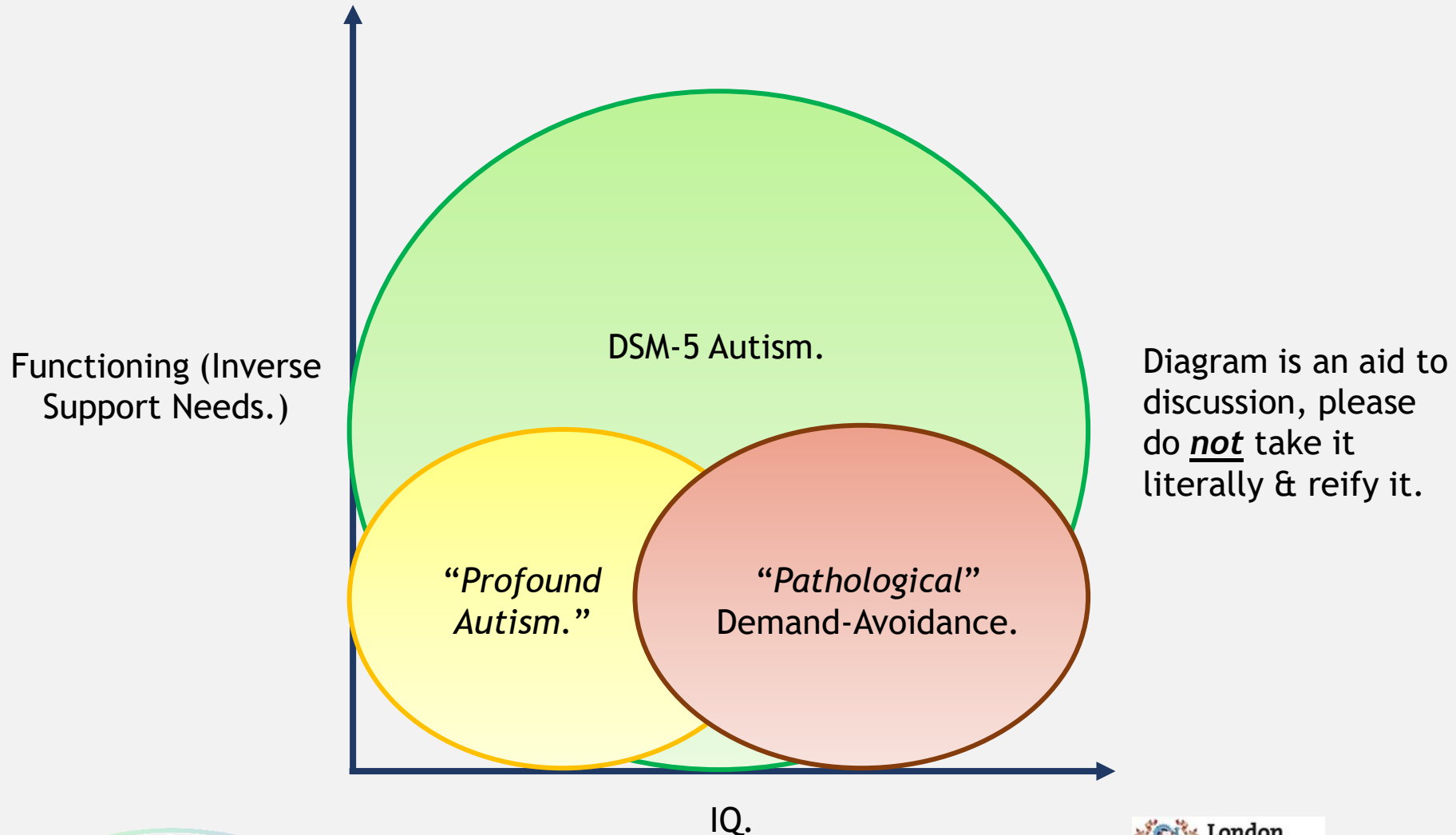
## “PATHOLOGICAL DEMAND-AVOIDANCE (PDA) PROFILE OF ASD” CONSTELLATION OF TRAITS WITHIN AUTISM SPECTRUM.



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

# CIRCLE WARS.

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



Adverse effects of “Profound Autism” & “ASD+PDA”.

# BOB THE BUILDER'S PROFILE.

## “*PDA Profile of ASD*” terminology.

- 1) “*Non-PDA autism*”, “*conventional*” autism (Christie 2007, p5), & “*classic*” autism (Kopp & Gillberg 2011, p2885).
- 2) Still used today, e.g., ‘*classic autism*’ (PDA Society 2022, p7), & “*conventional understanding of autism*” (PDA Society 2022, p12).
- 3) “*PDA Profile of ASD*” = Atypical/ unusual/  
unconventional/ unorthodox/ unpopular
- 4) Connotation PDA is not autism.

