

Autism – myth and reality

Christian Jarrett talks to researchers, people with autism and their relatives, to find out what autism is really like

Public awareness of autism has grown immensely in recent decades, thanks in large part to the 1988 multi-Oscar-winning film *Rain Man*. But so too has the spread of myth and misconception. Today few terms are hurled about with as much hype and abandon as ‘autism’ and ‘autistic’: worryingly, it even appears to have some currency as an insult (tinyurl.com/q5t8mdb). Thankfully the pernicious idea of autism being caused by ‘refrigerator mothers’ has been virtually eradicated. Instead we’re fed a near-daily diet of inaccurate autistic stereotypes, vaccine scare stories, and claims of autism epidemics and miracle cures.

This article attempts to set the record straight. From the idea that everyone with autism has a hidden talent, to the notion that all autistics are unfriendly, I’ll debunk popular myths about the condition. At the same time, and with help from researchers, people with autism and their relatives, my aim is to convey a sense of what autism is really like.

Not everyone with autism is a genius

There’s an iconic moment in *Rain Man*, in which Dustin Hoffman’s autistic character counts in an instant the exact number of cocktail sticks dropped on the floor by a waitress. In other scenes he demonstrates incredible powers of memory and calendar calculation (identifying the day of the week for any given date). The success of

the film has helped spread the mistaken idea that all or most people with autism are savants, with these and other exceptional talents.

This myth has also been helped along by popular books about autistic savants (including a chapter in Oliver Sacks’s 1985 classic *The Man Who Mistook His Wife for a Hat and Other Clinical Tales*) and by frequent media reports on gifted people with autism. Examples include the animal welfare expert Temple Grandin, whose life story was turned into an HBO film in 2010; and the creator of photorealistic cityscapes Stephen Wiltshire, who has appeared in numerous TV documentaries.

Although many people with autism have islands of relative or impressive strength – for example, superb maths skills or attention to detail – the reality is that approximately .05 per cent of the autistic population has an extreme talent or genius-level gift (no one knows the precise figure, but this estimate is from the National Autistic Society). The idea that everyone with autism has a gift may seem like a positive misconception, but it can create difficulties for autistic people and their parents.

‘It can be really discouraging for parents of children who are less able,’ says Dr Liz Pellicano, an autism expert at the Institute of Education in London. ‘It can be damaging because there’s an immediate perception that their child must be good at something, and they might not be.’

Allison Shefcyk agrees. She’s a

research assistant at the University of Connecticut and was diagnosed with autism at age three. ‘We have interests and talents like many people,’ she says, ‘but to say that we are superior in any way, it’s like we’re trying to justify our existence alongside other people, as if we have to keep up this myth, or nobody will want us.’

People with autism can be friendly and caring

Perhaps the most hurtful of the myths about autism is the idea that people with the condition are, by nature, asocial and selfish. It’s true that social difficulties are a hallmark of the condition, and there is plenty of research showing that people with autism struggle with ‘theory of mind’ (ToM) tasks that involve putting themselves in other people’s shoes. However, it’s important to realise that ToM involves two elements – a cognitive component and an emotional component. Although people with autism often struggle with the cognitive challenge of taking another person’s perspective, there is not necessarily anything lacking in their feelings for other people’s joy and pain.

Michelle Duncan is the mother of a nine-year-old boy with autism, and was diagnosed as being on the autism spectrum herself just 18 months ago. She can understand why people might get the wrong impression that autistic people are uncaring. ‘I’m not an outwardly emotional person, and there are times when I don’t feel like mixing in a group,’ she says. But she adds, ‘I help other people to the extent that it’s a detriment to myself. And actually one of the most common features of autistic people is that they have an innate sense of justice – they can’t stand to see injustice around them, even if it’s not directed at them.’

