

A creative, interpersonal, social scientist

Editor Jon Sutton meets **Professor Francesca Happé** to talk about autism, DSM-5, women in science, and more

You were on the neurodevelopmental disorders work group for the latest revision of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. How have you found that?

It's been an experience, for sure! It led me to think of lots of questions about autism that I hadn't before, like is autism a lifelong condition? To ask all those kinds of questions, counter to the things that I had grown up being taught. It was challenging, because particularly in the States the health system is so different that it has implications in terms of money for patients that are completely alien to anything we would know here.

So that makes it even more of a political issue for the work group?

Yes. I don't feel jaundiced by it, because the people on the panel all had the best intentions, and it wasn't a matter of the loudest voice winning, which I thought it might be. It was genuinely collaborative and positive in its aims. Of course it's worrying to change anything, and the fear of doing harm is real. But I think there are good reasons for the changes made.

Just talk me through them. DSM-5 overall treats things as more dimensional, and in autism it's a collapsing of several categories into autism spectrum disorder?

Yes. We were told that for the whole of DSM-5 we should recognise that things are typically dimensional, and that there should be more specification and description of the individual. So across

categories, things like adverse living circumstances and additional mental health difficulties should be specified and considered, all of which I think is really positive.

When it came to autism, and notably Asperger syndrome, although everyone said 'oh, I know what Asperger syndrome is', they were all using it slightly differently. First of all we thought 'can we put a sticking plaster on DSM-IV?', and tinker with the criteria so that they do work. But doing that would effectively say



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that Asperger syndrome is autism without a language problem and without intellectual deficits. But since autism isn't defined by a language problem or intellectual deficits, that doesn't really make sense.

So it ended up that the evidence was that clinicians are really good at telling

what's on the autism spectrum vs. what's not, but they're really bad at agreeing with each other about how you cut it up into these artificial categories of Asperger's, PDD-NOS, autism...

So it can end up depending more on what clinic you go to?

Exactly. And we know that naturalistically some children start off 'Kanner type', very classically autistic, and by adolescence they look 'Asperger's'. In some sense Asperger syndrome is a really useful exemplar-based definition, you've got in mind a prototypical person with Asperger syndrome and then a fuzzy set around that. People will still use Asperger's as a descriptive, but it doesn't work as a diagnostic category because it doesn't have any clear boundaries or anything that qualitatively distinguishes it from autism.

So the idea is instead to have a big category, then within that the individual is described, the clinician needs to say what their level of language functioning is, what their intellectual functioning is, did they have an unusual onset. The individual gets better described, you're not trying to shove people into slots they don't really fit into. Because also, although I'm not a clinician, the experience I have in clinical settings is that people are saying 'well, he doesn't really fit Asperger's, but it's the nearest we can get', or 'it will get him the services that he needs'.

And that seems to be in accord with what critics of DSM have been asking – that social circumstances are taken into account, that things are considered on a spectrum. But how in line with the research can all this be, when it seems to me there's so little agreement, even amongst top autism researchers, in terms of causes?

At the beginning of the DSM-5 process, they asked everyone to consider whether neurobiological information, including genetics and anything you can think of on the biological side, could be used to aid diagnosis in any of these conditions, and the resounding answer was no, or at least 'not yet'.

Which I find surprising, given that every study that you see on the biological side, even if it isn't directly related to autism, tends to be press released with the line 'this may be of use in the early diagnosis of autism'. It's a stock thing that's trotted out, as if that's the great hope. You don't see that coming, you don't even see that as the holy grail?

No. The sense that getting hold of the genes, or knowing exactly which part of the brain is abnormal in autism, that that's the holy grail itself... I think that's the view more in America than here, that the biology is the be all and end all. I think that's a very limited view, and everything we know about genetics suggests that knowing your genetic profile will only map fairly loosely onto your behavioural profile. So you never want to replace face-to-face diagnostics, which is about the need that someone has, with some kind of read-out of their genetic or neural make up, because you will get mismatch. You're bound to have, say, fathers of children with autism who have much the same genetic or neural read-out but aren't affected and certainly aren't impaired.

