Critical reflections on autism advocacy for and against autism subtypes.

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PROFILING MYSELF.

Conflicts of interest.

1) Developing various PDA tools.
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, not emotionally attached.
3) No-longer basing identity on diagnostic categories.
4) Equally respects divergent views & evidence to critically synthesise suitable interpretations on PDA.
5) PhD is investigating PDA & part of CADS at LSBU.
6) My interpretation of PDA & its literature.
7) May use medical model, reflecting source material is.
8) Recognise psychiatric categories are social constructs.

IN THE BEGINNING.

Introduction.

1) Critique constructs & need to validate difficulties.
2) Autism history.
3) Introducing "*Profound Autism*" & "*PDA Profile of ASD*".
4) Proposed subtypes terminology problems.
5) Autism & proposed subtypes advocacy history.
6) Proposed subtypes implications for advocacy.
7) Reflective questions.

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 2020).
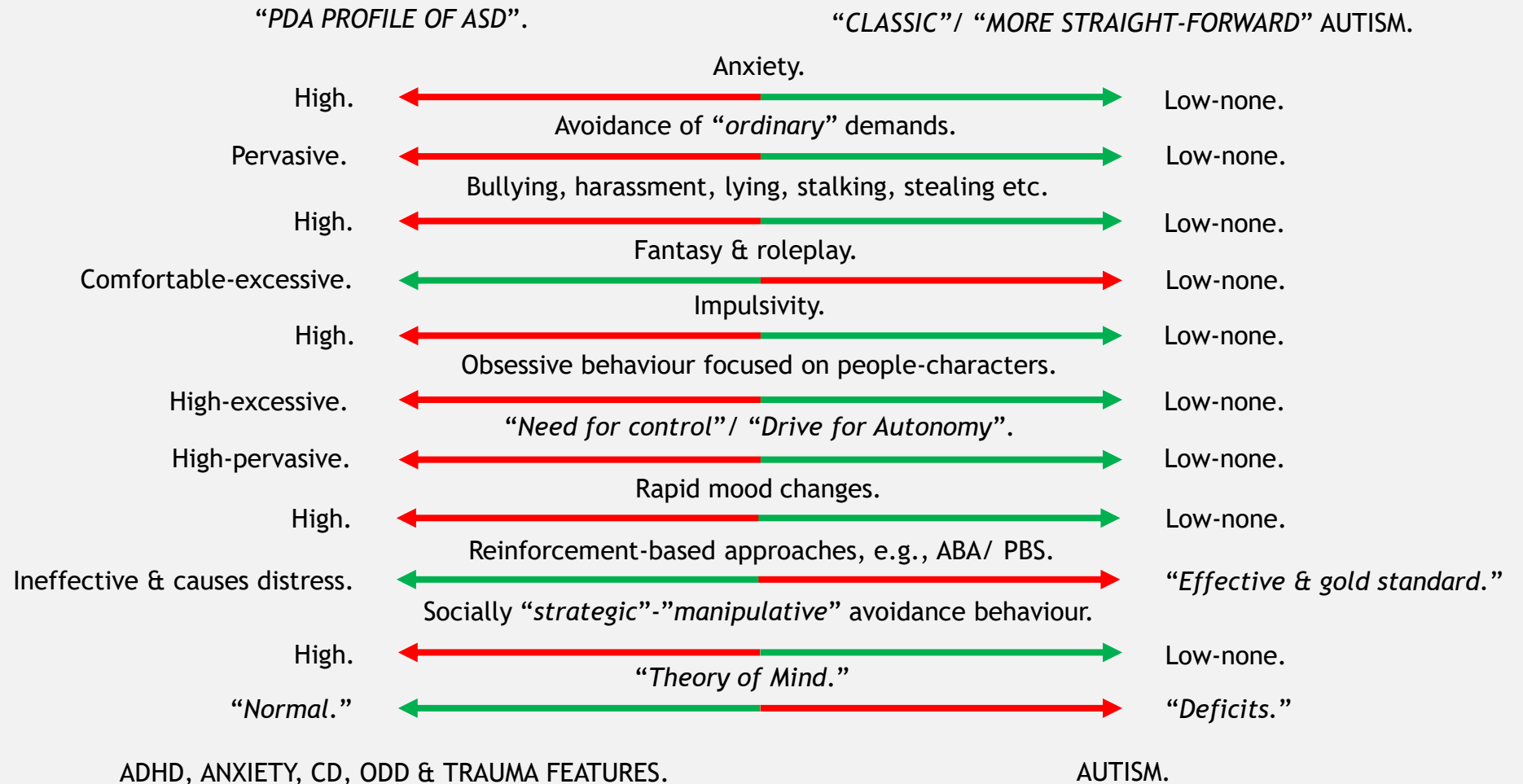8) Subtypes excluded to reduce stigma (Happé 2011).

