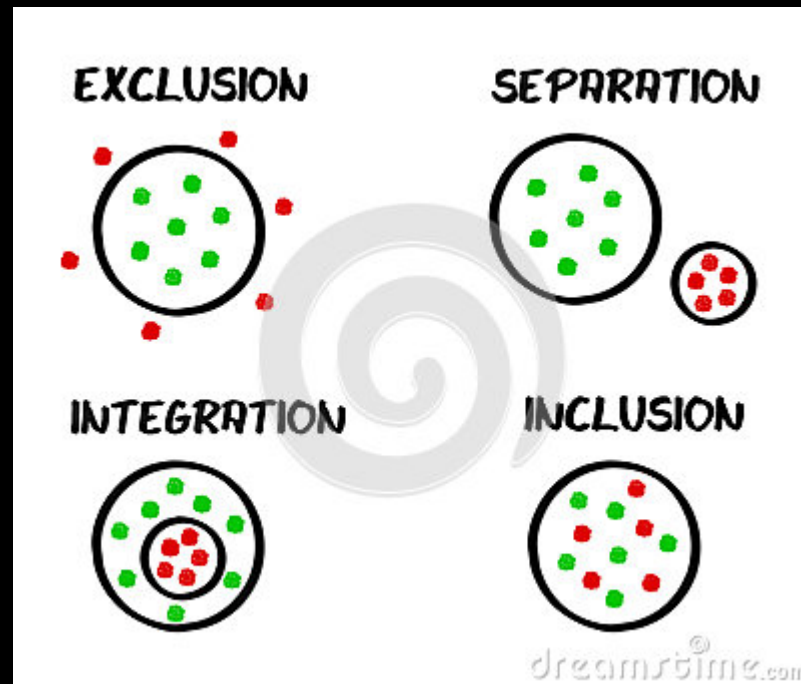


Autistic inclusion and participation



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A bit about me...

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).
- A background in Social Science (initially Sociology).
- Studying for a PhD in the education of people on the autism spectrum.
- Researcher at London South Bank University and the University of Birmingham.
- Soon to begin work as a part-time Lecturer at the Tizard Centre, University of Kent.
- Head of Autism Knowledge and Expertise (Adults and Community) at the National Autistic Society (part-time).



- “Some of us aren’t meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it.” (Lowell, 1999).



What do people mean by inclusion?

- “Being included in a group or structure.”
- Placement? Often neither inclusive or even ‘integration’.
- What does it mean to be part of a group when one is autistic?
- What helps an autistic person feel ‘included’ in something?

Normalisation and stigma

- To be defined as abnormal in society, is often conflated with being perceived as 'pathological' in some way and to be socially stigmatised, shunned, and sanctioned.
- The denigration of difference.



Idealised normalcy

- “Another way to decide what to teach a child with autism is to understand typical child development. We should ask what key developmental skills the child has already developed, and what they need to learn next. The statutory curriculum in the countries of the UK also tells us what children should learn. Then there are pivotal behaviours that would help further development: teaching communication, social skills, daily living or academic skills that can support longer-term independence and choices.” (Prof. Richard Hastings, 2013: <http://theconversation.com/behavioural-method-is-not-an-attempt-to-cure-autism-19782>).

Empowerment

- What is meant by 'socially appropriate', a 'social rule', 'social skill', 'functional'?
- By whose standards?
- What it means to be 'person-centred' – mutual respect and understanding?
- The 'double empathy problem'.

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).

Aims and objectives – controversies in the field

- Models of disability.
- Normativity or the acceptance/celebration of diversity?
- Behavioural outcomes and 'social skills' or understanding and autonomy?
- Baggs (2012) - communication page.
- Positivist RCTs and/or building collaborative communities of practice (Wenger, 1998).



