

# **Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities**

**Rackeb Tesfaye, Valerie Courchesne, Afiqah Yusuf, Tal Savion-Lemieux, Ilina Singh, Keiko Shikako-Thomas, Pat Mirenda, Charlotte Waddell, Isabel M Smith, David Nicholas, Peter Szatmari, Terry Bennett, Eric Duku, Stelios Georgiades, Connor Kerns, Tracy Vaillancourt, Anat Zaidman-Zait, Lonnie Zwaigenbaum and Mayada Elsabbagh**

The United Nations Convention on the Rights of the Child states children have the right to express their own views in all matters that affect them. To date, a large majority of research involving young people with autism spectrum disorder (ASD) has not sought their first-person perspectives. As such, major knowledge gaps remain regarding appropriate methods that are best suited to capturing the voices of a range of young people with ASD, particularly those who are minimally-verbal. In this review, we identified and summarised methods previously used in other research studies to obtain the first-person perspectives of young people with various disabilities. This approach was expected to provide greater insight on how to engage young people with ASD effectively as participants in research. We found 284 relevant articles on this topic. We identified six different primary methods (questionnaires, interviews, group discussion, narratives, diaries, and art) expressed through four modalities (language, sign language and gestures, writing, and images). A group of parents who have children with ASD were then presented with our results. During this consultation, parents identified barriers that may be encountered during participant engagement and gave input on how best to conduct first-person research with young people with ASD. An important message that emerged through this consultation was the necessity of consulting parents, young people, and other experts familiar with young participants, in order to construct optimal environments for self-expression. Identifying methodologies to fit the abilities of young people across the spectrum is needed to promote their empowerment and to better guide future research and policy to improve the quality of life for individuals with ASD.