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Do parents and clinicians agree on ratings of autism-related behaviors at 12 months of age? A study of infants at high and low risk for ASD

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Abstract

Given the emphasis on early screening for ASD, it is crucial to examine the concordance between parent report and clinician observation of autism-related behaviors. Similar items were compared from the First Year Inventory (Baranek et al., 2003), a parent screener for ASD, and the ADOS-2 Toddler Module (Lord et al., 2013), a standardized ASD diagnostic tool. Measures were administered concurrently to 12-month-olds at high and low risk for ASD. Results suggest that clinicians and parents rated behaviors similarly. In addition, both informants rated high-risk infants as more impaired in several social-communication behaviors. Furthermore, the format of questions impacted agreement across observers. These findings have implications for the development of a new generation of screening instruments for ASD.

Keywords

ASD; screening; ADOS-T; FYI; infancy; high-risk infants; clinical assessment; parent questionnaires

Introduction

With recent studies estimating the prevalence of autism spectrum disorder (ASD) at around 1.5% (Baio, 2014; Christensen, 2016), establishing the means to detect it early in development in the general population is imperative. The American Academy of Pediatrics recommended two universal ASD screenings before age two (Johnson & Myers, 2007) in order to promote more positive long-term outcomes for children with autism. Early

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identification can lower the age at which intensive intervention begins, potentially maximizing positive outcomes for social-communicative, cognitive, language, and adaptive functioning in children with ASD (Bradshaw, Koegel, & Koegel, 2017; Chawarska, et al. 2007; Dawson et al., 2010; Rogers et al., 2012; Rogers et al., 2014; Steiner, Gengoux, Klin, & Chawarska, 2013).

Many parents of children with ASD first become concerned about their children's development in the course of the first two years of life and in some cases, parents express concerns prior to the child's first birthday (Baghdadli et al., 2003; Chawarska et al., 2007; De Giacomo & Fombonne, 1998). Delays on the order of several years between initial parent concern and an eventual diagnosis have been attributed to multiple referrals or to the fact that parents were told to take a "wait and see" approach (Caronna, Augustyn & Zuckerman, 2007; Zuckerman, Lindly, & Sinche, 2015). In a nationally-representative US sample, more than half of children with an eventual ASD diagnosis experienced passive or reassuring provider responses to concerns expressed by parents, resulting in significantly longer delays to a diagnosis than for children whose pediatricians responded in a proactive way (Zuckerman et al., 2015). Availability of universal and reliable autism-specific screening measures could decrease the delay between the time at which parents first notice problems and the age of the ASD diagnosis.

Significant efforts to advance ASD-specific screening tools have been made in recent years. Adapted from the Checklist for Autism in Toddlers (CHAT; Baron-Cohen, Allen & Gillberg, 1992), the M-CHAT/F (Robins, Fein, & Barton, 1999) and its revision, the Modified Checklist for Autism in Toddlers-Revised with Follow-Up (M-CHAT-R/F; Robins et al., 2009) have been widely utilized in pediatric practices worldwide to screen toddlers between 16 and 30 months of age. In two recent studies, the positive predictive value (PPV) for ASD at 20 months using the combination of questionnaire and follow-up interview was .48-.54, with a PPV for any diagnosable developmental problem of .95-.98 (Chlebowski et al., 2013; Robins et al., 2014). That is, among those who screened positive for ASD on the M-CHAT at the age of 20 months, 48-54% had ASD and 95-98% had some developmental disorder, including ASD. A prospective population study of the M-CHAT (without Follow-Up questions) conducted in Norway revealed that 2/3 of children later diagnosed with ASD had screened negative at 18 months on this measure, which suggests that the instrument detected only approximately 33% of true ASD cases (Stenberg et al., 2014). Certainly many factors affect the M-CHAT's psychometric properties, among them its measurement and design features (e.g., yes/no question format, wording) (DeVellis, 2016) as well as its coverage of a relatively wide age range. As for question format, efforts are underway on another revision of the CHAT that extends response options to a 5-point scale (Q-CHAT; Allison et al., 2008; Magiati et al., 2015). To the issue of age range, the PPV of the M-CHAT for ASD was significantly higher when administered at 25 months (.61) than when administered at 19 months (.28) (Pandey et al., 2008). This suggests that the screening process would benefit from a developmentally sensitive approach. In acknowledgment of the developmental nature of ASD, the Social Attention and Communication Study protocol is a structured developmental observation implemented by nurses at well-child visits that uses different yet overlapping sets of items at 12, 18, and 24 months (Barbaro & Dissanayake, 2010). Infants with ASD exhibited patterns of strengths and weaknesses over time on this measure that

