

NEWS

# Novel protocol captures autism voices across the spectrum

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Visual aids and other strategies make it possible to interview young autistic people with intellectual disability or other communication challenges and to draw out valuable responses for research purposes, researchers at McGill University in Montreal, Canada, reported in May. The team piloted their flexible interviewing protocol, called Autism Voices, with 33 participants pulled from the longitudinal [Pathways in ASD study](#).

“We hope that our team contributed a first step towards what is now a growing research direction, trying to capture first-person perspectives for autistic youth,” says [Mayada Elsabbagh](#), associate professor of neurology and neurosurgery at the university, who led the effort. The protocol could also make it easier for minimally verbal autistic youth to participate in studies from which they have traditionally been excluded, yielding better data, she says.

Elsabbagh and her colleagues describe the method and some of its applications in [this video](#). Read the transcript below or [download it](#).

## Transcript:

**Mayada Elsabbagh:** We hope that our team contributed a first step towards what is now a growing research direction trying to capture first person perspectives for autistic youth. We see a lot of applications of this protocol and we're now actually considering ourselves in piloting with using some of those methods for imaging studies. Imaging studies are of course, very complicated. They involve a lot of instruction, and for that and other reasons, a lot of autistic youth had been traditionally excluded from these studies. So what we want to do is incorporate some of those methods into the instructions themselves to help the youth become more at ease, and that will help us obtain actually more valid data. Our team is very hopeful that we have already brought a great deal of impact from this project for the youth themselves, especially the ones who participated in our study directly.

**Rackeb Tesfaye:** We are the largest site of the longest running longitudinal study of autism in Canada. Our families have been a part of the study for over 10 years, and these youth are entering transition phases. They are adolescents transitioning into adulthood, and we wanted to know, what were their hopes for the future? What were the barriers that they were facing in day-to-day life? What do they enjoy about day-to-day life? And we didn't have their perspectives and their voices, and that's what we wanted to get.

One of the main problems that we address with Autism Voices is the inclusion of youth across the spectrum. And this means regardless of their verbal abilities, regardless of their cognitive abilities, we need to make sure that we are amplifying the voices of everyone on the spectrum. And this typically to this point has not been done within qualitative and quantitative research. We used universal design principles and strength-based principles in the Autism Voices protocol. This meant that every youth, regardless of their verbal abilities or cognitive abilities was presented with the same protocol. Each question had pictures that depicted the themes that we were going to talk about that structured the interview and youth were able to elaborate verbally if they had wanted, but also the youth who used fewer words were also able to respond with these pictures.

What we found during the interviews is that the why questions or the how questions were very hard. So we had to present questions in a way where they can select a choice. We also recognized that when we were talking about things that interested them, they wanted to engage more. So they would reach out for a pen and they would write their responses or they would be more invested in the conversation.

**Valerie Courchesne:** One of the challenges that we faced was that a lot of the kids, especially the minimally verbal and nonverbal youth, they would say yes, for example, they had a bias of response for yes. So when we were just giving them choices, they would pick yes. So we had to kind of redo the question and we ask them, okay, so what's your favorite? For example, what do you like most? What's your number one? Your favorite, your number two? Between those two, what do you prefer?

**Mayada Elsabbagh:** More often than not what we heard in those interviews is that the youth themselves feel that there's an assumption that they are either are unwilling or unable to share their first-person perspectives. And perhaps not surprising for us, that was completely not true.

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