

Pathological Demand Avoidance: A Case Study into Looping Effects and Commodification of Autism.

Abstract.

Hacking (1995) suggests autism is a human kind, and has used autism to discuss their evolution over time. Looping effects caused the autism human kind to evolve since 1995, with people identifying with the autism human kind, and the commodification of the autism human kind by the Autism Industry. Pathological Demand Avoidance (PDA) was created from the looping effects controlled by the Autism Industry. This has undermined autism self-advocacy by supporting the medical paradigm of the autism human kind. By refusing to engage with PDA, people of the autism human kind limit the commodification of autism; creating greater emancipation.

Keywords: autism, pathological demand avoidance, looping effects, human kinds, commodification, self-advocacy.

What are human kinds.

Kinds are systems of classification. Human kinds include behaviour, acts, or temperament, which can be used to classify sorts of people who are studied within social sciences. Human kinds are kinds that we would like to categorise and generate general and accurate knowledge about. These laws can be used to predict how an individual will react, even if only following probabilistic laws. Human kinds are different from natural kinds, as human kinds superficially apply to specific people in social situations; human kinds have values attached, natural kinds do not. There is a tension between human kinds and natural kinds, there being attempts to biologise human kinds. For instance it might be argued that people who are alcoholics carry a (biological) gene for alcoholism (Hacking 1995).

Autism and Pathological Demand Avoidance (PDA) as a human kind.

Autism is a human kind (Hacking 1995), accepted widely in the UK. Autism is included in Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), The ICD-10 Classification of Mental and Behavioural Disorders (ICD-10) and by the UK government. Autism has been used to classify 1.1% of the UK population (Brugha et al. 2012). In the process autism human kind is used to explain individuals' actions and behaviours,

particularly during the diagnosis process (APA 2013; WHO 1992). The Autism Act (2009) enshrines autism in UK law. Consultants can be hired to advise organisations when dealing with individuals who are classified under the autism human kind.

Recently, a newly created term ‘pathological demand avoidance’ (PDA) has been given the status of human kind by the Autism Industry, but its status is contested due to various reasons. Significantly the behaviours, acts or temperament described by PDA are also better described by other human kinds, notably autism and Opposition Defiant Disorder. Consider an individual classified by autism human kind, who after numerous years develops moderate social skills and is self-advocating while in the presence of an organisation. Due to the organisation not accepting the individual’s self-advocacy, the individual is labelled as having demand behaviours (Milton 2013). At least 70% of people who are categorised by autism human kind are also given the label of another human kind (Lai, Lombardo and Baron-Cohen 2014). Indeed, the actions, behaviours and temper proposed by PDA are often better explained by other human kind, which explains why PDA is not included in the 2 main diagnostic manuals.

PDA status as human kind is contested. PDA is not recognised by DSM-5, IDC-10 or legally by the UK Government (APA 2013; WHO 1992; DoH 2015). However the National Autistic Society recognises PDA as a human kind, and has been holding an annual PDA conference in recent years. PDA is recognised by the National Autism Trust (AET). However, NAS earns an income from AET and NAS line manages AET’s director. The Autism Industry is using Education Care Health Plans (ECHPs) and the SENDIST (special needs) tribunals which legally arbitrate on ECHPs to try and legitimise PDA.

What are looping effects?

Looping effects are how human kinds evolve over time (Hacking 1995). Hassall (2016) suggests that looping effects work by people of a diagnosis label amending their behaviours to reinforce their diagnosis label. This can work for instance on a socio-cultural level where people of the diagnosis label shape the category to become more socially desirable. Human kinds have values attached to them, despite attempts to biologise or medicalise these labels. Human kinds are shaped by people’s actions, which

in turn changes human kinds, offering new behaviours described by specific human kinds. Human kinds bestow an identity to people:

They enable us to redescribe our past to the extent that people can come to experience new pasts (Hacking 1995 p.24).

For instance some people identify as incest survivors, which amends their lives and family relationships. The incest survivors lives move beyond recovering from forgotten trauma; new descriptions are available, connected similarly to laws to other new descriptions, explanations and expectations. These are looping effects, which are how human kinds evolve over time (Hacking 1995).

PDA as a manifestation of looping effects and commodification.

Autism has been affected by looping effects since it was recognised by Leo Kanner in 1943. Kanner stated that the children he observed were “self-absorbed”; not interested in their peers. Within 20 years the connotations of the autism human kind had however reversed away from children of the autism human kind onto their “emotional refrigerators” parents (Hacking 1995 p.34-35).

