

Parent Report in Identifying Autism in Infants

Lauren Peterson

A thesis submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Science in the Division of Speech and Hearing Sciences (Speech-Language Pathology).

Chapel Hill
2013

Approved by

Linda R. Watson, Ed.D.

Elizabeth R. Crais, Ph.D.

Cara McComish, Ph.D.

Abstract

LAUREN PETERSON: Parent Report in Identifying Autism in Infants
(Under the direction of Linda R. Watson)

Parent report is often used in helping identify risk for developmental disabilities. However, limited research addresses the utility of parent/caregiver concerns in identifying risk for autism spectrum disorders (ASD). First Year Inventory (FYI) questionnaires (n=128) were sampled from an ongoing project, examining parent responses to open-ended questions about concerns regarding their 12-month-old. Parents of infants scoring at-risk on the FYI expressed significantly more concerns about their infants than parents of infants not at risk. Parents in both groups reported medical concerns most frequently. Among at-risk infants, infants whose parents had concerns did not exhibit significantly more ASD risk markers on a standardized ASD measure than infants whose parents had no concerns; however, those whose parents expressed concerns about their infants' social or language development had lower scores on a standardized communication measure. Findings in this study support the use of parent-reported concerns in identifying risk for ASD in infants.

Acknowledgements

A heartfelt thank you to the Early Development Project team at the University of North Carolina at Chapel Hill for allowing me to use data collected during their study. Thank you also to Dr. Linda Watson, Division of Speech and Hearing Sciences at UNC-CH for advising this research study. A final thanks to Dr. Elizabeth Crais and Dr. Cara McComish, Division of Speech and Hearing Sciences, for serving on my thesis committee.

The Early Development Project is supported by the Institute of Education Sciences, U.S. Department of Education, through Grant #R324A100305 to the University of North Carolina at Chapel Hill. The opinions expressed are those of the author and do not represent views of the Institute or the U.S. Department of Education.

Table of Contents

List of Tables	vi
Chapter	
1. Introduction	1
2. Review of the Literature	4
a. Early Parent Concerns about Children with ASD/Developmental Delays	4
b. Early Screening for ASD	6
c. Parents as Reporters.....	8
3. Methods	10
a. Participants	10
b. Measures	11
c. Procedures.....	12
d. Analyses	13
4. Results	15
a. Between Group Comparisons.....	15
b. Risk Markers Based on AOSI Scores.....	16
c. Parent Concerns on FYI in Relation to Standard Scores on Multiple Measures.....	18
5. Discussion	20
a. Between Group Comparison	20

b. Risk Markers Based on AOSI Scores.....	22
c. Parent Concerns on FYI in Relation to Standard Scores on Multiple Measures.....	23
d. Future Directions for Research.....	24
e. Conclusion	24
Appendices	
A. Coding Form	25
References	26

List of Tables

Table

1. χ^2 Analysis	15
2. Parent Concerns by Risk Criteria and Category	16
3. Mean AOSI Markers.....	17
4. A. Risk Factors on the AOSI.....	17
B. Parent Concerns in High AOSI Risk Infants	18
5. A. Mean CSBS Scores of Infants meeting FYI Risk.....	19
B. Mean SPA Scores of Infants meeting FYI	19

Chapter 1

Introduction

Early identification and intervention has been a rising priority in disabilities such as autism spectrum disorders (ASD). The current prevalence of ASD has been estimated as high as 1 in 88 children in the United States (Baio & Centers for Disease Control and Prevention, 2012). Due to this rising number, professionals are striving to provide high-quality intervention services to an overwhelmingly large population. Evidence suggests that intensive intervention services for ASD are most successful when they are implemented early on in a child's development (Fenske, Zalski, Krantz, & McClannahan, 1985; Lovaas & Smith, 1988); neuroscience has shown that early intervention strategies can have a profound impact on developing brains (Majdan & Shatz, 2006). However, identification of ASD is often delayed by numerous factors, complicating the process of "earlier" early intervention—services beginning before a child's second birthday.

The American Academy of Pediatrics (Filipek et al., 2000) recommends screening for ASD should occur at 18-months and again at 24-months, but several studies suggest that significant markers indicating risk of ASD are observable at an even earlier age (Baranek, 1999; Osterling, Dawson, & Munson, 2002; Pierce et al., 2011). The accurate screening of children younger than 18 months promotes earlier implementation of intervention services through the identification of concerns to be targeted. However, health care providers following the AAP guidelines use only surveillance for ASD risk indicators for children under

18 months of age; therefore, many red flags that could be picked up by standardized screeners likely will be missed. Strategies to assist in the identification of children at risk for ASD are needed to provide these children with follow-up, evaluation, and intensive intervention services as early as possible.

