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Versions of research works

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From humble beginnings: the development of the Participatory Autism Research Collective (PARC)

Dr. Damian E M Milton
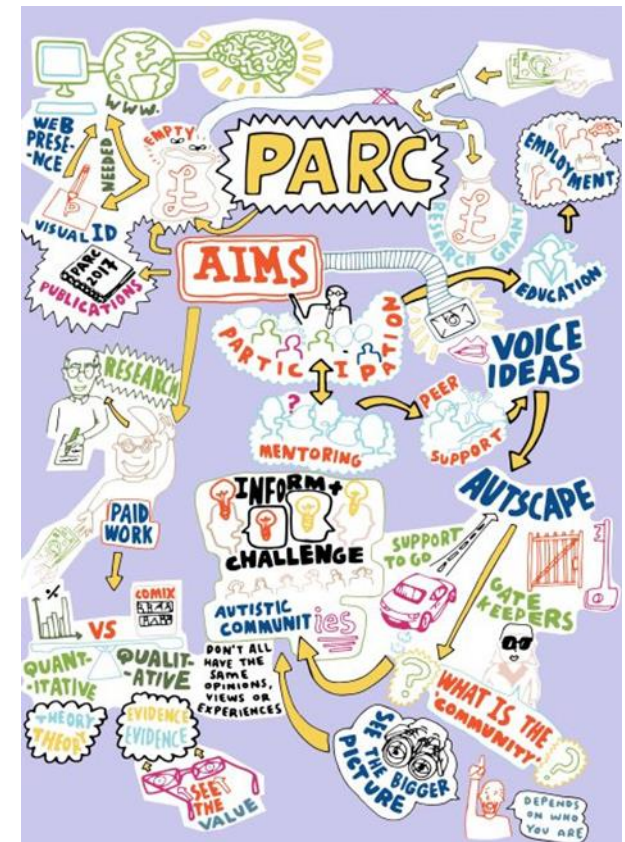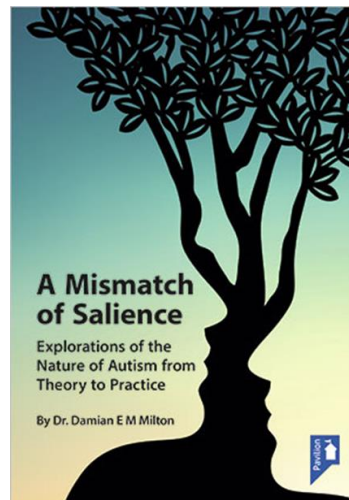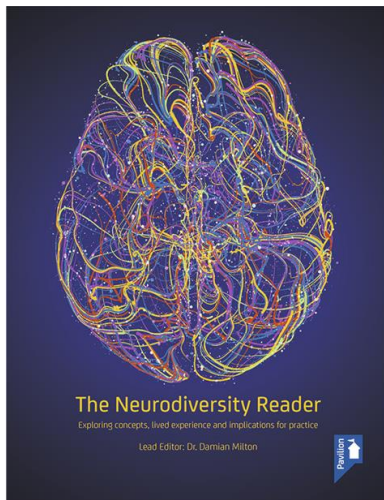
A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).

- A background in Social Science (initially Sociology).

- Senior Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent

- Visiting Lecturer at LSBU and UCL.

- Chair of PARC and director at NAT.

- Editorial team of the Autism journal.

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Introduction

- This presentation outlines key issues regarding participatory research, utilising experiences from a range of projects, such as the 'Transform Autism Education' project, and the 'Sensory School' project.

- The role of the Participatory Autism Research Collective (PARC) based in the UK will be explored.

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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).

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The autistic voice and the production of knowledge

- Autistic people rarely in the role of researcher, traditionally seen as research 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).

