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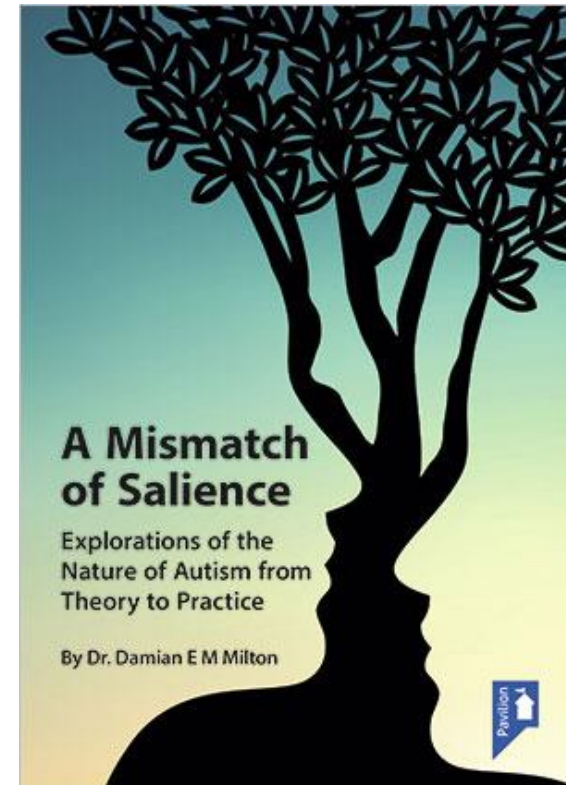
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Participatory research: perspectives, issues and ethics

Dr. Damian E M Milton



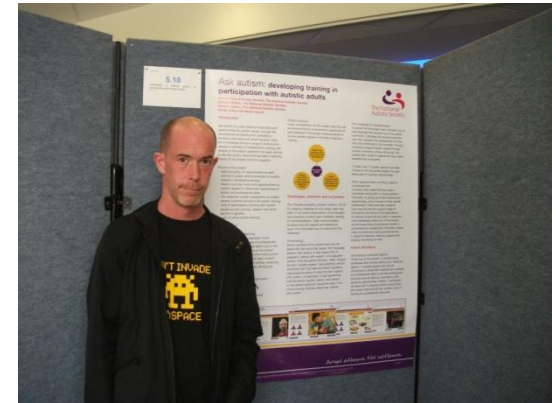
A bit about me

- 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 director at NAT.



A growing understanding

- Obtaining the views of disabled people – requirement of policy / legislation both nationally and internationally (UN, 2006).
- Lack of involvement and representation in organisations ‘for’ autistic people.
- Conflict between growing autistic voice and the discourse of dysfunction, deficiency, and dependency.
- A Future Shaped Together (Pellicano et al. 2013).
- The Shaping Autism Research UK project.



Nothing about us without us

- Having an autonomous voice – an essential requirement for individual well-being.
- For people on the autism spectrum however, there can be a number of barriers to participation in wider social life.
- People on the autism spectrum have often been excluded from contributing towards the decisions that directly affect their own lives.
- This has led many autistic-led advocacy groups to rally behind the slogan: ‘Nothing about us, without us’.

A sociological imagination

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



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.

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).



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.

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)

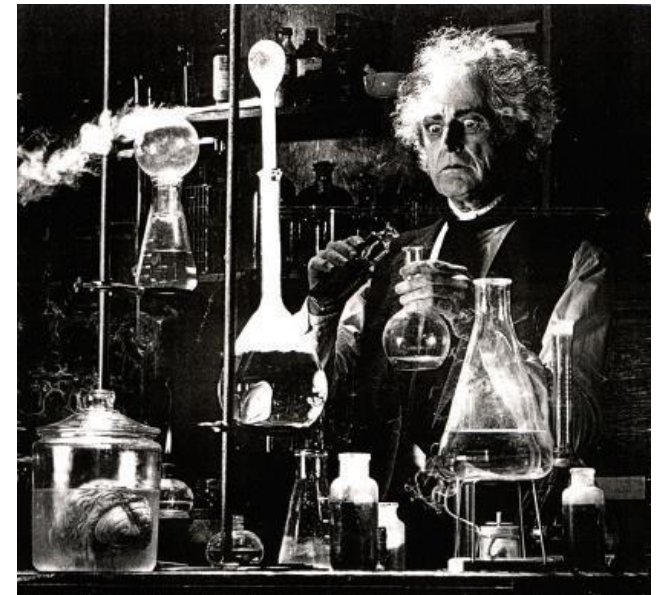
Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

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...



