

Demand Avoidance Phenomena (Pathological Demand Avoidance): an ethical challenge to its orthodoxy

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Demand Avoidance Phenomena (Pathological Demand Avoidance): an ethical challenge to its orthodoxy.

Richard Woods.

04th June 2019.

**Participatory Autism Research Collective,
Critical Autism Studies Conference.**

RECORDINGS.

Slide recordings.

- 1) I have made recordings for the slides, available at:
- 2) https://www.researchgate.net/publication/333682762_Demand_Avoidance_Phenomena_Pathological_Demand_Avoidance_an_ethical_challenge_to_its_orthodoxy
- 3) Audio files located in each slide's top right hand corner.

PERSPECTIVE.

My Bias.

- 1) The speaker meets its proposed profile, but that does not mean much.
- 2) Demand Avoidance Phenomena (DAP)
- 3) Significantly more compelling research, in quantity and quality, see previous talk (Woods 2019).
- 4) Highly contested, undermining credibility of all DAP “experts” (Vassilev & Pilgrim 2009), including the speaker.

OUTLOOK.

Re-construction.

- 1) Abstract based on a rejected article.
- 2) Happily share said essay if requested.
- 3) I want to say good things about DAP.
- 4) Instead of deconstructing it, constructing what I think an ethical position most people can live with.

OUTLOOK.

Questions and Response.

- 1) Take questions at the end.
- 2) Permission to record if I receive a copy of the recordings by Wednesday 12th of June 2019.
- 3) Include 100 word responses if received by above date.

OUTLOOK.

Commentary articles.

- 1) Please respond to the talk.
- 2) Possible journals: Autism; Autism Policy and Practice; Autonomy, the Critical Journal of Interdisciplinary Autism Studies; Canadian Journal of Disability Studies; Disability and Society; Good Autism Practice; Tizard Learning Disability Review.

IN THE BEGINNING.

Introduction.

- 1) Main DAP discourse.
- 2) Vulnerable groups.
- 3) Comorbid, not an ASD.
- 4) Research priorities.
- 5) Closing remarks.

WHAT IS IN A NAME?

A Suitable Name.

- 1) Demand to change its name (Eaton 2018b; Gillberg 2014; Milton 2017a; Newson et al 2003; PDA Society 2019; Reilly et al 2014; Sanchez 2018; Woods forthcoming).
- 2) DAP, *Demand Avoidance Phenomena*.
- 3) Will be clear later why this is appropriate.

LET'S TALK.

Main DAP Discourse.

- 1) Called Pathological Demand Avoidance or Extreme Demand Avoidance.
- 2) A distinct syndrome.
- 3) An autism subtype/ Pervasive Developmental Disorder.

TIME TO PROFILE YOU.

Autism + DAP Traits criteria.

- 1) Comfortable in role play and pretend.
- 2) Continues to resist and avoid ordinary demands of life.
- 3) Demand avoidance can use social strategies.
- 4) Lability of mood & impulsive.
- 5) Obsessive behaviour, often focused on other people.
- 6) Surface sociability, but apparent lack of sense of social identity, pride, or shame (Fidler 2019; Green et al 2018a; Thompson 2019).

TIME TO PROFILE YOU.

Credible DAP Points.

- 1) Benefit some person's in terms of understanding.
- 2) Bringing together some autistic persons.
- 3) DAPers do require appropriate strategies.
- 4) DAP supporters do mean well.
- 5) Lived experience.
- 6) Strong strategies.
- 7) Supportive Community.

DEPTH OF PERSPECTIVE.

Internalised Ableism.

- 1) Conspiracy theories, apparently, I have NPD.
- 2) Defamatory petition to have Damian Milton fired from NAS.
- 3) Instances of attacking those who disagree with main discourse.
- 4) Name calling, “Miltonsplaining”.
- 5) Secret documents responding to critique.
- 6) Speaker, has interrupted one DAP talk.
- 7) Surveillance of those with divergent opinion.

TIME TO PROFILE YOU.

General Position.

- 1) DAP is comorbid to autism, NOT an ASD.
- 2) Decisions about its ontology, nosology and aetiology need robust evidence to inform Policy and Practice.
- 3) DSM6/ ICD12 a generation away, no point making decisions on anecdotal evidence.
- 4) All research is transparent to all stakeholders.
- 5) Research agenda is DAPer-led.
- 6) Working name, *Demand Avoidance Phenomena*.

