

Autism assessment: an interview with Dr Sarah Lister-Brook

1. Can you tell us how you first became interested in autism?

It was actually when I was training. I was working in a long-stay hospital, as they were in those days, for people with intellectual disabilities and I came across this young man on a back ward who was heavily medicated, who had a diagnosis of schizophrenia. But when I read the clinical notes and got to know him a bit better it just didn't make sense to me, the schizophrenia.

And it just so happened that Judith Gould was also working in that department, spoke to her about the case and, in fact, she invited Lorna Wing to come and meet this gentleman and to work with me and do an assessment, so I felt very privileged. And Lorna came and confirmed my suspicions that he had autism, so it made quite a difference to his treatment, his care plan. So that was really the beginning for me.

2. Can you tell us about your current work?

Currently, I'm the Clinical Director of the National Autistic Society and that work involves overseeing the diagnostic and assessment services which are a national service that we provide across the lifespan and for all profiles of autism. And the other bit of my role is involved in overseeing the therapeutic work that goes on in our schools supporting children and young people.

So I lead, as the professional lead, the therapists, the psychologist working in the schools as part of a trans-disciplinary model. I also, my work involved thinking strategically about how we respond to needs out there in the world in terms of diagnosis and assessment and how we can improve our services. And of course I'm a clinician as well. So I'm a clinical psychologist by trade and that's what I do, also. In the clinics I work as one of the diagnosticians with everybody else.

3. When assessing autistic people, what makes a 'complex presentation'?

What's complex to one person isn't necessarily complex to somebody else. So for us, as diagnosticians and assessors, the complexity is around trying to get beyond the factors that might be obscuring the autism. So it may not be a complex presentation as in someone with severe intellectual disability and limited functional language, but really where there are difficulties in seeing or revealing the autism.

So that's, for me, is around where there are coexisting neurodevelopmental conditions, like ADHD or specific learning difficulties or intellectual disability,

as well as mental health conditions that might be overlapping. And then other factors that may be more to do with cultural expectations. I guess some professionals might have cultural, some sort of stereotyping about how people from different cultures present in terms of their behaviour. Obviously, we also know in some cultures that there aren't words for autism, it doesn't really exist in that sense.

The social context, because obviously autism is about social relationships and difficulties in that area, so the transactional aspects that go on and around in the social context. All of that can really make it quite difficult to be clear about the autism. As well as, of course, gender issues, as in gender can make a difference in the way the autism presents. So a number of factors.

4. What is the Lorna Wing approach to assessment?

At the Lorna Wing Centre we aim to provide what we would call a bespoke assessment. So that starts from the very beginning in trying to understand the needs of the individuals who have approached us for an assessment, what their best hopes are for the assessment, what they hope to achieve by having this assessment, but also to work out what maybe hasn't gone well for them before in a previous assessment or indeed to make sure that we get to the things that haven't been properly assessed before.

So we tend to see people for a second or a third opinion, so they may well have had some other assessment beforehand. So we will tailor the assessment to not only meet the needs of that individual for their experience but also to make sure that we get to the nub or the areas where there has been uncertainty and difficulty and provide what we hope is some clear evidence to make a decision.

5. What are the main barriers for autistic people in accessing a diagnosis?

I guess if we look at wait times, there is real capacity issues in terms of specialist teams. However, I'm not entirely convinced we need lots more specialist teams. I think there needs to be more differentiation in the pathways to getting an assessment. But together there also there are things around having knowledge and skills in our workforce.

So there a lot of professionals I know who are put in a position of doing specialist assessments but aren't well equipped with knowledge and skills to do it. So capacity, knowledge and skills, and I think really trying to ensure that

people have differentiated pathways so that they don't get stuck on long wait-lists to see specialist teams.

6. Can you explain what you mean by differentiated pathways?

So thinking more about how in primary care we can facilitate more rapid assessments, maybe through GP practises, so that there isn't this need to necessarily go through a protracted pathway to get to a specialist team. Not everybody needs to go and see a specialist team, I guess is what I'm saying, it may well be possible for it to be done in local team who are obviously trained in knowledge and skills, but not needing to deal with complex cases.

7. In your experience, what difference does diagnosis make to an autistic person?

I think fundamentally it gives understanding. So usually for autistic people themselves will often talk, "Now this makes sense, now I can make more sense "of the things that I've found difficult." For families, as well, that's really important trying to better understand their children, young people.

And I guess ultimately knowledge is power, so the more you know yourself, the more you know in terms of your, not just the things you find difficult but also your strengths 'cause, of course, the assessment is also about identifying the strengths. Together, it enables that person to move forward, get help, or indeed, just as I say, know themselves better.

8. What improvements would you like to see in post-diagnostic support?

I think it starts, almost with the assessment in that the assessment, ideally, should provide a clear profile of understanding of that individual's autism, because it isn't just about enable, as we know it's about profiling the autism.

So going forward with an informed assessment is key and I think the next step would be really to have a clear information hub 'cause I think one of the things that really is difficult post-diagnosis is trying to work out where to go next. And, ideally a key-worker model would be the perfect option but without a key-worker model, maybe clarity in terms of what the local offer is.

Now, local authorities have a duty to provide information about their local offer but still I think it's quite hard to navigate your way to services. And then the other thing that's really important is making sure that referrals are made to services where there are specific needs. So if there are additional mental health needs or learning needs that other resources are signposted and those opportunities are made available.

9. What are your views on the changes to the ICD-11 diagnostic criteria?

So in ICD-11 I think we're moving again, like DSM-5, to a more dimensional approach to assessing autism. So taking away the subgroups, the specific subgroups of autism and now it's thinking more about autism coexisting with levels of intellectual disability and functional language.

So I think that's very positive. And of course we are also losing subcategories like Asperger's syndrome, which I know for some people is quite a challenging idea because they're quite connected with Asperger in terms of their identity.

However, I think on balance as a clinician, that the new guidelines make more sense because it actually allows for more diversity in understanding the clinical presentation. And where people in the past may not have met criteria 'cause they might not satisfy the algorithm in that very rigid way, this actually gives us a lot more flexibility.