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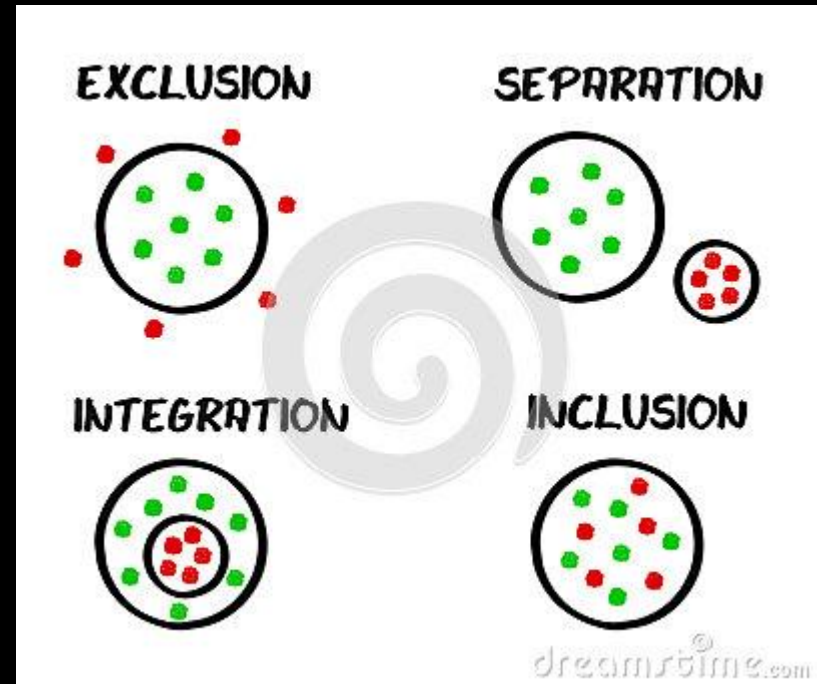
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Participatory autism research: barriers and opportunities



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Participation and insider knowledge

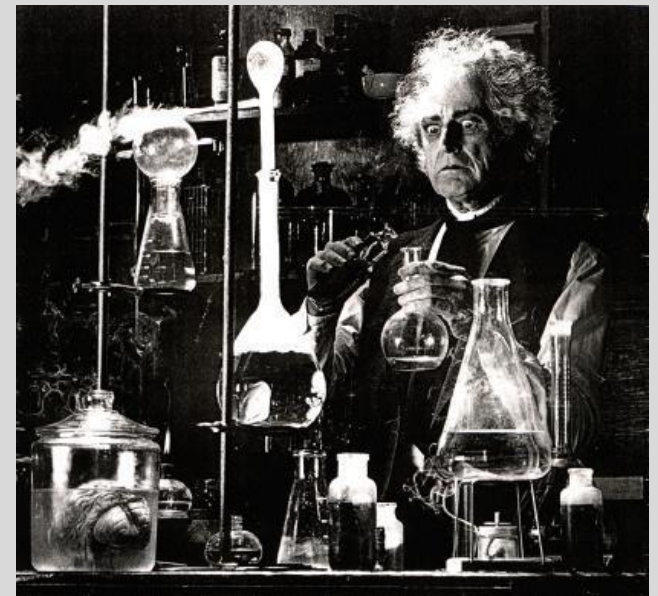
- "...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced."
(Williams, 1996: 14).

The 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).



Examples of sociological work (or closely related fields)

- Grinker – anthropological studies / prevalence studies.
- Qualitative and action research in the field of education: Anat Greenstein, Jill Smith
- Building collaborative communities (Wenger, 1998): the work of the Autism Education Trust.
- Media studies and representations of autism.
- The work of many autistic scholars and activists: Larry Arnold, Steve Graby, Hannah Ebben.
- AutSocGroup (Milton and Moon, 2012), The Theorising Autism Project (Greenstein, 2014).
- Links to Critical Disability Studies and Mad Studies (see McWade et al. 2015).
- Critical Autism Studies (e.g. Runswick-Cole et al., 2016).

AET consultation data

Stakeholder group	Understanding the individual pupil	Building relationships	Curriculum and learning	Enabling environments
Practitioners	<u>Staff training</u>	Involving and supporting parents	Differentiated curriculum (social skills)	Quiet and safe spaces
Parents	Staff training and understanding the individual	<u>Communication between staff and parents</u>	Individually tailored curriculum	Structure and routine
Children and young people	Understanding from staff	<u>Bullying (including 'friends')</u>	Subject content and delivery	Crowds and personal space
Common ground	Staff training needed	Better communication needed and understanding	Differentiation / tailored curriculum	Structured break times and safety
Tensions	Potentially what staff are trained in	Communication not being good enough and a lack of understanding	Social skills training	Differences in view regarding how environments should be managed

Mutual incomprehension

- “95% of people don’t understand me”.
- “Friends are overwhelming”.
- “Adults never leave me alone”.
- “Adults don’t stop bullying me”.

