

Autism research: an interview with Lorcan Kenny

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

I first became interested in autism when I started volunteering at the local special school when I was in school, and teaching kids to swim or help bring them to access swimming lessons, I guess. And I got quite interested in going down a career of getting into chemical psychology and supporting them in that, and then when I was doing my undergraduate... postgraduate research. I kind of was quite struck by the gaps that there are in knowledge and both, you know, in basic science and also in applied knowledge about how to support these people, so I then kind of started seeing a career in research, which brought me to the Centre for Research in Autism and Education, where I am now.

2. Can you tell us about your current work?

I'm doing a PhD at the moment, which is interested in people's everyday skills, the kind of things like managing your own money, and your time, and being able to switch between doing things you like and don't like, for example. And kind of normally in the research when that's measured, people use these quite artificial tasks that don't have very much to do with the real world. So they look at how people react to flashes on a screen, or how they can ignore information on the side of the screen, you know, and pay attention to the middle of the screen, which doesn't really have a whole lot to do with the real world. So what I'm interested in is measuring that in a more real-world context, getting someone to prepare cups of teas and sandwiches, seeing what kind of difficulties they have in following these instructions when I don't give them all the information that they need, something like that. And that's been quite interesting so far, since it might be capturing some information that some of these other measures are kind of missing out on.

So another exciting project that I'm also involved in is longitudinal study that my supervisor Liz Pellicano originally started about twelve years ago. So a group of autistic young people, who are now about seventeen, eighteen years of age, and we're interested in seeing what things that were measured when they were four or five, might be able to predict something about where they are in life now. So whether something about their cognitive profiles and their ability to understand others' mental states, or their ability to plan and organise, and can predict who's having some more difficulties or who's getting on quite okay into adulthood. And it looks like we can predict some things from very early in childhood. So that's a quite exciting finding that I think might have some real

implications for, you know, using these diagnostic, or prognostic indicators, I guess.

3. How might the presentation and features of autism change as children get older?

Yes, so in this longitudinal study that we run recently, one of the things we did was we asked parents to fill in a questionnaire about their children's symptoms, and we did three different time points, so when they were four or five, when they were about eight, and when they were about seventeen. And what we find is that on the whole, people are showing less symptoms as they get older. So that's, according to parents, it might be that these symptoms are less visible, that they're kind of...it's particularly true for what we call repetitive stereotyped behaviours, which is what autistic people refer to as 'stimming' or self-stimulatory behaviour, kind of hand flapping, those kind of things.

So it might be that they're the more externally obvious indicators that someone might be on the autism spectrum, and from some of the interviews and things, people talk about, you know, knowing that it's not socially appropriate to walk around making these gestures, making these flaps, so they've learnt to hide them or do them in private. Which is important because it's not saying these symptoms are gone away, it's that society has kind of taught them that they're not appropriate, and they hide them and try and mask and pass as a non-autistic person, which might be, in some cases, at the expense of their quality of life, or their, you know--it's what they do to relax, these kind of behaviours, and they're showing them less over time, and it might not be, you know, a good outcome for them to be showing them less over time. I guess we need more work in that to be able to fully understand that.

4. Your research has highlighted that some autistic people don't meet the criteria for autism when assessed later in their childhood. Can you explain what this may mean for those people and the implications for diagnosis?

In the longitudinal study, we assessed the participants on some of the standard diagnostic tools at three different time points. At the first time point, they were all meeting criteria for either autism or autism spectrum disorder. And then we reassessed them, two years later, and some of them actually were no longer meeting criteria. So according to the instrument, they weren't getting above the clinical threshold to meet any diagnostic category.

And then we did it again, at seventeen years of age, and we found that again there was about five of the twenty-four participants that we saw at that time-

point; somewhere around between 10 and 20% of their group are not meeting the cut-off at that point. But it's not the same ones who weren't meeting the cut-off the time before.

So what we're finding is that some people move in and out of the diagnostic category across different points in time. So if for example we only saw them at two time points and we think "These groups no longer meet criteria" and then we treat them in that way in our research papers or clinical practice, we might be missing some part of what's going on for them.