I'm much more interested in how people with autism understand the world, that's much more useful. The issue about whether earlier and earlier diagnosis is the most important thing is also a bit of a red herring. People rarely discuss the cost of false positive diagnosis, and there is a real cost. If you talk to some parents who have had that happen to them, where for example a language impairment has been misdiagnosed as autism, they're actually very cross and very upset. The whole idea that we have to make diagnosis earlier and earlier is predicated on the idea that the earlier you intervene the better, and while that may be true for some things it's simplistic. There may be a window of opportunity at a particular stage, and it may not be right at the beginning. The work of Mark Johnson is really interesting, with the infant sibs who are genetically at risk of autism, showing that there are markers early on, not so much behaviourally but in terms of event-related potential, for example, which are common to sibs of kids with autism who do and who do not turn out later to have autism. So the earlier the signs we look at, the more non-specific they will be. That work could be really important, if it teaches us what determines who transitions off an autistic pathway. But I'm not so excited by chasing earlier and earlier diagnosis, unless we know what we are going to do with that information, what we can do for that child and family.

You mention the autistic pathway... taking that lifespan approach seems to be quite unusual in developmental psychology and in autism in particular. It's very much focused on autism in children, but you're interested in what

happens when people with autism grow up?

Yes, and in fact that grew out of the DSM-5. We were encouraged to think about the presentation of conditions in different cultures, in both genders and across the lifespan. I thought 'that's interesting, I don't know anything about autism in old age, I'll go and look that up'. And there was nothing, I mean there was just nothing! Not even, say, documentation of whether people with autism have more heart problems in old age. That seemed to me such a striking gap.

"in old age we might be able to do even more... to improve quality of life"

Of course when you stop and think about it there are good reasons why there would be a gap there, to do with autism being a relatively new diagnosis, and the criteria having broadened, so the people we recognise now are different from the people we used to recognise, but still it's a tremendous gap. And it's been really disappointing to me that the people who usually fund our work on autism in children have not been as enthusiastic about funding our work on autism in old age.

Why is that, children are just more appealing when it comes to research funding in general?

I don't know, maybe I just wrote bad grants! But it does make you wonder, perhaps that's the corollary of the early intervention banner – 'if you miss that boat, it's too late'. I think in old age we might be able to do even more for people, to improve their quality of life. Temple Grandin says that her brain switched on at 50. So it may be that there are fantastic opportunities later in life.

There seems to be a strange kind of mystery around autism in children, where you have this unreachable child and that presents a challenge to scientists and the public in general. Whereas maybe with an adult with autism the general feeling might be 'that's just some weird old guy, that's the way he is, we're never going to get through to him'. It just seems to me that autism is perpetually fascinating in the public eye as well as the scientific eye... I think you could argue that it's quite overrepresented.

It is. I think if I were the parent of a child with intellectual disability of the 'ordinary', unlabelled sort, I'd be jolly cross how much money autism research gets, and how much press it gets. It is

disproportionate. And it is because it's fascinating. You're right, there's this stereotype of the beautiful, unreachable child with autism, with the faraway look. But what about the old guy with autism, with the faraway look? He's just as beautiful. It's part of our cultural lack of respect for the elderly too... they're already a disliked minority, add autism to that, these poor people have got no one to fight for them.

You've talked about the 'beautiful otherness' of the autistic mind, and again a lot of the coverage of autism you see in the press and on TV is very much about the fascination of the high end of the autism spectrum. But the parent of a child at the low end, who is rocking, biting, non-communicative... would they identify with the 'beautiful otherness' of the autistic mind?

When I started with Uta Frith's ideas of assets in autism, looking at what people with autism are good at, trying to think of tasks that children who are non-verbal can access, like embedded figures and block design, self-explanatory visual tasks, I did worry that if I was talking about assets in autism that would be seen as wishing away all the problems. But the response from families has been really positive, they're really pleased to hear people talking about things that people with autism are good at, even if there's plenty they struggle with.