were different than those of infants with other delays (Barbaro & Dissanayake, 2013). The CSBS-Infant-Toddler Checklist (Wetherby & Prizant, 2002) takes another approach to developmental sensitivity and uses age norms; though acknowledged to be a broadband screener, it does have utility for detecting infants with ASD at the end of the first year, particularly when scores on its social composite are considered (Wetherby, Bronson-Maddox, Peace, & Newton, 2008).

Another recent entry into the field of developmentally sensitive measures, the First Year Inventory (FYI; Baranek, Watson, & Crais, 2003; Reznick, Baranek, Reavis, Watson, & Crais, 2007; Turner-Brown, Baranek, & Reznick, 2012) is a parent-report ASD screener designed for a very narrow age range: the first birthday, plus or minus one week. In terms of design features, the FYI includes a broader range of response categories and types, including a four-point Likert scale and some multiple choice-formatted items. The latter is thought to better capture the range of supplemental strategies parents utilize to elicit responses from their infants, consistent with parents' experiences with a young child on the autism spectrum (Reznick, et al., 2007). The FYI has been normed on a sample of 1,496 12-month-old infants from the general population with reports of satisfactory face validity of the measure's constructs (Reznick, et al., 2007). In a follow-up of 699 of these infants at age 3 (Turner-Brown et al., 2012), 99% of children who scored below the cutoff at 12 months did not currently exhibit ASD symptoms, while of those who did exceed the cutoff, 85% exhibited developmental delays or other concerns and 31% were given a diagnosis of ASD.

As parents have an optimal perspective from which to observe and engage with their infants across diverse contexts, the parent-report format is a convenient, cost-effective means of potentially identifying children at risk for a later diagnosis of ASD, particularly as awareness of early autism symptoms is increasing (Chawarska et al. 2007, 2009; Ozonoff et al., 2009). Younger siblings of children with ASD are at higher risk for the disorder (recurrence risk estimates between 6.9% (Groenborg, 2013) and 18.7% (Ozonoff et al., 2011)) as well as for a range of clinically significant delays and social skill deficits (Charman et al., 2016) making it increasingly important to implement screening initiatives in high-risk (HR) populations (Rowberry et al., 2014).

However, detecting autism as early as the first birthday presents some challenges. First, the developmental course of autism does not proceed in a universal fashion. Although the behavioral manifestations of the disorder are clearly present in some infants by the first birthday, in many infants, various features emerge on different timelines and in assorted combinations over the first three years of life (Chawarska et al., 2014; Landa et al., 2007; Macari et al., 2012; Ozonoff, Heung, Byrd, & Hertz-Picciotto, 2008). Second, early language and communication delays, among the first symptoms of ASD to be noticed by parents, are not specific to ASD (Macari et al., 2012). Moreover, in high-risk siblings, for whom screening holds particular urgency, early delays in areas related to the core features of ASD (broader autism phenotype, BAP) are ubiquitous; up to 28% of HR infants without a later ASD diagnosis exhibit some such symptoms at 12 months (Georgiades et al., 2013; Macari et al., 2012; Ozonoff et al., 2014). These overlapping phenotypes make discriminating between infants with emerging ASD and infants with BAP features difficult. Yet distinguishing ASD from BAP may yet be possible via use of parent reporting. A study

of the FYI in infants at high familial risk for ASD suggested the measure's utility in discriminating across HR infants with various developmental outcomes; parents of HR infants later diagnosed with ASD rated their social functioning as more abnormal at 12 months reflected in the Social Communication domain and construct scores compared to HR infants who exhibited features of the broader autism phenotype (BAP) or other delays (Rowberry et al., 2014).

