

# Predictors of the age of autism spectrum disorder diagnosis: A North Carolina Cohort

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## Abstract

**Background and aims:** This study investigated timing of diagnosis for African American ( $n = 50$ ) and European American ( $n = 118$ ) children with autism spectrum disorder in a North Carolina sample.

**Methods:** Using survey methods, a total of 168 North Carolina families were recruited.

**Results:** The two racially diverse groups did not differ significantly in the age at diagnosis of autism spectrum disorder (African American:  $M = 49.72$ ,  $SD = 25.83$ ; European American:  $M = 43.78$ ,  $SD = 20.16$ ;  $t(75) = 1.45$ ,  $p = .15$ , 95% CI  $[-14.10, 2.22]$ ,  $d = .27$ ;  $BF_{10} = .582$ ). Exploratory analyses revealed that within the African American sample, the age of diagnosis was positively correlated with parental ratings of Social Motivation from the Social Responsiveness Scale ( $r = .30$ ,  $p < 0.05$ ). This correlation was non-significant and close to zero ( $r = -0.03$ ,  $p > 0.05$ ) for the European American sample. Additionally, children who received another initial diagnostic label had a later age of diagnosis for autism spectrum disorder. This finding had a larger effect size in the African-American group.

**Conclusions:** The differential findings for the two groups may reflect variable interpretations of autism spectrum disorder symptoms, or a greater impact of later diagnosis on symptom severity in certain populations.

**Implications:** Our findings reflect the need for continued exploration of symptom interpretation among various racial/ethnic groups.

## Keywords

Autism spectrum disorders, early diagnosis, parents, disparities, symptom severity

## Introduction

A diagnosis of autism spectrum disorders (ASD) can be a life changing event for families. It is widely presumed that an earlier diagnosis can provide valuable insight for caregivers about their child's symptoms and lead to better outcomes for children with ASD. Later diagnoses put children at risk to require more special education support. Research indicates that enrollment in intensive early intervention (EI) can lead to eventual placement into less supported or mainstream

educational settings for children with ASD (Dawson et al., 2010; Harris & Handleman, 2000). The importance of EI is also highlighted by a finding that the amount of speech and language services attended between the ages of 2 and 3 years was positively associated with cognitive and language scores at age four (Stone & Yoder, 2001). Together, these studies suggest that EI may yield better language or educational outcomes for children with ASD. Early diagnosis is not only the gateway to EI services, but it also can improve parents' understanding of their child's developmental

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challenges. Given the importance and benefits of early diagnosis, there is a wide-ranging public health effort to reduce the age of diagnosis of ASD. Furthermore, researchers have begun to conduct studies aimed at understanding factors related to the age of diagnosis of ASD and identifying variables that may delay or hinder early diagnosis.

Some studies have investigated the influence of socio-demographic variables on the age of diagnosis, such as the race and ethnicity of caregivers. Mandell, Listerud, and Pinto-Martin (2002) found that African American and Latino children were diagnosed 1.4–2.0 years later than European American children. This study derived its data from existing Medicaid and other health records in Philadelphia, Pennsylvania area. After controlling for socio-economic status (SES) the disparity in age of diagnosis remained. However, the findings related to the impact of racial group differences are equivocal. A follow-up study of factors associated with the timing of diagnosis revealed different results (Mandell, Novak, & Zubritsky, 2005). From a sample of 969 children in Pennsylvania, no significant age discrepancy emerged between European Americans and minorities and the timing of ASD diagnosis. Instead, a later age of diagnosis was correlated with rural residence, lower SES, and higher language abilities or functioning at assessment. For the latter study, the average age of diagnosis was 3.1 years for autism, 3.9 years for Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and 7.2 years for Asperger's Disorder. Similar to Mandell et al. (2005), neither Goin-Kochel, Mackintosh, and Myers (2006) nor Wiggins, Baio, and Rice (2006) documented a difference in the average age of diagnosis among racially different groups. Nevertheless, the question of potential disparities in age of ASD diagnosis associated with racial and ethnic group membership is yet to be fully resolved. For example, Mandell et al. (2009) examined data from 2568 eight-year-old children in the United States who met surveillance criteria for ASD as determined through abstraction of multiple evaluation records. They found that White non-Hispanic children were more likely than African American or Hispanic children or children in "other" ethnic/racial groups to have a documented ASD diagnosis in their records. These findings suggest that even as late as 8 years of age, the clinical diagnosis of ASD may be missed in non-White children more than in White children.