One strategy to facilitate early identification of ASD is the use of parental observations and concerns. Several studies have investigated the use of parental questionnaires in identifying infants at-risk for ASD and other developmental concerns (Pierce et al. 2011; Turner-Brown et al., in press; Wetherby et al., 2008). However, parents whose responses to standardized questionnaires indicate their infants and toddlers are at risk for developmental problems are not necessarily themselves aware of their child's risk of later developmental problems. Wetherby, Brosnan-Maddox, Peace & Newton (2008) found that below the age of 15 months, only half of parents of infants later diagnosed with ASD expressed concerns about their child's development. Beyond this study by Wetherby et al., previous studies have not examined the comments provided by caregivers in response to open-ended questions about developmental concerns in relation to future diagnostic outcomes for infants, leaving several questions about the reliability of parent-reported concerns unanswered. The purpose of this study was to assess the utility of concerns provided by parents/caregivers to predict identification of risk factors for ASD, developmental delays, or other disabilities in young children, as well as assess congruence of parental concerns with actual evaluation findings. There are two questions to address this issue:

1. How do the number and types of comments made by parents of infants who were later determined to be “at-risk” for ASD/developmental delays compare to the number and types of comments made by parents of infants who were not at risk?
2. Are parent concerns about infants at-risk for ASD congruent with the results of formal assessments?

Based on these questions, it was hypothesized that infants deemed at risk would have a greater number of parental concerns than infants not at risk for ASD, and based on the literature it was expected parents would have a higher quantity of concerns related to speech and language development compared to other areas of concern for at risk infants.

Chapter 2

Literature Review

In order to more thoroughly understand the existing relationship between parent report and early identification, the following literature review examines several domains related to this study. Three main areas are considered: early parent concerns in children with ASD and developmental delays, early screening procedures for ASD, and the role of parent report in the process of early identification.

Early Parent Concerns about Children with ASD/Developmental Delays

Several studies have indicated that some parents of children later diagnosed with ASD have many concerns about their children's development in the first two years of life. In a retrospective study, one third of parents expressed concerns about their child's development before the first birthday and they recognized many characteristics of ASD by age 2 (De Giacomo & Fombonne, 1998), yet most diagnoses of ASD are not made until a child reaches the preschool age or older. Evidence suggests intervention before age 4 promotes improved development in language, social skills, and cognition (Rogers, 2006). In a retrospective study, Chawarska et al. (2006) examined the age of recognition (AOR) of parent concerns regarding developmental abnormalities and the relationship between AOR and diagnosis/level of function in toddlers with ASD. Parents indicated concerns as early as the first year of life, with the majority indicating concerns by age 2. The concerns were generally related to speech and language development, social development, medical

concerns (e.g. gross and fine motor development, seizures), and nonspecific concerns related to eating and sleeping patterns. The authors found that parents identified concerns at an average of 14 months, with primary concerns differing based on the child's age/stage in development. Generally, the later the AOR, the more severe impairments of the child when examined at age 4, indicating the potential for earlier recognition to promote better functional outcomes for children with ASD and other developmental disabilities.

Guinchat et al. (2011) also retrospectively examined parental concerns in children with autism. The researchers developed a questionnaire using open-ended items and then divided the questions into specific categories. The researchers found three clusters of concerns: motor problems and passivity; emotional, hyperactivity, and sleep problems; and communication problems, poor social interaction and autism-like behaviors. These groups of concerns were also considered early awareness, intermediate awareness, and late awareness groups, respectively. The authors found that parents who expressed earliest concerns experienced the longest time between initial concern and diagnosis, and their concerns were not autism-specific. Results such as these suggest that some features of a child's development can raise concerns during infancy, well ahead of the time a child will be diagnosed. It also encourages professionals to consider parents as mindful and valid observers and reporters. Guinchat et al.'s findings support the reliability and importance of early identification of ASD and developmental delays through parent-reported concerns. The evidence indicates using parent-recognized concerns in infancy to facilitate earlier diagnoses is a promising strategy for screening and identification.

Early Screening for ASD

Other studies have demonstrated results supporting the recognition of early red flags in ASD through early standardized screening procedures (Volkmar, Chawarska, & Klin, 2005; Osterling & Dawson, 1994). Zwaigenbaum et al. (2005) completed a longitudinal study examining high-risk infants who had an older sibling previously diagnosed with ASD and comparing developmental markers between the two siblings. Their results indicate a noticeable distinction in children later receiving a diagnosis when compared with other siblings and low-risk children as early as 12 months of age. These conclusions were based on differences in behavioral markers such as eye contact and response to name; prolonged latency to disengage visual attention; patterns of early temperament; and delayed expressive and receptive language skills. From these findings, the authors concluded behavioral screens between 6 and 12 months of age may serve as a predictor in later ASD diagnosis.

Osterling and Dawson (1994) used retrospective home video tape analysis of children to assess the observable differences between typically developing infants and those later diagnosed with ASD. From their analyses, the authors indicated an identifiable difference in behaviors present by one year of age, including the absence of typically expected behaviors or the presence of unexpected ones. These results demonstrated observable variance in three major areas: social, joint attention, and certain “autistic” behaviors. The implications of the study lend support to the notion of identifying autism much earlier than most children receive a diagnosis. This validates the need to develop screening tools for surveillance of ASD and developmental delays in infants.

