

Title: Developing a classification system of social communication functioning of preschool children with autism spectrum disorder

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Abstract

Background: Impairments in social communication are the hallmark feature of autism spectrum disorder (ASD). Operationalizing 'severity' in ASD has been challenging; thus stratifying by functioning has not been possible.

Purpose: To describe the development of the Autism Classification System of Functioning: Social Communication (ACSF:SC) and evaluate its consistency within and between parent and professional ratings.

Methodology: (1) ACSF:SC development based on focus groups and surveys involving parents, educators and clinicians familiar with preschoolers with ASD; and (2) Evaluation of the intra- and inter-rater agreement of the ACSF:SC using weighted kappa (κ_w).

Results: Seventy-six participants were involved in the development process. Core characteristics of social communication were ascertained: communicative intent; communicative skills and reciprocity; and impact of environment. Five ACSF:SC levels were created and content-validated across participants. Best capacity and typical performance agreement ratings varied as follows: intra-rater on 41 children was $\kappa_w=0.61-0.69$ for parents and $\kappa_w=0.71-0.95$ for professionals; inter-rater between professionals were $\kappa_w=0.47-0.61$ and between parents and professionals $\kappa_w=0.33-0.53$.

Conclusions: Perspectives from parents, and professionals informed ACSF:SC development, providing common descriptions of the levels of everyday communicative abilities of children with ASD to complement DSM-5. Rater agreement demonstrates the ACSF:SC can be utilized with acceptable consistency in comparison to other functional classification systems.

Key words: Classification of functioning, preschool, ASD, social communication, ICF, and mixed methodology.

What this manuscript adds to the literature:

1. ACSF:SC is an ICF-based classification of ASD social communication, describing capacity and typical performance.
2. ACSF:SC provides a common language to classify what children can do.
3. ACSF:SC early evidence demonstrates consistent ratings by parents and professionals.
4. ACSF:SC provides a framework to develop additional ASD function-based classification systems.

The hallmark feature of autism spectrum disorder (ASD) has been difficulties in 'social communication'.¹⁻⁴ Knowing the range and nature of functional abilities in the field of childhood disability can facilitate development of tools useful for clinical practice (e.g., goal setting, counselling, management, and education) and research (e.g., clinical trials, prognosticating).⁵

During the exponential increase in the study of autism spectrum disorder (ASD) in the past 20 years,⁶ many tools have been developed to assess social communication,¹⁻⁴ all focusing on a wide range of deficits shown by these children. Two prominent measures of social communication in ASD are the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS).⁷ The ADI-R is an investigator-based interview of caregivers meant to provide a comprehensive understanding of the developmental history (including symptoms and inappropriate behaviours) of a child with ASD.⁸ Total scores are based on characteristics of social communication and other ASD symptoms; however, one limitation of the ADI-R is that it does not generate a severity metric for non-verbal children with ASD.⁹

The ADOS is a standardized observational measure to examine social communication, play and restricted and repetitive behaviours¹⁰ and can generate a severity metric based on total raw scores.¹¹ Both the ADI-R and the ADOS have been helpful in diagnosing ASD, but only the ADOS has severity levels, which have been utilized in research.

One clinical challenge with the ADOS severity levels is the lack of any descriptive meaning, because levels are generated from a total raw score of over 90 items. Furthermore, ADOS severity levels are not specific to social communication; ADOS severity is based on a range of symptoms, including deficits and abnormal behaviours. While the ADOS is currently a “gold” standard for autism diagnosis, children with the same ADOS severity may have quite different social communication performance. These differences in social communication may lead to differing functional abilities in daily life.

The major focus of key social communication measures in ASD has been on symptom/deficit-focused severity, but current research reveals distinctions in trajectories between ASD severity and functional ability – demonstrating how these concepts tell different stories when describing this very heterogeneous population.¹² As a result, targeting functioning for research seems to be promising in terms of describing potentially different prognostic models. Standardized measures like the Vineland Adaptive Behavior Scales 2nd Edition (VABS-2)¹³ and the Communication and Symbolic Behavior Scales (CSBS)¹⁴ can provide one way to describe function; however, VABS-2 data are limited in their clinical utility to describe the quality of a child's social communication, specifically what children ‘can do’.¹⁵ CSBS uses parent interviews and direct observations of the child's play to describe communication skills and symbolic development, including gestures, facial expressions, and play behaviors, but does not have a clinically useful classification of social communication.