The diagnostic process for children with developmental disorders, such as ASD, often begins with parental recognition, initiation, and presentation of relevant concerns to medical providers. Previous research on parental reporting behavior has focused on whether or not parents recognized or reported the

presence of atypical development (De Giacomo & Fombonne, 1998). Findings examining diagnosis or recognition of ASD indicate that several child related factors may influence age of diagnosis including (a) presence of concerning behaviors and severity of overall deficits (De Giacomo & Fombonne, 1998; Mandell et al., 2005; Twyman, Maxim, Leet, & Ultmann, 2009), (b) intellectual quotient level of the child (Mandell et al., 2009; Shattuck et al., 2009), (c) initial diagnoses other than ASD and (d) developmental history such as a regressive versus nonregressive pattern (Shattuck et al., 2009). Taken as a whole, these studies observed that the presence of comorbid conditions (e.g. intellectual disability; ID), regression, or more severe symptoms can decrease age of autism diagnosis. While other initial diagnoses such as Attention Deficit Hyperactive Disorder (ADHD) can increase the length of time before contacting professionals and/or receiving an ASD diagnosis. A more recent study used a retrospective medical record review and found that children who scored higher on the Childhood Autism Rating Scale (CARS), a score meant to estimate autism severity and functioning, had an earlier age of diagnosis in binary group comparison (early diagnosis and late diagnosis; Twyman et al., 2009) but their results did not reach a level of significance. The latter study did expand on the previous literature by using an ASD specific assessment; however, it did not examine differences in reported severity and age of diagnosis as a function of socio-demographic factors.

Given the variation in the previous studies examining age of diagnosis within and between racially diverse groups; we wanted to extend this research to a sample of North Carolina residents. Furthermore, we wanted to expand on the investigation of the relationship between childhood characteristics, including severity of symptoms, and timing of ASD diagnosis as a function of socio-demographic factors. The research questions for the current study are as follows: (a) Is there a later age of diagnosis among African American and European American children who have clinical diagnoses of ASD in a North Carolina sample? (b) Are higher levels of severity or socio-demographic factors associated with variance in age of diagnosis for within and between group comparisons?

## Methods

### *Participants*

A total of 192 North Carolina caregivers (59 African American; 131 European American) of children with a current diagnosis of ASD were recruited for this study. Race and demographic data were self-reported. With one exception (a caregiver recruited via a private

practice agency), all caregivers were recruited through the University of North Carolina Neurodevelopmental Disorders Research Center (NDRC) Autism Registry. The families in the NDRC registry had previously agreed to be contacted for research participation. Inclusion criteria for the participants were that they were the primary caregiver of a child with ASD. In addition, participants were only included if they had a child who: (a) was from 3 to 11 years old; (b) was diagnosed with ASD at 12 months or older by a qualified medical professional, service provider, or agency; (c) was ambulatory, with no severe motor impairments, other genetic disorders, evidence of other neurological impairments, or significant co-existing medical conditions; and (d) had a Social Responsiveness Scale (SRS) total scale score consistent with a diagnosis of ASD. Initially, the registry mailed 650 informational flyers to caregivers whose children fit the inclusion criteria to inform them about the study. Next, we mailed packages, which included the SRS, to 210 caregivers who agreed to participate in the study. Of the 210 questionnaire packages mailed, 192 were returned. We applied the inclusion criteria (e.g. meeting ASD threshold on SRS) for the participants who returned the questionnaires. After applying the inclusion criteria, a total of 168 caregivers remained eligible for the study. Thus, a total of 24 participants were excluded from the study because they did not meet the inclusion criteria.

