# How are stakeholders with autism spectrum disorder included in the social validation of augmentative and alternative communication research? A scoping review

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*Acknowledgements*

The authors report no conflict of interest. This project was funded by the Andrew W. Mellon Foundation. Opinions expressed and conclusions arrived at are those of the author and are not necessarily the funders.

***Declaration of interest***

The authors declare no conflicts of interest.

# ABSTRACT

*Introduction.* Social validation or the inclusion of stakeholders in the research process is beneficial as it may decrease bias, increases efficacy and prevents harm. For direct stakeholders like individuals with Autism Spectrum Disorder (ASD, social validation has mostly included participants who do not experience significant speech, language and communication limitations while frequently omitting individuals with ASD who have complex communication needs (CCN). The presence of CCN, indicates that augmentative and alternative communication (AAC) strategies are needed for individuals to express themselves. Social validation should not be limited to being participants in an intervention but should include involvement in the research process. This requires an understanding of the current trends, levels and mechanisms of involvement in AAC research. *Purpose.* This review aimed to identify and describe the inclusion of direct stakeholders with ASD in the social validation of AAC research. *Methods.* A scoping review was conducted following the PRISMA-ScR methodology to identify AAC research that included stakeholders with ASD (direct and indirect) for social validation and to evaluate their level of involvement using the TYPE pyramid framework. *Results*. Twenty-four studies were identified. Studies primarily included indirect stakeholders (e.g. caregivers) giving in-depth perspectives, while direct stakeholders were limited to being intervention participants. *Conclusions*. Voices of direct stakeholders with ASD and CCN remain limited or excluded in research. Reasons for the exclusion of individuals with ASD and CCN from research, and strategies for future inclusion are raised and discussed.

**Keywords:** Augmentative and Alternative Communication, Autism Spectrum Disorder, scoping review, social validation, stakeholder involvement in research

## 1. Introduction

Social validation in research, is a “method that facilitates involvement of multiple participants in the evaluation process” (Busse et al., 1995, p. 273) in order to ensure that goals are socially significant, methods are socially appropriate and outcomes are socially important (Wolf, 1978). In particular, because even though a specific intervention may achieve the anticipated goals, it is possible that participants may not consider the changes achieved to be valuable (Schlosser, 1999). For persons with disabilities, the need for social validation in research has been highlighted in the “nothing about us, without us” campaign for people with disabilities since the early 1990’s (Harrison et al., 2001; Stack & McDonald, 2014).

The inclusion of social validation in the research process has been shown to decrease bias, increase efficacy and prevent harm (Hoekstra et al., 2018), while improving outcomes and adherence for persons with disabilities (Logan, et al., 2017; Schlosser & Raghavendra, 2004). It is also not simply the implementation of research “on” individuals who will directly benefit from an intervention (direct stakeholders) (Johnson et al., 2009; Schlosser, 1999), but varies from inclusion in the design, planning and execution of research, to total control of a research project by direct as well as indirect stakeholders (individuals associated with the direct stakeholder e.g. caregivers, families, teachers and peers) (Scheim et al., 2019; Schlosser, 1999; Wong et al., 2010).

For direct stakeholders who have autism spectrum disorder (ASD), the need for social validation of research has also been emphasised by adult self-advocates, who assert that direct stakeholders should be seen as experts in the field and should work in partnership with researchers (Gillespie-Lynch, et al., 2017; Nicolaidis et al., 2011; Raymaker & Nicolaidis, 2013). Yet, the social validation of research in the field of ASD, typically defaults to indirect stakeholders with direct stakeholders who have ASD, remaining excluded (Chown et al., 2017; Fayette & Bond, 2018; Pellicano, et al., 2014). Furthermore, the few studies where direct stakeholders with ASD are included in social validation have been conducted with direct stakeholders who do not experience significant speech, language and communication limitations (DePape & Lindsay, 2016). This, even though estimates suggest that between 30% (National Research Council, 2001) and 71% (Abubakar, et al., 2016; Bakare & Munir, 2011) of direct stakeholders with ASD have complex communication needs (CCN). CCN are severe speech, language and communication impairments which result in difficulty or an inability to communicate, (comprehension or/and expression) solely using spoken language (Beukelman & Mirenda, 2013). Hence, a significant proportion of direct stakeholders who have ASD have been excluded from research (MacLeod, et al., 2014; Mirenda, 2008; Trembath, et al., 2014), while direct stakeholders who are able to make use of spoken communication are over-represented (Pellicano et al., 2014).

Having CCN, however, does not mean a direct stakeholder who has ASD is unable to communicate. Rather, it indicates that Augmentative and Alternative Communication (AAC) systems, may be required in order for direct stakeholders who have ASD to communicate effectively (Ganz et al., 2012; Mirenda, 2003). AAC includes a range of systems, which can be aided (e.g. picture boards, speech generating devices and picture exchange systems) or unaided (gestures and manual signing such as Makaton or Sign Language) (Beukelman & Mirenda, 2013).

Despite the challenges of including direct stakeholders with CCN in research, the field of AAC itself has highlighted the need for social validation over the past 2 decades, (Schlosser & Raghavendra, 2004). This has resulted in studies on the efficacy of specific AAC modes (aided vs unaided), types of AAC systems (e.g. speech generating devices vs picture exchange systems) and single subject studies (Ganz et al., 2012; Schlosser & Wendt, 2008) including direct stakeholders with CCN. These studies however, have been criticised for having a limited focus (individual skills in structured settings, for example requesting; or AAC system comparisons) (Ganz, 2015). The extent of direct stakeholder involvement in these studies also remains unclear (DePape & Lindsay, 2016; Ganz et al., 2017; Schlosser & Wendt, 2008).

