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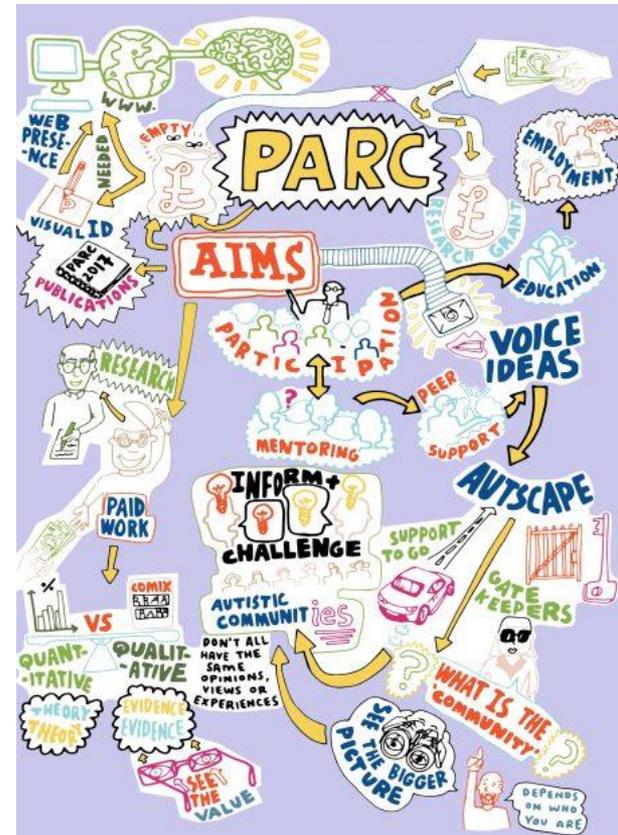
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Introduction to the Participatory Autism Research Collective (PARC) and the Neurodiversity stream

Dr. Damian E M Milton

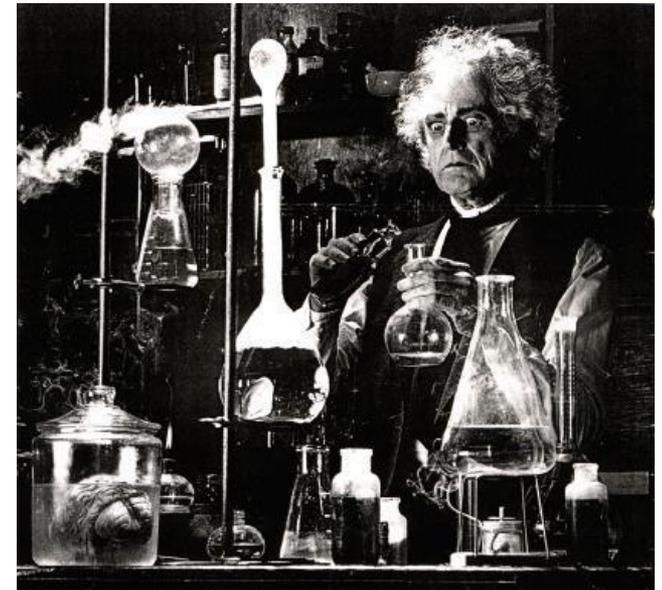


Participation and insider knowledge

- “...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).

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

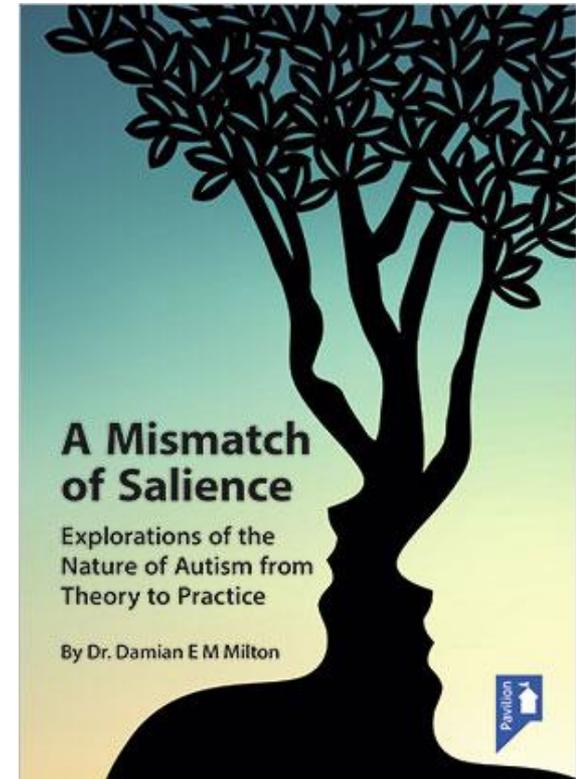
- The Participatory Autism Research Collective (PARC) was set up to bring autistic people, including scholars and activists, together with early career researchers and practitioners who work with autistic people.
- Our aim is to build a community network where those who wish to see more significant involvement 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.
- 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.

The Neurodiversity Stream

- Session A: Participation 1.30-3pm Tuesday
- Damian Milton: Introduction to the Participatory Autism Research Collective (PARC) and the Neurodiversity stream
- Sam Fellowes: Broadening the voice of neurodiversity through subtyping autism
- Emma Rice: Employing participatory methods: autistic pupils' sense of self and the influence of mainstream schooling.

The Neurodiversity Stream

- Session B: Discourse and Autism 3.30-5pm
Tuesday
- Mitzi Waltz: Getting from "you can't speak for my child" to "nothing about us without us": A brief history of diagnostic denial, misuse and misunderstanding in autism
- Kristofer Hansson and Ellen Suneson
Vulnerable Normality: Popular Neuroimaging and the discursive logic of the (dis)able(d) brain
- Elizabeth-Anne Graham: "He's just not autistic enough for the autism support base"

The Neurodiversity Stream

- Session C: Culture and Practice 11am-12.30pm
Wednesday
- Nicki Martin: Disabled Leaders in HE. What do we want?
Universal Design. When do we want it? 2010
- Dominic Griffiths: “He’s suffering from Neurodiversity”:
how do teachers understand this term and how does this
affect their practice?
- Hanna Bertilsdotter Rosqvist and Lindsay O’Dell:
Conversations in different languages: exploring and
connecting knowledges of autism in different epistemic
communities

The Neurodiversity Stream

- Session D: Neurodiverse ways of being 2.45-3.45pm Wednesday
- Karen Mogendorff: Neurodiverse ways of being in the world and what we can learn from it
- Larry Arnold: Context and subtext, a part of the world or apart from it?

The Neurodiversity Stream

- Session E: 4.15-5.15pm Wednesday
- Symposium: Major work ahead, the post psychiatric landscape of Autism
- Larry Arnold, Gillian Loomes, Stephen Kapp, Claire EvansWilliams and Dinah Murray

The Neurodiversity Stream

- Session F: Beyond the norm 9.30-11am
Thursday
- Hanna Bertilsdotter Rosqvist, Lindsay O'Dell, Alison Davies and Paul Stenner: "Being one of the weird kids": exploring spatiality, temporality and friendships of women with ADHD.
- Hanna Bertilsdotter Rosqvist and David Jackson-Perry: Not doing it properly? Tracking assumptions of healthy couple intimacy through an exploration of narratives of "non-sociable" autistic sexualities.

The Neurodiversity Stream

- Keynote: 11.30am-12.30pm Thursday
- Damian Milton: “Said the autistic endorsed autistic informed academic”: Neurodiversity, Academia and Activism.

Any questions?

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