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## The need for a developmentally based measure of social-communication skills

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### Abstract

The ability to demonstrate and quantify changes in social-communication skills has been hindered by a lack of existing measures with appropriate standardization and psychometric properties. Such a measure will be helpful for research in many populations, but will be particularly crucial for detecting incremental changes in youth with neurodevelopmental disorders, who may gain skills but still lag substantially behind same-aged peers. While study designs and statistical methods are under development to try to account for slow and/or non-linear, but potentially meaningful, improvements,<sup>1</sup> there is a dearth of measures designed to capture both growth and loss of social-communication skills. This opinion piece outlines the argument for such a measure, as well as primary issues to consider in its development.

### Lay Summary

This opinion piece outlines the need to develop a new measure of social-communication ability that is more sensitive to small, but potentially important, changes. Such a measure is necessary to

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demonstrate effectiveness of social-communication interventions for children with autism spectrum disorders and other neurodevelopmental disorders.

### Keywords

Autism severity; neurodevelopmental disorder; intellectual disability; outcome measure; response to treatment

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## Social-Communication Skills as an Intervention Target

We define social-communication ability as the appropriate use and modulation of verbal and nonverbal behaviors during interactions with others (see National Institute of Mental Health (NIMH)<sup>2</sup> and the Diagnostic and Statistical Manual for Mental Disorders<sup>3</sup> for other definitions). Intervention efforts are increasingly attempting to measure changes in social-communication deficits in children diagnosed with, or at risk for, autism spectrum disorders (ASD),<sup>4–7</sup> as these deficits are a core diagnostic feature of ASD.<sup>3</sup> Further, increased awareness that social-communication deficits are not specific to ASD but rather occur to various extents across all neurodevelopmental disorders (NDDs)<sup>8,9</sup> has inspired the recommendation that children with deficits undergo intervention to improve their social-communication, regardless of diagnosis or etiology.<sup>10–12</sup>

Unfortunately, while substantial evidence suggests that behavioral intervention can improve cognitive and language abilities as reflected on standardized measures,<sup>13–15</sup> demonstrating change in social-communication has been more difficult.<sup>16</sup> Clinicians and researchers agree that behavioral interventions, and potentially psychopharmacologic interventions, *can* positively impact social-communication development, but inadequate study methods and tools limit our ability to provide evidence to this effect.<sup>17,18</sup> One specific limitation is that available instruments focus on deficits and/or impairment, rather than on ability (see<sup>19–22</sup> and other reviews for comprehensive listings of existing outcome measures for ASD). However, due to the cascading effects of social-communication impairments, measurement of change should be focused on skill development, not just on the reduction of deficit.

The inability to measure incremental skill development in social-communication directly challenges the attempts of researchers and clinicians to document improvement (or lack of) in response to intervention. Federal agencies like the Food and Drug Administration (FDA) require validated items and scales for the establishment of treatment efficacy.<sup>23,24</sup> For example, the FDA provides guidance to help researchers understand how to consider different biomarkers/measures with respect to features such as “context of use” (e.g., for diagnostic vs. prognostic purposes).<sup>25</sup> Therefore, lack of adequately sensitive measures to evaluate change has profound implications for public health, as policy makers and insurance companies rely on the results of treatment trials to inform regulations regarding provision of and payment for such interventions. Other areas of NDD research are similarly impeded, including longitudinal examination of skill and symptom trajectories, as well as cross-disorder/syndrome phenotypic comparisons.

In the following sections, we outline key lessons learned from the use of existing social-communication measures, with a goal of moving toward more effective measurement strategies for documenting change.

## Screening/Diagnostic Measures versus Outcome Measures

Many efforts to quantify social-communication have focused on screening for or diagnosing ASD. Because diagnostic and screening tools identify impairments in broad symptom domains characteristic of a disorder or syndrome (in this case, social-communication impairments indicative of ASD), they do not comprehensively assess the differential manifestation of social-communication abilities across age, developmental, and language levels. This has the notable disadvantage of not providing information about specific impairments that are relevant to certain subgroups within a population. While some direct observation tools like the Autism Diagnostic Observation Schedule<sup>26</sup> have attempted to combat this by assessing different impairments depending on language/age groupings (i.e., “modules”), the content of most parent-report measures of ASD symptoms does not vary substantially based on age, language, or developmental level. The consequence of this is that individuals without functional use of language, for example, are rated on items that assess conversational ability or odd use of speech in the same way as individuals with complex language abilities.<sup>27,28</sup> As a result, variability in scores is driven largely by developmental variables and correlates, rather than by actual differences in social-communication ability.<sup>29–31</sup> Children who are younger and/or have lower cognitive and/or language abilities are more likely to exhibit worse performance on standard measures of social-communication, even if social-communication is an area of relative strength.<sup>32,33</sup> This problem is particularly apparent for individuals with a very low developmental level;<sup>34,35</sup> thus, in the case of certain genetic disorders associated with severe to profound intellectual disability, clinicians must independently judge to what degree scores on standard measures reflect true social communication problems, rather than other aspects of developmental delays.<sup>36–39</sup>

