

## What I Think About When I Talk About Autism

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Autism is a label that is applied to a diverse group of people. Autism is considered developmental, that is, it is something that is apparent from childhood and continues throughout the person's life, impacting on intellectual, emotional, social, physical or motor skills. But because autism – in its current definition – is a broad thing, sometimes people aren't diagnosed until way into their lives. If the impact of autism is obvious (boys- boys are *obvious* – *especially* when compared to autistic girls) then an early diagnosis is likely.

Of course, in the UK nothing is *that* simple. (Why would it be?) In one part of a county, the current waiting list for an assessment for autism through statutory services is currently thirteen months. That's pretty shoddy and inept, especially when the wellbeing of families and children is the price being paid by incompetent organisation of services. And once a diagnosis is received, the experiences of gaining insightful support are not uniform across the UK. The diagnosis is the first hurdle, but the water-jump is getting information & support following that diagnosis: "Here's the diagnosis, it's like a badge, or you could frame it, congratulations. Now take a leaflet and shove off."

Traditionally we say autism is present when we see certain patterns of behaviour. But here's the nub: behaviour isn't simply what we see in others, but its' thoughts, too.

This has led to practically everyone you meet thinking they know something about autism, even if it's derived from *Big Bang Theory* or *Mary & Max*. But no media representation can truly reflect people. We shouldn't assume every person with autism is the same, as we shouldn't assume all British people like fish and chips or crap public transport.

Autism 'behaviours' vary depending on mental capacity and age and opportunities offered. One common thread across 'the autisms' is "empathic capacity" (Delfos, 2005, p.84)- how easy does the individual relate to others? Another thing we know about autism suggests amongst the characteristics is an often *uneven* cognitive development- some people are skilled in one area significantly more than another – if we were to graph their profiles of skills the graph would seem a little 'spiky'.

For more than twenty years we've spoken of autism as one umbrella term to describe a *spectrum* of different *presentations* of autism. We know each of these presentations *tend* to have characteristics justifying our use of the term autism: these of course include differences from the abilities shown by others in terms of communication, social interactions and patterns of behaviour. These have become known, for good or ill, as the *triad of impairments*. Whether someone is intellectually gifted and eloquent, or has no speech, we might see similar characteristics in both.

Here's a conundrum then: if we are limited in recognising autism to behaviour, if the child with autism learns to behave in ways that are not considered 'autistic', are they

autistic any longer? Of course autism is more than observable behaviour: it is a way of thinking and experiencing the world (i.e., Grandin, 1995). Autism as a term encompasses people with profound intellectual disabilities (ID) and Nobel Prize Winners.

Whilst we might once have said the ‘spectrum’ of autism consisted of three distinct ‘groups’ or ‘types’, today we think this is less absolute. Still, some find the ‘three group’ spectrum helpful in terms of identity:

- Classic (or Kanner’s) Autism
- Asperger’s Syndrome
- Atypical Autism, sometimes confounded with pervasive developmental disorders (PDD).

Whilst each ‘type’ has unique indicators, it is true different people who’ve been diagnosed with one of these might appear no different to people ‘with’ a different ‘type’ of autism in some circumstances especially for support purposes (Wing, 1998). Therefore some ways of diagnosing autism have eliminated these three groups, combining them into a single ‘autism’.

People with autism like all humans have preferences and gifts at which they excel. Not all people with autism share the gifts outlined in fig.1, as not all those without autism (neurotypicals) do, but Vermeulen provides this as a guide to what you might encounter.

Gifts of people with and without autism	
With autism	Without autism
Literal Interpretation of Information	Contextual Interpretation (spirit of things)
Analytic Thinking (Not so Integrated)	Integrated Thinking (Not so Analytical)
Eye for Details (misses Big Picture)	Eye for Big Picture (Misses Detail)
Concrete Things & Facts (Vagueness not Welcome)	Abstract Things & Vague Ideas (Not So Good At Facts, Questions Literalism)
Rule Following	Living Between the Rules
Objectivity (‘Mind Blindness’)	Subjectivity (‘Theory of Mind’)
Realism (‘What Is’)	Surrealism (‘What Is Not’)
Perfectionism (‘Binary- Good or Bad’)	Flexibility (‘Shades of Goodness’)
Absolutes	Relativism
Calculations	Intuitive Feelings

Fig.1 Giftedness (adapted from Vermeulen, 2001, p.132)

We are some way from finding a simple and elegant explanation of what causes autism – perhaps there are, as Uta Frith suggests, long causal chains “of many kinds, including faulty genes, chromosome abnormality, metabolic disorder, viral agents, immune intolerance, and anoxia from peri-natal problems” (Frith, 2003, p.76), that lead to a myriad of neurological changes that may be profound or mild in their effect on the developing person. Having an explanation may change how we respond to autism. Regardless of causes and processes, whether autism is one thing or many, the outcomes can be profound.

