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In: Autistica - Autism Research Conference, 6 Sept 2018, London, UK.
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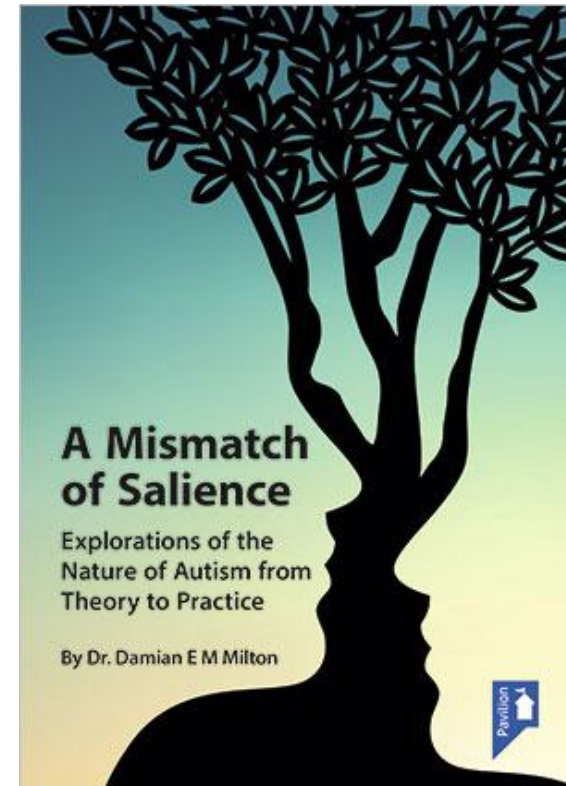
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Researching autism from a sociological perspective

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
- Researcher and Lecturer at London South Bank University.
- Autism Knowledge and Expertise Consultant at the National Autistic Society.
- Chair of PARC and project lead for NAT.



Introduction

- Traditions within the field and the normative / remedial focus.
- Critical and sociological research although growing in the field often remains hidden, or at least poorly invested in.
- This presentation will introduce the audience to exemplars of social research in the field of autism studies in order to show their potential benefit.
- Addresses the priorities listed in the recent James Lind Alliance project from a social model / sociological perspective.
- The presentation will conclude with recommendations for ways to move this much needed work forward.

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).

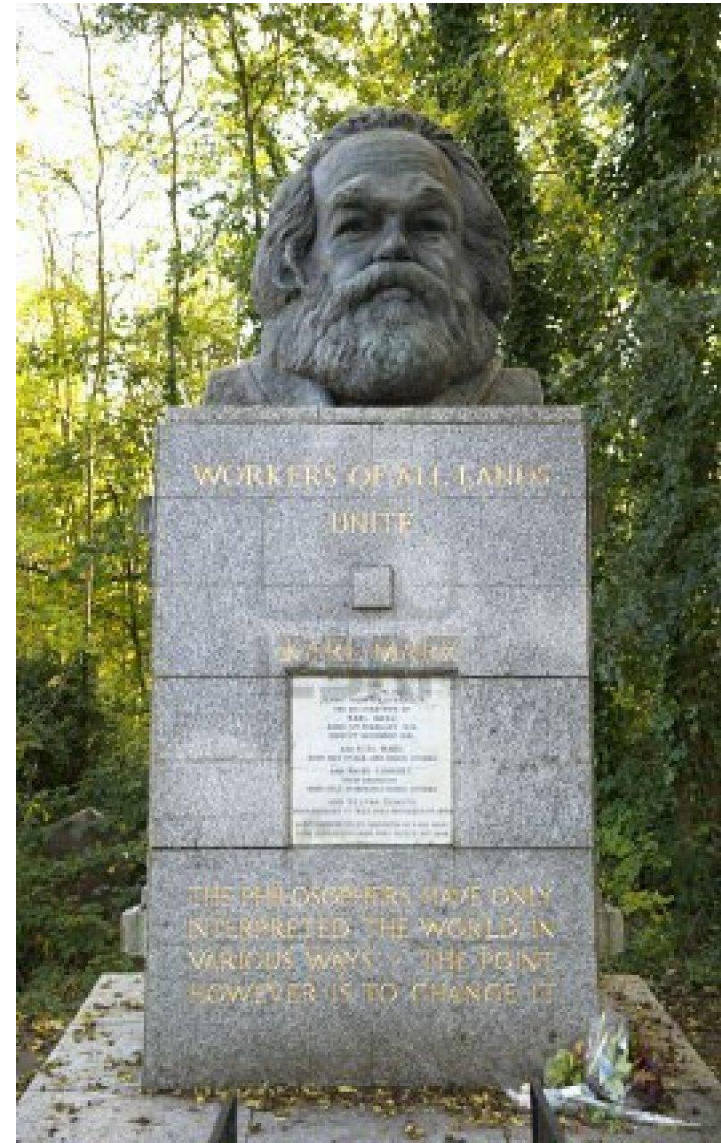


A sociological imagination

- “I may lack a social imagination, but I have a sociological one.” (Milton, 2011).
- C.W. Mills (1916-1962) – personal troubles and public issues.
- The origins of Sociology – a ‘science’ of society?