CAUTION REQUIRED.

Vulnerable groups.

- 1) Autistic persons.
- 2) DAPers.
- 3) DAP parents.
- 4) Autistics and DAPers known for internalising (Eaton 2018a; 2018b; Trundle et al 2017; Woods 2018b).

CAUTION REQUIRED.

Vulnerable groups.

- 1) DAP carers: Do face significant challenges from DAPers behaviour (Malik and Baird 2018).
- 2) Creates significant psychological pressures (Eaton 2018b; Fletcher-Watson and Happé; Malik and Baird 2018; Sherwin 2015).
- 3) High anxiety levels (Durà-Vilà and Levi 2019).

CAUTION REQUIRED.

Ethical Responsibilities.

- 1) Policy and Practice requires good quality evidence (Fletcher-Watson & Happé 2019; Green et al 2018b; Kay 2019).
- 2) Should be attempting to disprove their hypothesis (Rutter and Pickles 2016).
- 3) Balanced and accurate information should be presented (Brooks et al 2014; Dawson 2004; Rutter & Pickles 2016; Waltz 2007).

EXAMPLE, NOT THE BAND.

A problematic statement.

- 1) Christie leads developing understanding of main discourse (Fidler 2019).
- 2) *“To build on developments, insights and increasing recognition of PDA but maintain the integrity of how the condition is understood and the nature of support that is needed by individuals.”* (Christie 2018).
- 3) Should see flaws here!

TIME TO BE CLINICAL.

DAP as a comorbid.

- 1) APA/ WHO's place to decide what DAP is, e.g. a false form of attachment disorder (Milton 2017a).
- 2) Autism ex form of schizophrenia (Silberman 2015; Loong 2019).
- 3) Following DAP logic to nosology (DAP has specific strategies); it could be viewed as form of Catatonia & Personality Disorder, due overlap in respective strategies (Eaton 2018a; 2018b; 2018; Fieldman 2018).

THAT'S NOT TB.

DAP as a comorbid.

- 1) Core impairment is high anxiety levels (Christie 2007; Newson et al; Stuart et al 2019).
- 2) Anxiety is not part of autism profile & is a comorbid (Fletcher-Watson & Happé 2019; Gullon-Scott & Bass 2018; Malik and Baird 2018; Woods 2018a).
- 3) DAP is viewed as a comorbid within autism spectrum (Stuart et al 2019).

THAT'S NOT TB.

DAP as a comorbid.

- 1) DAP has no specificity (Attwood 2018; Christie et al 2012; Christie & Fidler 2015; Garralda 2003; Kay 2019; Malik and Baird 2018; Kay 2019; Wing 2002).
- 2) Interaction with comorbidities affects autism development (Brede et al 2017; Flackhill et al 2017; Green et al 2018a; Verhoeff 2012).
- 3) PDA developmental traits are not-needed for a diagnosis; does not need to be viewed as a PDD/ autism.

ANXIOUS MOMENT.

DAP as a comorbid.

- 1) O’Nions DAP model draws upon Anxiety Disorder & PBS literature (Kay 2019).
- 2) Vicious flower models for depression is from anxiety scholarship (Moorey 2010); overlaps DAP behaviours.
- 3) DAPers lived experience accounts suggest anxiety is due to fear of possible negative situations (Cat 2018; Thompson 2019); sign of OCD (Attwood 2015).

ANXIOUS MOMENT.

DAP as a comorbid.

- 1) Many clinicians have noted DAP is found external to autism (Flackhill et al; 2017; Gillberg 2014; Langton and Frederickson 2016; Trundle et al 2017); Observation noted in personal correspondences.
- 2) Empirical evidence indicates DAP is not unique to autism, its behaviours are not caused by autism and many DAPers are not autistic (Egan et al 2019; Green et al 2018a; Kaushik 2015).
- 3) Many developmental pathways (Christie 2018; Loong 2019; Thompson 2019).

ABSOLUTELY PHENOMINAL.

DAP as a comorbid.

- 1) What if, EDA-Q false positives are actually diagnostic overshadowing (Eaton 2018c)?
- 2) Case that there are *Demand Avoidance Phenomena* conditions, akin to “autisms” (Fletcher-Watson and Happé 2019; Wing et al 2011).
- 3) Good case for this name.

A MANIFOLD ISSUE.