For the social validation of research however, it is not sufficient to only report on the inclusion of direct stakeholders e.g. individuals who have ASD (Scheim et al., 2019; Wong et al., 2010), but it is also important to understand the researcher-stakeholder relationship in the project as this can provide understanding of the broader social validity of the study beyond the perspectives of individual stakeholders. In this regard, Schlosser (1999) proposed the AAC Social Validation Framework. The framework specifically defines a.) “who” may be included in social validation? For example direct or indirect stakeholders, the immediate or extended community. b.) “What” components of the intervention should be socially validated, for example, the goals, the methods and the outcomes, and c.) “How” social validation could be conducted within the field of AAC, for example through subjective evaluation or social comparison.

Although the AAC social validation framework can assist interventionists in identifying the elements of social validation, a review conducted by Wong et al (2010) emphasised the need not only for stakeholder involvement but also for stakeholder empowerment. An empowerment approach values stakeholders’ intrinsic strength and seeks to actively involve them in issues that they identify as important. They therefore proposed the Revised Typology of Youth Participation and Empowerment (TYPE) pyramid to address some of the limitations of previous involvement typologies. This typology reflects a social validation continuum relating to the level of involvement of stakeholders and researchers in studies. The TYPE pyramid represents not only who drives the research, but the amount of involvement of the stakeholders and researchers at each position. Five positions of stakeholder and researcher involvement are described with the highest level of involvement reflected in the third (middle) position, thereby creating the pyramid peak. In the first position, termed the vessel level of involvement, researcher involvement is high and stakeholders are involved as research subjects only. For example, a research study at this level would include direct stakeholders who have ASD as participants in an intervention, but not include them in the design or evaluation of the study. In the second position, the symbolic level, researchers retain control of the study but seek to include the perspective of stakeholders. A study at the symbolic level may include direct stakeholders who have ASD as intervention participants, as well as obtaining their perspectives on the intervention. In the third position, the pluralistic level, a peak of shared involvement is seen, with researchers and stakeholders sharing active roles throughout the study. In a pluralistic level study, direct stakeholders with ASD would be included in the study from conception to completion. For example, the stakeholders could be asked to contribute to design decisions for the study by asking them the best way to interview another person with ASD or to provide feedback following the intervention by discussing the results. Although research studies differ, the pluralistic level is the preferred level for studies with specific marginalised groups (Wong et al., 2010). Beyond pluralistic control is the fourth position, the independent level, where stakeholders control the study with input from researchers. In an independent level study, direct stakeholders with ASD may conceptualise and implement a study, but seek assistance from researchers in the research design and analysis phases. Studies at the fifth level of involvement are termed autonomous studies, and stakeholders have autonomous control of the research with no researcher involvement at all (Wong et al., 2010). The TYPE pyramid has been used as a tool to study social validation in reviews on youth engagement in eMental health literacy (King et al., 2015), and children’s involvement in oral health education (Hakojärvi et al., 2019) amongst others.

Currently a gap is evident in the literature regarding the level of involvement of direct stakeholders with ASD in the field of AAC. This scoping review was conducted to identify studies in the field of AAC in which social validation with direct stakeholders with ASD was conducted, and to describe the researcher-stakeholder relationship in the research process, using Wong et al.'s (2010) TYPE pyramid typology.

## 2. Methodology

### 2.1. Research aims

The main objective of this scoping review is to describe the extent to which participants with ASD are involved as direct stakeholders in the social validation of AAC research. This will be achieved through the following sub-aims:

i. The identification of studies that include social validation in AAC research that focuses on ASD.
ii. To describe the direct and indirect stakeholders involved in the social validation process of the studies.
iii. To describe and compare how direct and indirect stakeholders with ASD are consulted regarding social validation of the research studies, using the TYPE pyramid typology (Wong et. al., 2010).

### 2.2. Research design and phases

A scoping review was chosen for this study as it is:

*'a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge' (Colquhoun et al., 2014, pp.1292-1293)* and is not required to consider the quality of the studies included (Grant & Booth, 2009), which is helpful in introductory synthesis of

information in a field. The scoping review was implemented following the methodology recommended in the preferred reporting items for systematic and meta-analyses (PRISMA) statement (Moher et al., 2009), and the PRISMA extension for scoping reviews (Tricco et al., 2018). The PRISMA statement provides a standardised approach to guide researchers in reporting the number of identified studies that are included and excluded from a study and the reasons for exclusion in a standardised, evidence-based manner (Boland et al., 2017). PRISMA is the recommended methodology for systematic reviews in The Cochrane Collection (Higgins et al., 2019).

### 2.3. Search strategy

A multi-pronged search strategy was used with relevant studies obtained from online databases, as well as stakeholders, and organisations who were contacted to obtain additional studies. The databases were chosen based on a review by Schlosser, Wendt and Sigafoos, (2007) that reported on databases containing AAC literature and also in consultation with a subject librarian. The databases chosen were CINAHL, PsychINFO, PsychArticles and ERIC.

In modelling the requirement from the field for social validity from stakeholders, the second author of this review consulted with an advocate for persons with ASD. In addition, indirect stakeholders such as experts working in the area of ASD and AAC; a technology advisor from a private company that provides AAC devices in South Africa; and a neuro-developmental paediatrician who has a strong interest in ASD were asked to assist in the identification of additional literature for review. Hand-searching the reference lists of the identified articles against the inclusion and exclusion criteria was also conducted in order to identify studies that may have been missed in the database search (Schlosser et al., 2007).

