

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

Autism  
2019, Vol. 23(8) 1882–1896  
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DOI: 10.1177/1362361319831487  
journals.sagepub.com/home/aut



Rackeb Tesfaye<sup>1</sup> , Valerie Courchesne<sup>1</sup> , Afiqah Yusuf<sup>1</sup>, Tal Savion-Lemieux<sup>1</sup>, Ilina Singh<sup>2</sup>, Keiko Shikako-Thomas<sup>1</sup>, Pat Mirenda<sup>3</sup>, Charlotte Waddell<sup>4</sup>, Isabel M Smith<sup>5</sup>, David Nicholas<sup>6</sup>, Peter Szatmari<sup>7</sup>, Terry Bennett<sup>8</sup>, Eric Duku<sup>8</sup>, Stelios Georgiades<sup>8</sup>, Connor Kerns<sup>3</sup>, Tracy Vaillancourt<sup>9</sup>, Anat Zaidman-Zait<sup>3</sup>, Lonnie Zwaigenbaum<sup>10</sup> and Mayada Elsabbagh<sup>1</sup>

## Abstract

Most research regarding youth with autism spectrum disorder has not focused on their first-person perspectives providing limited insight into methodologies best suited to eliciting their voices. We conducted a synthesis of methods previously used to obtain the first-person perspectives of youth with various disabilities, which may be applicable to youth with autism spectrum disorder. Two-hundred and eighty-four articles met the inclusion criteria of our scoping review. We identified six distinct primary methods (questionnaires, interviews, group discussion, narratives, diaries, and art) expressed through four communication output modalities (language, sign language and gestures, writing, and images). A group of parents who have children with autism spectrum disorder were then presented with a synthesis of results. This parent consultation was used to build on approaches identified in the literature. Parents identified barriers that may be encountered during participant engagement and provided insights on how best to conduct first-person research with youth with autism spectrum disorder. Based on our findings, we present a novel methodological framework to capture the perspectives of youth with various communication and cognitive abilities, while highlighting family, youth, and expert contributions.

## Keywords

Autism, disabilities, first-person perspective, inclusion, lived experience, participatory research

## Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects 1%–2% of children globally (Elsabbagh et al., 2012). ASD is characterized by impaired social communication and interactions, as well as repetitive behavior and narrow interests (American Psychiatric Association, 2013). Youth with ASD experience an overall lower quality of life compared to their typically developing peers (Ikeda, Hinckson, & Krägeloh, 2014) and face many other challenges, including being bullied, having difficulty forming friendships (Humphrey & Symes, 2010; Rowley et al., 2012), having increased mental health issues (Cooper, Smith, & Russell, 2017), and struggling with transitions into adulthood (Cheak-Zamora, Teti, & First, 2015; Taylor & Henninger, 2015).

Capturing the unique first-person perspectives of youth with ASD is needed to further understand how these and

<sup>1</sup>McGill University, Canada

<sup>2</sup>University of Oxford, UK

<sup>3</sup>The University of British Columbia, Canada

<sup>4</sup>Simon Fraser University, Canada

<sup>5</sup>Dalhousie University, Canada

<sup>6</sup>University of Calgary, Canada

<sup>7</sup>Centre for Addiction and Mental Health, Canada

<sup>8</sup>McMaster University, Canada

<sup>9</sup>University of Ottawa, Canada

<sup>10</sup>University of Alberta, Canada

### Corresponding author:

Mayada Elsabbagh, Montreal Neurological Institute, 3801 University Street, Montréal, QC H3A 2B4, Canada.

Email: mayada.elsabbagh@mcgill.ca

other challenges can be addressed. Gaining such lived perspective of youth through qualitative analysis is common practice in mental health research (Palinkas, 2014); however, despite the large amount of research being conducted on youth with ASD, their voices remain largely uncaptured (DePape & Lindsay, 2016).

Advancing research to include the first-person lived experiences of young people with ASD is important, as this type of research with youth has positive outcomes for research, practice, and the individual themselves (Bailey, Boddy, Briscoe, & Morris, 2015; Graham & Fitzgerald, 2010; Grypdonck, 2006). For example, previous applications of participatory approaches involving youth with and without disabilities have informed policymaking (Perry-Hazan, 2016; Shier, Méndez, Centeno, Arróliga, & González, 2014) and have improved the quality of academic research and health service delivery (Bailey et al., 2015). Young people's participation in decision-making and the inclusion of their lived experiences in research is also associated with their empowerment and participatory citizenship by increasing their self-esteem, self-efficacy, ownership and belonging to a community (Andersen & Dolva 2015; Bailey et al., 2015; Graham & Fitzgerald, 2010). Youth with disabilities have also expressed that there is value in having their voices heard (Andersen & Dolva, 2015; Cavet & Sloper, 2004; A. Stafford, Laybourn, Hill, & Walker, 2003). Furthermore, the United Nations Convention on the Rights of the Child (United Nations; 1989) states that children have the right to express their own views in all matters that affect them. This right should also extend to the research conducted about and on youth with ASD.

A recent qualitative meta-synthesis on the first-person perspectives of individuals with ASD identified 33 research articles in the past 34 years (1980–2014) that have included the first-person lived experience of either children, adolescents, or adults (DePape & Lindsay, 2016). Although the objective of the synthesis was focused on the themes and narratives documented in the current literature, by extracting article information the authors did provide a list of methods used. The methods extracted from the 33 articles were overwhelmingly semi-structured oral-based interviews conducted with adults or older youth who were highly verbal. Of the 33 articles identified in the synthesis, 19 focused solely on the experiences of adults with ASD. Based on this information, major knowledge gaps remain regarding appropriate methods and conditions that are best suited to eliciting the voices of a range of youth with ASD, particularly those with minimal verbal abilities.

Calls have been made for future research to include the first-person perspectives and experience of youth living with ASD and to describe how these perspectives may vary by gender, age, disorder severity, and other socio-demographic factors (DePape & Lindsay, 2016). The clinical heterogeneity of ASD perspectives needs to be better captured. However, it is currently difficult to ascertain the

scope of methods that exist and how well they capture first-person perspectives of ASD youth with diverse abilities.