Elephant in the room.

- 1) Age of participatory research (Fletcher-Watson et al 2019; Parsons et al 2019; Pellicano et al 2018).
- 2) DAP driven by non-autistic groups (Christie et al 2012; Newson et al 2003; Sanchez 2018).

A MANIFOLD ISSUE.

Elephant in the room.

- 1) Thousands of DAPers (autistic and not) are not diagnosed with it.
- 2) Their perspectives need to be accounted for.
- 3) Citizen Power requires transparency (Arnstein 1969).
- 4) DAPers, including autistics and non-autistic DAPers need representation on PDA Development Group.

MANUAL OR AUTOMATIC.

Evidence Thresholds.

- 1) Almost impossible to subtype autism (Wing et al 2011; Fletcher-Watson and Happé 2019).
- 2) DAP needs exceptional quality evidence to be accepted as ASD subtype, e.g. more than Asperger's Syndrome.
- 3) Can be accepted into diagnostic manuals with “typical quality” evidence base if non-ASD comorbid.
- 4) DSM6 & ICD12 a generation away, might as well focus on gaining that evidence to inform policy and practice.

WHO'S INTERESTS?

Research Agenda.

- 1) Most autistic persons do not want autism subtyped or in diagnosis manuals (Chown & Leatherland 2018; Fletcher-Watson and Happé 2019).
- 2) DAP is not a autistic research priority (Cusack & Sterry 2016; Pellicano et al 2014).
- 3) UK has limited autism research funding (Pellicano 2014), has improved slightly in 2016 (Warner et al 2019).

WHO'S INTERESTS?

Research Agenda.

- 1) All stakeholders want better inclusive education practices (Dillon et al 2016; Hardy and Woodcock 2015; Milton 2013; Stewart 2012), not an additional ASD subtype.
- 2) DAP strategies are good practice (Green et al 2018b; Milton 2017a; Woods forthcoming).
- 3) Many non-DAPers benefit from its strategies (Gore et al 2019; Harrison 2017; Leatherland 2014; Loong 2019; Milton 2017a; Murray 2017; Stewart 2012; Williams 2018; Wood 2019; Woods, forthcoming).

TIME TO STRATEGISE.

Overlapping Strategies & Pedagogies.

- 1) Autism Catatonia (Eaton 2018b).
- 2) Autistic preferred approaches (Laurent 2019; Milton 2018).
- 3) Capabilities Approach (Woods, forthcoming).
- 4) Dielectric Therapy (Eaton 2018b; Fieldman 2018).
- 5) Evidence based practices (Green et al 2018b).
- 6) Inquiries based learning.
- 7) SPELL Framework (Milton 2017a).
- 8) Universal Design for Learning (Woods, forthcoming).

ROUND TABLE.

Summarising.

- 1) DAP, not PDA.
- 2) Comorbid, not ASD.
- 3) DAP carers are a vulnerable group.
- 4) Transparency and inclusion all stakeholders, autistic & non autistic DAPers.

ROUND TABLE.

Summarising.

- 1) Policy and practice decisions require good evidence.
- 2) At what specific evidence thresholds?
- 3) Not my personal views, what most persons could support.
- 4) Please respond to this.

POSITIVE FEEDBACK.

Acknowledgements.

- 1) Damian Milton for his DAP deconstruction that inspired my original DAP ethics essay.
- 2) Peer reviewers of journal *Autism*.
- 3) Everyone who has supported my academic work.
- 4) PDA Development Group, PDA Society & Harry Thompson did not respond to invitations to comment on topic.

POSITIVE FEEDBACK.

Commentary.

- 1) PDA Society did comment privately on the slides. They declined opportunity to comment the recordings.
- 2) What threshold is required for PDA Society and others to change their stance on PDA?
- 3) Generally, feedback has positive.

CHEAP PLUG.

Autism Policy & Practice.

- 1) Open Access autistic-led good practice journal.
- 2) Access via link below:
<https://www.openaccessautism.org/index.php/app/about>
- 3) Alternatively, contact Dr Mitzi Waltz.
mitziwaltz@yahoo.com

ANY QUESTIONS?

The End Game.

- 1) Contact Details:
richardwoodsautism@gmail.com
- 2) Twitter handle:
@Richard_Autism
- 3) My researchgate:
https://www.researchgate.net/profile/Richard_Woods10
- 4) Any questions?

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