HHS Public Access

Author manuscript

J Autism Dev Disord. Author manuscript; available in PMC 2023 June 23.

Published in final edited form as:

J Autism Dev Disord. 2018 October ; 48(10): 3367–3376. doi:10.1007/s10803-018-3598-6.

Parental First Concerns and Timing of Autism Spectrum Disorder Diagnosis

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Abstract

Specific developmental concerns can distinguish between an early versus later diagnosis of autism spectrum disorder (ASD). Caregiver survey responses of children ≥ 9 years-of-age (2012) with ASD were used to evaluate developmental concerns and associations with age of diagnosis [early (< 3 years: n = 106) vs. later (≥ 3 years: n = 432)] using logistic regression. Concerns arose at mean age 18 and 35-months for children diagnosed early versus later, respectively. Concerns about poor eye contact (aOR 1.81, CI 1.08, 3.05), pointing/gesturing (aOR 2.74, CI 1.60, 4.70), response to own name (aOR 3.03, CI 1.75, 5.23), and babbling/speaking (aOR 1.67, CI 0.98, 2.82) were associated with an early diagnosis. Caregivers and pediatricians are critical in early identification and timely entry into intervention.

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Authors' Contributions TAB conceptualized and designed the study, carried out the analyses, drafted the initial manuscript, and approved the final manuscript as submitted. FLL provided content and critical feedback on the manuscript. Approved the final manuscript as submitted. AAO provided content and critical feedback on the manuscript. Approved the final manuscript as submitted. JS provided content and critical feedback on the manuscript. Approved the final manuscript as submitted. LAC contributed to the conceptualization of the study, critically reviewed and revised the manuscript, and approved the final manuscript as submitted.

Conflict of interest None of the authors have financial relationships or any conflicts of interest relevant to this article to disclose.

Compliance with Ethical Standards

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the Institutional and/or National Research Committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. For this study analyses, formal consent was not required.

Electronic supplementary material The online version of this article (https://doi.org/10.1007/s10803-018-3598-6) contains supplementary material, which is available to authorized users.

Keywords

Autism spectrum disorder; Parent; Survey; Developmental concerns; Early diagnosis

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social-communication skills and restricted stereotyped behaviors (American Psychiatric Association 2013). Symptoms of ASD manifest before age 3, though may not be evident until later. U.S. legislation is in place to address the needs of children with developmental delays before age 3 years, an early intervention program under Part C of the Individuals with Disabilities Education Act (IDEA)("IDEA—Building The Legacy of IDEA 2004," n.d.). Furthermore, several studies and initiatives support identifying an earlier window, finding signs between 1 and 2 years of age that can be used for early identification and intervention (Ozonoff et al. 2010; Sacrey et al. 2015; Zwaigenbaum et al. 2015). Earlier diagnosis can lead to earlier intervention, essential for minimizing delays in social-communication skills, optimizing development, and improving parental well-being by reducing stress from untreated ASD (Zwaigenbaum et al. 2015).

While studies have shown that experienced clinicians can detect signs as early as 12 months (Luyster et al. 2009; Ozonoff et al. 2010; Szatmari et al. 2016; Zwaigenbaum et al. 2005), parents may also recognize early concerns useful for early identification of ASD. A prospective study of high-risk infants later diagnosed with ASD and their matched low-risk controls showed that differences in gaze, social smiles, and directed vocalizations were significantly different by 12 months of age (Ozonoff et al. 2010). Though prospective studies of this kind illuminate the potential for earlier identification of ASD, understanding the timing when different behavioral features become apparent to parents can highlight opportunities to improve the early detection of ASD in community and clinical settings.

Speech and language development have been the most commonly reported early concerns among parents of children with ASD and, in addition to other behavioral signs such as restricted/repetitive behaviors and socio-emotional responses, can be detected in the second year of life (Coonrod and Stone 2004; De Giacomo and Fombonne 1998; Herlihy et al. 2015; Matheis et al. 2016; Ozonoff et al. 2009; Richards et al. 2016). In contrast, high-risk design studies, such as the one mentioned earlier by Ozonoff et al. that follow infant siblings of children with ASD, has yielded an understanding that ASD may be evidenced by signs of social communication delays before 18 months (Szatmari et al. 2016). Though a speech and language delay is not specific and is no longer listed as a primary feature of ASD in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (Guinchat et al. 2012; Richards et al. 2016), similar to clinical observation studies, parent-reported communication problems can still be indicators of ASD in the 2nd year of life when signs of social delays are also present (American Psychiatric Association 2013; Vivanti et al. 2013).

