

Neurodiversity and self-advocacy

Dr. Damian E M Milton



A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).
- A background in Social Science (initially Sociology).
- Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.
- Autism Knowledge and Expertise Consultant, National Autistic Society.
- Visiting Lecturer, London South Bank University.
- Director, National Autistic Taskforce.
- Chair of the Participatory Autism Research Collective (PARC).

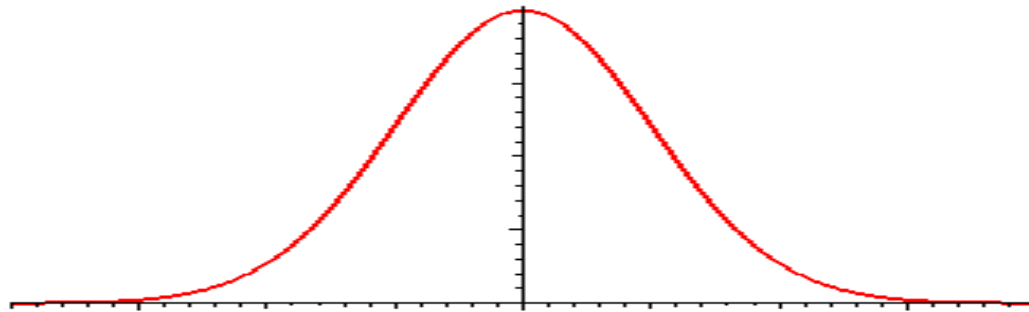


Introduction

- Explore the term neurodiversity and related concepts
- The influence of the social model of disability on the development of the neurodiversity movement
- Examine neurodiversity within a social / sociological context
- Reflect upon contested stakeholder views in the field of autism

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').*



Origins of the term

- The work of Judy Singer (1998)
- Earlier influences from the Autistic self-advocacy movement and in particular Jim Sinclair:
 - *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, 1992)
- 'The Institute for the Study of the Neurologically Typical'
- Continuing expansion of the 'neurodiversity movement' and challenge to orthodoxy

Neurodiversity

- At its base though: “**Neurodiversity** is the diversity of human brains and minds – the infinite variation in neurocognitive functioning within our species.” (Walker, 2014, original emphasis).

What neurodiversity is not...

- *“Neurodiversity is a biological fact. It’s **not** a perspective, an approach, a belief, a political position, or a paradigm. That’s the **neurodiversity paradigm**...not neurodiversity itself.”*
- *“Neurodiversity is **not** a political or social activist movement. That’s the **Neurodiversity Movement**...not neurodiversity itself.”*
- *“Neurodiversity is not a trait that any individual possesses. Diversity is a trait possessed by a group, not an individual. When an individual diverges from the dominant societal standards of “normal” neurocognitive functioning, they don’t “have neurodiversity,” they’re **neurodivergent**.”*
- Quotes from Walker (2014), *original emphasis*.

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.

Models of disability

- Models of disability:
- Medical: disability as something abnormal and pathological to be treated. Issue seen as within the individual.
- Social: split between social barriers of disability and physical/mental 'impairment'.
- Bio-psycho-social: taking into account biological, psychological and social aspects of disability.
- Some theorists also question the assumptions of 'impairment' and 'normalcy' (see Milton, 2012a).

Have you heard about that Social Model of Shape Difference all the squares are talking about?

You mean the idea that all differences between shapes are imaginary?

Exactly. See that guy over there? According to this theory, he can't roll as well as we do because of our *attitudes* toward him!

Have you ever heard anything more ridiculous?

I guess when we are not looking, they bounce around like basketballs. Ha Ha Ha Ha!

Oops, I thought I saw four right angles on that one. I must be hallucinating! Ha Ha Ha Ha Ha!

Actually, that's not at all what the social model is about. It's about how minority shapes are excluded from decision making roles, and therefore our needs are considered extraordinary while yours are seen as normal.

It's about power. The ways squares are silenced or ignored. How some shapes are subjected to treatments that would be considered abusive if they were done to circles.

So the social model is all about how squares are superior to other shapes. Can you believe he had the nerve to say that?

That's what I call rectangular logic. Ha Ha Ha Ha.