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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).
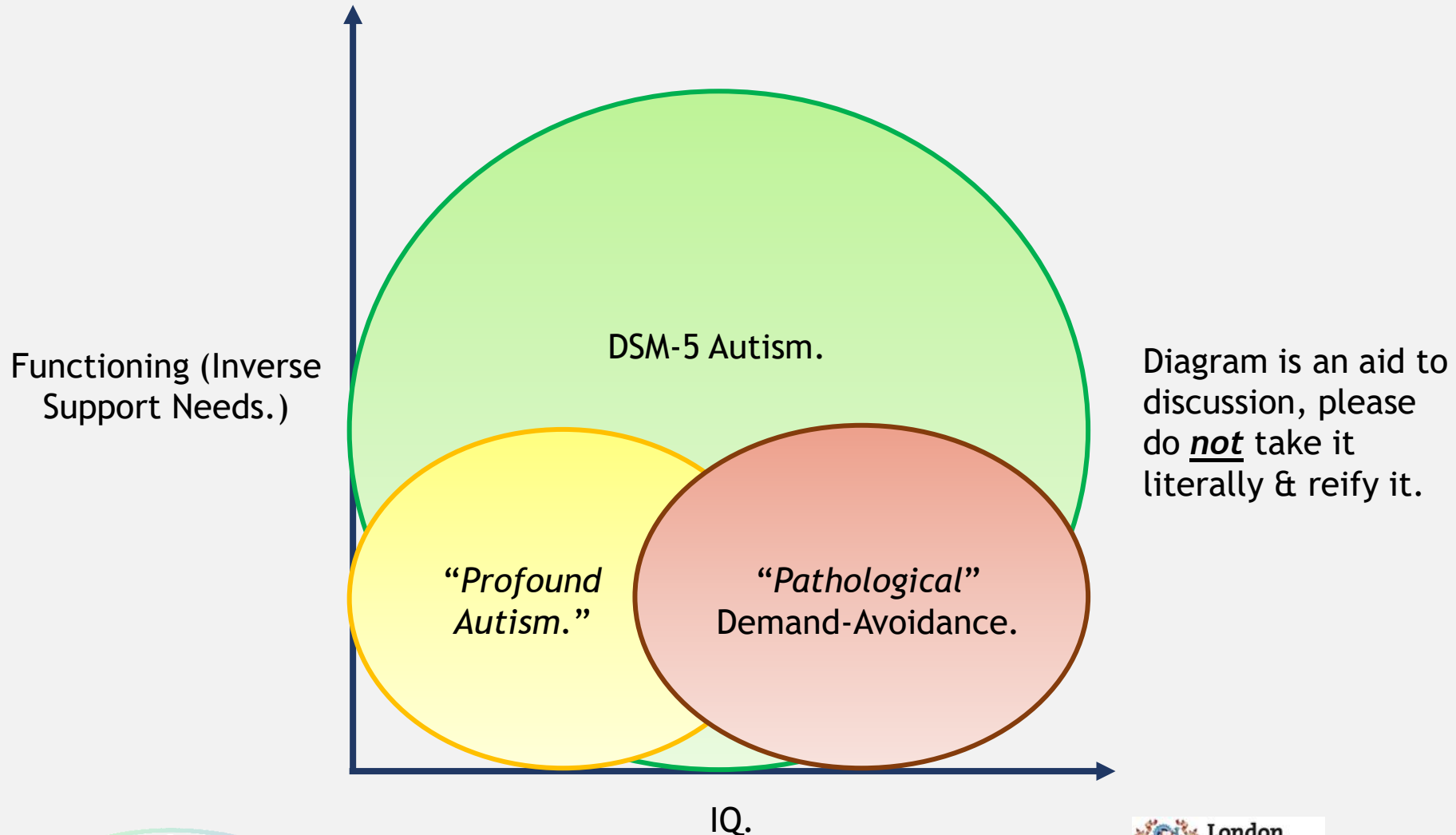
ROLEPLAYING A "*PROFILE OF ASD*".

