**Commentary: Demand Avoidance Phenomena, a manifold issue? Intolerance of uncertainty and anxiety as explanatory frameworks for extreme demand avoidance in children and adolescents: a commentary on Stuart et al. (2019).**

**Abstract**: Demand Avoidance Phenomena (DAP), is a neutral term for Pathological Demand Avoidance, which is sometimes conceptualised as an autism subtype. There is much ongoing controversy around the construct. In this commentary, I attempt to contextualise the recent article, Intolerance of Uncertainty and anxiety (Stuart et al, 2019) within wider discourses. This discussion provides tentative support for Monotropism autism theory and the growing body of research indicating that DAP may not be developmentally persistent (a high rate of persons not meeting clinical threshold into adulthood). Going forward I would suggest that Stuart and colleagues’ research should be replicated, in order to add to the DAP literature.

**Key Words**: Anxiety; Autism; Demand Avoidance Phenomena; Monotropism Theory; Pathological Demand Avoidance.

First proposed by Elizabeth Newson in 1980, Demand Avoidance Phenomena (DAP, commonly known as Pathological Demand Avoidance) as a Pervasive Developmental Disorder (Newson, Le Maréchal and David, 2003). It has gained interest due to caregiver campaigning, and is mainly envisioned as an autism subtype (Stuart et al, 2019). Alternative outlooks for DAP include: a form of Attachment Disorder, a form of Personality Disorder, or symptoms resulting from the interaction between autism and various comorbidities (Woods, 2019b). This article draws attention to a number of conceptual issues, while discussing the potential impact of Stuart et al’s (2019) research on the broader literature.

Stuart and colleagues (2019) state their research builds on Intolerance to Uncertainty (IU) in autism and this implies that DAP is a form of autism. DAP has no specificity (Woods 2019a; 2019b). It is argued high anxiety levels lead to extreme demand avoidance that provides the construct’s common name. Yet anxiety is not an autism symptom and is an external comorbid. Luke Beardon uses the following word equation:

“Autism + Environment = Outcome.” (Beardon, 2017, p43).

While between 42% -56% of autistic persons experience anxiety as a comorbid difficulty (Woods, 2019b); it is not automatically part of the autistic experience and can be alleviated by changing environment around the autistic person (Beardon, 2017). Under the equation anxiety is the outcome as it is caused by the environment. Monotropism theory views autistic anxiety as primarily caused by autistic persons being a minority group in an environment not readily adapted to our needs (Woods, 2019a). Pervasive anxiety experienced by autistic persons is either directly from a comorbid, or the result of comorbid difficulties interacting alongside autism; similarly autistic persons with co-occurring Attention Deficit Hyperactivity Disorder (ADHD) showed higher anxiety, less working memory and less empathy (Harmsen, 2019). The high anxiety levels frequently mentioned in the DAP literature are to an extreme end, within the top 2% of the human population (Christie et al, 2012). With around 40% of autistic population experiences co-occurring anxiety based disorders, the extreme anxiety levels reported in the DAP literature are plausibly the result of the interaction between autism and a different comorbidity. DAP can be explained by trauma (Woods, 2019a; 2019b). It is inappropriate to include DAP as part of the autism spectrum as it is a false equivalence fallacy.

DAP is not specific to autism, (Woods, 2019d). Developmental criteria are unnecessary for a DAP diagnosis as it has many different developmental trajectories (Stuart et al, 2019). Thusly, there are several Demand Avoidance conditions, akin to the proposed “autisms”, and there is insufficient evidence to favour any of DAP’s proposed ontologies over another (Woods, 2019b). Essentially, all anyone has to inform policy and practice in relation to DAP is opinion, including this author. It remains to be seen if DAP is a form of autism and therefore if these studies add to the autism literature.

Stuart and colleagues (2019) provide a general overview of the DAP literature. There are gaps and difficulties with the extant research and challenges objectively measuring DAP (Woods 2019a; 2019b). The authors observe that the Extreme Demand Avoidance-Questionnaire (EDA-Q) used in their trial had a ceiling effect and suggest that the anchor points are not very sensitive in capturing variations in behaviour at the more extreme end. A solution would be to change its anchor points from likeness of child to frequency of behaviours (ibid), other limitations include: (1) Detecting demand avoidance behaviours in other conditions and false positives; (2) Divergent scores between stakeholders; (3) DAP criteria are unstable as there is no consensus this topic (Woods, 2019; 2019b), and so the tool has not been standardised compared to current diagnostic criteria. For instance, DAP has 10 diagnostic traits (Woods, 2019b), the EDA-Q was developed before the adoption of “Sensory Differences” trait and so does not account for it; (4) Risk of confirmation bias due to vague questions, behaviours that are not unique and reliance on caregiver reports (Woods, 2019a); (5) The tool pathologises behaviours children naturally display when asserting their self-agency in hard times (Moore, forthcoming). Parts of DAP profile are hard to measure, such as “lacking sense of identity, pride or shame” (Woods, 2019a). Characterising the behaviours around DAP appear to be highly subjective (Woods, 2019b).