In addition to parent report measures that are appropriate for infants, standard diagnostic tools such as the ADOS are also now available for infants as young as 12 months of age. The past decade of high-risk prospective infant sibling research has resulted in greater awareness of the heightened risk of ASD in siblings of diagnosed children (Ozonoff et al., 2011), leading to more demand for monitoring of younger toddlers and infants. Given encouraging results using the FYI in the general population (Turner-Brown et al., 2012) and in high-risk siblings (Rowberry et al., 2014) as well as evidence that ASD symptoms emerge around 12 months based on direct assessment using the ADOS-Toddler (Macari et al., 2012) and the SACS (Barbaro & Dissanayake, 2013), the first birthday is an ideal time to begin screening in order to identify infants as their symptoms become apparent.

As a first step, it is important to understand how parent report and clinical ratings align at this age, as this would be crucial for designing new screeners. When comparing agreement on the presence or absence of autism-related behaviors in older toddlers and preschoolers, parents and clinicians have been found to agree moderately well, although they may focus on different aspects of behavior or have different frames of reference (Stone, Hoffman, Lewis, & Ousley, 1994). In younger toddlers, concordance may be lower for particular kinds of behavior. In a sample of 22-month-old toddlers diagnosed with autism, a comparison of ratings via direct clinician assessment (ADOS-G; Lord et al., 2000) and parent report (ADI-R; Lord et al., 1994) suggested a fair amount of agreement across informants for the Communication ($r=.49$) and Social Reciprocal Interaction algorithm scores ($r = .46$), but less agreement on Stereotyped Behavior ($r=.27$). Similarly, 12-month-old infants later diagnosed with ASD were rated as having more atypical behaviors than controls both by parents (FYI) and clinicians (ADOS-Toddler), with a moderate correlation ($r=.44$) between parent and clinician ratings of their social communication behavior but with no significant association between the two sources with regard to restricted, repetitive, and sensory-regulatory behavior (Rowberry et al., 2014). At the item level, parents and clinicians tended to differ on their evaluation of nonverbal social behaviors such as eye contact, social smiling, and facial expressions, but rated children similarly on communication items (Chawarska et al., 2007), suggesting that there may be meaningful disparities between parental and clinical perception of the severity of impairments in specific behaviors within the core areas.

Thus, both parents and clinicians note elevated levels of ASD-related delays and abnormalities by 12 months, but the agreement between the two important sources is only moderate and it is not clear what contributes to the inconsistencies. Taking advantage of overlap between the items on the FYI (Baranek et al., 2003) and the ADOS-2 Toddler Module (Lord et al., 2012), we examined congruency between parent report and clinical observation at 12 months in a prospective sample of infants at high and low risk for ASD. By contrasting the relationships between parent and clinician ratings in high and low risk

groups, we also examined if parents of children with ASD may be more or less adept at evaluating their infants' behavior compared to parents of children without any risk factors for ASD. The present study aims to investigate which specific behaviors are likely to elicit concordant judgments across parents and clinicians and which behaviors are more vulnerable to discrepancies. Furthermore, we explored the issue of the impact of design features on parent report for this age group.

Methods

Participants and Procedure

Participants included 137 (87 males; 63.5%) high-risk and 76 (38 males; 50.0%) low-risk infants from a prospective study of infants ($N = 213$). Infants who had an older sibling with ASD constituted the high-risk (HR) group; the older sibling's diagnosis was confirmed via clinical best estimate diagnosis and the ADI-R (Autism Diagnostic Interview-Revised; Lord, Rutter & Le Couteur, 1994) and/or ADOS (Autism Diagnostic Observation Schedule-G; Lord et al., 2000). Infants who had no first- or second-degree relatives with autism were considered to be low risk (LR). All parents granted permission for their infants to participate and the study was approved by the Human Investigation Committee. The majority of parents (85.9%) identified their child's race as Caucasian, with 5.2% Asian, 4.7% mixed racial heritage, 3.3% African-American, and 0.9% not reported. The proportion of Caucasian vs. non-Caucasian participants did not differ between the two risk groups ($p = .27$). Hispanic infants comprised 12.7% of the sample, with no significant difference across groups ($p = .88$). The level of educational attainment of both mothers and fathers was high, corresponding to slightly more than a 4-year college degree on average, and did not significantly differ across groups ($p = .84$ for mothers; $p = .29$ for fathers).