Autism has experienced 22 years of looping effects since Hacking’s work was released. The prevalence rate for autism human kind has risen steadily (Brugha et al 2012). More people have adopted the autism human kind. The Autism Industry primarily through the medium of academic research has grown substantially to transform the autism human kind into the leading impairment, trading autism human kind as a commodity (Mallett and Runswick-Cole 2012). More people have been assigned to the autism human kind by society to explain their behaviours, acts and temperament. The nature of autism human kind has been contested however by different stakeholders. For example, the medical profession has switched from categorising autism to assigning different levels of impairment (APA 2013; WHO 1992). By contrast, people who are categorised by the autism human kind sometimes claim autism is a different way of thinking compared to other human kinds (Lorcan et al 2016).

Hacking (1995) explains that when different stakeholders ignore the other stakeholders’ view about a human kind and that we are driven to subcategorise human kinds. Members of the autism human kind gain social skills and, becoming better self-advocates (Milton 2013). Due to the double empathy problem practitioners, professionals and experts can view this self-advocacy to be demand behaviours and resisting Predominant Neurotype

societal expectations (Milton 2012). This mismatch between autistic self-advocates and professionals, practitioners and experts, as PDA gives carte blanche to ignore autistic self-advocates, disregard the Nordic relational models of disability (Traustadóttir 2004). The Autism Industry seeks to divide the autism human kind to remove the voice of self-advocating people of the autism human kind, using PDA to explain and remove the threat posed by autism self-advocacy and autism self-regulation (Mallett and Runswick-Cole 2016). In the process the Autism Industry can further differentiate the autism human kind to create a new product to sell, such as the NAS annual PDA conferences, further perpetuating the commodification of autism human kind (Mallett and Runswick-Cole 2012). PDA creates and reinforces cultural barriers for people of the autism human kind (Barnes 2008), resisting efforts to move away from the medical paradigm towards social model paradigms. In this way PDA crafts disabling social barriers, removing the opportunity for autism self-advocacy and autism self-regulation, turning an impairment human kind into a disability (Goodley 2011).

Effects of PDA on evolution of Autism human kind.

With the need for kinds to be categorised and researched, PDA is diverting resources away from the limited UK research into Autism. At the same time PDA is not helping to fulfil wishes of people on the autism spectrum (Pellicano et al 2014). PDA is a spurious diagnosis for females (Hughes 2015) and is actively creating barriers to joining the autism human kind. New people will self-classify on the autism human kind, identifying with PDA. These individuals' memories will change to align with the descriptions of PDA. They will now adapt their behaviours, acts and temperament to reflect those expected of PDA. This forms new meanings of the autism human kind (Hacking 1995; Hassall 2016).

PDA as a category attributes actions, behaviour and temperament onto the individual and away from the organisations and how organisations treat such individuals. It switches moral emphasis away from organisations listening to people on the autism spectrum and places the issue back onto people on the autism spectrum. These all contribute to control the evolution of the autism human kind along the predominant medical paradigm, fragmenting the autism human kind into novel human kinds (Hacking 1995). The Autism Industry would have successfully divided the Autism human kind to form a new PDA human kind.

By reinforcing the deficit model of autism PDA allows Predominant Neurotype society to ignore the voice of people of the autism human kind (Mallett and Runswick-Cole 2012),

disregarding the growing view that autism is difference not a deficit. This looping effect encourages the commodification of autism, while entrenching vested interests of the Autism Industry. NAS for instance receives a significant income from PDA related activities. The fees for NAS's annual PDA conference ranges from £90 to £474. The online licence for Diagnostic Interview for Social and Communication Disorders (DISCO) diagnostic interview which are used to diagnose PDA, costs £420 for the first year and £90 for each subsequent year. A DISCO Refresher Course run by NAS costs £222 per person. NAS also argues social communication disorders are likely to be on (part of) the autism spectrum. The Autism Industry is using PDA to maintain the dominance of autism human kind over other impairment labels.

Autism human kind like other commodities is bound to market patterns of peaks and troughs. People who seek a PDA diagnosis are buying into a promise (Mallett and Runswick-Cole 2016). Promises of access to services and understanding of their own behaviours, act and temperament. As with other autism commodities, however the promise is left unfilled, because it is not legally recognised or widely accepted by the medical profession (DoH 2015; APA 2013; WHO 1992). *A PDA diagnosis does not ensure access to services or understanding from individuals or any organisation.*

What next for Autism human kind emancipation efforts?

