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A Parent-Report Instrument for Identifying One-Year-Olds at Risk for an Eventual Diagnosis of Autism: The First Year Inventory

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Abstract A parent-report instrument, the First Year Inventory (FYI), was developed to assess behaviors in 12-month-old infants that suggest risk for an eventual diagnosis of autism. The target behaviors were identified from retrospective and prospective studies. FYIs were mailed to 5,941 families and 25% (N = 1,496) were returned, with higher return rates for white families and for families with greater educational attainment. Ad hoc groups of questions afforded measurement of eight specific constructs, which were combined to establish a general risk index. Boys had higher risk scores than did girls. Maternal race and education influenced answers. A small percentage of infants appeared to be at notably elevated risk. Large-scale longitudinal research is warranted to determine whether the FYI can predict an eventual diagnosis of autism.

Keywords Autistic symptoms; Early infant screening · Social-communication · Sensory-regulatory functions

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Introduction

Autism is a developmental disorder generally marked by severe and pervasive impairments in several areas of development, including reciprocal social interactions and communication, and the presence of repetitive or narrowly restricted behaviors (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). The term 'autism' refers to the prototypical form of a spectrum of pervasive developmental disorders that includes ''Autistic Disorder'' as well as subthreshold disorders labeled ''Asperger's Disorder'' and ''Pervasive Developmental Disorder Not Otherwise Specified'' (DSM-IV-TR; APA, 2000). We will use the term ''autism'' to refer to the broader category of autistic spectrum disorders.

Age of diagnosis for autism is quite variable, and this variability may have implications for differentiating distinct types of autism (Volkmar et al., 2004). Clinical wisdom, parental insight, and the research literature suggest that some children who will eventually have a diagnosis of autism begin to manifest symptoms during infancy (Baranek, 1999; Gillberg et al., 1990; Hoshino et al., 1987; Short & Schopler, 1988; Siegel, Pliner, Eschler, & Elliott, 1988; Vostanis et al., 1998; Zwaigenbaum et al., in press), which is consistent with Kanner's original description of the disorder (1943). Autism is sometimes diagnosed before 3 years of age, but an early diagnosis, and particularly an early, definitive diagnosis is rare (Chakrabarti & Fombonne, 2005). One reason for the delayed diagnosis is that the conventional criterion for a diagnosis of Autistic Disorder requires at least six symptoms, reflecting some degree of impairment in social interaction and communication, and some evidence of restricted, repetitive or stereotyped behavior

(DSM-IV-TR; APA, 2000). Judging the presence of many of the DSM-IV symptoms (e.g., peer relations, pretend play, stereotyped interests) requires comparisons to behaviors that are unlikely to occur even in typically developing infants, which greatly decreases the probability of a formal diagnosis of autism before 2 years of age. Other symptoms, such as repetitive movements, are highly prevalent in typically developing infants (Baranek, 1999; Thelen, 1981) and thus are not easily identified as suggesting unusual qualities before the preschool years (Lord, 1995). Second, early symptoms of autism may vary widely across individual infants and may entail behaviors that are unusual but not necessarily problematic. Infants who manifest a few unusual behaviors are less likely to be diagnosed than infants who have a disorder associated with more sharply defined and salient characteristics (Gillberg et al., 1990; Howlin & Moore, 1997). Finally, even when infants and toddlers exhibit symptoms that are consistent with autism, it is often difficult to distinguish autism per se from other childhood disorders such as mental retardation or selective language impairment (Bailey, Hatton, Skinner, & Mesibov, 2001; Siegel et al., 1988).

For a variety of reasons, it would be advantageous to identify infants who will eventually be diagnosed with autism. From a clinical perspective, evidence suggests that early treatment is particularly efficacious (Dawson & Osterling, 1997; Lord, 1995; Rogers, 1998). More broadly, parents of a child who exhibits early symptoms of autism are often frustrated because their insights and concerns about their child's behavior are not easily expressed or responded to effectively (Schall, 2000). From a research perspective, early identification of infants who will eventually have a diagnosis of autism would enable researchers to conduct prospective studies of the physiologic underpinnings and specific neuropsychological processes underlying autism, to identify developmental pathways that lead to an eventual diagnosis of autism, to describe trajectories for adaptive social outcomes, and to evaluate the efficacy of various behavioral, educational, or medical treatments.

One strategy for identifying infants who are at risk for a later diagnosis of autism is to have infants participate in a battery of behavioral and developmental procedures. For example, Zwaigenbaum et al. (2005) tested infant siblings of children with autism using the Autism Observation Scale for Infants (AOSI; Bryson, Rombough, McDermott, Brian, & Zwaigenbaum, unpublished) in order to identify specific aspects of behavior and temperament that can be measured at 12 months and that predict an eventual diagnosis of autism. Stone and Lemanek (1990) used the Screening Tool for Autism in Two-Year-Olds, a set of 12 play-like interactions, to identify 24- to 36-month-old children in need of further diagnostic testing for autism. The advantage of a laboratory context is that data can be collected using standardized procedures at several points over time, with these procedures designed to evoke specific behaviors that are considered relevant for a diagnosis of autism (e.g., imitation, joint attention, pretend play, disengagement and shifting of visual attention). Moreover, behavior can be videotaped and coded subsequently using intensive, reliable observational techniques. The disadvantage of a laboratory context is that it is labor intensive, requiring extensive commitment from participating families as well as provision of trained staff and laboratory facilities. Although some infants will exhibit their typical behaviors in a laboratory context, other infants will be affected by travel or by being in an unusual context per se. Finally, it is not clear at present exactly what behaviors in very young infants predict an eventual diagnosis of autism.

From a research and public health perspective, it would be advantageous to identify infants who are at risk for an eventual diagnosis of autism using a more cost-effective method. A prime strategy for this surveillance is the use of a parent-report format (e.g., Charman, Swettenham, Cox, Baird, & Drew, 1998; Robins, Fein, Barton, & Greene, 2001). Effective use of parent report for assessment of infant behavior requires recognizing both the strengths and weaknesses inherent in this technique. The strengths of parent report are that parents are privileged and highly motivated observers of their infant's behavior, with most parents engaging in vast amounts of contact with the infant across varied situations and noticing virtually every facet of the infant's actions and emotions. An additional strength of parent report is that it can be evoked through the use of a questionnaire, which can be administered in various convenient contexts including via the mail. One weakness of parent report is that most parents have a very limited comparison sample, which makes it difficult for them to rate their child's behavior within a relative frame. Because evaluative judgments in this context are likely to be egocentric, with optimal often defined as one's own child's behavior, effective questionnaire items must be framed with clear referents and relatively objective response alternatives.

Researchers have developed a number of observer-report and parent-report instruments for assessing behaviors in infants and toddlers that can be used to calculate risk for an eventual diagnosis of autism (see Bryson, Rogers, & Fombonne, 2003; Filipek et al., 1999; Gillberg, Nordin, & Ehlers, 1996; Goin & Myers,

2004; Watson, Baranek, & DiLavore, 2003; Zwaigenbaum et al., in press, for reviews of the literature). For present purposes, we seek a measure that focuses on 12-month-olds and that detects risk for autism in a community sample rather than differentiates a diagnosis of autism within a group of children who are at risk for developmental disorders. By convention, the term ''level one screening'' refers to the identification of children in the general population who are at risk for atypical development, and ''level two screening'' refers to the specific differentiation of autism from other types of developmental delay (Filipek et al., 1999; Siegel et al., 1988). Our goal is intermediate between these two levels: we seek to identify one-year-old children in the general population who are at risk for atypical development and additionally, to highlight children whose risk patterns seem most suggestive of eventual autism.

