Sheffield Hallam University

Rational (pathological) demand avoidance: what it is not, what it could be and what it does.

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Rational (Pathological) Demand Avoidance: What is not, what it could be and what it does.

Richard Woods.
15th of May 2018.

MY BIAS AND PERSPECTIVES.

I am diagnosed autistic 6 years ago at the CLASS clinic.

I will be engaging RDA from using this Critical Autism Studies Definition:
"*The 'criticality' comes from investigating power dynamics that operate in Discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability'*" (Waltz 2014).

I am pro neurodiversity and the social model (Woods 2017b). However I do also support the medical model, I do have issues with it's language and its effects which I will discuss later.

I am a PGCert Autism and Asperger's Syndrome Student at Sheffield Hallam University.

I may make generalisations, this is not what I mean. I think the processes driving RDA are many interaction and intersecting; being variable with each person.

DISCLAIMER & SUPPORT MATERIAL.

Disclaimer.

- I have updated the power point since the talk.
- This has been by proof reading.
- Adding references and providing a full reference list.
- I have slightly expanded some points to cover relevant material and to act on feedback from the talk.
- I did not have time to go into as much depth as I would like to on all topics present, some of the points can be further developed.

Supplementary Material.

- This presentation builds on a previous essay I wrote, which can be accessed on my blog and can be accessed via this link:
https://rationaldemandavoidance.com/2018/05/15/critical-reflections-on-the-pathological-demand-avoidance-debate-a-response-to-the-practice-mk-blog-and-discussion/

FOOD FOR THOUGHT.

Through out the talk I will regularly display a list of traits, for reflection, are they associated with RDA or autism?

The list of 10 traits:
- Have a unique talent e.g. role play.
- Preference for stability in e.g. best friend or routines.
- Sensory sensitivities e.g. cannot wear certain clothes or finds certain sounds painful.
- Likes to have friends.
- Perfectionism e.g. will not stop until their work is perfect.
- Avoidance of eye contact.
- Has high anxiety.
- Restricted range of interests.
- Social awkwardness.
- Had language delay e.g. only spoke after 4 years old.
- Is clumsy.

DISABILITY HISTORY.

Key Dates.

- Middle Ages – 1800s: Disabled people seen as being possessed by demons
- Industrial Revolution: Disabled people are excluded from work force
- Post WW2: People should be helped by fixing them.
- 1950s onwards: Dominance of Medical Model.
- 1978: Warnock Report creates inclusive education in UK.
- 1981: Mike Oliver coins Social Model in a social worker training.
- 1983: DPI definition of Impairment and Disability.
- 1989: UN Conventions of Rights of a Child.
- 1995: Disability Discrimination Act.
- 2006: UN Convention of Disabled Peoples.
- 2010: Current Equality Act 2010.

DISABILITY STUDY CONCEPTS 101.

The Social Model.

Impairment: Is the functional limitation within the individual caused by physical, mental or sensory impairment.

Disability: is the loss or limitation of opportunities to take part in the normal life of the community on equal level with others due to physical and social barriers. (Goodley 2011).

Positives: It places emphasis on adapting environment for the needs of persons. Provides a focal point for Disability Rights Campaigners. Can be used with other interventions.

Negatives: It is a model, only describes disability and does not explain personal experiences. Can be a blunt tool, other people can become disabled (this can be a positive). Has been re-appropriated away from original interpretations. (Barnes 2003; Oliver 2013).

DISABILITY STUDY CONCEPTS 101.

Biological, Psychological & Social.

Impairment Effects: bodily activity and behaviour that are directly attributable to bodily variations designated "impairments" (Thomas 1999).

Disablism: focuses on the negative treatment towards disabled people and social policy (Goodley 2011).

Psycho-Emotional Disablism: The social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being (Reeve 2014; Thomas 1999).

Critique.

It is suggested that combining impairment effects and psycho-emotional disablism to the social model, it can resemble and function like biopsychosocial model.

SEND EDUCATION HISTORY.

Key Dates.

- 1944 Education Act 1944.
- 1978 Warnock Report.
- 1981 Education Act 1981.
- 1997 Excellence for all children: Meeting Special Educational Needs.
- 2001 SEN & Disability Act 2001.
- 2001 SEN Code of Practice.
- 2004 Removing Barriers to Achievement: The Government's Strategy for SEN
- 2006 Disability and Equal Duty Act.
- 2009 The Lamb Inquiry: Special Educational Needs and Parental Confidence.
- 2011 Support and Aspiration: A new approach to SEN and Disability.
- 2014 Children & Families Act 2014.
- 2015 SEN & Disability Code of Practice.
- (Goodley 2011); Hodkinson 2010; Runswick-Cole 2011; Woods 2017b).

EDUCATION DEFINITIONS.

Key words.

SEND: Special Educational Needs and Disabilities; this covers everything from autistic pupils to children in care, any pupil who is disadvantaged.