Other ‘uncommon features’ that might suggest autism include particular sensory preferences: if the bedrock of autism is neurological as we believe the evidence suggests, the processing of the sensory world may be different between neurotypicals and people

with autism. It is not uncommon for autistic individuals to see, taste, hear and touch a wholly different world. Textures commonly enjoyed by many people may be highly obnoxious to an autistic person. It's best to ask the person: if they do not speak, they tell us through their reactions.

Best to leave the final comment of this step to someone who lives her life within the difference we name autism, someone who neatly twists our perceptions:

"My way of functioning has also meant that occasionally I find it difficult to show understanding of other people. I can't help thinking that people are rather pathetic in their need to be loved by everyone; that they are naïve not to be able to disregard their own feelings, to keep things and people apart, even. But usually I just feel sorry for them when they can't... But now I've realised I needn't be sorry for them, because they do gain something from what seems so troublesome to me. They think it's good to get so involved, and that people really are concerned about others. They perhaps even want to be drawn into conflicts and then complain about it, because they think it's just part of life. They don't always mean what they say: they can say something is upsetting when in fact they like it," (Gerland, 1997, p.245-246).

What I think when I talk about autism is that I'm describing a spectrum of impressions – and my fragmentary account is only one slither. The *other* thing I think about when I talk about autism is that for each and every given account of autism I espouse, I'm acutely aware of the exceptions. I might be talking about the research on theory of mind whilst in my head I'm wondering at the apparent exceptions I know – *and I'm worrying, are we neurotypicals labelling this on people with autism when really our own theory of mind is often pretty shockingly underdeveloped?*

### A Two Way Street? Theory of Mind

When people attribute thoughts and feelings to others, and then display an appropriate emotional reaction, we say they empathise. Watch politicians: those people know how to do this brilliantly, at least as long as the cameras are rolling or the mics are recording. Mostly. Those who don't empathise are often viewed as being indifferent to others. Empathising requires the skill known as mind-reading, or theory of mind. This is at the heart of much research into autism, because often people with autism are reported to be "not automatically programmed to think about mental states" in others (Frith, 2003 p.79).

Theory of mind suggests we attribute to people we meet thoughts and feelings other than our own: another person can know or feel things we do not; they may not know or feel what we know or feel. (This means neurotypicals (people without autism) can easily lie to people- this is both an evolutionary boon *and* a moral problem!) Evidence suggests children with autism are delayed in developing 'theory of mind' or it is learned later. Brain imagining suggests reduced activation of some areas when people with autism face theory-of-mind tasks. This 'lack' of theory-of-mind is often referred to as 'mind-blindness'.

Many neurotypical children have a well developed theory-of-mind (attributing thoughts & emotions to others becomes 'innate' or 'intuitive' early in their lives) whereas children with autism may have to work out the rules logically. This means autistic children can learn the benefits of theory-of-mind sufficiently to pass tests and muster in some social

situations. Increase the complexity of social interactions, however, and 'mind-reading' is a fundamental challenge. (One way to think of this is that children with autism say what they see sometimes *regardless* of the feelings of others, whereas neurological children know the social benefits of lying about how Grandpa smells.)

Uta Frith gives a telling example of the consequences of a not-fully developed theory-of-mind:

"Josef took a trinket from a whole box of things by lucky dip and put it in a cup. He then ostentatiously let the child look inside, making it clear all the time that I (who sat at the other end of the table) was not allowed to look inside. He verified that this was understood by asking: 'Did you *see* what was in the cup?' and 'Did Uta *see* what was in the cup?' Now the critical questions were: 'Do you *know* what is in the cup?' and 'Does Uta *know*?' Astonishingly half of the autistic children who were tested, said, 'Yes, Uta knows [what is in the cup],' when I had not seen the object and could not have known. All were at a mental age above that at which normal children could easily give the right answer" (Frith, 2003, p.213)

Note *half* of children with autism passed this simple test. If a child with autism learns the benefit of *logically* 'allowing' another an independent mind (to not *know* what they know), this hypothetico-deductive method is more protracted than for a child not affected by autism. People with autism may be obliged to comprehend the benefits of ascribing to others independent thoughts and feelings *the slow way*. Make a social situation more complex and the 'processing lag' (or interpretation of what is expected) will take longer. For people with autism, understanding neurotypicals is sheer hard and confounding work.

Theory-of-mind is a description of an issue rather than an explanation (Bowler, 2007). Social interactions are more complex than simply saying someone passes through intuitive or hypothetico-deductive methods to arrive at the idea others have their own knowledge or feelings. Some who see more fundamental issues impacting on people dispute theory-of-mind as an explanation of autism, but it *is* helpful in understanding what we might otherwise perceive as callous indifference.