The present effort can be contrasted with its nearest neighbor, the Modified Checklist for Autism in Toddlers (M-CHAT) developed by Robins et al. (2001). The M-CHAT is an extension of the Checklist for Autism in Toddlers (CHAT: Baron-Cohen, Allen, & Gillberg, 1992). The CHAT is designed to identify signs of autism at 18 months. It includes nine parent-report ''yes-no'' questions that assess various behaviors that could indicate autism (e.g., lack of pointing or pretend play) combined with five items that are observed by a home visitor. Although the specificity of the CHAT has been reported to be high, the sensitivity is low and thus, many children who later received an autism diagnosis were not detected during the initial screening. In contrast, the M-CHAT relies entirely on parent report on the basis of 23 ''yes-no'' questions (e.g., Does your child enjoy being swung, bounced on your knee? Does your child understand what people say?) The goal of the M-CHAT is to broaden the CHAT's symptom checklist to identify a greater range of children with autism, to have the identification based entirely on parent report, and to shift the focal age group from 18 months to 24 months in order to improve sensitivity. The narrow response range of the questions (yes-no format), the low number of questions, and the fact that field testing has been conducted with older high-risk clinical samples are among the limitations of the M-CHAT.

Our goal here is similar to the goal of the M-CHAT: we seek to develop a parent-report instrument that focuses on identifying infants who are at risk for an eventual diagnosis of autism. Unlike the M-CHAT, however, we wished to focus on a younger cohort, expand items to include behaviors that would be salient and theoretically consistent with autistic manifestations during infancy (e.g., social-communicative as well as sensory-regulatory features), and use a format that allows for a broad range of response categories (e.g., Likert scaling and multiple-choice). In addition, we sought questions that reflect child symptoms that could represent ''red-flags'' at 12 months of age (e.g., absence of typically developing behaviors, and presence of unusual symptoms), as well as parent accommodations to problematic behaviors (e.g., amount of prompting or support provided to obtain optimal child responses), because the literature suggests that these types of compensatory strategies may reflect autistic features in young children (e.g., Baranek, 1999; Kasari, Sigman, Mundy, & Yirmiya, 1988; Watson, 1998). The present report describes the development of the items in this instrument, emphasizes its content validity for its intended purpose, and presents data from a large-scale mailing to a community sample designed to explore the measure's ease of use, the functionality of specific items, and strategies for scoring.

Development of the First Year Inventory (FYI)

Our first step was to identify a list of target behaviors manifested by infants that could indicate risk for an eventual diagnosis of autism. We reviewed findings from six main sources: retrospective reports about the infancy of children who have received a diagnosis of autism (e.g., Dahlgren & Gillberg, 1989; Greenspan & Wieder, 1997; Lord, 1995; Stone & Lemanek, 1990); case studies of infants later diagnosed with autism (Dawson, Osterling, Meltzoff, & Kuhl, 2000; Sparling, 1991); analysis of early videotapes of infants eventually diagnosed with autism, including results from extensive work in our own laboratory (Baranek, 1999; Baranek et al., 2005; Eriksson & de Chateau, 1992; Osterling & Dawson, 1994); screening studies of high-risk clinical samples (Robins et al., 2001; Stone, Coonrod, & Ousley, 2000); prospective studies of infants who had an older sibling with autism (e.g., Zwaigenbaum et al., 2005); and prospective studies of a community sample (e.g., Baird et al., 2000; Baron-Cohen et al., 1996; Gillberg et al., 1990; Suqiama & Abe, 1989; Wetherby et al., 2004).

On the basis of this vast literature and current theoretical conceptualizations about autism, we generated an initial target list of behaviors that could suggest that an infant is at risk for an eventual diagnosis of autism. For ease of presentation, we have organized the behaviors into two broad categories labeled ''Social-Communication'' and ''Sensory-Regulatory Functions'' and listed them in Tables 1 and 2. The citations following each behavior are not exhaustive, but rather, point out

selected reports that have implicated that behavioral domain as potentially relevant.

We additionally included several items in the FYI that might indicate generalized developmental delay (e.g., lack of pincer grasp, lack of ability to bear weight and take steps), and general medical concerns (e.g., ear infections). These behaviors are not specific to autism, but because up to 75% of children with autism may have concomitant developmental delays or associated medical concerns (e.g., Filipek et al., 1999), these items may be useful in establishing differential diagnosis.

We then formulated questions designed to evoke parent report of the relative frequency of the target behaviors. The wording of each question was refined on the basis of group consensus and feedback from expert autism professionals as well as parents of children with autism. Three pilot mailings were conducted (using the procedure described in detail later in this article) to test successive versions of the FYI with a community sample of parents. These 117 completed FYIs were used to fine-tune the wording of questions and the response alternatives. The present version of the FYI consists of a total of 63 questions: 46 questions with response alternatives ''never'', ''seldom'', ''sometimes'', and ''often''; 14 questions with 3 or 4 ad hoc multiple choice answers; one question in which the parent selects sounds they have heard produced by the infant by circling from a list of consonants (*p, b, t, d, k, g, m, n, w, y , h, s*); and two open-ended questions about parental concerns and unusual physical or medical characteristics.

The cover page of the FYI includes the following introductory paragraph:

> No two babies are alike. We are interested in some of the behaviors that make your baby unique. There are no right or wrong answers to these questions. They are just descriptions of the range of behaviors we find in one-year-olds.

Table 1 Social-communication target behaviors relevant for autism (with selected citations)

Failure to look up or orient toward a voice when the child's name is called	Baranek (1999), Osterling and Dawson (1994) Zwaigenbaum et al. (2005)
Difficulty hearing or discriminating among different speech sounds	De Giacomo and Fombonne (1998), Gillberg et al. (1996), Ohta, Nagai, Hara, and Sasaki (1987)
Lack of use of intentional expressions, including gestures, to communicate desires, wants, or interests	Neitzel et al. (2003), Osterling et al. (2002), Wimpory, Hobson, Williams, and Nash (2000)
Lack of babbling and delay in other aspects of language development	Zwaigenbaum et al. (2005)
Lack of response to adult or child prompts or bids for social interaction	Dawson et al. (2000), Kurita (1985), Lord (1995)
Lack of monitoring the gaze of adults, and failure to orient in the direction in which an adult is looking	Baron-Cohen et al. (1996), Hoshino et al. (1982), Stone et al. (2000)
Little orientation to faces	Bernabei, Camaioni, and Levi (1998), Maestro, Casella, Milone, Muratori, and Palacio-Espasa (1999), Zakian, Malvy, Desombre, Roux, and Lenoir (2000)
Averting gaze and failing to make eye contact	Adrien et al. (1992), Mars, Mauk, and Dowrick (1998), Rogers and DiLalla (1990)
Lack of coordination of gaze with other communicative behaviors	Dawson et al. (2000), Wetherby et al. (2004)
Tendency to withdraw from people and social interactions and to prefer being alone	Adrien et al. (1992), Gillberg et al. (1990), Hoshino et al. (1982)
Lack of social interest in others or engagement in reciprocal games	Adrien et al. (1993), Dahlgren and Gillberg (1989), Zwaigenbaum et al. (2005)
Relatively little emotional expression (e.g., social smiling), including facial, vocal, and gestural channels	Adrien, Ornitz, Barthelemy, Sauvage, and Lelord (1987), Adrien et al. (1993), Gillberg et al. (1990)
Limited (or no) giving or showing of objects to another in order to share enjoyment	Mars et al. (1998), Osterling and Dawson (1994)
Little affective response to another's emotion	Charman et al. (1998), Greenspan and Wieder (1997)
Lack of imitative behaviors	Charman et al. (1998), Gillberg et al. (1990), Kurita (1985)
Lack of initiating joint attention, or pointing at objects to direct the attention of another person	Lord (1995), Osterling and Dawson (1994)
Regression, or loss of social-communicative skills or interest	Osterling, Dawson, and Munson (2002), Greenspan and Wieder (1997), Maestro et al. (1999)
Passive temperament or being undemanding of parental attention	Hoshino et al (1982), Zwaigenbaum et al. (2005)
Few vocalizations with consonants	Wetherby et al. (2004)

Table 2 Sensory-regulatory target behaviors relevant for autism (with selected citations)