Segregation: When SEND pupils are educated in special schools.

Integration: When SEND pupils are placed into mainstream schools and are expected to adapt themselves to the environment.

Inclusive Education: When SEND pupils are placed into mainstream schools and the schools adapt to SEND pupils needs.
(Pellicano et al 2018; Rodriguez and Garro-Gill 2015).

Critique.
There is significant debate between of Special ed vs Inclusive ed, possibly as UNESCO has not defined Inclusion (Reindal 2016). Inclusion is seen as constant a journey, not a goal in itself (Haug 2017).

UK EDUCATION SYSTEM.

Current set up and operation.

- It is needs based, supposedly.
- Significant support is provided through EHCPs, via wrap around support by working with all stakeholders.
- Neoliberal market ideology is rampant, focusing on short term attainment.
- Under significant strain through austerity, applying cuts to Local Authority budgets and school budgets.
- Large numbers of academies that are independent of Local Authorities, academies are responsible for their own admissions.
- Argued focus on attainment is detrimental to inclusion; "super heads" likely to exclude under achieving pupils to raise results.
- Leads to huge variation is support for pupils across the country, in particular SEND pupils most at risk of the system failing them.
- Growing numbers of EHCPs are being refused.
- (APPGA 2017; Boesley & Crane 2018; Burch 2018; Hill et al 2016; Hodkinson 2010; Leatherland 2014; Lehane 2017).

DISABLED PERSONS IN THE UK.

Current Situation.

- Disability effects 13 million people in the UK; 1:5 people.
- 1,228,785 pupils in the UK have SEND label, that's 11.6% of pupil population.
- Having an SEND label 5 times more likely to be excluded and have less 5 good GCSEs (Equality and Human Rights Commission 2017).
- Disabled persons are most likely to be victims of austerity. It is argued that the government is discriminating against disabled persons (Committee on the Rights of Persons with Disabilities 2017).

Why is this so?

- Neoliberalism dominants UK culture and society, where each person is meant to be an independent self-regulating individual.
- In order to this, UK disability support is centred on the concept of the mythical norm (Burch 2018; Goodley 2011; Lehane 2017).

UNICRON; THE MYTHICAL NORM.

The Mythical Norm.

- In neoliberal times it is up to each person to seek help to fix any faults they have, so they can be an economically productive person.
- Since the 1950s the medical model of disability has been dominant in the UK.
- The medical model seeks to repair people if they are damaged.
- Tends to be easy for physical injuries.
- For invisible impairments this is a significant challenge, how to know what is faulty and how is best to be fixed?
- Psy-professions tend to use behavioural based tests to view if a person is psychology damaged, so they can apply interventions.
- These behaviour tests often measure behaviours against the normal (Goodley 2011).
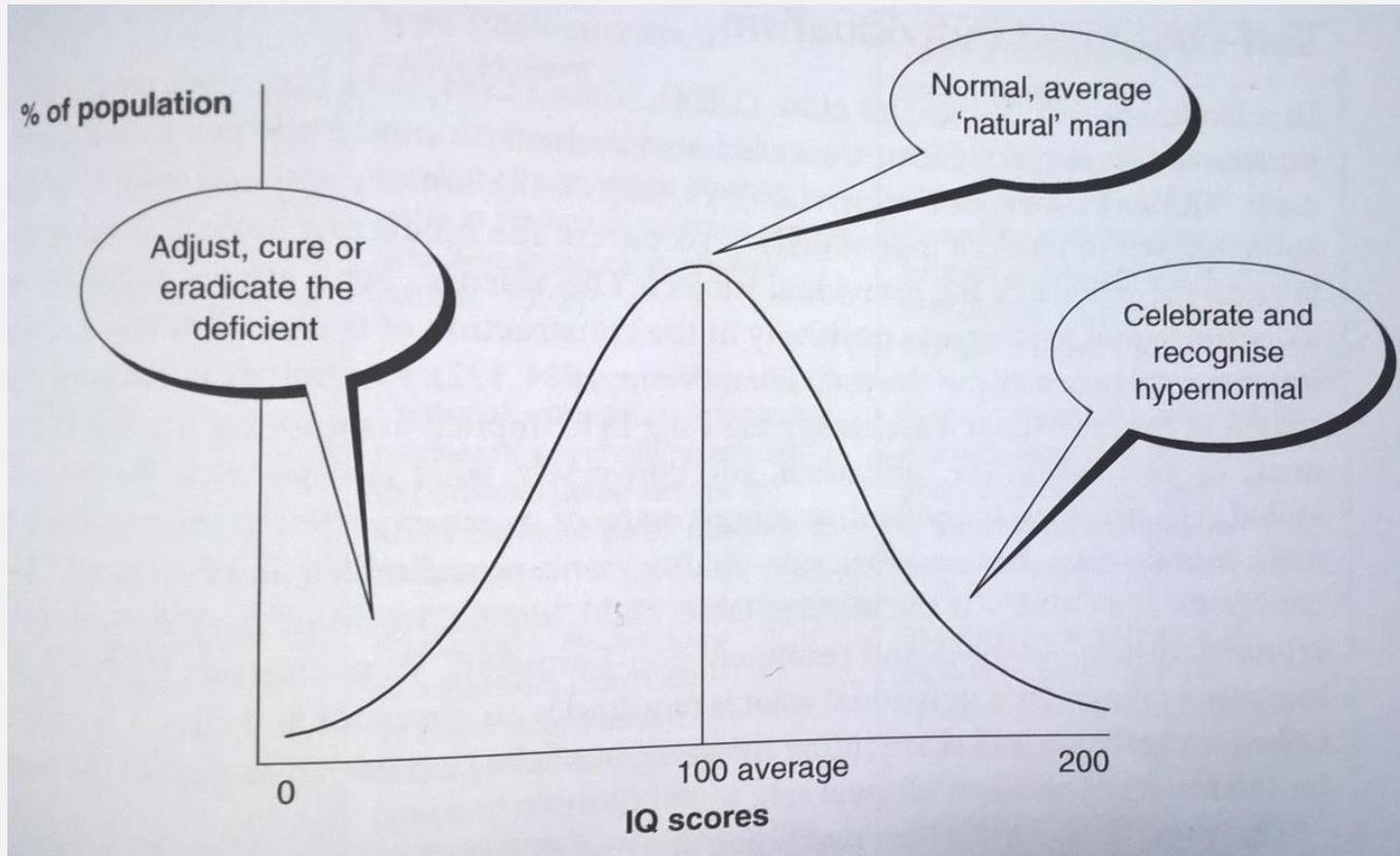- What is normal?