In light of the research on early intervention and the availability of resources for children under age 3 with developmental concerns, we evaluated parent-reported first concerns (individually and in combination) to identify which concerns are associated with an early

(less than 3 years old) versus a later (3 years and older) diagnosis. We hypothesized that parents were more often able to identify early non-verbal social communication delays leading to an ASD diagnosis before age 3. By using survey data from caregivers of children with ASD, a resource created by the Mental Health Research Network's (MHRN) Autism Registry (Becerra et al. 2017), findings can provide insight on opportunities for improving early identification and diagnosis of ASD.

Methods

Study Design and Setting

We analyzed survey responses from parents/caregivers of children and adolescents diagnosed with ASD receiving healthcare in four Kaiser Permanente (KP) sites located in Northern and Southern California, Georgia, and the Pacific Northwest. The web survey obtained information about parents' experience having a child with ASD, including demographic and diagnostic information used in the present analyses. Each site obtained approval for the study from its local institutional review board.

Source Population

Eligible individuals were children 17 years and younger who were KP members between February and April 2012, and who had at least one recorded ASD diagnosis in their KP medical record. Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Revision (DSM IV-R) criteria were consistently used across centers and a previous validation study found a high positive predictive value using the one diagnosis method (Coleman et al. 2015). All households with an eligible child were mailed a packet containing a recruitment letter which included a link and instructions to the web survey and a fact sheet explaining the study. Further details regarding recruitment can be found in a previous publication (Becerra et al. 2017).

Outcome Definition

The primary outcome was age when first ASD diagnosis was made, based on the survey response to the question: "How old was the child when he/she was given his/her first ASD diagnosis?" which was captured in free-text and subsequently dichotomized as < 3 vs. ≥ 3 years.

Predictor Variables

The primary predictor variables of interest were specific type and number of caregiver-reported first developmental concern(s) using a checklist of 13 concerns, mostly representing the common and core features of ASD and an adaptation of items from developmental and autism-specific screening tools (Baron-Cohen et al. 2000; Paul Brookes Publishing Co., Inc. 2017). Multiple responses were allowed for the question, "What was your first concern(s) about your child's development?"

Other variables of interest included characteristics of the caregiver who responded to the survey: age, race/ethnicity, language spoken at home, highest level of educational attainment, marital status, and annual household income; characteristics of the child: age,

sex, race/ethnicity, and specific autism diagnosis; and characteristics of the family: child has a sibling with ASD, and first person to express concern about ASD.

Statistical Analysis

To standardize the observation period such that every child had a comparable look-back period for parental reporting of diagnosis age and concerns, we restricted the analytic sample to children who were 9 years of age or older at the time of the survey and diagnosed with ASD at age 8 or younger. Age 8 was selected as the cutoff in accordance with the autism and developmental disabilities monitoring (ADDM) Network's methods for measuring peak prevalence of ASD (Autism and Developmental Disabilities Monitoring Network Surveillance Year 2006 Principal Investigators and Centers for Disease Control and Prevention 2009).

We used descriptive and Chi square statistics to test for differences in characteristics between children diagnosed early (< 3 years) and those diagnosed later (≥ 3 years). We calculated unadjusted and adjusted odds ratios (ORs) and 95% confidence intervals (CIs) using logistic regression to estimate the association between specific type and number of developmental concerns and age at diagnosis (< 3 years vs. ≥3 years old). We adjusted for potential confounders, known *a* priori to be associated with timing of ASD identification, including child's sex, ASD diagnosis type, sibling with ASD; caregiver's race/ethnicity, age, education, and annual household income (Becerra et al. 2014; Colbert et al. 2016; Fountain et al. 2011; Herlihy et al. 2015; Shattuck and Grosse 2007). We also assessed the consistency of associations across responses to the question, "Who was the first person to mention the possibility of having ASD?" [see Table 1 for categories].

