

# UTA FRITH

... on how much we have learned about autism,  
but how much more there is still to understand



Uta Frith is Emeritus Professor of Cognitive Development, University College London. She was elected a Fellow of the British Academy in 2001.

**At an event held at the British Academy in 2012 to celebrate women in the humanities and social sciences, you spoke about the empowering influence of your mother.**

I think I always dimly knew what a tremendous debt I owe to my mother, but I've expressed this only rarely. Although she never went to university and did not even have a secondary education, she was passionately interested in art and music, and particularly in poetry. I was told that, when I was asked as a tiny tot what I wanted to be when I grew up, I said 'Gedichterin' (a made-up word for poet-ess). What this tells me is that my mother gave me the confidence to be what I wanted to be, and that I modelled myself on her from very early in life.

Mothers are an extraordinary power source. They shape our attitudes and aims in very individual ways, different from the larger cultural context.

**You studied experimental psychology in Germany and then trained in clinical psychology in London.**

**As you have worked to understand aspects of human behaviour, where for you has been the balance between scientific curiosity and improving the lives of real individuals?**

I remember struggling with this question while training for clinical psychology. There was a fork-ing path: should I go into practice, and try to help people here and now, or should I try to do research in a lab, detached from real life? This has occasionally recurred as a dilemma for me, but it has always been resolved in favour of the ivory tower.

I still think that basic research, actually, blue skies research, is a vital necessity, if you really want to help people with mental health problems. And it is also necessary to distance yourself from the immediate urge to do something practical.

**Can you summarise what our current understanding of autism is?**

I have to give a rather personal view here. This is because I've been involved in autism research for nearly 50 years, starting when it was hardly known.

So what kind of thing is autism? It turns out that it is not one thing, but there are many varieties, forming what is now called the autism spectrum.

This covers a hugely heterogeneous group of people, but all individuals on the spectrum have this in common: they have characteristic difficulties in social communication, and they have repetitive and restricted interests and behaviours. These difficulties turn out to be highly detrimental to everyday living.

What causes autism? I think it's true to say that almost all cases of autism have genetic causes, often from *de novo* mutations, and these causes are likely to be different in different individuals. It helps to see that blind chance is at work here, and therefore autism is not something we can blame somebody for. We have tried to in the past, but it is time to give up on this idea. For me there is no way round the assumption that there is malfunction of some particular circuits in the brain, and this leads to the characteristic constellation of behavioural signs and symptoms. The critical link in the chain from genes to behaviour is that mental development is affected adversely.

To me autism is something of an unwanted side effect of evolution. The developing brain seems to be vulnerable in respect of just those accomplishments that we human beings pride ourselves in: our language and our extraordinary ability to negotiate a complex and seemingly unpredictable social world. Perhaps these accomplishments are a bit like the icing on the cake, where the cake is made up of many amazing abilities and skills that we share with other animals. The icing is very visible and glamorous compared to other animals, but if something is wrong with it, this does not mean that the rest of the cake is necessarily wanting. I always marvel at the fact that many important mental functions remain intact in autism.

I am a little at odds with current thinking, which is keen on blurring the boundaries between people

on the autism spectrum and the rest of the population. I can see why, and particularly when we look only at the milder end of the spectrum, Asperger syndrome. These are individuals who are highly intelligent and can therefore learn to compensate for underlying abnormalities. As the term compensation implies, I believe that they still have the characteristic dysfunction, in the mind and in the brain, but they manage to find ways around this and camouflage problems in their behaviour.

The irony is that I have to some extent been

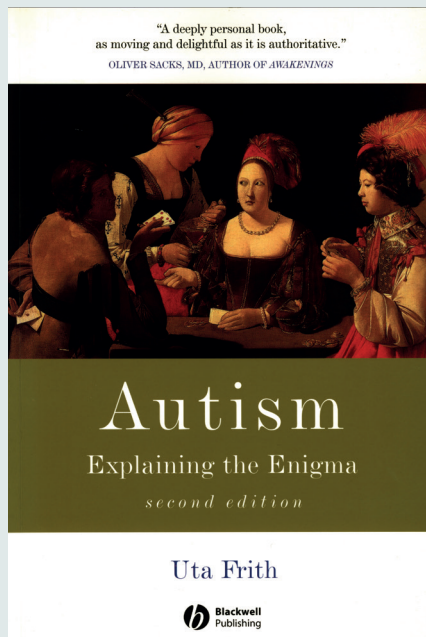
responsible for putting these fascinating individuals into the spotlight. In the early 1990s I translated Hans Asperger's oddly overlooked 1944 landmark paper and edited a book that promoted the idea of extending the autism spectrum to include cases such as he had described. Before then autism was strongly linked to intellectual disability. Now I am somewhat taken aback that Asperger syndrome tends to be seen as the more typical and common form of autism.