He probably bounced too high and hit his head on something! Ha Ha Ha Ha Ha!

Look at me! I've got corners! I'm invincible! Ha Ha Ha Ha Ha!

Please get off of me!

The 'pathology paradigm' and the damage it can do

- Working against the positioning of 'neuro-minorities' as neurological disorder, a pathological deviance from expected functional stages of development.
- The 'pathology paradigm' when applied to the education or care of those diagnosed often becomes a 'treatment program' of modifying behaviour as best one can to fit in with the mainstream culture of society.
- 'Masking' and the damage it can do.

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).*

Insider voices and theories

- Temple Grandin, Jim Sinclair, Donna Williams, Amanda Baggs, Claire Sainsbury.
- The emergence of autistic culture (Dekker, 1999).
- When sociological and cognitive theorising match up: Hypo-priors and ‘filling in the gaps’ (Milton, 2013).
- ‘Monotropism’ and the ‘interest model of autism’ (Murray et al. 2005; Lawson, 2010).

The machine-like metaphor

- *“The autistic is only himself...and is not an active member of a greater organism which he is influenced by and which he influences constantly.” (Hans Asperger).*



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'

- Building bridges between people of autistic and non-autistic dispositions is not always an easy process.
- Empathy problems as a 'two-way street' (Sinclair, 1992).
- The 'double empathy problem' (Milton, 2012b, Chown, 2014).
- Theory of autistic mind can often leave a great deal to be desired.
- 'Fork 'andles'!



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).*

Insider knowledge

- *“...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).*

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 benefits of utilising a 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).*

An 'interest model'

- 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'.
- Wider relevance? Links with neurocognitive theory.

- *“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.