### Data collection

After the initial mailing of the informational packets to targeted families, NDRC Autism Registry staff followed up with letters to nonresponders to ascertain interest/disinterest in the study. Once caregivers expressed interest in participation, the NDRC Autism Registry staff immediately sent a questionnaire package containing the SRS and the demographic survey (combined into an 8 × 11 survey booklet), and a small cash incentive (\$5.00). Returned questionnaires were tracked via participant-numbers (assigned by the researcher) that linked the questionnaires with the caregiver's response cards.

**Measures and questionnaires.** Parents were asked to complete a survey requesting information on family demographics and their diagnostic experiences. The survey included questions that focused on: (a) caregiver and child racial or ethnic group affiliation; (b) educational level attainment and income (as a measure of SES); and (c) agency or location where diagnosis of ASD took place (e.g. hospital, school, Children's Developmental Service Agency [CDSA] or the North Carolina Treatment and Education of Autistic and related Communication Handicapped Children [TEACCH] center).

The survey packet also contained the SRS (Constantino et al., 2003). The SRS is a 65-item rating scale that measures the severity of ASD symptoms as they occur in natural settings. The SRS was normed on a sample of more than 1600 children and is appropriate for use with children from 4 to 18 years of age (Constantino et al., 2003). Although the current study included a few 3-year-olds, the majority of the study sample ( $n=158$ ) was 4 years or older. Pine, Luby, Abbacchi, and Constantino (2006) validated the SRS via its correlations with teacher reports, the Vineland Adaptive Behavior Scale (VABS; Sparrow, Balla, & Cicchetti, 1984) composite score, and the social impairment/adaptive scores on the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), considered one of the gold standards in establishing a clinical diagnosis of autism. Pine et al. (2006) found the following correlations between the SRS and the above measures: teacher report ( $r=0.785$ ); VABS ( $r=-0.862$ ); and ADI-R ( $r=0.634$ ). The current study used the cut-off score of 59 for total scaled score as an inclusion criterion. According to Constantino et al. (2003), scores at or above this value indicate deficits in social and communication skills consistent with those associated with ASD. With regards to psychometric properties, Duku et al. (2013) reported good internal consistency for the 65-item SRS as indicated by strong item-total correlations between items and the total raw score (Cronbach's  $\alpha=0.93$ ) and acceptable internal consistencies for the SRS subscales with the majority of subscales above  $\alpha=0.70$  with the exception of the Social Awareness subscale which has an internal consistency of  $\alpha=0.60$ . A subset of SRS items, showed good concurrent validity ( $r=0.94$ ,  $p<0.001$ ) with the Child Behavior Checklist, a norm referenced outcome measure that evaluates internalizing and externalizing (emotional/behavioral) disorders (Duku et al., 2013).

**Explanation of analysis.** Descriptive statistics were calculated for all continuous and categorical demographic variables to better understand the characteristics of the sample. As previously noted, a small subgroup of the children was under the age of 4 years ( $n=10$ ). All analyses included in this report that utilize the SRS data were conducted for the overall sample, the sample of children under the age of 4, and the sample of children aged 4 years and older. No differences or differences in patterns of results were found between the two groups of children based on age; therefore, the entire sample was used for all analyses reported in this paper.

An independent samples *t*-test was used to evaluate the data to answer the first research question, *Is there a later age of diagnosis among African American and*

European American children who have clinical diagnoses of ASD for this North Carolina sample. A series of pairwise comparisons were used to evaluate the data relative to the second research question and evaluate whether higher levels of severity or socio-demographic factors are associated with variance in age of diagnosis within or between the African American and European American samples. Bonferroni's corrections were applied for the interpretation of statistical significance in order to maintain a familywise error rate of  $p < 0.05$ . The original intent of the authors was to analyze the data for this research question using a full factorial analysis of variance, but this approach was not possible given that the ANOVA assumption of homogeneity of variance was not found to be tenable for this sample. While ANOVA is known to be robust to violations of this assumption under some conditions, it was determined to be inappropriate given the combination of (a) unequal sample sizes of the comparison groups, and (b) the fact that the dependent variable of primary interest, age of child at autism diagnosis, was not found to be normally distributed within all comparison groups.