Abnormal pattern, focus, intensity, or duration of gaze	Adrien et al. (1992), Dawson et al. (2000), Gillberg et al. (1990)
Difficulty visually disengaging from a target and/or shifting visual attention to a novel stimulus	Baranek (1999), Zwaigenbaum (2005)
Hyper-responsiveness to sensory (visual, somatosensory, auditory, gustatory, or olfactory) stimuli	Baranek (1999), Gillberg et al. (1990), Greenspan and Wieder (1997)
Hypo-responsiveness to sensory stimuli	Baranek (1999), Greenspan and Wieder (1997), Hoshino et al. (1982)
Sensation-seeking behaviors or unusual sensory explorations of objects	Ornitz et al. (1977), Wetherby et al. (2004), Zwaigenbaum et al. (2005)
Problems focusing eyes and/or attention on one target for appropriate periods of time	Baranek (1999), Adrien et al. (1993)
Difficulties in making transitions from one activity to another	Wetherbv et al. (2004)
Lack of regular cycles of wake/sleep/feeding or dysregulation of wake/sleep/feeding cycles	Dahlgren and Gillberg (1989), Dawson et al. (2000)
Abnormal muscle tone or posture, or clumsiness	Adrien et al. (1993), Ohta et al. (1987), Ornitz, Guthrie, and Farley (1977)
Excessive irritability or tantrums, or difficulty calming when distressed	Gillberg et al. (1990), Hoshino et al. (1987), Wetherby et al. (2004)
Intensely repetitive motor stereotypies, including hand flapping, finger mannerisms, body rocking, or other unusual motor actions	Osterling et al. (2002), Wetherby et al. (2004)
Unusual play such as preference for parts of objects, attachments to odd objects, extensive solitary play, lack of pretend play, lack of play with varied toys	Baranek et al. (2005), Stone et al. (2000), Wetherby et al. (2004)
Excessive mouthing or licking of objects, toys, or hands	Baranek (1999), Dawson et al. (2000), Hoshino et al. (1982)

> Please answer each question as it applies to your baby within the week before or after your baby's first birthday. Please answer every question and give the most accurate answer you can. Again, we are not looking for any particular answer. We just want to know how your baby behaves and responds in various ways.

Demographic questions were included regarding the baby's birth date, due date, sex, birth order, and weight at birth. Race/ethnicity was assessed for the mother and the father via six response alternatives (i.e., White, Black/African-American, Hispanic/Latino, Asian, American-Indian/Alaskan Native, and Native Hawaiian/Pacific Islander) with the instruction to check one or more for each parent. Educational attainment was assessed as ''Highest grade completed or degree obtained''. Finally, the person filling out the form self-identified as mother, father, both, or other.

The production version of the FYI (Version 2.0: Baranek, Watson, Crais, & Reznick, unpublished) was typeset by the Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill. The copyrighted FYI is available from the authors.

The Present Study

Our long term goal is to develop an effective screening tool that will be useful for researchers who want to identify 12-month-olds who are at risk for an eventual diagnosis of autism, for pediatricians who want to make efficient use of parent report as an indicator of atypical development, for clinicians who want to diagnose autism as early as possible and identify homogeneous diagnostic subtypes that could differentiate etiology or suggest specific intervention strategies for individual children, or for parents who want to allay or confirm concerns regarding their child's develop. Obviously, attainment of this goal will require surveillance of tens of thousands of children for 3–5 years and thus be extremely expensive. In the present study, we pursued several short term goals that are necessary initial steps. Specifically, we conducted an extensive mailing to a community sample and used the resulting data to explore the FYI's operating characteristics, to develop a strategy for scoring the FYI, and to describe the distribution of FYI scores in this community sample.

Method

Participants

Participating families were selected from birth records that included a zip code for an address within 20–30 miles of Chapel Hill, NC. This radius, which included a diverse tri-city urban area as well as several rural

counties, provided a population with notable heterogeneity in race and socio-economic status. Because the current version of the FYI has not yet been translated into Spanish (and North Carolina has a growing immigrant population), families were excluded if either the mother or the father self-identified as Hispanic in the birth records (19.7% of families).

Weekly mailings were instituted during 2004 and 2005, with target families selected to include a child who would be celebrating his or her first birthday in the upcoming week. The total number of eligible families was 6,304. This total was reduced by 363 due to incomplete addresses or envelopes returned by the post office as undeliverable. Of the 5,941 FYI mailings that presumably were delivered, 1,496 were completed, for a return rate of 25%.

FYIs were completed for 50.2% males and 49.8% females, which closely approaches the population values of 50.8% and 49.2%, respectively, with population values calculated on the basis of the 6,304 families eligible for participation. The infants were classified as: firstborn in a one-child family (50%), second-born in a two-child family (31%), later than second-born (16%), and a few were firstborn in a two-child family (3%). The FYI was completed by the mother for 83% of families, the father for 5%, and both parents for 12%.

Self-identified race/ethnicity and education were reported on the birth records and the FYI. Table 3 tallies the percentages for each category.

Race/ethnicity and education for the mother were almost always the same as for the father, and most FYIs were completed by mothers, so we focused on the mother's race/ethnicity and education in all analyses. Mothers who checked more than one race/ethnicity category on the FYI (1.5%) were considered black if that category was included. Mothers who self-identified as white constituted 67% of the population and 85% of the sample. Mothers who self-identified as black constituted 25% of the population and 10% of the sample. The remaining FYIs were completed by individuals from other races or who failed to specify their race (8% of the population and 5% of the sample, respectively.)

Table 3 also tallies the self-reported highest grade completed or degree obtained. Relative to the population, the sample contains a lower percentage of mothers with a high school degree or less (12% vs. 26%) or with less than a college degree (11% vs. 19%), and a higher percentage of college graduates (39% vs. 30%) and post-graduates (36% vs. 25%). Table 3 cross-references race/ethnicity with education for the population and the sample. As would be expected given the demographics of this area, the white population was more highly educated, and 51% of the black population reported only high school education or less. The relatively high percentage of post-graduate education reported for the ''other or unspecified'' category was attributable to a large number of highly educated individuals of Asian descent.

The response rate in Table 3 is somewhat underestimated because the birth records with undeliverable addresses could not be matched to their demographic category, but it does reflect a true response rate from a broader ''population'' perspective. Notably, the response rate for the white families was much higher than the response rate for the black families (30% vs. 9%), and was lower for individuals who had gone no further than high school (11%) or had not completed college (14%) and higher for college graduates (31%) and post-graduates (34%). The effect of education was relatively similar across white and black families, but the percentage of participating families was only 10%

Table 3 Race and education of population and sample

Race		Education—*N* and (% of row in that category)					Total—*N* and (% of column in that category)
		Missing	H.S. or less	Some college	College graduate	Some post-graduate	
White	Population	8	765 (18%)	709 (17%)	1,508 (36%)	1,231 (29%)	4,221 (67%)
	Sample	26	119 (9%)	124 (10%)	526 (37%)	473 (32%)	1,268 (85%)
	Response rate		16%	17%	35%	38%	30%
Black	Population	4	800 (51%)	382 (24%)	239 (15%)	150 (10%)	1,575 (25%)
	Sample	6	52 (37%)	36 (25%)	29 (20%)	20 (14%)	143 (10%)
	Response rate		7%	9%	12%	13%	9%
Other or unspecified	Population	4	55 (11%)	78 (15%)	160 (32%)	211 (42%)	508 (8%)
	Sample	2	6 (7%)	7 (8%)	27 (31%)	43 (51%)	85 (5%)
	Response rate		11%	9%	17%	20%	17%
Total	Population	16	1,620 (26%)	1,169 (19%)	1,907 (30%)	1,592 (25%)	6,304
	Sample	34	177 (12%)	167 (11%)	582 (39%)	536 (36%)	1,496
	Response rate		11%	14%	31%	34%	24%

for black college graduates and post-graduates. This pattern of participation indicates that education and ethnicity influence even a relatively simple and benign request for health-relevant data about a child's development. This fact has implications for designing effective strategies to obtain normative data using an untargeted mailing of a parent-report instrument.

FYI Packet

The FYI packet included a cover letter with an explanation of the study, instructions for participation, and details regarding confidentiality, risks and benefits, and contact information. A response form allowed families to agree to be invited to participate in possible subsequent research. Parents also had the opportunity to be entered in a ''thank you drawing'' to win $100 (awarded monthly). The FYI and response form were returned via Business Reply Mail.

Excluded Data

Most parents complied with the request to complete the FYI ''within the week before or after your baby's first birthday'': the median difference between ''Date filled out'' and ''Baby's birth date'' was 365 days. However, inspection of the distribution of number of days revealed that some parents procrastinated and completed the FYI weeks or months after their child's birthday. It is impossible to determine whether these parents were successfully adopting a retrospective frame, so we eliminated data from the 39 families (3%) who completed the FYI more than 4 weeks after the child's birthday.

