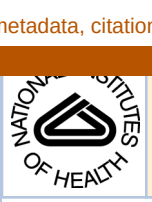

Published in final edited form as:
Autism. 2013 September ; 17(5): 527–540. doi:10.1177/1362361312439633.

The First Year Inventory: A longitudinal follow-up of 12-month-olds to 3 years of age

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Abstract

The First Year Inventory (FYI) is a parent-report measure designed to identify 12-month old infants at risk for autism spectrum disorder (ASD). The FYI taps behaviors that indicate risk in the developmental domains of sensory-regulatory and social-communication functioning. This longitudinal study is a follow-up of 699 children at 3 years of age from a community sample whose parents completed the FYI when their children were 12 months old. Parents of all 699 children completed the Social Responsiveness Scale – Preschool version (SRS-P) and the Developmental Concerns Questionnaire (DCQ) to determine age 3 developmental outcomes. In addition, children deemed at-risk for ASD based on liberal cut points on the FYI, SRS-P, and/or DCQ were invited for in-person diagnostic evaluations. We found 9 children who had a confirmed diagnosis of ASD from the sample of 699. ROC analyses determined that a two-domain cutoff score yielded optimal classification of children: 31% of those meeting algorithm cut-offs had ASD and 85% had a developmental disability or concern by age three. These results suggest that the FYI is a promising tool for identifying 12-month old infants who are at risk for an eventual diagnosis of ASD.

Keywords

Autism screening; First Year Inventory; social-communication; sensory-regulatory

Introduction

Autism spectrum disorders (ASD)[1] are neurodevelopmental disorders diagnosed by the clinical observation of core behavioral symptoms. Recent prevalence estimates of ASD are 1 in 110 children, approximately 1% of the general population (Centers for Disease Control, 2009). Diagnosis typically does not occur until the preschool years (Howlin & Moore, 1997; Wiggins, Baio, & Rice, 2006), and definitive diagnosis before age two is rare (Chakrabarti, 2005). Delayed identification of ASD results in a missed window of opportunity for early interventions, such as promoting the development of important pivotal skills in infancy (e.g., joint engagement, play) that are foundational for social relationships, academic success, and independence later in life. Thus, effective methods for early detection of risk for ASD are urgently needed.

Behavioral risk signs of ASD are evident prior to 12 months of age in many children who develop ASD (Baranek, 1999; Colgan et al., 2006; Landa & Garrett-Mayer, 2006; Osterling,

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[1]ASD refers to diagnoses including Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, and Asperger's Disorder. The use of the term autism alone refers to Autistic Disorder.

Dawson, & Munson, 2002; Zwaigenbaum et al., 2005), suggesting that earlier detection of ASD risk is possible. Although heterogeneity exists, the risk signs of infants who will eventually be diagnosed with ASD converge on two key developmental domains – social-communication and sensory-regulatory functions – that largely parallel the core deficits in older children with ASD (Frazier, Youngstrom, Kubu, Sinclair, & Rezai, 2008). By 9-12 months of age, many infants who will eventually receive a diagnosis of ASD show both the absence of typically developing social-communicative features such as shared affective engagement, imitation, social orienting, and joint attention, and the presence of unusual sensory-regulatory features such as repetitive play, sensory preoccupations, emotion dysregulation, hyporesponsiveness to novel stimuli, and atypical motor behaviors (Baranek, 1999; Garon et al., 2009; Gomez & Baird, 2005; Landa & Garrett-Mayer, 2006; Zwaigenbaum, et al., 2005).

Although this literature suggests that many children may show risk signs for ASD by 12 months of age, other research has reported that a considerable number of infants do not exhibit behaviors symptomatic of ASD during this period (Landa, Holman, & Garrett-Mayer, 2007; Werner, Dawson, Munson, & Osterling, 2005). For example, in one study examining developmental regression, 35% of parents of children later diagnosed with ASD reported that their child was asymptomatic at 10-12 months of age (Werner, et al., 2005). In addition, a prospective study with a high-risk sample of children demonstrated that 46% of children diagnosed with ASD at 24 months of age showed no obvious symptoms of ASD at 14 months (Landa, et al., 2007). These findings point to the likelihood that screening for ASD risk at very early ages would be expected to miss some children who later develop the disorder.