Distributions of the child's age at first concern (months), number of concerns, diagnosis age (years), concern-to-diagnosis time interval (months), and time since diagnosis (the difference in years between the child's age during the survey and their age at diagnosis) were described. In addition, we assessed differences in age at first concern between children with and without a sibling with ASD.

For all developmental concerns, we calculated frequencies and estimated bivariate Pearson correlation coefficients between concerns. Exploratory factor analysis with a hypothesis of two factors (one factor for each outcome group) was conducted to examine grouping patterns of all the developmental concerns. Specifically, we wanted to assess whether the developmental concerns found to be associated with an early ASD diagnosis grouped together. Factor analysis was performed using principal components extraction with varimax rotation with factor loading cut-off at 0.5.

Results

A total of 9109 children with ASD meeting survey eligibility criteria were identified across all sites. After excluding individuals who were not contacted because of an incorrect address (n = 175, 1.9%), 1155 parents responded to the survey (12.9%). Respondents reflected the population invited to participate with respect to child's sex, age at survey response, ASD diagnosis type, and age at ASD diagnosis. Additional details about responders and

non-responders are available in a previous publication describing the survey (Becerra et al. 2017).

We excluded 396 (34.3%) children younger than age 9 at the time of the survey and 161 (13.9%) children who were diagnosed after age 8, or age at diagnosis was unknown (n = 39, 3.4%). In addition, 7 (0.6%) children whose caregivers reported they currently did not have autism and 14 (1.2%) in which the subtype of autism was not specified were excluded. The final sample included 538 survey responses.

The overall mean age of diagnosis was 4.7 years (SD: 2.04) and the median was 4.1 years; 2.2 years (SD: 0.46) among children diagnosed < 3 years of age and 5.3 (SD: 1.80) among children diagnosed ≥ 3 years of age [Table 1]. Compared to children diagnosed later, children diagnosed early were more likely to be given a diagnosis of ASD or autistic disorder and more likely to have their pediatrician be the first person to mention the possibility of autism. Compared to children diagnosed early, children diagnosed later were more likely to be diagnosed with Asperger's syndrome or Pervasive Developmental Disorder—Not Otherwise Specified, and be identified first by their teacher. Children diagnosed early more often had a sibling with autism (20% versus 14%), though the difference was not significant (p = 0.11). There were no differences in socioeconomic characteristics between the early and later diagnosed groups, including caregiver education (p = 0.95) and household income (p = 0.23).

In general, most respondents (95%) reported first developmental concerns by or before age 6 years (≤ 3 years: 78%; ≤ 2 years: 59%). First developmental concerns arose at a mean age of 31.5 months (SD: 19.58); 18.1 months (SD: 7.15) for children diagnosed early and 34.8 months (SD: 20.25) for children diagnosed later [Table 2]. Findings were consistent between children with and without a sibling with ASD. The average time interval between age at first concern and age at diagnosis was 8 months for children diagnosed early and 28 months for children diagnosed later. The mean number of concerns was six among children diagnosed < 3 years of age and five concerns among children diagnosed ≥ 3 years of age [Table 2]. The most frequently reported number of developmental concerns across both outcome groups was three (14%), and only 4% of caregivers reported no concerns (n = 21).

Specific types of concerns associated with timing of diagnosis are shown in Table 3. Approximately 50% of survey respondents reported having concerns about their child not/rarely initiating social interactions; poor eye contact; unusual responses to touch, taste, smells, and/or sounds; focusing on objects or self rather than other people; and delayed or abnormal babbling/speaking. Among these commonly reported concerns, frequencies were similar across both diagnosis groups with some indication that poor eye contact and delayed or abnormal babbling/speaking concerns were more common in the early diagnosis group compared to the later diagnosed.