■ Quotes taken from Jones et al. (2012).

The 'double empathy problem'

- Building bridges between people of autistic and non-autistic dispositions is not always an easy process.
- The different perceptual worlds of the differently socially (dis)positioned.
- Empathy problems as a 'two-way street' (Sinclair, 1992).
- The 'double empathy problem' (Milton, 2012b, Chown, 2014).
- Theory of autistic mind can often leave a great deal to be desired.
- 'Fork 'andles'!



Expertise

- Collins and Evans (2007) suggest that expertise is primarily based on the acquisition of tacit knowledge.
- Ubiquitous expertise includes an endless number of skills and knowledge that sustain the forms of life and culture of society (e.g. fluency in natural language or moral sensibility).
- Specialist expertise requires immersion in the language and practice of expert communities.
- From “beer-mat knowledge” to “interactional” and “contributory” expertise.

Interactional expertise

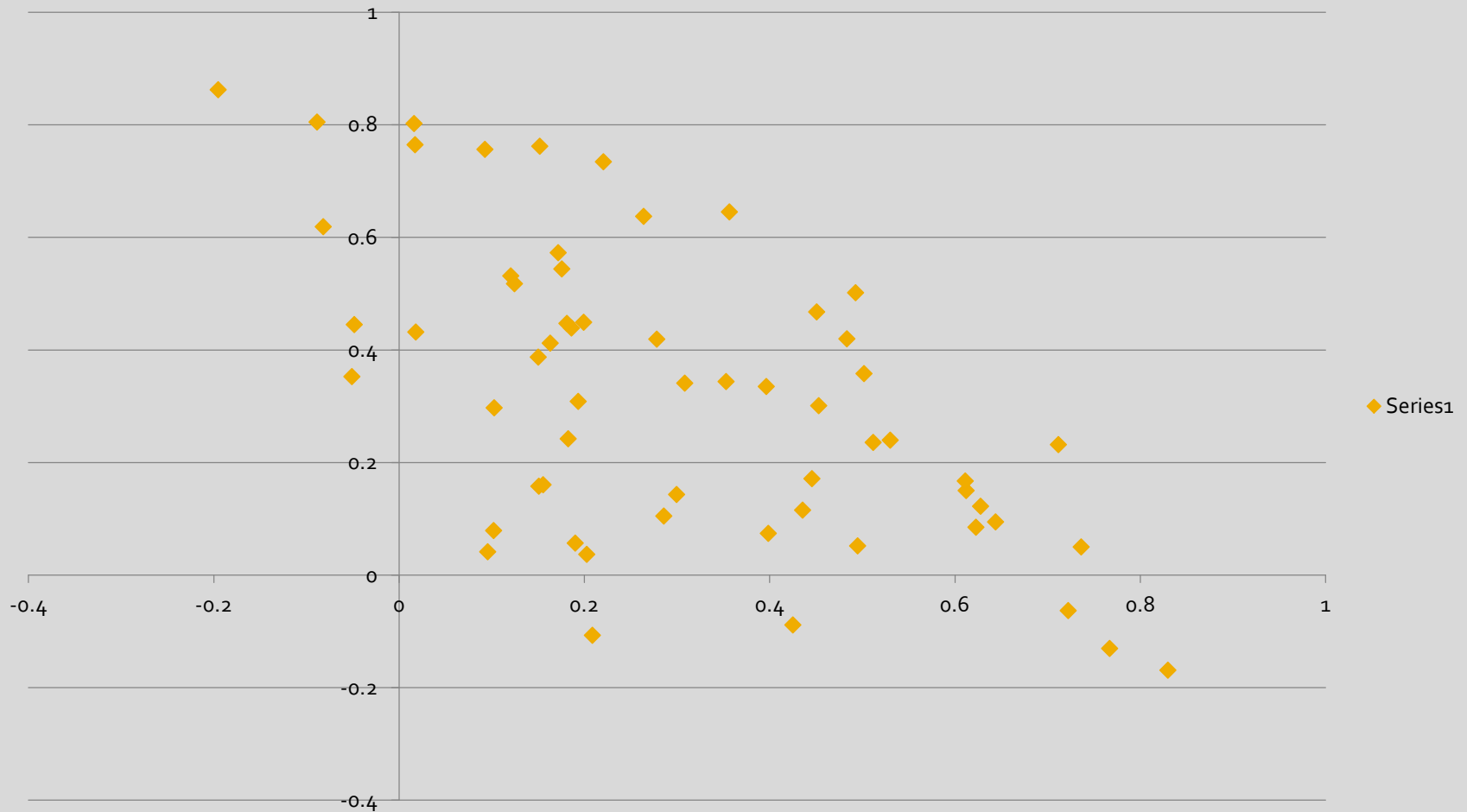
- How much interactional expertise is possible between autistic and non-autistic people (Milton, 2014a)?
- Gaining expertise in what it is to be autistic, would take immersion in the culture and practices of autistic people, yet it is questionable as to what extent such immersion is possible for non-autistic people and it is certainly doubtful that many established researchers have made the effort.

