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 12\textsuperscript{th} 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.
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).
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).
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.
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).
4) Dielectric Therapy (Eaton 2018b; Fieldman 2018).
5) Evidence based practices (Green et al 2018b).
6) Inquiries based learning.
7) SPELL Framework (Milton 2017a).
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.
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.
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](mailto:richardwoodsautism@gmail.com)
2) Twitter handle: [@Richard_Autism](https://twitter.com/Richard_Autism)
4) Any questions?
NOT THE FIRST BIBLE.

Bibliography.


NOT THE SECOND BIBLE.

Bibliography.


Bibliography.


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2) Garralda, E. (2003). Pathological demand avoidance syndrome or psychiatric disorder? *Archives of Disease in Childhood* (online only article). Retrieved from: [https://adc.bmj.com/content/88/7/595.responses](https://adc.bmj.com/content/88/7/595.responses) (Accessed 11 November 2018).


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