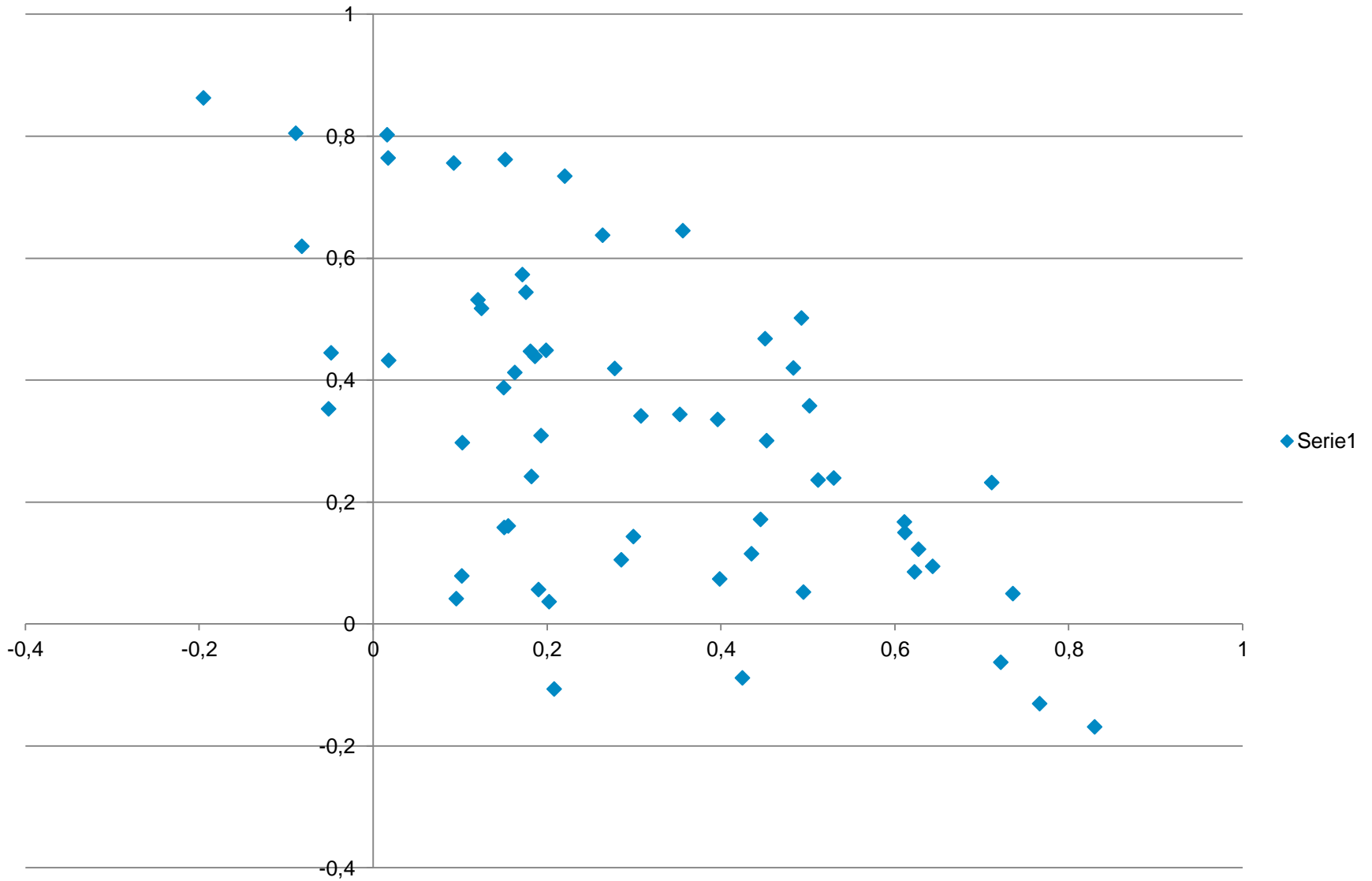
AET consultation data

Stakeholder group	Understanding the individual pupil	Building relationships	Curriculum and learning	Enabling environments
Practitioners	<u>Staff training</u>	Involving and supporting parents	Differentiated curriculum (social skills)	Quiet and safe spaces
Parents	Staff training and understanding the individual	<u>Communication between staff and parents</u>	Individually tailored curriculum	Structure and routine
Children and young people	Understanding from staff	<u>Bullying (including 'friends')</u>	Subject content and delivery	Crowds and personal space
Common ground	Staff training needed	Better communication needed and understanding	Differentiation / tailored curriculum	Structured break times and safety
Tensions	Potentially what staff are trained in	Communication not being good enough and a lack of understanding	Social skills training	Differences in view regarding how environments should be managed

