



Published in final edited form as:

Autism. 2015 January ; 19(1): 20–28. doi:10.1177/1362361313509731.

Parents' first concerns about toddlers with autism spectrum disorder: Effect of sibling status

Lauren Herlihy¹, Kelley Knoch¹, Bethany Vibert², and Deborah Fein¹

¹University of Connecticut, USA

²University of Denver, USA

Abstract

Symptoms of autism spectrum disorders may appear as early as 6 months, but parent concern, which can precipitate evaluation, often lags significantly. The presence of typical or atypical older siblings can change parents' sensitivity to departures from typical development. This study investigated type and age of parent's first concerns in toddlers with autism spectrum disorder, prior to diagnosis. Participants had (1) at least one older sibling with ASD (Sibs-ASD); (2) only typically-developing older siblings (Sibs-TD), or (3) were only/oldest (No-Sibs). Specific autism spectrum disorder diagnoses and symptom severity were similar among groups. Developmentally, No-Sibs showed the largest delays, followed by Sibs-TD, followed by Sibs-ASD. Mean age of first concern was 16 months for No-Sibs, 14 months for Sibs-TD, and 10 months for Sibs-ASD. Age of first concern differed significantly by group, even after controlling for mother's age and education. Concern about language was prevalent in all groups. Thus, the presence of an older child with typical or, especially, atypical development was associated with earlier concerns for the affected child, despite milder developmental delays. These findings underscore the importance of encouraging parents to report concerns to pediatricians, routine standardized screening for autism spectrum disorder, and the need for pediatrician vigilance, especially for only or oldest children.

Keywords

autism spectrum disorder; autism symptoms; parent concerns; younger siblings

Introduction

Substantial evidence suggests that autism spectrum disorders (ASDs) can be diagnosed in many children by around the second birthday, or in some cases even earlier, and that early diagnosis tends to be stable (Kleinman et al., 2008; Lord, 1995; Volkmar et al., 2004). However, prodromal symptoms of ASD, such as reduced social attention, often emerge earlier and evolve for several years (Ozonoff et al., 2008; Ozonoff et al., 2010). Identifying

Corresponding Author: Lauren Herlihy Department of Psychology University of Connecticut 406 Babbidge Road Storrs, CT 06268 USA lauren.herlihy@uconn.edu.

Declaration of conflicting interests

None.

ASD symptoms at the earliest age, before formal diagnosis is possible, can facilitate early intervention and positive outcomes (Dawson, 2008).

Increasing attention is being paid to the earliest signs of ASD in the first year of life, both by prospective studies of high risk children and by retrospective parent report. For example, differences between children at low and high risk for ASD (i.e., baby siblings of affected and unaffected children), and between high risk children with and without a later ASD diagnosis, have been noted as early as 3-6 months for social and regulatory symptoms (Werner et al., 2005), and as early as 6 months for social attention (Bhat, Galloway and Landa, 2010; Chawarska, Macari, and Shic, 2013). A prospective comparison of low risk children to high risk children with a later ASD diagnosis (Ozonoff et al., 2010) found no group differences at six months, but a gradual diminishing of gaze to faces, shared smiles, and social vocalizations in the ASD group, with significant group differences by 12 months. Differences in formally assessed cognition and language, and some repetitive behaviors, have been found by 14-16 months (Landa and Garrett-Mayer, 2006). Therefore, for many children with a diagnosis of ASD signs are present by the first birthday. However, detection of these signs by physicians or parents may be significantly delayed.

In standard pediatric practice, intensive, prospective assessment of even high risk children is not practical, and detection of developmental problems often relies on expression of parent concern, either on screening instruments or in spontaneous communication to physicians. In the general population, parents' expression of concerns about social development and behavior have been shown to correlate with a later diagnosis of a mental or developmental illness, leading Glascoe (2003) to stress the importance of taking parent concerns seriously. In children with risk factors for developmental delays (e.g., prematurity, low birth weight) parent concern correlates moderately with formal developmental assessment, although many parents miss signs of developmental delay (Rogers et al., 1992). The relationship of age of first concern to child outcome is a complex one, with mixed results (see discussion by Chawarska et al., 2007). On the one hand, earlier age of concern is associated with more severe symptoms and delays and therefore may presage worse outcome; on the other hand, earlier age of concern is associated with earlier access to intervention and therefore may lead to better outcome.