Potential barriers to inclusion

- Cognitive and linguistic demands may impair full involvement for those with learning disabilities, yet hearing views is important for participation/contribution (Lewis and Porter, 2004).
- Representativeness of peers and familiar adults as proxy informants (Lewis and Porter, 2004).
- Pictures and schedules – not always sure that views reported were the children's own (Preece and Jordan, 2009).

Inclusive strategies

- Informed consent.
- Opportunity for use of other mediums – drawing, photography, film – useful ‘aide-memoires’ (Powell and Jordan, 1992, cited in Preece and Jordan, 2009).
- Concrete manipulation – piles of like and dislike. Photographic narratives / scrapbooks (Preece and Jordan, 2009).

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).



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.
- First meeting held in April 2015.
- 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!

Objectives of PARC

- The initial objectives of PARC were set out as to:
- Address the isolation felt by many autistic researchers
- Ensure that research carried out by autistic people can be found and used
- Raise the reputation of participatory research methods in the field
- Critically comment on autism research which does not empower autistic people.

- In order to achieve these objectives it was suggested that PARC would:
- Encourage autistic people starting out in research
- Provide peer feedback on research and support with accessing funding
- Hold meetings and events.

Activity of the PARC group

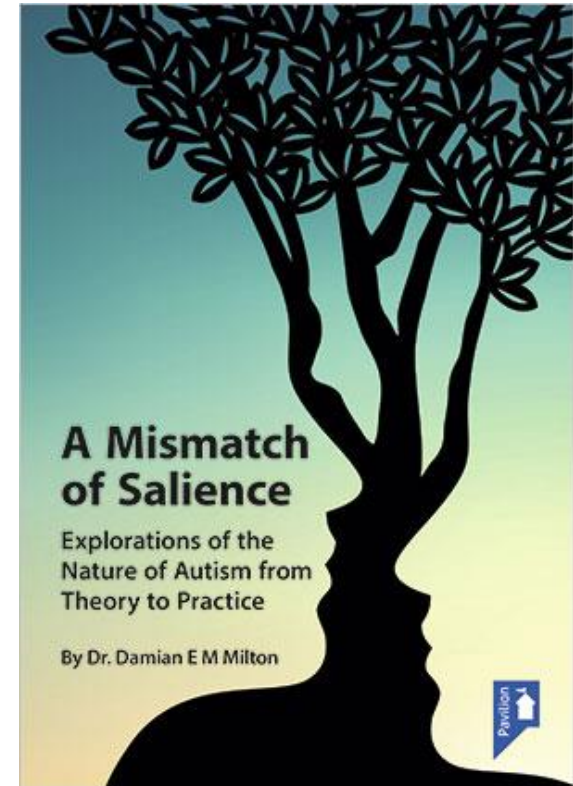
- The website for PARC continues to attract interest: www.PARCAutism.co.uk
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Events held in London, Birmingham, Sheffield, Nottingham, Glasgow and now Kent – with a wide range of contributors.
- Publications.

Conference streams

- Chairing a stream at the Learning Disability Today conference.
- Chairing a stream on 'Neurodiversity' at the Centre for Disability Research Conference at Lancaster University in September 2018.
- A PARC 'fringe' event partnering Scottish Autism's 50th Anniversary Conference in 2018.
- We also ran our own participatory research conferences at London South Bank University (LSBU) in 2018 and 2019.

Publications

- Two special editions of Advances in Autism (AIA), work in the field of education and autism.
- Recently published article for the Tizard Learning Disability Review.
- Partnership with Pavilion Press.



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)

So...

- Remaining difficulties (and opportunities).
 - What autism research would you like to see?
-
- For further information see following links:
 - www.PARCautism.co.uk
 - <https://kar.kent.ac.uk/73208/>

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