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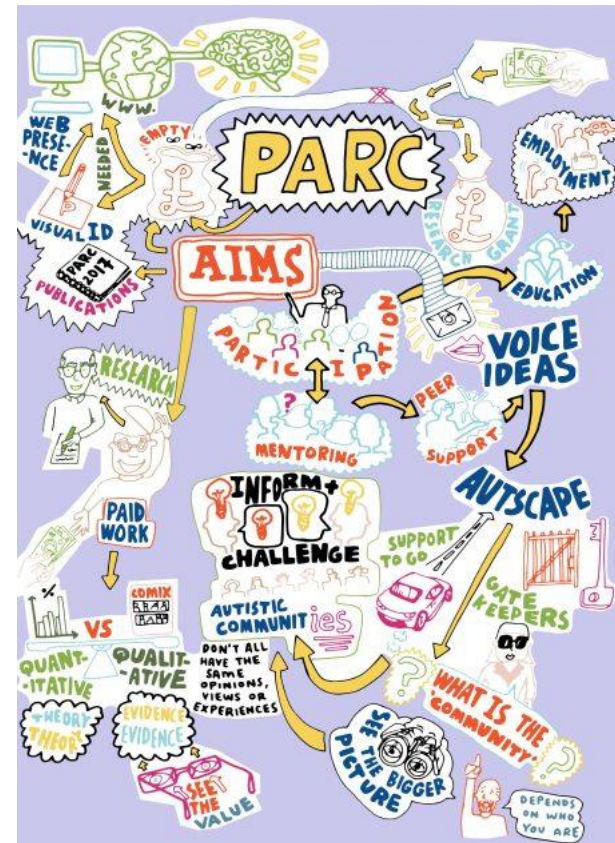
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Disability and diversity: the challenges faced by autistic people

Dr. Damian E M Milton



Introduction

- This presentation looks at the challenges of understanding and addressing the needs of such a diverse array of people in relation to both traditional models of disability and that of more recent proposals.
- This presentation will also comment on the work of the Participatory Autism Research Collective (PARC) in relation to meeting such needs.

Participation and insider knowledge

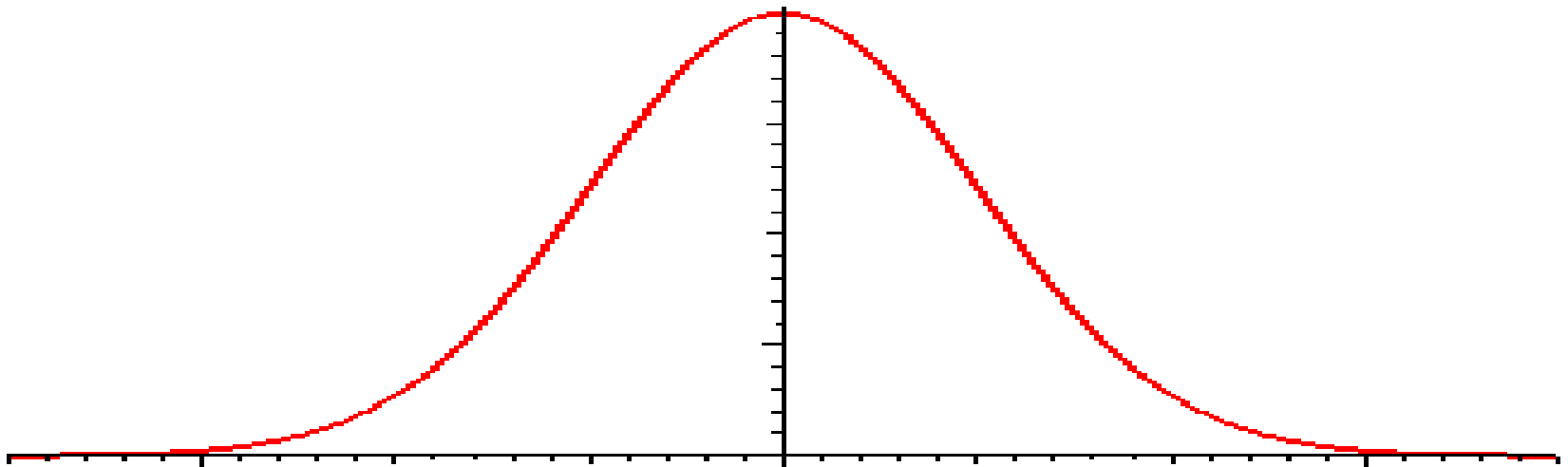
- “...right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced.” (Williams, 1996: 14).

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).
- Affirmative model (Swain and French, 2000).
- Active model (Levitt, 2017).

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').



The 'enigma'

- Autism has been variously described as everything from an evil spirit that robs parents of their children, to a differing cognitive style, or even a fundamental asset to human evolution.
- The spectrum of ways in which autistic people can present is so myriad, that it may be little wonder that the 'enigma' (Frith, 1989) still evades simplistic descriptions, as scientists search in vain for what exactly autism is.