Many factors affect the timing of first concerns. Parents have been shown to have more concerns about their younger child than about their older child (Glascoe, 2003), presumably because of the comparison available to a parent with a typically developing older child. In general, higher maternal education is associated with increased knowledge of child development (Ertem et al., 2007; Reich, 2005; Richman, Miller and LeVine, 1992), although almost all of the research in this area has involved adolescent mothers, low-income mothers, or mothers from developing countries. Furthermore, knowledge of child development does not necessarily translate into expressed concerns (Glascoe, 1999). Negative child behaviors and higher family socioeconomic status (SES) increase the likelihood of a parent's unprompted expression of concerns to a professional (Glascoe, 1999). In a fairly low income and education sample, Rogers and colleagues (1992) found that *accuracy* of parent's reported concerns was not associated with poverty, maternal education, or parent experience with older siblings.

With regard to ASD specifically, several factors have been shown to influence age of first concerns. As with general developmental concerns, having an older affected child may lead to earlier concerns about the younger sibling, since parents may have more awareness of early signs and often closely scrutinize the younger child's development (De Giacomo and Fombonne, 1998; Hess and Landa, 2012; McMahon et al., 2007, Ozonoff et al., 2009). Parents of children with ASD who also have concurrent intellectual disability, motor or language delays, and medical problems also tend to report earlier ages of first concerns (De Giacomo and Fombonne, 1998; McMahon et al., 2007). More severe clinical presentation (i.e., autistic disorder rather than pervasive developmental disorder not otherwise specified (PDD-NOS)) lowers age of concern (Chawarska et al., 2007; Goin-Kochel and Myers, 2005). In some studies, parents report concerns earlier about girls (Dawson, 2008; Horovitz et al., 2011), but this is not consistent (De Giacomo and Fombonne, 1998). The overall mean age of first concern was reported as 19 months by De Giacomo and Fombonne (1998); this might be expected to decline as public awareness about ASDs increases, and indeed was reported to be 14-15 months by Chawarska et al. in 2007. About one third of parents of children with ASD reported some concern by the time the child was 12 months, with a strong majority concerned by 24 months (Baghdadli et al., 2003; Chawarska et al., 2007; Gray and Tonge, 2001).

Although far from perfectly valid, early concerns are often related to a later ASD diagnosis (Chawarska et al., 2007), and to lower language and cognitive functioning (McMahon et al., 2007). Ozonoff et al. (2009), in a prospective study of high-risk children, found that parent concern at 12 months but not at six months was predictive of diagnosis. Hess and Landa (2012) elicited prospective parent concern for younger siblings of children with ASDs at ages 14, 24, and 36 months. Concern was prevalent at all ages (40%-75%) but was predictively valid for diagnosis only at the two older ages. Consistent with the general developmental delay literature (Rogers et al., 1992), parent concern about ASD had better specificity than sensitivity at detecting delays (i.e. when parents were concerned, these concerns were usually valid, but many children were missed).

The most commonly reported early concern in children later diagnosed with ASD is delay in language and communication (Chawarska et al., 2007; Coonrod and Stone, 2004; De Giacomo and Fombonne, 1998; Hess and Landa, 2012; Kozlowski et al., 2011; Wetherby et al., 2004). Social difficulties are the second most frequent parent concern (Chawarska et al., 2007; Hess and Landa, 2012; Werner et al., 2005; Young et al., 2003) and are less predictive than concerns about communication (Hess and Landa, 2012). Concerns about repetitive behaviors often arise later, as these behaviors may occur in early typical development and do not become a concern until they continue past a developmentally appropriate age (Werner et al., 2005). Other concerns such as motor delays are more often reported for children with general developmental delays than for ASDs (De Giacomo and Fombonne, 1998). Therefore, parent concern about ASDs appears to emerge on average a year after some behavioral signs may be present, and expression of concern to physicians may lag still more. It is therefore important to consider factors that influence timing and type of parents' early concerns about ASD, in order to improve clinical practice in eliciting these concerns.

This study investigated sibling status as a factor contributing to parent concerns for children who went on to receive an ASD diagnosis. Most existing studies of early parent concerns with ASDs have studied high (i.e., younger siblings of a child with ASD) versus low risk groups (i.e., younger siblings of typically developing children, usually not diagnosed with ASDs). Furthermore, most studies looked at children participating in intensive prospective studies or those already diagnosed with ASD, both of which might influence the parent reporting of first concerns. No previous study has examined the differential effects of having an older affected sibling, an older typical sibling, or no older sibling. We asked parents for their concerns about children in these three groups prior to their child's diagnosis, and without intensive prospective surveillance, but including only cases ultimately diagnosed with ASDs. The design was retrospective, which had the advantage of not sensitizing the parent to diagnostic or developmental concern by following the child prospectively. Additionally, screening and evaluation occurred around the second birthday so that the time between the probable age of first concern and evaluation was relatively short.