The search terminology for this review was piloted and adapted before use in the final search by the second author who also conducted the hand search. The search terminology are illustrated in Table 1.

**Table 1**

*Inclusion and exclusion criteria*

| **Criteria** | **Motivation** | **Inclusion** | **Exclusion** | **Search terms** |
|---|---|---|---|---|
| **Population**<br>(Participants) | This study aims to examine the involvement of individuals with ASD and CCN in AAC research, as it appears that their social validation is missing (Donaldson, Krejcha, & McMillin, 2017; Raymaker & Nicolaidis, 2013) from the research base | Individuals with a primary diagnosis of ASD (and related terms such as Asperger's), who have CCN. Individuals with co-morbid diagnoses were not excluded. Historical diagnostic terms now categorised as ASD were included e.g. Asperger's, Autism, Pervasive Developmental Disorder (not otherwise specified) (American Psychiatric Association, 2013). | Individuals with a primary diagnosis other than ASD | Autis* OR ASD OR PDD_NOS OR Pervasive Developmental Disorder* OR Asperger*<br>AND |
| **Context**<br>(AAC Research) | AAC is "an area of evidence based research, clinical and educational practice. AAC involves attempts to study and, compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication" (ASHA, 2005). | Aided and unaided communication systems. Including manual sign systems, speech generating devices and picture exchange systems. | Non-evidence-based communication interventions, such as facilitated communication training or the Rapid Prompting Method.<br>Studies that included participants with ASD who were able to communicate verbally. | Augmentative and alternative communication OR AAC OR Complex communication needs OR Minimally-verbal OR Non-verbal OR Multimodal communication OR Speech generating device OR Picture communication OR Sign language OR Voice output OR Unaided systems OR Gesture* OR Manual sign system OR Aided Symbols<br>AND |
| **Concept**<br>(Stakeholders consulted) | Social validation, or the inclusion of stakeholders in research (Light & Drager, 2007; Schlosser, 1999) has been shown to decrease bias, increase efficacy and prevent harm (Hoekstra et al., 2018). | Research in which stakeholders were consulted. Direct stakeholders were defined as individuals with ASD. Indirect stakeholders were defined as individuals without ASD, who were consulted during a study (Schlosser & Raghavendra, 2004). | Research that did not include consulting stakeholders.<br>Studies done with group-level data that included participants with a diagnosis of anything other than ASD, and where the data was not separated. | Stakeholder* OR Opinion* OR View* OR Involvement* OR Participat* OR Preference* |

| Criteria | Motivation | Inclusion | Exclusion |
|---|---|---|---|
| **Publication** | | Published in a peer-reviewed journal.<br>Full text available from The University of Pretoria library or Jonkoping University or Interlibrary loan.<br>Articles published in English. | Unpublished papers and grey literature.<br>Articles which could not be obtained from the University of Pretoria or Jonkoping University libraries or Interlibrary loans.<br>Articles published in any language, other than English. |
| **Design** | Articles were not excluded due to any quality criteria (Franz, Chambers, von Isenburg, & de Vries, 2017) | Qualitative and quantitative study designs. | Systematic reviews.<br>Guideline articles.<br>Opinion articles. |

| Database | Yield | Duplicates |
|---|---|---|
| PsychINFO | 255 | 0 |
| ERIC | 80 | 46 |
| CINAHL | 40 | 38 |
| PsychArticles | 6 | 6 |

### 2.4. Inclusion and exclusion criteria

Inclusion criteria for this review were guided by the ‘Population, Concept and Context’ format which is reported to facilitate a broader search and ensure that different methodologies and data are included (The Joanna Briggs Institute, 2015). Studies needed to meet all inclusion and no exclusion criteria in order to be included. The full inclusion and exclusion criteria for this review are represented in Table 1.

### 2.5. Selection of studies

The study selection process for this review followed the (PRISMA) (Moher et al., 2009), and the PRISMA-Scr extension methodology (Tricco et al., 2018). The screening of studies at abstract and full text level was conducted by the second and third authors independently using Covidence systematic review software (Mavergames, 2013). Results were compared for reliability (Tricco et al., 2018) and conflicts were discussed at each stage until 100% agreement was reached (Pham, et al., 2014). The results of the review process are illustrated in a PRISMA diagram (Figure 1) (Moher, et al., 2009).

