

Autism voices

By VALÉRIE COURCHESNE and RACKEB TESFAYE

Over the past six years, researchers involved in the largest study on Autism in Canada collaborated with families and autistic youth to develop the *Autism Voices Project*. Two of the lead researchers based at McGill University, Valerie Courchesne and Rackeb Tesfaye, spoke to us about the evolution of Autism Voices and their findings.

What is Autism Voices?

The project captures the lived experiences of autistic youth aged 11-18 with various language and cognitive abilities. The main goals were to create new methods that enabled youth to communicate their lived experiences and to use these methods to interview autistic youth about their perspectives on their future in different environments (e.g., home, school and community).

Why did the project start?

According to the United Nations' Convention on the Rights of the Child, it is a human right for all children regardless of their abilities to have input in all matters that impact them. Unfortunately, when we looked at the literature we found that autistic youth were rarely

invited to give their perspectives about their own lives. This was especially evident for youth who did not use verbal language or used it minimally. We wanted to fill this gap, by capturing the diverse perspectives of autistic youth on matters that impact them.

What challenges did you encounter while developing the project?

The major hurdle was this had never been done before. We had to create and adapt tools that would fit the diverse communication styles of youth we worked with. This meant creating universal questions that all youth could understand and providing them with various ways to respond. It also meant as researchers and clinicians we had to acknowledge that our default mode of communication prevented us from engaging with certain youth, so we needed to shift our own perspectives.

What helped you overcome the challenges you faced?

It took a lot of time, patience and collaboration. Over the years we had to trial and error different approaches.

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Original papers:

Tesfaye, R*, Courchesne, V*, Miranda, P., Nicholas, D., Mitchell, W., Singh, I., Zwaigenbaum, L., & Elsabbagh, M. (accepté) Autism Voices: Perspectives of the Needs, Challenges, and Hopes for the Future of Autistic Youth. *Autism*. 2022. *co-first authors

Courchesne, V., Tesfaye, R., Singh, I., Zwaigenbaum, L., Miranda, P., Nicolas, D. Mitchell, W., Elsabbagh, M. (2021). *Autism Voices: a novel method to access first-person perspective of autistic youth*. *Autism*, 1-14.

Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Shikako-Thomas, K., Singh, I., Szatmari, P. and Elsabbagh, M. (2019) *Assuming Ability: Synthesis of Methods Capturing First Person Perspectives of Children and Youth with Disabilities*. *Autism*, 23(8), 1882-1896.

This meant talking to families and youth multiple times to tailor the interviews. We also worked with communication experts and ethical experts who gave us input so that the methods would be as inclusive as possible. This was a big undertaking and to do the process justice we needed to take our time and have a lot of humility.

Can you tell us about the methods you used to capture the voices of autistic youth?

First, the idea for developing Autism Voices comes from a previous project that was done with children with Attention Deficit and Hyperactivity Disorder (ADHD) called ADHD Voices. We worked with Iliana Singh, the lead researcher on this project, as well as with parents of autistic youth, who have a wealth of expertise about their child's daily communication styles and preferences, to develop the Autism Voices method. We also built on previous work using known autistic strengths to measure intelligence in minimally verbal autistic children (i.e. strength-based assessment) and we used principles of universal design, meaning that all initial questions were suited for all ability levels. For example, we used picture cards to ask questions and visually demonstrate the structure of the interview for all participants, regardless of their intellectual and language level. To answer, participants could choose their preferred communication method; writing, texting, verbal answer, pointing, etc. and the interviews were applied flexibly to adapt to each participant.

What were some of the key findings that emerged from youth interviews?

Regardless of verbal abilities, all youth identified a few of the things they wanted or did not want in their future. This included **where they wanted to live**, what **professions they wanted to pursue** and the **interests** (e.g., music, movies) they wanted to continue developing. This was a particularly salient finding, because it emphasizes the need for autistic youth to be active participants in the planning of their own futures and that their interests need to be included.

Youth also expressed that **school was a primary area of stress** for them. Many of them described their school environments as unwelcoming or detrimental to their well-being. On the other hand, these autistic youth also indicated that they liked school, because it allowed them to **interact with peers** and **make friends**, which they didn't have many opportunities to do outside of school.

Overall, we found that better support systems in society are needed to ensure autistic youth can feel safe and reach their desired outcomes in life. This includes working with educators to create more inclusive environments, challenging public perceptions of autism, providing more tailored mental health care access and ultimately listening to autistic youth to inform these changes.

What surprised you during this project?

That it worked! The information obtained from non or minimally speaking participants in such a short period of time and with relatively basic adaptations indicates that many of them could express themselves with more formalized support. All youth were engaged during the interviews, they were trying to communicate with the interviewer and youth who were able to verbally communicate expressed that they enjoyed sharing their experience and being listened to.

For us, this further highlights the need for more opportunities like this for autistics, not only in research, but also within the community.

What impact do you think this project will have for the autism community?

We hope that by centering youth voices it allows them to have ownership in their lives and increases their feeling of empowerment. In addition to benefiting youth, this project can impact research and policies as well. The lived experience shared by autistic youth can help guide

academic research and make protocols more inclusive, their input can also inform the delivery of health services and current policies concerning them. 