The success of early screening procedures in identifying developmental delays and ASD has also been well documented in the literature. Pierce et al. (2011) outlined a procedure for screening at one-year well child checkups (WCCs) for infants. The authors set up screens for ASD, language delay (LD), and developmental delay (DD) using the Communication and Symbolic Behavior Scales Developmental Profile Infant Toddler Checklist, Wetherby and Prizant, 2005). Participants completed the questionnaire at one-year well baby checkups and were immediately scored and referred if necessary. Of those referred who followed up with further evaluation, diagnoses were accurately made for ASD, LD, and DD. These results indicate successful incorporation of screening procedures with a one-year well baby checkup. Through this study, the authors demonstrated the feasibility for pediatricians to implement developmental screening procedures during routine WCCs with accurate results. They did find, however, that pediatricians did not refer a substantial number of one-year-olds who failed the screening on to the research team for evaluations. Thus, potentially some unexplored factors still pose barriers to getting full assessments for one-year-olds who fail developmental screenings implemented by pediatricians.

Turner-Brown et al., (in press) also examined the success of early screening procedures using the First Year Inventory (FYI; Baranek, Watson, Crais, & Reznick, 2003). In the follow up to their longitudinal study, the authors examined responses to parent questionnaires of children at age 3 who were previously determined to be at-risk for ASD using the FYI at 12 months of age. Results of this study indicated 85% of children who met risk criteria on the FYI at 12 months old later demonstrated developmental challenges that required services by age three, with 31% of the children identified at risk being diagnosed

with ASD by age 3. Thus, children who met risk criteria on the FYI at 12 months were at high risk for ASD and at very high risk for a broader array of developmental problems. The FYI also had low false-positive identification rates, further demonstrating the strength of this tool. These findings support the potential success of early screening via parent questionnaires as a tool for identifying risk for ASD and other developmental disabilities in infants. However, in the Turner-Brown et al. study, just under half of the children diagnosed with ASD at age 3 met criteria for risk on the FYI at 12 months of age. This finding indicates that a parent questionnaire screener such as the FYI may fail to identify many children at 12 months of age who are later diagnosed with ASD; for this and other reasons, early ASD screening tools do not replace the need for continuous surveillance by healthcare providers occurring multiple times throughout a child's early development.

Parents as Reporters

Recent studies suggest that parent-reported behaviors are valid sources for identifying developmental concerns. Beauchesne and Kelley (2004) examined the reliability of parent report as a predictor in the early identification of ASD. Many tools are used to identify autism in young children; these tools are recognized as being accurate but with several limitations, such as parents/caregivers being unable to remember the timing of all developmental milestones. Other studies have shown that parent reports are sensitive in identifying global delays and deficits (Chawarska et al., 2007). Wetherby et al. (2008) and Pierce (2011) used the Infant-Toddler Checklist (Wetherby & Prizant, 2002) to gather information regarding specific behaviors both observed and unobserved by parents/caregivers. While parents accurately reported behaviors indicating potential risk for

developmental delays/ASD, noting behaviors does not necessarily indicate a level of parental concern about the infant's development. Therefore, the identification as at-risk based on the Infant-Toddler Checklist may be surprising to a parent if they expressed no concerns. Like the ITC, the instruments used in the present study (FYI) also uses a checklist of behaviors to determine risk level of infants. The possibility of at-risk status without documented parent concern is possible with this tool as well. This mismatch of parent and professional evaluation of a child's development can be overwhelming for parents, indicating a need to incorporate discussion of parent concerns when identifying infants at-risk for ASD or developmental delays.

Glascoe (2001) reported that parent concerns regarding specific areas of development can serve as an effective screening tool when properly elicited and categorized. This study utilized a specific checklist of concerns broken down into different areas of development where parents/caregivers noted specific concerns about their child. Glascoe used the Parents' Evaluations of Developmental Status (PEDS, Glascoe et al, 1999), a developmental screen that elicits parent concerns into three risk groups (high, moderate, low)—as part of the diagnostic measures in her study. She found that children whose parents reported concerns, yet who did not meet criteria for a diagnosis when assessed (false positives), often scored lower on measures of intelligence, language, and academic achievement than children whose parents expressed no concerns. Thus, false positive results on the PEDS indicate parent concerns that may be warranted instead of reflecting a shortcoming of the screener. Glascoe's findings substantiate the need for the collection and categorization of parent concerns to identify potential developmental risk in infants.

Chapter 3

Methods

Participants:

Information for this study was gathered using data from the Early Development Project conducted at the University of North Carolina at Chapel Hill. One hundred twenty-eight First Year Inventories (FYIs) were selected for this study. For an at-risk group, sixty-two questionnaires of infants who met risk criteria on the FYI were selected. For a control group, 66 questionnaires were randomly selected from infants whose scores were below the risk threshold on the FYI. All of the infants resided in central North Carolina at the time the FYIs were completed, and were 12 months of age +/- 2 weeks at the time their parents completed the FYIs.