"*PATHOLOGICAL DEMAND-AVOIDANCE (PDA) PROFILE OF ASD*"
CONSTELLATION OF TRAITS WITHIN AUTISM SPECTRUM.

"PDA PROFILE OF ASD".　　　　　　　　　　"CLASSIC"/ "MORE STRAIGHT-FORWARD" AUTISM.

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

"PDA PROFILE OF ASD"	Trait	"CLASSIC" / "MORE STRAIGHT-FORWARD" AUTISM
High.	Anxiety.	Low-none.
Pervasive.	Avoidance of "*ordinary*" demands.	Low-none.
High.	Bullying, harassment, lying, stalking, stealing etc.	Low-none.
Comfortable-excessive.	Fantasy & roleplay.	Low-none.
High.	Impulsivity.	Low-none.
High-excessive.	Obsessive behaviour focused on people-characters.	Low-none.
High-pervasive.	"*Need for control*"/ "*Drive for Autonomy*".	Low-none.
High.	Rapid mood changes.	Low-none.
Ineffective & causes distress.	Reinforcement-based approaches, e.g., ABA/ PBS.	"*Effective & gold standard.*"
High.	Socially "*strategic*"-"*manipulative*" avoidance behaviour.	Low-none.
"*Normal.*"	"Theory of Mind."	"*Deficits.*"

ADHD, ANXIETY, CD, ODD & TRAUMA FEATURES.　　　　　　　　　　AUTISM.

Critical reflections on autism advocacy on autism subtypes.

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CIRCLE WARS.

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

Functioning (Inverse Support Needs.)

DSM-5 Autism.

"Profound Autism."

"Pathological" Demand-Avoidance.

Diagram is an aid to discussion, please do ***not*** take it literally & reify it.

IQ.

Critical reflections on autism advocacy on autism subtypes.

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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.

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).

AN OLD ROLEPLAY.

PDA advocacy history.

1) Traditionally driven by non-autistic persons.
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) Increasingly autistics supporting *"PDA Profile of ASD"*.

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SPITTING IMAGES OR SPLITTING IMAGES?

Internalised ableism... Image by Sally Cat.

1) Internalised ableism, e.g., Sally Cat's defamatory petition against Damian Milton (Milton 2022).

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 2016a, 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 2017).

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).

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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 2017).