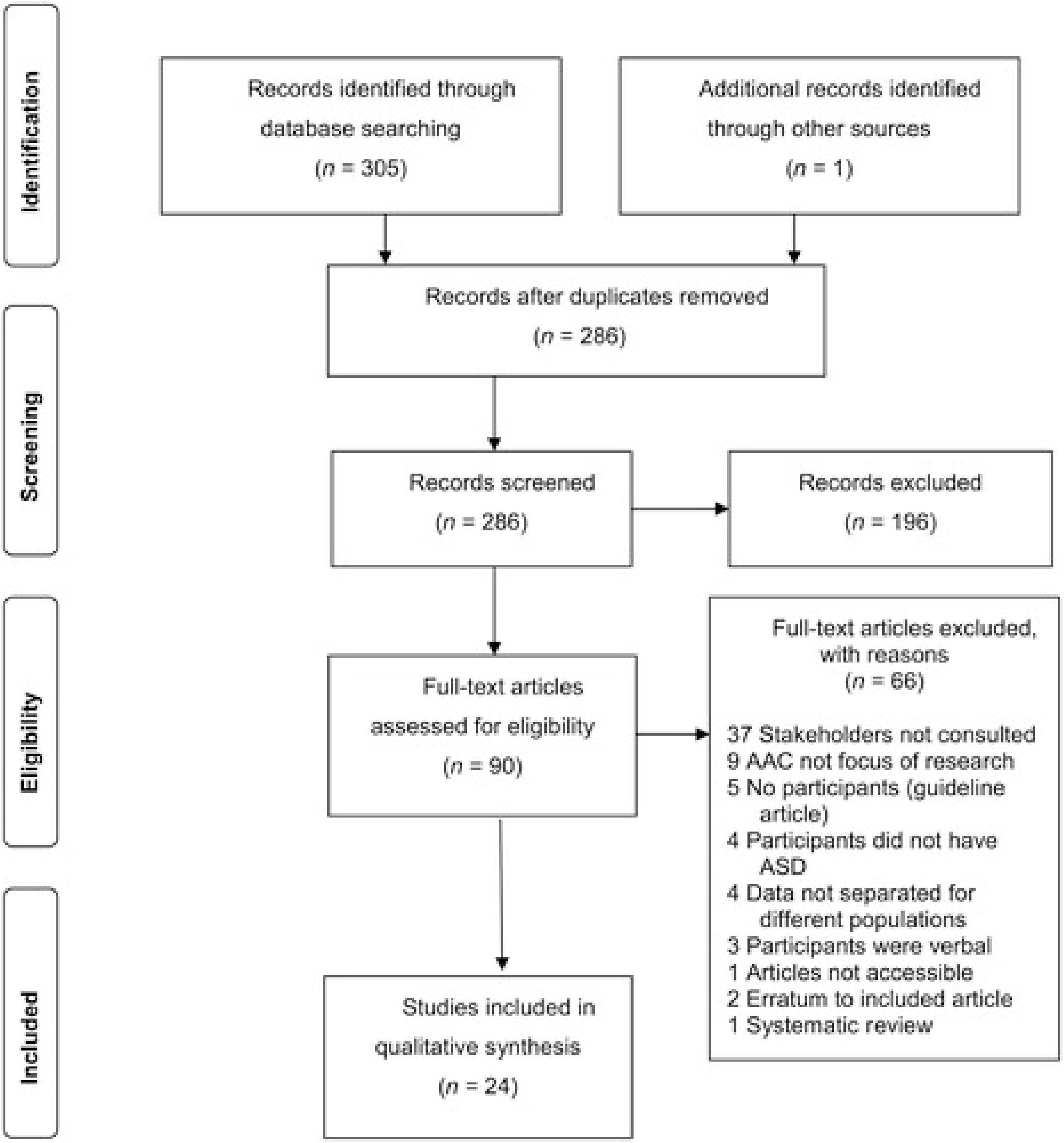

**Figure 1.** Study selection represented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram1 (Moher et al., 2009). AAC = augmentative and alternative communication; ASD = autism spectrum disorder.Data Extraction and analysis

Data were extracted, as recommended in the PRISMA extension for scoping reviews (Tricco et al., 2018), using an extraction tool designed specifically for this study. The tool captured relevant information on the key study metrics and detailed information on the study design, the number of stakeholders included, the description of direct stakeholders (individuals with

ASD) and other indirect stakeholders (parents, educators, facilitators, peers etc.), and the type of purpose of each study. Text based data was extracted relating to the involvement of stakeholders with ASD in AAC research. Data was extracted by the second author, and the reliability of the data extraction was checked by the first, third and fourth authors who independently evaluated the extracted data. Disagreements were discussed until consensus was reached. The data extraction tool is included in the Appendix.

### 2.6. Data Analysis

As the purpose of a scoping review is not to compare the data to pre-determined themes or categories (Boland et al., 2017), concepts and categories for analysis and discussion were identified by means of critical interpretative synthesis (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2006) by all the authors. Critical interpretive synthesis allows for the synthesis of both qualitative and quantitative data in a cyclical approach where concepts and categories are broadly identified and then refined in an ongoing process until all the data has been considered (Dixon-Woods et al., 2006). The critical interpretive synthesis was conducted between authors, with categories being identified, highlighted and discussed based on the extracted data until consensus was reached. The level of involvement of stakeholders (direct and indirect) was conceptualised from the data using Wong et al.'s (2010) TYPE pyramid framework by the second author and independently checked by all the authors (100% agreement was obtained).

## 3. Results

Twenty four articles, published between 2006 and 2018, met the inclusion criteria for this review and are reported in Table 2. Only the hand search provided one additional article not identified in the database search.

