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*Autism*. Author manuscript; available in PMC 2023 July 01.

Published in final edited form as:

*Autism*. 2022 July ; 26(5): 1176–1187. doi:10.1177/13623613211044345.

# The Influence of Race on Parental Beliefs and Concerns during an Autism Diagnosis: A Mixed Methods Analysis

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## Abstract

The purpose of this mixed methods study was to examine racial differences in parental beliefs and concern about ASD versus clinical judgment. The sample included 489 children with ASD undergoing their first ASD evaluation. Parent belief that their child had ASD was highest amongst parents of White children. White children whose parents believed the child had ASD had lower ASD severity. Parents of Black/African American and Hispanic children were more likely to report communication concerns than parents of White children. Parental concern about social communication was related to higher ASD severity for Hispanic children. Implications for diagnostic processes are discussed.

### Keywords

autism; diagnosis; parental concerns; race

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Declaration of Conflicting Interests: The authors declare that they have no conflict of interest or financial disclosures.

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Parents of children with autism spectrum disorder (ASD), and the providers who serve them, are the primary means through which children are evaluated and treated (Richards, Mossey, & Robins, 2016). When children present with delays, parents are often the “first responders” bringing their beliefs and concerns to providers. During evaluations, providers make clinical judgments that may or may not align with parental beliefs and concerns. This concordance (or lack thereof) may be exacerbated for families from different racial/ethnic backgrounds. Understanding the extent to which alignment between parental beliefs or concerns and clinical judgment is influenced by race is imperative for timely evaluation and treatment.

Research shows that parents often report concerns with their child’s communication (Zablotsky et al., 2017) and/or motor skills (Matheis et al., 2017). These concerns are brought to the attention of primary care providers at well-visits. Other, ASD-specific concerns include reduced nonverbal communication (e.g., poor eye contact) and a lack of response to name (Becerra-Culqui, Lynch, Owen-Smith, Spitzer, & Croen, 2018). Parental beliefs and concerns at primary care visits are one point of entry into the service delivery system.

Although research has examined the extent to which parental concerns align with clinician judgment, the findings are inconclusive, ranging from limited (Pinto-Martin et al., 2008) to moderate (Dale, Bates, Reznick, & Morisset, 1989), to high correlations (Pasco et al., 2019). Richards and colleagues (2016) found a positive correlation between the number of parental concerns and clinicians’ ratings on the Childhood Autism Rating Scale. However, no correlation was found between parental concerns and severity scores on the Autism Diagnostic Observation Schedule (ADOS-G). Although this study examined parental concerns and clinical judgement, it failed to determine whether race impacted this relation. However, there is evidence that the relation between parental concerns and clinical judgment may be influenced by the child’s race. A majority of this research focuses on how race impacts the receipt of a diagnosis and subsequent care. This evidence on disparities in access to care has shown that racial ethnic minority, low-income, and/or non-English speaking children with ASD are diagnosed later than White children (Stahmer et al., 2019).

We extend these findings to show how race may impact other aspects of the diagnostic journey. Research indicates that parents of racial-ethnic minority children often perceive their [children’s] condition to be more uncertain and are less likely to attribute it to genetic causes, which may impact how evaluation surveys are completed (McLeod & DiSabatino, 2019). Additionally, Black parents reported that primary care providers ignored their early concerns about developmental delays (Dababnah, Shaia, Campion, & Nichols, 2018). In specialty care, Black/African American families expressed more initial doubts about an ASD diagnosis compared to White families (Azad et al., 2019). Donohue et al. (2019) examined racial differences in parents’ concerns about their child’s development and found that Black parents reported fewer ASD-specific concerns. However, race was not associated with parents’ report of disruptive behavior, suggesting that some concerns may vary by race. Although this study examined parental concerns, it did not investigate the extent to which these racial differences in parental concerns align with clinical judgment.

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Blacher et al. (2014) found that White mothers reported more developmental concerns and ASD-specific concerns compared to Latinx mothers. However, Latinx children meeting diagnostic criteria obtained higher scores on the ADOS-G than White children. In a follow-up study, White and Latinx children did not differ by ASD classification, but White mothers reported significantly more concerns than Latinx mothers (Blacher et al., 2019).

