Autism – are we any closer to explaining the enigma?

Uta Frith introduces a special issue

Autism is a developmental disorder characterised by impairments in social interaction and both verbal and non-verbal communication, along with restricted, repetitive or stereotyped behaviour. Following more than a quarter of a century of extensive research from psychologists, are we any closer to explaining the enigma? Has stretching the diagnostic boundaries helped or hindered scientific and practical progress? A critical step in ‘solving the puzzle’ of autism is to consider the myths and realities surrounding autism, both for those living with it and their relatives. This issue gathers a variety of perspectives from those people and from leading researchers in the field.

At this time about 25 years ago I was nervously awaiting readers’ reactions to my book. Having been persuaded to go with the title Autism – Explaining the Enigma, I knew for certain that I hadn’t explained it. I had laboured on it for years and years, and most of the time I felt ‘Who am I to even try and write such a book?’ The main antidote for this feeling came from fellow psychologist John Morton, who took me from draft to draft with words like ‘you have something to say, so say it’.

In those days, books on autism were a rarity, and people were just beginning to ask what autism was. The film Rain Man, starring Dustin Hoffman and Tom Cruise, was a milestone in the rise of public awareness of autism. I remember how difficult it was for bookshops to decide which of their sections was suitable for the book. Mostly, it was placed with psychiatry texts, and ironically Frith was placed next to Freud. I would have much preferred to be placed with books on experimental psychology, because I believe that psychology provides the space where the enigma might eventually be solved. I could not imagine then that there would be a time when books on autism fill their own section, and when there would be this special issue of The Psychologist.

Almost as soon as I had finished the Enigma book, I became hopelessly attracted to Asperger syndrome. With time I met an increasing number of unusual adults with a provisional diagnosis of autism, who amazed me because they were far more able to converse than the now grown-up children whom I had first seen when I started doing research on autism in the 1960s. What struck me was their ability to provide insightful observations about their experiences. That opened up completely new possibilities to investigate the autistic mind. Adults like this had been mentioned by Hans Asperger in his landmark paper from 1944. I set about translating this paper and got in touch with other researchers who were similarly struck by these individuals, and the result was a book on autism and Asperger syndrome. I never anticipated how dramatic the impact of the concept of Asperger syndrome would be in the brief history of autism. Many psychologists and psychiatrists had only just become aware of autism, and now they had to embrace a whole autism spectrum (Wing, 1996). I believe the impact is still felt even if the label Asperger syndrome no longer appears in the 5th edition of the Diagnostic and Statistical Manual of the American Psychiatric Association.

One of the positive effects of the interest in Asperger syndrome is that we now know that autism can occur at all levels of intellectual ability, including very superior levels. On the negative side, this makes us sometimes forget that about half the cases diagnosed with an autism spectrum disorder suffer also from a marked degree of intellectual disability. It is this substantial group that presents the most challenging behaviour and the most difficult problems of management. However, problems in managing life cannot be blamed on intellectual disability. Instead they are the consequence of the profound social communication problems that are at the core of autism. In a truly epic study that reported a 40-year follow-up of 45 autistic individuals with an IQ >70, Howlin and colleagues (2013) found that 83 per cent were unable to live independently. Here is a plea for psychologists to take up their cause. Now I stick my neck out to mention another unforeseen side-effect of stretching the diagnostic boundaries. With more lenient criteria and heightened awareness of autism, the diagnostic process will inevitably produce false positives. Thus, there are individuals with problems in social relationships and other features that are reminiscent of autism, who have either claimed or been given the label Asperger syndrome, but actually belong to a different category. Sadly, this category is as yet undefined and may even be part of neurotypical individual variation. Meanwhile these people have changed the perception of what the syndrome is like. This perception is currently geared to emphasise the continuity between neurotypical and autistic development. While I like the idea of neurodiversity, I am not so sure that this necessarily means that there are only quantitative differences between people. The argument is also geared to deny that the nature of autism can be explained by cognitive
deficits. I find this problematic – but, given that I have thought and written about cognitive deficits in autism all my life, I would say that, wouldn’t I?

My deliberately provocative suggestion is to reconsider the mildest of the mild cases of Asperger syndromes. Perhaps these individuals should be classified as having ‘autistic-like personalities’ rather than an autism spectrum disorder. Everyone agrees that there is an enormous variety in all our individual experience and histories, just as there is in our personalities and temperaments. Not everyone is an extravert and happy only with other people. Some display little emotional warmth and some are narcissists that do not care very much about others and often don’t pay much attention to other people. There are also perfectly neurotypical tendencies that tend to make life difficult: pursuing a specialised interest, being obsessive, enjoying strict routines, dithering over decision, and so on. It seems to me entirely plausible that combinations of these social and non-social features can occur in one and the same person and can then present an autistic-like picture. Human social relationships are extremely complex, and failure is common. It is very desirable to be able to explain such difficulties without blame for the individual. They are indeed often outside the individual’s control. This is true for many medical conditions. Now if autism is a medical condition it can provide a ‘no-blame’ explanation. This would explain why perfectly neurotypical people like the idea that they – or one of their neurotypical friends – may be a ‘little bit autistic’. However, there is a conundrum. If you follow the argument above, these individuals do not have a medical condition. They may feel different from other people, but aren’t we all different and don’t we all have our problems?

And this is how I understand the campaign for neurodiversity. It would make perfect sense, for some people, to argue for abandoning the idea of autism as a separate and pathological condition. After all, these individuals do not suffer from any ‘condition’, and it is indeed wrong to say that they have cognitive or emotional ‘deficits’. They just have problems that might be a little bit worse than those of many other people. However, although I am entirely on the side of the neurodiversity campaign, I draw a line at including the whole of the autism spectrum. I am very well aware that this argument is still running and that it will take a lot of discussion and also empirical research to find out whether the line I want to draw can really be drawn.

But here is the line I would like to draw: people with autism really have a very different mind and different brain. To me this has always been what attracted me most to autism. It is very rare and a precious gift to get a glimpse into another mind that operates on different assumptions and with different premises. However, there need to be other voices in this discussion. Should we believe only in continua and quantitative differences, or by contrast, in categorical and qualitative differences? This is an enigma that is tantalisingly hard to resolve. I know which side I am on, but I am prepared to change my mind if the weight of the evidence convinces me.

Are we getting any closer to solving the puzzle? A critical step in this journey is to bust myths that have accumulated and to listen to voices from all parts of the community and from all those who are directly touched by autism. Myths and truths about autism have been intertwined in the many representations of autism in literature and film and our attitudes are often conflicted. We like to see autism as an interesting personality variant with potential for creative genius. This is what films and fiction mostly portray. We can also see that autism can be a terrible obstacle to living an ordinary life. We find it easy to be sympathetic to young children with autism, but often hard in relation to some adults, let alone old people. If the voices of people with autism are also heard they will give an important counterbalance to researchers’ and professionals’ pronouncements. Only by putting together many different viewpoints will we eventually know what autism is really like.

The sheer quantity of publications and its presence on many dedicated web pages confirms that autism research has thrived in the last 25 years. It has flourished in particular in the UK, and some of our most talented psychologists are represented in this issue. It is thrilling to me to think that the UK still has a head start in the psychology of autism.