Conditioned are we...

- 'Men make their own history, but they do not make it just as they please...The tradition of all the dead generations weighs like a nightmare on the brain of the living' (Marx, 1852/1970:15).
- Materially and discursively conditioned within an 'his'torical and cultural context.



...but uniquely and relativistically

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



Applying philosophy and constructing social theory

- Ontology and metaphysics – what is it?
- Epistemology and the theory of knowledge – how do we know what we know?
- Methodology – how do we practically test what we think we know, or explore what we do not?
- Differing answers to these questions have led to a number of paradigms, or ‘schools of thought’ being established in various disciplines and topic areas – particularly in the ‘social’ sciences.
- The work of C.P. Snow (1905-1980). Ontologists and empiricists...a tale of two table tennis players...

Tensions and dilemmas in sociology

- Culture and economics
- The macro and the micro
- Structure and human agency
- A postmodern world? Meta-narratives and relativism
- Variety of paradigms and resultant methodologies employed: Functionalism, Marxism, Feminism, Post-modernism, Interactionism...
- Funding (especially in relation to autism research)

Models of disability

- Models of disability:
- Medical: disability as something abnormal and pathological to be treated.
- 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).

The concept of neurodiversity and the neurodiversity paradigm and movement

- Neurodiversity as a ‘brute fact’.
- 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 autistic people or other forms of neuro-identity do not find life challenging. Autistic people are significantly disadvantaged in many aspects of life.

Insider views and theories

- Temple Grandin, Jim Sinclair, Donna Williams, Amanda Baggs, Claire Sainsbury.
- Theories that came from the community – some useful, some perhaps less so (e.g. ‘Intense World Theory’).
- 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).

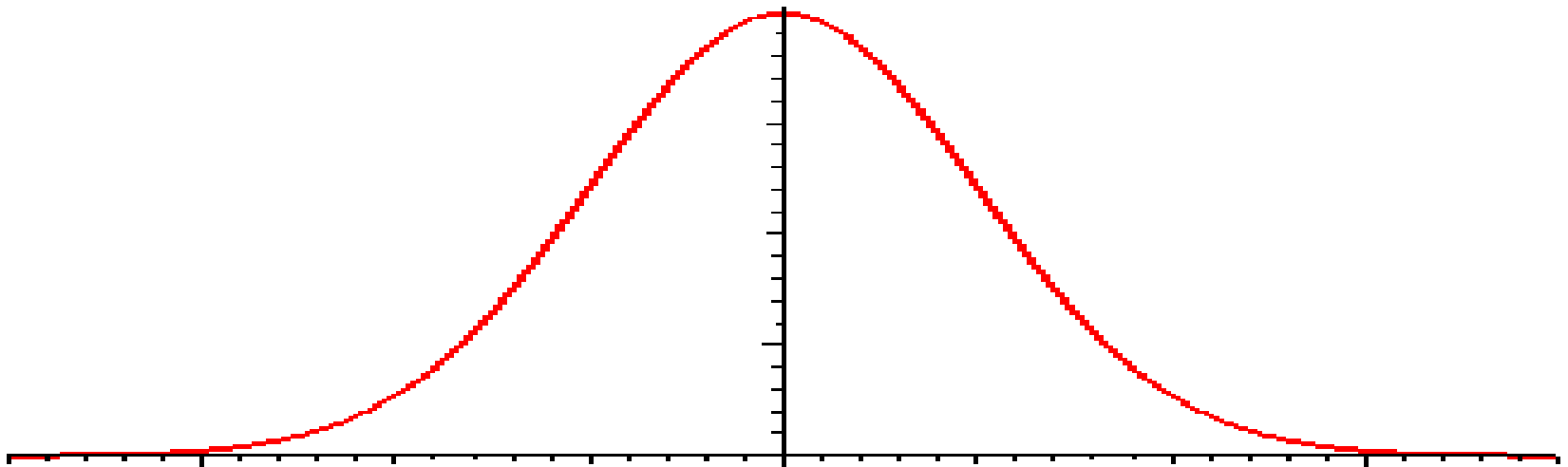
Aims and objectives – ethical controversies in the field

- Normativity or the acceptance/celebration of diversity?
- Behavioural outcomes and 'social skills' or understanding and autonomy?
- Baggs (2012) - communication page.
- Positivist RCTs and/or building collaborative communities of practice (Wenger, 1998).



