

Autism: Impaired compared to what?

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- “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).



A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).
- A background in Social Science (initially Sociology).
- On the scientific committee for Research Autism.
- Lecturer at the Tizard Centre, University of Kent.
- Head of Autism Knowledge and Expertise (Adults and Community) at the National Autistic Society.



What autism is not

- The result of bad parenting.
- A virus or disease.
- A reaction to MMR.
- A collection of behavioural deficits.
- In my view, autism is not a 'disorder' nor a 'condition'.
- So what is it?

Definitions of autism

- Origins of the term.
- The triad of impairments: social communication, social interaction and restricted interests/behaviours.
- Passive, aloof, and active-but-odd.
- Visual, sensory and pattern thinkers?
- Verbal ability and autism.
- Part of natural neurological diversity?
- An 'enigma' to some, a way of being in the world for both me and my son.

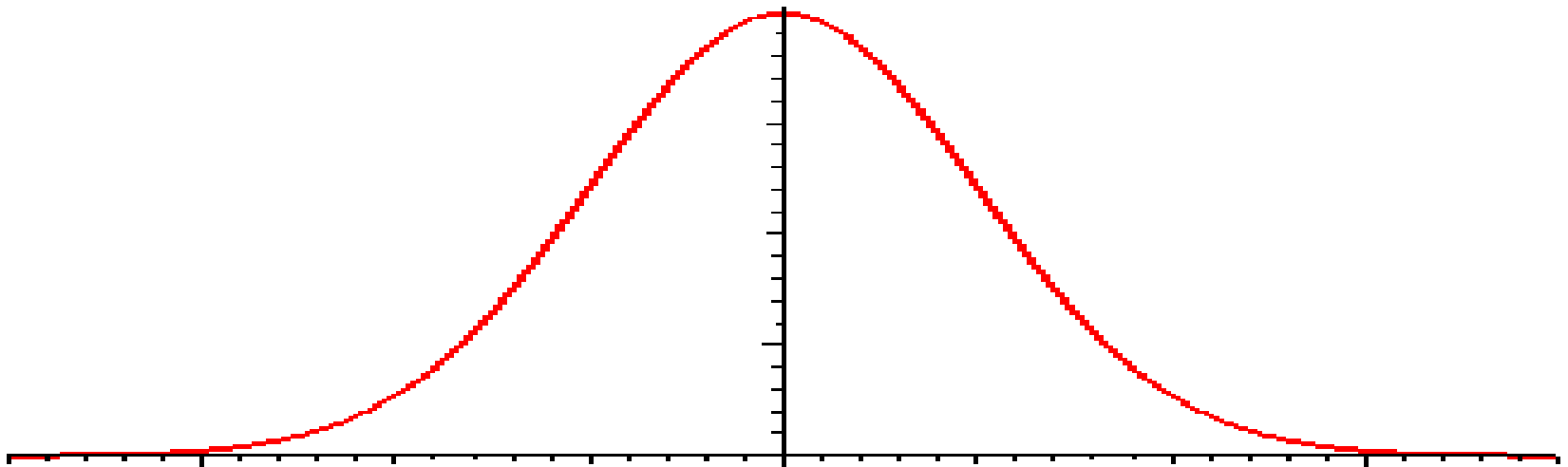
A different way of thinking

- Executive functioning theory.
- Weak central coherence theory.
- An interest model of autism.



The 'spiky profile'

- 'Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum.' (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').



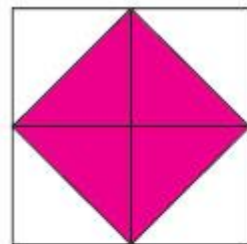
Sensory processing

- Not well recognised until recently.
- Sensory integration and fragmentation.
- Hypo and hyper sensitivity.
- Context and motivation.
- Stress, arousal and sensory overload.
- Meltdowns and shutdowns.
- Forgotten sensory issues.
- Effect of chronic stress levels.
- Low-arousal environments.

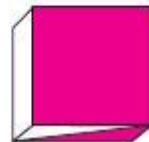


Enhanced sensory perceptions?