In recognizing the need for earlier identification, the American Academy of Pediatrics (Johnson & Myers, 2007) recommends that pediatricians conduct surveillance for ASD symptoms at each preventive care visit, and conduct specific ASD screening at children's 18- and 24-month visits. Given the presence of symptoms in at least a substantial number of toddlers by 12 months of age, and the frequent delays in referral and start to early intervention (Kalkbrenner et al., 2011; Ozonoff et al., 2010; Yirmiya & Charman, 2010), identification of children at 12 months who are at risk for an eventual diagnosis of ASD seems a worthy endeavor. A recent study showed promise having pediatricians complete a broad-band screening at 12 months with the Communication and Symbolic Behavior Scales-Infant Toddler Checklist (CSBS-ITC; Wetherby & Prizant, 2002), and found that the children identified as at-risk who later developed ASD began receiving early intervention services, on average, at 17 months of age (Pierce et al., 2011). The opportunity to begin intervention at such a young age could promote long-term positive outcomes. Most other research on early ASD screening has focused on toddlers older than 12 months (e.g., Dietz, Swinkels, van Daalen, van Engeland, & Buitelaar, 2006; Kleinman et al., 2008; Miller et al., 2011; Robins, 2001; Swinkels et al., 2006; Wetherby, Brosnan-Maddox, Peace, & Newton, 2008).

The FYI was developed as a parent-report screening tool for 12 month old infants at risk for a later diagnosis of ASD (Baranek, Watson, Crais, & Reznick, 2003; Reznick, Baranek, Reavis, Watson, & Crais, 2007) for research as well as eventual clinical purposes. It was developed specifically for 12-month-old infants because this age seems to map onto a period of critical developmental and neurobiological changes that are occurring in many infants who will eventually be diagnosed with ASD (Ozonoff, et al., 2010; Webb, Monk, & Nelson, 2001). Items on the FYI were chosen based on a comprehensive review of the literature of early behavioral risk markers and atypical features that can be detected in infants who eventually receive a diagnosis. These items are congruent with a conceptual model reflecting two developmental domains of functioning: social-communication and sensory-regulatory

functions. Thus, in comparison to the CSBS-ITC (Wetherby, et al., 2008), that measures primarily red flags for social-communication development, the FYI measures a broader range of behaviors.

Reznick et al. (2007) examined the psychometric properties of the FYI and developed a scoring algorithm based on the distribution of item scores in a normative sample of 1,496 infants from North Carolina. Factor analysis and construct shaping procedures were used to identify four constructs within the domain of Social-Communication (Social Orienting and Receptive Communication, Social-Affective Engagement, Imitation, and Expressive Communication), and four constructs within the domain of Sensory-Regulatory Functions (Sensory Processing, Regulatory Patterns, Reactivity, and Repetitive Behaviors), and to balance the extent to which questions about each of these 8 constructs contributed to an overall assessment of risk. See Reznick et al. (2007) for more details.

A second study utilized a retrospective version of the FYI (FYI-R; Watson et al., 2007) with children with ASD, other developmental disabilities, and typical development. Parents were asked to complete the questionnaire on the basis of memories of their child's behavior at 12 months of age. Results indicated that children with ASD received significantly higher risk scores than children with developmental delay (DD) or typical development. Further, more than 50% of children with ASD scored above the 99th percentile on the FYI-R risk score. Both of these studies suggest the potential of the FYI as an ASD-specific screening measure at 12 months of age, but neither study tested the predictive validity of the tool with a longitudinal sample.

The aim of the present study was to determine an effective FYI scoring cutoff for most accurately identifying infants who are at risk for a later diagnosis of ASD. This aim was met by conducting a longitudinal follow-up at three years of age of a subset of infants whose families completed the FYI at 12 months of age (Reznick, et al., 2007). Given the variability in onset patterns associated with ASD, as well as salience of early risk markers by parents, we hypothesized that only a subset of infants who eventually develop ASD would be showing behavioral risk signs at 12 months. Our aim was to establish a cutoff for the FYI risk score that would identify a majority of the infants at-risk for an eventual diagnosis of ASD while also ensuring that a high percentage of children identified would have ASD, thus minimizing false positive rates. An overarching goal of this program of research is to develop a psychometrically sound and clinically useful ASD-specific screener to augment tools used for progressive surveillance and screening of infants during well-baby checks in primary care settings. This longitudinal follow-up study is an important step in this long-term process.