A second issue involved interpreting the data from preterm infants. Most parents provided a due date, so gestational age at birth could be estimated using the number of days between the baby's birth date and due date. The modal number of days was 0, but the median was –4 days and the mean was –6.4 days, indicating delivery before the due date for a large number of infants. We set the criterion for prematurity as a delivery date entailing less than 37 completed weeks of gestation. From this perspective, the rate of preterm birth in the present cohort was 12%, which is close to the national average of 12.3% (Martin, Kochanek, Strobino, Guyer, & MacDorman, 2005). Preterm infants are unlikely to have attained normative age-related milestones at 12 months, so they were eliminated from the analyses. Specifically, we dropped FYIs for 166 infants who were born more than 21 days before their due date. This constraint also eliminated most infants who were relatively small: all of the infants whose birth onset was within range for the normative sample weighed 4 lbs. or more at birth. Subsequent research will be needed to establish age-appropriate FYI norms for 12-month-olds who were delivered before term, and a community sample of 11-month-olds would seem to be a good source for these norms.

Among the 39 FYIs eliminated due to late completion and the 166 FYIs eliminated due to preterm birth, nine of these FYIs were eliminated on the basis of both the lateness exclusion and the preterm exclusion. The final sample included data from 1,300 FYIs.

Results

Because of the large sample size, a relatively stringent criterion for statistical significance was adopted for all tests. Effects in analyses of variance and in correlations were deemed significant only if p was less than .01. We will first describe how we scored the FYI and then compare groups on the basis of sex, birth order, race/ethnicity, and education. Finally, we will explore the characteristics of children who seem to be at highest risk and describe a strategy for portraying profiles of individual children.

Scoring Procedures

Overall Score

Table 4 summarizes the distribution of responses to each question with response alternatives: Never, Seldom, Sometimes, and Often, and Table 5 summarizes the distribution of responses for the multiple-choice questions.

One indication of the FYI's ease of use is the lack of missing data. All but five questions had responses from 99.5% or more respondents, which suggests that the FYI questions have considerable clarity. Questions 33 and 40 had 2% missing data, which suggests that parents may not notice some subtle aspects of vision. Questions 47, 49, and 58 had 1% missing data, which could indicate possible limitations in the range of multiple-choice alternatives for these questions.

In order to compare and combine across items, the response alternatives on selected items on questions 1–46 were transposed such that typical behaviors were aligned as the left-most columns (''sometimes'' or ''often'') and atypical behaviors were aligned as the right-most columns (''seldom'' or ''never''). For

Table 4 Response distribution (%) for each FYI item on ''Never'', ''Seldom'', ''Sometimes'', and ''Often'' Questions

	Never	Seldom	Sometimes	Often
1. Looks when name is called	<1[b]	1[b]	8[a]	91
2. Bothered by loud sounds	8[a]	39	46	7[a]
3. Overly sensitive to touch	64	31	5[a]	<1[b]
4. Excited when knows what will happen next	<1[b]	<1[b]	8[a]	92
5. Trouble hearing	94	5[a]	1[b]	<1[b]
6. Avoids looking at you	53	30	15[a]	2[b]
7. Looks at your face for comfort	1[b]	6[a]	40	53
8. Ignores loud or startling sounds	34	42	21	3[b]
9. Spits out certain textures of foods	11	25	48	16[a]
10. Turns to look at pointed out object	1[b]	4[b]	39	56
11. Plays alone for an hour or more	27	29	31	13[a]
12. Looks at people when they talk	<1[b]	3[b]	44	53
13. Rocks body back and forth over and over	54	24	15	7[a]
14. Looks up from play when shown new toy	<1[b]	2[b]	39	59
15. Upset when switching activities	7	35	53	5[a]
16. Easy to understand baby's expressions	<1[b]	1[b]	14[a]	85
17. Presses against things	38	27	24	11[a]
18. Smiles when looking at you	<1[b]	<1[b]	9[a]	91
19. Tries to get your attention to show things	7[a]	16	40	37
20. Tries to get your attention for interactive games	5[a]	15	41	39
21. Tries to get your attention to obtain toy	2[b]	9[a]	32	57
22. Tries to get your attention for physical games	10[a]	23	40	26
23. Body feels loose or floppy	81	14[a]	4[b]	1[b]
24. Imitates mouth sounds	1[b]	4[b]	32	63
25. Imitates body movements	<1[b]	2[b]	23	75
26. Imitates activities with objects	<1[b]	1[b]	22	77
27. Difficult to calm when upset	20	62	17	1[b]
28. Sleeping and waking patterns are regular	1[b]	4[b]	20	75
29. Tries to get attention by sound and gaze	1[b]	4[b]	30	65
30. Repeats simple activity over and over	36	45	16	3[b]
31. Seems interested in other babies	<1[b]	5[a]	28	67
32. Babbles	<1[b]	1[b]	8[a]	91
33. Enjoys staring at bright lights	49	32	15[a]	4[b]
34. Uses communicative gestures	<1[b]	3[b]	12[a]	85
35. Responds to ''Where's ___?''	4[b]	10[a]	35	51
36. Uses pincer grip	<1[b]	1[b]	5[a]	94
37. Gets stuck on playing with a part of a toy	14	32	39	15[a]
38. Uses finger to point at things	12[a]	18	24	46
39. Plays or communicates less than in the past	80	14	5[a]	1[b]
40. Eyes line up when looking at object	1[b]	1[b]	3[b]	95
41. Regular feeding patterns	1[b]	2[b]	19	78
42. Enjoys rubbing or scratching objects	49	34	13[a]	4[b]
43. Body gets stuck in positions or postures	70	23	6[a]	1[b]
44. Enjoys making objects spin over and over	32	33	27	8[a]
45. Enjoys kicking feet over and over	42	33	19	6[a]
46. Stares at fingers while wiggling them	32	35	27	6[a]

[a] 1 risk point, [b] 2 risk points

questions 47–60, typical behaviors were aligned as the ''a'' or ''b'' response and atypical behaviors were aligned as the ''c'' or ''d'' response. The categorical responses were then translated into an ordinal scale, with 1 representing the typical response alternative and 3 or 4 representing the atypical response alternative. Atypical responses on question 2 (bothered by loud sounds) and question 51 (sensitivity to pain) fell on both ends of the response scale, so these two questions were ''folded'' to give either extreme a high score. Question 61 on the baby's use of consonants was scored as the total number of consonants produced divided by 3 and then was transposed. This formula yielded a response range between 0 and 4, with 3 or 4 as the more atypical response, and thus commensurate with the other questions.

To create an overall score on the FYI, we averaged across the ordinal response values for each question. Given the orientation of the items, a higher overall score reflects relatively atypical behavior. Cronbach's alpha

