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ORIGINAL PAPER

Family Experiences with the Diagnosis of Autism Spectrum Disorder: System Barriers and Facilitators of Efficient Diagnosis

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Abstract
This paper examines family experiences with the efficiency of ASD diagnosis. Children were age 8 or younger with ASD (n = 450). Outcomes were delay from first parent concern to diagnosis, shifting diagnoses, and being told child did not have ASD. Predictors were screening, travel distance, and problems finding providers. Logit models were used to examine associations. Screening was associated with reduced delay in diagnosis; problems finding providers were associated with greater delay. Screening, travel distance, and delay in diagnosis were associated with shifting diagnoses and being told child did not have ASD. Physician and parent training in communication and addressing mental health professional shortages and maldistribution may improve the diagnosis experiences of families of children with ASD.

Keywords Autism · Age at diagnosis · Policy

Introduction

The most recent data from the Centers for Disease Control indicate that although autism spectrum disorder (ASD) can be diagnosed as early as age 2 (Ozonoff et al. 2008) and first concerns by parents are commonly reported between 18 and 24 months (Zwaigenbaum et al. 2015), the median age of diagnosis of children is 4 years (Christensen et al. 2016). NonHispanic white children with ASD are more likely to receive a comprehensive evaluation and diagnosis before the age of 3, compared to other children (Christensen et al. 2016; Jo et al. 2015). The American Academy of Pediatrics continues to stand behind its recommendation to screen for ASD at 18 and 24 months (AAP 2016; Johnson et al. 2007) despite disagreement over the value of evidence supporting universal early screening for ASD (Siu et al. 2016; Dawson 2016; McPheeters et al. 2016; Voelker 2011; Al-Qabandi et al. 2011). Regional summits hosted by the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the Association of University Centers on Disabilities (AUCD) identified particular challenges for early screening and diagnosis among low income, rural, and non-English speaking populations (Peacock and Lin 2012). This paper examines system barriers and facilitators of efficient diagnosis that states can address.

Substantial evidence exists about child and family factors associated with age of diagnosis (Emerson et al. 2016; Herlihy et al. 2015; Miodovnik et al. 2015; Mazurek et al. 2017; Campbell et al. 2013; Goin-Kochel et al. 2006). This evidence includes predisposing (race, ethnicity, child age at evaluation, child age cohort), enabling (parent education, household income, usual source of care) and need (ASD severity, ADHD, speech-language problems, intellectual disability, developmental delay) factors, all characteristics of the classic public health conceptual framework, the Andersen Behavioral Health Model (Gelberg et al. 2000). In contrast, evidence is sparse on the system barriers families face and the strategies states and local governments can use to reduce problems obtaining a diagnosis. The contextual factors of the Andersen Model, identified here as system barriers (travel distance to a provider and problems finding

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a provider) and facilitators (completing screening forms), reflect the setting in which the child and family live, and impact their predisposing, enabling and need characteristics which, in turn, impact the child's health service use and health status.

The present study addresses this knowledge gap through a statewide survey of families of children in North Carolina to assess family experiences with diagnosis of autism, and system barriers and strategies to reduce these problems. We use the Andersen Behavioral Model as a conceptual framework and hypothesize that contextual factors, such as screening can improve timely diagnosis of ASD, while system barriers (travel distance to a provider and problems finding a provider) will delay timely diagnosis, controlling for family and child predisposing, enabling and need characteristics. This paper contributes to the literature by studying system factors in a state with strong autism awareness (Autism Society of North Carolina 2016) and typical access to services (Thomas et al. 2012b), by controlling for known child and family factors associated with diagnosis, and by fielding the survey in both English and Spanish and in rural areas to ensure diversity of participants.

