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## **Involving autistic people in research: an interview with Professor Liz Pellicano**

### **Can you tell us how you first became interested in autism?**

Before I started my PhD, which I did in Perth, Western Australia, I started working with a little boy; he was four at the time that I met him, he had a diagnosis of autism, he had only a few words, single words, so he wasn't really putting them together to make phrases or sentences. And so my job was to...do some speech and language activities with him in order to try and boost his spoken language and speech. And I did that only once a week for one hour; sometimes it was twice a week, but mostly once a week.

And essentially I kind of just fell in love with him and his family. They were amazing; they weren't well off, by any means, and yet they put in so much in order to try and support him, and they still do, I'm still in contact with them. Yeah, so I guess it was, you know, they...it was...they went through a lot of trying times as many families of autistic children do; he had lots of toileting issues, gastrointestinal issues, they also had issues when they were trying to find a school for him, the best school placement to support his needs. Yet, throughout all of that, they were amazingly resilient, and I guess I was just inspired by that.

Yeah, so that's how I kind of got into understanding, wanting to understand more about autism, more about the strengths and weaknesses associated with autism, and in particular trying to work out, what are the best ways to support autistic people and their families? And at the time, I was doing my PhD, but I was also training as an educational psychologist, so I was very much focused on kind of, on practice as well.

So yeah, so that's how I got into autism.

### **Can you tell us about your current work?**

The last few years, I've been really interested in trying to involve autistic people, their family members, those who support them, into the research process, and really listening to their needs and wants. And we're just, what I'm doing currently, is we're just finishing, or analysing, data

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from a study, where we've been following these children that I first saw in Perth, Western Australia when they were four to five years old, so over twelve years ago. So now they're at the kind of cusp of adulthood, they're sixteen, seventeen, eighteen years old, and we're really interested in where they are now. And I'm particularly excited about this project, in part because I remember, really vividly, all of the kids, and so I'm excited about where they are now.

But more importantly, I'm excited about the project because I think we've tried to take a more holistic approach to their kind of outcomes. So, lots of long term outcome studies have really focused on: are the people, how autistic are they now, what are their intellectual, what's the intellectual functioning, their IQ like now? And very crude measures like, do they have a job, Are they living on their own, do they have friends?

And we've taken those measures too, but we've also tried to understand, you know, their lives a bit more, so we've done [qualitative] interviews with them and their parents, to try and understand what their lives are like right now, what school's been like, whether they've got the, you know, how much support they've had and whether they think that's been effective, how much support they'll need, they think they'll need in the future, and what they want for their future lives.

So, so that's the work that I'm, we're doing at the moment which I'm obviously excited about, but I hope we'll really...inform how we...you know, might see what is a kind of good outcome from the perspectives of these young people. And so, in order to inform, you know, the services that will support kind of young people to move on up into adulthood.

### **Why do you think autism research has not traditionally focused on the needs of autistic people?**

I think a lot of the research is done by scientists, so they focus on medical and biological issues, trying to understand, for example, the genes associated with autism, the...you know, brain development in autism, underlying biology of autism, and as such, I think it tends to ignore the kind of human factor.

And you see this when you sometimes speak to researchers who are in wet labs, for example, who are trying to pinpoint the kind of genetic mechanisms in autism and, some of them have never knowingly met a person on the autism spectrum, and so I think that lack of engagement is one real reason why this is, kind of, predominance research on biomedical issues in autism.

### **What are the challenges of involving autistic people more in setting the agenda for autism research?**

I think there are lots of challenges, but one challenge is that the decisions that get made around research are usually done by scientists and administrators. And they often think they know best, and they often do know, you know, best in some respects. But, they don't necessarily, or they're not necessarily tuned to the needs of wants of the autistic community, or the realities of being autistic or living with someone who is autistic, and so I think that...again, lack of engagement is a real barrier to ensuring that the research is centred around autistic people's priorities.

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## **What methods can we adopt to ensure that autistic people's needs determine research priorities?**

I think that the first thing is that we actually need to listen to people, so we need to listen to autistic people, their family members, those who support them, the autistic community, in what they need and want from research. And I think there are efforts being made to do that, so a few years ago we did a study called 'A future made together' where we did a big consultation with the autistic community, around what they... how they felt about current research, but also what they wanted from future research.