## Results

The following section provides a statistical analysis of (a) group differences in age of diagnosis, (b) a statistical analysis of between group differences in reported severity, (c) a within-group correlation analysis between severity and types of social impairments and age of diagnosis, and (d) and a chi-square analysis of observed group differences in child characteristics related to demographic variables. The purpose of the first analysis was to replicate findings from a previous study (Mandell et al., 2005) in a North Carolina sample. The remaining statistical analyses were conducted to examine relationships among severity and socio-demographic factors on age of diagnosis which extends on the previous literature (Twyman et al., 2009). For all group comparisons and strength of associations

considered, both frequentist and Bayesian approaches were utilized to better understand the data. Though often presented as opposing approaches, it is the authors' perspective that the two families of techniques are actually complementary (Wakefield, 2013) in that frequentist methods focus on the null hypothesis while Bayesian methods estimate the probability of the data based upon the alternative hypothesis relative to the null hypothesis. Interpretation of the Bayes factor ( $BF_{10}$ ) for all analyses was guided by the evidence categories set forth by Jeffreys (1961) and reiterated by Wetzels and Wagenmakers (2012): (1) values less than 1 provide no evidence in support of the alternative hypothesis, (2) values between 1 and 3 provide anecdotal evidence, (3) values between 3 and 10 provide substantial evidence, (4) values between 10 and 30 provide strong evidence, (5) values between 30 and 100 provide very strong evidence, and (6) values larger than 100 provide decisive evidence in support of the alternative hypothesis.

*Group differences in age of diagnosis.* An independent samples  $t$ -test was conducted to investigate the question of whether African American children in this sample received a diagnosis of ASD at later ages than European American children. The test did not reach a level of statistical significance,  $t(75) = -1.60$ ,  $p = .11$ , 95% CI  $[-13.27, 1.39]$ . The mean age of diagnosis for African American children in the sample was 49.72 ( $SD = 25.83$ ) months, compared to 43.78 ( $SD = 20.16$ ) for the European American children. A Bayesian independent  $t$  test was also computed to test the alternative hypothesis that there is a difference between African American children and European American children on age at diagnosis; no evidence was found in support of this alternative hypothesis,  $BF_{10} = .582$ . Cohen's  $d$  for the difference between the means for age of diagnosis was .27, a small effect. Table 1 summarizes the group means and effect sizes of the continuous

**Table 1.** Demographic characteristics (continuous variables).

Child and family variables	A-A	E-A	$t$	$d$	95% CI		$BF_{10}$
	$M$	$M$			Lower	Upper	
Age (parent or guardian) <sup>a</sup>	37.16 ( $SD = 6.53$ )	38.24 ( $SD = 5.98$ )	-1.03	.17	-.99	3.14	
Current age (child) <sup>a</sup>	7.40 ( $SD = 1.74$ )	6.86 ( $SD = 2.20$ )	-1.53	.27	-1.17	0.10	
Age of diagnosis <sup>b</sup>	49.72 ( $SD = 25.83$ )	43.78 ( $SD = 20.18$ )	1.60	.26	-13.27	1.39	.582

<sup>a</sup>Measured in years, <sup>b</sup>measured in months; all  $p > .05$ .

demographic variables. We examined the SRS and demographic variables for group differences using independent samples *t*-tests. There were no significant differences between the groups on the SRS total raw score,  $t(166) = -.511, p = .61, 95\% \text{ CI} [-6.02, 10.22], d = .087$  or on four out of the five SRS subscales. On the SRS Awareness Subscale, the European American caregivers reported higher levels of severity on this measure,  $t(166) = -3.11, p = .005$  (Bonferonni's correction),  $95\% \text{ CI} [.63, 2.82], d = .53$ , which assesses one's ability to pick up social and nonlinguistic cues during interactions with others. Bayesian independent *t* tests were also computed to test the alternative hypothesis that there is a difference between African American children and European American children on the five SRS subscales. Of these, only the results for the SRS Awareness Subscale indicated that the data were more likely to occur under the alternative hypothesis. Specifically,  $\text{BF}_{10} = 14.195$  indicates that the observed data are fourteen times more likely to occur under the alternative hypothesis; this is strong evidence of a difference between African American and European American children. Table 2 summarizes the group means of the SRS subscales scores.

