What *is* autism, anyway?

Eilidh Cage with the latest in our series for budding writers
(see www.bps.org.uk/newvoices for more information)

> Whereas young children and dogs attach themselves to a given caregiver, cats seem to be far more independent. With that in mind, perhaps people on the autistic spectrum are more like cats than dogs? As a cat owner, I know my pet loves me in her own way, but she interacts on her own terms, not mine. Perhaps that's what autistic people do too?

These words come from some correspondence with one of my research participants, who has Asperger's. What he highlights, to me, is the fact that we still don't really know what autism is, despite decades of autism research. The fact that the criteria for diagnosing autism in the new version of the *Diagnostic and Statistical Manual* (DSM-5: American Psychiatric Association, 2013) re-categorises and redefines autism demonstrates this ensuing definition problem.

Many people will have had no experience of autism. Conversations about my PhD with others – the hairdresser, the dentist, people within academia but outside psychology – suggests that even if they have not met an autistic person, they may have a general idea of what autism might be. This is often the stereotyped view of autism, perpetuated by the oft-cited film *Rainman*, and now by more modern fictional characters, such as Sheldon from *The Big Bang Theory* (although his diagnosis is not explicit, see http://bit.ly/145wz4w). Outside of the fictional world, autism can be found in documentaries, such as Channel 4's *The Undateables*, to frequent stories in the news postulating potential causes of autism. It feels like autism is more in the public eye than ever before, and understandably, people may form ideas of what autism might be.

Yet, despite doing my PhD about autism, I often feel confused about what autism actually is. Every research article I read chants the same catchphrase: 'Autism is a neurodevelopmental condition, characterised by social and communicative difficulties, and restricted and repetitive behaviours and interests'. Although this wide definition does cover a general sense of autism, I don't feel it quite captures how an autistic individual might describe what it's like to have autism, or how a parent would describe their child with autism.

So who can tell us what autism is? People with autism themselves are a natural place to start, and there are many eloquent examples. The well-known Temple Grandin (2006) has given us all an insight into her life, as well as others like Wendy Lawson (2000) and Donna Williams (1992). However, this may only give a view from the intellectually able end of the spectrum. Recently, author David Mitchell translated the memoirs of a non-verbal 13-year-old Japanese boy, Naoki, with severe autism, who originally wrote his memoirs by pointing to the letters on a piece of cardboard (Higashida et al., 2013). This account beautifully portrays how Naoki experiences the world around him. Every account is different, and highlights this diverse spectrum of individuals with autism.

When we read about autism research, though, how much of it tells us something about this spectrum? In psychology, we strive to match our groups – for example, you might match individuals on their age, gender and intelligence score, to ensure that any differences between your groups are not due to these variables. However, this matching process presents a problem – many autistic individuals inherently have language difficulties that will affect how they perform on tests of verbal ability, making it difficult to match them to those without autism. So the group of autistic individuals you often end up with constitutes a representation of those who have better verbal ability (e.g. Asperger's and 'high-functioning' autism), surely limiting the picture of what we really know about autism as a highly heterogeneous condition.

The fact that autism forms such a wide-ranging spectrum may be part of the problem with deciding how we define autism. Yet, those who have developed typically show great variance in their personalities, likes and dislikes, and sociality. If we 'neurotypicals' (those who developed 'normally') can accept one another's differences, can we not accept too that autistic individuals show great variation in their personalities, likes and dislikes, and sociality? For me, this acceptance is what we should strive towards, if we were to live in a perfect world. Through my research and volunteering experience I have met some of the most brilliant, honest, warm-hearted children and adults – all with autism in varying severity. Surely autistic individuals deserve to have the right support and understanding to enable them to have fulfilled lives?

Perhaps psychological theory can tell us more about what autism is. Happé & Ronald (2008) argue that autism is 'fractionable' – that the three core

references

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th edn). Arlington, VA: American Psychiatric Publishing.

Bauminger, N. & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child Development, 71*(2), 447–456.

Cage, E., Pellicano, E., Shah, P. & Bird, G. (2013). Reputation management: Evidence for ability but reduced propensity in autism. *Autism Research, 6*(5), 433–442.

Calder, L., Hill, V. & Pellicano, E. (2013). 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism, 17*(3), 296–316.

Frith, U. & Frith, C. (2011). Reputation management: In autism, generosity Is its own reward. *Current Biology, 21*(24), R994–R995.

Grandin, T. (2006). *Thinking in pictures.* London: Bloomsbury.

Happé, F. & Ronald, A. (2008). 'The Fractionable autism triad'. *Neuropsychology Review, 18*, 287–304.

Higashida, N., Mitchell D. & Yoshida, K.A. (2013). *The reason I jump*. London: Sceptre.

Izuma, K., Matsumoto, K., Camerer, C.F. & Adolphs, R. (2011). Insensitivity to social reputation in autism. *Proceedings of the National Academy of Sciences, 108*, 17302–17307.