There are several limitations to note about these studies. First, they primarily include parents of younger children (e.g., toddlers; Donohue et al., 2019). Second, a majority of this research has been with Black or Latinx/Hispanic families (Blacher et al., 2014; 2019), with limited information on other racial groups, such as Asians. Third, research that has included other racial groups has not used mixed methods analyses (Stahmer et al., 2019). Limited studies have utilized emergent coding to qualitatively analyze parental concerns, and subsequently use those codes to better understand concordance with providers. The purpose of this study is to examine racial differences in parental beliefs or concerns and clinical judgment using a convergent mixed methods approach. We sought to answer the following questions:

1. To what extent does parental belief of ASD differ by race?
2. What are the major concerns reported by parents of children receiving an evaluation for the first time, and how do these concerns vary by race?
3. Does the association between parental belief in ASD and clinical judgment of ASD severity differ by race?
4. Is the relation between parental concerns and clinical judgment of ASD severity moderated by race?

## Method

### Participants

Data were obtained from children referred for an ASD evaluation between March 2014 and December 2019 to a large, university affiliated, ASD specialty clinic. The clinic provides medical, psychological, speech-language, occupational, and social work services to children with ASD and evaluates patients for initial diagnosis, second opinions, or diagnostic clarity. The analytic sample consisted of 489 children ages 1–15. Eligibility and exclusion criteria are summarized in Figure 1.

### Intake Questionnaire and Background and History Form

The clinic-developed intake questionnaire is used for the purposes of triaging patients. Prior to the appointment, parents also completed a second form – the Background and History Form (thereafter referred to as background form).

**Race.—**Child race was captured in the electronic health record (EHR) as White, Black/African American, Asian, Hispanic, multiracial, or other. We use these categories to be consistent with the language in EHR, and not label participants with an identity that they may not identify with (Noe-Bustamante, Mora, & Lopez, 2020; Salinas, 2020). We

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collapsed multiracial and other into a single category because of the sparseness of these samples.

**Parental Education.—**On the background form, parents reported their level of education as: high school, trade school, bachelor's, or graduate degree.

**Marital Status.—**Using the background form, individuals who were married or living together but not married were categorized as 'together'. Individuals who were divorced, separated, or never married were categorized as 'not together'. Individuals not belonging to any of these categories were categorized as 'other'.

**Insurance.—**Using medical records, individuals were classified as having either commercial (i.e., private), medical assistance, or other insurance.

**Parent's belief child has ASD.—**On the intake, parents were asked, "Regardless of clinician opinion (such as previous doctors), do you believe that your child has ASD?".

**Concerns about child.—**On the background form, parents provided responses to the question "What are your concerns about your child?" This question was used for the qualitative coding and mixed methods analyses.

## Clinical Assessment

**Diagnosis of ASD.—**ASD diagnosis was determined by a licensed medical provider (e.g., psychiatrist, neurodevelopmental pediatrician) or licensed psychologist based on DSM-4/DSM-5 criteria and team-based clinical judgment.

**ADOS-2.—**All children received the ADOS-2 (Lord et al., 2012), a semi-structured, standardized measure designed to assess symptomatology related to communication, social interaction, play and restricted, repetitive behaviors. This ADOS-2 has five modules (Toddler, Modules 1–4), with module selection based on chronological age and language at time of testing. No children were administered Module 4.

At the diagnostic appointment, the ADOS-2 was administered by a certified speech-language pathologist or a licensed psychologist, as part of a larger team-based evaluation. All clinicians completed an ADOS-2 clinical training workshop with a certified trainer. Then, they underwent a period of guided administration until they were reliable. Clinicians had access to booster trainings and research-reliable clinicians. They followed the manual guidelines to ensure that a language sample was obtained before or during the first few activities to confirm module selection. Clinicians were trained to change modules if a selected module was not appropriate (ADOS-2 manual, page 11).

**ADOS-2 CSS.—**Across all modules, an ADOS-2 CSS (score 1 to 10) was derived to reflect the severity of ASD-specific symptoms (Esler et al., 2015; Gotham, Pickles, & Lord, 2012). The CSS score allows for comparisons across modules. Higher ADOS scores and CSS scores reflect greater ASD symptom severity.

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**Simple phrase speech.—**A binary variable was derived to estimate expressive language level from A1 ("Overall Level of Non-Echoed Spoken Language" [p.11 on manual]) of Modules Toddler, 1, 2, and 3 (Lord et al., 2012). Children were categorized as "0" (non-phrase speech), if they were administered the Toddler Module, Modules 1 (pre-verbal to simple phrases) or Module 2 (phrase speech) and received an A1 score of 1, 2, or 3. Children were categorized as "1" (simple phrase speech), if: 1) they were administered Modules 1 or 2 *and* received an A1 score of 0; or 2) they were administered Module 3 *and* received any A1 score ranging from 0 to 3.