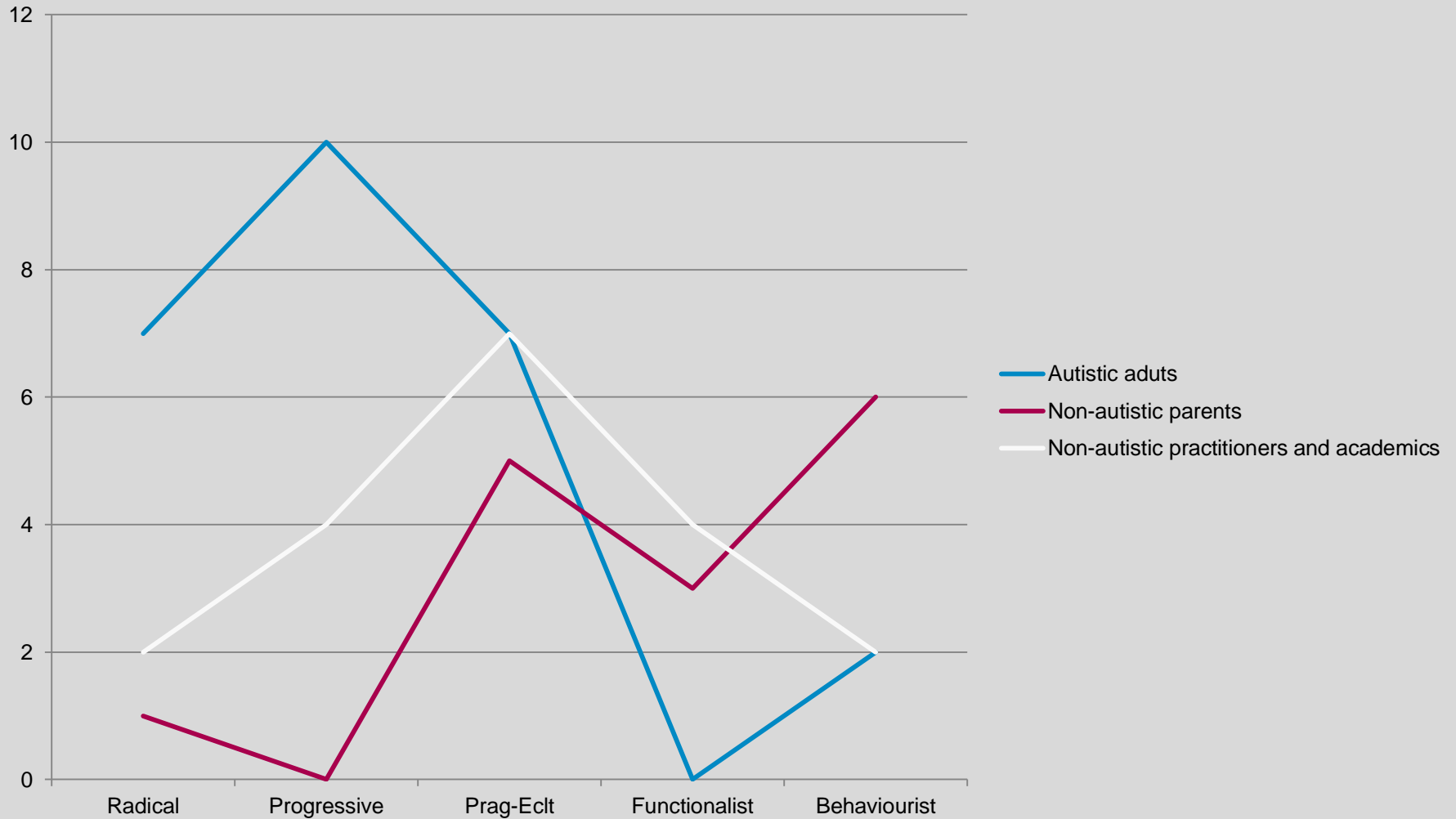
Stakeholder perceptions

- Findings from PhD research.
- Significant tensions over a number of issues:
- Celebrating the diversity of learners and not trying to 'normalise' them.
- Radical change in society.
- Pupil-led vs. teacher-led activities.
- Social skills training and the appropriateness of behaviour.
- The 'three-way dispositional problem'!

- *“Because otherwise he is trapped in a world where he cannot communicate his hopes and fears, particularly when I am dead and cannot look out for him.”*
- *“Difference should be accommodated, accepted and celebrated.”*



Spectrum of educational views



Common ground?

- Not a great deal!
- Against extreme normalisation?
- Enabling environments?
- Building relationships, communication and mutual understanding.

Participation and the production of knowledge

- *“In order for debates on the education of autistic people to move forward, it is argued here that researchers must move beyond the objectifying gaze of the scientific tradition; to be truly participatory with those they seek to produce knowledge about.” (Milton and Moon, 2012).*



The autistic voice in academia

- People on the autism spectrum rarely in the role of researcher, traditionally seen as passive subjects.
- The 'glass sub-heading' (Milton and Bracher, 2013).
- *“Of over \$314 million in research funding, only 3% went to research into services, supports and education and less than 1% went to research into the needs of adults.”* (Ne’eman, 2011).

Collaboration

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Avoiding tokenism...
- *“...place the voices and perspectives of self-advocates at the centre of the autism conversation, as we can speak with unique legitimacy and voice about our own lives.”* (Ne’eman, 2011).
- The Participatory Autism Research Collective (PARC):
www.PARCautism.co.uk



Acceptance and understanding

- *“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).