For other children with disabilities, including those with differing communication needs, it has been shown that providing the right support and environment and tailoring multiple approaches can be useful for eliciting their first-person perspectives and experiences (Cavet & Sloper, 2004; L. Stafford, 2017; Teachman & Gibson, 2013). Hence, widening our scope of investigation to draw from other disability groups outside of ASD may provide a useful framework to address the gaps associated with first-person methodology. This approach is particularly useful in ASD, as the heterogeneous symptomatology overlaps with many other childhood disabilities (e.g. speech and language impairment, intellectual disability, concurrent developmental disorders such as attention-deficit/hyperactivity disorder (ADHD)). However, systematic syntheses of such methods across various disabilities remain lacking. Reviews that have included information on methods and approaches eliciting the experiences of youth with disabilities have largely focused on a single disability group (e.g. Lindsay, 2014; Smith, Fox, & Trayner, 2015) and themes related to lived experience, with little emphasis placed on the utility of methods (DePape & Lindsay, 2016; Haegele & Sutherland, 2015).

Our main objective was to conduct a systematic synthesis of methods that have been previously used to obtain the first-person perspectives of youth with various disabilities. This synthesis differs from previous reviews as it focuses on methods and approaches that can be used to elicit first-person perspectives of youth with ASD, rather than synthesizing the perspectives themselves. By incorporating insights from various disabilities, this novel approach can then provide a literature-informed guide to create future inclusive protocols to capture the diverse voices of youth with ASD.

Our second objective was to gain the insights and perspectives of stakeholders on the methodologies extracted from the synthesis in regard to its usefulness in ASD research and any potential gaps in the identified approaches. Stakeholders are broadly defined as individuals with a particular interest in research and who can be impacted by the research process, these stakeholders can include youth, parents and a variety of others individuals (Elsabbagh et al., 2014; Yusuf & Elsabbagh, 2015).

A better understanding of methods used to capture the lived experiences of children and youth across disabilities is expected to provide greater insight on how to engage youth with ASD effectively as participants in research.

## Methods

A scoping review was conducted to identify methods used to obtain insight into the lived experiences of children and

youth with disabilities from the first-person perspective. A scoping review refers to a process of summarizing a range of literature in order to convey the breadth and depth of a field (Levac, Colquhoun, & O'Brien, 2010) rather than on the quality of the evidence obtained to answer the question. A scoping review is beneficial for our purposes as it can be used to synthesize existing information, like research methodologies, to reveal gaps in the literature. We followed established scoping review methodology outlined by Levac et al. (2010).

### Search strategy

Article searches were conducted on the PubMed, Academic Search Complete and Web of Science databases using the following keywords:

*“developmental disorder, disability, complex communication disorders, communication disorder, neurodevelopmental disorder, childhood disability, minimally verbal, augmentative and alternative communication (AAC), AAC,” and “qualitative, lived experience, biography, qualitative interview, personal narratives, autobiography, grounded theory, focus group, diaries, cameras, Photovoice” and “child, adolescent, teenager, youth”*

Terms and tools that have been associated with first-person literature were included in our search terms. For instance, AAC was used in the search term as it has been proposed as a potential method to capture the first-person experiences of youth with complex communication needs (L. Stafford, 2017). AAC is used to supplement or replace verbal speech through other modes of communication and strategies (e.g. writing, signing, use of images) suited to individual's abilities. Other approaches like photography have been suggested as a creative participatory method. In fact *Photovoice* (Wang & Burris, 1997), also included in the search term, is a common health research participatory method that engages underrepresented groups, like individuals with intellectual disabilities, as photographers to capture pictures from their own perspectives (Jurkowski, 2008; Lal, Jarus, & Suto, 2012).

### Article selection

Two reviewers (R.T. and A.Y.) independently reviewed the titles and abstracts of all identified studies and excluded irrelevant ones based on *a priori* inclusion criteria. Articles met the inclusion criteria if they had all of the following: (1) included a first-person perspective, (2) included individuals with any reported disability (e.g. neurodevelopmental disorders, physical disability, intellectual disability, etc.) who were 18 years of age or younger, (3) were published within the past 15 years (*by August 2017*), and (4) reported empirical original research. Single-subject research designs and review papers (e.g. meta-analyses or

systematic reviews) were excluded. We excluded any study that relied solely on participant observation and field notes to infer lived experiences, as this did not represent a first person perspective. Parents or other individuals used as a proxy to speak on behalf of youths were also excluded. Studies that included other first-person perspectives in addition to those of youth were also included.

The reviewers compared their decisions regarding inclusion/exclusion and reached consensus on any divergence that arose from their respective reviews. Citations from selected articles were then cross-referenced and added if they met the above inclusion criteria. We also selected articles that fit our criteria from the reference lists of four other reviews on the lived experiences of youth with various disabilities, including ASD, cerebral palsy, and Tourette syndrome (DePape & Lindsay, 2016; Haegele & Sutherland, 2015; Lindsay, 2014; Smith et al., 2015). Two hundred and eighty-four articles identified from our search strategy met the inclusion criteria.

Data from selected studies were extracted independently by two reviewers, including participant characteristics, methods, and study objectives (detailed in supplementary materials Table 1). To ensure inter-rater reliability, data from 10 random articles were extracted by the two reviewers and then compared for accuracy. No differences in the data extraction were found, and the two reviewers continued with analyzing separate articles.

### Stakeholder consultation

Following the synthesis, a stakeholder consultation was held to gain input on the utility of strategies and approaches identified in the literature for youth with ASD, and to gain further insight into how best to elicit their lived experiences. Consulting stakeholders is an important, but often skipped step, in validating and enhancing findings from a scoping review (Arksey & O'Malley, 2005).

For the purposes of our review and as a first step toward identifying effective methodologies to capture the perspectives of youth with ASD, we extended an open invitation to parents who were already actively involved in an ongoing longitudinal study on ASD. We recognize that drawing from the expertise of parents as our first step needs to further expand to include other stakeholders, like youth themselves, ASD adults, clinicians, and educators, to validate our findings. Despite the fact that parents can have differing viewpoints from youth with disabilities, which cannot fully reflect the lived experience of the youth themselves (Jacquez, Vaughn, & Wagner, 2013; Stalker & Connors, 2003), their insights on the methods identified in the scoping review can ultimately be useful to determine how to tailor them to better capture their child's perspectives. Parents of youth with ASD are shown to have strong knowledge of their children's strengths (Carter et al., 2015); additionally, they have been found to play a key

role in facilitating interactions with researchers (Shaw, Brady, & Davey, 2011). Even though parents can provide illuminating insights on how to effectively communicate with ASD youth, they have yet to be advised on the methodologies that can be integrated in lived-experience studies to elicit youth experiences. Furthermore, engaging parents in the design of a study is shown to be feasible and have a positive impact on family's research experience, while better addressing their research interests (Yusuf & Elsabbagh, 2015). Findings from this first consultation will be consolidated to present to aforementioned stakeholders, their insights on methodologies will be followed by a pilot to evaluate their efficacy on a range of youth with ASD.