**Diagnostic history, severity, and age of diagnosis.** As part of the demographic questionnaire, parents were also asked to identify any other diagnoses that their child received prior to the ASD diagnosis. In total,  $n = 77$  children were described as having a different diagnosis prior to being diagnosed with autism. The most common initial diagnoses identified by parents were developmental delay (DD;  $n = 24$ ), pervasive developmental delay (PDD;  $n = 9$ ), attention deficit disorder/ADHD

( $n = 14$ ), speech/language delay ( $n = 12$ ), sensory integration disorder ( $n = 5$ ), mental retardation (MR;  $n = 6$ ), and other (e.g. Obsessive Compulsive Disorder, Anxiety;  $n = 7$ ). Within this group, 19 of the children were identified as have received more than one diagnosis prior to the ASD diagnosis. The data related to other diagnostic history was obtained from the yes/no questionnaire item (i.e. did your child have a different diagnosis prior to being diagnosed with autism?) followed by an open-ended option to provide the diagnosis (see Table 3).

A series of pairwise comparisons were used to investigate whether diagnostic history (i.e. a diagnosis prior to being diagnosed with autism) or severity were associated with within-group differences in age of diagnosis. Significant differences in age of autism diagnosis as a function of diagnostic history were found for both African American children,  $t(48) = 4.11, p < 0.001, 95\% \text{ CI} [-39.36, -13.50]$ , and European American children,  $t(116) = 4.20, p < 0.001, 95\% \text{ CI} [-21.52, -7.73]$ . Within both groups (African American, European American), children with another diagnosis prior to being diagnosed with autism (African American:  $n = 21, M = 65.05, SD = 26.21$ ; European American:  $n = 56, M = 51.46, SD = 23.03$ ) were diagnosed with autism later than children who did not have another initial diagnosis (African American:  $n = 29, M = 38.62, SD = 19.31$ ; European American:  $n = 62, M = 36.84, SD = 14.12$ ). This difference was qualified by a large effect size for African American children, Cohen's  $d = 1.15$ , and a moderately large effect size for European American children,  $d = .77$ . Bayesian analyses yielded decisive evidence in support of the alternative hypothesis that there is a difference in

**Table 2.** SRS total and subscale scores.

Child scores on SRS	A-A	E-A	95% CI				BF <sub>10</sub>
	M	M	t	d	Lower	Upper	
SRS total score (raw scores)	101.12 (SD = 22.77)	103.22 (SD = 25.01)	-.51	.09	-6.02	10.22	.204
SRS motivation	15.86 (SD = 5.29)	15.53 (SD = 5.78)	.34	.06	-2.20	1.55	14.195
SRS communication	33.64 (SD = 9.59)	34.13 (SD = 8.74)	-.32	.05	-2.51	3.49	0.218
SRS cognition	20.02 (SD = 4.88)	19.43 (SD = 5.66)	.64	.11	-2.40	1.22	.190
SRS awareness <sup>a</sup>	11.74 (SD = 3.17)	13.47 (SD = 3.33)	-3.11	.53	.63	2.82	.191
SRS mannerisms	19.86 (SD = 5.53)	20.49 (SD = 5.92)	-.64	.11	-1.30	2.57	.219

SRS: Social Responsiveness Scale.

<sup>a</sup>Group differences are significant at the .05 level (two-tailed).

**Table 3.** Explanation of SRS subscales and their internal consistency.

SRS subscale	Description	Cronbach's alpha <sup>a</sup>
Total instrument		0.93
Social awareness	The ability to pick up on social cues. Represents the sensory aspects of reciprocal social behavior.	0.60
Social cognition	The ability to interpret social cues after they are recognized. Represents cognitive-interpretive aspects of reciprocal social behavior.	0.72
Social communication	Includes expressive social communication. Represents the motoric aspects of reciprocal social behavior.	0.85
Social motivation	The extent to which the individual is generally motivated to engage in social-interpersonal behavior. Items include elements of social anxiety, inhibition, and empathic orientation.	0.70
Autistic mannerisms	Includes stereotypical behaviors or highly restricted interests that are characteristic of autism.	0.79

SRS: Social Responsiveness Scale.