ASD researchers have recognized the need to move beyond listing “autistic deficits” and to identify the strengths and abilities of what people with ASD ‘can do’. There are currently no valid and reliable tools describing and classifying meaningful ‘levels’ of everyday social functioning.^{16,17} This lack is even more problematic with recent changes to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria¹⁸ that collapse communication-related symptoms into “social communication.” The DSM-5 has also removed ASD diagnostic subtypes (i.e., autism, Asperger, PDD-NOS) and presented a three-level scale of severity based on the amount of “support required”.¹⁹ Due to vague descriptions of “support”, and no evidence of the scale’s reliability or validity, it has been challenging for clinicians and researchers to apply it.¹⁹ In addition, the amount of ‘support’ does not describe actual functioning. A continuing gap in the field of ASD is how to classify the everyday functioning of a child with ASD in ways that have consistent and relevant meaning among people.

WHO’s International Classification of Functioning, Disability, and Health (ICF) provides a useful framework with which to consider children’s everyday abilities or “functioning.”²⁰ The ICF includes ‘impairments’ of ‘body structure and function’, specific areas of functioning (called ‘activities’), and how people are engaged in meaningful activities (‘participation’) – to describe what a person “can do.” This ICF framework allows the grouping of individuals with similar biopsychosocial characteristics.⁵ Clinically meaningful classification systems should

be based on key feature(s) that impact everyday function.⁵ Using the ICF activities and participation framework, resulting autism classifications will focus on how children's differing social communication affects their activities and participation in daily lives.

In cerebral palsy (CP) ICF-based classification tools have been developed and applied successfully around the world.⁵ The creation of the reliable and valid Gross Motor Function Classification System (GMFCS)²¹⁻²³ represented the first systematic way to describe levels of mobility functioning in people with CP.²³ The recognized usefulness of the GMFCS led to development of similar classifications for 'manual abilities'²⁴ and communication.²⁵ Prior to the availability of these classification tools, children with CP were imprecisely stratified using ill-defined words like 'mild', 'moderate' and 'severe' CP; similar challenges currently exist in the field of ASD (e.g., 'high-functioning' and 'low-functioning' autism). Valid and reliable social communication functioning categories inspired by the ICF framework could better characterize 'levels' of ability in children with ASD.

This paper reports (i) the development of a ICF activity/participation classification system, the Autism Classification System of Functioning: Social Communication (ACSF:SC) that classifies social communication functioning of preschool-aged children with ASD, and (ii) evaluate the ACSF:SC's consistency within and between parent and professional ratings.

Methods

Qualitative research methods were used in Phase 1 to collect data for construct development and refinement of the ACSF:SC, and to examine content validity.²⁶ Methods involved focus groups and web-based surveys. In Phase 2 quantitative methods were used to trial the ACSF:SC to examine the levels of agreement within and between raters classifying preschoolers with ASD.

Participants

Maximum variation recruitment²⁷ was used to select a purposeful sample of adult informants (Phase 1) and raters (Phase 2), including parents of children with ASD and professionals (clinicians and educators) with extensive experience with preschool-aged children with ASD. In Phase 1, focus group participants were from Southern Ontario. Parents were recruited via a flyer distributed through a listserv from a provincial autism organization, and an email invitation was forwarded to experienced clinicians and educators working in preschool ASD programs. Web surveys followed, with focus group participants recruited for survey #1 and an additional group of international experts for survey #2 for the final stages of refinement and content validity checks.

In Phase 2, rater agreement was evaluated. Recruitment targeted clinical and parent organizations, using snowball recruitment to identify multiple raters per child (i.e., ideally a parent of a child with autism and two professionals who work with the child). Diverse recruitment sites across Canada, from clinical to community-based programs, were invited to identify a sample of preschool

children with ASD demonstrating a range of abilities. Parents of preschool children with ASD (age 3 to < 6 years) were recruited first, and they nominated two professionals (educator and/or clinician) working with their child; these professionals were then assigned to one of two rater groups based solely on the timing of their responses in providing child ratings [Group #1 and #2].

Research ethics approval was received from the Hamilton Integrated Research Ethics Board, a jointly constituted board of St. Joseph's Healthcare Hamilton, Hamilton Health Sciences and McMaster University's Faculty of Health Sciences.

Phase 1 - ACSF:SC Development and Content Validation

Details of the construct of social communication functioning in the ACSF:SC were developed using exploratory qualitative case study methodology with focus groups.²⁸ This methodology elicited parents' and professionals' reports of observable functional social communication of preschool children with ASD within the context of western culture across key environments (i.e., clinical setting, day care and home). Three members of the research team (BD, MC and PR) facilitated focus groups. Homogeneous focus groups involving parents, educators or clinicians each met three times ('rounds') over an 8-month period (9 focus groups in total). Using open-ended questions groups were asked to describe social communication in everyday life.