I think we need to remember that autism is a very debilitating condition for at least half of those diagnosed. I keep thinking of the many autistic individuals I know who are very handicapped by their dire intellectual limitations and heart-rending inability to communicate. Here compensatory learning is a call too far. It is romantic to think, and also misleading, that such individuals must have a rich inner life, and if only they had the means to communicate, all would be well. And there have been attempts to reveal this rich inner life by a now thoroughly discredited technique referred to as facilitated communication (carers guide the arm or hand of the typist over a keyboard). It is quite upsetting to me that there are still stories circulating that reinforce this idea, trading on false hope.

#### How does autism usually manifest itself?

No two autistic individuals are alike. In the severe case there may be no language at all and there may be repetitive movements that lead to self injury. In the mild case, language competence may be at a high level and there may be only a touch of rigid and inflexible behaviour. Above all, there are big changes with age. For example, in infancy, one sign is a lack of response when being called by name; at pre-school, being oblivious to other children will come to the fore; at school, being preoccupied with narrow interests; in adulthood, one sign is not being able to sustain friendships. The sheer variety of behaviours is one of the reasons why diagnosis is very complex and relies on clinical judgement.

So how do we pull together this variety to explain the core features of autism that unite all cases on the spectrum? Autism researchers in the UK, from the 1960s, when I myself started out, have been guided by cognitive theories. They are called cognitive, not because they exclude the emotions – they absolutely don't – but because they focus on how the mind processes information. After all, this is what the mind/brain does. A lot of empirical work backs up the idea that information processing is interestingly different in autism, both in the social and in the non-social domain. This leads to advantages and disadvantages. For example, you may become a specialist in stick insects, and this may enable you to spot creatures that others would be unable to see, but it can also make you unable to tolerate small changes in your daily routines.



### As our understanding has developed over the last 50 years, have there been any particular moments of breakthrough?

On the whole, it has been a gradual process.

But, well, perhaps you could say that there was a breakthrough in our understanding of the precise nature of the social impairments in autism. This did not come out of the blue, but it was still a novel idea in the early 1980s. Here is the key notion: there is a purpose-made gadget in our human minds and brains that makes us able to see the invisible intentions of other social agents – and autistic people don't have this gadget.

It's still a strange idea. I think the most amazing aspect of this ability is that we automatically track the inner states of other people – and also our own mental states – just as if we had a social GPS. If we assume that it is missing in autism, we can explain why their social interactions are so characteristically off kilter, and why they find it almost impossible to go with the flow of a conversation, even if they have excellent language. It is as if they have to use a map instead of a GPS, a slower process, and clearly, not everyone can become an excellent map reader.

Try to imagine your social GPS is missing. You would not spontaneously think about intentions, desires and beliefs. You would not instantly assume that if Sally believes her marble is in her basket, then she will look for her marble in the basket, even if you know it is not there (Figure 1). You would have to work it out by long-winded logic.

Perhaps you would feel like a true behaviourist who says, 'I don't care what happens inside the black box of the mind, I simply observe behaviour. That is enough for me.' That sort of stance might well be found in an autistic person. It could be this stance that makes them so naïve, so honest, and so apparently untouched by things imagined or believed. But it can also make them intolerant of the way that we normally talk to each other. This always involves a bit of give-and-take, a bit of manipulation, aggrandising certain things that we might have done, minimising others. Likewise, when we listen to others, we always read between the lines and don't take utterances literally. These are tricky things for autistic people, and it is no wonder that they prefer to watch factual programmes on TV rather than soap operas.

Oliver Sacks has used the nice phrase 'an anthropologist on Mars'. The autistic person lives in a world of apparently hyper-social creatures, and what these creatures do requires deep study to make sense.

### You use the term 'mentalising'.

It's a deliberately strange word for a strange process: 'automatically taking mental states into account in order to explain and predict behaviour' – such a mouthful! We simply had to coin a new word for this ability, and mentalising seemed to stick.

Another term for it is 'theory of mind', which is quite popular. I don't like it as much, because it pretends that we consciously hold a theory about mental states. Well, some philosophers might, but I doubt that ordinary four-year-olds do.

### Has our understanding of autism developed through observation or specific experiments?

These are different sources that need to converge. In my own case, first insights have often come through observation, talking to parents and teachers, talking to clinicians, and through reading the work of other researchers. Such an insight is like getting a magnifying glass. It might enable one to see something that was not visible with just a list of anecdotes.

But in order to develop and test a theory from a first insight, rigorous experiments are essential. Once

you have a hypothesis, let's say about mentalising, you can design a task that requires mentalising, and another task that doesn't, but is identical in all other respects. Then by comparing the two tasks, you can find out what happens in behaviour, and what happens in the brain, when a person is engaged in mentalising.