Methods

Setting and Participants

The study took place in North Carolina from March 2014 through June 2015. North Carolina benefits from an active ASD research, services and advocacy community. The TEACCH Program at the University of North Carolina School of Medicine provides community-based services across the state, training programs, and research (TEACCH 2017). Additionally, the state has one of the largest state chapters of the Autism Society of America (Autism Society of North Carolina 2017). The estimated prevalence of ASD in the state (1/58 children) is higher than the mean across all 14 states of the Autism and Developmental Disabilities Monitoring Network (Autism and Developmental Disabilities Monitoring Network 2016). On the other hand, 41% of the state's population is rural (North Carolina Department of Commerce 2017) and the state has a shortage of mental health professionals (Thomas et al. 2012c). A state needs assessment revealed that only 6% of mental health providers (physicians and psychologists) with responsibility for behavioral health assessment and diagnosis were comfortable providing a diagnosis of ASD, and only about 6% were trained to conduct screening or assessment procedures for this population (Hooper and Pretzel 2013). Moreover, 90% of these providers reported being unfamiliar, untrained, and uncomfortable providing early intervention for this population. As a result, while the median age of diagnosis of ASD is 46 months, there are racial and ethnic disparities in prevalence (Autism and Developmental Disabilities Monitoring Network 2016). This variation in resources and outcomes makes North Carolina an ideal setting to study the barriers and facilitators of care (Thomas et al. 2007).

Participants were invited by the Autism Society of North Carolina (ASNC 2017) through their listserv to complete an online survey. Invitations to participate were also sent by email to local chapter lists of individuals interested in ASD but not members of the society. Participants were also invited to participate using the North Carolina Autism Research Registry via email invitation (Carolina Institute for Developmental Disabilities' North Carolina Autism Research Registry 2017). All invitations included a letter stating the purpose of the study. Surveys in paper format were also distributed at local ASNC meetings in areas with limited internet access and Spanish versions in areas with populations having limited English proficiency. Inclusion criteria were having a child age 8 or younger with a diagnosis of ASD provided by a professional. The ASD diagnosis was confirmed by parent report on the survey.

Survey Development and Distribution

The survey was developed and sponsored by the North Carolina State Implementation Grant (5-H6M-MC26248-01-02), Maternal and Child Health Leadership Education in Neurodevelopmental Disorders (5-T73-MC00030-23), and the Administration on Intellectual and Developmental Disabilities (90DD0676/01-03). These three groups comprise representatives from state agencies and advocacy groups, service providers, researchers, interdisciplinary graduate trainees, parents of children with ASD, and self-advocates. A collective aim of these groups is to reduce the age of early identification, diagnosis and entry into intervention for North Carolina children who have or are at-risk for a diagnosis of ASD. A subcommittee across the groups worked together to develop the survey. The survey was designed to gather information from parents of children with ASD about the key milestones of first concerns, identification, diagnosis, entry into intervention, and families' pathways to obtain these services, as well as to identify current needs of parents for services and supports.

The survey was developed in an iterative process with careful review of the existing literature, drafts of questions generated and reviewed by members of the above listed supporting groups, and in consultation with experts in survey design from the UNC Chapel Hill Howard W. Odum Institute for Research in Social Science. Once a pilot survey was drafted, it was completed by 17 families of young children with ASD to gain their feedback on any questions that were unclear or wording changes that were needed. The survey

was then finalized using the feedback provided. A Spanish version of the survey was also developed to ensure participation by a more representative sample of the state's population. As recommended, the Spanish version of the instrument was translated, back translated, and reviewed by two bilingual Latino team members (Behling and Law 2000). The survey contained 40 questions focused on information about the demographics of the child and family, when families had their first concerns, whether screening occurred, about the diagnosis (when it occurred, who provided it), about the child's entry into services (difficulty locating, accessing, or paying), and the impact on the family of caring for the child.

The online survey was programmed using Qualtrics. A link to the survey was sent via email. No identifying data were collected. Survey responses collected via paper were double entered and discrepancies resolved through discussion and re-examination of the paper-based response. Paper surveys were obtained at four Autism Society local meetings, including two meetings in Spanish and two held near American Indian communities. Participants were eligible to enter a raffle for a chance to win $50.00 in appreciation for their participation. The study was reviewed by the UNC Chapel Hill Office of Human Research Ethics and deemed exempt from oversight.