Table 5 Response distribution (%) for each FYI item on multiple choice questions

47.	a. Uses toy in same way all the time	12[a]
	b. Occasionally finds new ways to play	55
	c. Often explores new ways to play	33
48.	a. Plays with 1 or 2 special toys per day	3[b]
	b. Plays with 3–5 toys	27
	c. Plays with a large number of toys	70
49.	a. Almost always joins in new game immediately	29
	b. Joins with a little help	63
	c. Joins with a lot of help	6[a]
	d. Not interested in new games	2[b]
50.	a. Looks up from playing when shown a different toy	43
	b. Looks up if new toy moves, shakes or makes noise	54
	c. Looks up only if current toy is removed	3[b]
51.	a. Doesn't seem to notice painful experience	4[b]
	b. Reacts a little but calms quickly	93
	c. Very sensitive and cries for a long time	3[b]
52.	a. Turns toward you when you say baby's name	71
	b. Turns when name said several times	25
	c. Turns when name is loud or other sound is used	4[b]
	d. Doesn't turn when name is said	<1[b]
53.	a. Smiles and laughs in response to smile and laugh	92
	b. Smiles when touched or tickled	8[a]
	c. Smiles when swung or bounced	<1[b]
	d. Doesn't smile or laugh	<1[b]
54.	a. Sleeps 12+ hours per night	13
	b. Sleeps 10–11 h	71
	c. Sleeps 8–9 h	14
	d. Sleeps 7 or fewer hours	2[b]
55.	a. Wakes up 0 times per night	51
	b. Wakes 1–2 times	43
	c. Wakes 3 or more times	6[a]
56.	a. Walks independently	48
	b. Walks with hands held or with other aid	44
	c. Pulls to stand but doesn't walk	6[a]
	d. Doesn't pull to stand	2[b]
57.	a. Almost never gets upset	28
	b. Needs to be calmed 1–3 time per day	59
	c. Needs to be calmed 4–6 times	11[a]
	d. Needs to be calmed 6 or more times	2[b]
58.	a. Doesn't notice that sound is being imitated	<1[b]
	b. Notices sound but doesn't imitate it	11[a]
	c. Notices sound and imitates it	35
	d. Makes the sound several times	54
59.	a. Almost never keeps toy or object in mouth	29
	b. Sometimes keeps toy or object in mouth	50
	c. Often keeps toy or object in mouth	17
	d. Almost always keeps toy or object in mouth	4[b]
60.	a. Almost always looks at toy being handled	81
	b. Sometimes looks at toy being handled	19
	c. Rarely looks at toy being handled	<1[b]
	d. Almost never looks at toy being handled	<1[b]

[a] 1 risk point, [b] 2 risk points

can be interpreted as the average split-half reliability correlation across all possible splits. A Cronbach's alpha of .81 indicated impressive cohesion across the 61 questions on the FYI.

Constructs and Groups of Constructs

FYI items were developed to reflect various behaviors that could be regarded as premonitory symptoms of autism. One aspect of face validity would be for the items to be sortable into theoretically compelling constructs.

All 61 FYI items were included in an exploratory factor analysis using squared multiple correlations as prior communality estimates. The principal factor method was used to extract the factors, and this was followed by a promax (oblique) rotation. A scree test suggested at least six meaningful factors with

eigenvalues accounting for more than 5% of the variance, so six factors were retained for rotation. In interpreting the rotated factor pattern, an item was said to load on a given factor if the factor loading was .40 or greater for that factor and it was less than .40 for any other factor. Using these criteria, the first factor included eight items related to repetitive behaviors (e.g., body rocking, getting stuck in a simple activity, making objects spin). The second factor contained six items related to social-affective engagement and communication (e.g., getting your attention to show you something interesting or by using fingers to point). The third factor contained four items related to imitation (e.g., copy or imitate actions like clapping hands). The fourth factor contained four items related to regulatory patterns (e.g., sleeping, waking, and feeding). The fifth factor contained two items related to social orientation, and the sixth factor contained two items related to expressive language.

These results indicate that a cluster-based restricted model fits the present data, but the exploratory factor analysis approach highlights a small subset of the FYI items and does not establish a full complement of theoretically useful constructs. To accomplish this broader goal, we used a traditional item-total correlation approach (Nunnally, 1978), which could be labeled ''construct shaping''. Items were initially sorted into possible constructs on the basis of their thematic content (e.g., imitation, expressive communication, repetitive behavior). A Cronbach's alpha was calculated for the initial set of items in each construct group. We then inspected the correlation between each item in the construct and the construct score for the group with that particular item excluded. Items that did not have a strong positive correlation with the overall construct score (i.e., an *r* value above .30) were removed and were either assigned to another group or were deemed ''uncategorized''. When a set of coherent constructs emerged, we inspected the correlation between the score of each construct and the score of each individual item. Items were shifted to a new construct if the item fit conceptually with that construct, the correlation between that item and that construct was positive, and the net change to Cronbach's alpha was positive or negligible.

The Appendix lists the descriptive title, the Cronbach's alpha, and the items included in each of the eight constructs that emerged from the shaping process: Social Orienting & Receptive Communication; Social-Affective Engagement; Imitation; Expressive Communication; Sensory Processing; Regulatory Patterns; Reactivity; and Repetitive Behavior. The final category, labeled ''Questions Not in a Construct'' includes the nine items that did not fit with any construct. Some of the uncategorized items would have been expected to fit within a construct, and their lack of fit may indicate that the question was poorly worded. Other questions may have failed to attain construct status because they are the only question pertinent to a particular theme, or they reflect a behavior that is not directly related to autism (e.g., fine or gross motor development) but that might be helpful in establishing differential diagnosis.

Six of the eight constructs that emerged in the construct shaping analysis map onto factors from the initial factor analysis. The main difference between the bottom-up factor analytic solution and the top-down, iterative construct shaping solution is that the shaped constructs draw on more items and thus cover a broader range of behaviors. The construct shaping process is post hoc, but it reveals coherences in the data that have face validity. For example, in examining the imitation construct, we suspect that items 24, 25, and 26 cohere because they not only mention the words ''copy'' and ''imitate'' explicitly, but also they are listed in the FYI in contiguous order. Item 58 also refers to ''copy'' and ''imitate'' explicitly. Although Item 49 was designed to address Social-Affective Engagement, parents appear to interpret ''the infant's willingness to join a new game immediately or with a little help'' as an example of imitation. Similarly, on item 53, the parents who noted that their infant would smile or laugh in response to their own smile or laugh quite possibly saw this as another example of imitation. More important, the infant's tendency to smile or laugh in response to the parent's smile or laugh was related to responses on other questions that were explicitly about imitation or copying.

One constraint imposed on both approaches to identifying constructs is that each item could be assigned to a single construct only. From an alternative perspective, it would be reasonable to expect that some items might be considered theoretically relevant to more then one construct. We used the ''one construct per item'' strategy to maintain the possibility of independence among the constructs, but undoubtedly other useful constructs could be created that reconfigure the present items into equally interesting theoretically or statistically driven groupings. The present array of constructs is merely a starting point.

Construct scores were created for each infant by averaging response scores across all items in the construct grouping. Table 6 lists the correlations among the constructs.

The relation among construct scores in this matrix suggests the presence of two broad domains of

Table 6 Correlations among FYI constructs

Construct	Social-communication domain			Sensory-regulatory domain			
	Social-affective engagement	Imitation	Expressive communication	Sensory processing	Regulatory patterns	Reactivity	Repetitive behavior
Social orienting and receptive communication	.42*	.38*	.42*	.19*	.10*	.13*	.12*
Social-affective engagement		.33*	.49*	.03	.04	–.01	.04
Imitation			.35*	.12*	.03	.10*	.02
Expressive communication				.07	.03	.03	.04
Sensory processing					.18*	.30*	.38*
Regulatory patterns						.15*	.11*
Reactivity							.10*

* $p < .01$

constructs, and this was confirmed in a factor analysis on the eight constructs. The factor analysis approach described above was applied to each child's eight construct scores. The analysis revealed two distinct factors with significant eigenvalues. One domain of constructs could be labeled ''Social-Communication behaviors'' and included: Social Orienting and Receptive Communication; Social-Affective Engagement, Imitation, and Expressive Communication. The second domain of constructs could be labeled ''Sensory-Regulatory Functions'' and included: Sensory Processing, Reactivity, and Repetitive Behavior. The Regulatory Patterns construct had a sub-threshold weighting but was much more strongly aligned with the Sensory-Regulatory Function domain. The two domains of constructs were generally independent, but there was some overlap. For example, the Social Orienting and Receptive Communication construct had a significant correlation with each of the constructs in the Sensory-Regulatory Function domain. The other cross-domain relation was a weak correlation between the Imitation construct and the Sensory Processing and Reactivity constructs.

For an additional assessment of the validity of the two domains, we calculated the Cronbach's alpha across all of the questions in each domain. The values were .71 for the Social-Communication behaviors and .63 for the Sensory-Regulatory behaviors, suggesting impressive coherence across items.

Risk Scoring

Each question on the FYI probes for a behavior that has been associated to some degree with an eventual diagnosis of autism, as documented in the research and clinical literature. From this perspective, an infant who has more of these behaviors would seem to be at greater risk for an eventual diagnosis of autism. Moreover, given the low prevalence of autism, we make the additional assumption that most premonitory behaviors will be relatively rare in the general population. The FYI questions and response alternatives were pilot tested in an effort to insure that at least one response would be relatively rare and thus could function as an indicator of atypical behavior. The notably low response rate for a least one response alternative for each question in Tables 4 and 5 indicate that this goal was attained.