<sup>a</sup>Data from Duku et al. (2013).

age of autism diagnosis as a function of diagnostic history for both African American ( $BF_{10} = 151.0$ ) and European American ( $BF_{10} = 390.0$ ) children.

Additionally, a small positive correlation between the age of diagnosis and the severity (i.e. severity of symptoms) of the autism related symptoms, as measured by SRS Social Motivation Subscale, was identified for the African American group ( $r = .30$ ,  $p = .035$ ). This finding was further supported through the calculation of a Bayesian Pearson correlation, which indicates that the data are 1.5 times more likely to occur under the alternative hypothesis that there is a relationship between severity of symptoms and age of diagnosis for African American children ( $r = .30$ ,  $BF_{10} = 1.514$ ). Thus, within the African American group, children who had a later age of diagnosis were more likely to exhibit greater levels of social anxiety, inhibition, or difficulties with empathy and engagement in social-interpersonal behavior at the time of the data collection. This association was not found within the European American sample,  $r = -.03$ ,  $p = .78$ . This finding was further supported through the calculation of a Bayesian Pearson correlation, which indicates that the data are no more likely to occur under the alternative hypothesis that there is a relationship between severity of symptoms and age of diagnosis for European American children ( $r = -.03$ ,  $BF_{10} = .119$ ). This finding is not due to group differences on the SRS Social Motivation, as the mean scores on the subscale were not significantly different between the two groups  $t(166) = -.34$ ,  $p = .72$ , 95% CI  $[-2.20, 1.55]$ ,  $BF_{10} = .191$ . Fisher's  $z$  test was used to compare the correlation coefficients calculated for the two groups; the difference between the correlations was found to be significant,  $z = 1.96$ ,  $p = .05$ . For both groups, no other subscales on the SRS showed

significant associations with age of diagnosis within the contexts of testing the null or alternative hypotheses. Table 3 provides a brief description of the SRS subscale constructs.

*Group differences in child characteristics and socio-economic variables.* To investigate whether there were additional observed group differences in child level characteristics and socio-demographic variables, categorical demographic variables were examined (see Table 4). Chi-square analysis revealed that the proportion of premature births to the proportion of full term births among African Americans and European Americans were not significantly different,  $\chi^2(1) = .16$ ,  $p = .69$ ,  $BF_{10} = .230$ . Additionally, the proportion of significant medical concerns reported during pregnancy, delivery, or immediately post-natal were not significantly different between African Americans and European Americans,  $\chi^2(1) = .64$ ,  $p = .43$ ,  $BF_{10} = .240$ . Parents reported similar patterns in the place of diagnosis, with the majority of the children being diagnosed at a regional TEACCH center (state-supported program in North Carolina serving individuals with ASD and their families) or a regional Child Development Service Agency (part of the state's EI service system). Approximately, 46% of the African-American children and 39% of the European American children were diagnosed at a TEACCH center. The same questionnaire item showed that 28% of the African American children and 34% of the European American children in the sample were diagnosed at the CDSA. Finally, the other four diagnostic locations polled by this item had percentages of 10% or lower for both groups,  $\chi^2(5) = 2.19$ ,  $p = .82$ ,  $BF_{10} = .007$ . The proportion of children who received other diagnoses (e.g. ADHD, ID)

**Table 4.** Demographic questions and characteristics (categorical variables).

	African American (N = 50)		European American (N = 118)	
	N	%	N	%
<b>Child and family variables</b>				
Gender (female; respondent)	46	92	111	94
Gender (male; child)	44	88	99	84
Was child born prematurely? (yes)	12	24	25	21
Did child have medical concerns? (yes)	21	42	57	49
Where was your child diagnosed?				
School system	5	10	7	6
Developmental service agency	14	28	40	34
TEACCH center	23	46	46	39
Doctor's office	3	6	11	9
Private agency	3	6	8	7
Other	2	4	6	5
Did your child have another dx prior to ASD dx? (yes)	21	42	56	47
Educational status (maternal) <sup>a,*</sup>				
High school/GED or less	14	28	10	8
Some college or technical school	14	28	25	22
Associate degree	9	18	16	14
Bachelor's degree and beyond	13	26	65	56
Place of residency <sup>b,*</sup>				
Large city	9	18	9	8
Suburb	4	8	38	32
Small town or city	27	55	55	47
Rural area	6	12	16	13

TEACCH: Treatment and Education of Autistic and related Communication Handicapped Children; ASD: autism spectrum disorder.