Measures

Three outcome measures were examined for the current manuscript: delay in diagnosis, shifting diagnoses, and previously being told child did not have ASD. Delay in diagnosis was captured as the interval of time from first parent concern to diagnosis, measured in months as the difference between child age when the participant first became concerned about the child's development and child age when he or she was first diagnosed with ASD by a professional. The variable shifting diagnoses was captured as receipt of other diagnoses prior to being told the child had ASD. Those other diagnoses included one or more of the following: developmental delay, intellectual disability, mental retardation, hearing impairment, learning disorder, genetic or chromosomal disorder (e.g., fragile X), speech or language delay, attention deficit hyperactivity disorder, or sensory integration or sensory regulation disorder. Ever being told that the child did not have ASD was captured by affirmation to the question, 'Were you told specifically that your child did NOT have an Autism Spectrum Disorder by any North Carolina professional prior to your child's initial Autism Spectrum Disorder diagnosis?'

In order to identify system factors that might support or undermine efficient diagnosis, three measures were examined. Because screening has the potential to play such an important role in eventual ASD diagnosis, families were asked, 'Did you complete any forms about autism for your pediatrician or family doctor?' As distance to a professional or team can present a barrier, distance traveled to see the professional or team of professionals for the initial ASD diagnosis was measured as 20 miles (32 km) or less, 21–60 (34–97 km), or more than 60 miles (97 km) representing roughly 20 min, 21–60 min, and more than 60 min of travel time. Because locating a mental health professional can be a challenge, families were asked whether they agreed or strongly agreed with the statement, 'I have had problems finding the following types of professionals for my child' in reference to a psychiatrist or psychologist. Data were also collected on predisposing, enabling and need characteristics of the child and family, consistent with the Andersen Behavioral Model (Gelberg et al. 2000).

Analytic Methods

Logit models were used to examine the association between efficient diagnosis and system factors, controlling for child and family characteristics. Chi-square tests were used to identify characteristics of children and families associated with those system factors. Because these analyses were exploratory, tests use an alpha of .1. Analyses were conducted using SAS® software version 9.4.

Results

Participant Characteristics

Survey participants (n = 450) reported a mean age of their child with ASD of 73.2 months (6.1 years), 76.5% of families were white, 12.6% black (Table 1). These families were 13.3% Hispanic ethnicity, and 6.6% of all families spoke Spanish at home. Thirty-six (35.9%) percent of families had annual income of $45,000 or less, 10.6% of parents had at most a high school degree, and among their children, 39.6% had public insurance, 60.2% private insurance, and 6.9% no insurance. Most children (78.5%) had autistic disorder, 11.0% had Asperger's disorder, and 10.5% had pervasive developmental disorder. These diagnoses were determined prior to the most recent revision of the Diagnostic and Statistical Manual for psychiatric diagnoses (DSM; American Psychiatric Association 2013) and are consistent with a DSM-5 ASD diagnosis. Among families, 12.9% reported other siblings with ASD as well. The mean child age when parents were first concerned about development was 20.6 months. The mean age at diagnosis was 38.8 months. The mean interval from first parent concern to diagnosis of ASD, the delay in diagnosis, was 19 months, and 31.8% experienced an interval of at least 24 months. Prior to ASD diagnosis, 54.3% of children were

Table 1 Participant characteristics (n = 450)

Characteristic	N	Percent or mean (SD)
Outcome measures		
Interval from first concern to diagnosis (months)[a]	424	18.9 (15.3)
Delay in diagnosis ≥ 24 months[a]	135	31.8
Shifting diagnoses	241	54.3
Ever told child did not have autism	111	25.8
System factors		
Completed screening forms	186	47.4
Distance travelled for diagnosis		
0–20 miles	247	56.5
21–60 miles	154	35.2
>60 miles	36	8.2
Problem finding psych providers	143	34.0
Child and family characteristics		
Child age at survey (months)	445	73.2 (20.4)
Female child	72	16.0
Race		
White	309	76.5
Black	51	12.6
Other	90	10.9
Hispanic ethnicity	55[b]	13.3
Primary autism diagnosis[d]		
Autistic disorder	351	78.5
Asperger's disorder	49	11.0
Pervasive developmental disorder	47	10.5
Child age at first developmental concern (months)	438	20.6 (12.9)
Insurance[c]		
Any public insurance	167	39.6
Any private insurance	254	60.2
No insurance reported	29	6.9
Primary language spoken at home is Spanish	27	6.6
Household income is $45,000 or less per year	142	35.9
Participant education is high school or less	44	10.6
Any siblings with ASD	58	12.9
Service experiences		
Child age Early Intervention initiated (months)	418	29.7(14.3)
Child age at first professional diagnosis (months)	436	38.8 (16.5)
Early Intervention before diagnosis	205	49.9