To translate the probabilistic data on response alternatives into a scoring scheme, we awarded the least frequent response alternative on each question one risk point. If the response was not only least frequent but also extremely unusual (i.e., the response alternative was selected by fewer than 5% of all parents), it was awarded a second risk point. The superscripts in Tables 4 and 5 indicate response alternatives that were awarded one risk point ([a]) or two risk points ([b]). Some questions offered several opportunities for receiving risk points (e.g., any response other than ''Often'' was unusual in Question 1: ''Looks when name is called''), while other questions afforded only a single point-generating option (e.g., the response ''Often'' in Question 8: ''Ignores loud or startling sounds'').

Question 61 on the baby's use of consonants was scored as follows: infants who produced three or fewer of the 12 consonants (8.1%) received 1 risk point. Infants who produced 1 or fewer of the consonants *b*, *d*, and *m* (1.4%) received an additional risk point due to the typically early acquisition of these sounds.

One strategy for defining each child's risk index would be to tally the total number of risk points accrued across the 61 specific questions on the FYI. However, this approach is problematic for two reasons. First, nine of the FYI questions did not load on any of the eight constructs, which suggests that these

questions were either irrelevant or poorly constructed. Second, as revealed in the Appendix, the constructs varied in the number of relevant questions they contained. For example, the construct Repetitive Behavior was comprised of 11 questions and Reactivity was comprised of only three questions. Given the assignment of possible risk points per question, an individual infant might attain a maximum of 16 risk points on Repetitive Behavior but a maximum of only 5 risk points on Reactivity. Thus, a simple tally of risk points could arbitrarily weight Repetitive Play as being as much as three times more relevant than Reactivity. Further research might reveal a differentiated weighting strategy that enhances the FYI's sensitivity and specificity, but for the present, we will assume that each of the eight construct domains has equal relevance.

We used a multistep process to generate a risk score that would be commensurate across the eight constructs. First, we tallied the total number of risk points accrued by each child for each construct and inspected the distribution of point totals across children (i.e., how many children received 0 risk points, 1 risk point, 2 risk points, etc. for each construct). On the basis of these distributions, a system was established for translating the risk-point total for each construct into a risk score that ranged between 0 for children who received no risk points to 50 for children whose risk-point total placed them at or above the 99th percentile on that construct. An important aspect of this risk score assignment was that it reflected a quasi-logarithmic scale, thus awarding more points to children with more unusual answers.

The distributions of total risk points varied somewhat across constructs, but a general rule of thumb for the risk score assignment was that a risk-point total near the 50th percentile received a risk score of 10, a risk-point total near the 75th percentile received a risk score of 13, a risk-point total near the 90th percentile received a risk score of 20, a risk-point total near the 95th percentile received a risk score of 30, and a risk-point total near the 98th percentile received a risk score of 40. The risk scores assigned to other risk-point totals were interpolated within this scale.

We conducted an initial check on the risk score assignment by tallying the total risk score across the 1,300 children for each construct. Most children had a score of 0 on most constructs, but scores on individual constructs could be as high as 50. When we summed these risk scores across children for each construct, we found that differences in the shapes of the distributions caused disproportionately large total scores on some constructs. In order to equate each construct's possible contribution to the overall risk score, we shifted the risk-score assignment up or down for individual constructs until we attained an acceptably low range of total risk scores across the eight constructs.

When the risk score assignments were established, the process for creating each child's risk score was straightforward: we simply averaged risk points across the eight constructs to create a risk score with a theoretical range of 0–50. Figure 1 shows the frequency distribution of risk scores, rounded to the nearest whole number. The modal risk score was 0 (10% of the sample), and most children obtained relatively low

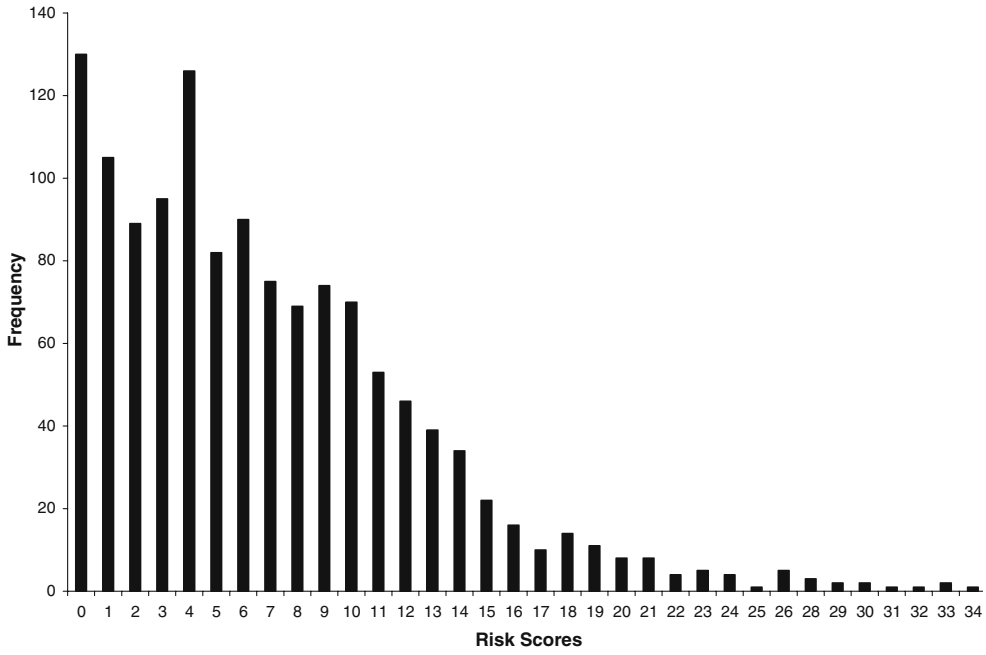

Fig. 1 Distribution of FYI risk scores

scores. The median score was 5.75, and 90% of the sample scored below 15. The shape of the distribution in Fig. 1 suggests an obvious change of inflection at a risk score of 17, which defines the upper 5% of the distribution. The risk score algorithm was designed to differentiate among children with relatively high risk, and the notable positive skew in Fig. 1 indicates that this goal was accomplished.

Group Comparisons

Sex

Boys had higher risk scores than girls, F (1, 1,291) = 10.04. This sex difference was more dramatic at the extremes: 11 of the highest 13 risk scores were assigned to boys. When we divided the risk scores into more or less equal decades, there were more boys than girls in each of the five highest decades and more girls than boys in each of the five lowest decades.

Scores across constructs were analyzed using one-way MANOVA, between-groups design. This analysis revealed a significant multivariate effect for sex, Wilks' lambda = .97, F (8, 1,284) = 5.55. One-way ANOVAs indicated significantly higher scores for boys on Social Orienting and Receptive Communication, F (1, 1,291) = 8.21, Imitation, F (1, 1,291) = 12.36, and Expressive Communication, F (1, 1,291) = 34.44.

Family Type

A question on birth order allowed us to categorize 1,243 of the children as falling into one of three family types: first born in a one-child family (51%), second born in a two-child family (32%), and later than second born (17%). The latter category was somewhat over-represented among black mothers and less educated mothers, but the present sample size is too small to allow robust analysis at that level of differentiation. From a broader perspective, there was no effect of family type on the FYI risk score. On the construct scores, first borns were perceived as less problematic on Reactivity than second borns, F (2, 1,238) = 5.39.

Race/Ethnicity and Education

Risk scores differed by mother's race, F (1, 1,192) = 10.21, and education, F (2, 1,192) = 27.87, but these main effects were subsumed by a race × education interaction, F (2, 1,192) = 12.39. Black mothers with less education rated their infants at highest risk. Across constructs, there was a significant multivariate effect for race, Wilks' lambda = .97, F (8, 1,185) = 4.66, for education, Wilks' lambda = .92, F (16, 2,370) = 6.62, and for the race × education interaction, Wilks' lambda = .97, F (16, 2,370) = 2.27. The significant effects within constructs were relatively haphazard and not notably interesting.