Parents were asked to complete the First Year Inventory (FYI; Baranek *et al.*, 2003) within two weeks prior to the assessment at 12 months. At 12 months all children underwent direct assessment by Ph.D.-level clinicians blind to each infant's risk status using the Mullen Scales of Early Learning (MSEL) (Mullen, 1995) and the Autism Diagnostic Observation Schedule-2 – Toddler Module (ADOS-T; Lord et al., 2012). The MSEL was used to assess verbal and nonverbal development, with developmental quotient (DQ) scores derived from age equivalent (AE) scores in Receptive and Expressive Language (verbal) and in Fine Motor and Visual Reception (nonverbal), whereby $DQ = (\text{mean of AE scores} / \text{chronological age}) \times 100$. The ADOS-T quantifies autism-related symptoms, with Social Affect and Restricted Repetitive Behavior algorithm scores. The two groups did not differ significantly on the MSEL verbal and nonverbal DQ scores, though there was a trend toward the HR group having lower VDQ compared to the LR group ($p = .06$) (see Table 1). However, the infants in the HR group scored significantly higher than LR infants on the ADOS-T Total Algorithm score ($F(1,209) = 10.55$, $p = .001$), which was driven largely by elevated scores on Social Affect ($F(1,209) = 10.04$, $p = .002$). Scores on the Restricted Repetitive Behavior algorithm scale were marginally elevated in the HR group ($p = .07$) (see Table 1).

Measures

Two measures were used to quantify the degree of ASD-related behaviors in the HR and LR samples: the First Year Inventory (FYI) and the ADOS-T. The FYI is a parent questionnaire that is designed to screen for ASD at 12 months in the general population. The scale consists of two domains, the Social Communication Domain and the Sensory-Regulatory Domain. The majority of its 63 questions (n=47) are formatted in a Likert-type scale. These questions are formulated to elicit parent report about the frequency of behaviors, e.g., “When you point to something interesting, does your baby turn to look at it?” with the response options of: “never”, “seldom”, “sometimes”, and “often”. The remaining fourteen questions have multiple choice options, and a few behaviors are addressed in both the Likert and multiple choice formats (e.g., “Response to Name”).

The ADOS-2 Toddler Module (Lord *et al.*, 2012) is a standardized diagnostic tool designed for infants and toddlers between 12 and 30 months of age. Forty-one items comprise this module of the ADOS and fall into Social Affect (SA) and Restrictive and Repetitive Behavior (RRB) domains.

Eight items were identified across the FYI and the ADOS-T measures that tapped into comparable social-communicative and sensory-regulatory/repetitive constructs and were worded in a very similar manner (see Table 2). The items included those that are well known in the literature as early “red flags” for autism: unusual eye contact, low frequency of babbling, behaviors related to stereotyped and restricted interests, and impaired response to name—an empirically documented indicator in infancy for an eventual risk of receiving an autism diagnosis (Baranek, 1999; Dawson, Osterling, Meltzoff & Kuhl, 2000; Osterling & Dawson, 1994; Miller et al., 2017; Nadig, et al., 2007; Wetherby, et al., 2004). Items under consideration from both measures are behavior ratings on a scale of zero to three. On the ADOS-T, a score of zero represents typical behavior and higher numbers reflect progressively more atypical behavior. On the FYI, a score of zero corresponds to “never”, which is the most atypical response for the majority of its questions and “often”, a score of three, captures the most typical behaviors, with “seldom” and “sometimes” scoring one and two respectively. For the purposes of this study, some FYI item scores were reversed in order to be aligned with those of the ADOS-T.

Statistical Analysis

The analytic strategy involved comparing parent concerns (FYI) with clinician judgment (ADOS-T) in the low-risk and high-risk groups separately using three strategies. First, we created composite scores for each measure based on sums of the eight items from each scale to yield an FYI Composite and ADOS-T Composite, and performed Pearson's correlations across the two variables. Second, to compare the members of each of the 8 pairs (parent report vs clinician observation), we performed repeated measures mixed ANOVAs with group as the between-subjects factor and measure as the within-subjects factor. Lastly, we compared responses across three similar items tapping into a baby's response to his or her name, two from the FYI and one from the ADOS-T, using a repeated measures mixed ANOVA. Statistical calculations were performed using IBM SPSS Statistics Version 21 (IBM, 2012).