[a]There are 6 cases where age of first parent concern is after age of diagnosis. These cases are included in analyses using the binary measure of delay, in the category interval of delay is less than 24 months

[b]Ethnicity not reported for 37 cases

[c]Public and private insurance are not mutually exclusive; insurance information not reported for 28 cases

[d]Autistic disorder, PDD, and Asperger's Disorder were combined into an Autism Spectrum Disorder (ASD) after DSM-5 was released, updating DSM-4 diagnostic criteria used at the time of survey development

diagnosed with other autism-related conditions, i.e. experienced shifting diagnoses, and 25.8% of families were told their child did not have ASD. There were 47.4% of families who completed screening forms during this interval. While only 8.0% of families traveled over 60 miles to obtain the diagnosis, 34.0% said that they had problems finding a psychologist or psychiatrist. The mean age when children initiated Early Intervention services was 29.7 months. Half (49.9%) of children began Early Intervention services prior to their ASD diagnosis.

Participant Characteristics by Experience of System Factors

Table 2 provides a description of characteristics of children and families in our sample who experienced the system factors examined: completed screening forms, travel 60+ miles, or problems finding a provider. Families who completed screening forms were more likely to have a child with pervasive developmental disorder, less likely to have experienced a delay in diagnosis of at least 24 months, and were less likely to start Early Intervention services prior to diagnosis. Families who had to travel at least 60 miles for their child's diagnosis were more likely to have experienced shifting diagnoses, and to have seen three or more professionals in the process of diagnosis. Families who reported having problems finding a psychologist or psychiatrist were more likely covered by public insurance, to have experienced delay in diagnosis of at least 24 months, to be told their child did not have ASD, and to have seen three or more professionals in the process of diagnosis. These data do not indicate differences in experiences of completing screening forms, travel distance or problems finding providers by race or ethnicity, and analyses stratified by minority status (not shown) show similar patterns.

Associations of System Factors and Diagnosis Experiences

Table 3 shows the associations of system factors and diagnosis experiences. If a family completed screening forms, their odds of experiencing a delay of at least 24 months from first parent concern to diagnosis of ASD was reduced 37% (OR 0.63, CI 0.38, 1.02), controlling for child and family characteristics. Families who had problems finding a psychologist or psychiatrist had nearly twice the odds of delay in diagnosis (OR 1.89, CI 1.13, 3.18). Completing screening forms and traveling between 20 and 60 miles were associated with 44% (OR 1.44, CI 0.94, 2.21) and 45% (OR 1.45, CI 0.91, 2.30) greater odds respectively of shifting diagnoses. Traveling over 60 miles was associated with 2.3 times the odds (OR 2.34, CI 0.99, 5.50) of shifting diagnoses, while delay in diagnosis increased the odds of shifting diagnoses by 70% (OR 1.70, CI 1.03, 2.79). Delay in diagnosis was also associated with 2 times the odds (OR 2.02, CI 1.18, 3.47) of being told that the child did not have ASD. Minority race and ethnicity, and older child age at first parent concern were both associated with lower odds of delay in diagnosis. Compared to a diagnosis of autistic disorder, having a diagnosis of Asperger's was associated with greater odds of delay in diagnosis and being told that the child did not have ASD, perhaps secondary to many of these individuals being higher functioning. Having public insurance was associated with increased odds of shifting diagnoses.

Discussion

For families whose child was ultimately diagnosed with ASD, completing screening forms reduced the odds of experiencing a delay in diagnosis, but it also increased the odds of receiving shifting diagnoses other than ASD during that interval of time. These findings reflect the sensitivity of screening instruments and the challenges of diagnosing young children with ASD (McPheeters et al. 2016; Zwaigenbaum et al. 2015; Al-Qabandi et al. 2011; Ozonoff et al. 2008). Findings also reflect the interrelatedness of the timeframe of diagnosis and shifting diagnoses, evident in the findings presented here on the association of diagnosis delay and shifts.