Children with first concerns regarding poor eye contact were at greater odds of being diagnosed early versus later (adjusted odds ratio [aOR] 1.81, 95% confidence interval [CI] 1.08, 3.05; Table 3). Abnormal babbling/speaking was associated with an early diagnosis, though the results were not statistically significant (aOR 1.67, CI 0.98, 2.82). The direction

of associations was similar when the first person to mention possible ASD was a parent or a pediatrician (poor eye contact: aOR 2.81 [CI 0.71, 11.11] vs. aOR 4.91 [CI 0.78, 30.81], respectively; abnormal babbling/speaking: aOR 1.17 [CI 0.27, 5.13] vs. aOR 10.68 [CI 1.09, 104.83], respectively), and the abnormal babbling/speaking association was significant when pediatricians were the first to mention possible autism. Focusing on objects or self rather than other people (aOR 1.11, CI 0.66, 1.85), and unusual responses to touch, taste, smells, and/or sounds (aOR 1.17, CI 0.70, 1.97) did not distinguish between an early versus a later diagnosis. Concerns about initiating social interactions was associated with a later diagnosis (aOR 0.58, CI 0.34, 0.99), regardless of who was the first person to mention possible autism.

Though not as common overall, concerns about sleeping irregularities and regression were also associated with an early diagnosis. Pointing/gesturing and having a delayed/absent response to own name were quite frequently reported in the early diagnosis group and were also found to be associated with an early diagnosis in the adjusted models [Table 3]. The direction of these associations was the same regardless of who (parents or pediatricians) first mentioned possible autism (pointing/gesturing: aOR 6.55 [CI 1.44, 29.75] vs. aOR 1.33 [CI 0.20, 8.78], respectively; delayed/absent response to own name: aOR 5.26 [CI 1.23, 22.47] vs. aOR 3.85 [CI 0.52, 28.38], respectively), though the associations were only significant when parents were the first to mention it. The likelihood of an early diagnosis increased by 11% on average with increasing number of developmental concerns (aOR 1.11, CI 1.02, 1.21).

Correlations (r) between concerns ranged from −0.12 to 0.44 [Table 4]. Among developmental concerns positively associated with an early diagnosis, delayed/absent response to own name was moderately correlated with delays in pointing/gesturing ($r = 0.42$) and poor eye contact ($r = 0.36$). A delay in pointing/gesturing was also moderately correlated with delayed or abnormal babbling/speaking ($r = 0.34$). Though not/rarely initiating social interaction was the only concern found to be associated with a later diagnosis, this concern was also moderately correlated with having poor eye contact ($r = 0.39$). Concerns about sleeping irregularities and regression had weaker correlations with other developmental concerns ($r < 0.24$).

In the exploratory factor analysis, concerns about delayed/absent response to own name, not pointing/gesturing, and delayed or abnormal babbling/speaking were found to occur together [Supplemental Table 1].

Discussion

This study based on survey data of caregivers with children with ASD provides important information regarding associations between parental concerns about early development and age of ASD diagnosis. First, significant differences were found between children diagnosed early compared to those diagnosed later in the average age of first parental concern and the average duration in seeking/attaining a diagnosis. Second, we found that concerns about delays in pointing/gesturing, response to own name, babbling/speaking, and poor eye contact were associated with an early diagnosis. Although our study was based on prevalent cases, discerning between parent-reported developmental concerns that lead to an early versus a

later diagnosis provides a valuable understanding of how best to target early identification efforts.

Diagnosis and concern age in this study is comparable to other studies, demonstrating a consistency across U.S. and non-U.S. samples of children of the same age. The average age of ASD diagnosis among children in this study was 4.7 years, comparable to the diagnosis age of 5.3 years found in another national survey study (2011 Survey of Pathways to Diagnosis and Services) (Zablotsky et al. 2017). Similarly, the median diagnosis age was 4.1 years in this study, similar to the 4.2 median diagnosis age in the 2012 ADDM Network sample of 8 year old children (Christensen et al. 2016). However, compared to the ADDM Network's 87% of children with ASD with documented developmental concerns by or before age 3 years, the proportion with reported concerns by this same age in this study was lower (78%), potentially due to the different concern ascertainment methods. Yet, among children diagnosed before age 3, concerns arose at the average age of 18.1 months in this study, comparable to other studies of young children that found the average age of first concern between 16 and 28 months (Herlihy et al. 2015; Kishore and Basu 2011).