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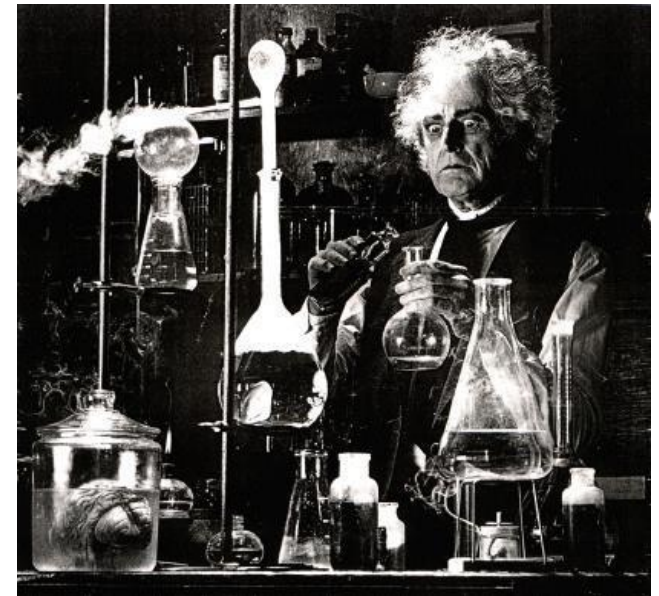
Participatory research

- A range of theoretical and methodological approaches.

- Yet with the main objective of ceding 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.

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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)

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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).

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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).

Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.

- The Theorising Autism Project.

- The Autonomy journal.

- The Research Autism mentoring project.

- Shaping Autism Research UK seminar series.

- The sensory school project.

- 'Believe in us' project.

Types of Participation in Communities of Practice

outsiders · tangential · peripheral · episodic · experts · regular · beginners · leaders · core

adapted from Wenger, 2002

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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!

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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.

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- 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.

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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 Kent – with a wide range of contributors.

- Online events and workshops.

- Building international connections.

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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.

- Playing A/Part conference 2019 and IARF 2021.

- We also ran our own participatory research conferences at London South Bank University (LSBU) in 2018 and 2019, and are running three online conferences in 2021.

- Event ethos.

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Publications

- Two special editions of Advances in Autism (AIA), work in the field of education and autism.

- Partnership with Pavilion Press.

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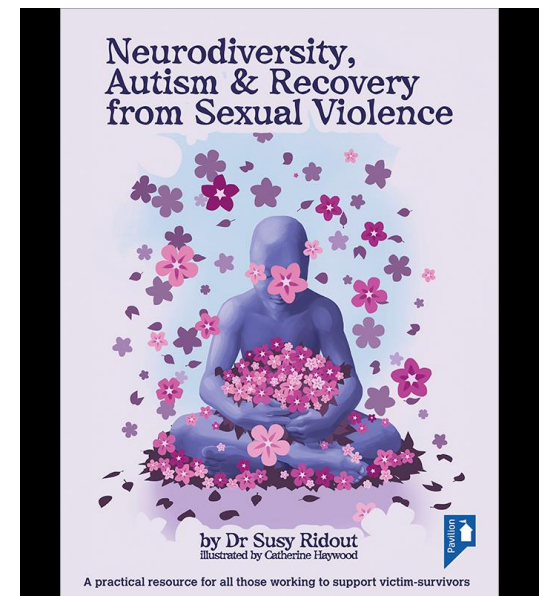
Key issues moving forward

- Funding!

- Intersectionality.

- Learning/intellectual disability.

- Yet opportunities:

- The power of individual and collective endeavours.

- Interdisciplinarity.

- Translation to practice.

- Links with policy developments.

- Collaborative communities of practice.

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Discussion points

- How can we as a research community build small steps toward participation, yet at the same time avoid tokenistic gestures?

- How do autistic researchers help each other with the emotional labour of being an autistic researcher researching autism (taking into account how we are often written about)?

- How can we access funding and work with allies?

- What are the potential benefits of being an 'outsider researcher'?

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