# BOB THE BUILDER'S PROFILE.

**“PDA Profile of ASD” terminology.**

- 1) “*PDA Profile of ASD*” = “*complex*” & ‘*perplexing*’ (PDA Society 2022, p4+6).
- 2) “*Non-PDA autism*” = “*More straightforward presentation of autism*” (Fidler & Christie 2019, p 59 & 73).
- 3) Connotation “*Non-PDA autism*” are easy etc.

# BOB THE BUILDER'S PROFILE.

***“PDA Profile of ASD” terminology.***

- 1) *“marked demand avoidance within their autism diagnosis, there is a range of terminology that is used in formulations, including ASD with:*
  - *a PDA profile / a Pathological Demand Avoidance profile*
  - *a demand avoidant profile / a profile of demand avoidance*
  - *extreme / pervasive demand avoidance” (PDA Society 2022, p22).*

# BOB THE BUILDER'S PROFILE.

## Proposed subtypes terminology.

- 1) Excuses PDA's non-autism features.
- 2) "*PDA Profile of ASD*" is a functioning category.
- 3) False dichotomy, allows some autistics to be viewed as less autistic, e.g., see Hughes & Maenner (2023).
- 4) Both proposed subtypes risk diagnosing non-autistic persons with autism (Kapp 2023; Woods 2022a), & risks confusing co-occurring issue with autism (Pukki et al 2022; Woods 2022a; Woods et al 2023).
- 5) Stereotypes cause us problems (Des Roches Rosa 2023).

# AN OLD ROLEPLAY.

## Autism advocacy history.

- 1) Traditionally dominated by caregivers.
- 2) Autism industry aimed at caregivers (McGuire 2016).
- 3) “*Don’t mourn for us*” (Sinclair 1993).
- 4) Most autistic persons do not want autism subtypes (Fletcher-Watson & Happé 2019; Kapp & Ne’eman 2019).
- 5) Many autistic advocates & researchers are against “*Profound Autism*” & functioning labels (Kapp 2023).
- 6) Recent activities e.g., Opposing AIMS-2 & Spectrum10K.

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

Rationale for both proposed subtypes.

- 1) Has different support needs from other autistic persons.
- 2) Prioritise needs of this vulnerable & underserved group.
- 3) Group is often excluded from research.
- 4) Prioritise research funding to this group (Lutz 2021).
- 5) Split autism category into two (Singer 2022).
- 6) Strategic planning.
- 7) Comparison of research findings.
- 8) Enabling access to certain resources.
- 9) To better understand CYP (Christie 2019).



# 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).

# PROFOUNDLY DISTURBING?

## Subtyping autism & DSM-5.

- 1) PDA was informally excluded from DSM-5.
- 2) Most autistics do not want autism subtyped.
- 3) Seems SCD is not used much (Kapp & Ne'eman 2019).
- 4) DSM-5 autism criteria not designed to create autism subtypes (Kapp 2023), let alone attribute “*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.
- Designing tools which assume PDA is a “*Profile of ASD*”.
- Recruiting participants from sources which are knowledgeable in “*PDA Profile of ASD*”.

# A FEATURE FILM?

## What do these features indicate?

- 1) *“I complain about illness or physical incapacity to avoid a request or demand.”* (Egan et al 2019, p485).
- 2) *“Attempts to negotiate better terms with adults.”* (O’Nions et al 2014, p763).
- 3) *“Apparently manipulative behaviour.”* (O’Nions et al 2016, p415).

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

## Proposed subtypes problems for self-advocacy.

- 1) Many features pathologised in PDA, are those people often express to exert their self-agency when distressed/ stressed (Moore 2020).
- 2) “*PDA Profile of ASD*” represents pathologising of autistic advocacy (Milton 2017; Woods 2017a).



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

Proposed subtypes problems for self-advocacy.

- 1) *“When people generally said to be incapable of communication find ways of making clear what they do and don’t want through means other than words, this is self-advocacy” (p. 223). Baggs clarified that self-advocacy includes what some refer to as behavioral problems in response to abuse or violence against them [176].” (Kapp 2023, p10).*

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

Proposed subtypes problems for advocacy.

- 1) PDA contains many unpleasant-criminal behaviours which requires intent to commit them (Woods 2022b).
- 2) PDA, but not autistic traits predicted stalking (Linenberg 2021).
- 3) PDA does not have ToM deficits (Bishop 2018).
- 4) PDA’s social avoidance behaviours described as “*manipulative*” or “*strategic*”, gives others carte blanche to ignore our views (Woods 2017b).

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

Proposed subtypes problems for advocacy.

- 1) “*Profound Autism*” advocates claiming autistic neurodiversity supporters are harassing them (Singer et al 2023).
- 2) “*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).