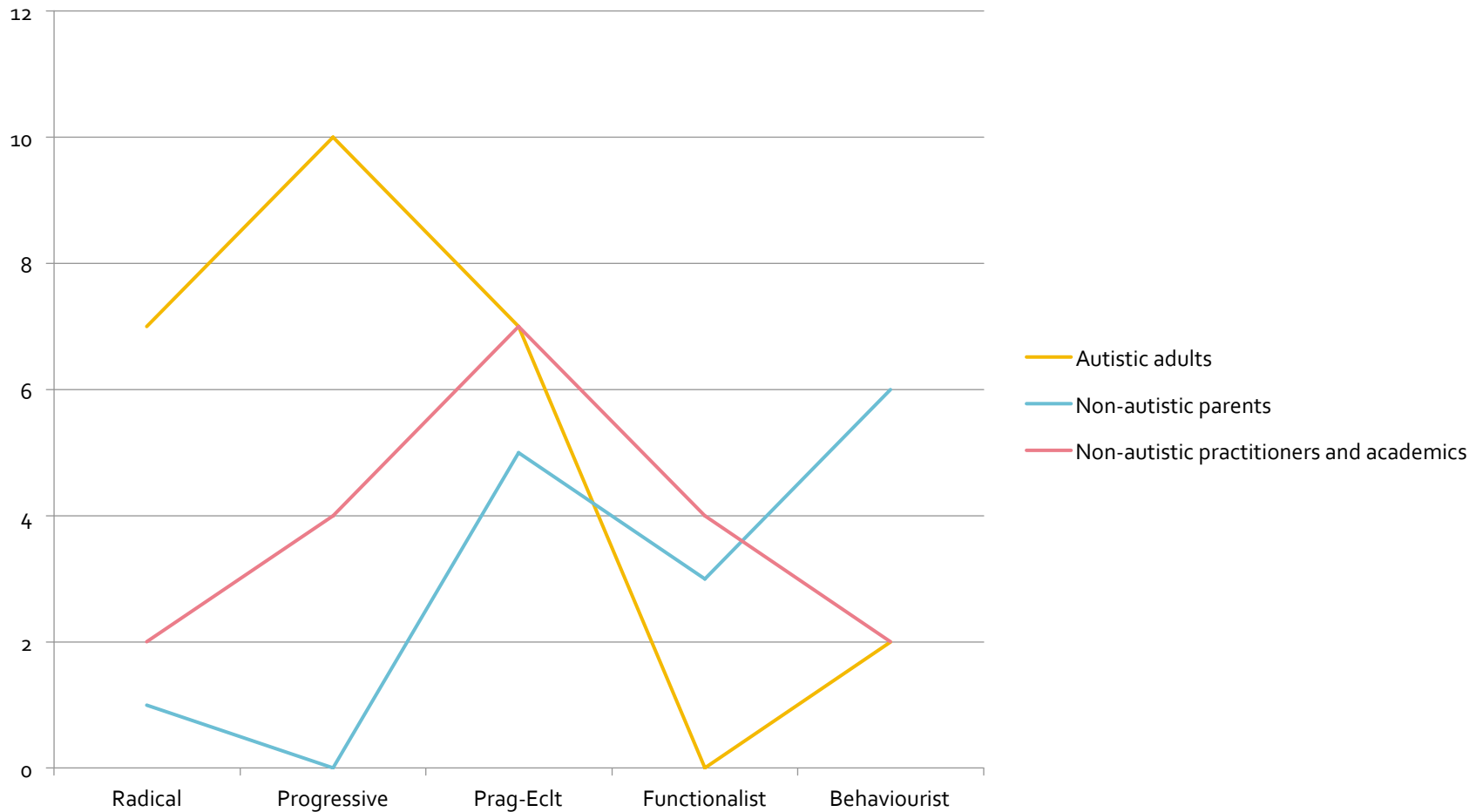
AET consultation data

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

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'!

Spectrum of educational views



Common ground?

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

Wellbeing and belonging

Main themes

Meeting personal needs

Living with the consequences of an othered identity

Connection and recognition

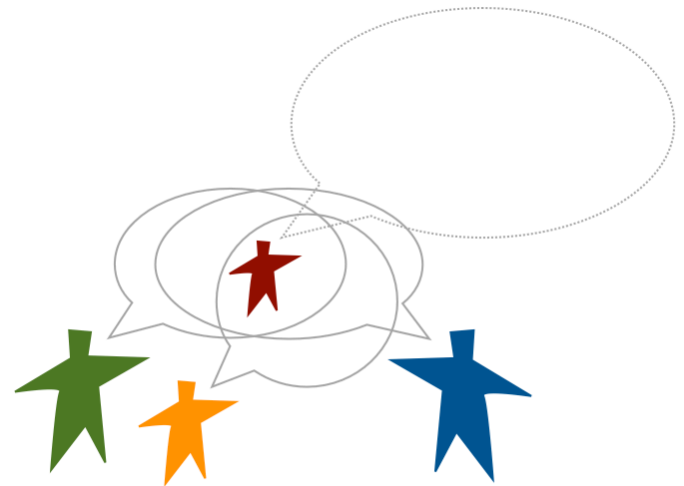
Relationships and advocacy

Key points for inclusion

- Acceptance of the autistic way of being, work with the autistic person and not against their autism.
- Explore interests and fascinations together.
- Having strong rapport and building mutually fulfilling and trusting relationships.
- Encourage autistic companionship.
- Encourage understanding of non-autistic people and culture, rather than teaching how to poorly mimic what one is not.
- 'Low arousal' is not 'no arousal' – many sensory experiences are fun!
- Wellbeing and belonging for autistic people are affected by common personal issues, but the barriers (public issues) some have in finding it are much greater than it is for others.

My definition of inclusion

- Inclusion is not physical placement, but a feeling of belonging within a community of practice.
- Easier said than done, but not impossible...

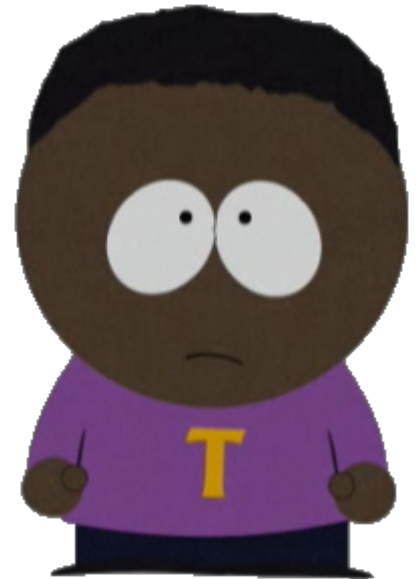


Co-production

- “Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours” (New Economics Foundation).
- To what extent is this currently possible?
- To what extent is this ideal taken seriously in service provision or research?

Collaboration

- Avoiding tokenism...
- "...place the voices and perspectives of self-advocates at the centre of the autism conversation, as we can speak with unique legitimacy and voice about our own lives." (Ne'eman, 2011).



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.
- The Cygnet mentoring project and the use of Personal construct theory (PCT).
- The Participatory Autism Research Centre (PARC) at London South Bank University.
- The National Autism Project (NAP) and Westminster Commission.
- Shaping Autism Research UK.





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, 2014).

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- Ne'eman, A. (2011) Question and Answer interview, accessed at <http://www.talkaboutautism.org.uk/community/live-qa-events/o10611-ari-neeman>
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