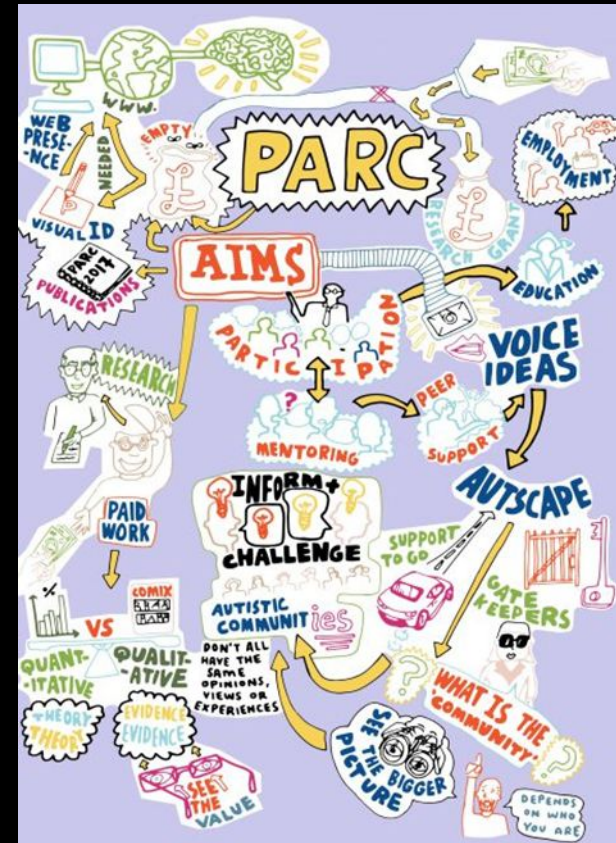


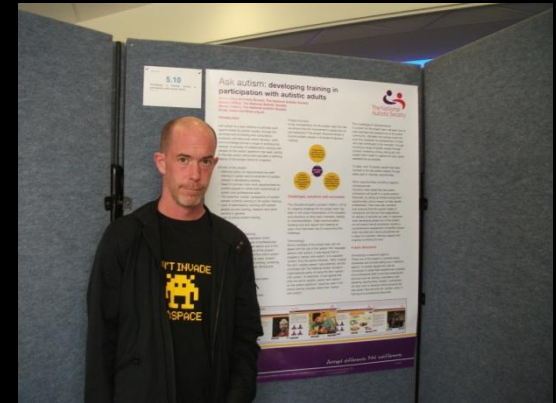
Participatory Research: The Art of the Possible

Dr. Damian E M Milton



NOTHING ABOUT US, WITHOUT US

- Lack of involvement and representation in organisations 'for' autistic people.
- Conflict between growing autistic voice and the discourse of dysfunction, deficiency, and dependency.
- A Future Made Together (Pellicano et al. 2013).
- The Shaping Autism Research UK project.
- The call for participatory research from the autistic community (Milton and Bracher, 2013).



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).

INTERACTIONAL EXPERTISE

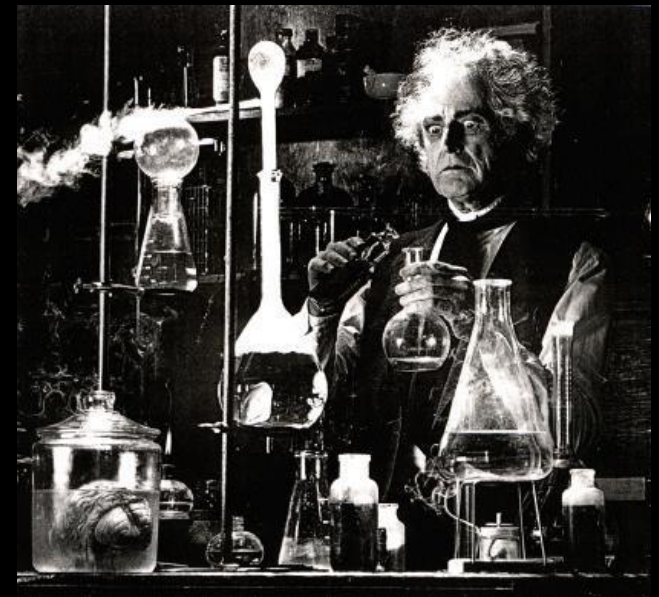
- How much interactional expertise is possible between autistic and non-autistic people (Milton, 2014a)?
- Gaining expertise in what it is to be autistic, would take immersion in the culture and practices of autistic people, yet it is questionable as to what extent such immersion is possible for non-autistic people and it is certainly doubtful that many established researchers have made the effort.
- In some areas of research, this is beginning to change. Yet one can also see barriers to its progression.

ARNSTEIN (1969)

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

THE AUTISTIC VOICE AND THE PRODUCTION OF KNOWLEDGE

- Traditionally seen as passive subjects of research.
- 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).



COLLABORATION

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Avoiding tokenism...



POTENTIAL BARRIERS TO INCLUSION

- Cognitive and linguistic demands may impair full involvement for those with learning disabilities, yet hearing views is important for participation/contribution (Lewis and Porter, 2004).
- Representativeness of peers and familiar adults as proxy informants (Lewis and Porter, 2004).
- Pictures and schedules – not always sure that views reported were the children's own (Preece and Jordan, 2009).

INCLUSIVE STRATEGIES

- Informed consent.
- Opportunity for use of other mediums – drawing, photography, film – useful ‘aide-memoires’ (Powell and Jordan, 1992, cited in Preece and Jordan, 2009).
- Concrete manipulation – piles of like and dislike. Photographic narratives / scrapbooks (Preece and Jordan, 2009).

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)

PARTICIPATORY METHODS IN PRACTICE (A WORK IN PROGRESS)

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.
- Shaping Autism Research UK seminar series.
- The Participatory Autism Research Collective (PARC) www.PARCAutism.co.uk
- The National Autism Trainer Programme (NAPT).



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!

CONCLUSION

- “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)

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