

Pathological Demand Avoidance: Is it time to move beyond the pathological need to not to develop more inclusive pedagogical practices?

WOODS, Richard

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/24751/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

WOODS, Richard (2019). Pathological Demand Avoidance: Is it time to move beyond the pathological need to not to develop more inclusive pedagogical practices? *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1 (6).

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Pathological Demand Avoidance: Is it time to move beyond the pathological need to not to develop more inclusive pedagogical practices?

Richard Woods.

Letter to the Editor.

The National Autism Projects report 'The Autism Dividend' (Lemmi et al 2017, p10) states that "that most policy and practice is not supported by evaluation of effectiveness and cost-effectiveness in studies of good quality."

I am writing to give a specific example where I feel that inadequate research is leading to poor educational advice given the dangers of over pathologisation of traits that do not need to be addressed this way, the Autism Education Trust (AET) is a government funded body responsible for raising inclusive education practices for autistic persons in the United Kingdom (UK). As part of its work AET has republished 2 PDA articles exploring working practices for those diagnosed with PDA (Carlile 2011; Christie 2007). This is despite PDA only being a proposed SEND label and its surrounding controversy (Christie 2007).

Carlile (2011) and Christie (2007) suggest following working practices:

- A specific keyworker to build a trusted relationship.
- Being flexible & adaptable.
- Indirect praise.

URL: <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/CO3/html>

- Letting things go.
- Negotiating by providing choices to pupils.
- Positive relations.
- Thinking aloud.
- Tone of voice.
- Treating anger as communication.
- Use humour.
- Use of role play, novelty and variety of lesson material.
- Visual communication methods.

It is striking that besides a specific key worker for each person (due to the financial costs); most of these adjustments are suitable for most children, not just those diagnosed with PDA (Milton 2017). Implementing most of these practices with all pupils would help all pupils with their wellbeing and feel part of the school community, which is pivotal to reaching the highest level of inclusive education. In the process it would develop better general teaching pedagogies of a highly trained general teaching staff (Haug 2017). This could be a pathway of widespread adoption of universal design (UD) in education and the capabilities approach, which I propose could be the methodology of choice for achieving the highest form of inclusion. Combining both UD and the capabilities approach would benefit all students by transferring over adjustments and pedagogies that work for most students (Dalkilic and Vadeboncoeur 2016; Burgstahler and Russo-Gleicher 2015), which is the most effective way to practice inclusion (Haug 2017).

Some of the adjustments could be seen to be implementing UD and the capabilities approach (Carlile 2011; Christie 2007). For example using visual communication methods is an autism adjustment, it is also part of UD and also benefits other non-autistic students. (Burgstahler and Russo-Gleicher 2015). While negotiating, letting things go and indirect praise could be part of practicing the capabilities approach; this is a letting the person choose their functioning of choice by providing the capability for the person to do the functioning. Letting things go and having a positive relation with a pupil is showing that the person's potential is valued (Dalkilic and Vadeboncoeur 2016). However this interpretation of PDA adjustments is possibly naïve as there could be a struggle for power within the discourse of these 2 PDA papers (Milton 2017); further research is needed to investigate this.

It is concerning that AET has published these 2 PDA articles for schools to use (Carlile 2011; Christie 2007). There are multiple assumptions in these articles which contradict AET's other work. Carlile (2011) suggests these individuals have surface level Theory of Mind. Theory of Mind is medical model of disability theory claiming autistic individuals suffer a deficit compared to non-autistic people. This contradicts the double empathy problem in which both autistic and non-autistic individuals struggle to understand each other (Milton 2012). All autism stakeholders wish for schools to practice more inclusive autism adjustments (Milton 2013). Advocating for continuing "pigeon-holing" and "one-size fits all" ideology of label specific adjustments prevents these inclusive practices being shared between labels, which is imperative for autism due to its myriad and frequent comorbidities. Due to the psycho-emotional disablism autistic persons' face (Milton 2013), they will sometimes logically and rationally avoid certain demands non-autistic people consider to be trivial. Due to this it would be emancipatory for PDA to be christened *Rational Demand Avoidance*; this would recognise the autistic persons' perspectives of what is a suitable level of demands.

URL: <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/CO3/html>

By publishing the 2 PDA papers AET have provided an opportunity to re-examine the bias towards label specific adjustments and to see if this is a direction of inclusive education we wish to be pursuing; To look beyond the pathological need for label specific adjustments and try to focus on good quality general pedagogies that benefit everyone in our pursuit of inclusive education, over an ever increasing need for medical labels.

Disclosure statement.

No potential conflict of interest was reported by the author.

References.

Burgstahler, S. and Russo-Gleicher, R., 2015. Applying Universal Design to Address the Needs of Postsecondary Students on the on the Autism Spectrum. *Journal of Postsecondary Education and Disability*, 28 (2), 199-212.

Carlile, J., 2011. Helping Your Helping your child with PDA to play: eight strategies for supporting a child with Pathological Demand Avoidance Syndrome at home. *Good Autism Practice*, 12 (2), 51-55.

Christie, P., 2007. The Distinctive Clinical and Educational Needs of Children with Pathological Demand Avoidance Syndrome: Guidelines for Good Practice. *Good Autism Practice*, 8 (1), 3-11.

Dalkilic, M. and Vadeboncoeur, J., 2016. Re-framing Inclusive Education Through the Capability Approach: An Elaboration of the Model of Relational Inclusion. *Global Education Review*, 3 (3), 122-137.

Haug, P., 2017. Understanding inclusive education: ideals and reality. *Scandinavian Journal of Disability Research*, 19 (3), 206-217.

Lemmi, V., Knapp, M. and Ragan, I., 2017. *THE AUTISM DIVIDEND: Reaping the rewards of better investment*. The National Autism Project.

Milton, D., 2012. *So what exactly is autism?* Autism Education Trust.

Milton, D., 2013. 'Reversing the vicious circle of psycho-emotional disablism in the education of autistic people'. In: Banerjee, P., Barrie, R. & Hand, M. *Championing research, educating professionals: how compatible are elitism, inclusion and social justice?*

Birmingham: University of Birmingham, pp 127-134.

Milton, D., 2017. "Natures answer to over-conformity": deconstructing Pathological Demand Avoidance. In: Milton, D. *A Mismatch of Salience: Explorations of the nature of autism from theory to practice*. Hove: Pavilion Publishing and Media Limited, 2017, pp 27-38.