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A critical reflection on the development of the Participatory Autism Research Collective

Dr. Damian E M Milton

The Neurodiversity Reader

Exploring concepts, lived experience and implications for practice

Lead Editor: Dr. Damian Milton

Pavilion
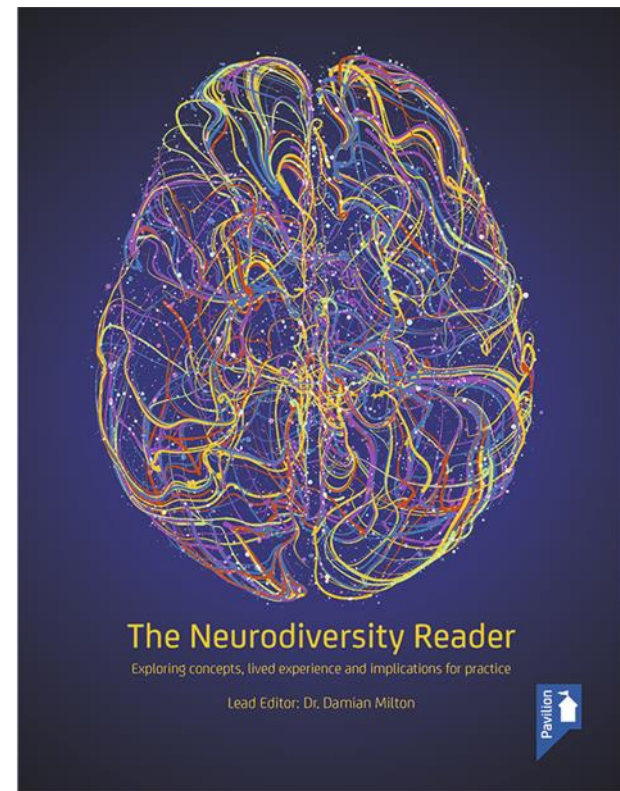
A bit about me

- 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.

- Chair of PARC and director at NAT.

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A sociological imagination

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

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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.

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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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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.

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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.

- Influence of previous autistic-led projects.

- 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.

- 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.

- We also ran our own participatory research conferences at London South Bank University (LSBU) in 2018 and 2019.

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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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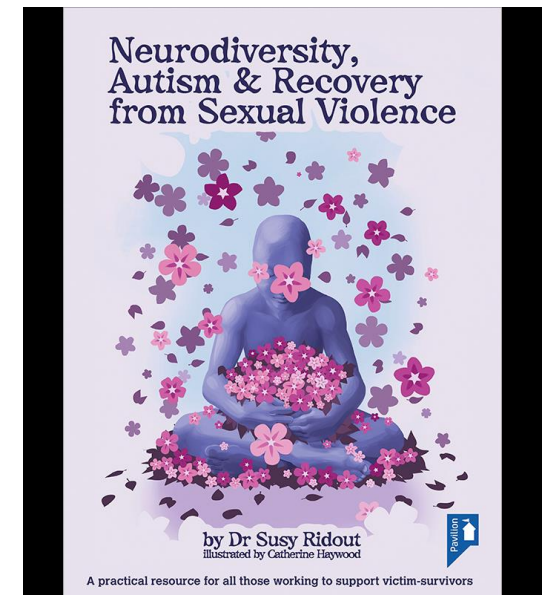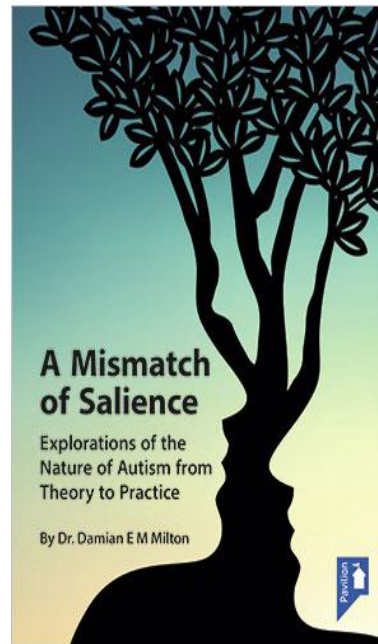
Key issues moving forward

- 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 we 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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