**A gadget in our human brains makes us able to see the invisible intentions of other social agents – autistic people don't have this gadget.**

### Have there been any blind alleys in the research?

There have been lots of blind alleys! Observation, reading the literature, having good ideas and doing well-designed experiments – these still do not prevent blind alleys. There has to be a bit of luck. You have to try many different things. You can't just gamble on one idea. There were many different ideas, and some emerged as being stronger than others. But even the stronger ideas are far from being explored fully.

### There are now more diagnoses of autism. Is that because we are better at diagnosing, or because, with increased public awareness, more parents are presenting their children for diagnosis? Or is it that there are just more definitions of autism now and a wider spectrum?

All of these things are true. But the main thing is that our idea of autism – and the criteria that need be fulfilled – have widened enormously. They are so wide now that I fear they will have to be retracted again, or some subdivisions will have to be made. Before we took account of Hans Asperger's clinical descriptions the criteria were too narrow, and many individuals were missed who should not have been. There has since been a tendency for the pendulum to swing in the opposite direction.

It has been fascinating to observe how much

people have become aware of autism as a condition that affects at least 1 per cent of the population. I remember talking to an old classmate of mine at a reunion in the 1980s. He had become a busy paediatrician and had seen hundreds, probably thousands, of children. I was very surprised when he said he had never seen an autistic child. Now I would expect quite a different response.

Autism now appears everywhere, in the press, in films, plays and books, and this is a good thing on the whole, but it can also give rise to misunderstanding. In fiction an autistic person will inevitably be portrayed as a savant – someone who is absolutely brilliant at something like maths. This has become the essence of autism in the public imagination, but it's a distortion. It is very rare to find these extraordinary specialists, and many parents of autistic children feel distressed when everyone expects them to show some astounding talent, and they just don't.

**When there is a diagnosis of autism, what is the reaction of the patient?**

If you have a diagnosis in early childhood, when autism becomes obvious, the child would not know, and you often hear parents asking 'When can we tell them? Can we tell them at all?' Often it turns out that it is not hard to do this when the time is right. It can come as a relief.

It can also come as a relief to people who have discovered their diagnosis as adults, often having worked it out themselves. It gives an explanation for the characteristic problems they have to struggle with. They can now negotiate with their family, letting them know that certain things are impossible for them, even though they seem incredibly easy for everyone else.

**Do you think we are now in danger of medicalising ranges of normality?**

I do understand when people are worried about the medicalisation of what might simply be personality variants. In the colourful rainbow of individual differences there must be a space for the personality who is egocentric, single-minded and socially inept. Providing a medical term seems like giving an excuse for behaving badly. I would argue that such an excuse is acceptable where a significant mind/brain abnormality exists.

Here it would be harsh to hold affected individuals responsible for their problems. This is one of the reasons why I am clinging to categories, not just positions on a continuum. With a well-defined medical category we are able to say, 'Oh well, they can't help it. They need support.'

This is autism.' This is similar in the case of blind people. If we know they are visually impaired, we are prepared to give help.

**How do you react when the allegation resurfaces that some cases of autism may be linked to the MMR vaccine?**

This is a story that refuses to die. When the theory was first proposed, it was taken very seriously by researchers, including me. It was tested in substantial investigations in different countries, comparing data before and after the triple vaccination was introduced. These studies gave conclusive evidence that MMR vaccination did not cause autism. Sadly, the belief in MMR as a cause of autism persists despite the evidence.

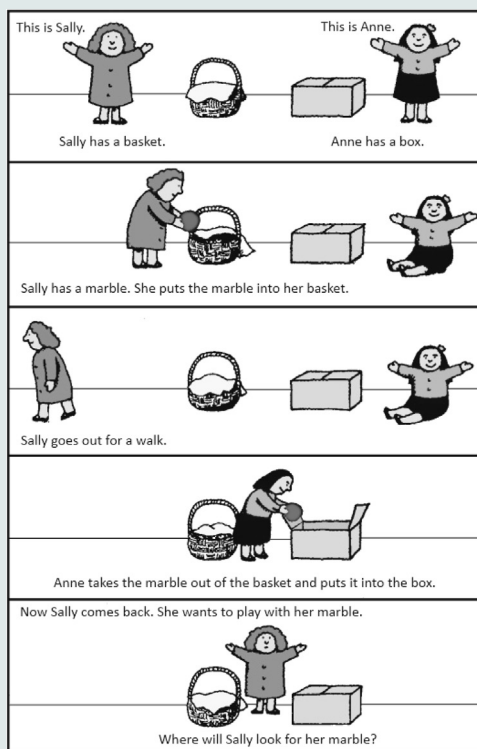
Why? I think parents are desperately seeking an explanation for what they consider to be a terrible fate that has befallen them out of the blue. I can understand this, and I can also understand that they would feel satisfaction if there was an explanation that puts the blame on an identifiable agent, rather than the blind chance of the genetic lottery. Human beings crave this sort of explanation. But as far as autism is concerned, this is the wrong story.