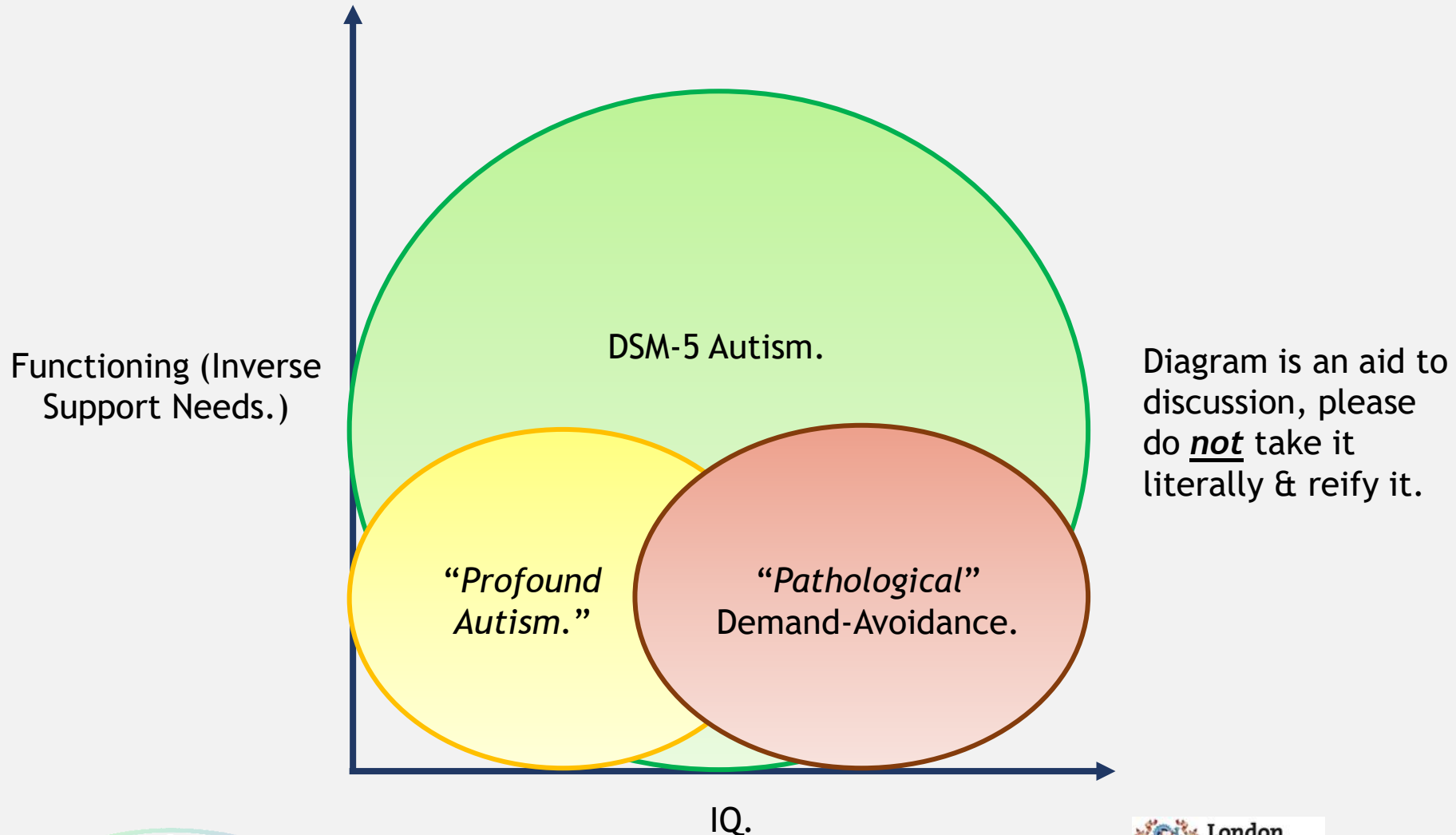
# WHO HAS A “*PATHOLOGICAL*” NEED TO CONTROL WHOM?

## Proposed subtypes problems for advocacy.

- 1) “*Profound Autism*” intended for those who cannot advocate (ASF 2022; Singer 2022; Singer et al 2023).
- 2) Autistic IQ scores often depends on context of the IQ test & the tool being used, e.g., best tool to RPM (Kapp 2023).

# CIRCLE WARS.

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



Adverse effects of “Profound Autism” & “ASD+PDA”.

# A “PROFOUND” CHALLENGE FOR WHOM?

## Risk of diagnostic overshadowing.

- 1) What is diagnostic overshadowing?
- 2) Diagnostic overshadowing is an issue for autistics:  
*“dismissal of explicitly severe physical symptoms of amyotrophic lateral sclerosis, and multiple sclerosis as “oppositional behavior” due to the patients being non-speaking Autistics.”* (Woods et al 2023, p1656).
- 3) Especially with ID, such as constipation.
- 4) Can result in deaths due physical ill health issues not being treated in time (Woods 2023).