**Table 2**

*Studies included for review,direct and indirect stakeholder involvement*

| Study | Purpose | Design | Stakeholders direct/(indirect) | Involvement of stakeholders direct/ (indirect) | Involvement level$^1$ |
|---|---|---|---|---|---|
| 1. Achmadi, et al. (2014) | To establish the preference between an SGD, picture exchange and MS and assess performance during maintenance sessions at 12, 15 and 18 months post-intervention. | Alternating treatment design | 3 children with ASD<br>(none) | AAC system preference assessment. Reaching for a system indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 2. Agius & Vance (2015) | To determine whether acquisition of requesting skills is quicker with picture exchange or an iPad. To assess the preference for picture exchange or an iPad, and to see whether pre-schoolers with ASD can be taught navigation skills for iPad operation. | Multiple baseline design across participants with adapted alternating treatment. | 3 children with ASD<br>(3 parents) | AAC system preference assessment. Reaching for a system indicated a preference.<br>(Completed the Treatment Acceptability Rating Form-Revised in relation to the SGD and PE.) | Symbolic<br>(Symbolic) |
| 3. Banda, Copple, Koul, Sancibrian & Bogschutz (2010) | To assess whether individuals with ASD can learn requesting using an SGD by watching video modelling and whether these skills could be generalized post intervention. | Multiple baseline across subjects | 2 young adults with ASD<br>(Staff at the care centre: number not specified). | The individuals with ASD were not consulted during the study.<br>(Completed a Likert Scale questionnaire about feasibility, the importance of requesting skills, the use of SGD and whether the participant had benefited from the study.) | Vessel<br>(Symbolic) |
| 4. Bedwani, Bruck & Costley (2015) | To assess whether the LAMP programme could be used to teach individuals with ASD to use AAC. | Multiple participant, single case with subject experimental design. | 7 children with ASD<br>(7 Parents and 2 educators) | Individuals with ASD were not consulted during the study.<br>(Completed a rating scale questionnaire, and a follow-up telephonic interview.) | Vessel<br>(Symbolic) |
| 5. Boster & McArthry (2017) | To consult with parents and speech therapists regarding the design interface of applications for individuals with ASD. | Focus group. | None<br>(5 Parents and 8 Speech Therapists) | No direct stakeholder involvement.<br>(A focus group was conducted on features of AAC Apps, including navigation and animation, and which features may appeal to children with ASD.) | No involvement<br>(Symbolic) |
| 6. Cannella-Malone, Fant & Tullis (2009) | To use picture exchange with a Peers protocol to teach two participants with ASD to greet, make requests and respond to peers. | Multiple baseline across behaviours. | 1 child with ASD<br>(1 peer) | The individual with ASD was not consulted during the study.<br>(Completed a questionnaire to assess their | Vessel<br>(Peer - |

| Study | Purpose | Design | Stakeholders direct/(indirect) | Involvement of stakeholders direct/ (indirect) | Involvement level[1] |
|---|---|---|---|---|---|
| | | | (1 Parent and 3 Educators) | perception of the importance and effectiveness of the intervention.) | Symbolic)<br>(Adults - Symbolic) |
| 7. Chung & Douglas (2015) | To evaluate the post-intervention relationship between participants with ASD, using an SGD and their peers. | Non-concurrent multiple baseline. | 3 children with ASD<br>(6 peers, 1 Speech Therapist, 3 paraprofessionals and 4 educators) | Brief interviews were held with participants regarding whether they liked talking to their peers.<br>(Brief interviews with peers)<br>(A questionnaire was completed by the adults.) | Symbolic<br>(Peers- Symbolic)<br>(Adults - Symbolic) |
| 8. Copple, Koul, Banda & Frye (2015) | To evaluate whether pre-schoolers with ASD can be taught to request using an SGD after video-modelling intervention and whether these skills can be generalized. | Partially non-concurrent multiple baseline across subjects. | 3 children with ASD<br>(3 parents) | The individuals with ASD were not consulted during the study.<br>(Completed a five question rating scale regarding the intervention.) | Vessel<br>(Symbolic) |
| 9. Couper et al., (2014) | To determine how quickly children with ASD can learn different AAC systems and if they have a preference for a specific system. | Alternating treatment design | 9 children with ASD<br>(none) | AAC system preference assessment completed before, during and after the interventions.<br>(N/A) | Symbolic<br>(N/A) |
| 10. Flores, Musgrove, Renner, Hinton, Strozier, Franklin & Hill (2012) | To evaluate whether an iPad is an appropriate requesting device in comparison to a low tech AAC system that uses graphic symbols. | Alternating treatment design | 3 children with ASD<br>(Programme staff: number not specified) | The individuals with ASD were not consulted during the study.<br>(Completed a questionnaire on the use of the iPad.) | Vessel<br>(Symbolic) |
| 11. Genc-Tosun & Kurt (2017) | To assess whether discrete trial training intervention is successful when using an iPad as an SGD. | Multiple-probe across participants | 3 children with ASD<br>(3 parents and 4 educators) | The individuals with ASD were not consulted during the study.<br>(Watched video clips from the intervention and then completed questions regarding the use of the iPad.) | Vessel<br>(Symbolic) |
| 12. Hamm & Mirenda (2006) | To investigate outcomes post-school for a number of individuals with CCN. | Qualitative – written surveys and interviews | 2 adults with ASD<br>(Parents: two inferred, but not | No direct stakeholder involvement[2].<br>(Proxy participation in interviews planned for direct stakeholders.) | No involvement<br>(Symbolic) |

| Study | Purpose | Design | Stakeholders direct/(indirect) | Involvement of stakeholders direct/ (indirect) | Involvement level[1] |
|---|---|---|---|---|---|
| | | | specified) | | |
| 13. Hines, Balandin, Togher (2011) | To explore the communication experiences of parents of adults with ASD, especially in terms of AAC. | Narrative interviews | 13 adults with ASD<br>(16 Parents) | No direct stakeholder involvement.<br>(Parents participated in semi-structured interviews regarding the challenges in their adult child's communication.) | No involvement<br>(Symbolic) |
| 14. Lorah, Tincani, Dodge, Gilroy, Hickey & Hantula (2013) | To compare the acquisition of mand with picture exchange and SGD (iPad), and evaluate participant's preferences for either system. | Alternating treatment design | 5 children with ASD<br>(none) | AAC system preference assessment completed. A choice indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 15. McLay, et al., (2015) | To compare acquisition, maintenance and preference between SGD, picture exchange and MS | Alternating treatment design | 4 children with ASD<br>(none) | AAC system preference assessment completed. A choice indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 16. McLay, Schäfer, et al., (2017) | To expand the 2015 McLay et al. study (study 14). To assess whether the intervention identified would be more effective in teaching 'more', whether this would be maintained over time and the preference between three different AAC systems. | Alternating treatment design | 2 children with ASD<br>(none) | AAC system preference assessment completed at baseline, intervention and long-term follow up. A choice indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 17. Park, Alber-Morgan & Cannella-Malone (2011) | To evaluate the effects of mother-implemented picture exchange training on the communication of children with ASD. | Changing criterion | 3 children with ASD<br>(3 Mothers) | The individuals with ASD were not consulted during the study.<br>(A 5-point Likert Scale questionnaire was completed to assess perceptions of goals, procedures and outcomes.) | Vessel<br>(Symbolic) |
| 18. Son, Sigafoos, O'Reilly & Lancioni (2006) | To compare the acquisition of requesting with PE against VOCA. | Alternating treatment design | 3 children with ASD<br>(none) | AAC system preference assessment completed. A choice indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 19. Talkington, McLaughlin, Derby & Clark (2013) | To evaluate the effectiveness of the Flip 'n Talk system for teaching communication skills. | Single case multiple baseline | 1 child with ASD<br>(Educator and educational assistants (number | The individuals with ASD were not consulted during the study.<br>(Not specified.) | Vessel<br>(Not specified) |