Results

Preliminary Analyses

Initial checks of the data showed that the FYI item ratings were not normally distributed, similar to what was observed in the norming sample (Reznick et al., 2007). Parents overwhelmingly used the half of the scale that included the options “Often” and “Sometimes” and rarely used the “seldom” and “never” options, resulting in moderate skewness across all items (skewness values ranging from .61 -3.38, with nearly all values above 1) (see Figure 1). This issue was not as prevalent for the ADOS-T items, for which skewness values ranged from -.05 – 1.68, with only 3 values above 1 (see Figure 2). Given the differences in item response distribution between measures, all items across both measures were converted to z-scores for the item-level analyses to enable direct comparison. Similar to its component items, the FYI composite score was also not normally distributed (skewness = 1.60). Because of this, a square root transformation was applied to this variable prior to analysis (Bartlett, 1947). The ADOS-T composite exhibited a fairly normal distribution (skewness = 0.43) (see Figures 1 and 2). Both FYI transformations (of items and the composite) reduced skewness to acceptable levels.

Parent versus Clinician Ratings

To assess the overall consistency across informants for the selected pairs of FYI and ADOS-T items, we ran Pearson's correlations on the composite scores in the combined samples. The FYI and ADOS-T composite scores were moderately correlated with one another, $r(211) = .34, p < .001$.

Repeated measures mixed ANOVAS on each pair of items with group as the between-subjects factor and informant as the within-subjects factor yielded three basic patterns of results: 1) main effect of risk group only, whereby the HR group was rated as more atypical than the LR group regardless of informant (Showing, Unusual Eye Contact, Response to Name (comparison including FYI Question 1, Likert scale), Directed Vocalizations); 2) a risk group by informant interaction (Amount of Babbling); and 3) no main effect of risk group or informant (Gestures, Repetitive Behavior, and Response to Name (comparison with FYI Question 52, multiple choice)).

HR infants were rated by both informants as more impaired than LR infants on the following items: *Showing* (ADOS-T B12/ FYI Q19) ($F(1,209) = 12.61, p < .001$); *Unusual Eye Contact* (ADOS-T B1/ FYI Q6) ($F(1,210) = 8.59, p = .004$); *Response to Name/Likert* (ADOS-T B7/ FYI Q1) ($F(1,210) = 4.12, p = .040$); and *Directed Vocalizations* (ADOS-T A2/ FYI Q29) ($F(1,209) = 4.05, p = .045$). There was an interaction between risk group and informant for the item capturing *Amount of Babbling* (ADOS-T A1a/ FYI Q32) ($F(1,210) = 7.55, p = .03$); paired comparisons showed that the discrepancy between informants was significant for the LR group ($p = .03$) but not for the HR group (see Figure 3). There were no significant main effects or interactions for *Gestures* (ADOS-T A8/ FYI Q34), *Repetitive Behavior* (ADOS-T D5/ FYI Q30), or *Response to Name/multiple choice* (ADOS-T B7/ FYI Q52), all p values $> .11$.

Response to Name Items—In the FYI, the question regarding an important red flag for ASD in infancy, response to name, is posed twice: once in the Likert scale response type, with alternatives of “often”, “sometimes”, “seldom”, and “never”, and the second time as a multiple choice question: “What do you typically have to do to get your baby to turn toward you: a) simply say your baby's name, b) say your baby's name several times, c) say your baby's name loudly or use other means, such as clapping, d) your baby doesn't turn when name is said.” Wording effects on parental rating were examined using repeated-measures mixed ANOVA with type of question as the within-subjects variable and risk group as the between-subjects factor (Figure 4). In contrast to the previous item-level analysis, in this case, the unstandardized ratings were considered here and in the contingency table below. There was a significant main effect of question type, $F(2, 209)=28.13$, $p<.001$ (partial eta squared = .21), but no main effect of risk group and no interaction. Planned contrasts indicated that responses to ADOS-T item B7 differed from both FYI Q1 ($p<.001$) and FYI Q52 ($p<.01$), and Q1 and Q52 differed from each other ($p<.001$).