Among families whose child was ultimately diagnosed with ASD, delay in diagnosis and shifting diagnoses may reflect either diagnostic error or utilization of best practices in diagnosing young children. Parents are often, but not always the first to recognize developmental delay and ASD-like behaviors (Ozonoff et al. 2008). When pediatricians take action in response to parent concerns, the period of time between parent concerns and diagnosis can be shortened (Zuckerman et al. 2015). The diagnostic process may be slowed, however, by a number of clinical issues. Longer intervals of delay and professional disagreement (being told "no" regarding the presence of ASD before "yes") may simply serve as markers for case complexity, comorbidity, or mild severity (Miodovnik et al. 2015; Zwaigenbaum et al. 2013; Ozonoff et al. 2008; Chawarska et al. 2007). Importantly, these findings suggest that the experience of shifting diagnoses is associated with receipt of early intervention services which can then lead to an accurate diagnosis subsequently. In other cases, delays may be longer or result in error because parents have difficulty articulating concerns, and pediatricians respond with reassurance (Zuckerman et al. 2015, 2014; Woolfenden et al. 2015; Ryan and Salisbury 2012). Moreover, prior to Affordable Care Act reforms, providers had an incentive to identify diagnoses other than ASD, in order to assure insurance coverage of services for the family (Parish et al. 2012; Peele et al. 2002). Ultimately, these findings reinforce the value of referring to early intervention services when there are any concerns by parents or providers, regardless of whether an ASD diagnosis can be confirmed at the time.

More training for parents and providers has the potential to reduce delays and shifts in diagnoses, and misunderstandings resulting from them. Healthcare providers in North Carolina have expressed a desire for continuing education on ASD risk signs and screening (Crais et al. 2014). Providers have also expressed reluctance to raise concerns about ASD (Crais et al. 2014), but families would often prefer to know

Table 2 Participant characteristics by experience of system factors

	Completed screening forms		Travelled 60 + miles for diagnosis		Problem finding psych providers	
	n (%)	p	n (%)	p	n (%)	p
Overall	186 (41.7)		36 (8.2)		143 (34.0)	
Outcomes and service experiences						
Delay in diagnosis ≥ 24 months[a]						
Yes	46 (34.1)	*	13 (9.8)		54 (41.5)	*
No	134 (45.4)		22 (7.5)		87 (31.0)	
Shifting diagnoses						
Yes	106 (43.6)		25 (10.6)	*	85 (37.6)	
No	80 (39.4)		10 (5.0)		57 (29.8)	
Ever told child did not have autism						
Yes	52 (46.8)		8 (7.3)		47 (43.9)	*
No	132 (40.0)		28 (8.6)		96 (30.7)	
Source of diagnosis						
Individual	50 (39.1)		13 (10.4)		48 (39.7)	
TEACCH center	44 (39.3)		10 (9.0)		38 (35.8)	
Regional CDSA	52 (44.1)		4 (3.4)		28 (24.8)	
Other team	32 (43.8)		6 (8.8)		22 (33.3)	
3 + Professionals seen before ASD diagnosis						
Yes	83 (40.7)		22 (10.9)	+	89 (45.9)	**
No	98 (42.2)		14 (6.1)		54 (24.3)	
Early Intervention before diagnosis						
Yes	75 (36.6)	*	15 (7.4)		70 (34.5)	
No	96 (46.6)		19 (9.3)		68 (34.3)	
Not answered	15 (42.9)		2 (6.9)		5 (26.3)	
Child and family characteristics						
Child gender						
Male	160 (42.7)		29 (7.9)		127 (35.6)	
Female	26 (36.6)		7 (10.3)		16 (25.4)	
Race/Ethnicity[b]						
White not Hispanic	122 (43.7)		21 (7.5)		89 (32.0)	
Black not Hispanic	19 (38.8)		3 (6.1)		21 (42.9)	
Hispanic/Latino	21 (38.2)		6 (11.5)		18 (32.7)	
Other/multiracial	10 (31.3)		4 (12.9)		14 (43.8)	
Primary autism diagnosis						
Autistic disorder	143 (41.0)	+	27 (7.9)		105 (32.2)	
Aspergers disorder	17 (34.7)		7 (14.3)		18 (37.5)	
PDD	26 (55.3)		2 (4.3)		20 (44.4)	
Child age at first developmental concern						
12 months or less	58 (43.6)		10 (7.8)		43 (34.7)	
13–24 months	87 (41.0)		17 (8.2)		63 (31.3)	
25 months or older	38 (40.9)		8 (8.7)		35 (39.3)	
Type of insurance						
Public	68 (40.7)		19 (11.7)		64 (38.6)	*
Private only	94 (41.6)		15 (6.6)		76 (33.8)	
None	11 (37.9)		1 (3.4)		3 (10.3)	
Participant education						
High school or less	15 (34.1)		5 (11.9)		11 (25.6)	
More than high school grad	156 (42.2)		29 (7.9)		130 (35.1)	
Any siblings with ASD						
Yes	23 (40.4)		3 (5.4)		22 (39.3)	
No	163 (41.9)		33 (8.7)		121 (33.2)	