Focus group discussions were audio-taped, transcribed and coded (i.e., content analysis)²⁹ using the qualitative software program NVIVO 9. Data collected from these three perspectives were triangulated to increase the rigour of the construct themes. This enabled the convergence of the data to best describe the breadth of social communication functioning observed in preschoolers with ASD across contexts. Findings from the focus groups led to development and refinement of the ACSF:SC.

Two heterogeneous focus groups and two internet-based web surveys further refined and provided content validation of the ACSF:SC. The focus groups involved participants new to the study to provide feedback on the ACSF:SC. To maximize participation in these mixed focus groups of parents, educators and clinicians, a trained facilitator guided discussions and summarized anonymous feedback and votes using real-time laptop-based responses within group exercises.³⁰

Following these groups, a second step used two web-based surveys to gather additional feedback about the clarity and utility of the ACSF:SC. In the first survey, all participants from all focus groups were invited to review a new draft of the ACSF:SC and levels for clarity and understandability. Based on those results, revisions were made to the level descriptions. A second survey was completed by a new group of international clinicians and researchers. Responses involved opportunities for people new to these construct descriptions

to provide feedback on the operational definitions, levels, and applicability to characterize preschool children that they knew and/or worked with. Ratings on a 4-point Likert scale and qualitative comments examined participants' levels of agreement on the clarity and understandability of the social communication functioning construct.

Phase 2 - ACSF:SC Rater Agreement

Following Phase 1, intra- and inter-rater agreement of the ACSF:SC was assessed as rated by parents and professionals. Participants completed the ACSF:SC ratings (both capacity and typical performance) on a specific child they knew on two occasions (2-4 weeks apart) blinded to other raters' responses or their own prior judgments. Parents rated only their own child, and two professionals independently rated that same child – a total of 3 independent ratings per child. Demographic data were collected about the child, the rater's relationship to the child, and frequency of observations of the child's social communication. To evaluate the rating process, and the utility and perceptions of using the ACSF:SC, quantitative and qualitative data were collected from the raters through a Thought Process Questionnaire (TPQ) - a 10-15 item survey that was developed by the investigators based on principles of cognitive interviewing³¹.

Weighted kappa (κ_w) statistics, applying quadratic weighting, were used to estimate the chance-corrected agreement between pairs of raters. Multiple

analyses were done for ACSF:SC rater agreement: intra-rater, two time points obtained 2-4 weeks apart; and Time 1 inter-rater agreement (between parents and professionals; and between professionals [Group #1 vs. #2]). The professionals were stratified into two groups based on the order of their response to rating the same child. This stratification provided pairwise analyses between parents and professionals (rating the same child) possessing meaningful agreement values expected from the ACSF:SC within clinical practice. Strength of agreement (kappas) were based on <.20 as poor, .21 to .40 as fair, .41 to .60 as moderate, .61 to .80 as good, and .81 to 1.00 as very good.³²

Results

Phase 1

In Phase 1, 76 participants contributed to the development, refinement and content validation activities: 4 homogeneous focus groups (n=31); 2 heterogeneous focus groups (n=10 and n=9, respectively); web survey #1 (n=23) with participants from all focus groups; and web survey #2 (n=26) with international experts. Twelve participants were parents of a child with ASD. Professionals had a broad range of designations and experience (Table 1).

[Insert Table 1 about here]

Qualitative analysis of the focus group transcripts from Round 1 resulted in 393 coded statements across the three homogenous groups. Coded statements

were grouped into 14 categories (Appendix A). The number of codes for each category ranged from 1-151. Eleven of the 14 categories had codes from each of the focus groups.

In Round 2, homogeneous focus group participants (n=23) provided feedback and 4-point ratings (i.e., 'not important' to 'very important') for the importance of each category to social communication for preschool children with ASD. Categories rated as important were: Level of Awareness (96%); Attempting and Initiating (96%); Flexibility and Social Interactions (87%); and Intent and Purpose of Communication (83%).

In Round 3, categories were collated to identify key categories with high frequencies of ratings, and high importance ratings for social communication. This resulted in collapsing the 14 categories into 4 key characteristics:

- (1) **Child's communicative intent** (based on "Intent and purpose" and "Attempting and initiating");
- (2) **Child's social skills and strategies** (based on "Awareness and level of early engagement", "Imitation and repetition"; "Ways of demonstrating verbal and non-verbal communication");
- (3) **Flexibility in an interaction** (based on "Flexibility in social interactions");
- (4) **Environment** (based on "Partner preference", "Partner and environment adaptations", "Social partner and environment expectations", and "Building trust and engagement over time").