Measures:

Several assessment tools were used to collect the data analyzed in this study: the First Year Inventory, collected when infants were 12 months of age; and the Autism Observation Scale for Infants, the Communication and Symbolic Behavior Scales-Developmental Profile, and the Sensory Processing Assessment. All data was collected when the infants were 13 to 15 months of age.

The First Year Inventory (FYI, Baranek et al., 2003; Reznick et al., 2007) is a screening tool designed to identify 12-month-old children in the general population who are at-risk for autism. The FYI (2.0) consists of 63 total items organized into two domains: social-

communication behaviors and sensory-regulatory behaviors. The FYI has 46 statements for which parents check the frequency with which their child displays select behaviors; 14 multiple choice items; 1 item on sound production; and 2 open-ended questions regarding whether anyone has had concerns about the child's development, and whether the child has any unusual physical or medical features. Parents are asked to complete the questionnaire within 2 weeks of their child's first birthday. Infants who attain risk scores at or above the 94th percentile on the social-communication domain and at or above the 88th percentile on the sensory regulatory domain meet the criteria for being "at risk" for ASD (Turner-Brown et al., in press). The current study focuses on the open-ended portion of the questionnaire, which is not considered in computing the risk scores.

The Autism Observation Scale for Infants (AOSI; Zwaigenbaum et al., 2005) uses 18 markers to identify children at risk for autism. Systematic presses are used during semi-structured play with infants to assess target behaviors, and the AOSI is scored based on total risk markers observed during the assessment. This measure was chosen due to interest in examining the association between infants having more early symptoms of ASD based on observation and a higher number of parent concerns based on the FYI open-ended questions. At the time the Early Development Project was initiated, the AOSI was selected as the best available instrument used to examine ASD early risk markers based on direct observation of the child.

The Communication and Symbolic Behavior Scales-Developmental Profile (CSBS; Wetherby & Prizant, 2002) is a standardized, norm-referenced instrument used to assess young children with functional communication ages between 6 and 24 months. The

Behavior Sample scores were used for this study.

The Sensory Processing Assessment for Young Children (SPA; Baranek, 1999b) is a play-based assessment sensitive to maturational changes. It measures approach-avoidance to sensory toys, sensory seeking behaviors, and orienting responses across three sensory modalities. The SPA discriminates different patterns of sensory responses between children with ASD and children with other developmental disabilities.

Procedures:

In the Early Development Project, FYIs are mailed to non-Latino families in a six-county catchment area in central North Carolina, based on publicly available birth records. The FYIs are mailed two weeks prior to an infant's first birthday, and parents are asked to complete the form and return it in a postage-paid envelope by a date two weeks after their child's first birthday. A letter accompanying each FYI explains that, with the family's permission, the research team will contact them in the event that their infant scores at risk on the FYI and invite them to participate in an intervention study. The letter also requests that parents complete the FYI even if they are not concerned about their child's development. The response rate to these mailings ranges from approximately 16% to 18%. Between 1% and 2% of the infants whose parents complete the FYI score at risk on the FYI. When an infant's score meets the risk threshold, the Early Development Project Coordinator contacts the family to determine if they are eligible for the study (e.g., the family speaks English in the home at least 50% of the time; the infant does not have previously identified severe sensory or motor disabilities). The project coordinator also asks the family if they are willing to come to an assessment site for in-person pretest assessments. For families who

are eligible, these pretest assessments occur when the infant is between 13 and 15 months of age. After the pretest assessments and the findings are shared with the families, the families who consent are randomized to a treatment group, and then participate in post-test assessments after a 6- to 8-month intervention phase. For the purposes of the current study, however, only data from the FYIs (at 12 months of age) and the pretest assessments (at 13 to 15 months of age) were examined.

This study focused on parent responses to the open-ended questions at the end of the FYI, in which parents are asked if they have any concerns about their child's development, and if anyone else has expressed concerns about their child's development. The parent comments in response to these questions were categorized in terms of area of concern (see Appendix for categorization system) and person with concern (mother, father, other person, undeterminable). The categorization system was originally developed by the FYI researchers to categorize parent concerns about their children in the follow up study of the FYI normative sample at 3 ½ years of age (Turner-Brown et al., in press), and was adapted by the author for use in this study. The author was blind to the children's risk status for ASD while categorizing parent comments.

Analyses:

The first set of analyses compared concerns among parents of infants scoring at-risk on the FYI to concerns among parents of infants scoring below the risk threshold. A quantitative test was conducted to compare the number of parental concerns for children in the two groups using a χ^2 analysis. Tables of the types of concerns by group are presented descriptively.