Subtypes – how useful in practice?

- Although various attempts have been made to categorise differing subgroups of the autism spectrum, e.g. ‘Asperger Syndrome’, ‘low-functioning autism’, ‘atypical autism’; it is highly questionable as to how accurately such distinctions can be made and how useful they are in practice.

The concepts of neurodiversity, the neurodiversity paradigm and the neurodiversity 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.
- Affirmative and active models closely relate to views widely held within the community, along with social and post-social model views.

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.

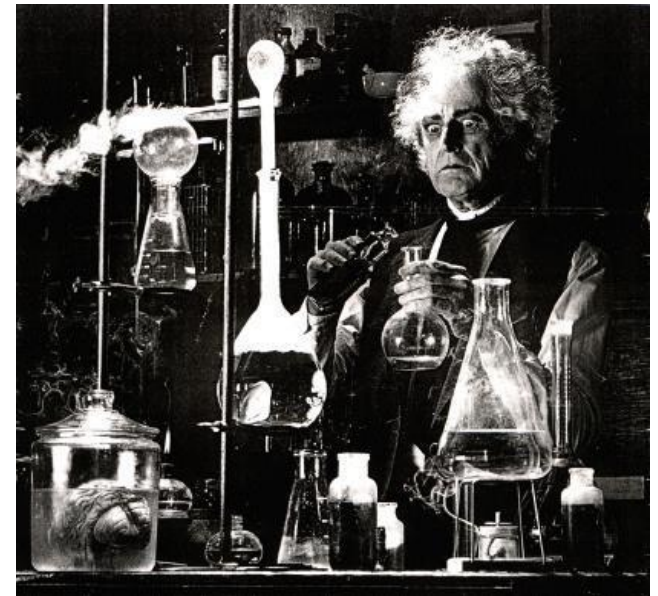
Aims and objectives – controversies in the field

- Normativity or the acceptance/celebration of diversity?
- Behavioural outcomes and 'social skills' or understanding and autonomy?
- Baggs (2012) - communication page.



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).



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.

The Participatory Autism Research Collective

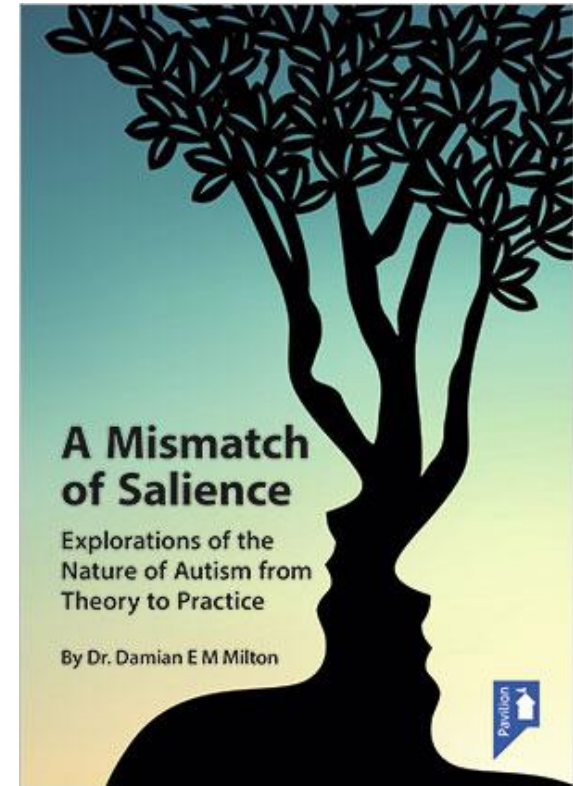
- The Participatory Autism Research Collective (PARC) was set up to bring autistic people, including scholars and activists, together with early career researchers and practitioners who work with autistic people.
- Our aim is to build a community network where those who wish to see more significant involvement of autistic people in autism research can share knowledge and expertise.
- Not just for researchers!

Activity of the PARC group

- The website for PARC continues to attract interest: www.PARCAutism.co.uk
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Expanding to a number of regions – events held in London, Birmingham, Sheffield and Nottingham. Discussions held at Edinburgh and Kent.
- Partnership with Pavilion Press.
- Conferences

Publications

- Special edition of the Scandinavian Journal of Disability Research (SJDR) regarding a critical dialogue on Neurodiversity.
- Special edition of Advances in Autism (AIA), work in the field of education and autism.
- Invited to write an article for the Tizard Learning Disability Review.
- Partnership with Pavilion Press.



Reinvigorating the 'Theorising Autism Project'

- A series of workshop days
- One of these workshop days has already looked at research regarding the 'double empathy problem'. Another is likely to look at 'monotropism' and related theory and research.

Any questions?

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