In addition, because screening and diagnostic tools are designed to capture clinically significant departures from typical behavior, they are not always sensitive to the subtle changes in behavior that occur within an individual over time. Behaviors that are the most diagnostically relevant may not be the most useful for capturing differences in skill level *within* a given domain. That is, crossing a diagnostic threshold is not the same as capturing incremental change in the rich substrate of abilities that comprise social-communication. For example, if a child only integrates verbal and nonverbal modes of communication when requesting highly preferred activities, he/she might still be judged as having an impairment on a diagnostic measure. However, on a measure of change, the child’s ability to integrate at all may be important for capturing response to behavioral interventions that target integration. As with any categorization of a dimensional variable, a great deal of detail is lost in the subtleties of behaviors that are important for detecting change.

## Developmental Considerations for Measuring Social Communication

Behavioral manifestations of social-communication ability change over time, as behaviors that are very important early on are continuously replaced with different, more

developmentally relevant behaviors. However, the developmental age of a child with NDD often lags behind chronological age. In typically developing infants and toddlers, joint attention behaviors, or the shared focus of two individuals on an object mediated with nonverbal communication, are central to social interaction and are of critical importance in diagnostic assessments of young children.<sup>40</sup> As children grow older, discrete joint attention-based behaviors such as pointing, showing, or shifting gaze in response to another person's gaze shift, are less relevant for conceptualizing social-communication ability.<sup>41,42</sup> Expectations for typical social-communication behaviors are more nuanced in later pre-school and school-age, and evaluations come to rely more heavily on a child's ability to modulate their behavior to different social partners and contexts. For an 8-year-old with severe intellectual disability, the joint attention behaviors developmentally expected of a toddler may still be relevant—even though these behaviors are not usually treatment targets for 8-year-olds. On the other hand, acquisition of these skills in the same 8-year-old cannot be expected to proceed in the same way as in a typically developing toddler, so applying measures designed for young children will not necessarily provide a valid estimate of social-communication ability.

The extreme variability in phenotypic presentation of children with NDD according to developmental level has led many investigators to implement stringent limits on the age and IQ range of children enrolled. This has resulted in a treatment literature that is not generalizable to a substantial proportion of children with NDDs,<sup>43</sup> who nonetheless receive clinical services according to that evidence base. A developmentally anchored measure of social-communication will enable the inclusion of research participants (and subsequently children in the community) who span a wide age and ability range, in order to establish generalizability of treatments for social-communication deficits. Investigators and clinicians will use this measure to quantify a child's level of social-communication ability relative to an appropriately defined reference group, rather than simply attempting to control for IQ, age, and/or other behaviors at the point of analysis.<sup>44,45</sup> Evaluating social-communication *within specific developmental levels* is necessary to obtain information that goes beyond, and is separable from, cognitive and language abilities.

## Measuring Change

In most areas of medicine, the goal of treatment is symptom reduction (e.g., to lower blood pressure or reduce the number of manic episodes). Treatment of NDDs is uniquely challenging, as it often requires twin goals of reducing impairing symptoms and promoting skill acquisition, although these are not mutually exclusive. For instance, the diagnostic symptoms of ASD are largely *negative*; it is the absence of expected social and communicative abilities and behaviors that marks an ASD diagnosis rather than the presence of such behaviors (the opposite is usually true of restricted and repetitive behaviors). The definition of *expected* is the crux of the issue; many instruments base this expectation on age, but expectations must vary based on other phenotypic aspects of the child, including language and cognition.<sup>46</sup> Thus, difficulties in measurement have limited inclusion of social-communication as primary outcomes in many treatment studies,<sup>16,17,47–49</sup> even when reduction of social-communication deficits is the primary treatment goal.<sup>15,17,50,51</sup> The measurement of positive symptoms is more tractable, as the target reduction can be readily

quantified. As a result, pharmacologic intervention on some associated *positive* symptoms, such as hyperactivity and irritability, and to some extent restricted and repetitive behaviors, 47,52 has been more vigorously pursued. Ironically, this conflation has resulted in a field of data on treatments for ASD without much information about how the treatments affect the core social-communication symptoms of ASD. Although a few measures have been recently developed to assess change in these symptoms,<sup>53–55</sup> parent-report measures typically use the exact same item set regardless of age, developmental, or language level, thus limiting our ability to evaluate improvements in children of varying developmental levels.