These four main characteristics were reduced to 3 based on research team consensus: Child's social intentions; Child's communication skills/strategies and reciprocity [reciprocity seen as an advanced skill/strategy]; and Impact of environment on child's social communication (typical performance vs. ability in an optimal setting). Participants preferred the term 'reciprocity' to 'flexibility' and provided a more refined characterization of what reciprocity looks like as a higher social communication skill, rather than being its own separate characteristic. Note that these characteristics formed the foundation of the ACSF:SC levels, where participants defined each level of ability, and 'environment' was represented for the two rating contexts to consider (i.e., capacity and typical performance). The ACSF:SC is found in Appendix B, and is freely accessible with the User Guide at www.canchild.ca.

For the heterogeneous focus groups, of the 33 responses to the invitation 19 parents and professionals were available to participate. Participants were given the ACSF:SC and were asked to use a 4-point Likert scale to score whether the levels of social communication functioning were: (a) accurate but needed some minor alterations (n=11), (b) unable to assess its accuracy with all the revisions needed (n=4) (c) very accurate and it definitely on the right track (n=2), and (d) way off the mark or not accurate at all (n=1) (NB: one participant did not respond).

Qualitative feedback from the participants was grouped into: (1) changes to wording, (2) additional information needed for utilizing the descriptions, (3)

suggested changes to levels within the tool, (4) issues with examples provided, and (5) questions about meaning and concepts. All feedback was reviewed and considered by the team in revising toward a new draft.

Results from Survey #1 included responses from twenty-three participants (5 parents and 18 professionals) from all focus groups. In rating the ACSF:SC levels, 83% (19/23) of participants reported that each of the levels and their distinctions was clear and understandable. Overall participant ratings of ease of choosing level of ability for one preschool child they knew (either strongly agree or agree) based on 4-point Likert scale was 70% (best capacity) and 78% (typical performance) of the survey sample.

In Survey #2, 76 international professionals new to this work were invited to provide feedback about the clarity, understandability and utility of the ACSF:SC. Thirty-seven responded with 26 willing and available to participate, 8 unable to complete, 2 ineligible, and 1 unable to participate at all.

The participants rated clarity and understandability of each of the 5 ACSF:SC levels as well as distinctions between contiguous levels. The most frequent comment from the participants related to clarifying questions around the application of these levels. Example comments included, "It is not clear if child needs to meet all criteria for their level" and "How frequently does the child have to initiate or respond for it to be considered something they can do rather than just trying?".

Participants in Survey #2 also used the ACSF:SC to rate a preschool child with ASD with whom they had worked. Of the 26 participants, 21 (81%) were able to provide a rating based on a child's capacity, and 19 (73%) on typical performance for a preschool child with ASD (Table 2).

[Insert Table 2 about here]

Twenty of 26 participants (77%) reported it was easy to rate the child's ACSF:SC capacity level and 17 (65%) found it easy to classify the child's typical performance in their usual environment. Only 3 people reported difficulty in rating level of capacity of social communication and 6 participants had difficulty when considering the child's typical performance.

Phase 2

Twelve Canadian sites (in British Columbia, Alberta, Manitoba and Ontario) recruited parents and professionals for both the agreement and validation studies. Forty-one children (90% male, mean (SD) age 4.3 years (0.7)) were classified on the ACSF:SC by their parent; 58% of the sample were users of augmentative and alternative communication. Parent-nominated professionals (n=64) included educators (53%) and clinicians (47%), who each had a minimum of 8 years of experience. Of the professionals, 93% stated that they were seeing the child they rated on a monthly basis (at minimum). Professionals were categorized as belonging to Group #1 or Group #2, based on the order in which the investigators received respondents' rating (Table 3).

[Insert Table 3 about here]

Intra- and inter-rater agreement ratings are summarized in Table 4. Intra-rater agreement testing involved 30 parents and 34 professionals rating a specific child on two occasions (two weeks apart). Intra-rater agreement of weighted kappa point estimates were $\kappa_w=.61$ for parents and a range of $\kappa_w= 0.74$ to $.95$ for professionals. Point estimates for inter-rater agreement between both groups of professionals [i.e., Groups #1 vs #2] were in the range of $\kappa=.59$ to $.61$, while parent-professional agreement ranged from $\kappa=.33$ to $.53$.

[Insert Table 4 about here]

Data from the TPQ for raters completing the ACSF:SC demonstrated 89-100% fidelity in completing ratings following the user guide instructions. Rater perceptions of utility and comprehensibility (i.e., ease of matching child descriptions to abilities) of the ACSF:SC were positive responses for 77-92% of parents and 92-97% of professionals. Ninety percent of parents and 85% of professionals classified the Capacity rating \geq Typical Performance ratings, as predicted by our hypothesis.