It looks more like the symptoms kind of wax and wane across time and according to context. So it might be that when we assess them at one time point, they're having a particularly challenging time, and so some of the symptoms might be coming out in the observation, in the diagnostic process whereas when we see them another time, you know, within that year, they're, you know, very much in a calm place or within that hour setting that we're doing the assessment. Or just, you know, within the assessment they still appear as though they have quite a different quality to their social interaction, but not exactly the right way for diagnostic instruments.

So, in terms of implications, I think we need to be careful about excluding people from scientific research groups. When we're running group-based analysis that are aiming to make generalisable statements about autism, because if we just say that these people don't meet criteria, they don't go on our autism sample, and then we make this claim about all autistic people based on this. But actually, it's not all of autistic people, it's all of the autistic people who are still meeting criteria on one particular assessment at one particular point in their life.

So I think that, combined with the people telling us that being autistic is a very important, central and sometimes very positive part of who they are as a person, means that we need to be quite careful in... kind of, clinical practice and in research about, you know, saying someone is no longer on the spectrum just because they don't reach criteria on tools that we know are imperfect and have all sorts of measurement errors that we know about.

5. What are the main difficulties in transitioning from a special school to a unit in a mainstream school?

So this is a project where we looked at a special school in London that was specific for children on the autism spectrum. Where they set up this satellite classroom model, where they had a classroom in a primary school, and a classroom in a secondary mainstream school, and they sent some certain

number of students with staff from the special school to the satellite classes, and we tried to do some research about what was going well and what could be done differently.

And I guess, I mean it's quite self-evident, but I think the biggest challenge is the transition itself, because we're talking about a group of people who we know, almost by definition, struggle with change, and they struggle with uncertainty, and this can create really big anxiety which means that they kind of stop accessing the other parts of school life because their anxiety takes over.

So I think the difficulty is managing that anxiety, and a lot of that comes from communication and preparations. So, you know, if it's a case of bringing children very gradually to see the new school and not just kind of saying "Next year, you're going to go to this new school," and then on day one, you know, in September, they're dropped into this school that they've never seen before. So, giving them an opportunity to try on the uniform one day, and then an opportunity to go to the gate the next day, and an opportunity to see what the classroom will look like the next day, and just explaining to them, and their families, you know, what's going to be the same, and, crucially, what's going to be different. Because I think, you know, one of the big difficulties and challenges was that they knew they were transitioning away from an outstanding school, and they knew the support was there and they knew the expertise for autism was there.

What they didn't know was where they were going, so it was just kind of reassuring them that actually you still have access to that expertise because of the satellite model, because they were bringing staff who were trained and supported by the special school that has all of this expertise.

6. What does your research with GPs tell us about their current understanding of autism?

So we ran an online survey with the Royal College of General Practitioners to assess a couple of things; one, the extent of knowledge that general practitioners in the UK have around autism, but also their self-efficacy, or how confident and comfortable they felt in working with people in their practice who had an autism diagnosis.

And what was quite interesting was the level of knowledge that came through in the survey was quite high; they seemed to know, at least in the questions we were asking them, about, you know, the core diagnostic characteristics and

these kind of things about, you know, the prevalence in males and females and those kind of questions.

Although, it may be that those who answered the survey were those who were more knowledgeable in the first place, because they saw the link and they clicked on it and they decided that they were going to take part. But, even in this group who might have been biased towards having a lot of knowledge, we found that, despite having lots of knowledge about autism, they didn't have that much confidence in knowing what to do.

And one of the things that came through as well as... about 40% of the GPs reported never receiving any form of training about autism, at all. So, if we think about how many people they see on a day to day basis, and that autism affects 1% of the population, they're going to be working with autistic people, and the fact that they don't...they've never got any formal training is quite surprising.

But then I guess, given that they have lots of knowledge, I think what we're suggesting in this research is that actually, the kinds of things that might improve it. Improve their ability to work in this way is, you know, getting experience of meeting autistic people, and the kinds of training that isn't sitting down and rote learning things about the medical condition, and the diagnostic features. But actually having conversations with autistic people, receiving training from autistic trainers, who can tell them, you know, from their experience when they've gone to see the GP the things that they found difficult.

Giving them practical strategies like, you know, using visual symbols and timetables. Being very explicit in instructions they're giving them about medication, these kind of things that, you know, aren't the things about "what is autism" or "what is autism, what isn't autism" These kind of things that can be practical, kind of strategies that they might be able to use in their clinical practice.