Note: Percentages were calculated from only those responding to specific questionnaire items.

<sup>a</sup>For European American group,  $n = 116$ .

<sup>b</sup>For African American group,  $n = 46$ .

\*Significant at .01.

prior to the ASD diagnosis were not significantly different with 42% of African Americans and 47% of European Americans receiving other previous diagnosis,  $\chi^2(1) = .42, p = .52, BF_{10} = .215$ . The only categorical variables with significant group differences were maternal education status and place of residency. A higher proportion of European Americans had higher levels of education,  $\chi^2(13) = 16.81, p = .001$ ; Bayesian  $\chi^2$  analysis yields  $BF_{10} = 31.31$ , which provides very strong evidence in support of the alternative hypothesis that there is a relationship between race and material education. Finally, a higher proportion of African Americans lived in urban areas,  $\chi^2(3) = 12.71, p = .005$ ; Bayesian  $\chi^2$  analysis yields  $BF_{10} = 13.15$ , which provides strong evidence in support of the alternative hypothesis that there is a relationship between race and geographic location. Table 4 summarizes the Chi-square analyses of the categorical demographic variables.

## Discussion

The purpose of this study was to extend research that previously examined differences between racial/ethnic group membership and age of diagnosis to a sample of North Carolina residents recruited via a research participant registry. This study did not find differences between the African American and European American children on age of ASD diagnosis. Although this finding is consistent with more recent studies about age of diagnosis of ASD (Goin-Kochel et al., 2006; Mandell et al., 2005; Wiggins et al., 2006), it is inconsistent with the earlier study by Mandell et al. (2002). Discrepancies in the findings may be due to differences in participant selection and recruitment procedures among the studies. Mandell et al. (2002) used a Medicaid sample, whereas Mandell et al. (2005) and Goin-Kochel et al. (2006) studies and the present study used self-selected samples. Thus, our sample characteristics may limit

comparability of the current study to the earlier Mandell study. Overall, the participants in this sample were more educated than the North Carolina population as a whole (72% of the African Americans and 92% of the European Americans had some college, technical degree, or beyond). Most families were enrolled in the Research Registry through state-supported centers that provide free and comprehensive assessment for ASD. North Carolina has a long history of these free and highly specialized assessment services for individuals with ASD, leading to widespread awareness of the services among primary care providers and other professionals who provide services to families with young children. These findings may indicate that a combination of educational attainment, well-known free and specialized community resources, and awareness of ASD may attenuate the previous disparities observed for ethnic minority groups on the age of diagnosis of ASD. In fact, the CDC/Autism and Developmental Disabilities Monitoring Network found that North Carolina reported higher percentages of children who were identified with ASD and received comprehensive assessments at earlier ages when compared to the other 11 monitoring sites (Christensen et al., 2016).

Although the age of diagnosis was not significantly different between the groups, this study did find group variations in the severity and type of symptoms associated with later age of diagnosis. Within the African American group, more severe symptoms on the SRS Social Motivation Subscale, which measured social anxiety, inhibition, and engagement, was correlated with a later age of diagnosis. This relationship was not found in the European sample. Previous research has found moderate negative correlations between the SRS Social Motivation Subscale and daily functioning as measured by the Vineland-2nd edition (Gjolaj et al., 2011). That is, participants with elevated SRS Social Motivation scores (i.e. more severe impairments in this area) are more likely to be impaired in day-to-day functioning, one of the symptoms associated with ID. Although our sample size and collection methods do not permit in-depth analyses of differences in sub-categories of initial diagnosis, anecdotally, there appear to be some categorical differences between the ethnic groups in initial diagnostic labels. For example, none of the African-American children in this sample received an initial diagnosis of Pervasive Developmental Disorder (PDD) diagnosis compared to nine of the European American children. Prior to the update to the Diagnostic and Statistical Manual of Mental Disorders classification for autism, many clinicians often used the PDD label to refer to children who had some, but not all, characteristics of autism or children who showed relatively mild symptoms.