Our convenience sample yielded four parents (two mothers and two fathers) with children diagnosed with ASD. From this convenience sample, we specifically sought parents with a diverse range of experiences in raising youth with various abilities to represent a heterogeneous capture of ASD. This was done to ensure that multiple perspectives on the diverse methodologies presented would be captured. Their children were all boys aged 13 and 15 years. Two were minimally verbal and attended specialized schools. The two others were enrolled in mainstream schools, with average verbal and cognitive abilities.

A semi-structured discussion guide was developed (see Appendix 1). The parent group consultation lasted approximately 90 minutes and was audio-recorded. During the group consultation, parents were first invited to share their experiences on eliciting perspectives and first-person experiences from youth with autism, including any communication barriers they have encountered with their own child. They were also asked to reflect on methods and optimal environments they believed would be best suited to capture various language and cognitive abilities. A summary of results obtained in the scoping review was also presented to parents to facilitate discussion and to assess the suitability of the approaches and methods that were identified in the review for youth with ASD.

### **Stakeholder analysis**

The audio recording was transcribed verbatim and analyzed using thematic analysis (Braun & Clarke, 2006). The discussion guide was used as an initial list of guiding concepts to help facilitate coding; however, given the natural open-endedness of the discussion additional topics were covered. Data were coded independently line-by-line to identify emerging concepts by two researchers (R.T and V.C), one of whom was not involved with the stakeholder discussion, allowing for another perspective. NVivo software (Version 11, QSR international) was used to assist in the coding process. All initial codes from the two independent analyses comprised the same concepts, indicating

consistency in coding. The two coders then discussed appropriate labeling for these concepts, which were then renamed and consolidated into overarching themes and subthemes. We assessed the quality and trustworthiness of our analysis (Lincoln & Guba, 1986) using multiple iterative stages as suggested (Braun & Clarke, 2006), and discussion debriefs with other researchers on the team (peer debriefing). Identified themes and subthemes were then independently reviewed and revised by a third researcher (M.E.). All researchers then met again to refine and finalize the themes presented in the next section under stakeholder consultation.

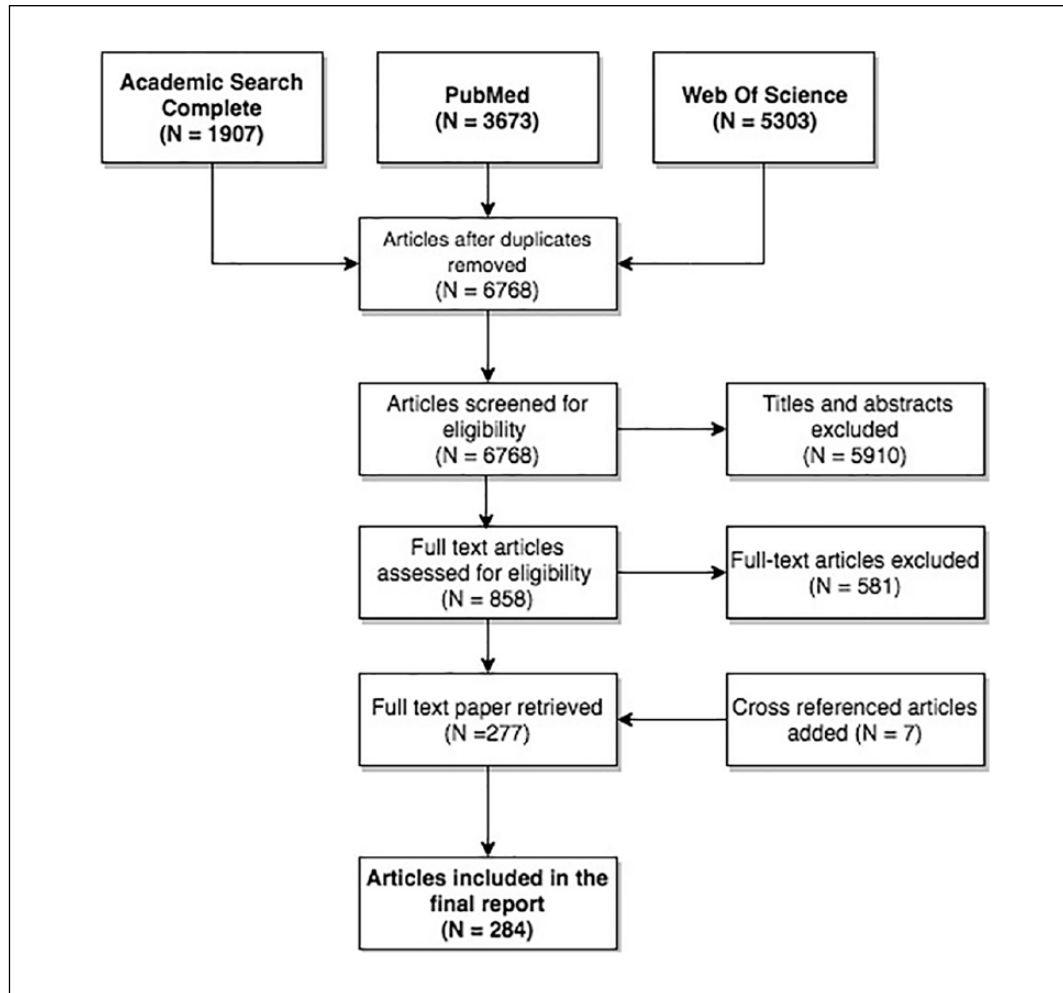
## **Results**

### ***General characteristics of scoping review articles***

Based on our search criteria, 6768 articles were initially found. Two hundred and seventy-seven full-text papers were retrieved in addition to seven cross-referenced articles (see Figure 1). In our final step, we included 284 papers. These studies differed substantially in their objectives, in participant demographics, and in having other respondents without disabilities included. The following description summarizes these general study characteristics. For a more detailed extraction of study characteristics, see Table 1 in the supplementary materials.