Methods

Procedures and Participants

Families who participated in the FYI normative study (Reznick, et al., 2007) and who gave consent to be re-contacted were invited to participate in this longitudinal follow-up. Sample sizes and recruitment procedures are described below for two phases: the initial FYI screening mailing at 12 months of age, and the subsequent follow-up mailing at age 3 years. All research procedures were approved by our IRB. Families who participated in diagnostic evaluations also signed written consent forms. Table 1 provides the final sample's demographic information.

FYI completion at 12 months—The FYI was completed by parents of 1,305 full-term infants within a week of their child's first birthday (191 of the initial sample of 1496 were either born pre-term or did not include sufficient information on the FYI to conclude

gestational age). Families were recruited through community mailing based on North Carolina birth records (see Reznick et al., 2007, for details). At the time, no scoring algorithm had been developed to indicate high and low risk; thus, no information was communicated with families at the time about scores on the FYI. A total of 1,192 of these families signed a form indicating their willingness to be contacted for subsequent research. The specific methods and the degree to which this sample was representative of the population were discussed in detail by Reznick et al. (2007). The sample had considerable diversity, but as is typical of mailed surveys, it did represent a disproportionate number of Caucasian and highly educated families.

Follow-up procedure at 3 years—The 1,192 families who agreed to be contacted were invited to participate in the current follow-up study. Specifically, within 6 months following the child's third birthday, each family was mailed a recruitment letter, the Social Responsiveness Scale-Preschool Version (SRS-P; Pine, Luby, Abbacchi, & Constantino, 2006) and the Developmental Concerns Questionnaire (DCQ; Reznick, Baranek, Watson, & Crais, 2005), which asked specific questions about parent concerns and child diagnoses, along with $5 to encourage participation. In completing these questionnaires and sending them back, parents provided informed consent for this study. All families were informed in a cover letter that they might be invited to bring their child to our laboratory for a follow-up evaluation that would include diagnostic assessment for ASD. A total of 699 families responded to the mailing. All DCQs were coded to determine whether any child had a diagnosed developmental disability, including ASD, or concerns related to DD/ASD, and SRS-Ps were scored to determine level of ASD symptoms. Thus, the DCQ and SRS-P outcome results were obtained at age 3 on the entire follow-up sample of 699 children.

To validate the SRS-P and DCQ data, a subsample of children was invited to participate in a comprehensive in-person diagnostic evaluation using liberal criteria. The goal was to complete evaluations of the children most likely to have ASD. These liberal estimates of probable risk status included: (1) FYI total risk score at or above the 90th percentile; (2) SRS-P at or above a total score of 60; (3) Parents noted either a diagnosis of ASD or symptoms consistent with a diagnosis of ASD on the DCQ (e.g., symptoms in language, social, play, sensory, repetitive behavior were considered) or family history of ASD; and/or (4) Mild elevations and concerns noted across measures. In addition, a randomly selected control group, who met none of these criteria, and whose FYI scores were below the 25th percentile, was also invited to participate to ensure that the diagnostician would be blind to each child's FYI risk status.

Parents of 28 children meeting one or more of the risk criteria agreed to have their children complete the age 3 diagnostic evaluation. This reflected a subsample of the 153 children who were eligible based upon meeting one or more of the four criteria described above (See Tables 1 and 2 for a description of these children). An additional five eligible families, who were not able to participate in the in-person evaluation, provided additional detailed information about their child's diagnostic status via a follow-up mailing that requested specific information about the results of any previous diagnostic evaluations. Ten control children also completed this evaluation process, for a total of 38 diagnostic evaluations.

Diagnostic assessments: Thirty-eight families participated in the in-person diagnostic assessments conducted by a licensed psychologist (LTB), a licensed occupational therapist, and a trained research assistant. Informed consent was provided for completion of the assessment at the time of the visit. These assessments were completed an average of 103 days after parents completed the DCQ and SRS-P. To avoid biased diagnosis, the psychologist was blind to the child's original FYI score. However, to facilitate accurate assessment, the psychologist was given information about current developmental or

behavioral concerns noted by parents on the DCQ. Given that children who completed the assessment included those with high FYI scores, low FYI scores, and other current concerns (regardless of FYI score), it was not possible for the clinician to identify who were controls and who was invited specifically because of a high FYI score at 12 months. Children completed the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000). Parents completed a clinical interview and the Vineland Scales of Adaptive Behavior – Second Edition to assess early developmental history and current ASD symptoms according to DSM-IV criteria. Assessment results were communicated with families in verbal and written form. For children who were newly diagnosed by the psychologist (for either ASD or another DD), families were given referrals to appropriate early intervention services.