- The block design and embedded figure tests.



original



(a)

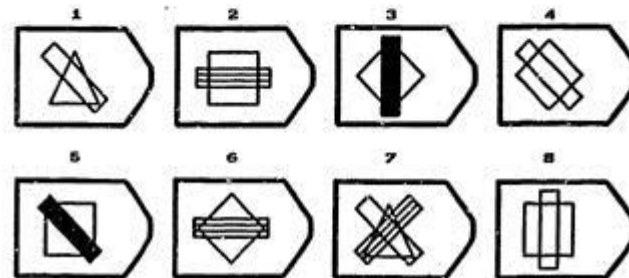
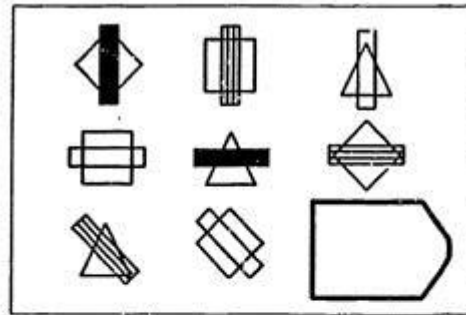
Types of block available for making the pattern



(b)

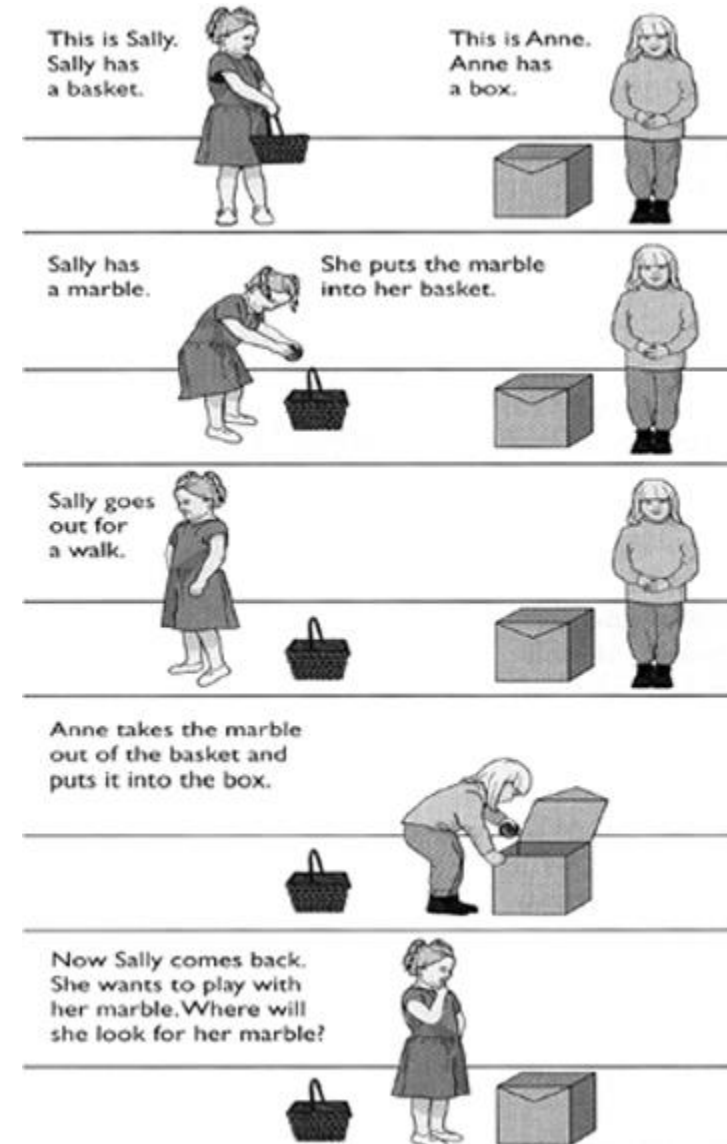
Non-verbal intelligence

- 'Non-verbal' intelligence tests (Dawson et al., 2007).



Theory of mind and social interaction

- The ability to empathise with others and imagine their thoughts and feelings, in order to comprehend and predict the behaviour of others (also called 'mind-reading' and 'mentalising').



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'

- The different perceptual worlds of people with differing dispositions and effect on interactions (Milton, 2012, 2014, Chown, 2014).
- Empathy problems as a 'two-way street' (Sinclair, 1992).
- In this theory, it is not only the autistic person who struggles to read the intentions and motivations of non-autistic people, but the same can also be said in reverse.
- Theory of autistic mind can often leave a great deal to be desired.
- 'Fork 'andles'!



Aims and objectives – controversies in the field

- Normativity or the acceptance/celebration of diversity?
- Baggs (2012) - communication page.
- Scientific trials and/or building collaborative communities of practice (Wenger, 1998).



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 autistic voice

- “...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.
- 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 stigma of being 'othered' and the normalisation agenda

- 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 (Tajfel, 1981).
- Autism diagnostic framing and the implementation of remedial interventions.

- *‘When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed?’*
(Victoria, ‘Are You Taking Something for It?’, issue 76, 12).