**Study objectives.** Identified studies captured the first-person perspectives of youth on a variety of topics including: living with the condition or disability; forming sexual or religious identities; community participation and leisure; transitions into adolescence and adulthood; interactions with peers, services and institutions; and participation in research studies. Feasibility studies that reported on methods to capture youths' perspectives and engagement were also identified.

**Participants.** The number of participants with disabilities in each study ranged from 2 to over 600, but most studies included fewer than 20 school-aged children. The two most common disability groups included were children and youth with cerebral palsy and ASD. Many studies characterizing participants with ASD did not specify criteria for diagnosis, or indicated that ASD was self-reported (e.g. Mitchell & Beresford, 2014). Other groups included children with: other neurodevelopmental disorders (e.g. ADHD, Down's syndrome), intellectual disabilities, learning disabilities, sensory disabilities (e.g. visual or hearing impairment), speech and language disorders, and other medical conditions (e.g. spinal cord injury, brain injury). Several authors did not specify the disability type for their participants. For a detailed list of disability groups, see Table 2 in supplementary materials.



**Figure 1.** PRISMA search strategy.

Sixty-three studies included some children and youth with communication impairments, speech difficulties, or minimal verbal skills. Few captured the voices of youth with communication impairments or minimal verbal abilities solely, and when these youth were included with other highly verbal participants their perspectives represented the minority (e.g. Batorowicz, Campbell, von Tetzchner, King, & Missiuna, 2014). Several studies excluded children and youth who were “minimally verbal” or had communication difficulties (e.g. Cussen, Howie, & Imms, 2012), either during initial screening or through incomplete participation due to communication challenges. Some studies used parent proxies to speak for children who were less verbal than other participants (Kirk, 2008) or to interpret communication (e.g. Evans, Neophytou, De Souza, & Frank, 2007).

Many studies did not include basic information to characterize participants—in particular, studies did not report on the nature of participants’ impairments, particularly if they had multiple disabilities or if the group varied in disability types (e.g. King et al., 2014; Kirk, 2010; Rutherford,

2012; Wren, 2017). Moreover, some studies did not adequately report demographic information such as gender and age, although most studies involved school-aged children. Similarly, participants’ cognitive and communication abilities are likely to have a major impact on researchers’ ability to capture first-person perspectives, but were poorly characterized in most studies

*Other respondents.* Overall, 135 studies included the perspective of other respondents such as parents, educators, siblings, peers, health care professionals, decision-makers, sports coaches and other stakeholders. Multiple perspectives were often used to triangulate data about the question of interest, to ensure consistencies, divergences, or to illuminate new points of view that were distinct from those of child and youth participants. For instance, one study explored, from the perspectives of different stakeholders, potential design barriers at school that youth with physical disabilities may experience. This study found that students with disabilities identified more barriers than school principals or special education teachers (Pivik,

2010). Other studies have found consensus among perspectives. A 2016 study by Nguyen et al. revealed that both youth with various developmental disabilities and chronic medical conditions and their parents agreed that youth became increasingly independent in managing their medical needs as they transitioned into adulthood. While recognizing their children's growing independence, parents also provided additional perspectives on the limitations of their children's independence that the youth themselves did not directly identify. This highlights the important need to obtain multiple layers of perspectives that can be used to gain a comprehensive understanding of lived experience.

**Interview modes.** Three different interview modes were most frequently described in the literature: (1) in-person, (2) telephone, and (3) online (e.g. instant messaging, video messenger, social media, email). Overall, the most frequently used mode was in-person.

**Setting.** In-person communication was most commonly utilized in participants' homes, schools or familiar community locations (e.g. community centers, outdoors, church.). Families and youth were often asked to choose their preferred locations. Few studies occurred within an academic research site or a workplace environment. However, many authors did not specify the location of their interaction(s) with children and youth.

**Administrator.** Nearly all methods were administered by researchers, yet their backgrounds and professional training typically were unspecified. However, in one study (Kramer et al., 2013), youth with disabilities conducted group discussions and program evaluations with disabled peers, supervised by researchers and an advocate. Another study enlisted the assistance of a media professional to guide a podcast project that captured the experiences of youth with ASD (Stevenson, Cornell, & Hinchcliffe, 2016).

### **Synthesis of research methods used to capture first-person perspectives**

To address the main objective of this scoping review, we extracted the range of methods used to obtain the first-person perspectives of children and youth (Table 1 supplementary materials) and further synthesized these into: (1) primary methods that were used to obtain first-person perspectives; (2) communication output modality, which refers to how youth engaged with the primary method(s) to communicate their perspective; and (3) facilitation techniques, which were secondary methods the researchers used to improve the capture of first-person perspectives. The synthesis is illustrated in Figure 2 and detailed below.

**Primary method.** Six methods were identified: (1) questionnaires/surveys; (2) one on one interviews; (3) group discussion, including focus groups; (4) narratives (e.g. essay or letter writing); (5) diaries; and (6) art (e.g. drawing, photography, crafts). The most frequently applied primary method was open-ended interviews, followed by group discussions and questionnaires (the latter term was used interchangeably with the term survey across studies.)

**Communication output modality.** Children and youth used various communication modalities to engage with primary methods, including (1) oral language; (2) sign language, which included American Sign Language, British Sign Language, and Makaton signing, and gestures; (3) written language, either handwritten or typed; and (4) image-based communication. The latter could be used in various ways, for instance first-person perspectives could be elicited through drawing, taking photographs or by using pictorial or graphic symbols chosen by the participant to express themselves.

Various devices, tools, and systems were used in conjunction with various output modalities (noted in Figure 2 with \*). These included Talking Mats (Allard et al., 2014; Murphy, 1997), Blissymbolics (Hultman, Forinder, & Pergert, 2016), Picture Exchange Communication System (Hultman et al., 2016), Minspeak (Batorowicz et al., 2014), eye transfer frame, and communication books and alphabet boards (e.g. Hynan, Goldbart, & Murray, 2014). These approaches were used to convey image-based communication in one-on-one interviews (Carroll & Sixsmith, 2016), groups discussions (Allard et al., 2014) and/or to complete questionnaires (Donohue, Bornman, & Granlund, 2014).