Measures

The FYI, SRS-P, and DCQ were completed by the entire follow-up sample (n=699). The Mullen Scales of Early Learning, the Vineland Adaptive Behavior Scale, and the Autism Diagnostic Observation Schedule were used only with the 38 children receiving further in-person diagnostic evaluations as part of validation procedures.

The First Year Inventory (Baranek et al., 2003; Reznick et al., 2007) is a norm-referenced, 63-item parent-report screening tool designed to identify 12-month-old infants who are at risk for an eventual diagnosis of ASD. The FYI measures behaviors across two key developmental domains: Social-Communication and Sensory-Regulatory functions. The FYI scoring algorithm involves the assignment of risk scores (0, 1, or 2 points) for item responses based upon frequencies in the normative sample. A quasi-logarithmic risk score ranging from 0-50 points (based on the percentile score associated with the total risk points) is generated separately for each of the eight constructs as well as the two domains. The Social-Communication and Sensory-Regulatory Domain scores are averaged to obtain a total FYI risk score. Higher scores indicate that the child's parent reported more atypical behaviors. The FYI risk score yields a percentile score to facilitate interpretation. See Reznick et al. (2007) for a complete description of the FYI scoring procedures.

The Social Responsiveness Scale- Preschool Version (Pine et al., 2006) is a 65-item rating scale completed by parents to quantify ASD symptoms. The SRS-P yields a total score, with higher scores indicative of more ASD symptoms. The SRS-P has been shown by Pine and colleagues (2006) to have strong test-retest and inter-rater reliability as well as agreement with social impairment on the ADI-R (Rutter, Le Couteur, & Lord, 2003). Items are based on the well-validated Social Responsiveness Scale, for which a cut-off T-score of 60 indicates a high probability of ASD (Constantino, 2005).

The Developmental Concerns Questionnaire (Reznick et al., 2005) is a parent-report measure that inquires about whether a parent or professional has been concerned about the child's development in any way. A series of open-ended questions are used to gather information about specific types of developmental concerns; whether, when, and by whom any evaluations have been completed; and whether and by whom any clinical diagnoses have been offered. This procedure is similar to, though somewhat more comprehensive and detailed than, methods used in other screening follow-up efforts (Baird, 2000; Kleinman, et al., 2008).

The Mullen Scales of Early Learning (Mullen, 1995) evaluate cognitive ability of children birth through 68 months of age. Children completed four scales (Visual Reception, Fine Motor, Expressive Language, and Receptive Language) that are combined to yield an Early Learning Composite (ELC), similar to an IQ, with a mean of 100 and a standard deviation of

15. The MSEL has strong psychometric properties and was used as a measure of developmental level.

The Autism Diagnostic Observation Schedule (Lord et al., 2000) is a widely used observational measure designed to assist diagnostic evaluation of ASD. It involves 45 minutes of interaction during which a child experiences a standard set of presses for social, communication and repetitive behaviors. A scoring algorithm classifies children as having "autism," "ASD," or "not ASD." Module 1 was used with nonverbal children, and Module 2 was used with children who had phrase speech.

The Vineland Adaptive Behavior Scales – Second Edition (Sparrow, Cicchetti, & Balla, 2005) is a parent interview that inquires about an individual's adaptive behavior skills. Normative scores are provided in the domains of communication, socialization, daily living, and motor skills. The VABS-2 has strong psychometric properties and is commonly used in assessment of young children with developmental disabilities.

Classification of Children

Using all information gathered from our sample of 699, we determined "best estimate" diagnostic outcomes in one of 4 categories: 1) Diagnosis of ASD, 2) Diagnosis of other developmental disability, 3) No professional diagnosis, but developmental concerns noted or observed, and 4) No developmental concerns. The categorization was based upon review of all information gathered; however, for the children who participated in a formal diagnostic assessment, those results took precedence over parent report on the DCQ. A primary rater coded all 699 DCQs, and a secondary rater coded 30%. Each child was classified in one category only; thus, if a child was classified as *diagnosed or* treated, he or she would not also be classified as *concerns only*.