**Can autistic difficulties be ameliorated through behavioural remedies?**

Indeed they can. There are many kinds of behavioural programmes, and they all work, but may suit different families and individuals. Sometimes a programme of, say, 40 hours a week of intensive behaviour modification can be very effective. Sometimes doing nothing much apart from providing a structured and loving environment can be enough.

It is frustrating that we don't know why certain things seem to benefit some individuals, and not others. It's a bit like an art rather than a science, and where medicine was 100 or 200 years ago.

**This is a hypothetical question. If a pill was developed that could turn off exaggerated autistic traits,**



The Sally-Anne test of the ability to attribute a false belief. From Uta Frith's book *Autism: Explaining the Enigma* (1989, 2nd edition 2003).



**how far along the autistic spectrum would someone have to be for you to consider it was appropriate or ethical to administer it?**

I would be so relieved if that kind of pill was available – but then I would say this – given my preference for categories over a continuum! Another hypothetical question is whether it will eventually be possible to tell apart categories, to tell apart abnormal from normal function. I imagine people who believe in a continuum would have no reason to welcome such a pill. They would probably not wish to decide when a trait is exaggerated and when it is not.

**Can some of those with autism end up leading functional lives?**

Absolutely. We now have real-life histories, longitudinal studies over many years, so we know what can happen over a lifetime. And the range is so varied! At one extreme there is, for example, early death from epileptic seizures, which unfortunately is not uncommon – and at the other extreme there is the possibility of a contented life and of contributing to some important endeavour. Some individuals no longer even fulfil the criteria of the diagnosis.

**Where do you think the next breakthrough in autism research will come?**

What a difficult question! There is an enormous amount of effort being spent on genetics, and a slightly less intense effort on how some critical brain circuitry works or doesn't work. Both of these avenues are promising, but need huge data sets. Actually, what they need is progress in technology and in the basic sciences, in our understanding of how the brain works and how genetic interactions result in developmental irregularities and influence the brain's ability to process information. That is where I would wish the breakthrough would happen.

I am very happy that there is a new generation of researchers who are developing Bayesian theories to explain differences in the way autistic individuals process information. These suggest there is an imbalance between the weighting given to prior expectations and incoming information. If true this would give a neat explanation of why autistic people can often be hypersensitive and also why they may often not see the wood for the trees.

**You have done a lot of media work on autism. You did a programme for the BBC *Horizon* series and you will be doing others. And you also did one on OCD, 'The Monster in My Mind'. What is your motivation in doing that kind of work?**

It is worth telling people about scientific research that is consistent and sound. As scientists we need

to justify what we are doing and why we are doing it. And we need to try to do away with misunderstandings. I am trying to make complex concepts simpler and my ulterior motive is to make people critical of what they read about mental health and disease – and also to make them question themselves and become aware of their own preconceptions.

Science communication has a lot in common with story telling, but far more interesting to me is fostering curiosity – and stirring up a critical attitude, so that my story can be probed and improved. That would be very satisfying to me.

**What can we learn from autism about our social nature?**

Autism is the model case for learning about social communication – precisely because that is the core problem in autism. When something goes wrong, it is often in that very place that we can gain an insight into how we function. If nothing goes wrong we take our amazing cognitive abilities for granted to the extent that they are totally invisible to us. In the history of medicine, we have often learned how our bodies function through looking at some pathology that has opened our eyes to the underlying mechanisms. Take the case of mentalising: who would have thought that this ability was common-place and that it needed any explanation? But when it has gone wrong, we suddenly see how important it is for our everyday social life. Then we can ask questions about the neural substrates and evolutionary history of mentalising. Autism has opened our eyes to the fragility of our mind/brain.

**You have been recognised for your work by election as a Fellow of the British Academy, a Fellow of the Royal Society, and a Fellow of the Academy of Medical Sciences. When you go about your work, can you tell whether you are now being more of a British Academy person, a Royal Society person or an Academy of Medical Sciences person, or do you find all these differences to be a bewildering division of knowledge that does not exist?**

I totally agree with that analysis. I am not aware of any divisions of knowledge. There are no borders for knowledge and scholarship. Similarly I neither feel German nor British – but European. In that sense, I am quite used to not considering which particular compartment or which Academy I might fit in. We all know that the idea of 'the two cultures' is archaic. The Academies have to work together to further our knowledge and to develop better methodologies to do so. This applies whether we are studying music, medicine or maths. It is the same precision, the same critical attitude, the same rigour that serves all these disciplines. ♡♡

It is worth telling people about research that is sound, but far more interesting to me is fostering curiosity.