Kim Southall can also understand how the uncaring/asocial myth has spread. Kim is the mother of a seven-year-old boy with autism and she co-founded the Autism Aware UK charity (autismaware.co.uk) with her husband

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The MMR vaccine does not cause autism

In 1998 the British paediatrician Andrew Wakefield and his colleagues published a small study in the respected *Lancet* medical journal that implied the MMR vaccine (for measles, mumps and rubella) plays a causal role in autism. The world's media sensed a scare story and they fed parental fears with years of sensational headlines. In fact, many large-scale studies have failed to find a link between the MMR vaccine and autism. The *Lancet* paper was retracted in 2010, judged to be flawed and fraudulent. The same year Wakefield was struck off the doctors' register after being found guilty of dishonesty and professional misconduct. The MMR/autism myth continues to cost lives, as vaccine rates struggle to reach pre-scare levels.

Jon. 'People with autism tend to be quite aloof and they don't know how to be in certain social situations,' she says. 'Some of them also don't like to be held close because they have a sensitivity to touch, but it's absolute rubbish to say that they're not loving or capable of love. Our son is really lovely and all the people I've ever met with autism, they've all been very loving.'

The myth of the unfeeling autistic person has also been given oxygen thanks to studies suggesting that, compared with 'normal people', those with autism are less prone to contagious yawning – interpreted by some researchers as an automatic marker of empathy. For example, in 2007 a team led by Atsushi Senju at Birkbeck College reported that 25 neurotypical children yawned more while watching yawning videos, whereas 24 children with autism did not.

Far less publicised, however, was a failed replication of that finding, published by the same group (Usui et al., 2013). This time the children with autism were prompted to look at faces in the yawning videos and they now displayed just as much contagious yawning as controls. This result 'corroborates previous findings that individuals with ASD can demonstrate behavioural contagion,' the researchers said.

People with autism do not have a broken mirror neuron system

A related autism myth concerns mirror neurons, one of the most hyped concepts in neuroscience (see my piece at tinyurl.com/qbupkco). Although the majority of research into the existence and function of mirror neurons has been performed in monkeys, this hasn't stopped

evangelists proposing that these cells are the neural source of human empathy, human culture and basic social skills such as imitation. Suggestions have followed from University of California neuroscientist Vilayanur S. Ramachandran, and others, that the reason people with autism have social difficulties is because they have a broken mirror neuron system.

In a cover article for *Scientific*

American in 2006 Ramachandran and his colleague Lindsay Oberman explained their reasoning: 'Because these [mirror] neurons appeared to be involved in

abilities such as empathy and the perception of another individual's intentions, it seemed logical to hypothesize that a dysfunction of the mirror neuron system could result in some of the symptoms of autism. Over the past decade, several studies have provided evidence for this theory.'

However, this early support for the broken mirror theory has not been sustained. In 2013, in a fatal development for the theory, Dr Antonia Hamilton at UCL, an expert on mimicry and imitation in autism, published a systematic review of 25 relevant studies including brain imaging and eye-tracking research. Overall, she found little evidence to support the broken mirror theory.

'I don't think it explains anything,' she says. 'It doesn't tell us anything that's specific to autism because we've got so many indications that children can imitate when they're getting the right inputs.' Contrary to the predictions of the broken mirror theory, people with autism

do not have an imitation problem *per se*, Dr Hamilton explains, but rather they struggle to decide when and how much to imitate – a subtle social skill that most of us take for granted.

Of course, some people with autism are unfriendly or uncaring, just as some neurotypical people are. But it's time to abandon the broken mirror theory and the related hurtful myth that lack of feeling and emotion is an inherent part of the condition. In fact, it is arguably the rest of us who need to show more understanding of what the world is like from the perspective of a person with autism.

Allison, the University of Connecticut researcher with autism, provides a clue. She likens life with the condition to visiting a foreign land. 'It's like taking somebody who talks a foreign language to a country whose customs and language they're not familiar with,' she says, 'and yet they're still expected to know the rules, and they get in a lot of trouble for not knowing them.'

Celebrating strengths, recognising difficulties

Central to a better understanding of autism is striking a balance – recognising the advantages of the condition, but also acknowledging the difficulties it can impose on people with the disorder and their relatives. Related to this is appreciating the huge variety on the autistic spectrum. At one end are those with severe autism, who may be non-verbal and unable to care for themselves. At the other, are those with Asperger's, for

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autism

whom the effects of the condition may be far more subtle (note that changes to US psychiatry's diagnostic code in 2013 mean Asperger's is no longer classified as a separate condition).