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').



Examples of sociological work or closely related fields

- Grinker – anthropological studies / prevalence studies.
- Qualitative and action research in the field of education: Anat Greenstein, Jill Smith
- Large-scale quantitative analysis – Paul Shattock
- Building collaborative communities (Wenger, 1998): the work of the Autism Education Trust and the Transform Autism Education project.
- Media studies and representations of autism.
- The work of many autistic scholars and activists: Larry Arnold, Steve Graby, Melanie Yergeau, Hannah Ebben.
- Links to Critical Disability Studies and Mad Studies (see McWade et al. 2015).
- Critical Autism Studies (e.g. Runswick-Cole et al., 2016).

An example: 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 (Milton, 2012b; Chown, 2014).
- Empathy problems as a ‘two-way street’ (Sinclair, 1992).
- Theory of autistic mind can often leave a great deal to be desired.
- ‘Fork ‘andles’!
- A critique of the one-sided account provided by ‘theory of mind’ based largely on micro-sociological theory, personal experience and qualitative data.
- Subsequent research to support theory – Brett Heasman, Noah Sasson, Morten Gernsbacher, Robert Chapman, Gemma Williams, Catherine Crompton...

Expertise

- Collins and Evans (2007) suggest that expertise is primarily based on the acquisition of tacit knowledge.
- Ubiquitous expertise includes an endless number of skills and knowledge that sustain the forms of life and culture of society (e.g. fluency in natural language or moral sensibility).
- Specialist expertise requires immersion in the language and practice of expert communities.
- From “beer-mat knowledge” to “interactional” and “contributory” expertise.

Interactional expertise

- How much interactional expertise is possible between autistic and non-autistic people (Milton, 2014a)?
- Gaining expertise in what it is to be autistic, would take immersion in the culture and practices of autistic people, yet it is questionable as to what extent such immersion is possible for non-autistic people and it is certainly doubtful that many established researchers have made the effort.

AET consultation data

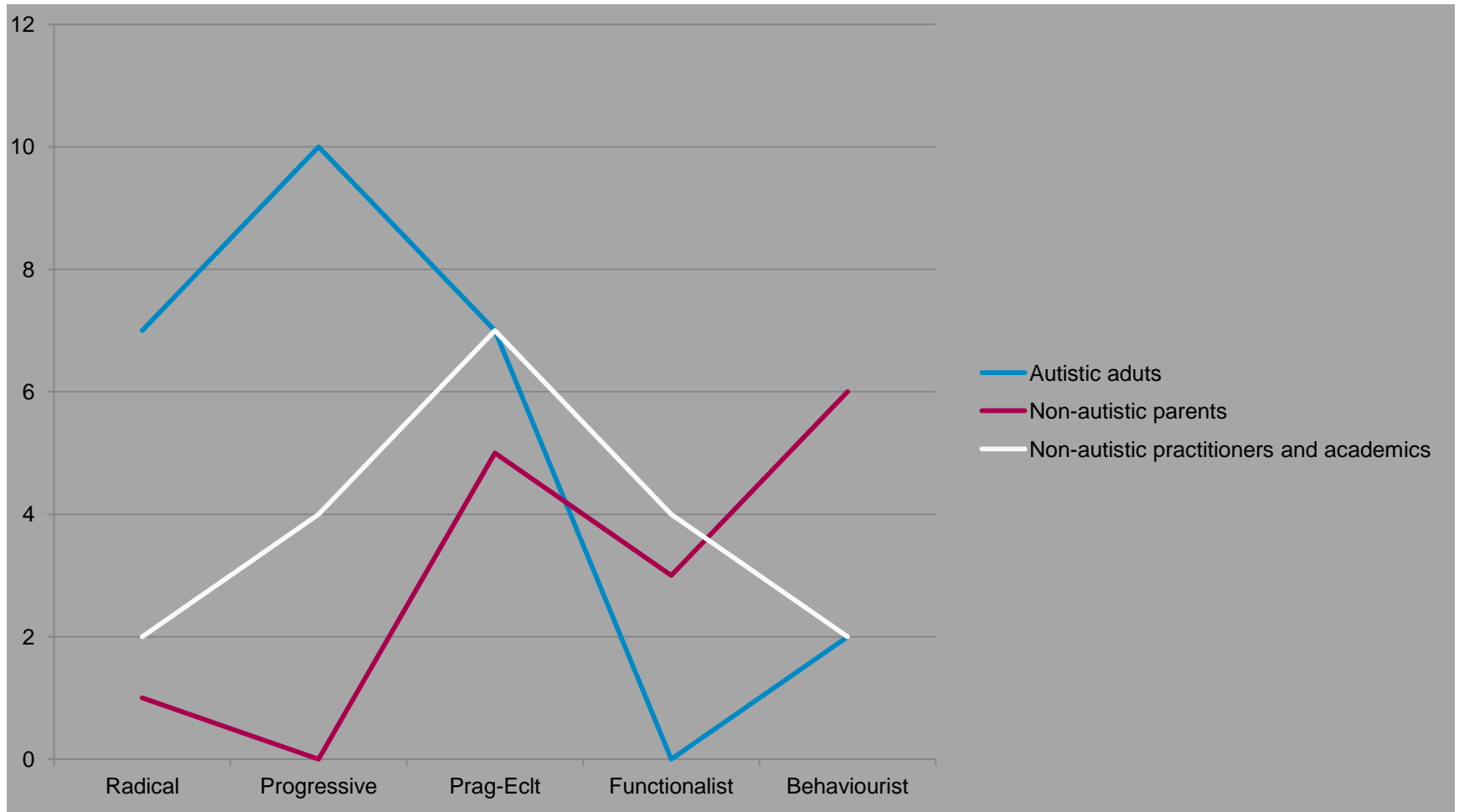
Stakeholder group	Understanding the individual pupil	Building relationships	Curriculum and learning	Enabling environments
Practitioners	<u>Staff training</u>	Involving and supporting parents	Differentiated curriculum (social skills)	Quiet and safe spaces
Parents	Staff training and understanding the individual	<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.