The first hypothesis was that parents with no older children (No-Sibs) and parents with only TD older children (Sibs-TD) groups would express ASD-specific concerns less frequently than parents with an older child with ASD (Sibs-ASD), who are expected to be sensitized to specific signs of ASDs. The second hypothesis was that the age of first concern would be lower for the two groups where the proband has an older sibling, since parents in the No-Sibs group may have no models of typical or atypical development. Since the presence of an older child affected with ASD might increase parent scrutiny of the development of the younger child, we further hypothesized that age of first concern would be lowest in the Sibs-ASD group. We also examined the influence of maternal age and education on first concerns.

Method

Sample

The participants for this project were selected from a larger, ongoing study designed to validate screening questionnaires for ASDs in toddlers: the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2001) and its current research revision, the M-CHAT-R (Robins, Fein, and Barton, 2009). There were 69 children who met criteria for the current study, including 1) screening positive on the MCHAT or MCHAT-R, 2) receiving an ASD diagnosis at the time of evaluation, but having no prior diagnosis, 3) having data about the presence or absence of siblings, and 4) having complete responses to items of interest on the History Form or Autism Diagnostic Interview-Revised. Gender, ethnicity, age at screening and evaluation, and specific ASD diagnoses are seen in Table 1 and did not differ between groups. Participants received one of the following Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev; DSM-IV-TR; American Psychiatric Association, 2000) ASD diagnoses: autistic disorder, PDD-NOS, or ASD with low mental age, a term used in the M-CHAT study for a child who meets criteria for an ASD and has a mental age below 12 months. Ongoing data analysis indicates that virtually all of these children go on to receive an ASD diagnosis at 4 years of age.

The sample was divided into three groups based on sibling status: the Sibs-ASD group consisted of 21 toddlers with an older sibling with an ASD. Of these participants, 17 had an older sibling whose diagnosis was confirmed through our research study (10 with autistic disorder and 7 with PDD-NOS), 1 older sibling was diagnosed by his pediatrician, and 3 were based on diagnoses by other specialists. The Sibs-TD group consisted of 27 toddlers with at least one TD older sibling and no older sibling with ASD. The No-Sibs group consisted of 21 toddlers who were the oldest or only child. Demographic information is presented in Table 1, including years of maternal education, which was used as a proxy for socioeconomic status (SES). Parents completed questionnaires and participated in the diagnostic evaluation. The majority of participating parents were mothers ($n=61$), with six fathers, and in two cases, both mother and father reporting.

Measures

History Form is a parent self-report 156-item questionnaire with multiple choice and open-ended questions related to family composition, pregnancy and birth history, developmental milestones, and family health history. It included an open-ended question that asked parents to, "Please describe what worries you most about the child." Parents' spontaneous responses were then coded into ASD-Specific Concerns (communication/language concerns, social deficits, restricted or repetitive behaviors, confirmed or suspected ASD) and Non-ASD-Specific Concerns (motor difficulties, inattention and hyperactivity, cognitive and developmental delays, skills regression, eating/feeding, sensory difficulties, sleep, referral from a doctor or treatment provider, tantrums or inappropriate behaviors, other). All concerns were coded, without reference to the order in which they were listed.

Parents also responded to an open-ended question: "At what age (if ever) were you first worried about the child's development?" These responses were converted into months. Information about siblings and any developmental or psychological concerns for the siblings were also collected both by free response and by a multiple choice item, which offered eight categories: depression, mental retardation, learning disability, autism, attention deficit hyperactivity disorder (ADHD), social difficulties, anxiety, and other.

ADI (multiple versions)—Information about parent concerns was also collected from open-ended questions on the ADI-R (Lord et al., 1994). Some alternate forms, such as an early version of the toddler research ADI, were used but in all cases the relevant questions were the same: "When did you first notice that something was not quite typical about your child?" and "What first concerned you about your child's development?" These items were substituted for missing History Form data.

Mullen Scales of Early Learning—The Mullen Scales of Early Learning assesses general developmental functioning in young children (Mullen, 1995), with inter-scorer reliability from .91-.99. Receptive Language, Visual Reception, and Expressive Language were compared among groups (Mullen, 1995). The lowest standardized Mullen T-score for domains is "less than 20," but was coded as 19 for current data analysis.