UNICRON; THE MYTHICAL NORM.

A Gaussian Curve.
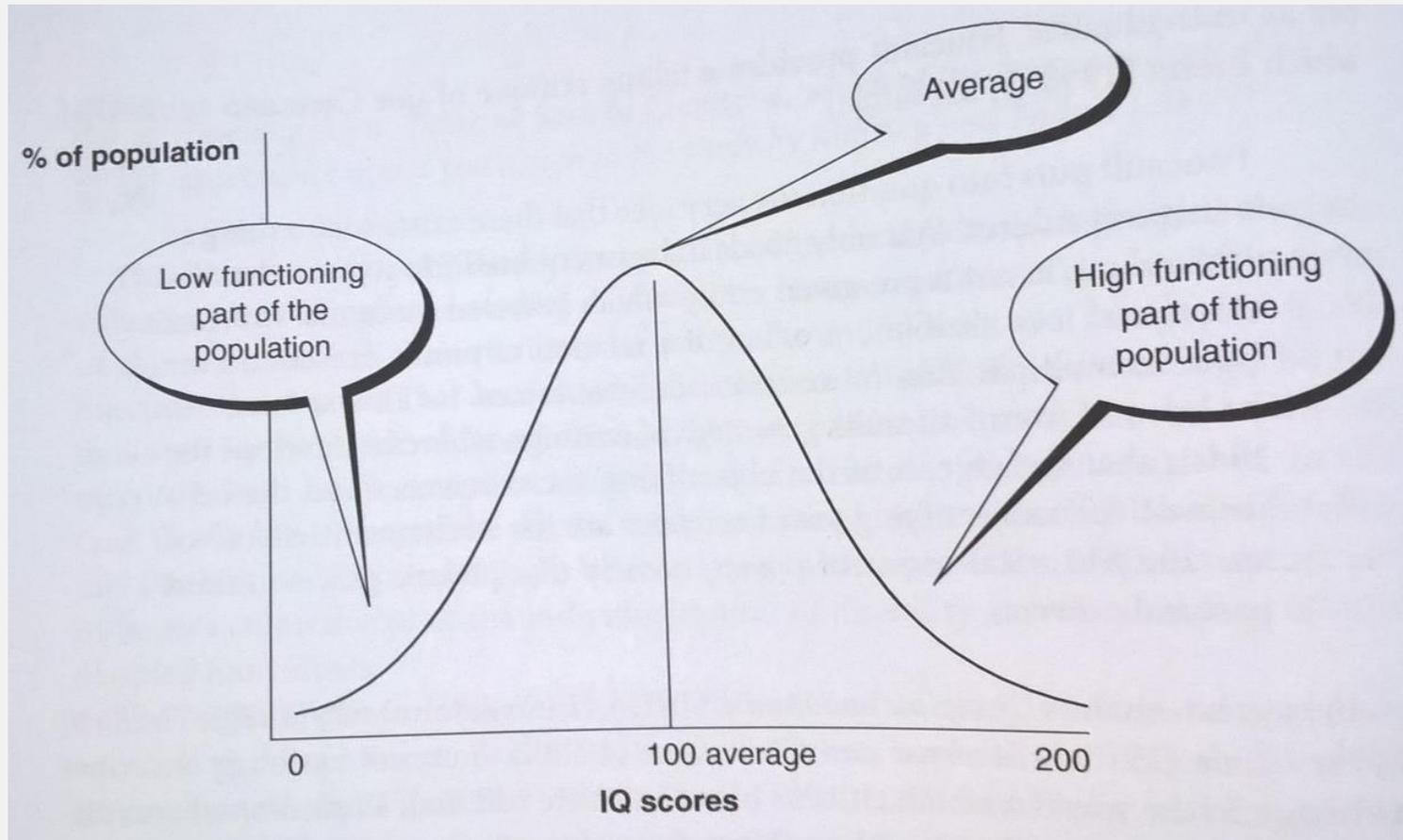
The bell shape shows collection of different values for a characteristic, e.g. intelligence (Goodley 2011, is source of graph).