The thing is to have a broad recognition of what those sorts of skills and talents are. They're not always the mathematician at Cambridge, they can be the child who amazes their parents because they get upset about tiny changes in their environment, an ornament moved a fraction of an inch, or who shows that they remember somewhere they've been before by going straight to a particular location. Parents are really aware that pretty much every individual with autism is surprisingly good at something, compared with their other abilities, and like us as parents of neurotypical kids, we're kind of pleased and intrigued by that, but it doesn't mean we don't recognise that our children find other things difficult.

You want to focus on the positives.

Yes, and it's delightful when your child surprises you by how different they are from you. So I think it is really important to recognise, particularly when you're talking about talents, that it is infuriating for parents when a well-meaning neighbour says 'Oh, I hear your child's autistic, what's his talent?', and they want to say 'Well, his talent is lying down in

autism

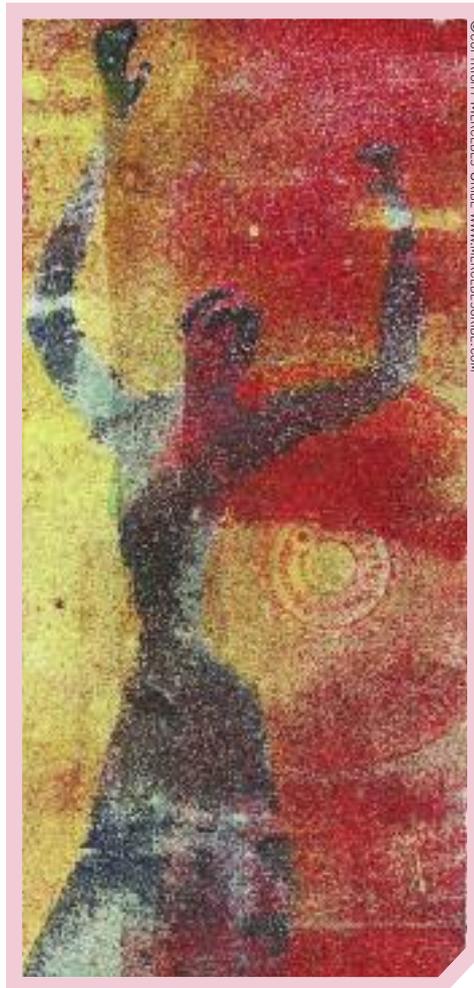
the supermarket and screaming and screaming because the fluorescent lights are upsetting him'. But if you talk about it in another way, they often will say 'I do realise his world is utterly different, and there are some things about how he sees the world that are really extraordinary, and opened my eyes'.

And you believe that all people with autism have the potential to develop those skills to the level you would call savant ability?

I don't know. I think there's a lot of untapped ability. I think people with autism all have something that would stand out against their other background of skills that's unusual. Pam Heaton's work suggests that a large number of musically untrained people with autism have the potential to develop perfect pitch, and that is a real starting point for developing musical skills. It's important that we don't somehow prize some things or value the individual because they're good at certain things. If one's interested in talents in autism it's because those are ways that the individual can find more of a niche or be more integrated into society to the extent that they want to be, that give them pleasure, that help neurotypicals to understand that person... It's not that it gives the person more value; the child whose talent is watching drops of water drip from their fingers for hours on end, seeing the minute differences between them, has absolutely inherently as much value, whether or not they then go on to develop beautiful drawings or something. So it is a difficult area, but I think we are shortchanging people with autism if we don't recognise that there is potential there that's hard for neurotypicals to recognise because they don't show it in the ordinary way due to their social difficulties.

Coming back to this disagreement between autism researchers... If autism is increasingly being treated as dimensional, and there's a lot of debate around whether the triad of impairments is 'coherent', genetically, cognitively and neurally, does it still make sense to think of autism as a unitary concept at all?