The second set of analyses examined only the infants who scored at risk on the FYI. These infants (n=62) were subgrouped based on whether parents expressed any concerns or not, and then the subgroups were compared on the total number of risk markers on the AOSI using a univariate analysis of variance (ANOVA). The data on the distribution of risk markers across the two groups are presented descriptively in a table. In addition, the number of parent concerns are presented descriptively for subgroups of infants created based on the number of risk markers on the AOSI; those infants with 0-4 markers were considered “low AOSI risk,” and those with 5 or more markers were considered “high AOSI risk.” The breakdown of infants considered high AOSI risk is also presented descriptively in terms of the type of parent concerns reported, as well as the number of individual concerns expressed on the open-ended portion of the FYI.

For the third set of analyses, the infants who met risk criteria on the FYI and who participated in assessments at 13-15 months of age were first subgrouped based on whether or not parents had concerns related to language and social communication domains; these subgroups were compared on mean CSBS total standard scores using ANOVA. Next, the infants were subgrouped based on whether or not their parents indicated sensory regulatory and behavioral concerns. Three comparisons were made using ANOVA related to the three sensory patterns measured on the SPA: sensory-seeking, hypo-responsivity and hyper-responsivity.

Chapter 4

Results

Between Group Comparisons

One hundred twenty-eight FYIs were examined, 62 of which were for children who met risk-criteria on the FYI. The remaining 66 infants who did not meet criteria were used as a control group. Of those meeting risk criteria, 40 parents (64%) expressed concerns, whereas for children who did not meet risk criteria, only 9 parents (13%) expressed concerns. A χ^2 analysis (<http://graphpad.com/quickcalcs/contingency1/>) was performed based on whether or not parents reported concerns and whether or not an infant met risk criteria on the FYI (see Table 1). Using Fisher's exact test, the two-tailed results were statistically significant, $p < .0001$, indicating that parents of children who scored at risk on the FYI were significantly more likely to report concerns than parents of children who scored below the risk threshold.

Table 1. χ^2 Analysis

	Concerns- Yes	Concerns- No
FYI* Risk Criteria- Yes	40	22
FYI Risk Criteria- No	9	57
*FYI=First Year Inventory		

Those concerns expressed by parents were categorized based on four domains: language (e.g. not using any words, “quiet baby”); social (e.g. not engaging with others, unusual play, no pointing/gestures); behavioral (e.g. unusual sensory behaviors, aggression, difficulty with transitions) and medical/motor/other (e.g. poor gross motor skills, feeding concerns, sleep disturbances). The highest number of concerns provided by parents whose infants met criteria fell into the medical/other category (24). Language was the second highest area of concern (15). For parents of children who did not meet the risk threshold on the FYI (n=66), only 9 parents expressed concerns. The most prevalent category of concerns among those infants not at risk was also related to medical/other (6), followed by social concerns (3); no behavioral concerns were noted in this group. The breakdown of concerns for each group can be seen in Table 2.

Table 2. Parent Concerns by Risk Criteria and Category

	Infants at Risk (n=62)	Infants not at risk (n=66)
Type of Concern	Number of Parents Reporting Concern	Number of Parents Reporting Concern
Language	15	1
Social	9	3
Behavioral	8	0
Medical/ Other	24	6

Risk Markers Based on AOSI Scores

For infants who scored at-risk on the FYI, risk markers on the AOSI were measured, with a possible range from 0 to 18 markers. An ANOVA was used to compare groups of infants whose parents expressed concerns to those whose parents did not express concerns on the FYI, based on the mean number of risk markers. The breakdown of mean number of

markers and standard deviations can be seen in table 3. The results of the ANOVA were not statistically significant, $f = 1.05$, $p = .31$.

Table 3. Mean AOSI* Markers

	Number of infants	Mean Number of Markers	Standard Deviation
Expressed Concerns	35	4.7	2.9
No Expressed Concerns	19	3.8	2.9

*AOSI=Autism Observation Scale for Infants

Infants with more than 5 markers were included in the high AOSI risk group, and those with 4 or less markers were considered to be low AOSI risk. Thirty-one infants comprised the low AOSI risk group, and the remaining 24 were categorized as high AOSI risk. For each number of markers, the amount of parents expressing concerns was enumerated and a percentage was calculated. Table 4A shows the full breakdown of this analysis. The percentage of parents expressing concerns was highly variable. The highest number of risk markers for an infant in this sample was 11; the parents of that infant expressed no written concerns on the FYI. No association was apparent between increasing number of markers on the AOSI and percentage of parents expressing concerns on the FYI.

Table 4A. Risk Factors on the AOSI

Number of Markers	0	1	2	3	4	5	6	7	8	9	10	11
Number of children with # of markers	2	8	8	7	6	1	9	5	4	2	2	1
Number of parents with concerns on FYI	0	7	3	4	4	1	7	3	3	2	2	0
Percentage (%)	0	87.5	37.5	57.1	66.7	100	77.8	60	75	100	100	0

A further descriptive analysis was conducted of information for infants in the high AOSI risk group. Most parents in this group noted only one concern (12), and most concerns reported fell into the medical/other category (11). A complete breakdown of these findings can be seen in Table 4B.