Consistent with one other study that comprehensively reviewed first concerns from caregivers and providers using health/education diagnostic records of children with autistic disorder which found that nonverbal communication was associated with an early diagnosis, our study was specific in finding that poor eye contact, pointing/gesturing, and delayed/absent response to own name were associated with an early diagnosis (Maenner et al. 2013). In addition, several other studies have reported that verbal communication delays are a concern often reported by parents (Herlihy et al. 2015; Matheis et al. 2016; Richards et al. 2016; Zablotsky et al. 2017). Though a speech delay is not specific to ASD (Guinchat et al. 2012; Richards et al. 2016), it may be the most obvious developmental delay compared to non-verbal communication difficulties. Thus, given that a delay in speech and language is common, further probing or follow-up assessment for early intervention, even before a diagnostic status can be confirmed, could address functional concerns through specific short-term interventions. Developmental monitoring can also support the child and family while they wait.

Concerns regarding the ability to initiate social interactions was an indicator of a later diagnosis, a novel finding made possible by the age of the study sample. Most other studies of parents' first concerns are based on samples of young children and with different comparison groups (Herlihy et al. 2015; Matheis et al. 2016; Sacrey et al. 2015). Thus, they are limited in assessing the association between parent-reported concerns in initiating social interactions and a later ASD diagnosis. Although young children have the capacity to initiate interactions by social referencing or seeking shared enjoyment, e.g., through eye contact and pointing/gesturing, this finding could be explained by the increasing expectations to interact with peers as children get older. This challenges a common response to "wait and see" that some parents and health providers may result to, waiting to observe children in education or childcare settings where the social demands could be more telling of children's capacities. It is also possible that our results reflect a different underlying ASD phenotype of children diagnosed later than those diagnosed early. For example, a large proportion of children diagnosed after age 3 in this study had Asperger's syndrome (35%),

a less severe ASD phenotype with respect to impairments in language communication and comorbid cognitive delays (American Psychiatric Association 2013). However, we did not have detailed information about children's cognitive and speech functioning that could have provided additional insight, a limitation of this study. Because Asperger's disorder was eliminated from the DSM-5 this may be less of an issue in current cases of ASD. Still, adopting a prevention approach regardless of whether a child ultimately receives an ASD diagnosis could prevent delays in intervention, especially given that children diagnosed later had over a 2-year average period between first concern and first diagnosis.

Focusing on objects or self rather than other people and unusual responses to touch, taste, smells, and/or sounds were prevalent developmental concerns that did not distinguish between an early and a later ASD diagnosis. Parent concerns about unusual responses to sensory stimuli may not have triggered early identification during our study period because it is a newer criterion for the diagnosis of ASD in the DSM-5. Unusual responses to sensory stimuli are often associated with social-emotional behavior such that interacting in social environments first requires regulating an emotional response that is dependent on effectively processing everyday sensory stimuli, e.g., light, touch, sound. Given their importance and prevalence (92% of children 10–14 years with ASD)(American Psychiatric Association 2013; Green et al. 2016), being recognized as a core symptom of ASD may allow more children to be diagnosed earlier. Although a prevalent concern, having a preference for objects or self rather than other people is an ASD symptom described in both the DSM IV-R and the DSM-5 that did not distinguish between an early and a later diagnosis, potentially because of the low expectations for children to interact with others at younger ages.

The factor analysis results further helped characterize how parents identify patterned delays. Delays in basic social-communication, i.e., pointing/gesturing, response to own name, and babbling/speaking, can be evident as early as 4 months when babbling is expected to emerge (Centers for Disease Control and Prevention n.d.). Subsequently, children not meeting developmental milestones in responding to own name at 6 months and pointing at 9 months is a pattern that seemed to be evident to parents early enough to seek a diagnosis of ASD before age 3.

Unlike other studies, children of parents with a higher education and income were not more likely to be diagnosed at an earlier age (Fountain and Bearman 2011; Magaña et al. 2013). The absence of differences in socioeconomic indicators between the two outcome groups may reflect the characteristics of the study population which was an insured population, potentially reducing the heterogeneity of the sample. Since the survey was web-based, responders may have had more access to the internet compared to non-responders resulting in a representation of largely computer- and health-literate families. Though response rates were lower among black and Asian subgroups (Becerra et al. 2017), we had a considerable number of study participants from minority populations represented in these analyses (38%).

