**PDA: A PREVENTABLE DELICATE ACTIVITY.**

There are many ongoing-historical debates surrounding “*Pathological*” Demand-Avoidance (PDA), mirroring the intense interest in it. One of these debates centres on PDA’s name, due to a strong aversion for the “*pathological*” descriptor, often perceived as being demeaning and derogatory to those identifying with PDA. Leading to about a dozen different names in print, referring to PDA. More common alternatives terms include Rational Demand-Avoidance and Extreme Demand-Avoidance. Anecdotally, one’s preferred term for PDA, seems to be based upon ideological lines.

Broader context is that much of the autism research, policy, and practice has entrenched inferior quality ethics and standards. Often informed by autism theories which have poor-quality evidence, and little explanatory value of autistic lived experience. Autistic persons are rarely meaningfully engaged in autism research, policy, and practice. From this vacuum, PDA as a “*Profile if ASD*”, has become a “*culture-bound concept*” in the UK.

Since 2020, National Institute for Health and Care Excellence (NICE), Royal College of Psychiatrists​ (RCP)​, British Psychological Society​ (BPS)​, and two systematic reviews have all concluded there is no good quality evidence to suggest what PDA is, what features are associated with PDA, and acknowledged the controversies and existing divergent viewpoints on PDA. There is no consensus over how to diagnose PDA in the literature, or between topic experts. This is partly due to the ongoing-historical debates in PDA, for example, is PDA seen in non-autistic persons (including in Newson’s research)? NICE, RCP, and BPS have not produced guidance on PDA, as it is unethical to do so​,​ with PDA lacking good quality evidence for PDA and lack of consensus between topic experts.

PDA’s evidence base is small and generally poor quality. Still, PDA’s evidence base is conflicted, with certain studies indicating PDA is linked to autism, while others do not. Similarly, some studies indicate PDA is seen in non-autistic persons, while other studies indicate PDA is exclusive to autistic persons. Some studies suggest PDA is a distinct Disorder/ Syndrome, some others do not. Thus, it appears unwise to assume any one outlook on PDA is valid and other worldviews are not.

PDA is a positive source for many vulnerable people, who can be in crisis. Subsequently, there are strong power differentials present. Even those critical of PDA, accept there is a genuine need for support for both those expressing PDA features and their caregivers. However, it can be said there is a need for all autistic persons and their caregivers to be suitably supported. It remains to be seen if “*PDA Profile of ASD*” is beneficial to those being assigned a PDA diagnosis, such as with the report of Kent’s Special Education Needs Disability schools denying an educational placement to those diagnosed with PDA. Furthermore, concerns over, who would wish to employ someone who has a “*pathological*”/ “*extreme*” response to “*ordinary*” (others) demands?

Many bold claims are made about PDA, like autism has expanded and now includes PDA. Many autism experts view the breadth of autism to be static over the last decade. Comparison studies between Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-4) and DSM-5 autism criteria, suggest autism’s breadth contracted by at least a fifth with the DSM-5. Some argue autism has been expanded too far. Autism subtypes were removed from the DSM-5 as all attempts to successfully divide autism have failed. Autism subtypes were excluded from the DSM-5 to reduce stigma, for all autistic persons; partly upon the lobbying of Autistic Self Advocacy Network, as most autistic persons do not want autism to be divided. Simultaneously, PDA literature acknowledges PDA has many characteristics which make it difficult to fit PDA within autism. There is a need to follow typical ethical practice and to be restrained in the claims surrounding PDA.

Some supporters who strongly identify with the “*PDA Profile of ASD*” narrative are claiming they have extra rights to PDA, like they should be platformed over those with different perspectives on PDA. No stakeholder group has a monopoly on PDA. Under Academic Freedom, researchers can investigate PDA’s competing viewpoints. Crucially, under The Equality Act, the threshold when someone counts as disabled with PDA, is when their demand-avoidance has a substantially impairing effect upon them for at least 12 months. This is applicable to individuals regardless of if they are autistic or not, and if they believe in “*PDA Profile of ASD*”, or not. Those with divergent viewpoints to “*PDA Profile of ASD*,” have done and will continue to investigate PDA, contributing to how PDA is understood.

Overall, PDA is a passionate topic for many, and for good reasons, both for its supporters and those hesitant of reifying PDA. There is a need for more caution and nuanced discussion surrounding PDA, while following typical ethical standards. Both autistic persons and those identifying with PDA, deserve better than how PDA is frequently portrayed.

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