Table 4B. Parent Concerns in High AOSI Risk Infants

Types of Concern	Number of Parents Reporting
Language	6
Social	5
Behavioral	3
Medical/Other	11
Number of Parent-Reported Concerns	Number of Parents Reporting
0	6
1	12
2	3
3	3
4+	0

Parent Concerns on FYI in Relation to Standard Scores on Multiple Measures

An ANOVA was used to compare mean CSBS scores of at risk infants whose parents reported language and social concerns. Table 5A displays the mean CSBS scores for the group of infants whose parents did not report language or communication concerns, and the mean scores for those whose parents did report concerns in these domains. The analysis yielded statistically significant results, $f=5.8$, $p=.019$, indicating that infants whose parents expressed concerns about language and social areas scored significantly lower on the CSBS than infants whose parents expressed no concerns in these areas. Cohen’s effect

size value was found to be $d=0.68$, which is considered moderately large

(<http://www.uccs.edu/~lbecker/>).

Table 5A. Mean CSBS* Scores of Infants meeting FYI Risk

	Language Concerns	No Language Concerns
Number of Infants	19	35
Mean CSBS Score	77.6	84.8
Standard Deviation	11.2	10.0
*CSBS=Communication and Symbolic Behavior Scales—Developmental Profile		

Infants meeting risk criteria on the FYI were next subgrouped based on parent-reported sensory-regulatory and behavioral concerns. An ANOVA was used to compare mean SPA scores across three domains (sensory seeking, hypo-responsivity, and hyper-responsivity) for parents who reported behavioral concerns. Mean scores for each SPA measure of infants whose parents expressed behavioral concerns as well as scores of infants whose parents did not express behavioral or sensory concerns are presented in Table 5B. The results of the analyses were nonsignificant for all three SPA scores: sensory-seeking, $f = .01$, $p = .979$; hypo-responsivity, $f = 1.22$, $p = .274$; hyper-responsivity scores, $f = .06$, $p = .810$. Because only 7 parents expressed concerns related to the sensory-regulatory domain, there was very limited power for the subgroup comparisons on SPA scores.

Table 5B. Mean SPA* Scores of Infants meeting FYI Risk

	Behavioral Concerns	No Behavioral Concerns
Number of Infants	7	48
Mean Score: SPA Sensory Seeking	2.30	2.30
Standard Deviation: Sensory Seeking	.64	.76
Mean Score: SPA Hyposensitivity	2.03	2.41
Standard Deviation: Hyposensitivity	.71	.85
Mean Score: SPA Hypersensitivity	1.42	1.45
Standard Deviation: Hypersensitivity	.09	.32
*SPA=Sensory Processing Assessment		

Chapter 5

Discussion

Between Group Comparisons

The purpose of this study was to assess the extent to which concerns expressed by parents/caregivers predict the identification of risk factors for ASD, developmental delays, or other disabilities in young children, as well as to assess congruence of parental concerns with actual evaluation findings. Of the 62 infants meeting risk criteria on the FYI, 40 of their parents reported concerns, with the largest number reporting only one concern. Of these concerns, the most were related to medical/other concerns, refuting the initial hypothesis that the highest number would be related to language and communication development. However, language concerns were the second largest group—nearly twice as large as behavior or social concerns, still indicating a strong presence among the concerns of parents. Two factors may help explain the contrasting findings with previous literature. The factors include when the parents are asked about their concerns and the age of the child when the parents are asked. First, it is important to recognize that the literature is mainly based on retrospective studies (Osterling and Dawson, 1994; Chawarska et al., 2006; Guinchat et al., 2011), where parents who suspected or knew their child had an ASD diagnosis were asked to reflect back on behaviors early in life, as well as prospective studies that looked at children older than 12-months (De Giacomo & Fombonne, 1998; Glascoe, 1997). Second, in speech and language development, we expect children at 2 years will be

using words to communicate, whereas we do not expect words as the main form of communication at 12 months. Because of this, literature focusing on older children may be more likely to find speech and language concerns expressed by these parents.

Only nine parents of infants who did not meet risk criteria on the FYI expressed concerns, with the most reporting medical/other concerns, congruent with the findings of the group meeting risk criteria and again refuting the initial hypothesis. This result indicates parents' greater awareness of potential medical issues affecting their infant's development, including feeding/swallowing issues, general motor skills development, chronic illness, or sleep disturbances. It is possible parents report more concerns in this category because an infant's overall health may create a greater impact on a family's daily life than other types of issues around the end of the first year of life (e.g. parents know that children are expected to eat but they may not know that they are expected to communicate using gestures). However, further investigation is required in order for this suggestion to be considered plausible.

The results of the two-tailed χ^2 analysis showed statistical significance in parent concerns for infants scoring at risk on the FYI versus those scoring below the risk threshold. This indicates a strong relationship between parents/caregivers reporting concerns and the meeting of risk criteria. Thus, parents demonstrated the ability to evaluate risk factors related to their child's development and report their concerns in response to open-ended questions, supporting the validity of utilizing parents' concerns in assessment of a child.