People increasingly talk about 'the autisms', because autism is so heterogeneous. I think it's probably pretty certain that there are going to be lots of different causes in different individuals. In the future we might talk about 'autism



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type 1' and 'autism type 2', or something where we can link it to particular aetiologies that have particular consequences for prognosis or treatment. But we're a long way from that. So the heterogeneity that I've been interested in is the idea that there are different causes for the different parts of what we call autism, so for the social and the communication and for the non-social aspects. And that is debated. So we talk about an autism spectrum, and some people like John Constantino would say 'yes, there's one dimension: you're a bit autistic, you're a bit more autistic, you're really autistic'. Whereas I would sketch it in a multidimensional space, where how much social and communication difficulty you have is pretty much independent of how rigid or repetitive you are, which are again independent of how your intellectual functioning is and how your language is. But I don't think that's the same as 'there's no such thing as autism'.

Until we get to the stage where there's autism 1, autism 2, autism 3, and they're shown to be so different as to

not all be autism, you're happy carry on down the road of autism research?

One of the things that people have thought about this 'fractionated triad' idea is that it means there's no such thing as autism; there's just the unlucky coincidence of these different difficulties or cognitive styles, and when they come together we call it autism. I don't really mean that, because there is something about getting that particular set of difficulties that has a catalytic effect that qualitatively changes them. So if you just have social and communication difficulties, but you don't have an extraordinary eye for detail and a sort of rigidity perhaps due to executive problems, you can compensate for some of your social and communication problems in such a way that they will look different. When you get the particular mix that is autism all together, you get something that qualitatively looks different so that that really is autism. And autism is incredibly easy to recognise in its core form. And even when I talk about type 1 and type 2 and the idea that at some point the different aetiologies might be useful to us, it could be that at the behavioural level all those aetiological subtypes look identical. So people quite often ask me if I think that everyone's a bit autistic, and it depends what level you're looking at. Behaviourally, you can certainly put everything on a continuum and it's all shades of grey, and you make your clinical cut off where somebody is impaired and asking for help. You don't just go out and start Asperger spotting.

So just because I put my CDs in alphabetical order...

Exactly. Or I hate all this, 'Einstein...'

...historical diagnosis?

Yes. So that's at the behavioural level, it all merges together difficulty keeping conversations going, small talk and all the rest. At the cognitive level I think it's more complicated, so problems in theory of mind, and representing others' mental states, probably is a qualitative difference. Most neurotypicals can do this, and most people with autism can't, at least initially – they may find ways later in life to do it. That's a real big difference, not shades at all. But then the eye for detail, we hypothesise very much on a continuum, and you see it in the relatives of people with autism, that don't have any difficulties, and so on.

Then aetiologically, who knows? It could be that it's like high blood pressure and it's a continuum and then you pass a threshold and it's a problem, and it really begins to show behaviourally. Or it could

be that it's like the rare mutations, genetically, something really special.

Still so much to do, then! What are your main research priorities at the moment, what are the most promising directions?

I'd like to do something on ageing and autism just because it's so important. I'd like to see if we can turn our ideas about detail focus into educational interventions. We think at the moment it's rather separable – how good you are at details, and how difficult you find it to put information together to get the big picture, are different dimensions. That encourages us to think that we can improve the ability of people with autism to see the big picture when they need to, without taking away their eye for detail. We want to develop interventions to help, for example, kids to learn that some problems are 'zoom out' problems and others are 'zoom in', if you take a video analogy.

We've been doing some work with girls, trying to understand whether some of the difference in the gender ratio is us missing girls with autism, or that girls genuinely compensate better. And then the fractionated triad work has led us to realise that there are quite a lot of kids out there in the population who only have one aspect of autism; they might just have rigid and repetitive behaviour, they might just have communication problems, or they might just have social problems, and I really want to know what those kids are like. Parents rate their difficulties as just as severe as those who have the full triad of autism – how impairing are they? Are they getting any diagnosis, do they need help, or actually when you don't strip away compensation routes, can they manage all right?

Well that should keep you busy! And as if that wasn't enough, I know other areas are important to you, such as being a female scientist.