Clearly, more research is needed to determine whether this association reflects diagnostic differences from the clinician or parental interpretation of more severe interpersonal deficits or the result of a later diagnosis having a greater impact on interpersonal behaviors for African American children. With regards to the former possibility, another study indicated that African American children were more likely to receive another diagnosis prior to ASD, and more likely to receive a diagnosis of conduct or adjustment disorders (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). The most common initial diagnoses of African-American children in this sample were DD, ADHD, or communication delay. Perhaps for some African American children within this sample, greater levels of social-interpersonal deficits that were captured on the Social Motivation subscale of the SRS resulted in other diagnoses that were more reflective of global delays or behavioral disorders.

Overall, receiving an initial diagnosis other than ASD is likely to impede the process of receiving an autism diagnosis. The current study also found that there was an association between a later age of diagnosis and an initial diagnosis other than ASD for both racial groups, which is consistent with earlier research (Levy et al., 2010). A unique finding of this study was that there was also a greater effect size in the relationship between a later age of diagnosis and having another initial diagnosis for the African-American children. Essentially, for the African-American children who received other initial diagnoses, the original classifications stayed in place longer, when compared to the white children, and resulted in an even later age of identification of ASD.

The findings from this study should be interpreted with some considerations and caution. First, the participants recruited only reflect those who enrolled in the registry and agreed to be a part of this study. They are not fully representative of the North Carolina population; for example, their educational levels are skewed to the higher end of the distribution compared to the state population as a whole. The results of this study do not reflect children with ASD whose families did not sign up for the registry, or children who meet the ASD criteria but have not received the appropriate diagnosis. Additionally, the response rate to the initial informational mailing of flyers ascertaining interest in the study can introduce some nonresponse bias in the response sample. However, of the surveys mailed out, a high percentage (91%) was returned. Also, because of the nature of the recruitment process (the registry was only able to provide de-identified assessment scores for the participants) we were unable to link scores on cognitive assessments or VABSs contained in the registry database to specific children. With regards to

pre-survey severity, determining the exact nature and severity of early autism symptoms for individual children was not possible with a retrospective methodology. We did examine the possibility of parental recall of level of concern was biased by the child's current level of symptom severity, and found that the correlation between a measure of early parental concern and the SRS scaled score was small ( $r = .10$ ) and nonsignificant ( $p = .20$ ). Given this, the severity of current ASD-related symptoms was not a contributor to parents' reported pre-diagnostic levels of concern.

### Clinical implications

Despite these limitations, the findings of this study have important implications. The results suggest that a prior diagnosis other than ASD can hinder early diagnosis of ASD. Although children may have comorbid disabilities and symptoms (i.e. ID), it is important that ASD is identified as early as possible regardless of functional status. Some clinicians may presume that a developmental disability or ID diagnosis fully accounts for the manifestation of symptoms; but the core features of ASD are unique from other disabilities and require targeted intervention. Nonspecific diagnostic classifications may delay access to specialized services for ASD, particularly for children in a cultural subgroup where the symptoms of ASD may be interpreted differently by families or service providers. Furthermore, given that the findings suggest that these initial "other" diagnosis may delay diagnosis in minority groups even more; there may be a need for targeted ASD awareness campaigns in communities with large minority populations that stress the symptoms of ASD. Finally, the findings also indicate that within the African American community, variations of symptom type and symptom interpretation may be associated with age of diagnosis. Currently, very few studies have examined differences in African Americans and other ethnic minority groups' interpretations of ASD symptoms or what may influence those interpretations.

### Future directions

Given that this study was limited in sample size, further research is needed to examine why different interpretations of symptoms (e.g. social anxiety, inhibition, and non-engagement), or the presence of co-morbid conditions may have a greater effect on delaying age of diagnoses in minority populations. In addition, an investigation of relationships between child factors and age of diagnosis, the influence of diagnostic history (e.g. another initial diagnosis) may impact age of diagnosis, perhaps to a greater extent for African-American children.

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