Talking Mats was one of the most common image-based systems used. This technique was developed to include youth with disabilities actively in discussions and decisions that affect them (Cameron & Murphy, 2002). The technique allows for pictorial symbols to be pointed at and moved around a mat or digitally (e.g. using an iPad), which can then be photographed to archive the participant's viewpoint (Cameron & Murphy, 2002). Non-verbal forms of communication, including gestures, pointing and sorting were used to interpret youths' views in many studies, including those that used Talking Mats. However, the modality of communication output was based on how participants conveyed their messages (e.g. via images), rather than how they chose their message (e.g. pointing).

Other aids were used for text-based communication and included on screen keyboards (e.g. Carpe, Harder, Tam, & Reid, 2010; Hynan, Goldbart, & Murray, 2015) and speech-generating devices (e.g. Batorowicz et al., 2014). Although messages were presented orally when these aids were used, the output modality was typing, so these were considered to be text-based methods.

		Communication Output Modality			
		ORAL LANGUAGE	SIGN LANGUAGE and GESTURES	WRITTEN TEXT	IMAGE-BASED (pictures, graphic symbols)
Primary Methods	1. QUESTIONNAIRES /SURVEY	+ Elicitation ●		* + Elicitation ●	* ●
	2. INTERVIEW	+ Interpretation + Elicitation ●	●	* + Interpretation + Elicitation ●	* ●
	3. GROUP DISCUSSION	+ Interpretation + Elicitation ●		* + Interpretation ●	* ●
	4. NARRATIVE	●		●	
	5. DIARIES	●		+ Elicitation ●	●
	6. ART				* ●

**Figure 2.** Synthesis of methods used to capture first-person perspectives of youth with disabilities.

\*Devices, tools and systems used to transmit output.

Six primary methods interacted with four modalities to capture the lived experiences of youth. Dark dots indicate an interaction between a primary method and communication output modality. *Primary method 1:* Questionnaires or surveys (used interchangeably) could be completed using oral language, text, or images. *Primary method 2:* Interview questions could be responded to using oral or sign language, text or images. *Primary method 3:* Group discussions could be carried out in oral language, with written responses to questions posed to the group or using image based responses. *Primary method 4:* Narrative methods included written letters or essays, and other narrative methods like storytelling or interviewing others could be audio-recorded and turned into a podcast (Stevenson, Cornell, & Hinchcliffe, 2016). *Primary method 5:* Diaries of participants' lived experiences could be written or image-based, using photos. Other diaries were produced with oral language, recorded with audio with or without video. *Primary method 6:* Art-based methods, which included crafts and photography (e.g. photovoice), were employed and analyzed using content analysis or in addition to interviews. Photographs were taken digitally, with a disposable camera, or using alternative technologies like SensCams (Hodges et al., 2006). *Elicitation techniques:* Methods used to catalyze and enrich the delivery of the primary method included means such as drawing and role playing. *Interpretation:* This approach refers to the assistance of parents or professionals for communication between the interviewer and youth.

In most cases, the communication devices, tools, and systems used in these studies were those used by children and youth prior to study participation. However, in some studies, researchers taught youth to use novel communication modalities or aids to capture first-person perspectives (e.g. Carroll & Sixsmith, 2016; Donohue et al., 2014). In other studies, participants' familiarity with the mode of communication used to elicit information was not stated (e.g. Sloper, Beresford, & Rabiee, 2009).

*Facilitation techniques.* Along with these communication methods and modalities, many studies also included elicitation and interpretation techniques to facilitate gathering of first-person perspectives. Previous research has shown that facilitation techniques: elicit information that might otherwise be missed in traditional interviews, increase participants' comfort and reduce their anxiety, help the interviewer to navigate preferred communication styles, and build rapport by diminishing power dynamics (Teachman & Gibson, 2013).

Elicitation techniques were intended to catalyze and enrich the use of the method and/or made participants feel comfortable during the study. Examples included interviewers asking participants to take photos, fill in sentences, draw, circle responses, role-play, imagine scenarios (mentalization), make lists, or provide captions for cartoons. Outputs of these techniques were then used to stimulate conversation and act as a point of reference for further questioning. A few researchers have also noted that engaging youth with facilitative methods that use imagery and stories were most effective when tailored to suit individuals and their environments (Barter & Renold, 2000). For example, cartoon captioning (e.g. thought bubbles) is a technique that assists youth with ASD in understanding the representation of social interactions, and its cartoon imagery can be designed to resemble children's physical traits and convey a story with a character with whom the participant identifies (Barter & Renold, 2000; Teachman & Gibson, 2013). Such an approach can also include photographs depicting children's familiar surroundings, such

as familiar home and school settings, rather than templates that have less resonance.

The majority of elicitation techniques were used for in-person, oral interviews with children and youth. However, some elicitation techniques were used during group discussions, interviews (written and AAC), questionnaire completion (i.e. using visual scales), and diary production (i.e. rating emotions on a scale daily). Photos and visual cues representing themes or topics of interest were the most commonly used elicitation techniques. Photo elicitation is a form of Photovoice whereby photos can be archival (already taken) or generated by a non-participant to elicit conversation (e.g. Danker, Strnadová, & Cumming, 2017) as a facilitation technique. Photovoice and photo elicitation within our identified studies were common strategies applied to elicit the first-person perspectives of youth with disabilities such as ASD (e.g. Danker et al., 2017; Ha & Whittaker, 2016; Hill, 2014; Obrusnikova & Cavalier, 2011; Teti, Cheak-Zamora, Lolli, & Maurer-Batjer, 2016). These photo methods have been proposed as engaging tools to elicit the perspectives of youth, particularly those with speech and communication impairments, as they rely less on verbal responses (Aldridge, 2007). One Photovoice study including minimally verbal youth used a Microsoft SensCam (Hodges et al., 2006) as a technical support (Carroll & Sixsmith, 2016). Microsoft SensCam is a wearable camera that automatically captures pictures from the perspective of the wearer, providing a visual account of the daily routine. The interpretation of photos, which can be difficult to convey for minimally verbal youth, has been supported by using Talking Mats strategies to categorize photos (e.g. “I like” or “I don’t like”) and elucidation by parents (Carroll & Sixsmith, 2016; Germain, 2004; Preece & Jordan, 2010).