The potential for biased reporting of first developmental concern information between the diagnosis groups is an important limitation of this study. Parents were expected to recall information across varying time periods, thus it may have been more difficult for caregivers with long time periods since their child's diagnosis to recall concern and diagnosis details

compared to caregivers with shorter time periods since diagnosis. Because we restricted the sample to children age 9 and older, the recall periods were expectedly longer for caregivers of children diagnosed early compared to those diagnosed later. Thus, underreporting of developmental concerns by parents of children diagnosed early could have caused the results to be biased toward the null, or caused the underestimation of the association between concerns and diagnosis age. However, the average recall periods across both diagnosis groups were long, potentially limiting recall bias across comparably long recall periods in both diagnosis groups. With respect to external validity, the results are representative of those who responded. Inherent in most survey studies, responders may be a non-random group and may not represent all caregivers with children 9 years of age or older with ASD. It is also important to note that the concerns reported in the survey do not necessarily reflect concerns parents reported to their child's pediatrician. Thus, the age at first concern may represent retrospection, or thoughts at the time that were not expressed to others, and therefore cannot be directly linked to the age at diagnostic evaluation. In addition, parents and pediatricians were equally likely to be the first person to mention the possibility of autism in children diagnosed early, making it also possible that first developmental concerns reported by parents could have been elicited by pediatricians.

The American Academy of Pediatrics (AAP), one of the most respected authorities on pediatrician practices, first released a policy statement in 2001 to help pediatricians recognize the early symptoms of ASD and encourage them to value parent concerns about their child's development (Committee on Children With Disabilities 2001). In more recent years, caregivers have been expected to report concerns during brief surveillance with pediatricians during well child care (WCC) visits. Pediatricians see a child for 11 WCC visits by his/her third birthday, perform developmental surveillance at all visits, and conduct three standardized developmental screenings, all of which can be points of contact to address developmental concerns together with parents (American Academy of Pediatrics 2017). Of note, the developmental concerns regarding poor eye contact, pointing/gesturing, response to own name, and babbling/speaking found to be associated with an early ASD diagnosis reflect similar questions from common developmental/ASD screening tools, e.g., Ages and States Questionnaires, Modified Checklist for Autism in Toddlers (Baron-Cohen et al. 2000; Paul Brookes Publishing Co., Inc. 2017). Our findings support use of targeted questioning during unstructured developmental surveillance pediatric visits or standardized screening at all second and third year WCC visits.

Conclusion

Identifying developmental delays in early childhood can be very nuanced and parents may have difficulty recognizing deficits. To ensure children across the diagnostic spectrum have timely identification, it is critical that education and awareness campaigns continue, and that pediatricians pay attention to parental concerns, identify developmental delays early, and initiate referrals so that families can benefit from clinical and therapeutic advances in early intervention.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This project was funded by a grant from National Institute of Mental Health (Grant # 1U19MH092201).

Funding This project was funded by a Grant from National Institute of Mental Health (Grant # 1U19MH092201).

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Table 1

Caregiver and child characteristics by child age at first autism diagnosis, n = 538

	Early diagnosis (< 3 years) n = 106		Later diagnosis (≥ 3 years) n = 432		p-value
	n	%	n	%	
Diagnosis age (years)					
Mean (standard deviation)	2.2 (0.46)		5.3 (1.80)		
Median	2.0		5.0		
First quartile, third quartile	2.0, 2.5		3.5, 7.0		
Range	(1.0, 2.9)		(3.0–8.8)		
Caregiver age (years)					0.93
18–34	6	5.7	20	4.6	
35–44	41	38.7	165	38.2	
≥ 45	57	53.8	222	51.4	
Missing	2	1.9	25	5.8	
Caregiver race/ethnicity					0.78
White (non-Hispanic)	71	67.0	270	62.5	
Hispanic	15	14.2	62	14.4	
African American/Black	3	2.8	22	5.1	
Asian/Pacific Islander	8	7.5	26	6.0	
Multiple	3	2.8	15	3.5	
Other	3	2.8	6	1.4	
Missing/prefer not to answer	3	2.8	31	7.2	
Language spoken at home					0.13
English	97	91.5	392	90.7	
Other language	7	6.6	14	3.2	
Missing/prefer not to answer	2	1.9	26	6.0	
Highest level of education					0.95
High school or less	8	7.5	29	6.7	
Some college	28	26.4	117	27.1	
College degree	37	34.9	150	34.7	
Graduate degree	30	28.3	108	25.0	