THE MEAN NORMAL.

Normal replaces average. Bottom end becomes disability to be cured. Top end becomes celebrated "hypernormal" (Goodley 2011, is source of graph).

THE MEAN NORMAL.

Normal and Its implications.

Normal: Using statistical averages to describe the ideal person. It is impossible for a person to meet the statistical averages as individuals have uneven profiles. "Normal" is a myth, being it does not exist.

- With normal being a myth, powerful stakeholders can arbitrarily define what traits are a deficit to be fixed and which traits are acceptable.
- In 1973 the American Psychology Association cured thousands of people of Borderline Mental Retardation due to changing how IQ scores are used (Goodley 2011).

MEDICAL MODEL DEFICITS.

How do autism and normal fit together?

- Autistic people have spikey skills profiles (Milton 2017; Wilkinson 2016).
- Autism labels that we display can vary over time (Lawson 2010).
- Nothing is unique or universal to autism, what is found in autism can be found outside of autism.
- Autism + Environment = Outcome (Beardon 2017).
- Where a person thinks autism starts and stops is based on their bias (Milton 2013; 2017) and culture.
- This can be seen in the difference in UK and USA prevalence rates: 1.1% (Brugha et al 2012) vs 1.68% (Balo et al 2018).

What does mean for autism and the mythical norm?

- We do not know where autism starts or stops; its boundaries are dynamic, mobile and diffuse; dependent on the situation of the autistic person & their observers bias.
- Autistic persons are a demographic of extremes and may not follow Gaussian statistics.

FOOD FOR THOUGHT.

What does this profile fluidity mean for RDA?

With autism having unstable foundations, what might that mean for RDA considering RDA is viewed against autism?

The list of 10 traits:
- Have a unique talent e.g. role play.
- Preference for stability in e.g. best friend or routines.
- Sensory sensitivities e.g. cannot wear certain clothes or finds certain sounds painful.
- Likes to have friends.
- Perfectionism e.g. will not stop until their work is perfect.
- Avoidance of eye contact.
- Has high anxiety.
- Restricted range of interests.
- Social awkwardness.
- Had language delay e.g. only spoke after 4 years old.
- Is clumsy.

MEDICAL MODEL DEFICITS.

How does the medical model affect autistic persons.

- Autism is legally seen as a mental disorder (Mucalhy 2016).
- We can be sent to forensic hospitals for life (Moxon 2016).
- Most UK research spending is biology based (Pellicano et al 2014).
- Stigma, leads to mental health issues (Humphrey & Lewis 2008).
- Stigma contributing to negative perceptions of autistic persons (Nicole et al 2015).
- 80% of autistic persons experience depression and anxiety (Lemmi et al 2017).
- Suicide and attempted suicide rates at 9 times higher than non-autistic persons (Hirvikoski et al 2016; Moses 2017).
- Mercy killings by autism parents (McGuire 2016; Waltz 2008).
- Employment rates are only 32% (National Autistic Society 2016).
- In Western countries there are problems with mainstreaming autistic pupils (Pellicano et al 2018). Particularly mentioned by teachers (Kiloran et al 2014; Lindsay et al 2013).
- I am not saying all autistic problems are due to medical model, but it is a factor.

RDA AS A SYMPTOM.

RDA and Education System?

- With budget cuts to schools and Local Authorities and fracturing of support, it is harder for children with social, emotional and mental health needs (includes autism) to gain an EHCP (Boesley and Crane 2018).
- Subsequently these pupils are most likely to be excluded in current times. These labels have behaviour overlap with RDA and are being seen in recent samples (Brede et al 2017; O'Nions et al 2017).
- This increases pressure on parents to access support for their child. When added to psychological demands of being a RDA carer, psycho-emotional disablism is a possibility.
- Likely same for the child, which is suggested by Brede et al (2017).
- This creates extra demand for support and a pupils needs can be measured by how many labels they have. Various stakeholders turn to a label that could assist a child gain support they should already be receiving; in this case RDA.
- This creates a rat-race, where it is parent vs parent scrambling to acquiring labels to ensure their child's needs are met.