Risk Markers Based on AOSI Scores

The results of the ANOVA comparing mean number of AOSI markers for infants whose parents expressed concerns against infants whose parents did not express concerns was found to be statistically nonsignificant, although the subgroup whose parents had concerns showed slightly more risk markers on the FYI, an average of 4.69 markers versus an average of 3.84 markers for children whose parents expressed no concerns. Further descriptive analyses of the data on AOSI risk markers revealed a great deal of variability among parents, and no consistent trend in parent concerns was found in association with the number of markers. The mean percentage of parents expressing concerns in the high-risk group was higher than the low risk group, but again the data were not consistent. A higher number of markers would suggest a greater risk of ASD, yet the number of parents with concerns did not systematically increase with risk markers. The parents of the child with the highest number of markers (11) expressed no written concerns. These findings indicate that while many parents have concerns about their children's development in the first year of life, there is still a possible lack of awareness in parents and caregivers about potential developmental issues. On the other hand, the lack of association may reflect measurement properties of the AOSI. Preliminary validity data for the AOSI are based on assessments of infant siblings of children with ASD in one longitudinal study (Zwaigenbaum et al., 2005), but the findings have not been replicated with different samples, such as a sample identified through community-based screenings such as in the current study using the FYI.

Parent Concerns on FYI in Relation to Standard Scores on Multiple Measures

The mean CSBS scores were calculated for at risk infants whose parents expressed language and/or social concerns on the open-ended section of the FYI. These infants were found to have significantly lower scores on the CSBS than those who did not express concerns. This result helps answer the second research question: parents do express concerns that match the findings of formal evaluations. While significance was not found for infants whose parents expressed sensory-regulatory concerns on any of the SPA measures (sensory-seeking, hyposensitivity, hypersensitivity), the sample for this subgroup was only 7 infants. This analysis should be repeated on a larger sample size in order to determine whether or not parents are likely to report concerns congruent with assessment results across multiple domains or just in language and communication.

Overall, the at-risk infants of parents without expressed concerns had better scores on the AOSI and CSBS. However, only the score differences on the CSBS were determined to be significant. Parents expressing concerns were more likely to have infants with greater risk, but the examination of parent concerns in relation to AOSI risk markers highlighted that some parents without expressed concerns had infants with a number of red flags for developmental problems as well. This result demonstrates the continued need to educate parents about typical early childhood development with the hope of a greater number of parents recognizing and expressing concerns related to infant development when screening for ASD and other developmental delays.

Future Directions for Research

Future directions for research include examining usefulness of parent report in identifying issues beyond ASD in infant development, such as cognitive impairments. The role of parent education on child development could also be addressed in future studies: what do parents know about typical infant development, where and when are they learning this information, and what impact can be seen on parent report measures based on previous child development education. Because parents were so adept at identifying medical and motor concerns in their infants, benefit may exist in studies addressing patterns of these types of concerns in infants as red flags for risk of ASD as well.

Conclusion

The overall results of this study further support the argument for parent-reported concerns as a valid measure when assessing an infant's risk for developmental problems. While some parents expressed no concerns, many parents accurately identified concerns related to their infant's development. In order to help close this gap, professionals need to start collaborating with parents to better educate and inform them about typical development and signs or symptoms that may indicate their child is at-risk for ASD or other developmental disabilities. Empowering parents to recognize signs may help accelerate the process of early identification and intervention, which may improve future outcomes for these children. It is important to remember that parents are the experts on their children, and professionals should continue to place stock in their reports.

Appendix A: Coding Form

DCQConcern (Individual expressing concern about child)

- 0 = No concern from parent or professional
- 1 = Other person concerned, no parental concern
- 2 = Some parental concern
- 3 = Many parental concerns

DCQTypeConcern (Type of concern expressed by parent or other)

- 0 = No concern

Language

- 1.0 = Language NOS
- 1.1 = Articulation/pronunciation (lisp, stutter, dropping letter sounds)
- 1.2 = Language delay

Social

- 2.0 = Social NOS
- 2.1 = Social (not interested in other kids or shy)
- 2.2 = Anxiety/Fearfulness (other than social shyness)
- 2.3 = Unusual play with toys

Behavior

- 3.0 = Behavior NOS
- 3.1 = Rigid behavior (trouble with transitions, insistence on sameness)
- 3.2 = Aggressive behavior/ tantrums
- 3.3 = Overactivity/disruptive/compliance
- 3.4 = Sensory behavior (staring at lights, sifting items)

Medical/Motor/Other

- 4.0 = Medical/ Motor NOS
- 4.1 = Motor problems (fine and gross motor)
- 4.2 = Medical problems (heart problem, etc.)
- 4.3 = Ear/hearing problems (tubes in ears)
- 4.4 = Other (potty training, feeding, sleeping)