## Measures of Deficit versus Skill

By definition, diagnostic instruments must focus on impairments. However, a measurement of change for a neurodevelopmental disorder must focus instead on skill *development*, or ability. Adaptive behavior is among the most commonly measured ability constructs in NDDs, and researchers have been successful in documenting change in children with conditions affecting social-communication development over time<sup>56–61</sup> and/or in response to treatment.<sup>5,6,62,63</sup> Adaptive functioning scales such as the Vineland Adaptive Behavior Scales<sup>64,65</sup> may represent a more developmentally appropriate measurement of social and communication behavior. Unlike measures of social-communication deficits (e.g., ASD symptom measures), Vineland ratings are based on whether a child performs skills independently, queried in the approximate order of acquisition of a typically developing child. Item sets are administered based on both the child's developmental and chronological age level, and the child's scores are compared to children of the same age to yield a standardized score.

A focus on behaviors that parents expect to see is a particular strength of skill-based parent-report measures like the Vineland.<sup>66</sup> However, aspects of the Vineland limit its ability to accurately capture change. For example, the scores lack psychometric validity in the very low range of ability, and construction depends on the assumption of homogeneous developmental trajectory, which is not true in many NDDs.<sup>67</sup> Children with lower mental ages have different skill sets than chronologically younger children of the same mental age, so measures normed on typically developing populations may not capture the full range of abilities exhibited by children with NDDs. Significant variability in cognitive profiles has been documented extensively within multiple neurodevelopmental disorders. Questions about skills must therefore be sufficiently flexible to account for differences in language or motor skills, which may be more or less advanced than other aspects of development. In addition, the Vineland includes many items (e.g., about getting together with peers) that may be heavily influenced by contextual factors such as where a child lives and/or how motivated or capable the parent is of arranging social opportunities.

## Moving Forward

The lack of a measure to quantify social-communication ability independent of other developmental variables has thus far been a barrier in studying NDDs.<sup>68,69</sup> A logical next step is to create a measure designed to evaluate social-communication abilities, for use in children with and without varied neurodevelopmental conditions. We have undertaken this in

a multisite scale development project. Our initial steps of measure development include using existing data from multiple cohorts of children with ASD, non-ASD diagnoses, and typically developing children to form an understanding of the age, sex, IQ and more general (e.g., adaptive) functioning effects on measures of social-communication, and identify which behaviors are best suited for a developmentally-based, skills-focused quantitative measure of social-communication. The purpose of such a measure is not diagnostic, but rather to provide a measure of social-communication ability that is sensitive to incremental changes in skills. The measure will be adaptive, with bifurcations based on important distinctions, such as the language level and age of the child, to ensure that the items administered are appropriate for a given child. Thus, the product will be a parent-report, computerized adaptive test (CAT), rigorously developed with item response theory. This is an empirical approach to the selection of items and alternate questions (used for retesting as well as validity), as well as start and stop points.<sup>70</sup>

We plan to take a variety of steps to ensure reliability, validity and feasibility of this developmental assessment of social communication abilities, but note upfront that validation efforts will be limited by the lack of a gold-standard against which it can be directly compared. Such limitations are particularly relevant for those with moderate-to-severe-to-profound ID, due to lack of tools that have previously been validated in these subpopulations. Our review of the literature indicates that since the quantification and skill-based approach to this measure mostly closely aligns with the pieces of domains of existing adaptive functioning, specific subdomains of adaptive behavior scales will be useful comparators. We will also examine correlations with other existing measures that explicitly measure social-communication, although for those that are developed for purposes of diagnosing specific neurodevelopmental disorders, we expect discrepancies to exist across measures.

Although we hope development of such a tool will be a useful step forward, it will not fill all gaps. Direct observation measures are necessary to complement a parent-report evaluation of changes in social-communication abilities, and may be especially important for observation of outcomes from early intervention (e.g., BOSCC).<sup>55</sup> Direct assessment and/or self-report measures may also be helpful in quantifying changes in social-communication, especially pertaining to an individual's ability to make use of certain types of information and respond appropriately.<sup>71,72</sup> As a field, it is crucial that we work to separate the use of different measures for different purposes (e.g., diagnostic measures for diagnosis, rather than for measuring treatment outcomes) and more openly attend to the limitations of our tools.

In sum, social communication impairments occur in a variety of behavioral and genetic conditions and are often a focus of treatment, regardless of if and how a specific diagnosis is made. Therefore, moving away from ASD symptom measures to show changes in social-communication, and focusing instead on acquisition of developmentally expected social-communication skills, will represent a major step forward in our attempts to think more dimensionally about the construct of social-communication.



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