## Data Analysis

A convergent mixed method approach was used to capitalize on the strengths of both quantitative and qualitative approaches (Creswell & Clark, 2017; Leech & Onwuegbuzie, 2010). Both types of data (e.g., child race, parent concerns) were collected concurrently from the intake and background form (Figure 2). Then, quantitative and qualitative analyses were conducted. Results of these analyses were merged to (a) compare the 12 qualitative themes across racial groups, and (b) examine parental concerns as predictors of ASD severity across racial groups.

**Quantitative methods.—**Characteristics of the child and parent were summarized across the five racial groups. Chi-square or ANOVA tests were used to assess whether these characteristics, including parental belief of ASD, differed significantly by child race. A p-value less than .05 was deemed statistically significant (Table 1).

**Qualitative methods.—**On the background form, responses to the question "What are your concerns about your child?" were analyzed using the constant comparative method, moving between text and codes to derive recurring themes (Bradley, Curry, & Devers, 2007; Glaser & Strauss, 2017). Three study authors read the parents' responses, and met to practice coding 25 responses together to begin developing a codebook. Then, emergent consensus coding was conducted with each response assigned to two coders, blind to racial category (Creswell & Clark, 2017). During initial coding, the two coders read each response and completed line-by-line coding independently, identifying key words/phrases to establish initial codes. Codes were generated from the parents' responses without clinical interpretation. Then, the coders met and established consensus. The coders met throughout the emergent coding process to resolve discrepancies and revise the codebook. Axial coding was completed, in which the codes and their definitions were refined, collapsed, and consolidated into larger themes (Charmaz, 2014).

Coders established a codebook with 60 codes, comprised of 12 themes: academic, cognition, developmental, emotional/behavioral, life skills, seeking diagnostic clarity or resources, motor skills, atypical behaviors, health, sensory, social, communication (Table 2 has definitions/examples; Table S1 has codes). Credibility of themes was assessed through investigator triangulation (Merriam & Tisdell, 2015). We created two ASD-specific themes to assess whether ASD severity was associated with ASD-specific parent concerns, which are comprised of codes from the 12 main recurring themes (i.e., there was overlap): restrictive or repetitive behavior (RRB) and social communication (American Psychiatric

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Association, 2013). This process has been used in previous clinic papers (Pfeiffer, Hollingue, Dillon, Kalb, Reetzke, & Landa, 2021).

**Mixed methods.—**The number of qualitative codes and themes, as well as the number of words in the parents' responses (i.e., length of responses) to the question "What are your concerns about your child?" were included as quantitative variables. The percentage of parents who endorsed each theme was summarized, as well as the number of codes and themes across the five racial groups. A chi-square test was used to assess whether the percentage of parents endorsing each theme differed between each racial group when compared to White parents. T-tests were used to compare the number of codes and themes between the racial groups. As a sensitivity analysis, we performed regression models with endorsement of theme (logistic) or number of codes or themes (linear) as the outcome and race as the predictor. We adjusted for age, as differences in child age across the racial groups might influence the number/types of themes endorsed.

We wanted to assess whether parental belief that their child had ASD (prior to diagnosis) was related to ADOS-2 CSS score, and whether this association differed by the child's race. We performed multivariable linear regression models with ADOS-2 CSS score as the outcome and parent belief of ASD (binary) as the predictor, adjusting for parental education, marital status, insurance, and child age. We stratified the model by child race to evaluate whether parental belief of ASD and ADOS-2 CSS were moderated by race.

Lastly, we tested whether endorsement of one of the two ASD specific themes was associated with the child's CSS score. Multivariable linear regression models were used with CSS score as the outcome, each ASD specific theme as a predictor (each in a separate model), adjusting for parental education, marital status, insurance, child age, and parental concern word count. We stratified each of these models by child race to determine whether the relation between endorsing a theme and the child's ASD severity differed by race.

**Community Involvement:** Patients from an outpatient ASD specialty clinic were involved in this study.

## Results

### Participants

Our sample included 489 children in the following racial groups: White (48%), Asian (10%), Black/African American (23%), Hispanic (6%), multiracial or other (13%). Child's age ranged from 14 months to 15 years ($M = 5.4$, $SD = 3.4$). and differed across racial groups (ANOVA; $p < .001$) with White children being the oldest ($M = 6.1$ years, $SD = 3.6$) and Asian children the youngest ($M = 4.4$ years, $SD = 2.2$); 79% were male. See Table 1.