References

- Baio, J., & Centers for Disease Control and Prevention (2012). Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Morbidity and Mortality Weekly Report. Surveillance Summaries*. Volume 61, Number 3. *Centers For Disease Control And Prevention*.
- Baranek, G. T. (1999a). Autism during infancy: a retrospective video analysis of sensory-motor and social behaviors at 9-12 months of age. *Journal Of Autism & Developmental Disorders*, 29(3), 213-224.
- Baranek, G. T. (1999b). Sensory Processing Assessment for Young Children (SPA). Unpublished manuscript, University of North Carolina at Chapel Hill.
- Baranek, G. T., Watson, L. R., Crais, E., & Reznick, S. (2003). First-Year Inventory (FYI) 2.0. University of North Carolina at Chapel Hill.
- Beauchesne, M. A., & Kelley, B. R. (2004, January/February). Evidence to support parental concerns as an early indicator of autism in children. *Pediatric Nursing*, 30(1), 57-67.
- Bryson, S. E., Zwaigenbaum, L., McDermott, C., Rombough, V., & Brian, J. (2008). The Autism Observation Scale for Infants: Scale Development and Reliability Data. *Journal Of Autism & Developmental Disorders*, 38(4), 731-738.
- Chawarska, K., Paul, R., Klin, A., Hannigen, S., Dichtel, L. E., & Volkmar, F. (2007). Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 37, 62-72.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry*, 7(3), 131-136.
- Fenske, E. C., Zalenski, S., Krantz, P. J., & McClannahan, L. E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis & Intervention In Developmental Disabilities*, 5(1-2), 49-58.
- Filipek, P. A., Accardo, P. J., Ashwal, S. S., Baranek, G. T., Cook, E. r., Dawson, G. G., & ... Volkmar, F. R. (2000). Practice parameter: Screening and diagnosis of autism: Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology*, 55(4), 468-479.
- Glascoe, F. P. (1997). Parents' concerns about children's development: Prescreening technique or screening test?. *Pediatrics*, 99(4), 522.

- Glascoe, F. P., Filipek, P. A., Accardo, P. J., Baranek, G. T., & Cook, E. R. (1999). Parents' Evaluations of Developmental Status. *Journal Of Autism And Developmental Disorders, 29*(4), 439-484.
- Glascoe, F. P. (2001). Are overreferrals on developmental screening tests really a problem? *Archives of Pediatric and Adolescent Medicine, 155*, 54-59.
- Guinchat, V., Chamak, B., Bonniau, B., Bodeau, N., Perisse, D., Cohen, D., & Danion, A. (2012). Very Early Signs of Autism Reported by Parents Include Many Concerns Not Specific to Autism Criteria. *Research In Autism Spectrum Disorders, 6*(2), 589-601.
- Lovass, O., & Smith, T. (1988). Intensive behavioral treatment for young autistic children. In B. B. Lahey, A. E. Kazdin (Eds.). *Advances in clinical child psychology, Vol. 11* (pp. 285-324). New York, NY US: Plenum Press.
- Majdan, M., & Shatz, C. J. (2006). Effects of visual experience on activity-dependent gene regulation in cortex. *Nature Neuroscience, 9*(5), 650-659.
- Osterling, J., & Dawson, G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal Of Autism And Developmental Disorders, 24*(3), 247-257.
- Osterling, J. A., Dawson, G., & Munson, J. A. (2002). Early recognition of 1-year-old infants with autism spectrum disorder versus mental retardation. *Development And Psychopathology, 14*(2), 239-251.
- Pierce, K., Carter, C., Weinfeld, M., Desmond, J., Hazin, R., Bjork, R., & Gallagher, N. (2011). Detecting, studying, and treating autism early: The one-year well-baby check-up approach. *The Journal of Pediatrics, 159*(3), 458-465.
- Reznick, J. S., Baranek, G. T., Reavis, S., Watson, L. R., & Crais, E. R., (2007). A parent-report instrument for identifying one-year-olds at risk for an eventual diagnosis of autism: The First Year Inventory. *Journal of Autism and Developmental Disorders, 37*(9), 1691-1710.
- Rogers, S. J. (1996). Brief Report: Early Intervention in Autism. *Journal Of Autism & Developmental Disorders, 26*(2), 243-246.
- Turner-Brown, L. M., Baranek, G. T., Reznick, J. S., Watson, L. R., & Crais, E. R. (in press). The first year inventory: A longitudinal follow-up of 12-month-old to 3-year-old children. *Autism*.
- Volkmar, F., Chawarska, K., & Klin, A. (2005). Autism in infancy and early childhood. *Annual Review Of Psychology, 56*(1), 315-336.

Wetherby, A., Brosnan-Maddox, S., Peace, V., & Newton, L. (2008). Validation of the Infant-Toddler Checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism: The International Journal Of Research & Practice*, 12(5), 487-511.

Wetherby, A. M., Prizant, B. M. (2005). *Communication and Symbolic Behavior Scales Developmental Profile*. Baltimore, MD: Brookes Publishing.

Zwaigenbaum, L., Bryson, S., Rogers, T., Roberts, W., Brian, J., & Szatmari, P. (2005). Behavioral manifestations of autism in the first year of life. *International Journal Of Developmental Neuroscience*, 23(2-3), 143-152.