Other sources of likely bias that undermine the validity of this research have not been accounted for. These of bias are from the studies’ participants; DAP carers. Firstly, DAP carers are a vulnerable group and often experience high anxiety levels (Woods, 2019a; 2019b); this is not discussed in Stuart et al (2019). Completing 150 questions (Stuart et al, 2019), could lead to question fatigue among participants. Secondly, the carers completed all 4 questionnaires used in Study 1, providing a common rater bias. Thirdly, it is recognised that the surge in interest into DAP since before 2010 can lead to persons to be “on the lookout” for features of DAP (O’Nions et al, 2016). This is interest is plausibly driven by social media campaigning by DAP carers. The sample was sourced through the PDA Society and their participation in this research, one would assume, indicates their support for the construct. It is also reasonable to assume that the participants are knowledgeable on DAP. Therefore, this is a credible source of confirmation bias.

The central message of Stuart et al’s results is that IU is the salient driving factor behind many behaviours in DAP. Specifically, leading to: control behaviours withdrawing into fantasy and roleplay; and behaviour characterised as meltdowns. I would argue that these results more directly support a different theory around autism, Monotropism (for more information see Woods, 2019a), and suggests other mediators of behaviour, with IU and anxiety being a final common pathway. Monotropism predicts that autistic persons tend to have a binary cognitive style, with the autistic person being either certain or uncertain, resulting from only having attention to a few items of salient information. This leads autistic persons to be predisposed to have higher IU which in turn can drive anxiety. Monotropism also predicts that these high anxiety levels can lead to meltdowns, shutdown or panic attacks (ibid). Thus the escalation behaviours seen in Study 2 could be better explained through internalising mechanisms and “attention tunnels” starting over interests that are frequently engaged with.

There is debate over whether Monotropism is applicable to ADHD. The EDA-Q detects demand avoidance behaviours in ADHD (Woods, 2019b). The tool’s discriminatory capability with Social, Emotional and Mental Health (SEMH) differences, is however unproven (O’Nions et al, 2014), which is noted by Stuart et al (2019). Persons who are distressed tend to notice smaller deviations from their expectations, and this is represented by a need for control and sensory differences. Such persons who are highly aroused are more likely to present with distress behaviour (challenging behaviour) (McDonnell, 2019). The symptom of demand avoidance is common to SEMH conditions that are frequently comorbid to autism (Woods, 2019b). Trauma based conditions along with SEMH both should produce similar results to Stuart et al (2019). Importantly as the sample contains limited numbers of autism or DAP diagnoses and lacks an exclusionary cut off (Stuart et al, 2019), SEMH and similar conditions could potentially be represented. A significant sized minority of the sample may not be autistic It is difficult to draw substantial conclusions.

Stuart and colleagues observed DAP behaviours substantially decrease with age and this has ramifications for clinical practice. The EDA-Q has 2 thresholds, with the lower one for those aged 12 and above (O’Nions et al, 2014). Wider literature suggests, between 44% - 89% of participants, do not meet the caseness for DAP into adulthood (Woods, 2019b), and this is significantly higher than found in autism (Iammi, Knapp and Ragan, 2017); indicating DAP is not a form of autism. There are attempts to control the numbers of DAPers identified, partly by diagnosing it over a 2 year time period (Summerhill and Collett, 2018). A diagnosis approach over a 2 year time period risks biasing the DAP profile as this is likely to result in the most severe cases being diagnosed, with individuals with “milder” presentations no-longer meeting the clinical threshold for DAP at an older age. The Stuart et al (2019) paper tentatively supports the notion that there is little scientific justification for this aspect of the assessment pathway.

Stuart and colleagues’ two studies provide a description of a proposed interaction between IU, anxiety and DAP. DAP is not a research priority of the autistic population (Woods, 2017). The clinical need for the DAP construct is contested (Woods, 2019b), the implications of conducting potentially unnecessary research on a vulnerable group, like DAP carers; should receive higher attention in the research literature and likewise, respecting the wishes of autistic persons. Their results would benefit from replication using research methods that does not inherently reify DAP. If DAP is to be accepted, its diagnostic and screening tools need good quality research to produce comprehensive and valid measurements for DAP.

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