RDA & DISABILITY STUDIES.

RDA defined by impairment and impairment effects.

RDA Impairment traits: High Anxiety.

RDA Impairment Effects traits: The "demand behaviour", liability of mood and impulse control.

Why these?
- The core trait is high anxiety levels.
- The demand behaviour is how a RDAer attempts to regulate and adapt to the high anxiety.
- The high anxiety levels and demand behaviours can be seen as interactive process, with being labelled "demand behaviour" as disablism due to the RDAer vulnerability to internalising (Eaton 2018b; Trundle et al 2017).
- Other RDA traits can viewed as a different way of being, therefore they are not necessarily a defect.

RDA AND LOOPING EFFECTS.

RDA Driven by looping effects.

- 2 types of looping effects.
- First: Is that when as a person identifies with a label, they will change their memories & thought patterns to align with the new identity (Woods 2017a). Goffman (1963) notes that it is easy for persons to align their actions with an identity.
- RDAers are thought to be susceptible to internalising (Eaton 2018b; Trundle et al 2017). It is plausible that there is some form of this looping effects present in some RDAers.
- Second: Hacking (1999) suggests that the connotations attached to a human kind evolve over time as labelled persons interact with those around them. Autism label connotations have evolved; it possible that the interaction with the many autistic persons who have progressed through UK education system over the last decade (Cutting 2017), have altered their behaviours due to how education staff have interacted with them. Labelling effects are expressed in those working with RDAers (Brede et al 2016).

RDA AND CONDITIONING.

Are RDAers being conditioned?

- Classical conditioning: when a person associates act with a stimuli.
- Operant conditioning: where a person is conditioned using rewards and punishments (Chown 2016).
- It is argued that these strategies do not work with RDAers as they will simply take the reward (Christie 2007).
- RDA being a form of behaviourism and the RDA strategies meant to be used all the time (Christie et al 2012), comparable to the 40 hours per week typical of ABA.
- Autistic persons can benefit from being put in charge (Milton; 2017; Stewart 2012; Woods 2017b).
- Brede et al (2016) describes RDA strategies being used with 8 pupils. It suggests that conditioning can occur with RDAers, noting some RDAers can benefit from such adjustments,
- Brede et al (2016) worryingly highlights examples of RDAers being rewarded/ bribed after distress behaviour.
- There is little to prevent RDAers generalising RDA behaviours from these processes.

RDA AS REBRANDED AUTISM.

What is the evidence?

- RDA overlaps, autism ADHD and ODD. Recent literature are finding these labels in there samples (Brede et al 2017; O'Nions et al 2017; Trundle et al 2017).
- This literature also suggests RDA is autism due to the a need for routine being found among RDAers and this believed to separate RDA from autism (O'Nions et al 2017).
- Participants behaviour maybe due to their experiences (Brede et al 2017).
- Labelling effects are being found in those working with RDAers (Brede et al 2016), this means practitioners are assuming all pupil behaviour is due to RDA.
- Autistic authors, frequently cite this effect as colouring observer's perspectives of their actions (Loomes 2017; Woods 2017b; Yergeau 2010).
- Looping effects, conditioning and rebranding autism can intersect on many levels leading to the assumption a person has RDA & contributing to RDAers displaying RDA behaviour profile.

RDA AS A FORM OF CONTROL.

RDA and power.

- Foucault (1978), that power is subtle comes with resistance and knowledge. Power is everywhere, no one can possess it.
- A technology is a form of power that stakeholders can use to control other people. Traditionally the state would have used the power to end life.
- Modern days the state exercises many technologies to influence how people act; for instance SEND Code of Practice is argued is about preparing students to be independent economically productive citizens (Burch 2018; Lehane 2017).
- Charities, clinicians and parents are using RDA to alter a person's behaviour. With fracturing and competitive education market, it is up to each person to be responsible and learn about the latest autism research; in this case RDA. These stakeholders have provided commodities (Woods 2017a), for people to buy and partake in as part of continual professional development or to assist diagnosed RDAers in their class.
- Some RDAers are also doing the same as other stakeholders.

RDA AS A FORM OF CONTROL.

RDA and Stigma.

- Goffman (1963) social deviants traits: have collective denial (demand behaviours), failing to use any opportunity for advancement that society allows (lacks self-identity), show disrespect to their betters (demand behaviours), lack piety (lacks pride) and are failures of motivational schemes [(typical rewards do not work on RDAers (Christie 2007; Newson et al 2003)].
- Labels create stigma, needs negative meanings and stereotypes.
- Stigmatised can try to control their information and resist stigma.
- Common autism + RDA diagnosis, makes escaping stigma hard.
- Typically autistic persons would emphasise their humanity, caring nature, likes to have friends and humour to resist autism stigma. Displaying these traits is covered in RDA stereotypes and can be dismissed due to labelling effects. If an RDAer logically objects to these stigma, it is them showing demand behaviours.
- Viewed with RDAer internalising, stigma explains some of RDAer mental ill health issues (Eaton 2018a; Eaton 2018b).