The *diagnosis of ASD* included children with a diagnoses of an ASD. The *diagnosed or treated* category included children who had received diagnoses of a developmental disorder (e.g., language disorder, sensory-processing disorder, DD, but not ASD), as well as children who had received early intervention services to address developmental, language, sensory processing, or behavioral problems. The *developmental concerns* category included children whose parents reported developmental concerns about their child or who indicated that someone else (e.g., a family member) had concerns about their child, but the parents did not indicate any specific diagnosis or having received any services for specific developmental problems. The *no concerns* category included children whose parents reported that neither they nor anyone else had any concerns about their child's development, and no diagnoses or services had ever been received.

Results

Outcome classifications

Raters agreed on the classification category for 90% of the children upon review of all collected information; consensus was obtained and used for all disagreements. The sample in each outcome category is described below. Further, Table 3 presents the agreement between the DCQ categories, SRS-P scores, and clinical diagnosis.

ASD Outcomes

A total of 9 children with ASD (autism=6; PDDNOS=3) were identified in this sample of 699 3-year-olds. Six of these children were confirmed by our team's diagnostic evaluation and met threshold for ASD on the ADOS (Three of these children had previous diagnoses from other professionals, and three were newly diagnosed.) An additional three children

who did not participate in the evaluation were identified through parent report via the DCQ or the follow-up mailing, which indicated that the child had received a diagnosis of ASD by a licensed professional (i.e., two through school systems, one by a pediatric neurologist). Thus, these 9 children with ASD represent 1.3% of our sample of 699 children on whom we collected follow-up data. See Table 4 for more detailed information about these 9 children.

Non-ASD Outcomes

A total of 43 from our sample of 699 children (6%) were in the *diagnosed or treated* group, as they had been diagnosed with, and/or treated for, non-ASD developmental problems. An additional 82 of 699 (12%) children were in the *developmental concerns* group, indicating parents reported some concern or that a professional had noted some concern about the child, yet they had not yet been diagnosed, or a diagnosis had been ruled out. Finally, 574 of 699 (82%) of the children were in the *no concerns* group. In all cases, parents reported having no concerns about their child's development, no history of a developmental disability diagnosis or intervention, and no professional concerns about their child.

Determination of FYI Cutoff Scores to Predict ASD Diagnosis

Total FYI cutoff score—Receiver Operating Characteristic (ROC) analyses were conducted to determine how well the FYI risk score predicted diagnostic outcome. For this analysis, outcome categories were collapsed into two: ASD and no-ASD. This analysis allowed examination of how accurately children with and without ASD were classified with all possible FYI scores. Next, false positive and false negative rates were calculated. Using this method, a total risk score (i.e., the average of the social communication and sensory-regulatory domains) of 19.2, which is at or above the 96th percentile, was chosen as the best cutoff score. A total of 29 children met this cutoff. Four of those 29 had a confirmed ASD, indicating 14% of children who screened positive on the FYI at 12 months using this total score cutoff developed ASD (PPV = .14). Further, 4 out of 9 (44%) children identified with ASD met the total score cutoff, indicating that approximately half of children who developed ASD were identified as at-risk by the FYI at 12 months. The overwhelming majority of children who did not have ASD at age 3 (665/690, or 97%) screened negative on the FYI at 12 months, and, similarly, the overwhelming majority of children who screened negative on the FYI did not have a diagnosis of ASD at age 3 (665/670, or 99%). Given that our determination of diagnostic outcome of the full sample of 699 was not based upon in-person evaluation of all 699 children, the psychometric estimates of the FYI presented here and in the following paragraph should be considered preliminary in nature.

Two-domain FYI cutoff score—Based on the conceptual model of the FYI, symptoms in both the Social-Communication and Sensory-Regulatory Domains are considered to be central to determining early risk for an eventual diagnosis of ASD. To explore this perspective, we conducted a second ROC analysis to calculate the optimal cutoffs separately for each of the two FYI domains. For the Social-Communication Domain, a domain score of 22.5, which is at the 94th percentile, yielded the optimal classification of children with ASD at age 3. For the Sensory-Regulatory Domain, a score of 14.75, which is at the 88th percentile, yielded optimal classification of children with an ASD diagnosis at age 3. Using each domain score separately did not improve upon optimal classification over the FYI total score: 40 children met the cutoff for the Social-Communication domain and 70 for the Sensory-Regulatory domain, suggesting increased false positives (PPV = .1 and .06, respectively).