- *“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 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).

Arnstein (1969)

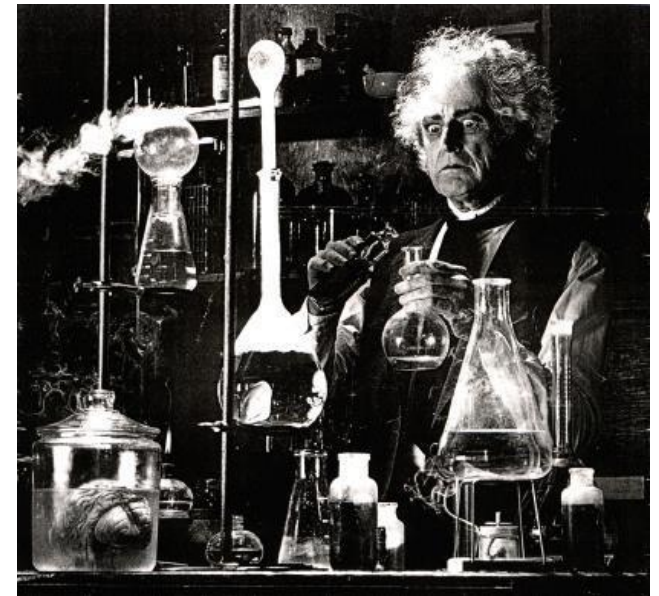
Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

Participation in knowledge production

- “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 and the production of knowledge

- 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...



Participatory research

- A range of theoretical and methodological approaches.
- Yet with the main objective of handing power from the researcher to research participants, who are often community members or community-based organisations.
- In participatory research, participants have control over the research agenda, the process and actions taken.
- Most importantly, people themselves are the ones who analyse and reflect on the information generated, in order to obtain the findings and conclusions of the research process.

Emancipatory research

- “By definition emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process, but whether this is achievable is a highly contentious issue.” (Barnes, 2001)

The James Lind Alliance priorities

- Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?
- Which interventions are effective in the development of communication/language skills in autism?
- What are the most effective ways to support/provide social care for autistic adults?

- Which interventions reduce anxiety in autistic people?
- Which environments/supports are most appropriate in terms of achieving the best education/ life/ social skills outcomes in autistic people?
- How can parents and family members be supported/educated to care for and better understand an autistic relative?

- How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
- How can we encourage employers to apply person-centred interventions & support to help autistic people maximise their potential and performance in the workplace?
- How can sensory processing in autism be better understood?

- How should service delivery for autistic people be improved and adapted in order to meet their needs?
- Which interventions are effective in the treatment/management of challenging behaviour in autism?
- How can training for health and social care professionals be improved so that they are more able to recognise symptoms of autism/treat autistic people appropriately?

Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.
- The Autonomy journal – and Autism, Policy and Practice (APP).
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- Shaping Autism Research UK seminar series.
- The Participatory Autism Research Centre (PARC) at www.PARCautism.co.uk
- The National Autism Project (NAP) and Westminster Commission.
- The National Autistic Taskforce (NAT).



Conclusion

- “Traditional methods of consulting and working in partnership may not always be effective, and new avenues for connection may need to be sought, however when collaborative ventures are pursued, and when people on the autism spectrum feel included and empowered, the ability to live as one chooses greatly increases.” (Milton, 2014b)

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