RDA AS A FORM OF CONTROL.

RDA and Internalised ableism.

Ableism: a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human (Campbell 2008).

- Internalised ableism is when an oppressed group adopts and expresses discourses linked to ableism.
- Parts of the RDA community has done this, with there is only one RDA truth; being it is not autism, but a distinct syndrome part of autism spectrum (O'Nions et al 2017; Trundle et al 2017).
- Some RDA supporters react negatively and aggressively towards any contradicting critique.
- This divides the autism (and autistic) communities, which can be exploited to control us. For example not uniting to argue for more support for all autistic persons and autism carers.

RDA AND NEURDIVERSITY.

RDA as a threat to Neurodiversity.

- Labelling effects are a significant problem; by observers assuming all RDA behaviour is due RDA it risks ignoring legitimate concerns by autistic persons.
- Potentially dangerous when added with double-empathy problem and autistic persons tend to operate differently to dominant social values.
- Concerted campaign to get RDA recognised along its dominant discourses; to get RDA into the diagnostic manuals. This is the opposite of many neurodiversity supporters, who do not view pathologising of autism.
- RDA is not a stable label, with different interpretations of its criteria (Green et al 2018; Reilly et al 2014). There is evidence of "label creep", where traits associated with autism are being seen as demand behaviour (O'Nions et al 2017).

ETHICS OF RDA.

Core ethical concerns.

- Lack of good quality research to suggest what RDA is (Green et al 2018).
- RDA can be explained by autism, which provides stronger legal rights.
- We do not know what RDA is or the side effects of the diagnosis. Due to the mental health problems typical in RDA and effects of stigma.
- There is a case to argue RDA should not be diagnosed as Autism + RDA traits.
- Lack of evidence that RDA strategies work and how often they should be used.
- The silencing of critique running contrary to the dominant RDA discourses.
- RDA is being driven by powerful stakeholders; disability charities, charities and clinicians (Newson et al 2003; Christie 2007; Christie et al 2012; Woods 2017a), traditionally this has been at the expense of disabled persons; nothing about us without us.

FOOD FOR THOUGHT.

Which of these traits are autism or RDA?

Before concluding, I would like to remind you of these traits.

The list of 10 traits:
- Have a unique talent e.g. role play.
- Preference for stability in e.g. best friend or routines.
- Sensory sensitivities e.g. cannot wear certain clothes or finds certain sounds painful.
- Likes to have friends.
- Perfectionism e.g. will not stop until their work is perfect.
- Avoidance of eye contact.
- Has high anxiety.
- Restricted range of interests.
- Social awkwardness.
- Had language delay e.g. only spoke after 4 years old.
- Is clumsy.

CONCLUSION.

So what can be done?

- I echo Garralda (2003) that current existing labels should be used where possible.
- There urgently needs to be an ethical debate on the merits of RDA.
- There is a pressing need for research into autistic demand behaviour (The Westminster Commission on Autism 2016).
- The Autism Act (2009), should be fully resourced to ensure all front line LA and NHS staff receive up to date autism training, including neurodiversity perspectives.
- The government should fully resource schools, Local Authorities and NHS Trusts to allow them to meet their statutory duties.

ANY QUESTIONS.

The End Game.

- My opinions are more developed than, I only have an hour to do the talk.
- Contact details: richardwoodsautism@gmail.com
- Link to my blog, *Rational Demand Avoidance*: https://rationaldemandavoidance.com/
- Are there any questions?

REFERENCES.

Reference List Page 1.

All Party Parliamentary Group on Autism (APPGA)., 2017. *Autism and education in England 2017: A report by the All Party Parliamentary Group on Autism on how the education system in England works for children and young people on the autism spectrum* (online). London: All Party Parliamentary Group on Autism. Available at: http://www.autism.org.uk/get-involved/campaign/appga/highlights.aspx (Accessed 09 May 2018)

Balo et al (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. Morbidity and Mortality Weekly Report, 67 (6), 1 – 23.

Barnes, C., 2003. Disability Studies: what's the point? 2003. *Disability Studies: Theory. Policy and Practice: University of Lancaster, September 04 2003.* Lancaster: University of Lancaster, pp. 1 - 27.

Beardon, L., 2017. *Autism and Asperger Syndrome in Adults.* London: Sheldon Press.

Brede, J., et al., 2016. Back to school: *Paving the path to re-integration for autistic children previously excluded from education* (online).London: University College London. Available at: https://www.pdasociety.org.uk/files/download/2a32d322a8e3afd (Accessed 09 May 2018).

Brede, J., et al., 2017. Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school. *Autism & Developmental Language Impairments*, 2, 1 – 20.

REFERENCES.

Reference List Page 2.