In addition, we constructed a contingency table of the FYI's (untransformed) Response to Name Questions 1 (Likert-type) and 52 (Multiple Choice) to further understand not only how parents in both LR and HR groups responded, but also what adaptive strategies parents used to elicit a response to name (Table 3). This table revealed that in both risk groups, parents were far more likely to use the “Often” option on the Likert-style question (Question 1) than the other options (sometimes, seldom, never): LR group median = 0, interquartile range = 0; HR group median = 0, interquartile range = 0. The parents of LR infants endorsed “Often” 93.4% of the time and “Sometimes” 6.6% of the time, never endorsing “Seldom” or “Never”. The parents of HR infants endorsed “Often” 83.9% of the time, “Sometimes” 14.6% of the time, with “Seldom” and “Never” chosen by 0.7% each. In contrast, when answering FYI item 52, the multiple-choice-style question, the proportion of responses was less skewed. For this item, 73.7% of LR parents and 75.9% of HR parents used the highest response (simply say the baby's name), and 18.4% of LR parents and 19.7% of HR parents endorsed the second option in the scale (say baby's name multiple times). None of the LR parents and 3.6% of the HR parents chose the third option (say baby's name loudly or use other means such as clapping).

Furthermore, some parents (18.4% of LR parents and 10.9% of HR parents) who responded on the Likert-style question that their infant “Often” looked when his or her name was called also reported having to say the name several times on the multiple-choice-style question (FYI Q52). In addition, four HR parents who responded that their infant “often or sometimes” turned in response to name also endorsed needing to use strategies such as calling the infants' name loudly or clapping.

Discussion

The present study comparing parental rating and direct assessment of one-year old infants' social-communication behavior yielded several important findings. First, the FYI's Likert-style questions often resulted in compression of responses into the categories of “Often” and “Sometimes”, while the measure's items with a multiple choice format, similar to those of the ADOS, allow for use of a greater range of ratings. Thus, parent questionnaires that

truncate the options even further, using, for example, a yes/no format, may have an unintended impact on the results. This phenomenon should be investigated more directly as it is highly consequential for the interpretation of existing screening instruments as well as for the design of new measures. Secondly, results indicated that once the responses on both measures were standardized, parents and clinicians rated key indices of infants' social-communicative functioning similarly. Parents' responses on the First Year Inventory (FYI) were in close agreement with clinicians using the ADOS-T with respect to seven of the eight behaviors analyzed, including Unusual Eye Contact, Showing, Directed Vocalizations, Gestures, and Repetitive Behavior. Clinicians and parents disagreed on only one behavior: LR parents rated their infants as more typical in Amount of Babbling than clinicians. This one exception aside, parents of HR and LR infants were comparable to each other in terms of their consensus with clinicians. Thirdly, behaviors that discriminated the risk groups from each other according to both informants included Showing, Unusual Eye Contact, Directed Vocalizations, and Response to Name. These are critical ASD-related behaviors around the first birthday, and early impairments in these areas may have implications for a later ASD diagnosis.

One of these four critical behaviors, Response to Name, exists in two different formats on the FYI and results were different for each. The Likert scale response format (How often does your baby respond to his or her name...with response options "often, sometimes," etc.) generated disparate ratings between HR and LR infants, with parents of HR infants more likely to endorse this behavior as abnormal compared to parents of LR infants. When the response format was multiple-choice (with concrete examples of what is required to achieve the response), however, group differences were no longer significant. Comparing these two Response to Name items with the ADOS item, it became clear that the score of the parent-reported multiple-choice item was closer to the clinician rating than the Likert-type item, for both HR and LR parents. This suggests that the wording and format of items influence what parents report.

What emerged upon closer inspection of the distribution of responses across the two Response to Name items on the FYI was that the multiple choice format resulted in broader use of the range of options than the Likert-type format. This was true for the Likert-style FYI items generally and consistent with data from the normative sample (Reznick et al., 2007). There are a few possible explanations for this. First, because it is a screening instrument, the FYI is designed to measure atypicality and thus its Likert items do not possess balanced keying (including an equal number of positive and negative options); instead it provides more granularity on the atypical end of the scale (options: Sometimes, Seldom, Never) than on the typical end (option: Often). The multiple choice question for Response to Name on the FYI provides an important expansion of the positive end of the scale to include two relatively typical behaviors (baby responds immediately, baby responds after a few calls). Second, the multiple choice item relating to response to name describes circumstances under which a baby produces the behavior, providing clearly operationalized choices that also include accommodative strategies parents might use to elicit behavior (e.g., repeating the child's name several times, increasing volume, clapping). In contrast, the Likert scale's options do not specify what it takes for the infant to respond. That is, one may still endorse the response "sometimes" or "often" even if multiple prompts or other

