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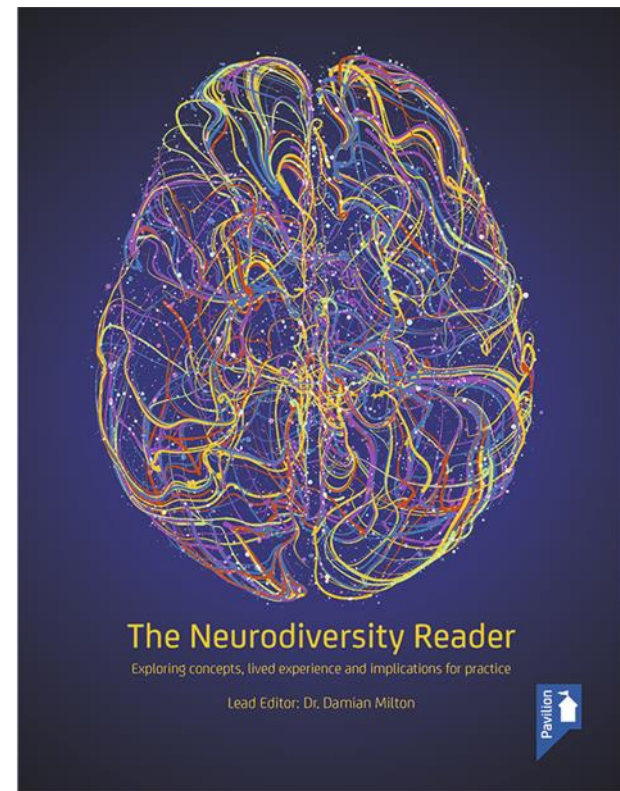
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The Participatory Autism Research Collective (PARC)

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).
- 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.



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).

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.

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

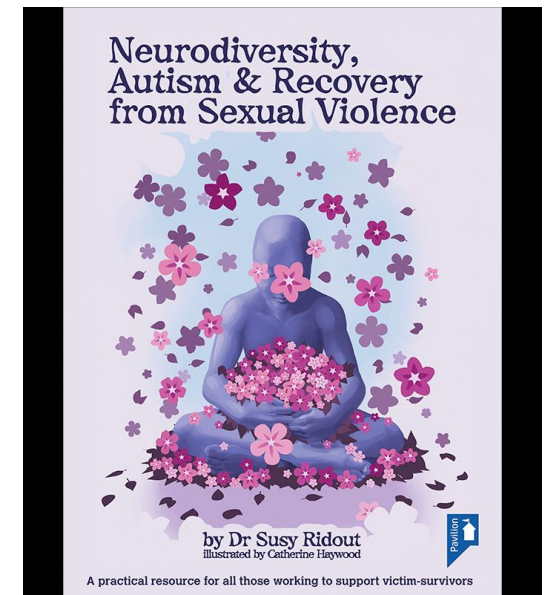
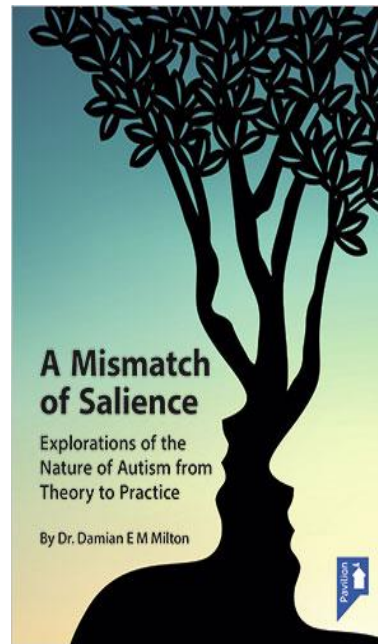
- The website for PARC continues to attract interest: www.PARCAutism.co.uk
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Events held in London, Birmingham, Sheffield, Nottingham, Glasgow and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

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, with another coming this year on 7th June 2021.

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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