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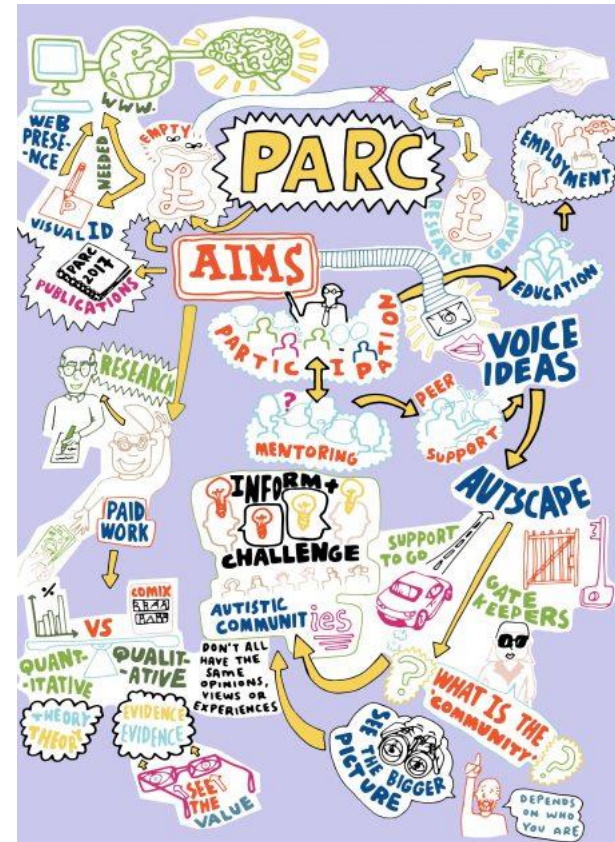
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The development of the Participatory Autism Research Collective (PARC)

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.
- 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.

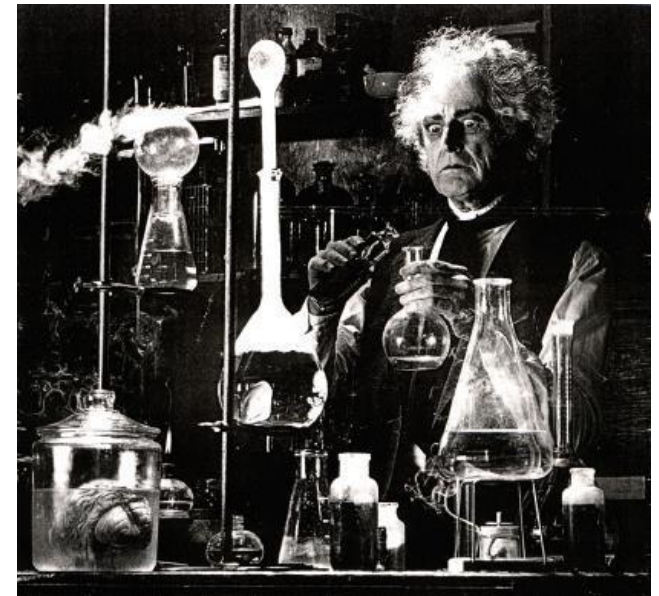
- In order to achieve these objectives it was suggested that PARC would:
- Encourage autistic people starting out in research
- Provide peer feedback on research and support with accessing funding
- Hold meetings and events.

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).



Arnstein (1969)

Degrees of citizen power	Citizen control
	Delegated power
	Partnership
Degrees of tokenism	Placation
	Consultation
	Informing
No power / non-participation	Therapy
	Manipulation

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.

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)

Participation in knowledge production

- “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).

Creative methods of engagement

- “Traditional methods of consulting and working in partnership may not always be effective, and new avenues for connection may need to be sought, however when collaborative ventures are pursued, and when people on the autism spectrum feel included and empowered, the ability to live as one chooses greatly increases.” (Milton, 2014b)

Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.
- The Ask autism project.
- The Theorising Autism Project.
- The Autonomy journal.
- Mentoring project based at LSBU and the use of Personal construct theory (PCT).
- The National Autism Project (NAP) and Westminster Commission.
- Shaping Autism Research UK seminar series.
- The National Autistic Taskforce.
- The Participatory Autism Research Collective (PARC).



Activity of the PARC group

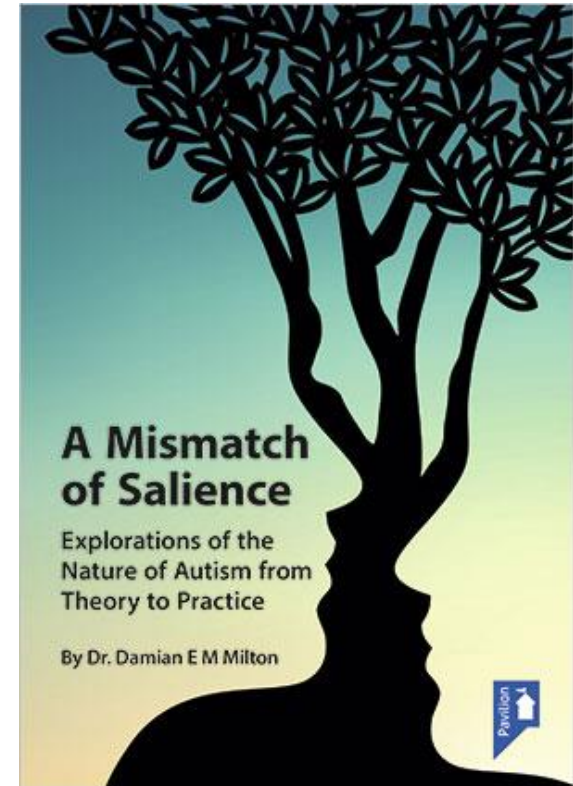
- The website for PARC continues to attract interest: www.PARCAutism.co.uk
- This has included links to events set up by PARC members or other related material.
- Critical blog posts regarding research and practice in the field.
- Events held in London, Birmingham, Sheffield, Nottingham, Glasgow and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

Publications

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

So...

- Remaining difficulties (and opportunities).
- What autism research would you like to see?

- For further information see following links:
- www.PARCautism.co.uk
- <https://kar.kent.ac.uk/73208/>

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