| Study | Purpose | Design | Stakeholders direct/(indirect) | Involvement of stakeholders direct/ (indirect) | Involvement level[1] |
|---|---|---|---|---|---|
| | | | not specified). | | |
| 20. Torelli, Lambert, Da Fonte, Denham, Jedrzynski, Houchins-Juarez (2016) | To predict mand independence, problem behaviour and mand preference during certain situations. | Not specified | 1 child with ASD<br>(1 mother) | AAC system preference assessment completed. A choice indicated a preference.<br>(The parent was presented with data from the study and asked to select the device she thought was most appropriate for her child.) | Symbolic<br>(Symbolic) |
| 21. Trembath, Iacono, Lyon, West & Johnson (2014) | To explore the views and experiences of support workers and family members regarding low-tech communication aids for adults with ASD. | Semi-structured interviews | 4 adults with ASD<br>(1 Mother, 5 support workers and 1 sibling) | No direct stakeholder involvement[2].<br>(Semi-structured interviews on low-tech communication systems for adults with ASD.) | No involvement<br>(Symbolic) |
| 22. Van der Meer, et al., (2013) | To teach more advanced communication using a preferred AAC device, in order to assess whether preference remains stable with more complicated communication | Alternating treatment design | 2 children with ASD<br>(none) | AAC system device preference assessment completed. A choice indicated a preference.<br>(N/A) | Symbolic<br>(N/A) |
| 23. Van der Meer, Sigafoos, et al., (2014) | To assess whether social communication can be taught using a preferred AAC system using a modified behavioural intervention | Clinical case study | 1 child with ASD<br>(1 mother) | The individual with ASD was not consulted during the study.<br>(Not specified) | Vessel<br>(Not specified) |
| 24. Waddington, vWogan der Meer, Carnett & Sigafoos (2017) | To teach a child with ASD to approach his/her communication partner in various settings to make requests | Multiple baseline across settings with different partner in each setting | 1 child with ASD<br>(1 Mother and 1 teaching assistant) | The individuals with ASD were not consulted during the study.<br>(Completed the Treatment Acceptability Rating Form-Revised pre and post intervention.) | Vessel<br>(Symbolic) |

Note.

[1] Based on the TYPE pyramid (Wong et al., 2010) direct/ (indirect)

[2] These studies aimed to survey direct stakeholders. However, the participants did not have sufficient communication skills (AAC or spoken/written language) to enable them to participate.

Most of the studies (n=22) identified were quantitative studies that included a social validation component. Two qualitative studies considered the experience of parents in communication interventions and AAC (Hines et al., 2011; Trembath et al., 2014) and their adult children's post-school outcomes (Hamm & Mirenda, 2006). The most frequent study design was an alternating treatment design, and the majority of intervention studies focused on requesting skills.

Direct stakeholders (persons with ASD) (n=83), and indirect (parents, siblings or immediate community members) (n=86) stakeholders were included in the identified studies, although not all studies reported on the number of indirect stakeholders involved.

## 3.1. Direct stakeholders

*Demograhics*

Most direct stakeholders were male (n=72). A large proportion of the direct stakeholders were over 18 (n=22), but all of these came from four studies (Banda, et al., 2010; Hamm & Mirenda, 2006; Hines et al., 2011; Trembath et al., 2014) whilst the remaining 20 studies account for 50 direct stakeholders under 18 years. The majority of studies focused on young children in the 2-6 year age range. The demographic data of direct and indirect stakeholders is presented in Table 3.

**Table 3**

*Demographic data of stakeholders*

| Demographic | Direct stakeholders (n=83) | | Indirect stakeholders (n=86[1]) | |
|---|---|---|---|---|
| Sex | Male | 72 | Parents | 47 |
| | Female | 11 | Educator | 13 |
| | | | Speech therapist | 9 |
| | | | Facilitators/ paraprofessionals | 9 |
| | | | Peers/ siblings | 8 |
| Age | <4 yrs | 7 | Not reported | |
| | 4-6 yrs | 20 | | |
| | 6-8 yrs | 5 | | |
| | 8-10 yrs | 6 | | |
| | 10-12 yrs | 7 | | |
| | 12-18 yrs | 4 | | |
| | Over 18 yrs | 22[2] | | |
| Diagnosis of direct stakeholder [3] | ASD (n=19)<br>Autism (n=8)<br>Autism and intellectual disability (n=2)<br>ASD and Down Syndrome (n=1)<br>Pervasive developmental disorder (n=1)<br>Autism, severe global developmental delay and intellectual disability (n=1)<br>Autism and global developmental delay (n=1)<br>Autism, moderate intellectual disability, developmental co-ordination disorder and epilepsy (n=1)<br>High functioning autism and global developmental delay (n=1) | | | |

*Note:*

[1] Not all studies reported the number of indirect stakeholders involved.