Boesley, L. & Crane, L., 2018. 'Forget the Health and Care and just call them Education Plans': SENCOs' perspectives on Education, Health and Care plans. *Journal of Research in Special Educational Need*s. DOI: 10.1111/1471-3802.12416

Burch, L., 2018. Governmentality of adulthood: a critical discourse analysis of the 2014 Special Educational Needs and Disability Code of Practice. *Disability and Society*, 33 (1), 94 - 114.

Campbell, F., 2008. Exploring Internalized Ableism Using Critical Race Theory. *Disability and Society*, 23 (2), 151–162.

Chown, N., 2016. *Understanding and Evaluating Autism Theory*. London: Jessica Kingsley Publishers.

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.

Christie, P., et al., 2012. *Understanding Pathological Demand Avoidance Syndrome in Children: A Guide for Parents, Teachers and Other Professionals*. London: Jessica Kingsley Publishers.

Committee on the Rights of Persons with Disabilities, 2017. *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention* (online). Geneva: United Nations High Commissioner for Human Rights. Accessed 07 September 2017. Available at:
www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc

REFERENCES.

Reference List Page 3.

Cutting, A., 2017. *Rise in exclusions for autistic pupils in England* (online). United Kingdom: National Autistic Society. Available at: http://network.autism.org.uk/knowledge/insight-opinion/rise-exclusions-autistic-pupils-england (Accessed 16 May 2018).

Eaton., J., 2018a. *PDA and mental health* (online). London: National Autistic Society. Available at: http://network.autism.org.uk/knowledge/insight-opinion/pda-and-mental-health?utm_source=AutismInsight11Jan2018&utm_medium=Email&utm_campaign=AutismInsight11Jan2018&utm_content=Story3B&dm_i=YA3%2C5E176%2CFZ686G%2CKULDG%2C1 (Accessed 09 May 2018).

Eaton, J., 2018b. *A guide to mental health issues in girls and young women on the autism spectrum: diagnosis, intervention and family support*. London: Jessica Kingsley Publishers.

Equality and Human Rights Commission., 2017. *Being Disabled in Britain*. Manchester: Equality and Human Rights Commission. Available at: https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf (Accessed 30 May 2017).

Foucault, M., 1978. *The History of Sexuality, Volume 1: An introduction*. New York: Random House.

Garralda, M., 2003. Pathological demand avoidance syndrome or psychiatric disorder? E-letter. *Archives of Disease in Childhood*. Available at: http://adc.bmj.com/content/88/7/595.abstract/reply#archdischild_el_512 (Accessed 16 May 2018).

REFERENCES.

Reference List Page 4.

Goffman. E., 1963. *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Group.

Goodley, D., 2011. *Disability Studies, An Interdisciplinary Introduction*. London: Sage Publishers Inc.

Green, J., et al., 2018. Pathological Demand Avoidance: symptoms but not a syndrome. *Lancet Child & Adolescent Health*. DOI: https://doi.org/10.1016/S2352-4642(18)30044-0

Hacking. I., 1999. *The Social Construction of What?* London: Harvard University Press.

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

Hill, A., et al., 2016. The One Type of Leader Who Can Turn Around a Failing School. *Harvard Business Review* (online). 03 March 2017. Available at: https://hbr.org/2016/10/the-one-type-of-leader-who-can-turn-around-a-failing-school (Accessed 14 September 2017).

Hirvikoski, T., et al., 2016. Premature mortality in autism spectrum disorder. *British Journal of Psychiatry*, 2016; 208: 232 – 238.

Hodkinson, A., 2010. Inclusive and special education in the English educational system: historical perspectives, recent developments and future challenges. *British Journal of Special Education*, 3 (2), 61 - 67.

REFERENCES.

Reference List Page 5.

Humphrey, N. and Lewis, S., 2008. 'Make me normal' The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. *Autism*, 12(1) 23 – 46.

Killoran, K., et al., 2014. Exploring preservice teachers' attitudes towards inclusion. *International Journal of Inclusive Education*. 18 (4), 427-442.

Lawson, W., 2011. *The Passionate Mind*. London: Jessica Kingsley Publishers.

Leatherland, J., 2014. The Potential Impact of the SEN Green Paper "Support and Aspiration: A new approach to special educational needs and disability" on the educational inclusion of autistic children in mainstream schools. *Autism Policy and Practice*, 1, 139 - 166.

Lehane, T., 2017. "SEN's completely different now": critical discourse analysis of three "Codes of Practice for Special Educational Needs" (1994; 2001; 2015). *Educational Review*, 69 (1), 51 – 67.

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

Lindsay, S., et al., 2013. Educators' Challenges of Including Children with Autism Spectrum Disorder in Mainstream Classrooms. *International Journal of Disability, Development and Education*, 60 (4), 347-362.

Loomes, G., 2017. It's only words: a critical 'insider' perspective on the power of diagnosis in the construction of autistic social identity. *Good Autism Practice*, 18 (1), 20 – 24.

REFERENCES.

Reference List Page 6.