Profiles of Individual Children

Open-ended Questions

Questions 62 and 63 were open-ended queries about concerns with the baby's development or any unusual physical or medical characteristics. These questions tapped similar information, so they were combined for analysis. The 250 responses covered a wide range of problems such as congenital defects, growth issues, allergies, and various physical anomalies. Additional concerns were usually about eating and sleeping, and progress toward milestones of language, motor, or cognitive development and dentition. Concerns were expressed across the entire range of risk scores, with increasing concern associated with higher risk. Starting at the lowest risk score and dividing the infants at the 20th percentiles, concerns were expressed for 15%, 18%, 27%, 20%, and 28% of infants in each group. Concerns were expressed for 40% of infants in the highest 5% of risk scores.

There was no obvious qualitative difference in the types of concerns expressed for infants with higher risk scores. This finding is consistent with the premise that led to the development of the FYI—most of the behaviors that professional opinion, the research literature, and statistical norms identify as indicators of risk in 12-month-old infants are not necessarily things that concern parents. Moreover, with a sample of only 1,300 children, prevalence rates for autism, which can vary between 1:500 and 1:150 (Centers for Disease Control and Prevention, 2006) predict as few as three cases of autism in the present cohort and as many as 8. From this perspective, it is notable that parents of two infants in the highest risk group did report an autistic symptom pattern: an infant with a risk score of 21 was described as evidencing hyperactivity, low eye contact, no clapping or gestures, and poor eating; and an infant with a risk score of 28 was described as having no words, infrequent communication, poor eating, and a tendency to reject new foods.

Profile Scores

A person-oriented, diagnostic approach to characteristics of infants who might receive an eventual

diagnosis of autism would focus on each infant's configuration of symptoms. The FYI can provide this perspective when the pattern of risk scores is examined across the eight constructs described above. Table 7 lists the profiles of the 12 children with the highest risk scores.

Analysis of these cases provides a differentiated view of infant behaviors that may be useful in eventual efforts to identify and diagnose atypically developing infants and to explore theoretically and therapeutically relevant subtypes within the broad spectrum of disorders labeled ''autism''. Additionally, it is interesting to note that most of infants with high risk scores were awarded more risk points for the Social-Communication domain than for the Sensory-Regulatory domain. Within the Sensory-Regulatory constructs, scores for the highest risk infants were relatively low on Sensory Processing and Repetitive Behaviors and notably low for Reactivity. Given that risk point totals were similar across constructs, the implication is that risk on these three constructs may have clustered in other children but not the group above the 99th percentile in overall risk.

Considering race and education, the results suggest that mothers who are black or have lower educational attainment are more likely to describe their children as being at risk in the domains of Social-Affective Engagement and Regulatory Patterns, and less likely to report risk in imitation. This categorization could suggest racial differences among children, but a more likely explanation is that the two groups of mothers may have different standards for what they consider typical development. FYI norms and scoring may need to reflect these differences. These observations are hardly definitive, but the profile scores provide an interesting window that could be valuable in subsequent research.

Discussion

Our goal in this research was to assess the FYI's ease of use, explore strategies for scoring, and gather preliminary normative data. The FYI performed well on this maiden voyage. Regarding ease of use, we received no calls from parents seeking clarification or additional information, there were few notations on the returned paperwork, and there were few unanswered questions. The FYI is effective in a direct-mail context, and we are confident that if the FYI was administered in a pediatrician's office or a health department clinic as part of a well-baby visit, almost all parents would find it comprehensible and user friendly. Additional work is in progress to develop a Spanish version of the FYI.

The 25% return rate for the FYI was well within expectations for an unsolicited request for parental time and personal data, for a mailing based on addresses that were a year old, and for a parental investment that provided little promise of direct compensation. We suspect that the return rate could be increased if we expanded the use of incentives to encourage participation. The race and education effects on participation indicate that black families are particularly difficult to recruit, with additional caution if parents have not graduated from college. A successful effort to develop population norms will require a multi-faceted recruitment strategy that could

Table 7 Construct profiles of the 12 children above the 99th percentile for risk

Risk score	Demography			Social-communication domain				Sensory-regulatory domain			
	Sex	Race	Education	Social orienting and receptive communication	Social-affective engagement	Imitation	Expressive communication	Sensory processing	Regulatory patterns	Reactivity	Repetitive behavior
34.38	M	White	College	**41**	**45**	**49**	**40**	35	0	**47**	18
32.88	M	Black	HS	**47**	**43**	**41**	**43**	15	**45**	0	29
32.75	M	Black	HS	**41**	**45**	**41**	20	35	**40**	0	**40**
32.25	M	Black	< HS	**45**	**43**	20	18	**47**	**42**	0	**43**
31.13	M	Other	Post	**40**	39	**40**	0	**50**	**45**	35	0
29.5	M	Black	HS	**40**	**50**	20	**40**	0	**46**	0	**40**
29.5	F	White	HS	13	**45**	30	18	**40**	**46**	35	9
29.38	M	White	College	**40**	**49**	**46**	**45**	15	0	0	**40**
28.75	M	Black	HS	**50**	39	**41**	**43**	15	**42**	0	0
28.13	M	White	Post	30	0	**45**	20	35	**42**	35	18
28.13	F	White	Post	**43**	28	**40**	**40**	15	**46**	0	13
27.5	M	White	Post	13	0	**40**	**45**	**44**	0	35	**43**

HS = high school, College = college graduate, Post = post-college graduate degree, scores above the 98th percentile are bolded

include targeted mailings as well as distribution of the FYI in pediatricians' offices and health department clinics.

We used two approaches to quantitative scoring of the FYI. An overall score has some utility, and an iterative item-to-total correlation procedure revealed a set of theoretically sound constructs that reflect the general behavioral domains that guided our generation of specific items. Alpha coefficients were moderately low for some of these constructs, which would be expected given that most constructs had relatively few questions, but the strong face validity of the constructs is their key support. The most significant aspect of these constructs is that they may be relevant in efforts to predict autism or to differentiate among subcategories within the autistic spectrum.

An alternative approach to scoring the FYI was to assign risk points on the basis of behaviors that have been observed in infants who eventually receive a diagnosis of autism and that are notably rare in a community sample. Items and response alternatives for the FYI were constructed to provide at least one answer that could be deemed as an indicator of risk, and a general index that sums across risk points seems quite feasible. The specific criterion for defining high risk remains arbitrary, but the skewed distribution of risk scores, the prevalence of boys with extremely high scores, and the increase in parental concern for infants with high scores gives us confidence that the FYI is identifying infants with highly atypical behaviors who are at risk for an eventual diagnosis in the spectrum of developmental delays. Subsequent research will be needed to establish an absolute threshold for identifying children at risk for autism.

Finally, we described a technique for identifying individual profiles across constructs, and we explored data from open-ended questions regarding parental concerns. There is little that can be said about the effectiveness of the profiles without longitudinal data, although they do suggest an important differentiation among early symptoms. The open-ended data were consistent with our contention that higher FYI scores reflect atypical development. However, some parents who reported highly atypical behaviors did not mention any concerns. There are various reasons why parents might not be overly concerned by infant behaviors that are viewed as atypical by professionals, but from a surveillance perspective, we find it notable that many infants who are exhibiting highly unusual patterns of behavior are not triggering concern from caregivers.

The sex differences in the present data suggest that boys are at higher risk than girls. This effect is not surprising given that males are generally regarded as being four times more likely than girls to be diagnosed with autism (e.g., Chakrabarti & Fombonne, 2005; Croen, Grether, & Selvin, 2002; Yeargin-Allsopp et al., 2003) and they are also at higher risk for other developmental delays (Harmon, Contrucci, & Stockton, 1992; Marlow, Wolke, Bracewell,, & Samara, 2005).