p values based on Chi-square: $^{+}p < .10$, $*p < .05$, $**p < .01$

[a]There are 6 cases where age of first parent concern is after age of diagnosis. These cases are included in

Table 2 (continued) analyses using the binary measure of delay, in the category interval of delay is less than 24 months

[b]Ethnicity not reported for 37 cases

rather than miss the opportunity to intervene early (Barton et al. 2011; Zwaigenbaum et al. 2009). The experience of shifting diagnoses may reflect a need for more training in administering ASD diagnostic tools and recognizing ASD characteristics. Importantly, providers may feel discouraged by lack of appropriate referral options and by waitlists for formal assessment and diagnosis, and these feelings of discouragement may serve as an incentive to over-reassure and under-refer. Better strategies for communicating the strengths and weaknesses of screening for developmental delay or ASD need to be developed to prepare primary care physicians for these conversations, to overcome their reluctance to broach this topic with parents, and to avoid parent misunderstanding and dissatisfaction that can undermine long term relationships (Mazurek et al. 2017; Carlsson et al. 2016).

Families report a desire to reduce delays and shifts in diagnoses (Carlsson et al. 2016; Goin-Kochel et al. 2006). The CDC's *Learn the Signs. Act Early*. initiative to educate professionals and parents on developmental milestones should improve detection and communication about developmental concerns (Centers for Disease Control 2017). Parent training in health activation can increase their confidence and self-efficacy in communicating with providers, and has the potential to empower parents to persevere to get their needs met through the diagnosis and treatment choice processes (Thomas et al. 2017b). Parents and providers could benefit from an increased sense of shared decision-making if parents better understood the process of diagnosis and providers understood the impacts of shifting diagnoses on the family (Fueyo et al. 2015).

The findings on long travel distances and problems finding providers highlight the challenge of mental health professional shortage. Families in remote areas or regions with fewer professionals with expertise in ASD diagnosis may go through a series of assessments with tentative diagnoses that ultimately lead to the diagnosis of ASD. While North Carolina has a reputation of excellence in providing state-supported regional centers for assessment of children with disabilities including ASD (TEACCH 2017; NCDHHS 2017), recent shifts in funding levels and structure have increased waiting and travel times for many of these services. Some families might be able to afford services in the private sector, but the US as a whole and North Carolina in particular have a shortage of mental health professionals (Thomas et al. 2012a, c, 2009; Becker et al. 2010; Ghosh et al. 2011; Hanrahan 2009). This concrete barrier for children with ASD and their families provides a clear motivation for state and local governments to support increased training of mental health professionals, and to explore strategies to make efficient use of their mental health workforce. Renewed and increased state funding of regional centers for assessment of children with disabilities would provide nearby and well-staffed services for families going through the process of diagnosis of a young child with ASD (TEACCH 2017; NCDHHS 2017). Political support of the Affordable Care Act in its entirety, including both restrictions on denial of health insurance based on pre-existing conditions and also upholding the standards of essential health benefits would send the message to providers that they can indeed count on ACA changes remaining in place over time. Providers who have confidence about the longevity of ACA changes may, for example, have the incentive to expand their practice to include children with autism. Recent evidence shows that ACA changes reduce unmet healthcare needs among adults with disabilities and mental health conditions and increase employment (Hall et al. 2017; Thomas et al. 2017a). State-mandated coverage of autism assessment, diagnosis and treatment also has the potential to incentivize providers to engage in these activities (Parish et al. 2012). Future work should develop integrated care models, such as streamlined partnerships between primary care and early intervention service providers, to make efficient use of a limited workforce (Rotholz et al. 2017; Roth et al. 2016; Soltis-Jarrett 2014). Future work should also examine how access to existing integrated care models, such as medical homes, improves the diagnostic process for children with ASD (Cheak-Zamora and Farmer 2015).