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.
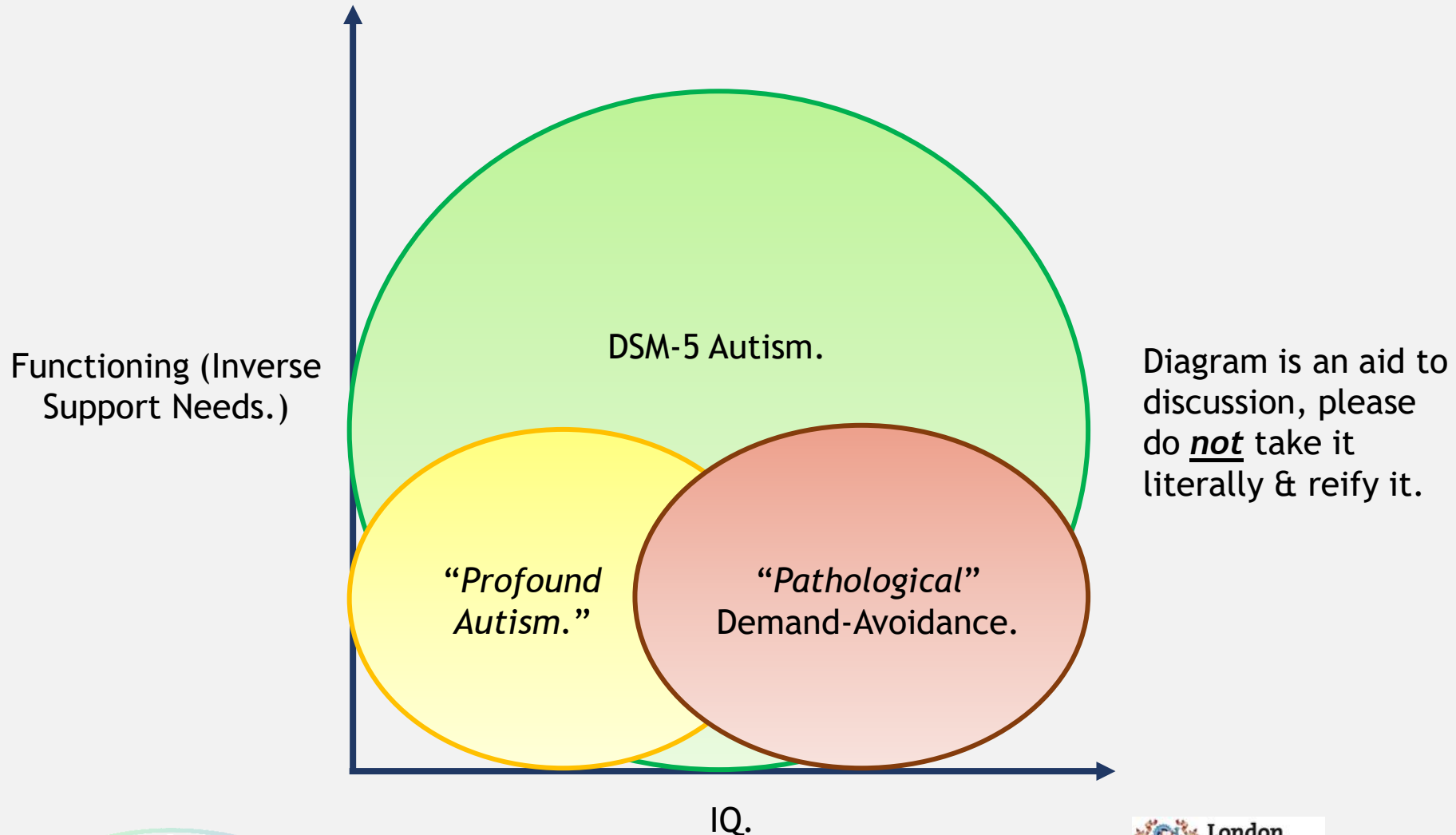4) "*Profound Autism*" & other ableist terms should be used (Singer et al 2023).

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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.

Functioning (Inverse Support Needs.)

DSM-5 Autism.

Diagram is an aid to discussion, please do **_not_** take it literally & reify it.

"Profound Autism."

"Pathological" Demand-Avoidance.

IQ.

AVOIDING VARIANCE?

Reflective questions.

1) What is the impact of efforts to sub-type autism upon solidarity amongst the autistic community?
2) What are the potential harms potential application of *"Profound Autism"* &/ or *"PDA Profile of ASD"*?
3) Could well-informed person-centered practice be preferable to one based on categorical subtyping (Milton 2019)?
4) What are the other likely effects of *"Profound Autism"* &/ or *"PDA Profile of ASD"* on autistic advocacy?

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ANY QUESTIONS?

The End Game.

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2) Twitter handle: @Richard_Autism
3) My researchgate: https://www.researchgate.net/profile/Richard_Woods10
4) My Youtube channel: https://www.youtube.com/@autimedes
5) Any questions?

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ARE WE THERE YET?

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