McGuire, A., 2016. War on Autism. *United States of America*: University of Michigan Press.

Milton, D., 2013.'Reversing the vicious circle of psycho-emotional disablism in the education of autistic people'. In: *Championing research, educating professionals: how compatible are elitism, inclusion and social justice?* University of Birmingham, pp 127-134.

Milton, D., 2017. *A Mismatch of Salience: Explorations of the nature of autism from theory to practice*. Hove: Pavilion Publishing and Media Limited.

Moses, T., 2018. Suicide Attempts Among Adolescents with Self-Reported Disabilities. Child Psychiatry & Human Development, 49 (3), 420 – 433.

Moxon, L., 2016. *Problematic sexual behaviour: teaching autistic children about public and private behaviours*. (Conference talk to Understanding and supporting challenging behaviour conference, National Autistic Society). 11 October 2016.

Mucalhy, S., 2016. *What skills can be useful when dealing with conflict*? (Conference talk to Autism and Social Skills, National Autistic Society). 25 November 2016.

National Autistic Society., 2016. *NAS TMI Employment Report* (Online). Great Britain: National

Autistic Society. Available at: http://www.autism.org.uk/get-involved/mediacentre/news/2016-10-27-employment-gap.aspx (Accessed 15 January 2017).

REFERENCES.

Reference List Page 7.

Newson, E., et al., C, 2003. Pathological demand avoidance syndrome: a necessary distinction within the pervasive developmental disorders. *Archives of Disease in Childhood*, 88 (7), 595 – 600.

Nicole, L., et al., 2015. College Students' Perceptions of Peers with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 45 (1), 90 – 99.

Oliver, M., 2013. The social model of disability: thirty years on. *Disability & Society*, 28 (7), 1024 - 1026.

O'Nions, L., et al., 2017. Dimensions of difficulty in children reported to have an autism spectrum diagnosis and features of extreme/'pathological' demand avoidance. *Child and Adolescent Mental Health*. DOI: https://doi.org/10.1111/camh.12242

Pellicano, L., et al 2018. The current illusion of educational inclusion. *Autism*. DOI: 10.1177/1362361318766166

Reeve, D., 2014. *Psycho-emotional disablism and internalised oppression*, in J. Swain, S. French, C. Barnes and C. Thomas (eds) Disabling Barriers – Enabling Environments, 3rd Edition, London: Sage, pp. 92 - 98.

Reilly, C, et al., 2014. Pathological Demand Avoidance in a population-based cohort of children with epilepsy: Four case studies. *Research in Developmental Disabilities*, 35 (2014), 3236–3244.

REFERENCES.

Reference List Page 8.

Reindal, S., 2016. Discussing inclusive education: an inquiry into different interpretations and a search for ethical aspects of inclusion using the capabilities approach. *European Journal of Special Needs Education*, 31 (1), 1 - 12.

Rodriguez, C. and Garro-Gill, N., 2015. Inclusion And Integration On Special Education. *Social and Behavioural Sciences*, 191, 1323 - 1327.

Runswick-Cole, K., 2011, Time to end the bias towards inclusive education? *British Journal of Special Education*, 38 (3), 112 - 119.

Stewart, C., 2012. 'Where can we be what we are?': the experiences of girls with Asperger syndrome and their mothers. *Good Autism Practice*, 13 (1), 40 – 48.

The Westminster Commission on Autism., 2016. *A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People* (online). London: The Westminster Commission on Autism. Available at: https://www.basw.co.uk/resource/?id=5480 (Accessed 16 May 2018).

Thomas, C., 1999. *Female Forms: experiencing and understanding disability*. 1st Edition. Buckingham : Open University Press.

Trundle, G., 2017. Differentiating between pathological demand avoidance and antisocial personality disorder: a case study. *Journal of Intellectual Disabilities and Offending Behaviour*, 8 (1), 13 – 27.

REFERENCES.

Reference List Page 9.

Wilkinson, L., 2017. *A best practice guide to assessment and intervention for autism spectrum disorders in schools*. 2nd ed. London: Jessica Kingsley Publishers.

Waltz, M., 2008, Autism = Death: The social and medical impact of a catastrophic medical model of autistic spectrum disorders. *Journal of Popular Narrative Media*, 1(1), 13 - 24.

Waltz, M., 2014. Worlds of Autism: Across the Spectrum of Neurological Difference. *Disability & Society*, 29 (8), 1337 – 1338.

Woods, R., 2017a. Pathological demand avoidance: my thoughts on looping effects and commodification of autism. *Disability & Society*, 34 (5), 753 - 758.

Woods, R., 2017b. Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt. *Disability & Society*, 32 (7), 1090 – 1095.

Yergeau, M., 2010. Circle Wars: Reshaping the Typical Autism Essay. *Disability Studies Quarterly* (online), 30 (1). Available at: http://dsq-sds.org/article/view/1063/1222 (Accessed 18 February 2018).