[2] All participants over 18 came from 2 studies

[3] Not all studies reported on co-morbidities

### *Social Validation of AAC by direct stakeholders*

The social validation mechanisms used in the studies were mapped and described for both direct and indirect stakeholders according to the TYPE pyramid (Wong et al. 2010).

Vessel level. Vessel level involvement in studies was the most common level of involvement for direct stakeholders (n=10), with studies considering requesting items (n=5) (Banda et al., 2010; Cannella-Malone, et al., 2010; Copple, et al., 2015; Flores et al., 2012; Waddington, et al., 2017) or the implementation of specific communication systems (n=5) (Achmadi et al., 2014; Bedwani, et al., 2015; Genc-Tosun & Kurt, 2017; Park, et al., 2011; Talkington, et al., 2013).

Symbolic level. Direct stakeholders were involved in studies at a symbolic level through the use of AAC system preference assessments (n=9). In most of these, researchers presented the direct stakeholders with various AAC systems and asked which system they would like to use, or waited until the direct stakeholder reached for a particular system (Achmadi et al., 2014; Agius & Vance, 2016; Couper et al., 2014; Lorah et al., 2013; McLay et al., 2017; Son, et al., 2006; Torelli et al., 2016; Van Der Meer et al., 2013). Across studies, the mean preference for a SGD was 65.5%, picture exchange was 21.28% and manual signing 8.33%. No selection of any device was noted in 19.25% of cases but not all studies noted "no selection" as a possible response. In two studies the authors reported unsuccessful attempts to consult with direct stakeholders, and indirect stakeholders were then asked to respond instead (Hamm & Mirenda, 2006; Trembath et al., 2014).

No involvement. No involvement from direct stakeholders was reported in four studies (Boster & McCarthy, 2018; Hamm & Mirenda, 2006; Hines et al., 2011; Trembath et al., 2014). Two of these studies did plan on including direct stakeholders but reported being unsuccessful in this regard (Hamm & Mirenda, 2006; Trembath et al., 2014).

## 3.2. Indirect stakeholders

### *Demographics*

The indirect stakeholders identified in this review were mainly parents (n=47). Educators (n=13), speech therapists (n=9), facilitators or paraprofessionals (n=9) and peers or siblings (n=8) were also included. Two studies did not report how many paraprofessionals/ care staff were included, and seven studies did not report involvement of indirect stakeholders. Further details of the indirect stakeholders were not included in most studies. The demographic data of direct and indirect stakeholders is presented in Table 3.

### *Social Validation of AAC by indirect stakeholders*

The social validation mechanisms used in the studies were also mapped and described for indirect stakeholders according to the TYPE pyramid (Wong et al. 2010).

Symbolic level. All indirect stakeholders were included in studies on a symbolic level. Studies considered the perceptions of indirect stakeholders regarding different AAC systems (n=6) (Agius & Vance, 2016; Boster & McCarthy, 2018; Flores et al., 2012; Genc-Tosun & Kurt, 2017; Torelli et al., 2016; Trembath et al., 2014), perceptions on interventions carried out (n=6) (Banda et al., 2010; Bedwani et al., 2015; Cannella-Malone et al., 2010; Copple et al., 2015; Park et al., 2011; Waddington et al., 2017) and the experiences of communication of direct stakeholders by indirect stakeholders (n=4) (Chung & Douglas, 2015; Hamm & Mirenda, 2006; Hines et al., 2011; Trembath et al., 2014).

## **3.3. Comparison of the social validation by direct and indirect stakeholders**

Three studies which reported on social validation for both direct and indirect stakeholders included all stakeholder at the same validation level (symbolic). In two of these studies, direct stakeholders provided information on preferences through the selection of a communication system while the indirect stakeholders completed questionnaires and interviews (Agius & Vance, 2016; Torelli et al., 2016). The third study undertook interviews with direct stakeholders while indirect stakeholders completed a questionnaire (Chung & Douglas, 2015).

The remaining studies (n=8) which reported on social validation for both direct and indirect stakeholders had different levels of involvement. Direct stakeholders were involved on a vessel level as participants "on" whom an intervention was conducted, while indirect stakeholders completed questionnaires and interviews on the interventions that their direct stakeholders had been involved in (Banda et al., 2010; Bedwani et al., 2015; Cannella-

Malone et al., 2010; Copple et al., 2015; Flores et al., 2012; Genc-Tosun & Kurt, 2017; Park et al., 2011; Waddington et al., 2017).

## 4. Discussion

Evidence-based practice within the field of AAC obligates clinicians and researchers to involve the direct stakeholder in their communication intervention decisions (Roulstone, 2015; Schlosser, 1999, 2003; Schlosser & Raghavendra, 2004). Yet, this scoping review paints a discouraging picture of the current involvement of persons with ASD in the very AAC research which should be guiding that evidence-based practice. Direct stakeholders were included at lower validation levels than indirect stakeholders in most cases.

In addition, it has been stated that AAC interventions should focus on improving the linguistic, operational, social and strategic competence (Light & McNaughton, 2014), in order to allow the person to express more than needs or wants but also social closeness, exchange of information, and participation for direct stakeholders who have CCN (Light & McNaughton, 2014). The intervention studies included in this review focused only on the teaching of requesting, which undermines the breadth and importance of full communication competence (Light & McNaughton, 2014, 2016). The limited scope of interventions identified in this review, may well reflect the limited nature of direct stakeholder involvement in comparison to indirect stakeholder involvement in research. In particular caregivers may highlight meeting needs and behaviour regulation as most important for communication (Fried-Oken et al., 2006), while individuals themselves would highlight social closeness as more important (McNaughton et al., 2019).