Child Autism Rating Scale (CARS) measures the severity of autism symptoms and is usually completed by a trained observer (Schopler et al., 1995). Internal consistency and inter rater

reliability are good and scores above 25.5 are consistent with an ASD (Chlebowski et al., 2010).

Procedures

Parents of participants completed the M-CHAT(-R) during a visit to their pediatrician's office or with their early intervention provider when their child was between 18 and 24 months old. Participants who screened positive received a follow-up phone interview. Those who continued to screen positive received a free, developmental and diagnostic evaluation at the University of Connecticut performed by a licensed psychologist or a developmental pediatrician experienced with ASDs and a graduate student in clinical psychology. Clinical best estimate diagnosis followed DSM-IV-TR criteria and was based on parent interview, observation of children, and standardized measures including the ADI, CARS, and Autism Diagnostic Observation Schedule (ADOS).

Statistical Analyses

The primary analyses concerned group differences in type and age of first concerns, tested with chi-square and analysis of variance (ANOVA), respectively. The effect of sibling status on age of first concerns was further explored with a hierarchical regression, controlling for performance on the Mullen Visual Reception subscale and CARS score. Secondary analyses examined group differences that might affect age and type of first concerns, such as cognitive level, symptom severity, specific diagnosis, gender, ethnicity, maternal age at the time of the child's birth, and maternal education. Correction for multiple comparisons was not performed because of the small number of primary analyses.

Results

Group characteristics

Chi-square tests returned no significant group differences on gender, ethnicity, or specific ASD diagnosis (see Table 1). One-way ANOVAs found no significant group differences in age at screening or evaluation, maternal education, or CARS score ($p > .05$). There were significant group differences in maternal age at child's birth, with the Sibs-ASD having an average age of 34 years, Sibs-TD of 31 years, and the No-Sibs of 27 years (see Table 1); all groups differed from each other. There were no significant group differences in Receptive Language, but significant differences emerged on the Mullen Expressive Language and Visual Reception T-scores with Sibs-ASD having the highest mean score and No-Sibs having the lowest mean score (see Table 1); the Sibs-TD group had intermediate scores and did not differ from the other two groups.

Primary Analyses of Frequency and Age of First Concerns

We predicted that parents in the No-Sibs and Sibs-TD groups would express ASD-specific concerns less frequently than parents in the Sibs-ASD group. A chi-square test (see Table 2) for group differences was not significant, although there was a trend for the parents in the No-Sibs group to report the fewest ASD-specific concerns. Therefore, our first prediction was largely unconfirmed. Consistent with prior studies, the most commonly reported first concern was language delay/communication difficulties, with the second most frequent

concern being social symptoms; only a small percentage of parents reported concerns about restricted/repetitive behaviors or a prior suspicion of autism (see Table 2).

The second hypothesis was that parents in the Sibs-ASD group would have the earliest concerns, followed by Sibs-TD, with the latest concerns in the No-Sibs group. A one-way ANOVA returned significant group differences in the age of first concerns (See Table 3). Post hoc analyses revealed significant differences ($p < .01$) among all three groups, with parents in the Sibs-ASD group reporting concerns at the earliest age ($M = 10.1$ months), parents in the Sibs-TD group reporting concerns 6 months later ($M = 14.6$ months), and parents in the No-Sibs group reporting concerns at the latest age ($M = 16.2$ months). Thus, the second hypothesis was confirmed.

Child Characteristics

The age of first concerns data were further analyzed with a hierarchical regression to explore the effect of sibling status while controlling for child characteristics as measured by scores on the Mullen Visual Reception Scale and ASD symptom severity on the CARS. Assumptions of normality, linearity, multicollinearity, and homoscedasticity were upheld. Scores from the Mullen and the CARS were entered in step 1, and explained 4% of the variance in age of first concerns. When sibling status was entered into the model, the model as a whole was significant ($F(2, 61) = 3.82, p = .01$). Sibling status accounted for an additional 12% of the variance in age of first concerns and was the only statistically significant variable in the model ($\beta = 0.37, p < .01$). These results confirmed our prediction that parents who had an older child with ASDs became concerned about their younger child's development on average prior to their first birthday, while parents of only/oldest children were likely to develop concerns later than the other groups, even though these children had significantly greater developmental delays.