Finally, we examined the number of children in our sample who met the cutoff criteria for both domains. Results indicated that only 13 children met this two-domain criterion, and that 4 of those 13 had ASD, for a PPV of .31 in this sample. Other rates of classification were

nearly identical to the total score cutoff, with 44% of children with ASD screening positive on the FYI, 99% of children who screened negative not having ASD, and 99% of children without ASD screening negative on the FYI. The two-domain scoring criterion was an improvement over using a total FYI score criterion because it maintained the same level of sensitivity for this sample while decreasing considerably the rate of false positive screens.

Examination of the false positive rates was important to determine what characteristics were associated with an at-risk status at 12 months in the absence of a confirmed diagnosis of ASD at age 3. With the total risk cutoff score at the 96th percentile, we identified 24 false positives (3%) in the full sample of 699 children, with false positives defined as children who did not have ASD. Approximately 65% of these 24 children had other developmental diagnoses or concerns besides ASD at age 3. Using the more stringent two-domain criterion yielded only 9 false positives in this sample. The majority (7/9 or 78%) of these children with a false positive designation had a documented history of a developmental disorder or parental concerns about their development at age 3. Thus, 85% of children who met the two-domain cutoff at 12 months had ASD, another diagnosed developmental disability, or concerns about a developmental disability at age 3.

Examination of the false negative rates in our sample was important so that we could determine which children who eventually received a diagnosis of ASD were not detected by the FYI at 12 months. As shown in Table 4, the same five children (# 3, 4, 5, 6, and 9) were missed with both scoring criteria (i.e., total risk score and the two-domain cutoffs). Three of these children (#5, 6, and 9) scored below the 25th percentile on the Sensory-Regulatory domain. Those same three children also scored below the 75th percentile in the Social-Communication domain and below the 40th percentile on the total FYI score. The other two children showed mildly elevated scores in both domains, with total FYI scores at the 76th and 77th percentiles. However, these children were not necessarily less impaired on developmental measures at age 3 than the children designated as true positives.

Discussion

This study is the first to assess the utility of using a parent-report instrument mailed to a community sample to identify 12 month-old infants who are at risk for an eventual diagnosis of ASD. In addition, this longitudinal study uniquely provides follow-up to three years of age of children initially screened at 12 months of age regardless of their risk status on the FYI, thus allowing classification estimates for 699 children. Results indicated that a scoring algorithm that defined risk on the basis of meeting separate cutoffs in both the Social-Communication and Sensory-Regulatory Domains of the FYI identified 44% of infants at 12 months who received a diagnosis of ASD by 3 years, and that 31% of 12 month-olds meeting the two-domain criterion received an ASD diagnosis by 3 years. In total, 85% of infants who met the two-domain cutoff at 12 months of age experienced some developmental challenges that warranted evaluation and/or services by age 3. This rate is comparable, if not slightly higher than rates presented by Pierce et al. (2011), who reported that 20% of positive screens on the CSBS-ITC at 12 months developed ASD and 75% had some form of DD at age 2. Given the very early age at initial FYI screening and the amount of time between the FYI screening and diagnostic confirmation (i.e., ~2 years), these findings are encouraging and suggest promise in the approach of using parent report of infant behaviors as a tool for identifying 12 month-olds who are at risk for an eventual diagnosis of ASD. However, the findings are also not definitive given the small sample and number of children identified with ASD, and the scoring cutoff requires validation in an independent sample to assess its clinical utility.

Nearly half (4/9) of the children with ASD at age 3 met risk cut-offs on the FYI at 12 months. This rate is consistent with reports of the proportion of children with ASD who exhibit early onset of observable symptoms (Landa et al., 2007; Ozonoff et al., 2010; Werner et al., 2005). Specifically, several studies indicate that between 35% and 46% of children with ASD have "late onset" of symptoms (Landa et al., 2007; Werner et al., 2005), and recent prospective research has shown that developmental regression is likely occurring in a large proportion of children with ASD after 12 months (Ozonoff et al., 2010). Possible explanations of missed cases at 12 months of age, then, are (a) that no behavioral indicators have emerged in some children; (b) that researchers have not yet identified all of the key behavioral indicators at 12 months of age that predict an eventual diagnosis of ASD; and/or (c) researchers have not yet found a way to reliably tap parental report for key behavioral indicators. Additional research is needed to identify other behaviors that may be risk signs and to help parents recognize and identify these behaviors in their own infants.