accommodative strategies are needed to gain the infant's attention, a pattern of responding that was observed in the current study. In summary, Likert-type items, provided keying is balanced, offer information regarding frequency of a behavior, while well-designed multiple choice questions can provide more clarity with regard to conditions under which a given behavior is observed. Furthermore, getting at the style of infants' responses on parent questionnaires takes a step closer to how clinicians rate behavior on an assessment like the ADOS.

The single discrepancy between expert clinician observations and parental report was noted in the LR group for amount of babbling, where clinicians rated infants as less vocal than their parents did. At this age, communicative behaviors can be highly context-dependent. The novelty of the clinical environment might serve to suppress verbal behaviors in infants. Further evidence of such suppression is reflected in performance on the Verbal Scales of the Mullen, where the LR infants as a group scored slightly below average. Although it is possible that HR parents would be either more accurate reporters of their infants' behavior than parents of low-risk children (due to greater awareness of early infant social-communication milestones given the presence of an older child with ASD), or less accurate reporters (due to contrast effects (Eaves, 1976) of the older affected sibling), but this study did not provide evidence of either bias; the HR parents' ratings were as well-aligned with the observations of the clinicians as the LR parents.

Taken together, these findings highlight the strength of parent report to align with clinician judgments and to identify behaviors that are considered red flags for ASD, as well as illuminate aspects of design format of items that enhance or minimize discrepancies across informants. Furthermore, this study suggests that the more closely the screener questions align with the structure of clinicians' ratings (in the case of the ADOS, multiple choice structure), the more convergent the observations will be across informants. These results underscore the importance of wording and format of screener questions, as slight variations in how the question is presented can produce dramatically different results. Further exploration into operationalizing screener questions in a more finely-grained manner is needed; such adjustments may improve agreement across parents and clinicians.

There are several caveats to the study. First, the two instruments, while comparable in rating behaviors from a 0 to 3 scale, still leave room for differences in how the behaviors are assessed by parents and clinicians. Perhaps most obviously, the ADOS ratings are based on direct observations across a few activities and structured tasks, and the FYI ratings are based on composite impressions across many observations in various contexts. Future directions should involve pairing even more similarly worded questions and response options to further examine congruency across informants, as well as providing structured probes to parents analogous to assessment items (Smith et al., 2016). On the other hand, discrepancies in responses across informants serve to illuminate context and measurement effects on behavioral expression (Gagne et al., 2011; Saudino, 2005; Saudino, 2009). Furthermore, perhaps owing to the study's prospective design, it included a large number of families with high levels of education (Zwaigenbaum et al., 2007). Extension of this work to a broader socio-economic spectrum will be needed.

With the promise of early intervention for toddlers and young children (Bradshaw, Koegel, & Koegel, 2017; Bradshaw, Steiner, Gengoux & Koegel, 2015; Dawson et al., 2010), screening for ASD at earlier ages remains at the forefront of both public health and research endeavors. Prospective studies of HR siblings suggest that the symptoms of ASD at 1 year of age (Macari et al., 2012) are not the same as those only 6 months later (Chawarska et al., 2014). Thus, research into screening at the first birthday presents a fruitful avenue of investigation with potentially significant implications for early detection and treatment. Gaining an understanding of the impact of design features on parents' responses on screening tools could inform how to improve screening efforts.

Conclusions

As this study illustrates, there are ways in which discrepancies between parents' and clinicians' views of behavior may be minimized. With increasing awareness of autism in recent years, this study carries important public health implications, especially in light of bolstered efforts to screen and build empirical evidence promoting early intervention. These findings suggest a need to examine sources of discrepancies between parental report and concurrent clinician rating of key diagnostic features as well as the impact of screening instruments' design features. Although recent studies have proposed addressing the issue of parents' knowledge of child development as a means to improve earlier detection of developmental delays or having pediatric primary practitioners administer screening tools more frequently, this study contributes a more immediate and perhaps more effective means to address these current public concerns, through careful attention to the construction and wording of screening questions.

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Figure 1.