Maternal characteristics

Maternal age at child's birth and maternal education were significantly correlated with each other only for the No-Sibs group ($r = .66, p < .01$), a large effect. Maternal age correlated with age of first concerns only within the Sibs-TD group ($r = .39, p < .05$, medium effect), with older mothers reporting later concerns. An analysis of covariance (ANCOVA) for age of first concerns, controlling for maternal age, was highly significant ($F(2) = 7.66, p = .001$), indicating that group differences in age of first concern were not attributable to differences in maternal age. Maternal education correlated with age of first concerns only for the No-Sibs group ($r = .52, p < .03$, large effect); unexpectedly, more educated mothers reported concerns later. A hierarchical regression was run for each group with age of first concerns as the dependent variable, maternal age as step 1, and maternal education as step 2, to examine the effect of maternal education, controlling for age. The overall model was significant only for the No-Sibs group ($F = 3.77, p < .05$). Step 1 (maternal age) was not a significant predictor of age of first concerns. For step 2 (maternal education and controlling for age), adjusted $R^2 = .25, \beta = .75, t = 2.63, p < .02$; thus, the effect of maternal education for this group was not attributable to age.

Marital and employment status were also considered as potential contributors to group differences in age of first concerns. All mothers were either married or living with a partner, except for one mother in Sibs-TD (age of first concern = 6 months) and three mothers in No-Sibs (ages of first concern 3, 12, and 18 months, $M= 11$ months). There were no group differences in the frequency of mothers who were homemakers versus working outside the home at least part time ($\chi^2 = 2.05, p>.05$). The frequencies of homemakers versus mothers who worked outside the home were: 13 and 7 for Sibs-ASD, 12 and 15 for Sibs-TD, and 12 and 9 for No-Sibs. Furthermore, for the entire sample there were no significant differences in mean age of first concern between homemaker mothers ($M= 12.62$ months) and mothers who worked outside the home ($M= 14.76$ months). For the No-SIBS group alone, the mothers who worked outside the home also had first concerns two months later than the homemakers (15 vs. 17.2 months), but again the difference was not significant. Although also not significant, the same pattern held for the Sibs-TD mothers (13.2 vs. 15.9), but not for the Sibs-ASD mothers, where working outside the home versus homemakers mothers' means were within 1 month of each other.

Discussion

This study examined the effect of sibling status on the age at which parents first became concerned about their child's development and on the nature of these concerns, in a sample of toddlers with ASD. Groups were similar on age at screening and evaluation, ethnicity, gender, maternal education, child's specific diagnosis, and severity of autism symptoms. The No-Sibs group was more developmentally delayed than the Sibs-ASD group, with the Sibs-TD group having intermediate scores.

We hypothesized that parents with an older child with ASDs(Sibs-ASD) would report ASD-specific concerns for the proband more frequently than parents in the other two groups. Overall, a majority (72%) of parents reported ASD-specific concerns, with no significant group differences; thus, this prediction was not confirmed. Language/communication delays were the most commonly reported (56% of parents), consistent with previous reports (De Giacomo and Fombonne, 1998). Some prior studies have reported higher rates of social concerns (Werner et al., 2005; Young et al., 2003) than the 20% in this study. Social concerns may be more apparent in light of later development, and social milestones are probably less well understood by parents than language milestones. It is noteworthy that only 6% of parents of toddlers in the current study reported concerns about restricted and repetitive behaviors, which is consistent with previous assertions that these do not become a concern until they continue past a developmentally appropriate age (Werner et al., 2005).

Prior studies have generally shown that parents who have an older child with ASD, who have a younger child at-risk as well as heightened awareness, report more concerns early in development than parents with a typically-developing older child (Chawarska et al., 2007; Ozonoff et al., 2009). It is likely that the high overall frequency of ASD-specific concerns in this study, especially related to language, contributed to this lack of group differences.

As predicted, significant differences emerged between all groups in age of first concerns. Parents with an older child with ASDs reported concern about their younger child on

average prior to their first birthday (10 months), whereas parents with an older TD child reported concerns on average around 14 months, and parents of oldest or only children reported concerns on average around 16 months of age, shortly before the screening that resulted in the evaluation. This is consistent with previous research suggesting that parents of children with an ASD become more aware of the symptoms, sometimes even hypervigilant (McMahon et al., 2007). Current findings also support the idea that parents who have a typical child for comparison will be concerned at an earlier age (De Giacomo and Fombonne, 1998; Glascoe, 2003; Horovitz et al., 2011), but not as early as parents with an older affected child. The timing of these concerns is also consistent with existing literature indicating that parents often report initial concerns when the child is 12-17 months (Chawarska et al., 2007), and in some cases as early as the second half of the first year (De Giacomo and Fombonne, 1998; Werner et al., 2005). Despite the fact that children in the oldest/only child group were the most developmentally delayed, their parents were concerned at the latest age. All children in this study received ASD diagnoses, and did not differ in specific diagnosis or symptom severity. The differing age of first concerns in this study, therefore, is likely related to parent experience and expectations rather than differences in the child's development.