This North Carolina survey via the HRSA-funded ASD State Implementation Grant provided a mechanism to collect detailed information from families about their early screening and diagnosis experiences. Several limitations are important to consider. Inclusion in the sample was based on parent report of the child being given an ASD diagnosis by a professional; it was not independently confirmed at the time of the study. Any families included in the sample whose child did not actually have ASD may lead to a downward bias in the association of screening with study outcomes which, in turn, would contribute to making our findings conservative. While our implementation protocol yielded good variation in race, ethnicity, language and income, only 31.6% of families reported income below the state median, and minority participation was not aligned with the state population, with a lower proportion of black (11.3 vs. 22.1%) and higher proportion of Hispanic (13.3 vs. 9.1%) families than in the state (United States Census Bureau 2016). Our recruitment strategy of using the ASNC network and Autism Registry to distribute the surveys and web-based data collection protocol

Table 3 Logit models for autism diagnosis experiences

	Interval concern to diagnosis ≥ 24 months				Other diagnosis prior to ASD				Ever told child did not have autism			
Independent variable	OR	(95% CI)	P1	P2	OR	(95% CI)	P1	P2	OR	(95% CI)	P1	P2
System factors												
Completed screening forms	0.63	(0.38, 1.02)	0.059	0.059	1.44	(0.94, 2.21)	0.093	0.093	1.49	(0.92, 2.41)	0.108	0.108
Distance travelled for diagnosis												
21–60 miles	1.29	(0.75, 2.20)	0.354	0.567	1.45	(0.91, 2.30)	0.118	0.077	1.02	(0.60, 1.74)	0.930	0.396
> 60 miles	1.40	(0.59, 3.30)	0.442		2.34	(0.99, 5.50)	0.052		0.51	(0.19, 1.40)	0.194	
0–20 miles	Ref				Ref				Ref			
Problem finding psych providers	1.89	(1.13, 3.18)	0.016	0.016	1.04	(0.66, 1.65)	0.866	0.866	1.34	(0.81, 2.24)	0.257	0.257
Delay in diagnosis ≥ 24 months[a]	NA				1.70	(1.03, 2.79)	0.037	0.037	2.02	(1.18, 3.47)	0.010	0.010
Shifting diagnoses or ever told not autism	1.42	(0.84, 2.41)	0.195	0.195	NA				NA			
Child and family characteristics												
Female child	1.03	(0.52, 2.03)	0.941	0.941	0.83	(0.45, 1.51)	0.532	0.532	1.34	(0.68, 2.65)	0.394	0.394
Race/Ethnicity[b]												
Black not Hispanic	0.30	(0.12, 0.72)	0.007	0.008	0.93	(0.48, 1.82)	0.833	0.868	0.61	(0.26, 1.43)	0.253	0.596
Hispanic/Latino	0.36	(0.16, 0.81)	0.013		0.87	(0.44, 1.72)	0.695		1.15	(0.53, 2.49)	0.718	
Other/multiracial	0.61	(0.23, 1.60)	0.313		1.35	(0.56, 3.24)	0.505		1.25	(0.47, 3.30)	0.659	
White not Hispanic	Ref				Ref				Ref			
Primary autism diagnosis												
Asperger's disorder	5.98	(2.71,13.18)	< 0.001	< 0.001	1.09	(0.54, 2.22)	0.805	0.912	2.96	(1.42, 6.15)	0.004	< 0.001
PDD	0.70	(0.29, 1.67)	0.416		1.15	(0.56, 2.33)	0.705		3.03	(1.47, 6.27)	0.003	
Autistic disorder	Ref				Ref				Ref			
Age at first concern (months)	0.93	(0.90, 0.95)	< 0.001	< 0.001	0.99	(0.98, 1.01)	0.546	0.546	0.99	(0.97, 1.01)	0.370	0.370
Type of insurance												
Public	1.51	(0.87, 2.62)	0.139	0.313	1.64	(1.01, 2.65)	0.044	< 0.001	0.82	(0.47, 1.41)	0.467	0.194
None	0.96	(0.32, 2.89)	0.945		0.21	(0.07, 0.58)	0.003		0.32	(0.09, 1.15)	0.080	
Private only	Ref				Ref				Ref			
High school or less	1.34	(0.56, 3.20)	0.514	0.514	1.34	(0.60, 2.97)	0.474	0.474	0.83	(0.32, 2.14)	0.694	0.694
Any siblings with ASD	0.82	(0.41, 1.63)	0.566	0.566	0.93	(0.50, 1.72)	0.818	0.818	1.34	(0.67, 2.66)	0.407	0.407
Sample size (# events/total obs)		125/401				221/401				103/401		
C-statistic	0.762				0.669				0.698			