Yes. I was lucky to get the Royal Society's Rosalind Franklin Award in 2011, and that was for a project that's still ongoing to create some books for primary school children called 'My Mum's a Scientist'. This came about because I was in the playground dropping off my own children and a friend of my daughter came up and said, in front of me, 'Is your mum a scientist?', and my daughter said 'Yes', and he said 'Wow!' and he was really amazed. And I found that so interesting and funny, it was as if he'd asked whether I was an astronaut or something really exciting! That set me thinking about what kids know about what it is to be a scientist.

So I'm trying to produce these books based on real women scientists, teaching a bit about the science but also about what it means to be a scientist.

Recently I was asked to give a lecture in Cambridge about women in science, so I've started to do some thinking about where young children get ideas about science and scientists, and why it is that – at least in America and Britain, although it's very different in different cultures – children aged seven are already saying 'maths is for boys', even though at that age there's absolutely no sex difference in achievement? Similarly, girls are saying in some big surveys 'I like science, but I can't imagine being a scientist'. What is it that they think a scientist is, that they can't identify with?

So there's a really interesting story to be told there. The story that I'm interested in telling, because it relates to social intelligence and social insight, has to do with conformity and the way that unlike people with autism, neurotypicals from very early on not only *can* read minds but they *can't help* but read minds. So there's an obligatory osmosis of other people's attitudes and views.

That's interesting, because my perception of a lot of your peers and mentors is that you've been embedded within really formidable, socially intelligent, socially supportive network of female scientists.

I've been incredibly lucky, to have Uta [Frith] as a fantastic supervisor and mentor, and many other really wonderful women scientists, and wonderful male scientists who've been very promoting of women. But it's still shocking, maybe you experience it too as a parent, young kids in primary school will somehow form the assumption that nurses are women and doctors are men. So the base rate of assumptions about what girls are good at and not good at is still very biased against science. There are kids and older adults who are good at being different and don't mind being different, but for the ones who do want to be like others, which is the majority because of social osmosis, we

have to give them role models of scientists so they can think 'yes, I want to be like that'.

And to be like that in terms of an approach to life as well, like you were saying about 'zoom out' and 'zoom in' on problems. I've found with my own children, trying to pass on that scientific way of thinking, regardless of trying to pass on the idea of being a scientist as a career move... I think children respond to the idea of looking for evidence and solving mysteries.

Absolutely. But I think science is just taught in entirely the wrong way. We're training people to memorise facts, and conduct experiments that are like recipes where they can go wrong and you've failed. We don't convey that science is creative, interpersonal, that actually social skills matter, that it's about discovery... I think we need to change a lot.

Resources

Papers

- Happé, F. & Frith, U. (2014). Annual Research Review: Towards a developmental neuroscience of atypical social cognition. *Journal of Child Psychology and Psychiatry*, 55, 553–577.
- Robinson, E.B., Lichtenstein, P., Anckarsäter, H., Happé, F. & Ronald, A. (2013). Examining and interpreting the female protective effect against autistic behavior. *Proceedings of the National Academy of Sciences USA*, 110, 5258–5262.
- Dworzynski, K., Ronald, A., Bolton, P. & Happé, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry*, 51, 788–797.
- Happé, F. & Charlton, R.A. (2012). Aging in autism spectrum disorders: A mini-review. *Gerontology*, 58, 70–78.
- Happé, F. (2011). Criteria, categories and continua: Autism and related disorders in DSM-5. *Journal of the American Academy of Child and Adolescent Psychiatry*, 50, 540–542.

Books

- Happé, F. (1994). *Autism: An introduction to psychological theory*. Psychology Press.
- Happé, F. & Frith, U. (Eds.) (2010). *Autism and talent*. Oxford: Oxford University Press.

Other recommended resources

- The latest edition of the IACAPAP Textbook of Child and Adolescent Mental Health is free online at tinyurl.com/nte3tj7 and has an excellent chapter on ASD (with links to video materials)
- The National Autistic Society has a variety of resources on ageing and autism: tinyurl.com/m7hu4f5