The groups differed on maternal age, but covarying maternal age did not reduce the sibling status group effect. The groups did not differ in maternal education, which was used as a proxy for SES. In the No-SIBS group only, maternal education was positively correlated with age of first concern (with a large effect size), and this was not attributable to maternal age, or marital or work status. Prior literature suggests that maternal education is associated with better knowledge of child development, but this may not translate into direct concern about one's own child. It is possible that more highly educated mothers in the group without older children had less direct experience with typically developing children outside their own nuclear family than the less educated mothers. Although no group differences were significant, it was somewhat suggestive that the full-time homemakers reported concerns two months earlier in the Sibs-TD and No-Sibs groups as well as the combined sample; this would need to be confirmed with a larger sample and information gathered about many other factors, such as the number of hours worked, in order to investigate it further.

It should be pointed out that all parents knew that there was some concern about their child's development based on a positive M-CHAT(-R) screen; this may have colored their report of age of first concern. It is quite possible that had these children not been picked up by screening, parents, especially in the No-Sibs group, might have reported concern later. However, the brief time that elapsed between the reported age of first concern and age of evaluation probably resulted in little or no distortion or telescoping of the recollection of concern (Hus et al., 2011)

The order of age of concern is the reverse of the functioning level of the children, with parents of the lowest functioning group being concerned latest. This confirms that having an older child is important in being sensitized to even mild delays, and that having an older child with ASD increases this sensitivity. It would be expected that younger siblings of children with ASD would receive more developmental surveillance from physicians as well as from parents; nevertheless, the age of screening did not differ between groups, despite

parents' earlier concerns, nor had any of the younger siblings already received a diagnosis. It is possible that parents' early concerns were not expressed to physicians or did not result in screening or referral. Therefore, despite the expected vigilance of parents and physicians, this group needs to participate in standardized screening for ASDs and for general developmental delays.

Limitations include sample size, which limited the ability to make comparisons by parent or child gender or ethnicity. Since these children were not followed from the first year of life, we cannot rule out the explanation that the Sibs-ASD children actually did have earlier appearing symptoms; the similarity among groups in specific ASD diagnosis and symptom severity, as well as the fact that the Sibs-ASD group was least developmentally delayed, argues against this possibility. Since we did not follow screen-negative children, we could not verify the validity of parent concerns. Whereas the Sibs-ASD parents reported earlier concerns that were validated by diagnosis, they may have also had unwarranted early concerns about younger siblings with typical development. Concern raised by the child's positive M-CHAT(-R) screen may have influenced parents' recollection of earlier concerns.

This study further illuminates the influence of sibling status on the nature and timing of parents' first concerns about children with ASD. The American Academy of Pediatrics (Johnson and Myers, 2007) recommends screening all children for ASDs at 18- and 24-month well-child visits, but this remains elusive. Current findings underscore the importance of promoting awareness about the early signs of ASD, encouraging parents to raise their concerns with their child's pediatrician, even before the first birthday, and promoting vigilant developmental surveillance, especially for only or oldest children, where parents have no prior model of typical development.

Acknowledgements

We are very grateful to members of the Early Detection laboratory and to participating families and children.

Funding

The study was funded by National Institutes of Health (NIH) grant HD39961 and Autism Speaks support to the Baby Sibs Research Consortium.

References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed.. Text Revision.. American Psychiatric Association; Washington, D.C.: 2000.
- Chawarska K, Paul R, Klin A, et al. Parental recognition of developmental problems in toddlers with autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2007; 37:62–72. [PubMed: 17195921]
- Chawarska K, Macari S, Shic F. Decreased spontaneous attention to social scenes in 6-month-old infants later diagnosed with autism spectrum disorders. *Biological Psychiatry*. 2013 Epub ahead of print.
- Chlebowski C, Green JA, Barton ML, Fein D. Using the childhood autism rating scale to diagnose autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2010 Available Online First 01/07/2010. PMID: 20054630.
- Coonrod EE, Stone WL. Early concerns of parents of children with autistic and nonautistic disorders. *Infants and Young Children*. 2004; 17(3):258–268.