# A FEATURE FILM?

Associated with trauma or highly distressed individuals:

- 1) *“Seems as if s/he is distracted ‘from within’”* (O’Nions et al 2014, p763).
- 2) *“Knows what to do or say to upset specific people.”* (O’Nions et al 2014, p763).
- 3) *“(Lacks) Awareness of own identity.”* (O’Nions et al 2016, P415).
- 4) *“I am driven by the need to be in charge.”* (Egan et al 2019, p485).

# A FEATURE FILM?

An act any person would display to assert their self-agency:

- 1) *“I complain about illness or physical incapacity to avoid a request or demand.”* (Egan et al 2019, p485).
- 2) *“Attempts to negotiate better terms with adults.”* (O’Nions et al 2014, p763).
- 3) *“Apparently manipulative behaviour.”* (O’Nions et al 2016, p415).



# A “PROFOUND” CHALLENGE FOR WHOM?

## Risk of diagnostic overshadowing.

- 1) *“If “profound autism” is realized, at best co-occurring conditions and their associated supports will be missed, at worst it will likely contribute towards preventable deaths.”* (Woods et al 2023, p1656).
- 2) Diagnostic overshadowing concerns are applicable to *“PDA Profile of ASD”*.

# PREDICTABLY CRIMINALLY IGNORANT?

child had this particular type of autism and while the person carrying out the assessment said she showed symptoms, that diagnosis was not made. Instead her child was diagnosed with a borderline condition.

The woman believed her child had a much more severe type of autism and thought she would not get the proper supports.

## **'Alarming' texts**

Detailing the evidence that will be heard, Murray said that the woman texted her friends to say she felt numb that her child had been diagnosed with a severe type of autism.

While the final report from the assessment was not available, the woman became totally obsessed and devastated by the diagnosis according to her family who said she had been sending "alarming" texts and not sleeping.

She sent text messages to friends saying that everything she read on the internet about this type of autism was "horrible" and that she feared for her child's future and that of her family, said Murray.

The prosecution barrister went on to tell the court that family and friends described the mother in the days leading up to the killing as "obsessed with the diagnosis" and "devastated".

She had attended her GP and had been prescribed sleeping tablets after reporting that she was extremely stressed about her child. She was also seeing a counsellor.

Outlining the circumstances of the deceased's death, Murray said the mother rang emergency services on 10 February 2018 to say that she had suffocated her daughter on purpose.

## O'Riordan (2019).

# DEFINITION OF MADNESS?

Practical & ethical problems with proposed autism subtypes.

- 1) “*Profound Autism*” is unhelpful descriptor, not convey a person’s specific features & needs (Pukki et al 2022).
- 2) Same can be said of “*PDA Profile of ASD*”, as it is meant to much more than only demand-avoidance (PDA Society 2022).
- 3) Both “*Pathological Demand Avoidance*” & “*Profound Autism*” are demeaning & negative terms to attribute to a person (Pellicano et al 2022; Woods 2020b).

# NO RESISTANCE IS FUTILE.

Proposed subgroups are likely a risk to autistic lives.

- 1) *“This is particularly important for some people with autism, including those with Asperger syndrome, who may face very significant challenges in their everyday lives, despite having average or above average IQ.”*  
(DoH 2015, p15).
- 2) Autistic persons not attributed with either proposed subgroup likely have their difficulties dismissed due to misconception it is ‘*mild*’ autism/ not autism (Woods 2017b).

# NO RESISTANCE IS FUTILE.

**Proposed subgroups are likely a risk to autistic lives.**

- 1)Autistics systemically poorly treated by broader society & culture (Botha 2021; Grant et al 2023; Woods 2017b).
- 2)Autistics high rates co-occurring mental health issues (Lai et al 2019; Woods 2020a).
- 3)High suicide rates (Hirvikoski et al 2016; Moses 2017).
- 4)If both subgroups are accepted, likely many autistics would be denied support, either through needs being dismissed, or suitable strategies being denied to them.
- 5)Predictable consequences!

# AVOIDING VARIANCE?

## Reflective questions.

- 1) What is the impact of efforts to sub-type autism upon solidarity amongst the autistic community?
- 2) How many autistic deaths are required before we stop attempting to create subgroups?
- 3) What do autistics need to do for other stakeholders to respect wishes to not divide autism into subgroups?

# 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\\_Woods\\_10](https://www.researchgate.net/profile/Richard_Woods_10)
- 4) My Youtube channel:  
<https://www.youtube.com/@autimesdes>
- 5) Any questions?



# THE FIRST JOB REFERENCE.

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# ARE WE THERE YET?

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