References

- Asperger Square 8 blogsite (2014):
http://4.bp.blogspot.com/_1vPB2M2IMil/SucK5Gau3TI/AAAAAAAAACeQ/X8ANAC-forQ/s1600-h/social.model.png
- Cameron, L. (2012) *Dyspathy: the dynamic complement of empathy*. The Open University.
- Chown, N. (2014) More on the ontological status of autism and double empathy, *Disability and Society*, Vol. 29(10): 1672-1676.
- Collins, H. and Evans, R. (2007) *Rethinking Expertise*. London: University of Chicago Press.
- Dekker, M. (1999): "On our own terms: Emerging autistic culture". *Autism99* (online conference).
- Lawson, W. (2010) *The Passionate Mind: how people with autism learn*. London: Jessica Kingsley.
- Marx, K. (1852/1970) The Eighteenth Brumaire of Louis Bonaparte. In R. Tucker (ed), *The Marx-Engels Reader*. New York: Norton, pp. 436-525.
- Mason, M. (2000) *Incurably Human*. Nottingham: Inclusive Solutions.
- McWade, B., Milton, D. and Beresford, P. (2015) Mad Studies and Neurodiversity: a dialogue. *Disability and Society*, vol. 30(2): 305-309.
- Milton, D. (1999) *The Rise of Psychopharmacology [Masters Essay – unpublished]*. University of London.
- Milton, D. (2011) 'Who am I meant to be': in search of a psychological model of autism from the viewpoint of an 'insider'. *Critical Autism Seminar 18/01/11*. Sheffield Hallam University.
- Milton, D. (2012a) Embodied sociality and the conditioned relativism of dispositional diversity. *Theorising Normalcy 2012*. University of Chester, 26/06/12.
- Milton, D. (2012b) On the Ontological Status of Autism: the 'Double Empathy Problem'. *Disability and Society*. Vol. 27(6): 883-887.
- Milton, D. (2013) "Filling in the gaps", a micro-sociological analysis of autism. *Autonomy: the Journal of Critical Interdisciplinary Autism Studies*. Vol. 1(2). Accessed from: <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/7/html>
- Milton, D. (2014a) Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism: The International Journal of Research and Practice* (special edition 'Autism and Society'), Onlinefirst, 17/03/14.

- Milton, D. (2014b) *What is meant by participation and inclusion, and why it can be difficult to achieve*. NAS Ask autism conference: Participation and inclusion from the inside-out: autism from an autistic perspective, London Jan 2014.
- Milton, D. (2016) Disposable dispositions: reflections upon the work of Iris Marion Young in relation to the social oppression of autistic people. *Disability and Society*, Vol. 31(10): 1403-1407.
- Milton, D. and Moon, L. (2012) 'The normalisation agenda and the psycho-emotional disablement of autistic people', *Autonomy* Vol. 1(1).
- Milton, D. and Bracher, M. (2013) Autistics speak but are they heard? *Medical Sociology Online*. Vol. 7(2): 61-69.
- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability and Society*, 31(4), 520–534. <http://doi.org/10.1080/09687599.2016.1186529>
- Murray, D., Lesser, M. and Lawson, W. (2005) Attention, monotropism and the diagnostic criteria for autism. *Autism*. Vol. 9(2), pp. 136-156.
- Ne'eman, A. (2011) Question and Answer interview, accessed at <http://www.talkaboutautism.org.uk/community/live-qa-events/010611-ari-neeman>
- Runswick-Cole, K., Mallet, R. and Timimi, S. (Eds) (2016) *Re-Thinking Autism: Diagnosis, Identity and Equality*. London: Jessica Kingsley.
- Sinclair, J. (1992) *Don't Mourn For Us* [online] http://www.autreat.com/dont_mourn.html
- Singer, J. (1998; republished 2016): "NeuroDiversity: The Birth of an Idea". Faculty of Humanities and Social Science, Sydney: University of Technology.
- Walker, N. (2014) *Neurodiversity: some basic terms and definitions* [online] <http://neurocosmopolitanism.com/neurodiversity-some-basic-terms-definitions/>
- Wenger, E. (1998) *Communities of Practice: Learning, Meaning and Identity*. Cambridge: Cambridge University Press.
- Williams, D. (1996) *Autism: An Inside-Out Approach*. London: Jessica Kingsley.
- Young, I. (2005, first published 1990), "Five faces of oppression", in Cudd, Ann E; Andreasen, Robin O., *Feminist theory: a philosophical anthology*, Oxford, UK Malden, Massachusetts: Blackwell, pp. 91–104.

THE UK'S EUROPEAN UNIVERSITY



www.kent.ac.uk

University of
Kent