- Dawson G. Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*. 2008; 20:775–803. [PubMed: 18606031]
- De Giacomo A, Fombonne E. Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry*. 1998; 7:131–136. [PubMed: 9826299]
- Furnham A, Buck C. A comparison of lay-beliefs about autism and obsessive-compulsive disorder. *International Journal of Social Psychiatry*. 2003; 49:287–344. [PubMed: 14727695]
- Goin-Kochel RP, Myers BJ. Parental report of early autistic symptoms: Differences in ages of detection and frequencies of characteristics among three autism spectrum disorders. *Journal on Developmental Disabilities*. 2005; 11:21–39.
- Gray KM, Tonge BJ. Are there early features of autism in infants and preschool children? *Journal of Paediatrics and Child Health*. 2001; 37(3):221–226. [PubMed: 11468034]
- Hess CR, Landa RJ. Predictive and concurrent validity of parent concern about young children at risk for autism. *Journal of Autism and Developmental Disorders*. 2012; 42:575–584. [PubMed: 21584850]
- Glascoe FP. The value of parents' concerns to detect and address developmental and behavioural problems. *Journal of Paediatrics and Child Health*. 1999; 35:1–8.
- Glascoe FP. Parents' evaluation of developmental status: How well do parents' concerns identify children with behavioral and emotional problems. *Clinical Pediatrics*. 2003; 42:133–138. [PubMed: 12659386]
- Horovitz M, Matson JL, Turygin N, et al. The relationship between gender and age of first concern in toddlers with autism spectrum disorders. *Research in Autism Spectrum Disorders*. 2011; 6(1):466–471.
- Hus V, Taylor A, Lord C. Telescoping of caregiver report of the Autism Diagnostic Interview-Revised. *Journal of Child Psychology and Psychiatry*. 2011; 52(7):753–760. [PubMed: 21410473]
- Johnson CP, Myers SM. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*. 2007; 120(5):1183–1215. [PubMed: 17967920]
- Kleinman J, Robins D, Fein D, et al. The Modified Checklist for Autism in Toddlers: a follow-up study investigating the early detection of autism spectrum disorders. *Journal of Autism and Developmental Disorders*. 2008; 38:827–839. [PubMed: 17882539]
- Kozlowski AM, Matson JL, Horovitz M. Parents' first concerns of their child's development in toddlers with autism spectrum disorders. *Developmental Neurorehabilitation*. 2011; 14(2):72–78. [PubMed: 21410398]
- Landa R, Garrett-Mayer E. Development in infants with autism spectrum disorders: A prospective study. *Journal of Child Psychology and Psychiatry*. 2006; 46(2):629–638. [PubMed: 16712640]
- Lord C, Rutter M, Couteur AL. Autism diagnostic interview - revised: A revised version of a diagnostic interview for caregivers of individuals with pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. 1994; 24(5):659–685. [PubMed: 7814313]
- Lord C. Follow-up of two-year-olds referred for possible autism. *Journal of Child Psychology and Psychiatry*. 1995; 36(8):1365–1382. [PubMed: 8988272]
- McMahon CR, Malesa EE, Yoder PJ, et al. Parents of children with autism spectrum disorders have merited concerns about their later-born infants. *Research and Practice for Persons with Severe Disabilities*. 2007; 32(2):154–160.
- Mullen, EM. *Mullen Scales of Early Learning*. AGS Edition.. American Guidance Service, Inc.; Circle Pines, MN: 1995.
- Ozonoff S, Heung K, Byrd R, et al. The onset of autism: Patterns of symptom emergence in the first years of life. *Journal of the International Society for Autism Research*. 2008; 1(6):320–328.
- Ozonoff S, Young GS, Steinfeld MB, et al. How early do parent concerns predict later autism diagnosis. *Developmental and Behavioral Pediatrics*. 2009; 30(5):367–375.
- Reich S. What do mothers know? Maternal knowledge of child development. *Infant Ment. Health J*. 2005; 26:143–156. doi: 10.1002/imhj.20038.
- Robins DL, Fein D, Barton M. *The Modified Checklist for Autism in Toddlers, Revised (M-CHAT-R)*. 2009 Self-published.

