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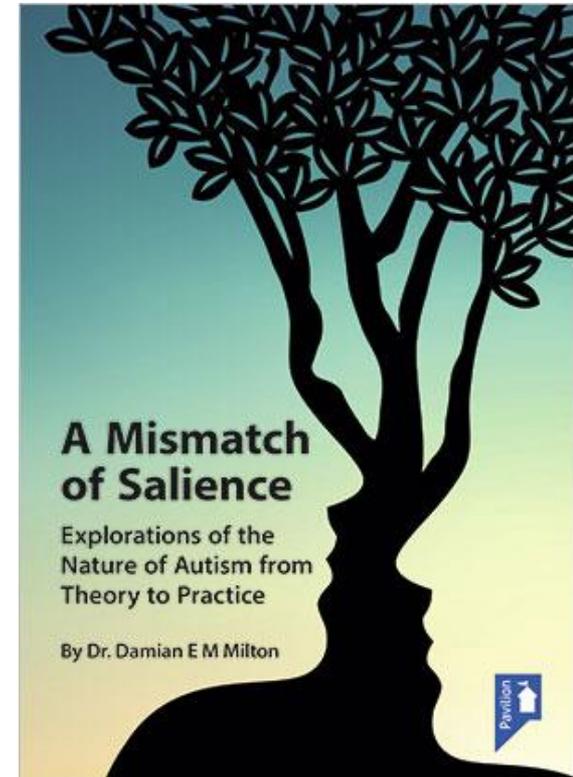
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Autistic community and culture: challenging (normative) behaviour

Dr. Damian E M Milton



A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).
- Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.
- Visiting Lecturer, London South Bank University (LSBU).
- Director at the National Autistic Taskforce (NAT).
- Chair of the Participatory Autism Research Collective (PARC).



Introduction

- From Plato through Hobbes to recent politics – hegemonic normalcy.
- From the outset autism has been defined as other to this normative ideal.
- Alternative theories of autistic experience.
- Social relationality and social othering.
- Autistic identity, community and culture.

The social othering of autistic people

- *The autist is only himself...and is not an active member of a greater organism which he is influenced by and which he influences constantly. (Asperger, 1991: 38).*

Ontological status of autism

- The triad of dominant theories.
- Positioning of autism as a neurological disorder, a pathological deviance from expected functional stages of development.
- This approach when applied to the education or care of those diagnosed often becomes a ‘treatment program’ of modifying the autistic person as best one can to fit in with the mainstream culture of society.

The neurodiversity movement

- *The **Neurodiversity Movement** is a social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent...The Neurodiversity Movement is not a single group or organization, is not run by any single group or organization, and has no leader. Like most civil rights movements, the Neurodiversity Movement is made up of a great many individuals, some of them organized into groups of one sort or another. (Walker, 2014, original emphasis).*

The neurodiversity 'paradigm'

- Variations in neurological development as part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one's deviation from statistical or idealised norms of embodiment or observed behaviour.
- This is not to say that those who identify as neurodivergent do not find life challenging. Neurodivergent people are often significantly disadvantaged in many aspects of life.
- Draws heavily upon the social model of disability.

The social model of disability

- *Because most of us are not ill at all, but have injuries or genetic conditions of a permanent nature, the goal of 'getting better' is impossible to achieve, but changing the way we are treated as disabled people is possible. Therefore the social model is full of hope for us. (Mason, 2000: 57).*

Participation and voice

- *...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced. (Williams, 1996: 14).*

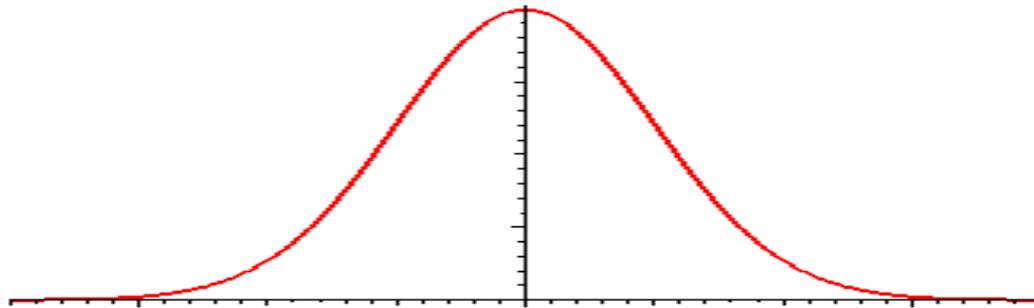
Insider knowledge

- Insider and outsider perspectives.
- Positionality.
- Situated knowledge.
- Neurodiversity.
- Disposition.



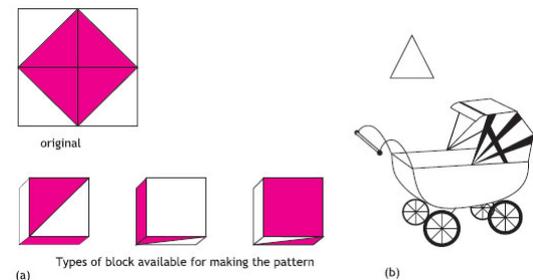
Normalcy and the bell curve

- *Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum. (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').*



An 'interest model' of autism

- Autism and monotropism (Murray, 1992; Murray et al. 2005; Lawson, 2010).
- Attention as a scarce resource.
- Monotropic attention strategies and the 'attention tunnel'.
- Monotropism, repetitive behaviour and interests, and 'flow states'.



- *We suggest that the uneven skills profile in autism depends on which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience. (Murray et al. 2005: 143).*

Monotropism and social context

- Experiences of 'failure' or the condemnation and mocking of others, can be devastating.
- This can be highly influential on which interests are followed through, and which are stopped through feelings of fear and anxiety.

Disruptions to flow and sensory overload

- Disruptions to this flow can lead to a fragmented perception of incoming stimuli, feelings of an unwanted invasion, and reactions of meltdown, shutdown, and panic attacks.



A case in point: table tennis



Mutual incomprehension

- *“95% of people don’t understand me”.*
- *“Friends are overwhelming”.*
- *“Adults never leave me alone”.*
- *“Adults don’t stop bullying me”.*

- Quotes taken from Jones et al. (2012).

The 'double empathy problem'

- A case of mutual incomprehension?
- Breakdown in interaction between autistic and non-autistic people as not solely located in the mind of the autistic person. The theory of the double empathy problem sees it as largely due to the differing perspectives of those attempting to interact with one another (Milton, 2012a; 2014; Milton et al. 2018; Chown, 2014).
- Theory of autistic mind can often leave a great deal to be desired.

Empathy and culture

- *It is argued here that 'empathy' is a convenient illusion, and the phenomenon that people speak of when referring to it has more to do with language and a sense of 'shared' cultural meanings/symbols. (Milton, 2011b).*

The sociality of an 'outsider'

- With autistic people, especially those who acquire verbal articulacy, one often finds the sociality of an 'outsider' (Becker, 1963).
- Also, it is often said that one of the most defining features of autism is a 'spiky' cognitive profile (Milton, 2012b) that can lead to extreme strengths in areas of interest, but also potentially a widening of perspective and sociality, particularly in later years of development.
- Such a sociality is then often stigmatised (Milton, 2011) rather than being seen as a potential asset within communities of practice.



Autistic sociality

- Collins (2010) points out that domesticated animals, whilst immersed in human society are not able to be socialised, in the sense one does not encounter vegetarian, arty, or 'nerdy' dogs, they are simply just dogs.
- Yet one does encounter autistic people who are vegetarian, artistic, and certainly 'nerdy'.
- Autistic people have distinct interests and abilities that involve social practices, and this includes those who are deemed 'non-verbal' who are often musical or artistic, and whose bodily movements have been argued to be a form of language (Baggs, 2007, Milton, 2012c).

Autism and gendered norms

- *The construction of coherence conceals the gender discontinuities that run rampant... (Butler, 1990: 135).*
- *I think for a woman to identify as a woman is a culturally enforced effect. I don't think that it's a given that on the basis of a given anatomy, an identification will follow. I think that 'coherent identification' has to be cultivated, policed, and enforced; and that the violation of that has to be punished, usually through shame (Butler in interview with Liz Kotz: [A photograph of a young child with dark, curly hair, wearing a red jacket with white stripes on the sleeves, standing outdoors. The background shows a cityscape with buildings and trees under a hazy sky.](http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&ved=0ahUKEwigwYjUm5LZAhVnBsAKHSEkBqMQFggyMAE&url=http%3A%2F%2Fartsites.ucsc.edu%2Ffaculty%2Fgustafson%2FFILM%2520165A.W11%2Ffilm%2520165A%255BW11%255D%2520readings%2520%2FJudith%2520Butler%2520handout.doc&usg=AOvVaw3hV6R7FboPMjHPNk4R21ix).)</i>● The 'Neuroqueer'.</div><div data-bbox=)*

Gender policing

- If self-identifications lack ‘central coherence’, or are not ‘cultivated’ (or are ‘hyper-cultivated’), it is suggested by Butler (1990) that sanctions and shaming will follow.
- Goffman (1963) regarded stigma as the disjuncture between the way someone acts and the way others would wish them to. He talked about how one managed social interactions if one carried a visible or invisible ‘spoiled identity’. Not only do autistic people carry stigmatised identities, but may also struggle to manage social interactions (partly because of this stigma and othering though).
- In this sense we all ‘police’ our own gender performance and that of others according to Butler’s theory (although this presumes a ‘self-awareness’ that is discursively constructed).

Normalcy and masking

- *I had virtually no socially-shared nor consciously, intentionally expressed, personhood beyond this performance of a non-autistic 'normality' with which I had neither comprehension, connection, nor identification. This disconnected constructed facade was accepted by the world around me when my true and connected self was not. Each spoonful of its acceptance was a shovel full of dirt on the coffin in which my real self was being buried alive... (Williams, 1996: 243).*

Cultural imperialism

- Those that have power in society can determine how those in a position of powerlessness are interpreted and talked about (Young, 1990).
- Notions such as 'ableism' and 'mansplaining' can be seen as having roots in similar notions of a taken-for-granted unconscious frame of reference which renders the 'other' invisible.



Psychsplaining

- *Those categorised by psych-professionals are often reduced within such relationships to that of the ‘sick role’ (Parsons, 1951), with one’s own interpretations of oneself undermined by the ‘expert knowledge’ being projected upon the autistic person, who by default is positioned in a relatively powerless social position of medical ‘patient’. (Milton, 2016).*

Psycho-emotional disablement

- Disability researchers such as Carol Thomas and Donna Reeve suggested that psycho-emotional dimensions of disability constitute a form of social oppression, operating at both a public and personal level, affecting not only what people can 'do', but what they can 'be'.
- Responses to the experience of structural disability.
- In the social interaction one has with others.
- Internalised oppression.
- These issues can be particularly marked in a marginalised group stigmatised by their differences in 'social interaction' itself (Milton, 2012).

Some quotes to conclude:

- *Grant me the dignity of meeting me on my own terms...Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us. (Sinclair, 1993)*

- *When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed? (Victoria, 'Are You Taking Something for It?', issue 76, 12; cited in Milton and Sims, 2016).*

Challenging normalcy

- *It is the ‘personal tragedy model’ and resultant ‘normalisation agenda’, supported by some of the world’s largest autism charities, and the resultant need induced in parents of autistic people to ‘behaviourally modify’ them, that has done most to disable autistic people living in society today... (Milton and Lyte, 2012).*

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