And there's also been some work recently done by the UK charity Autistica, who collaborated with the James Lind Alliance, and again they did a consultation with stakeholders around identifying the priorities for future research.

And so I think we've kind of, all of that work has really shown that people really want research that has a more immediate practical concern. So we're, I think we're starting to understand what people, so we are listening, but I think it needs, we need to do more than just listen; I think we need to develop relationships with members of the autistic community, as researchers.

In collaborations with, you know, about research, so it's actually involving them in the process, I think as researchers we tend to forget that, our collaborations are relationships; some of them are very easy and some of them we really have to work quite hard at. But it would be the same for a researcher/autistic member collaboration, you know, it is a relationship, so we need to get to know them, we need to find out what their expertise is, and how our kind of expertise can be complimentary.

I think the difference between, like a researcher/researcher collaboration and a researcher/autistic community collaboration is a power differential, and I think we really have to address that when we make, have out in the open about how we, you know, how to make sure that, people are on equal footing, there's an equal partnership there. As researchers, or scientists, we bring a certain type of expertise, you know, for research design, analysis, interpretation, those kind of things.

But members of the autistic community also bring experiential expertise, you know, of what it's like to be autistic, or to live with someone who's autistic, and I think as researchers we really need to value that expertise, and that's one way that, and getting to know people as, you know, in a relationship is one way in which we develop that, that engagement.

It's...I think it really needs to come partly from researchers, I think researchers have to actually make efforts to promote autistic involvement in research, and if they don't do that, then we're just not going to have any. I mean we've had some amazing contributions to autism research from autistic people, so, Robyn Steward, who's an educator and campaigner, Damian Milton, who's a scholar and sociologist, and Michelle Dawson, who's a scientist, and I think as researchers we need to...promote opportunities in which autistic people can develop research and advocacy skills that would be important in those collaborations and in research more generally.

## **How can we try to ensure true autistic participation in research, practice and governance isn't just tokenistic?**

I think it's all to do with the standards to which we hold ourselves. I think people need to be bolder in identifying tokenism when it happens. I think we especially need to call it out when we see it. And if we don't do that, then people will just keep disregarding autistic voices, and they'll keep getting excluded from the very decisions that affect them.

## **How can researchers ensure full participation from autistic people who struggle with verbal communication?**

I think that's a really good and important question, which I don't think many people have really mastered, including me, unfortunately.

We did do a study recently where we did try to involve young autistic people who had moderate learning difficulties and additional issues with spoken communication, more in the research process. So we were looking at the views and experiences of children and young people with special educational needs, some of whom were autistic and some that were not, who were living in residential special schools. So some of these young people were living there for fifty-two weeks a year, you know, barely see their parents or families, so we were really interested in their experiences.

But as part of that research project, we had a young researcher's group, and so the group was made up of...young people who had moderate learning difficulties, issues with spoken communication, some of whom were deaf, some of whom were autistic, and we met with them three times during the project, so the first two times were basically before the project actually got off the ground, and the final time was at the end of the project, when we'd done the analysis and we went, basically, we had done the interpretation, but we went back to them and said "Is this right, or you know, is this what you would think?"

And it was brilliant, I mean, they were, we had to develop activities that would, you know, elicit their views, that weren't just talking to one another; we did some kind of post-it activities, they were supported by their learning support assistants, or teaching assistants, we did this kind of diamond ranking activity where they kind of ranked the importance of statements and things like that. So we got a really good sense of what they thought about the issues that we were researching, but also our methods in particular. And we did actually change what we were doing on the basis of what they told us, you know, so, some things worked and some things didn't work, and we did change that, and I think our, our...you know, our actual project in the end was much better for it.

I don't think in the slightest that we fully involved them in the research process, but we did our very best with the resources that we had, and, I think we involved them more than is done typically, which isn't very hard, given that, you know, their involvement is not very much at all, but I do think that's a real issue because otherwise we get people speaking for them, and that's not necessarily good, so...