Universal design and autistic people

- “Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.”
- In order to make design, whether bespoke or universal in orientation, one must endeavour to understand the needs of autistic people.



Collaboration

- Setting the agenda and 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).



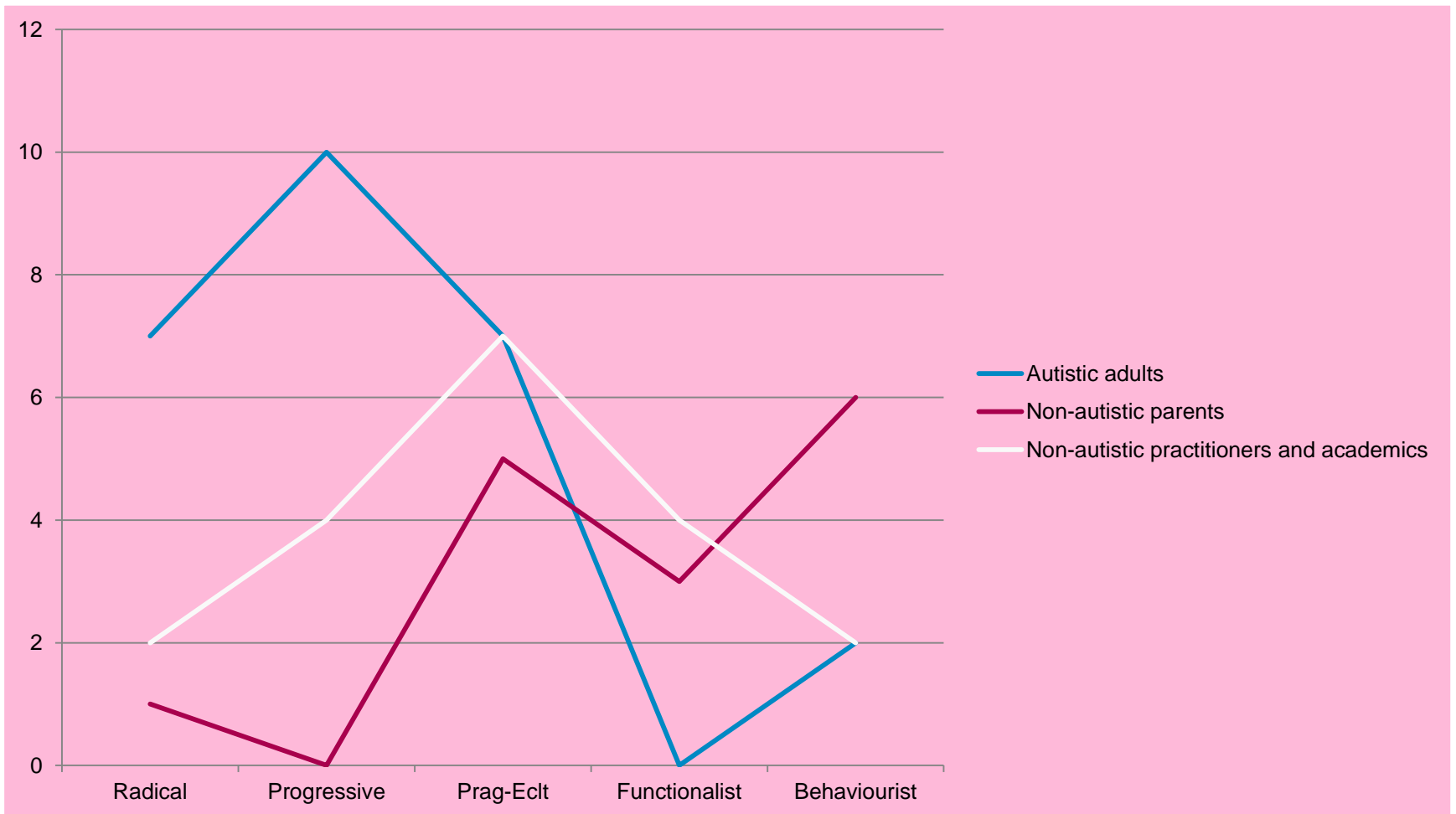
AET consultation data

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.

Implications for service providers

- There is a spectrum in theory and practice more generally regarding service provision for 'autistic people'.
- These narratives and practices can be said to be embedded within the wider discursive debate that exists between the medical and social models of disability as played out in the field of autism.
- There is an increasing complacency around the idea that lead professionals and practitioners have a good understanding of what 'good autism practice' entails, for me this is an ongoing imperfect process of interaction and should never be seen as a given.
- Working with the autistic person and not against 'their autism' – humility and building tacit rapport.
- This will require participation and not tokenism...

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.

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