Another, albeit rare, facilitation technique was interpretation, whereby six studies used the assistance of parents or professionals to clarify the communication between the interviewer and youth.

### Stakeholder consultation

Upon the presentation of methodologies extracted from the review, parents all expressed that choices, like those shown in Figure 2, would be best to have if they were approached to take part in a study of a child’s lived experience. They all agreed with the following parent, who noted,

*I think it would be nice, if somebody called me they gave you these options [referring to figure 2]. So ideally, if it were presented in this way, we can do it this way or this way, at your house, here, wherever. That would be great. So that’s what I take from that. It really depends on the person. And the parent would probably be the best to say ok that would work, and this would not work. (Parent #4)*

Although information on each methodology category was provided, it was clear that going through each one would provide differing perspectives of efficacy (e.g. one parent with a highly verbal child liked group discussions, while that was not a feasible option for the youth of another parent). Hence, parents collectively decided that these diversity of methods should always be provided as options, while specific methods sparked broader group discussion based on parent experiences that are captured in the themes below.

We identified six themes during the consultation. All themes and subthemes are detailed below. For selected parent quotes per theme and subtheme see Table 3 in the supplementary materials.

#### **Theme 1. The necessity of capturing first-person perspectives of children and youth.**

When asked about their thoughts on research involving the lived experience of youth with ASD, all parents expressed that youth involvement was important. Two subthemes emerged from this conversation.

##### *Subtheme (a): Youth with ASD should be heard*

All parents agreed that children and youth need to be considered as individuals and not overlooked. They emphasized youth have the right to convey their lived experiences.

##### *Subtheme (b): First-person perspectives can inform the experience of future diagnostic journey’s*

Parents expressed not having much support in understanding their children’s perspectives when they were starting on their journey of receiving a diagnosis. They believed that studies including the lived experiences of youth across the spectrum could be comforting to parents who are starting to navigate their child’s diagnosis and help them understand what they can expect in the future.

#### **Theme 2. Assuming the ability of youth with ASD.**

Throughout the discussion, parents emphasized that research involving children and youth with ASD, and general daily interactions with these children and youth, should not primarily focus on their communication and other “deficits,” but rather assume that they are capable of communicating in some way. According to parents, their children’s abilities are often underestimated and it is important for others, especially professionals, to understand this.

Parents also described experiencing conflict in that even they may under-estimate their children’s abilities. But they also wanted to be strong advocates for their children when others doubted their child’s potential.



**Theme 3. Parents' experiences with communication barriers.**

Based on their personal experiences, parents identified common barriers to communicating with youth, as described below.

*Subtheme (a): Oral communication challenges with youth*

Parents whose children were minimally verbal or who use speech in atypical ways identified these as being the most salient communication barriers for them.

*Subtheme (b): Cognitive differences as a mutual challenge*

Parents agreed that they had different and rigid viewpoints from their children and tended to impose their own understanding of the world and acknowledged that this presented a barrier to clear communication with their children, irrespective of their oral language abilities.

**Theme 4. Experiences with communication facilitators.**

Parents gave several examples of what worked for them and other parents in their communities with respect to eliciting communication. They noted that the best strategies and methods to facilitate communication were often discovered serendipitously.

**Theme 5. Reaching out to experts for input.**

Parents suggested reaching out to a range of experts, both professionals and those who had personal relationships with the child, to identify individuals who communicate best with their children and could provide insight to approaches best suited for them.

**Theme 6: Tailoring the approach for youth and parent participation.**

*Subtheme (a): Providing appropriate and comprehensible information*

Parents stressed the importance of their children knowing why they are participating and being involved in the research process. Presentation of the reasons for participation, according to parents, was viewed as needing to be suited to each child's level of understanding.

*Subtheme (b) Finding the "hook": capture intrinsic interests and motivation*

All parents emphasized that each child has his or her own interests, and participation is heavily reliant on capturing those interests. If methods can integrate activities the children are interested in, they would more likely participate.

*Subtheme (c): Give parents options to make decisions*

Parents identified several methods that may be suitable for research with their own or other children with ASD. They strongly believed that parents should be consulted with regard to the methodological details included in the research protocol, based on their experiences with their children's capabilities. They did not think it appropriate for researchers to make independent decisions about research methodology for individuals.

*Subtheme (d): Emphasize questions not the methods*

Parents highlighted that children's or youths' levels of engagement depended largely on being asked the "right" questions. One parent emphasized that for their child sticking to concrete questions and not asking about emotions would yield a better continuity of conversation, which was not the case for all parents

*Subtheme (e): Incentives*

All parents agreed that rewards and incentives are a substantial factor for motivating youth to participate in research.

*Subtheme (f): Creating a comfortable and safe research space*

Participants described the importance of accounting for the relationship dynamics between interviewers and young people with ASD. For instance, face-to-face interaction and eye contact might make some youth uncomfortable; hence, choosing another, perhaps more activity-based method (e.g. sitting next to versus across from each other, or talking while doing something) would be helpful. Parents also highlighted that the location of the interaction with the youth would ideally be chosen by the youth and parents. Another topic of discussion was terminology used with youth and the disclosure of their diagnosis. One parent offered insight into the importance of knowing whether to refer to the diagnosis, as some children may reject this label, or not yet know. Therefore, researchers need to take this into consideration while developing lists of guiding questions for children and youth.

*Subtheme (g): Keep it short*

The time spent capturing the lived experiences of youth was a factor that parents identified. Parents suggested that limiting the time spent questioning youth (an hour or less)

as their interest would fade; multiple sessions were thought to be a feasible alternative in eliciting rich data requiring long engagement with youth.

## Discussion

Our goal for this article was to identify existing methodological approaches used to capture the voices of youth with diverse abilities—to inform methods that may be applied to elicit the first-person perspectives of youth with ASD. To achieve this, we first conducted a scoping review to identify articles that attempted to capture the lived experiences of youth with varying abilities from the first-person perspective to document the methods used. We then conducted a stakeholder consultation, during which parents of youth with ASD were asked to respond to the results of the review and to provide insights based on their lived experiences with their children. This second phase was done to inform how the identified methods from the scoping review can be better applied to eliciting the experiences of youth with ASD.