	Early diagnosis (< 3 years) n = 106		Later diagnosis (≥ 3 years) n = 432		p-value
	n	%	n	%	
Missing/prefer not to answer	3	2.8	28	6.5	
Marital status					0.34
Married/living with partner	87	82.1	321	74.3	
Single/separated/divorced/widowed	17	16.0	83	19.2	
Missing/prefer not to answer	2	1.9	28	6.5	
Annual household income					0.23
Less than $60,000	25	23.6	120	27.8	
$60,000–$99,999	37	34.9	115	26.6	
$100,000 or more	30	28.3	138	31.9	
Missing/prefer not to answer	14	13.2	59	13.7	
Child characteristics					
Child age at survey response (years)					0.90
9–10	33	31.1	139	32.2	
11–13	37	34.9	141	32.6	
14–17	36	34.0	152	35.2	
Child sex					0.46
Male	88	83.0	371	85.9	
Female	18	17.0	61	14.1	
Child’s race/ethnicity					0.45
White (non-Hispanic)	65	61.3	234	54.2	
Hispanic	24	22.6	85	19.7	
African American/Black	3	2.8	24	5.6	
Asian/Pacific Islander	6	5.7	19	4.4	
Multiple	4	3.8	32	7.4	
Other	1	0.9	9	2.1	
Missing/prefer not to answer	3	2.8	29	6.7	
Diagnosis					< 0.001
Autism spectrum disorder	53	50.0	136	31.5	
Asperger’s syndrome	10	9.4	150	34.7	
Autistic disorder	32	30.2	81	18.8	

	Early diagnosis (< 3 years) n = 106		Later diagnosis (≥ 3 years) n = 432		p-value
	n	%	n	%	
Pervasive developmental disorder—not otherwise specified	11	10.4	65	15.0	
Sibling with autism					0.11
No	84	79.2	370	85.6	
Yes	21	19.8	59	13.7	
Don’t know/missing	1	0.9	3	0.7	
First person to mention possible autism					< 0.001
Parent/guardian	26	24.5	100	23.1	
Another family member	15	14.2	31	7.2	
Pediatrician	26	24.5	45	10.4	
Another health care provider	19	17.9	94	21.8	
Teacher/child care provider	9	8.5	102	23.6	
Someone else	11	10.4	53	12.3	
Don’t know	0	0.0	7	1.6	

p-values are based on Chi square test for differences. Missing, Don’t know, or Prefer not to answer categories were not included as categories in the test for differences

Table 2

Distributions of concern and diagnosis information, n = 538

	Early diagnosis (< 3 years) n = 106	**Later diagnosis (≥ 3 years) n = 432**
Age at first concern (months)		
Mean (standard deviation)	18.1 (7.15)	34.8 (20.25)
Median	17.0	36.0
First quartile, third quartile	12.0, 24.0	24.0, 48.0
Range	(1.0–32.0)	(0.0–96.0)
Number of concerns		
Mean (standard deviation)	5.8 (3.31)	4.8 (2.93)
Median	6.0	4.0
First quartile, third quartile	3.0, 8.0	3.0, 7.0
Range	(0.0, 13.0)	(0.0, 13.0)
Concern-to-diagnosis interval (months)		
Mean (standard deviation)	7.9 (6.80)	28.3 (23.10)
Median	7	24
First quartile, third quartile	2.0, 12.0	12.0, 43.0
Range	(0.0–24.0)	(0.0–92.0)
Time since diagnosis (years)		
Mean (standard deviation)	10.1 (2.52)	7.1 (3.12)
Median	9.7	7
First quartile, third quartile	8.0, 12.2	5.0, 9.0
Range	(6.1–16.0)	(0.4–15.0)