Human interactions are a two-way street. Neurotypicals are profoundly gifted at not telling the truth and manipulating others (and themselves!) for their own benefits, but we seldom accuse ourselves of pathological indifference to the welfare of others. Neurotypicals are skilled at 'morally disengaging' (or 'turning down' their own theory-of-mind) with people in distress.

If theory-of-mind holds as one of the central issues for a person with autism, imagine the potential impact on communication and social interactions: one might appear uninterested in the welfare of others, unwilling to communicate when from the perspective of the person with autism, what the other person is saying is boring or not relevant. It can be argued then that theory-of-mind deficits are not unique to people with autism or other neurological conditions (we know people profoundly impacted by schizophrenia likewise struggle with theory-of-mind tests), but to more or less degrees by many humans.

Neurotypicals communicate in a code called language that is often illogical: we often don't mean what we say or say what we mean. Neurotypicals survive assuming contexts

are as relevant to meaning as actual words: people with autism are often left bemused and alone in such exchanges. To ascertain the *real* meaning of language, a degree of empathising is necessary.

*A man with AS (Asperger's) whom we met recently told us that he thought the question 'Where do you live?' was not a good question. 'What information are they after?' he asked. 'Do they want to know which country I live in, or which county I live in, or which city I live in, or which neighbourhood, or which street, or which house?'*  
(Wheelwright, 2007, p.171)

If someone is able to process the *literal* meaning of language rather than the *contextual* meaning, how might a person interpret the following terms?

- "Give me your hand"
- "Let's toast the bride"
- "It's raining cats and dogs."

It could be the person with autism answers literally, whereas the neurologically typical child might understand the metaphor or intended meaning. Who is more accurate?

Autism, then, is "a challenge of mutual understanding and a process of translation... Failure of understanding can go both ways. We have no idea what it is to see the world through the eyes of autism," (Happé, 2001, p.9).

This doesn't stop people talking about autism: for example, you'll hear, "people with autism are not creative". (Tell that to Bartók and Kandinsky. Tell that to the many actors and musicians and writers making a good life with autism.) You'll encounter, "people with autism have bizarre and selfish behaviours", at which point you might suggest to the speaker they go ask instigators of pogroms, people working in car sales, and politicians about selfish or bizarre behaviours, too. "People with autism are rigid thinkers" is a common trope, but consider the perspective of Vermeulen when he notes "*resistance to changing our ideas about autism is sometimes greater than that seen in people with autism. So noted a young man with autism, too, and the way he formulates it is clear proof of two facts: (1) people with autism can have a driver's licence and (2) people with autism do have a sense of humour: 'In May of 1989 I drove 1,200 miles to attend to 10<sup>th</sup> annual TEACCH conference, where I learned that autistic people can't drive...'*" (Vermeulen, 2001, p.24-25).

Gerland provides another example of how neurotypicals' own theory-of-mind abilities might be overstated:

"...if it looked like defiance, it had to be defiance. They measured me according to the way they measured themselves. They started with the premise that I was the same as they were, and if I wasn't really like them, then I ought to be," (Gerland, 1997, p.13).

Are neurotypicals so reliable that theirs is the only standpoint that counts? Do you think neurotypicals are *correct* to label autism a disability, to say *autistic spectrum disorder* rather than *condition* or *difference*? Are we so developmentally delayed we fail to understand the benefits of neurodiversity?

## Some Useful Items to Consider Exploring

Bowler, D. (2007), *Autism Spectrum Disorders: psychological theory and research*, Chichester, Wiley

Delfos, M.F. (2005), *A Strange World- Autism, Asperger's Syndrome, and PDD-NOS: a guide for parents, partners, professional carers, and people with ASDs*, London, JKP

Frith, U. (2003), *Autism: explaining the enigma* (second edition), Oxford, Blackwell

Gerland, G. (1997), *A Real Person: life on the outside*, London, Souvenir Press

Grandin, T. (1995), *Thinking in Pictures: and other reports from my life with autism*, New York, Vintage Books

Happé, F. (2001), "Forward", in Vermeulen, P., *Autistic Thinking: this is the title*, London, JKP

Vermeulen, P. (2001), *Autistic Thinking: this is the title*, London, JKP

Wheelwright, S. (2007), "Systemizing and empathising in autism spectrum conditions", in J.M.Pérez, P.M.González, M.L.Comí, C.Nieto (Eds.) *New Developments in Autism: the future is today*, pp.155-184, London, JKP

Wing, L. (1998), "The history of Asperger's syndrome", in E.Schopler, G.Masibov and L.J.Kunze (Eds.) *Asperger's Syndrome or High Functioning Autism?* London, Plenum