Lawson, W. (2000). *Life behind glass: A personal account of autism spectrum disorder.* London: Jessica Kingsley.

Pellicano, E., Dinsmore, A. & Charman, T. (2013). *A future made together.* London: Institute of Education.

Williams, D. (1992). *Nobody nowhere.* Canada: Doubleday.

difficulties in autism (social interaction, communication, and restricted and repetitive behaviours and interests) are separable, with different genes underlying each, and each manifesting themselves with varying severity. By this account, there is no single cause of autism, and each individual will have different degrees of each symptom. Another way of encapsulating autism comes from Christopher Gillberg, who claims that autism rarely exists on its own – it is almost always associated with other disorders, such as attention deficit hyperactivity disorder, specific language impairment, or obsessive compulsive disorder (http://bit.ly/1az08f2). He argues that we should not focus on 'the autism', but these comorbidities too, in order to gain a full understanding of each individual. Both of these accounts lend to an approach of considering the individual when it comes to autism.

In my own PhD research, the results of my first study with autistic adults were considerably more confusing than anticipated, which may in part have triggered my questioning of what autism really is. I came to the conclusion that it is not a simple case of autistic individuals completely lacking an ability to do one thing – rather, there are a number of factors that reduce the likelihood that they show the 'neurotypical' behaviour. In other words, we shouldn't immediately assume that an autistic person cannot do something – rather there might be a myriad of reasons why they don't. For example, my research focuses on the fact that people change what they're doing when other people are around, probably so they can maintain a good reputation. Those with autism, however, don't give more to charity when they're watched (unlike typical adults), perhaps due to difficulties with thinking about what other people are thinking (Izuma et al., 2011).

In my study (Cage et al., 2013) we gave our participants a reason to change their behaviour when watched – that the person they were donating money to was not only watching them donate, but she would have the chance to donate to them next. Here, you can essentially manipulate another person to get some more money – and while autistic adults did change their behaviour slightly in this situation, they did not change it as much as the typical participants, who gave the person watching considerably more money. One possible reason autistic adults changed their behaviour less could be because they are less drawn to this need to manipulate. Such honesty in autism has been noted by many before (Frith & Frith, 2011), and perhaps we can learn a few lessons from it. Why is it that typical individuals often lie, manipulate and protect their own image?

Are autistic adults less drawn to the need to manipulate behaviours?

One of the reasons many of us find psychology so interesting is because we don't really understand why people do the things they do. This is probably why people with autism add in a whole new dimension of intrigue for researchers. However, this can sometimes come across as a search for 'deficits' and 'disadvantages' compared to typical people, with discussions of 'impairments' and 'failures'. Although this is not intentionally harmful, researchers should try to be careful with their phrasing.

When another psychology PhD student asked what my research was in, I broadly told her 'autism'. I was taken aback by her reply: 'Ugh – autism. Everyone's researching that. I'm so bored of autism'. Indeed, a lot of people do research autism, but this is not without good reason. Autism has a real impact on people's lives, and its incredibly important research helps give those with autism the best chance at life. However, a recent survey of autism research in the UK from my research centre found that many people with autism and their families report a discrepancy between what they want to be researched and what British researchers are actually researching (Pellicano et al., 2013). Autistic adults reported that they would be most interested to see research into how public services can best meet the needs of autistic people. Research by the National Autistic Society suggests that only 12 per cent of adults with autism are employed, even though many could do well working in a structured environment (http://bit.ly/1k6M8Pu). Why are so few employed? Imagine how it must feel to have autism in such a social world, where job applications so often specifically ask for 'excellent interpersonal and communication skills'. Yet autistic people are capable of being social, and evidence suggests that many do want to have friends, even if they may find it difficult to make them (Bauminger & Kasari, 2000). On the other hand, some individuals with autism just want to be alone (Calder et al., 2013). Understanding more about autism could help autistic individuals to gain and hold down full-time employment.

We can all do our bit in accepting autistic individuals and understanding the struggles that families may face, even if we don't know exactly what autism is right now. We can do this by a number of means. As researchers, perhaps thinking of ways of engaging – for example, forums where voices can be heard and listened to – is one way of guiding research towards important issues that autistic individuals and their families feel need to be addressed. Autistic voices are just as interesting as autistic brains. There should also perhaps be more dialogue between clinicians, teachers and academics so that we are all on the same page before we listen. The next generation of autism researchers (myself included), also need to be aware of the ethical issues linked to autism research, so that we produce the best possible research.

So what is autism? Autism could not be what we think it is. Autism is something we'll probably never all agree about. Autism is not just found in children. Autism is close to many people's hearts. Maybe, people with autism are a bit like cats.

Eilidh Cage *is a PhD student at the Centre for Research in Autism and Education (CRAE), Institute of Education, University of London*
e.cage@ioe.ac.uk