Table 3

Associations between first developmental concern(s) and age at autism diagnosis, n = 538

	Total		< 3 years (n = 106)	≥ 3 years (n = 432)	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
	n	%				
Number of developmental concerns					1.11 (1.03, 1.18)	1.11 (1.02, 1.21)
Type of concern						
Did not sleep as much as other children	119	22.1%	33.0%	19.4%	2.04 (1.28, 3.27)	2.87 (1.59, 5.19)
Lost skills or regressed	126	23.4%	40.6%	19.2%	2.87 (1.82, 4.53)	2.86 (1.60, 5.10)
Abnormal motor development/muscle tone	138	25.7%	22.6%	26.4%	0.82 (0.49, 1.35)	0.68 (0.37, 1.27)
Delayed/absent response to own name	151	28.1%	50.0%	22.7%	3.41 (2.19, 5.30)	3.03 (1.75, 5.23)
Did not point/gesture/imitate	154	28.6%	46.2%	24.3%	2.68 (1.72, 4.16)	2.74 (1.60, 4.70)
Repetitive behaviors: hand-flapping/rocking	197	36.6%	37.7%	36.3%	1.06 (0.68, 1.65)	1.09 (0.64, 1.86)
Did not engage in pretend/imitative play	239	44.4%	51.9%	42.6%	1.45 (0.95, 2.23)	1.33 (0.79, 2.24)
Delayed/abnormal babbling/speaking	245	45.5%	60.4%	41.9%	2.11 (1.37, 3.26)	1.67 (0.98, 2.82)
Other people expressed concerns	247	45.9%	34.9%	48.6%	0.57 (0.36, 0.88)	0.60 (0.35, 1.05)
Focused on objects/self than other people	255	47.4%	45.3%	47.9%	0.90 (0.59, 1.38)	1.11 (0.66, 1.85)
Unusual responses to touch/taste/smell/sounds	267	49.6%	46.2%	50.5%	0.84 (0.55, 1.29)	1.17 (0.70, 1.97)
Had poor eye contact	277	51.5%	60.4%	49.3%	1.57 (1.02, 2.41)	1.81 (1.08, 3.05)
Did not/rarely initiate social interaction	278	51.7%	46.2%	53.0%	0.76 (0.50, 1.17)	0.58 (0.34, 0.99)

Adjusted for child sex, specific autism diagnosis; caregiver race/ethnicity, age, education, marital status; household language and income; person who identified concern, sibling with autism

Table 4

Developmental concern distributions and Pearson's correlation coefficients, n = 538

Developmental concern	Pearson's correlation coefficients												
	Developmental concern												
	1	2	3	4	5	6	7	8	9	10	11	12	13
Did not sleep as much as other children	1.00												
Lost skills or regressed	0.10	1.00											
Abnormal motor development/muscle tone	0.08	0.02	1.00										
Delayed/absent response to own name	0.21	0.21	0.13	1.00									
Did not point/gesture/imitate	0.20	0.16	0.17	0.42	1.00								
Repetitive behaviors: hand-flapping/rocking	0.17	0.24	0.22	0.19	0.27	1.00							
Did not engage in pretend/imitative play	0.17	0.14	0.15	0.32	0.44	0.25	1.00						
Delayed/abnormal babbling/speaking	0.08	0.13	0.12	0.22	0.34	0.15	0.25	1.00					
Other people expressed concerns	−0.01	0.04	0.09	−0.01	−0.01	0.07	0.05	−0.12	1.00				
Focused on objects/self than other people	0.15	0.16	0.14	0.16	0.24	0.24	0.27	0.08	0.04	1.00			
Unusual responses to touch/taste/smell/sounds	0.24	0.02	0.22	0.11	0.12	0.29	0.20	−0.03	0.15	0.26	1.00		
Had poor eye contact	0.17	0.11	0.13	0.36	0.27	0.22	0.26	0.09	0.07	0.31	0.21	1.00	
Did not/rarely initiate social interaction	0.11	0.12	0.18	0.28	0.34	0.31	0.35	0.17	0.07	0.36	0.21	0.39	1.00

J Autism Dev Disord. Author manuscript; available in PMC 2023 June 23.