'People who are waiting for a diagnosis, all they tend to hear about are the negatives,' says Kim. When she first learned that her son could be autistic, she had a sense that 'I'm going to raise this child who won't do well at school, probably won't get a job, and will need care for the rest of his life.' Being a parent of a child with autism has been a challenge – no question. Kim's son couldn't speak until he was four, has full time one-to-one support at school, and needs medication to get to sleep at night. But now, aged seven, his reading, writing and numeracy are ahead of his peers. 'He's proved to us that no matter what people's perceptions are, or what you read, they are individuals, and they'll go at their own pace, and they can achieve anything,' says Kim. 'It isn't all doom and gloom.'

This is the message backed by groups like the Autism Friends Movement (AFM), whose aim is 'to educate the

public that the autism spectrum is not always a disability'. AFM and other elements of what's become known as the 'autism pride movement' also aim to give people on the autism spectrum their own voice. Everyone I spoke to welcomed this aspect of the pride movement.

'Much of current research is developed under what professionals believe parents need and want, but rarely ask us [people with autism] directly for our opinions; even when formulating research and policy that has a direct impact on our lives,' says Allison. 'Call it pride, call it perseverance, call it what you may; but speaking for yourself and others with the hope that they can have a better tomorrow is a wonderful thing that must be cultivated for people with autism.'

Controversy

Where things get more contentious is with the campaign by AFM and others against the development of 'cures' for the condition. 'We don't want to lose who we are and have future autistics wiped through genetic screening,' says the AFM

website. But not everyone touched by autism agrees with this approach. 'I understand why some people are offended by the term "disorder",' says Kim, 'but if somebody was to give me a cure, I would take it because I know how difficult life is for my son.'

Part of this controversy is about how to characterise autism – as a disorder or simply a different way of being. AFM state that autism is a 'difference to be valued'. In an article published by the Royal Society in 2009, the leading autism experts Professors Francesca Happé and Uta Frith refer to 'the beautiful otherness of the autistic mind'. Others go further. Michelle suggests 'exaggerated excellence' as a moniker for the condition. 'I think that when you're autistic anything you set out to achieve, you go that bit further – more into the detail,' she says.

But while these attempts to romanticise and celebrate the condition are laudable, they clash with many people's everyday experiences. Take, for example, the perspective of Dr Carl Walker, a psychologist and mental health expert at Brighton University. He

Creativity

I've heard it said I'm some quaint, programmed husk
Who cannot think beyond a rigid box.
Cold facts, harsh figures, dance at my fingertips
While sweet imagination slips me by.
But I can spot the spondee in a verse
And signpost trochees, dactyls, and iambs;
Uproot acrostics in a pyrrhic rush,
Uncover the choree and the dibrach.
The anapaest and amphibrach are clear
As colours in a painting, to my mind.
The cog-wheels of each line keep churning round
As dative clauses latch onto the vine.
And I can spot grand theories spinning round
And sit back as they crash, crumble, and die.
And then I pick the pieces up, and form
Afresh, new truths from old malignant lies.
And what about the beauty of the box?
Why ever would I want to think outside?
When I can grasp its roots and functions, and
Gain a creative angle you're denied?
My world's not yours.
I spy what you cannot
And yet am blind to what you clearly see.
We're different, yes.
But don't infer from that
That my brain lacks your creativity.

By Jonathan Andrews, a 20-year-old with autism, for the Create Art for Autism competition – see www.createartforautism.com. For more of Jonathan's work, see tinyurl.com/omz9vcu and tinyurl.com/ppf3n6h



remembers the troubled school days of his older brother, who has a diagnosis of Asperger's and is unemployed. 'I like the idea of celebrating otherness,' Dr Walker says, 'so there's something very attractive and seductive about [Happé and Frith's] description, but unfortunately 16-, 15- and 14-year-old angry young men at school don't have the capacity to see and understand beautiful otherness.'

For people with less severe autism or Asperger's, who attend mainstream schools, Dr Walker's assessment is blunt: 'It can be a fucking horror show,' he says. 'It's dreadful. Much of the legacy that people with autistic spectrum disorder have comes from the exclusion, the marginalisation, the abuse, the difficulties they have at school, trying to fit into a world that doesn't make sense to them.'

For a further sense of the reality of autism for many, it's perhaps also worth heeding the findings from a recent study that investigated the current status of 60 people first diagnosed with autism as children between 1950 and 1979 (Howlin et al., 2014). Although they all have intelligence in the 'average range' (i.e. an IQ of over 70), Patricia Howlin and her colleagues found that only 27 per cent of them were now living independently or semi-independently – the others were being cared for at home or in a residential facility.

Looking ahead

Unfortunately, the desire persists among the media, and some experts, to encapsulate autism in a single unifying theory. Last year, for example, an article about the new 'intense world' theory of autism (tinyurl.com/p5o6879) attracted great interest. Developed by the head of the EU's ambitious Human Brain Project, Henry Markram (who has an autistic son), and his wife Kamila (a neuroscientist and autism researcher), the theory proposes that the strengths and impairments of autism are caused by oversensitive sensory and emotional systems in the brain.

Although well-intentioned, this new theory, and others like it, risks falling into the old traps of oversimplification and romanticisation. Like the broken mirror theory it could also be plain wrong and, when promoted too rapidly, lead to misguided treatments, such as the withdrawal of stimulation. Writing for the Simons Foundation Autism Research Initiative (see tinyurl.com/k25kteo), Professors Anna Remington and Uta Frith pointed out that there is in fact huge variation in sensory sensitivity among people with autism, and they fear that the deliberate, routine



Is there really an autism epidemic?

It's true the number of children being diagnosed with autism has increased hugely over recent decades. There was a five-fold increase in the UK during the 1990s alone, although there's evidence this rise had plateaued by the early 2000s (Taylor et al., 2013). According to the National Autistic Society, the prevalence in the UK is now around 1 in 100, although they warn that this is an approximation. In March 2014 the Centers for Disease Control and Prevention in the US declared that the prevalence in that country is now 1 in 68 (this compares to a prevalence estimate of 1 in 150 in 2002).

The dramatic increase in rates of autism has led to scare stories about possible causes (see box on MMR vaccine), and research into possible environmental causes, such as air pollution (Volk et al., 2013). However, the reasons for the rise are currently subject to debate, and many experts think it is probably almost entirely due to a mix of broadened diagnostic criteria and greater awareness of the condition.

Such an argument was supported by a study published in 2008 by Dorothy Bishop and her colleagues. They studied 38 adults diagnosed with a developmental language disorder (but specifically *not* autism) in their childhood, and found that 12 of them would meet contemporary diagnostic criteria for autism or autism spectrum disorder.

withdrawal of stimulation could be a harmful approach.

The pair are also concerned about the Markrams' claim that this minimisation of environmental stimulation could be a way for parents to unleash their autistic children's inner genius. In an interview with the *Huffington Post* (tinyurl.com/lot68ec), for example, the Markrams stated that 'We actually think if you could develop a filtered environment in the early phase of life you could end up with an incredible genius child without many of the sensory challenges.' Sadly, this kind of talk risks sending the message that autistic children's worth is tied to their having some hidden super ability (the very sentiment that we heard earlier is resented by Allison and other people with autism).

Final thoughts

The reality is that the simple term 'autism' conceals a world of complexity. A recurring theme to emerge from my

conversations with parents, researchers and people with autism was the diversity of autism experiences. For some people, autism may truly seem like a gift. For others, it has made life intolerably difficult. And there are acres of ground between these poles. We need to respect these differences and avoid the temptation to simplify the autism story.

We must also be careful with the language we use – talk of disorder and cures can be offensive to people who feel their autistic nature is a fundamental part of who they are. That doesn't mean they don't want help. It does mean recognising that people with autism have feelings, giving them a voice, and being sensitive to the way we discuss the challenges they face in world that's dominated by 'neurotypicals'.

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