Within this review, direct stakeholders were involved at vessel (merely a participant in an intervention) and symbolic levels (researcher maintains control, but direct stakeholders are given an opportunity to provide their perceptions), and some studies did not include any direct stakeholders. However, even though studies have been classified as including direct stakeholders at a symbolic level, they actually only reported on the direct stakeholder's preference for a specific type of AAC system based on their selection between the systems that were in front of them (n=8). This essentially includes the voice of the direct stakeholders only after the fact, i.e. once the planning and implementation of systems has been concluded. Thereafter, direct stakeholders were required to select from a limited range of prescribed options which may exclude them from reporting their true preferences and desires. The dependence on choices to determine preference may have been influenced by the high number of quantitative methodologies used in the comparison of communication systems in this review. The final study classified as including direct stakeholders at the symbolic level, spoke with direct stakeholders in an interview, but only reported on one question, which was "did they enjoy their experience?" (Chung & Douglas, 2015). Overall however, the opportunities offered for participants to express preference were extremely limited in breadth.

In contrast to the direct stakeholders, the indirect stakeholders included in studies in this review, were all included at a symbolic level, and provided with multiple opportunities to share their perspectives across a broad spectrum of areas. Furthermore, four studies asked indirect stakeholders to share their experiences of AAC and life experiences for people with ASD who use AAC. This, in spite of literature on proxy reporting which has identified non-observable factors such as emotions or quality of life to be unreliable when reported by a proxy (Eiser & Morse, 2001; Erhart et al., 2009). Hence the validity of the results obtained for these studies needs to be carefully considered.

For researchers, it is a positive development that direct stakeholders with ASD are being included in research. However, the dilemma of being ready to listen to a direct stakeholder who does not have functional communication abilities, poses a challenge that requires careful methodological design and application for them to reliably communicate the full extent of their true perspectives (Fayette & Bond, 2018). In future research, this needs to be given special attention rather than defaulting to less complex options like gathering indirect stakeholder perspectives that limits or side-lines the direct stakeholder.

For all studies, the exclusion of the voices of direct stakeholders or limiting their involvement, threatens the social validity of the research thereby limiting the applicability of results in evidence-based practice (Roulstone, 2015; Schlosser & Raghavendra, 2004).

## 5. Implications for future research

For future research with individuals who have ASD and CCN, the design of methodologies that facilitate the plurality of research, should be prioritised in order to create a power-balanced, rich, reliable and ethical epistemological base (Hart, 1992; Mcdonald, 2017; Raymaker, 2016). In addition, the inclusion of qualitative designs and participatory action research may provide better opportunities for direct stakeholders who have ASD to be actively involved in the investigation of their human experiences (DePape & Lindsay, 2016; Fayette & Bond, 2018; Minkler & Wallerstein, 2003).

Research in the AAC field could, for example, borrow from the participatory design approaches used in the field of Human Computer Interaction (HCI) where persons with ASD, including those who have CCN (Wilson, et al., 2019) actively participate as experts in the design of technologies for their benefit (Frauenberger, et al., 2016). In this field, the person with ASD and CCN’s role has evolved from being a research subject whose responses inform conclusions (vessel level) to that of co-designer or partner (pluralistic level) in research design (Wilson et al., 2019).

Within these methodologies however, researchers need to provide appropriate and reliable tools for communication with direct stakeholders, even if this requires the direct stakeholders be taught a communication system prior to providing input to the study (Agius & Vance, 2016; Haas, et al., 2016). Perhaps, as suggested by Mirenda (2008), direct stakeholders who are competent AAC users could consult to identify factors which have led to their success, such that this can be replicated (Mirenda, 2008).

Furthermore the limited amount of research conducted with adolescents from 12 – 18 years of age identified in this review, highlights the ongoing need for research beyond the early years, as communication is not a static developmental goal, but one which changes and develops as children grow and mature (Holyfield et al., 2017; Fayette & Bond, 2017).

## 6. Limitations

Publication, database and linguistic bias (Schlosser et al., 2007) may have impacted on the results of the search, due to the exclusion of unpublished literature, the use of only four databases and only studies in English included. The search terms used may have resulted in certain studies being omitted. A further limitation of this study was the limited of reporting of coding in the data extraction and analysis in the methodology.

In terms of social validity, although a direct stakeholder with ASD and indirect stakeholder organisations were included in the initial planning of this research study, the final results of this study were not referred back for further comment which would have been preferred.

## 7. Conclusions

This scoping review has given a broad overview of the available evidence on the inclusion of direct stakeholders with ASD and CCN's in the AAC research process being at symbolic and vessel levels of validation. Although the primary barrier for direct stakeholders with ASD and CCN may be the lack of an effective communication system, researchers in the field of AAC are uniquely equipped to address this challenge. If combined with input from other fields where increased social validation is being addressed for direct stakeholders with disabilities, it can allow for the full and rich participation of people with ASD and CCN in all stages of the research process.

## 8. Funding Statement

This project was funded by the Andrew W. Mellon Foundation awarded to the fourth author. Opinions expressed and conclusions arrived at are those of the author and are not necessarily the funders.

## 9. Declaration of interest

The authors declare no conflicts of interest.

## 10. Acknowledgements

Autism South Africa: for allowing the second author time to commit to this research; experts in the field of ASD in South Africa that were consulted.

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