- Robins DL, Fein D, Barton M, et al. The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. *Journal of Autism and Developmental Disorders*. 2001; 31(2):131–144. [PubMed: 11450812]
- Rogers BT, Booth LJ, Duffy LC, et al. Parents' developmental perceptions and expectations for their high-risk infants. *Developmental and Behavioral Pediatrics*. 1992; 13(2):102–107.
- Schopler, E.; Reichler, RJ.; Renner, BR. *The Childhood Autism Rating Scale (CARS): For diagnostic screening and classification of autism*. Irvington; New York: 1995.
- Volkmar F, Lord C, Bailey A, et al. Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*. 2004; 45:135–170. [PubMed: 14959806]
- Wetherby AM, Woods J, Allen L, et al. Early indicators of autism spectrum disorders in the second year of life. *Journal of Autism and Developmental Disorders*. 2004; 34(5):473–493. [PubMed: 15628603]
- Werner E, Dawson G, Munson, et al. Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. *Journal of Autism and Developmental Disorders*. 2005; 35(3):337–350. [PubMed: 16119475]
- Young RL, Brewer N, Pattison C. Parental identification of early behavioural abnormalities in children with autistic disorder. *Autism*. 2003; 7(2):125–143. [PubMed: 12846383]

Table 1

Demographics.

	<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>	Significance
	<u>Sibs-ASD</u>	<u>Sibs-TD</u>	<u>No-Sibs</u>	
	(<i>n</i> = 21)	(<i>n</i> = 27)	(<i>n</i> = 21)	
Gender (<i>n</i>)				
Male	14	22	18	NS
Female	7	5	3	
Ethnicity (<i>n</i>)				
White	17 (81.0%)	17 (63.0%)	14 (66.7%)	NS
Hispanic/Latino	3 (14.3%)	2 (7.4%)	3 (14.3%)	
African American	1 (4.8%)	3 (11.1%)	1 (4.8%)	
Biracial	–	2 (7.4%)	1 (4.8%)	
Unknown	–	3 (11.1%)	2 (9.1%)	
Mean age at evaluation	25.1 (4.1%)	25.5 (4.3%)	26.3 (5.2%)	NS
Mean age at screening	21.9 (4.2%)	21.9 (3.8%)	21.8 (4.1%)	NS
Diagnosis (<i>n</i>)				
Autistic disorder	10	10	10	NS
PDD-NOS	9	14	9	
ASD-low mental age	2	3	2	
Mullen mean T-score (SD)				
Expressive Language	30.3 (12.1) *	25.2 (9.6)	21.6 (2.2) *	$F = 4.62, p = .01$
Receptive Language	30.2 (12.6)	23.5 (10.6)	23.1 (6.2)	NS
Visual Reception	33.8 (13.3) *	29.9 (8.9)	25.6 (7.0) *	$F = 3.37, p = .04$
CARS				
Mean total score (SD)	31.7 (5.4)	32.1 (4.5)	31.8 (5.5)	NS
Mean maternal age at birth (SD)	34.4 (3.9) *	30.9 (4.6) *	27.3 (6.0) *	$F = 11.04, p < .01$
Mean years maternal education (SD)	15.1 (2.7)	13.9 (2.6)	14.5 (2.1)	NS

ASD: autism spectrum disorder; TD: typically developing; PDD-NOS: pervasive developmental disorder, not otherwise specified; SD: standard deviation; CARS: Child Autism Rating Scale.

* Significant at $p < .05$ level.

Table 2

Percentage of parents endorsing ASD-specific concerns.

	Group		
	Sibs-ASD (<i>n</i> = 21)	Sibs-TD (<i>n</i> = 27)	No-Sibs (<i>n</i> = 21)
ASD concerns	76%	81%	57%*
Social development	19%	29.6%	9.5%
Language or communication	52%	63%	47.6%
Restricted and repetitive behaviors	9.5%	–	9.5%
Suspicion of autism	4.5%	–	–

ASD: autism spectrum disorder; TD: typically developing.

* $\chi^2 = 4.6, p = .099$.

Table 3

Age of parents' first concerns.

	Group			Significance
	Sibs-ASD (<i>n</i> = 21)	Sibs-TD (<i>n</i> = 27)	No-Sibs (<i>n</i> = 21)	
Age of first concerns				
Mean in months (SD)	10.1 (5.1) **	14.6 (6.4) **	16.2 (6.2) **	$F = 5.96, p = .004$

ASD: autism spectrum disorders; TD: typically developing; SD: standard deviation.

** Significant at $p < .01$ level.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript