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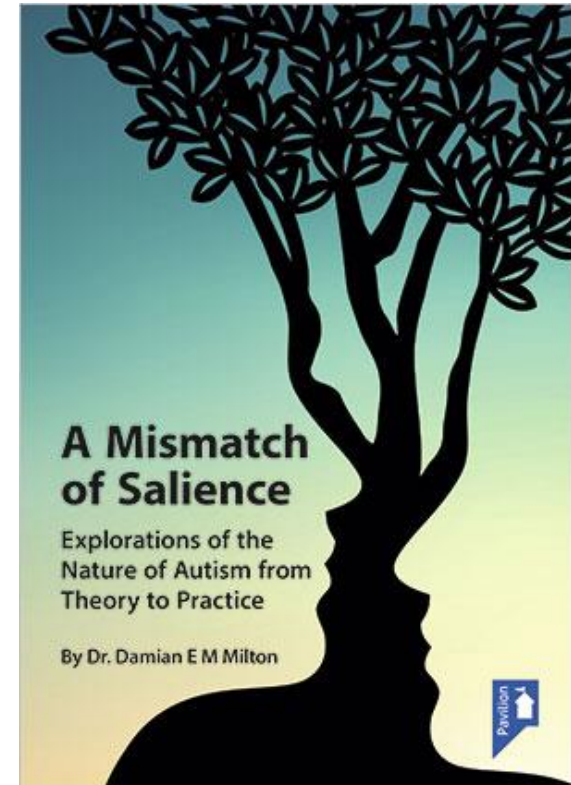
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# Challenging Normalcy

*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.
- Autism Knowledge and Expertise Consultant, National Autistic Society (NAS).
- 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 by outsiders by its appearances (Williams, 1996).
- Alternative theories of autistic experience.
- Social relationality and social othering.
- Implications for practice.

# The social othering of autistic people

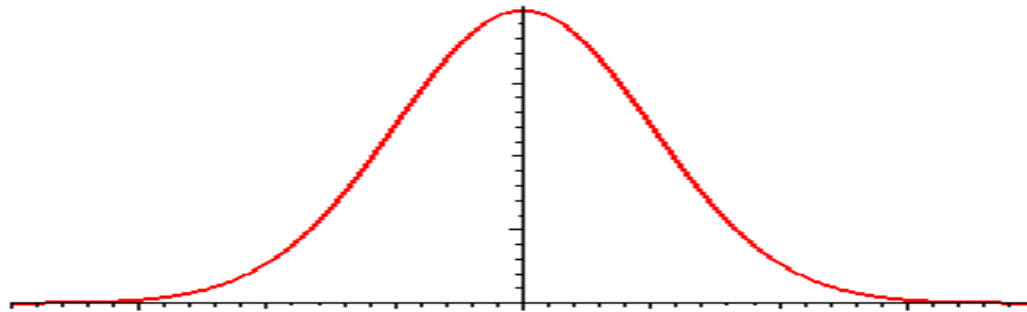
- *The autist is only himself...and is not an active member of a greater organism which he is influenced by and which he influences constantly. (Asperger, 1991: 38).*

# 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.

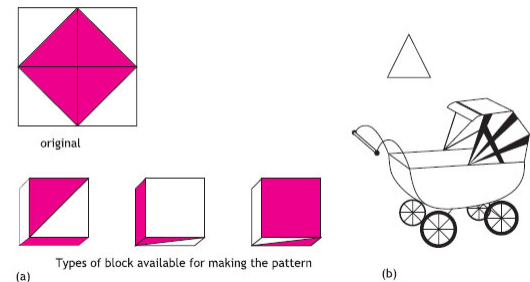
# Normalcy and the bell curve

- *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'.





# The concept of 'flow states'

- 'Going with the flow' and being 'in the zone'.
- A form of optimal experience that can be beneficial to feelings of happiness and wellbeing.
- Described as being so involved in an activity that nothing else seems to matter.
- Flow experiences require complete immersion in an activity, whether playing a musical instrument, completing a complex technical task, or reading a book.

- Flow can also happen within social interactions, for example: when one is talking to a good friend.
- Activities that lead to a flow experience can be called autotelic (from Greek: auto=self, telos=goal), as such activity is often seen as an 'end-in-itself' for the individual experiencing it, with end rewards often being just an excuse to participate in the activity.

- People on the autism spectrum are often said to be ‘tuned out’ from the social world operating around them.
- Sometimes this is a large mischaracterisation, at times it is because the individual in question is fully engaged in a given activity and could be said to have achieved a state of flow.

- *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.

# Dyspathy

- Cameron (2012) uses the term 'dyspathy' to highlight how empathy is often blocked or resisted by people.
- Such research supports the earlier social psychological theories of Tajfel (1981), which found that people felt increasing emotional connection to those deemed within their social 'in-group', whilst stereotyping 'outsiders'.
- *If we were to be continually tuning into other people's emotions, we would be perpetually anxious or exhilarated, and very quickly exhausted. We must therefore have very efficient inhibitory mechanisms that screen out most of the emotional empathy being carried out by our brains, without us even noticing. (Cameron, 2012).*

# 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 (or their 'ethno'). (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 stigmatised (Milton, 2011) rather than being seen as a potential asset within communities of practice.



- *They [autistic people] are creating the language in which to describe the experience of autism, and hence helping to forge the concepts in which to think autism. (Hacking, 2009, p. 1467).*

# 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).

- *...the individual is a temporary and leaky repository of collective knowledge. Kept apart from society for any length of time and the context sensitivity and currency of the individual's abilities will fade. (Collins, 2010: 133).*

# Learning about social life

- Much social skill or behavioural training with autistic people are predicated upon breaking down social information into explicit strings of information which does little to help autistic people adjust to the changing flux of negotiated socially constructed realities.
- Recently however, methods such as 'Intensive Interaction' (Nind and Hewitt, 1994) which focus on relationship building and child-led activities have begun to challenge this dominance within the field.



# Autism and intervention

- How one perceives autism naturally leads to a perception of what is considered 'best' with regard to service provision.
- The 'window of opportunity' discourse has produced an ever-growing range of 'early interventions'.
- It is interesting to note how this emphasis is at a time when the autistic person has no say in the matter.



# Optimal outcomes?



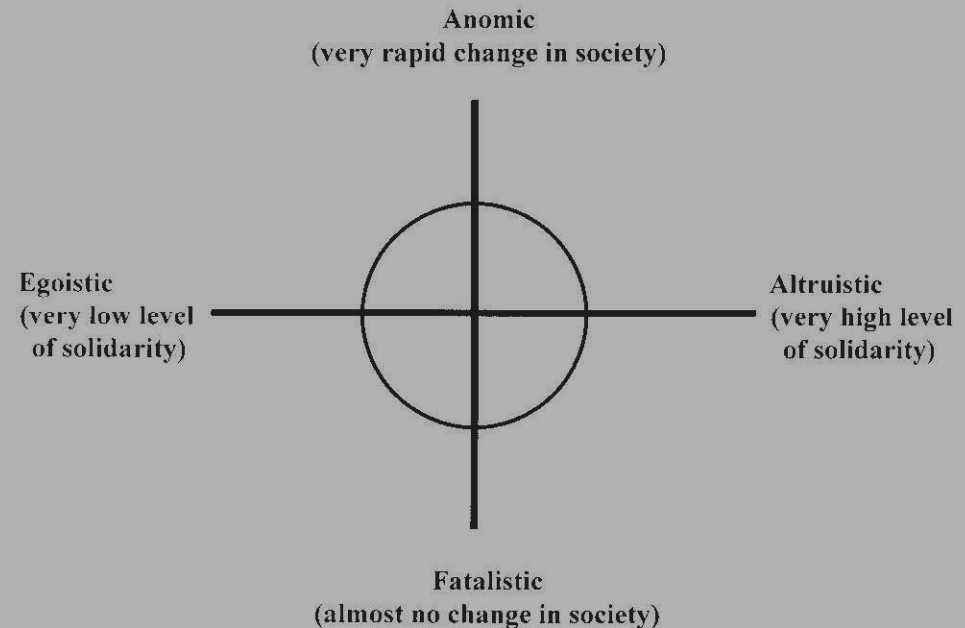
# Normalcy and masking

- *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).*

# Durkheim and suicide

- Durkheim (1897) suggested a personal need for 'equilibrium'. Too little or too much could lead to dysfunction and suicide. Thus people were seen to need a level of social control and sanction – 'for their own good' and for the 'good of society'.

## A Summary of Durkheim's Study of *Suicide: A Study in Sociology*



# Parsons and the 'sick role'

- Parsons (1951): Illness and disability seen as a deviancy from functional norms in need of professional monitoring and surveillance.
- Power seen as vested in the professional 'expert' and not the 'patient'.
- Safilios-Rothschild (1970) – the 'rehabilitation role'
- The 'normalisation agenda' and autism.



# 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).



# 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).*

## 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)*

- *We need to see the world from the autistic perspective and apply approaches based on a mutuality of understanding that are rational and ethical – which respect the right of the individual to be different – yet recognises and deals with distress and offers practical help. We should encourage and motivate the person to develop strengths rather than focus on 'deficits'. This will mean offering opportunity for development while supporting emotional stability. (Mills, 2013).*

- *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, many of whom remain undetected by those who would potentially provide them with support. (Milton and Lyte, 2012).*

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