[a]There are 6 cases where age of first parent concern is after age of diagnosis. These cases are included in analyses using the binary measure of delay, in the category interval of delay is less than 24 months

[b]Ethnicity not reported for 37 cases

with some paper surveys available to attendees of ASD support meetings likely skewed our sample towards more connected, better educated, and perhaps more affluent families. While our data did not indicate disparities for minority participants, this may reflect that we were more likely to reach parents who were well-connected with the service system and parent support networks. The fact that the associations between family characteristics and outcomes are maintained for minority families in our sample indicates that findings are robust for the kind of minority families we succeeded in enrolling. Understanding the unique successes in North Carolina as well as challenges of seeking a diagnosis for a range of different racial and ethnic groups could benefit from targeted exploration to elucidate the particular experiences of these groups. Additionally, participants included families with children 8 years old and younger. With the recognition and prevalence of ASD increasing over the past 8 years, family experiences of the diagnosis process are likely changing as well. Examination of administrative records may be an additional source to portray current patterns of service use and the concerns that lead to diagnosis.

The findings presented here highlight a need for training for parents and providers to improve communication about the ASD screening and diagnosis process. Findings underscore how mental health professional shortages constitute barriers to efficient diagnosis for children with ASD. Findings also contribute to the dialogue about the benefits and challenges of screening for developmental delay and ASD as well as the efficiency of ASD diagnosis. Importantly, having public insurance compared to private insurance was associated with only one of our three outcome measures: experiencing shifting diagnoses prior to diagnosis of ASD. While health reform has brought significant improvements in both health insurance coverage and breadth of eligibility, these findings point to unresolved issues. In sum, these findings from parents and caregivers provide a clear motivation for states and local governments to address mental health professional shortage and maldistribution, their collaboration with primary care and early intervention service providers, and communication with parents to improve the screening and diagnosis experiences of children with ASD.

Author Contributions MM made substantial contributions to the analysis of the data, revised the manuscript critically for important intellectual content, and gave final approval of the version to be published. KT made substantial contributions to conception, design and interpretation of data, drafted the manuscript, and gave final approval of the version to be published. CW made substantial contributions to analysis and interpretation of the data, revised the manuscript critically for important intellectual content, and gave final approval of the version to be published. RC made substantial contributions to conception and design, acquisition of data and its interpretation, revised the manuscript critically for important intellectual content, and gave final approval of the version to be published. EC and RE made substantial contributions to conception and design, reviewed the manuscript critically for important intellectual content, and gave final approval for the version to be published. SRH made substantial contributions to conception and design, and interpretation of data, revised the manuscript critically for important intellectual content, and gave final approval of the version to be published.

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Compliance with Ethical Standards

Conflict of interest Drs. Martinez, Thomas, Williams, Christian, Crais, Pretzel and Hooper declare that they have no conflict of interest.

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. This article does not contain any studies with animals performed by any of the authors.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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