Distribution of First Year Inventory (FYI) composite scores in HR and LR sibs.

Note: FYI composite is the sum of items 1, 6, 19, 29, 32, 30, 34, and 52. All items except 6, 30, and 52 were reverse-scored.

Figure 2.
Distribution of ADOS-Toddler composite scores in HR and LR sibs.
Note: ADOS-Toddler composite is the sum of items A1a, A2, A8, B1, B7, B12, and D5.

Note: HR>LR, $p < .05$.

Note: HR>LR, $p < .01$.

Note: HR>LR, $p < .05$.

Note: HR>LR, $p < .001$.

Note: Risk group x informant interaction; $p < .05$.

Figure 3.

Comparisons of selected pairs of z-score transformed items across the ADOS-Toddler and the FYI. Higher z-scores indicate greater impairment.

Figure 4.

Comparison of Response to Name items (untransformed) across the ADOS-Toddler (B7), FYI Q52 (Multiple Choice), and FYI Q1R (Likert). Higher values indicate more atypical behavior. Error bars indicate ± 1 SE.

Note: * $p < .01$; ** $p < .001$.

Table 1
Participant characteristics at 12 months

	High-Risk n=137	Low-Risk n=76	<i>p</i> -Value	Partial η squared
Sex (% male)	63.5%	50.0%	.06	
Age in months	12.46 (0.59)	12.34 (0.55)	.13	
Mullen Verbal DQ	86.31 (18.92)	91.72 (20.54)	.06	
Mullen Nonverbal DQ	113.30 (13.61)	116.07 (12.65)	.12	
ADOS-T Social Affect	8.09 (4.70)	6.12 (3.45)	<.01	.046
ADOS-T Restricted Repetitive Behavior	1.02 (1.34)	0.68 (1.18)	.07	
ADOS-T Total Score	9.11 (5.43)	6.80 (3.80)	.001	.048

Abbreviations. Verbal DQ: Verbal developmental quotient; Nonverbal DQ: Nonverbal developmental quotient.

Note: *p*-values for Age, Mullen scores and ADOS scores were determined using multivariate ANOVA; *p*-value for Sex was determined using Fisher's exact test.

Table 2
Corresponding First Year Inventory and ADOS-Toddler items

Pair	ADOS-Toddler	FYI
1	A1a. Frequency of Babbling	Q32. Does your baby babble by putting sounds together, such as 'ba-ba', 'ga-ga-ga', or 'ba-dee'?
2	A2. Frequency of Spontaneous Vocalization Directed to Others	Q29. Does your baby try to get your attention by making sounds and looking at you at the same time?
3	A8. Gestures	Q34. Does your baby use gestures such as raising arms to be picked up, shaking head, or waving bye-bye?
4	B1. Unusual Eye Contact	Q6. When you and your baby are facing each other, does your baby turn his or her eyes to avoid looking at you?
5	B7. Response to Name	Q1. Does your baby turn to look at you when you call your baby's name?
6	B7. Response to Name	Q52. What do you typically have to do to get your baby to turn towards you? a. simply say your baby's name b. say your baby's name several times c. say your baby's name loudly or use other means, such as clapping d. your baby doesn't do this yet
7	B12. Showing	Q19. Does your baby try to get your attention to show you something interesting?
8	D5. Unusually Repetitive Interests or Stereotyped Behaviors	Q30. Does your baby get stuck doing a simple activity over and over?

Table 3
Contingency table with two items measuring Response to Name on the First Year Inventory (FYI)

Response to Name (Q1, Likert-type): How frequently does your baby turn to look at you when you call your baby's name?	Response to Name (Q52, Multiple Choice-type): "What do you typically have to do to get your baby to turn towards you?"			
	a. Simply say your baby's name	b. Say your baby's name several times	c. Say your baby's name loudly or use other means, such as clapping	d. Your baby doesn't do this yet
	Often	14 (18.4%)	1 (1.3%)	0
	Sometimes	4 (5.3%)	1 (1.3%)	0
	Often	15 (10.9%)	1 (0.7%)	0
	Sometimes	12 (8.8%)	3 (2.2%)	0
	Seldom	0	1 (0.7%)	0
	Never	0	1 (0.7%)	0

Note: Percentages in parentheses are percentages of each risk group.