Within the context of this community sample, we find it interesting that mothers who were black and/or less educated assigned higher risk scores to their infants. Some reports suggest that the prevalence for autism is comparable for black and white children (e.g., Yeargin-Allsopp et al., 2003), whereas others indicate an increased risk for autism in children born to black mothers (Croen et al., 2002) and disparities in early detection of autism based on ethnicity and other sociocultural factors (Mandell, Listerud, Levy, & Pinto-Martin, 2002). The present data cannot resolve this issue, particularly given the differences in response rate for mothers who are black and/or less educated. However, we note that other bases for this disparity include cultural or educational differences in parental knowledge of typical child development; parental sensitivity and/or coping with behaviors that could be construed as problematic in their infants; or differences in the home environment that might affect symptoms, particularly related to regulatory functions. This interpretation would be consistent with well established findings in general child development and temperament (e.g., Bynum & Brody, 2005; Martini, Root, & Jenkins, 2004). Whether this effect is about infants per se or about how parents answer questions remains to be seen, but future development of the FYI might include questions to assess the parent's knowledge about child development or sensitivity to the child's temperament.

Given the emphasis on early screening for autism and stepped-up national awareness campaigns (e.g., Autism Information Center, 2005), there is a need for the development of better clinical instruments to assist physicians and other health professionals in engaging in systematic surveillance, conducting early screening, and referring children who are at risk for delay for comprehensive developmental evaluations and early intervention. Likewise, prospective studies of children known to be at greater genetic risk (i.e., siblings of children with autism) may benefit from tools that can be used efficiently and cost-effectively to identify subsamples of the population who merit more careful examination for clinical and/or research purposes. Longitudinal research will be needed to determine whether the FYI constructs and risk scores will meet these needs. Likewise, large-scaled prospective studies

will be needed to establish the FYI's psychometric properties (i.e., sensitivity, specificity, positive/negative predictive value). The normative data from this study and the evidence for the FYI's validity invite and encourage these important undertakings.

Appendix

FYI Constructs

Social-Communication Domain

Social Orienting & Receptive Communication (Alpha = .55)

1. Does your baby turn to look at you when you call your baby's name?

5. Does your baby seem to have trouble hearing?

10. When you point to something interesting, does your baby turn to look at it?

12. Does your baby look at people when they begin talking, even when they are not talking directly to your baby?

14. Does your baby look up from playing with a favorite toy if you show him or her a different toy?

31. Does your baby seem interested in other babies his or her age?

35. When you say ''Where's (a familiar person or object)?'' without pointing or showing, will your baby look at the person or object named?

50. What do you typically have to do to get your baby to look up from playing with a favorite toy?

a. Just show him or her different toy.
b. Move, shake or make a noise with the different toy.
c. Take the favorite toy away and give your baby the different toy.

52. 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.

Social-Affective Engagement (Alpha = .66)

4. During familiar games like ''I'm gonna get you,'' does your baby get excited because he or she knows what will happen next?

7. In new or strange situations, does your baby look at your face for comfort?

16. Is it easy to understand your baby's facial expressions?

18. Does your baby smile while looking at you?

19. Does your baby try to get your attention to show you something interesting?

20. Does your baby try to get your attention to play games like peek-a-boo?

21. Does your baby try to get your attention to obtain a favorite toy or food?

22. Does your baby try to get your attention to play physical games, like swinging, tickling, or being tossed in the air?

Imitation (Alpha = .64)

24. Does your baby copy or imitate you when you make sounds or noises with your mouth?

25. Does your baby copy or imitate your actions, like sticking out your tongue, clapping your hands, or shaking your head?

26. Does your baby copy or imitate you when you do something with a toy or object, like shaking a rattle or banging a spoon on the table?

49. When you introduce your baby to a new game (peek-a-boo, so-big, patty-cake, etc.) how does your baby respond?

a. Almost always joins in immediately without any help.
b. Usually joins in, with a little help.
c. Joins in only with a lot of help
d. Doesn't seem very interested in new baby games.

53. What do you typically have to do to get your baby to smile or laugh at you?

a. Smiling and laughing is enough.
b. Usually need to touch and tickle.
c. Usually need to swing and bounce.
d. Your baby doesn't do this yet.

58. If you start a game by copying or imitating a sound your baby makes, what does your baby typically do?

a. Doesn't seem to notice the sound.
b. Looks at you, but doesn't make the sound.
c. Looks at you and makes the sound.
d. Plays the game, making the sound several times.

Expressive Communication (Alpha = .45)

29. Does your baby try to get your attention by making sounds and looking at you at the same time?

32. Does your baby babble by putting sounds together, such as 'ba-ba', 'ga-ga-ga', or 'ba-dee'?

34. Does your baby use gestures such as raising arms to be picked up, shaking head, or waving bye-bye?

38. Does your baby communicate with you by using his or her finger to point at objects or pictures?

61. Number of consonants produced.

Sensory-Regulatory Functions Domain

Sensory Processing (Alpha = .38)

3. Does your baby seem overly sensitive to your touch (for example, fuss or pull away when you touch him or her)?

6. When you and your baby are facing each other, does your baby turn his or her eyes to avoid looking at you?

9. Does your baby spit out certain textures of foods, such as lumpy or chunky pieces?

17. Does your baby forcefully press his or her face, head, or body against people or furniture?

23. When your baby is awake and you pick him or her up, does your baby's body feel loose or floppy?

59. When your baby is awake and not eating, does your baby keep a toy or object in his or her mouth?

a. Almost never
b. Sometimes
c. Often
d. Almost always

Regulatory Patterns (Alpha = .60)

28. Are your baby's sleeping and waking patterns regular from day to day?

41. Are your baby's feeding patterns regular from day to day?

54. On a typical night, how many hours does your baby sleep?

a. 12 or more.
b. 10–11.
c. 8–9
d. 7 or fewer.

55. On a typical night, how many times does your baby wake up?

a. 0 times.
b. 1–2 times.
c. 3 or more times.

Reactivity (Alpha = .45)

15. Does your baby get upset when you need to switch your baby from one activity to another one?

27. Is it difficult to calm your baby once he or she becomes upset?

57. Which of the following best describes your baby's typical day?

a. Almost never gets upset.
b. Gets upset and needs to be calmed 1–3 times.
c. Gets upset and needs to be calmed 4–6 times.
d. Gets upset and needs to be calmed 6 or more times.

Repetitive Behavior (Alpha = .78)

11. Is your baby content to play alone for an hour or more at a time?

13. Does your baby rock his or her body back and forth over and over?

30. Does your baby get stuck doing a simple activity over and over?

33. Does your baby enjoy staring at a bright light for long periods of time?

37. Does your baby seem to get stuck on playing with a part of a toy (such as an eyeball, label, wheel or tag), instead of the whole toy?

42. Does your baby enjoy rubbing or scratching toys or objects for long periods of time?

43. Does your baby seem to get his or her body stuck in a position or posture that is hard to move out of?

44. Does your baby enjoy making objects spin over and over in the same way?

45. While lying down, does your baby enjoy kicking his or her feet over and over for long periods of time?

46. Does your baby stare at his or her fingers while wiggling them in front of his or her eyes?

48. Which of the following describes your baby's interest in toys on a typical day?

a. Plays with one or two special toys most of the time.
b. Plays with a small number of toys (3–5).
c. Plays with a large number of toys (6 or more).

Questions Not in a Construct

2. Does your baby seem bothered by loud sounds?

8. Does your baby ignore loud or startling sounds?

36. Does your baby use the first finger and tip of the thumb to pick up a very small object like a raisin or a Cheerio?

39. Do you get the feeling that your baby plays or communicates with you less now than in the past?

40. Do your baby's eyes line up together when looking at an object?

47. Which of the following best describes your baby's typical play with a favorite toy?

a. Uses the toy in more or less the same way all the time.
b. Occasionally finds a new way to play with the toy.
c. Often explores new ways to play with the toy.

51. What is your baby's usual reaction to somewhat painful experiences, like bumping his or her head?

a. Doesn't seem to notice.
b. Reacts a little but gets over it quickly.
c. Seems very sensitive or cries for a long time.

56. Which of the following best describes your baby's skill level?

a. Walks independently.
b. Walks with hand(s) held, holding a push-toy, or holding onto furniture.
c. Pulls up to stand but doesn't walk yet.
d. Does not pull up to stand yet.

60. Which of the following best describes the way your baby coordinates his or her eyes and hands while playing with a toy?

a. Almost always looks at the toy that he or she is physically handling.
b. Sometimes looks at the toy that he or she is physically handling.
c. Rarely looks at the toy that he or she is physically handling.
d. Almost never looks at the toy that he or she is physically handling.

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