These results do suggest that many children with eventual diagnoses of ASD may be missed at 12 months. A negative screen on the FYI at 12 months, for example, could not be considered an indication that future screening is unnecessary. Rather, continued surveillance and screening for ASD would be encouraged at multiple points in development given the heterogeneity in characteristics and developmental course present in this population. Future research is needed to determine how the FYI and comparable tools could fit into ongoing surveillance and screening efforts for ASD, an important area for all autism screening research (Dawson, Fein, Rogers, & Zwaigenbaum, 2011).

One concern with screening at such a young age is the rate of false-positives – e.g., how many children will be falsely identified as being at high risk. That 31% of FYI positive screens developed ASD by age 3 and 85% developed ASD or other developmental concerns was encouraging in this study. These results indicate that an overwhelming majority of children who screen positive on the FYI indeed experience some delay in development by age three that may warrant early intervention. This lack of autism - specificity at such a young age is not entirely surprising, and is consistent with other tools at this age. It is encouraging that a false-positive screen, for the most part, would not alarm parents unnecessarily as their child likely would have some form of developmental concern warranting intervention services.

What is the potential utility for the FYI? A screening tool that identifies approximately half of the children from a community sample at 12 months of age who are at high risk for an eventual diagnosis of ASD theoretically has considerable benefits. At a minimum, early identification at this rate can fuel research. For example, the FYI could be used to recruit a community sample that is at even higher risk of an eventual diagnosis of ASD than infants who have a sibling with ASD, where rates are approximately 10% (Constantino, Zhang, Frazier, Abbacchi, & Law, 2010), and would provide the opportunity to study a different subpopulation of infants at-risk—i.e., those without high genetic liability. This method could also promote further neurodevelopmental and clinical research on early symptoms as well as the development and evaluation of the efficacy of early intervention and prevention programs.

There are potential clinical uses for the FYI as well. Current recommendations by the AAP include autism-specific screening beginning at 18 months, but also include ongoing surveillance throughout early childhood. Thus, the FYI may eventually be useful in these settings. The scoring cutoff for the FYI must first be validated to provide true estimates of sensitivity, specificity and positive predictive value. In addition, the FYI in its current form may need to be shortened to increase its clinical utility. Current research has demonstrated that follow-up by physicians is often low in early autism screening, thus there are many

challenges when considering new or younger screening (e.g., Dietz et al., 2006; Miller et al., 2011)

Each of these goals is part of our ongoing research. Identification of children at risk for ASD at 12 months could provide a substantial number of children and their families with access to intervention services months or years before they would otherwise receive a traditional diagnosis. In addition, our results suggest that the FYI is effective in identifying some children who will eventually have a diagnosis of ASD and who do not have concomitant severe DDs (based on evaluations at three years of age), and thus may not be identified by more general developmental screenings. The long-term benefit of such early access to clinical services could be to optimize child outcomes, alleviate family stress, and limit the long-term economic burdens on society (Ganz, 2007; Jarbrink, McCrone, Fombonne, Zanden, & Knapp, 2007).

In summary, this longitudinal study demonstrates that the FYI shows promise for screening at 12 months of age and may “add value” to existing research methods and eventually, ongoing surveillance and screening efforts for ASD. There are limitations to this study that warrant consideration. First, this study was not designed as an epidemiological study. The original FYI norms were developed on a sample of 1,305 infants, some of whom did not give consent for follow-up contact and/or respond to our follow-up mailing at age 3. Thus, our final follow-up sample included just over half of the original cohort of children whose parents completed FYIs at 12 months of age. It is not known to what extent the attrition rate may have affected our absolute prevalence rates. Furthermore, the families who participated in our study tended to be more educated and less racially diverse than the general population. We were encouraged that the rate of ASD in our sample of 699 (1.3%) is well within the range of prevalence rates reported in recent research (Rice et al., 2010). Nevertheless, it is probable that there are additional unidentified children with ASD in the portion of the sample who did not respond to our 3-year-old follow-up mailing. It is also probable that there are unidentified children with ASD among the families who did respond to our age 3 follow-up mailing but were missed by our measures. More comprehensive in-person diagnostic evaluations with a clinician blind to the full range of initial FYI scores for all children in a community-based sample would be ideal to confirm outcomes, and completing only 38 in the present study was a limitation. Feasibility of such large-scale diagnostic protocols continues to be a major limiting factor, and has no precedence in ASD research studies to date.