Discussion

The absence of a systematic functional classification system for ASD has prompted this work to create a novel ICF-based classification system of functioning in ASD, the ACSF:SC. In Phase 1, the key characteristics of social communication in preschool children with ASD were identified and confirmed by multiple stakeholder groups with autism experiences in a range of settings (i.e., home, community, education, and clinical). These key characteristics were then used to distinguish between levels of social communication functioning. Phase 1 results demonstrated the content validity of the level descriptions and ratings of the ACSF:SC trialed by participants in each survey study.

In Phase 2, intra-rater agreement was good for parents ($\kappa_w=0.61$ to 0.69) and good to very good for professionals ($\kappa_w=0.71$ - 0.95), demonstrating some initial ACSF:SC stability and raters' consistent understanding of the ACSF:SC levels. The inter-rater agreement between parents and professionals Group #1 ($\kappa_w=0.33$ to 0.43) was fair while parents and professionals Group #2 ($\kappa_w=0.47$ to 0.53) were moderate agreement. Between-professional agreement was moderate to good ($\kappa_w=0.59$ to 0.61). Confidence intervals were wide, likely due to having a small sample size with ratings on only 41 children. Based on the marginal frequency proportions in the current study, an estimated weighted kappa of 0.70 , and a lower 95% confidence limit of 0.60 , we anticipate that approximately 130 children would be required for a subsequent reliability study.

This preliminary evidence demonstrates slight professional group differences, whereby the Group #2-parent agreement demonstrated a higher kappa statistic than the Group #1-parents, potentially linked to the larger number of educators in Professional Group #2. A potential explanation may be that educators typically observe children on a daily basis, giving them a broader view of the child's social communication; in contrast, clinical professionals typically observe children much less often. This issue will be examined in future research. Overall, the ACSF:SC shows similar results compared to the intra- and inter-rater agreement with other classification tools: GMFCS between professionals ($\kappa_w=.55$, children <2 years; and $\kappa_w=.75$ for children 2-12 years)²³; and CFCS between parents and professional ($\kappa_w=.49$) and between professionals ($\kappa_w=.66$).²⁵

This research is the first step towards a common language (the ACSF:SC) for parents and professionals using a strengths-based approach to describe and classify social communication abilities for both verbal and non-verbal children with ASD. **The ACSF:SC is not an assessment or diagnostic tool.** Rather, this classification system can provide guidance for clinicians and researchers using the DSM-5 to stratify groups of pre-school children with ASD. Clinicians and educators may use this quick tool for goal setting and understanding potential differences in social communication abilities based on capacity and typical performance ratings within different contexts (or by different raters familiar with the child). Future research could utilize the ACSF:SC to stratify participants

based on abilities and outcomes evaluation to determine the 'functional' impact of existing and novel interventions. Prospective studies using the ACSF:SC would also be valuable to examine developmental course of social communication functioning.

One potential critique of the current work is that a relatively small sample (n=31) of participants from Southern Ontario were involved in the focus groups to develop and shape the ACSF:SC in Phase 1. Although the focus of saturation obviates the need for large sample sizes in qualitative research,³³ a more regionally diverse sample of parents would have been ideal. The surveys from international participants demonstrated content validation of the ACSF:SC beyond this sample from Southern Ontario.

A second critique is that this study reports the descriptions of social communication functioning in preschool children with ASD at one time point. In ASD, social communication changes with time; this was deliberately not addressed in the current work to develop the classification system, but is the focus of work currently underway by the investigative team to explore stability of ACSF:SC over time.

A third potential critique concerns whether the 5-level descriptions of the ACSF:SC will include children with Asperger's syndrome typically diagnosed after age 6 years.³⁴ The construct of social communication functioning was based on the observations and experiences of parents and professionals commenting on

children with ASD who are typically diagnosed at 3-5 years.³⁵ This will be an important point during planned development and testing of the social communication functioning construct with children older than 5 years.

Unlike existing autism *assessment* tools, the ACSF:SC *classifies* preschoolers' social communication based on their strengths and more specific support needs, major components that could be complementary when using the DSM-5 diagnostic framework for ASD. This work demonstrates how to develop a classification system of functioning that engages experts involved with children with ASD (including their parents) at every step from the outset of development, to refinement and evaluation of content and consistency. Future research by our group will look at ACSF:SC ratings longitudinally and expand the ACSF:SC to older children with ASD.

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