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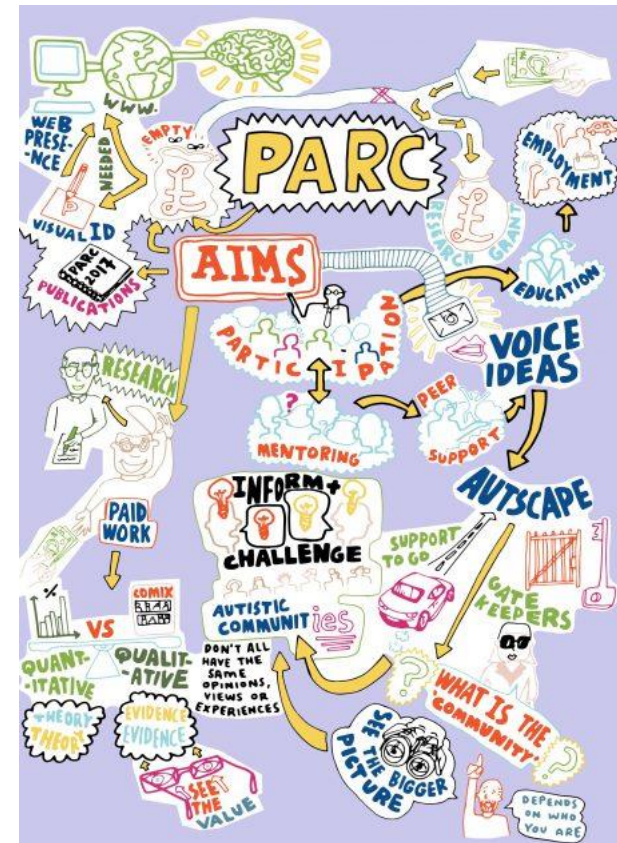
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The development of the Participatory Autism Research Collective (PARC)

Dr. Damian E M Milton



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!

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).

Aims and objectives – controversies in the field

- Normativity or the acceptance/celebration of diversity?
- Behavioural outcomes and 'social skills' or understanding and autonomy?
- Baggs (2012) - communication page.



Have you heard about that Social Model of Shape Difference all the squares are talking about?

You mean the idea that all differences between shapes are imaginary?

Exactly. See that guy over there? According to this theory, he can't roll as well as we do because of our *attitudes* toward him!

Have you ever heard anything more ridiculous?

I guess when we are not looking, they bounce around like basketballs. Ha Ha Ha Ha!

Oops, I thought I saw four right angles on that one. I must be hallucinating! Ha Ha Ha Ha Ha!

Actually, that's not at all what the social model is about. It's about how minority shapes are excluded from decision making roles, and therefore our needs are considered extraordinary while yours are seen as normal.

It's about power. The ways squares are silenced or ignored. How some shapes are subjected to treatments that would be considered abusive if they were done to circles.

So the social model is all about how squares are superior to other shapes. Can you believe he had the nerve to say that?

That's what I call rectangular logic. Ha Ha Ha Ha.

He probably bounced too high and hit his head on something! Ha Ha Ha Ha Ha!

Look at me! I've got corners! I'm invincible! Ha Ha Ha Ha Ha!

Please get off of me!

Square Talk

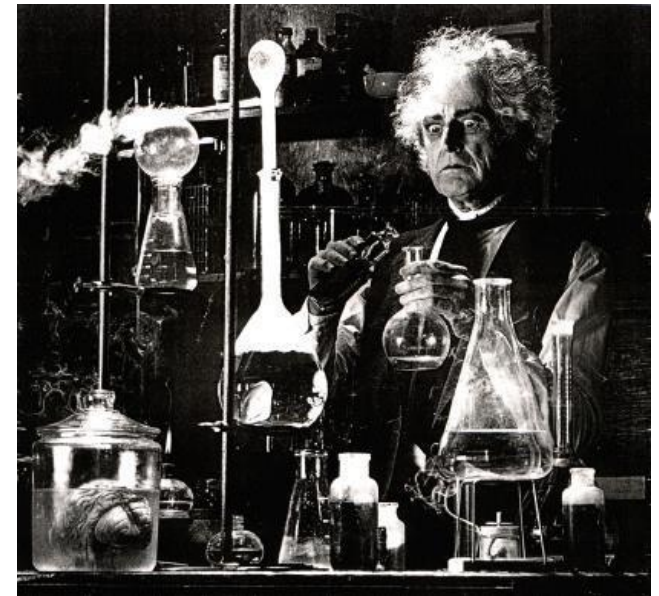
Asperger Square 8

The concept of neurodiversity

- 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.

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.

Activity of the PARC group

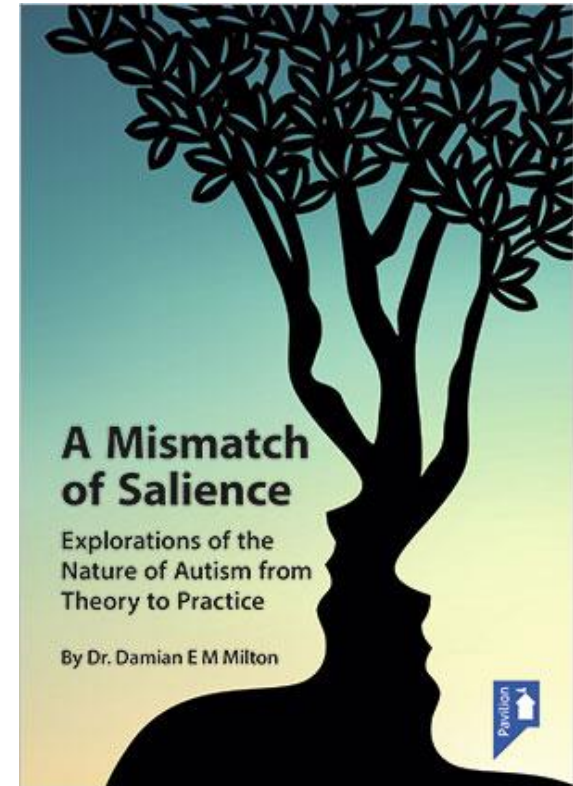
- The website for PARC continues to attract interest: www.PARCAutism.co.uk
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Events held in London, Birmingham, Sheffield, Nottingham, Glasgow and hopefully soon in Kent.
- 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.
- We also ran our own participatory research conference at LSBU on 18th July 2018.
- And now the PARC fringe in Glasgow.

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 – or a series of events on this topic.

Any questions?

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