The results of our review, which included 284 articles, identified methodological limitations. For example, basic participant characteristics and study design information were not well reported in many studies. This lack of systematic reporting needs to be addressed in future research. Despite the seemingly high number of identified articles, according to our review, individuals with speech and language impairments and complex communication needs tend to be the least represented in research capturing the first-person perspectives, compared to youth with well-developed verbal abilities. One major barrier accounting for this exclusion stems from the limited methodological approaches that have been applied to capture the voices of youth with a range of cognitive and verbal abilities, as previously noted (Beresford, Tozer, Rabiee, & Sloper, 2004; Germain, 2004; Hill, 2014; L. Stafford, 2017; Teachman & Gibson, 2013). This issue was illustrated by the large majority of studies in our review—across disabilities—using semi-structured interviews as a main method to elicit first-person experiences, which mirrors previously published results of a review on the first-person perspectives of individuals with ASD (DePape & Lindsay, 2016).

We were also able to expand on findings from DePape and Lindsay's (2016) review. In particular, by broadening our search terms and including youth with other disabilities we were able to identify more studies that included ASD youth. This outcome is largely due to many studies involving youth participants with a variety of diagnoses in their samples that also included ASD. Extending the scope of our review therefore led to the identification of a wider range of relevant methods that could be adapted for ASD research. For instance, a greater variety of facilitator methods were used in other or combined disability groups (e.g. vignettes, pictorial questionnaire scales, sentence starters),

while no studies including ASD youth alone used accessible methodologies like Talking Mats. Studies using Talking Mats can inform future lived experience studies with ASD youth as they demonstrate how to integrate approaches for minimally verbal youth and those with cognitive impairments, which can also be used in parallel with other methodologies such as questionnaires or Photovoice, and technologies like SensCams (Allard et al., 2014; Carroll & Sixsmith, 2016; Donohue et al., 2014; Germain, 2004; Sloper et al., 2009).

Overall, a range of methods and communication modalities was identified by this scoping review and confirmed by parents as potentially useful to capture the lived experiences of youth with ASD. However, it is important to note that pairing the right method with the optimal modality for each individual is crucial, as a mismatch may not fully capitalize on a youth's communication capabilities, and risks limited or inaccurate conclusions from collected data. For instance, a written modality, like emailing, may be preferable and facilitate a more comfortable social environment in which youth can express themselves (Benford & Standen, 2011; Jones, Quigney, & Huws, 2003), yet it may also increase chances of misinterpreting emotions or valuable nonverbal cues (Shepherd, 2003). Other facilitation techniques identified included the provision of word options to complete a question (Loyd, 2015). Such a technique may be useful for youth with ASD, as close-ended questions may be an easier way to elicit information than open-ended questions (Bruck, London, Landa, & Goodman, 2007; Preece, 2002). Harrington, Foster, Rodger, and Ashburner (2014) reported adapting their communication style when interviewing youth with ASD to incorporate simple language and drawing on the participant's vocabulary, while avoiding figures of speech that are hard to interpret for many individuals with ASD. This is in line with parents' indications that questions and wording are as important as the methods used. The appropriate use of language also ties into the need to address cognitive abilities because simple language can render relevant concepts more readily understood by youth with lower cognitive abilities, hence reducing a mismatch between what versus how they understand. The use of personalized facilitator methods echoes calls from parents to tailor activities to the interests of youth. Alternative methods that can be customized for youth with ASD are the approaches used in social stories (Gray, 1994), shown to be effective in qualitative research (Beresford et al., 2004). Social stories have been used for many years as an intervention approach to help youth with ASD better interpret, understand and cope with daily social interactions (Karkhaneh et al., 2010). Hence, social stories can be a useful method to engage participants during research interviews, serving as a catalyst for more meaningful and tailored conversations. Hence, the methods and guidelines used to construct social stories could be useful to engage participants during research

interviews, serving as a catalyst for more meaningful and tailored conversations.

Notwithstanding these possibilities and modification in approach, ensuring that the interpretation of extracted information reflects the views of youth with communication impairments indeed represents a challenge. The possibility that parents or researchers may interject with their own perspectives must always be considered (Preece & Jordan, 2010). For example, with Photovoice, the content analysis of photos by researchers can be discrepant from the views of youth (Ha & Whittaker, 2016). Hence, involving youth participants in the interpretation of data to whatever extent possible is always warranted. This issue of inappropriately interpreting outputs of facilitation techniques calls for researchers to be mindful of imposing views of interpreters, including themselves.

To maximize children's abilities to express their own lived experiences, parents have stressed that it is imperative to include families as partners, which is in line with previous research (Abbott, 2013; L. Stafford, 2017; Teachman & Gibson, 2013). Parents are equipped to share insight into the daily routines and communication styles that are helpful, useful and preferred by their children. Parents can also inform researchers about their child's strengths and abilities, which should always be used as the foundation for selecting methodologies and tailoring facilitation techniques. Other researchers have expressed the importance of meeting with families prior to conducting research activities, to build rapport with the youth (and family) and to become familiar with any communication impairments or preferences (Abbott, 2013; L. Stafford, 2017; Stalker & Connors, 2003). These initial meetings are believed to maximize participation and improve the overall experience for youth involved (L. Stafford, 2017), and can help guide the formation of research objectives and planning (Teti et al., 2016). However, if an introductory meeting is not feasible, phone interviews with parents can also be scheduled (Carroll & Sixsmith, 2016).

Parents in our study along with past study recommendations have also encouraged researchers to consult with other experts involved in youths' lives who can inform on optimal approaches to communicating with these youth (Loyd, 2015). Based on consulting parents and experts, as with youth input, researchers should always aim to use youth's accustomed method of communication prior to introducing new techniques (Stalker & Connors, 2003) and build on the youth's strengths to adapt the method to their evolving needs. These consultations should also extend to setting preferences, which was a common choice presented to families in the studies identified by our scoping review. Beyond methods and settings, researchers should consider who may be best suited to capture the lived experience of youth, as this may be someone other than the researchers (e.g. peers or another familiar person). This consideration and decision should be discussed with

families, including youth. Collecting information from various sources regarding methodology will lead to the most optimal approach to eliciting youth's perspective, as the triangulation of information can provide a holistic understanding on how to engage youth.