Despite these limitations, this longitudinal follow-up study demonstrates that the FYI holds promise as a tool for identifying 12 month-olds who are at risk for an eventual diagnosis of ASD. Ongoing research involves creating a revised version of the FYI that is more feasible for use in primary care settings with a broader age range of children as well as using the FYI as a means to identify children at risk in the context of efficacy studies of early intervention programs.

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Table 1

Demographic Characteristics of Total Sample

Samples	Sex (% male)	Maternal race (% Caucasian)	Maternal Education (% who attended college)
Age 3 mailing N = 1,192	50%	87%	88%
Age 3 sample who returned mailing (DCQ/SRS-P) N = 699	49%	91%	91%
Met one or more eligibility criteria for age 3 diagnostic evaluation (includes controls) n = 153	57%	89%	84%
Completed in-person diagnostic evaluation or provided additional parental report n = 43	58%	98%	95%

Table 2

Description of Children Invited for In-person Diagnostic Evaluation[a]

Reason for invitation	Number who met criteria	Number who completed evaluation	Number who provided additional parental report	Number with confirmed ASD
FYI score >= 90%	64	18	4	4
SRS-P Score >= 60	12 (4)[b]	5	1 (4)[b]	5 (2)[b]
Mild elevations on FYI or SRS-P or DCQ report of ASD symptoms/dx./fam. hx.	77	5	0	0
TOTAL	153[b]	28	5[b]	9[b]

[a]Does not include children brought in as controls; none were diagnosed with ASD or any other developmental disorder.

[b]Numbers in parentheses indicate additional children who met both FYI >= 90% and SRS-P >= 60

Table 3

Clinical diagnosis, DCQ and SRS-P agreement

Developmental Concerns Questionnaire Categories		
Parents report no concerns about their child's development		
SRS-P range	Confirmed clinical outcomes (of 43) *	Total n (of 699)
SRS-P < 28	15/15 (100%) No clinical dx.	437 (63%)
SRS-P 28 - 59	8/9 (91%) No clinical dx	149 (29%)
	1/9 (11%) PDDNOS	
SRS-P >=60	N/A	1 (< 1%)
Parents report some concerns about their child's development		
SRS-P range	Confirmed clinical outcomes (of 43) *	Total n (of 699)
SRS-P < 28	1/2 (50%) No clinical dx.	36 (5%)
	1/2 (50%) Dx. of Expressive Language Disorder	
SRS-P 28 - 59	2/2 (100%) No clinical dx.	32 (5%)
SRS-P >=60	2/4 (50%) Autism	7 (1%)
	1/4 (25%) PDDNOS	
	1/4 (25%) Cerebral palsy	
Parents report their child has been in early intervention or has an established diagnosis of a developmental disability		
SRS-P range	Confirmed clinical outcomes (of 43) *	Total n (of 699)
SRS-P < 28	N/A	15 (2%)
SRS-P 28 - 59	2/5 (40%) Global DD	15 (2%)
	1/5 (20%) No current dx.	
	1/5 (20%) Fine Motor Delay	
	1/5 (20%) PDDNOS	
SRS-P >= 60	4/6 (67%) Autism	7 (1%)
	1/6 (33%) No current dx.	
	1/6 (33%) Sensory processing disorder	

* Confirmed clinical outcomes for 43 children who completed in-person diagnostic evaluation or provided detailed follow-up information about clinical diagnoses

Table 4

Characteristics of Children with ASD Diagnoses

Case #	Sex	Age (mos.) at dx. [a]	FYI %ile	FYI Social-Comm %ile	FYI Sensory-Reg %ile	SRS-P Total score	Mullen ELC	ADOS Algorithm Classificat ion	Clinical Dx.
1[b]	M	45	100	100	97	54	104	ASD[c]	PDDNOS
2	F	42	99	98	94	53	132	ASD[c]	PDDNOS
3	M	42	76	70	77	92	62	AUT[d]	Autism
4	M	42	77	80	65	79	127	ASD[c]	PDDNOS
5	M	45	42	67	24	101	52	AUT[d]	Autism
6	F	43	27	56	24	63	91	AUT[c]	Autism
7	M	40	100	95	100	91	-	-	Autism[e]
8	M	43	96	94	88	98	-	-	Autism[e]
9	F	36	38	66	24	95	-	-	Autism[e]

[a] For diagnoses based on parent report-only, this age represents the age at which parents reported their child's diagnosis was made.

[b] Highlighted rows indicate the specific children who screened at-risk on the FYI

[c] Module 2

[d] Module 1

[e] Parent report only.