'Stakeholder' perceptions

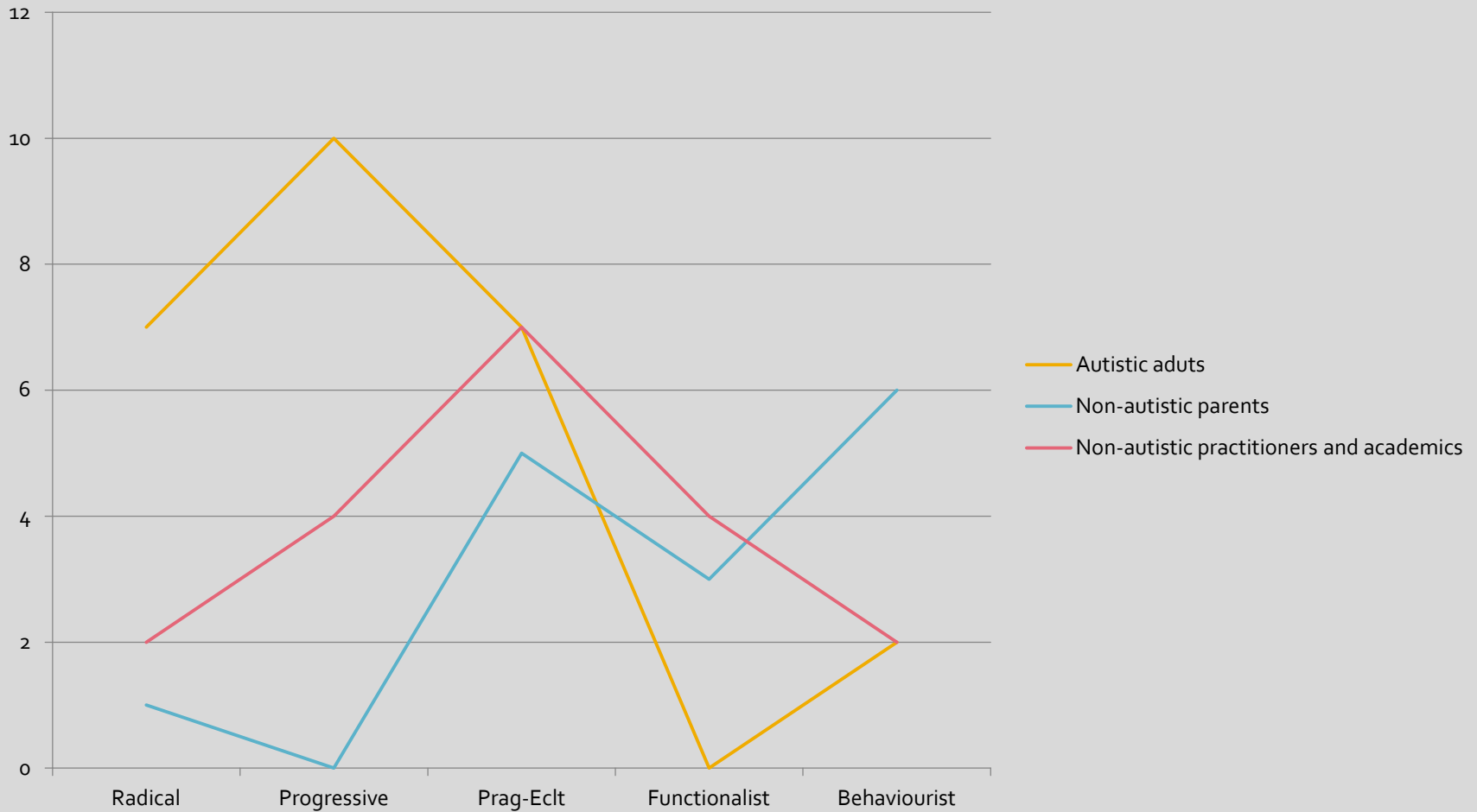
- Findings from PhD research.
- Significant tensions over a number of issues:
- Celebrating the diversity of learners and not trying to 'normalise' them.
- Radical change in society.
- Pupil-led vs. teacher-led activities.
- Social skills training and the appropriateness of behaviour.
- The 'three-way dispositional problem'!

- *"Because otherwise he is trapped in a world where he cannot communicate his hopes and fears, particularly when I am dead and cannot look out for him."*
- *"Difference should be accommodated, accepted and celebrated."*

Correlation Matrix (factors 1 and 2)



Spectrum of educational views



Common ground?

- Not a great deal!
- Against extreme normalisation?
- Enabling environments?
- Building relationships, communication and mutual understanding.

Collaboration

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Building capacity and communities of practice.
- Valuing and respecting varied expertise and building mutual understanding.
- Avoiding tokenism...



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)

Next steps

- The Participatory Autism Research Collective (PARC)
- Regular meetings
- Seminar days, book launch events and conferences
- Publications
- Peer support and mentoring
- Yet, seeking funding...

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