Throughout the process, from the selection of methodology to the elicitation of their perspective, it is crucial that researchers always assume the capabilities of youth with ASD. This assumption should be translated into researchers' decision-making steps as well as providing participants with as much autonomy and support as possible.

### *Limitations and future directions*

Capturing the voices of youth with ASD and other disabilities is becoming a greater priority in research, as reflected by the number of articles extracted within 2017 (to date), which is more than in past years. We urge future researchers to characterize their participants better, including more detailed and standardized information on youths' diagnoses and communication abilities to ensure that conclusions can be drawn based on a spectrum of abilities and respective perspectives. Like others before us (Harrington & Foster, 2014), we strongly recommend that authors document the struggles and benefits of using various techniques, to help guide other researchers in determining the adaptability and appropriateness of methods among the population with ASD. A further step would be to consolidate protocols, methods, and question guides from existing literature into an online repository accessible by other groups who similarly wish to capture the voices of youth with disabilities including ASD.

Although a scoping review is useful to map the state of existing literature and to identify current research gaps, providing information on the quality of each method was beyond the scope of our current objective. Therefore, we included all studies relevant to the scope of the established topic. Hence, further research is needed to evaluate the efficacy of identified methods being used to elicit the first-person perspective and adaptations of these methods for youth with ASD.

Incorporating a stakeholder component to inform or validate findings of a scoping review adds methodological rigor and provides insight beyond that found in the literature (Levac et al., 2010). However, the lack of diverse stakeholder perspectives in our consultation was a major limitation of this study. Our convenience sample of parents was small, limited in youth's age and ability range. The sample also did not include the representation of girls, nor were there insights of other stakeholders, such as youth and adults with ASD, or educators and clinicians consulted. As mentioned, our consultation was used as a first step to validate methodology used in the lived experience literature. Parents of children with ASD were selected as our initial stakeholders, as no published

information exists regarding their insights on effective methodologies and approaches that can be applied to eliciting first-person experience. We aim to extend our consultation to other groups of stakeholders, including individuals with ASD, building on the knowledge gained from parents and existing literature. We hope our current findings will also catalyze the efforts of other researchers to use these insights to consult with underrepresented stakeholder groups and adapt them in their protocols to elicit lived experience.

## Conclusion

Our synthesis of information from both the literature and parent stakeholders has provided a novel methodological framework for researchers. Researchers also ought to consider increasing transparency by describing their methodological challenges, and by providing research protocols (e.g. questions, methods, guidelines) to inform future studies. We conclude that the methods applied with young people with various disabilities can be adapted for a diverse range of youth with ASD, including image-based techniques like Talking Mats. The most salient theme to emerge from this work is the necessity of consulting parents, youths, and other experts (e.g. educators, clinicians, family members) familiar with youth participants to construct optimal environments for self-expression and reliable interpretation. Researchers should favor a flexible approach to first-person research that can evolve as they collaborate with youth participants, families and experts, rather than following a prescriptive research protocol. To accomplish this, we advocate that researchers draw from existing literature to utilize tools that can be tailored based on each individual's strengths to elicit their perspectives regardless of their communication, functioning, or intellectual abilities. Identifying optimal methodologies to fit the abilities of youth across the spectrum is needed to promote youth empowerment and to better guide future research and policy.


## Funding


The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Research was supported by the Canadian Institutes of Health Research, KidsBrain Health Network, Fonds de recherche du Québec and by the Joan & Jack Craig Chair in Autism Research.

## Supplemental material

Supplemental material for this article is available online.

## ORCID iDs

Rackeb Tesfaye  <https://orcid.org/0000-0002-1924-4721>

Valerie Courchesne  <https://orcid.org/0000-0001-7768-5448>

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## Appendix I

### ASD voices: Guide for stakeholder validation focus groups

April 10th 2017

*About ASD voices and the objectives to the consultation.* ASD voices is a study designed to capture the first-person perspectives of a diverse range of youth with ASD about their lived experience (at home, school, and the community) and their aspirations for the future. By this I mean information that accurately represents the views of children or youth themselves.

Currently, we have very little knowledge about first-person perspectives of children and youth that can guide practice or policy, and influence future research.

The diversity of voices among children and youth with autism is often not fully captured and represented. It is challenging to be inclusive because there is wide variation in terms of how autism impacts different individuals. Examples include verbal communication and cognitive level.

*In our group discussion today, we invite you to think about and discuss constructive ways to collect firsthand information about the experiences and perspectives of children and youth with autism.* We believe that you are experts in the day-to-day experiences and perspectives we are hoping to capture

1. To start, I would like us to go around the table and invite you to say your name and tell us if you feel it is important for researchers to capture these firsthand experiences and perspectives?
2. What are the barriers that might limit researchers from gaining as full an understanding as possible?

*Probe:* Can we now specifically consider the diversity of autism and think about youth with verbal language delay or impairment

3. \*What methods would best invite the experiences and perspectives of youth with autism? What is it about these methods that makes it well suited to autism?

*Probe:* Think back to what has worked best in getting your child to communicate what they're concerned about or what they wish for?

4. Who in your opinion, would be the most effective person in obtaining these perspectives and in what environments?
5. Do you have any other thoughts/recommendations?

*Discussion of identified methods in research.* Before our session today, we reviewed existing research to identify the range of ways that information has been obtained from children and youth with autism or other conditions. We now want to know what you think about the approaches we identified from research.

Beyond these approaches, there may be other ways that have not yet been identified or used in the literature. If that's the case, you are welcomed to also let us know of any other possibilities that make sense to you.

To get started, my colleague will briefly present to you the different approaches we found in research.

1. Do you think these methods have the potential to accurately elicit the firsthand experience and perspectives of a child or youth with autism?
2. Do you think these methods are sensitive to the range of communication challenges or cognitive ability associated with autism including children and youth who are minimally verbal and those with lower cognitive functioning?
3. Do you think these methods could be engaging for children and youth with autism?
4. Which methods do you think are worthwhile to use in a research study seeking to understand the firsthand experiences and perspectives of youth with autism?

Thank you for your insights and participating in this study. We will be doing further analysis of our conversation today, and use this information to pilot various methods with children and youth. In the future, we look forward to sharing our findings with you along with an international community of researchers interested in this important topic.