The Autism Industry has remained in active control of the direction of evolution of the autism human kind, by promoting PDA. If things are to improve for people of autism human kind, we need to seize control of our own definition away from the Autism Industry. By not engaging with PDA we can resist the commodification of the autism human kind, enabling individuals to escape concrete impairment identities (Mallett and Runswick-Cole 2016). SENDIST Tribunals panels should accept that the UK Government does not legally recognise PDA. SENDIST tribunals ignoring PDA diagnoses could enable greater autism self-advocacy and self-regulation. By refusing to be categorised with PDA or being placed onto different levels to our peers on the autism spectrum, we can guide looping effects in a manner that would see the social model of disability fully practiced in our lives, leading to emancipation of people of the autism human kind.

References.

American Psychological Association (APA), 2013. *Diagnostic and Statistical Manual of Mental Disorders* (Ebook type), 5th Edition (DSM-5). Washington: DC, APA. Available

at: <http://ebookcentral.proquest.com/lib/ntuuk/reader.action?docID=1811753&ppg=75>
(Accessed on 18 January 2017).

Barnes, C., 2008. *Disability and the Academy: A British perspective* (Online). Leeds: University of Leeds. Available at: <http://disability-studies.leeds.ac.uk/files/library/Barnes-paris-presentation.pdf> (Accessed on 15 February 2017).

Brugha, T., et al., 2012. Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007. *Adult Psychiatric Morbidity Survey* (Online). Available at: <http://content.digital.nhs.uk/catalogue/PUB05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf> (Accessed 14 January 2017).

Department of Health (DoH), 2015. *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*. (Online). London: The Department of Health. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf (Accessed 16 January 2017).

Goodley, D., 2011. *Disability Studies: An Interdisciplinary Introduction*. London: Sage Publications Limited.

Great Britain. Parliament, House of Commons. 2009. *The Autism Act 2009* (Online).

Kew, Kent. The National Archives. Available at:

<http://www.legislation.gov.uk/ukpga/2009/15/contents> (Accessed 16 January 2017).

Hacking, I., 1995. The looping effects of human kinds. In: Sperber, D., Premack, D. and Premack, A. *Causal Cognition: A Multidisciplinary Debate* (Online). Oxford: Oxford University Press. Available at:

<http://www.oxfordscholarship.com/view/10.1093/acprof:oso/9780198524021.001.0001/acprof-9780198524021-chapter-12> (Accessed 04 February 2017).

Hassall, R., 2016. Does Everybody with an Autism Diagnosis Have the Same Underlying Condition? In: Runswick-Cole, K., Mallett, R. and Timimi, S., 2016. *Re-Thinking Autism*. London: Jessica Kingsley Publishers. 2016, pp. 49-66.

Hughes, E., (2015). Does the different presentation of Asperger syndrome in girls affect their problem areas and chances of diagnosis and support? (Online). *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1 (4). Available at:

- arnold.net/Autonomy/index.php/autonomy/article/view/AR17 (Accessed 16 September 2015).
- Lai, M., Lombardo, M., and Baron-Cohen, S., 2014. Autism. *The Lancet*, 383, 896–910.
- Lorcan, K., et al., 2016. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20 (4), 442–462.
- Mallett, R. and Runswick-Cole, R., 2012. Commodifying Autism: The Cultural Contexts of “Disability” in the Academy. In: Goodley, D., Hughes, B., and Davis, L.J. *Disability and Social Theory: new developments and directions*. Basingstoke: Palgrave MacMillan, 2012, pp. 33-51.
- Mallett, R. and Runswick-Cole, R., 2016. The Commodification of Autism: What’s at Stake? In: Runswick-Cole, K., Mallett, R. and Timimi, S., 2016. *Re-Thinking Autism*. London: Jessica Kingsley Publishers. 2016, pp. 110-131.
- Milton, D., 2012. On the ontological status of autism: the ‘double empathy problem’. *Disability and Society*, Vol. 27, No. 6, 883–887.
- Milton, D., 2013. ‘Natures answer to over-conformity’: *deconstructing Pathological Demand Avoidance*. *Autism Experts* (Online Blog). 27 March 2013. Available at: <http://autismexperts.blogspot.co.uk/2013/03/natures-answer-to-over-conformity.html> (Accessed 04 February 2017).
- Pellicano, L., Dinsmore, A. and Charman, T., 2014. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18 (7), 756–770.
- Traustadóttir, R., 2004. *Disability Studies: A Nordic Perspective* (Online). Lancaster: Lancaster University. Available at: http://www.lancaster.ac.uk/fass/events/disabilityconference_archive/2004/abstracts/traustadottir.htm (Accessed on 15 February 2017).
- World Health Organisation (WHO), 1992. *The ICD-10 Classification of Mental and Behavioural Disorders*. Geneva: WHO. Available at: <http://ebookcentral.proquest.com/lib/ntuuk/reader.action?docID=344020> (Accessed on 18 January 2017).