### Parent Belief of Child ASD across Racial Groups (Quantitative)

The proportion of parents who believed their child had ASD (prior to diagnosis) differed by race (Chi-square; $p < .001$) and was highest in parents of White children (80.3%), followed by parents of multiracial or other (73.8%), Black/African American (67.3%), Hispanic (61.3%), and lastly Asian children (40.8%). The length of parent response to child

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concerns differed by race (ANOVA; $p < .001$), and was longest in White parents, followed by multiracial or other, Asian, Hispanic, and Black/African American parents (Table 1).

### Parent Concerns across Racial Groups (Mixed Methods)

The proportion of parents who endorsed each of the qualitative themes, stratified by race, is summarized in Table 3. The most prevalent themes were communication (61%), social (51%), and emotional/behavioral (48%) concerns. See Table 2 for theme definitions/examples.

Among Asian children, emotional/behavioral (34.7%) and ASD-specific RRB (26.5%) concerns were lower relative to White children (57.5% and 45.7%, respectively; chi-square $p < .05$). Communication concerns were higher in Asian (75.5%) compared to White children (47.4%; Chi-square; $p < .05$). Parents of Black/African American children had fewer concerns about cognition (19.1%), emotional/behavioral (39.1%), sensory (8.2%), social (40.0%), and ASD-specific RRBs (20.9%) relative to White children (cognition 33.8%; emotional/behavioral 57.7%; sensory 19.7%; social 57.3%; ASD-specific RRB 45.7%; $p < .05$). Communication concerns were higher in parents of Black/African American children (73.6%) relative to parents of White children (47.4%; $p < .05$).

Parents of Hispanic children had fewer sensory concerns (3.2%) and ASD-specific RRB concerns (22.6%) relative to those of White children (sensory 19.7%; ASD-specific RRB 45.7%). Parents of Hispanic children had greater communication (77.4%) and ASD-specific social communication (96.8%) concerns relative to those of White children (communication 47.4%; ASD-specific social communication 78.6%). Parents of multiracial or other children had less frequent cognition (16.9%) and social (40.0%) concerns relative to those of White children (cognition 33.8%; social 57.3%). Parents of multiracial or other children had greater motor (16.9%) and communication (69.2%) concerns relative to White children (motor 7.3%; communication 47.4%).

After adjusting for child's age, all of the differences persisted with the exception that the communication theme was no longer higher in Asians vs. Whites, and the ASD-specific Social Communication theme was no longer higher in Hispanic vs. Whites (Table 3). On average, parents of Asian, Black/African American, and multiracial or other children had fewer number of codes or themes relative to those of White children ($p < .05$).

### Parent Belief Child has ASD as Predictor of ASD Severity (Quantitative)

Among the White children, those whose parents believed their child had ASD had a lower CSS Score ($\beta = -0.8$, 95% CI [−1.4, −0.1], $p < .05$). However, in the Asian, Black/African American, Hispanic, and multiracial or other children, there was no significant association between parents' belief that the child has ASD and the child's CSS score ($\beta = -0.9$–$0.2$, $p > .05$; confidence intervals in Table 4). This suggests that in White children only, parent belief that the child has ASD is actually related to *lower severity* of ASD (Table 4). Our finding persisted after adjusting for parental education, marital status, insurance, and child age.

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### Parent Concerns as Predictors of ASD Severity (Mixed Methods)

We observed a positive association between the social communication theme and ADOS-2 CSS score among Hispanic children only (β = 5.26, 95% CI [1.63, 8.88], p < .05; Figure 3; Table S2). When we assessed what *codes* (within ASD social communication theme) were driving this association, we found that concern about eye contact and the child not responding to their name were associated with the CSS score (eye contact: β = 2.57, 95% CI [0.99 – 4.15], $p < .01$; respond to name: β: 3.14, 95% CI [0.92 – 5.35], $p < .05$). This suggests that with Hispanic children, a parent mentioning concern about lack of eye contact or response to name is associated with higher ASD severity. We found no significant association between the RRB theme and CSS score in any of the racial groups (see Table S2).

## Discussion

In this study, we showed that whether parents believed their children had ASD and the concerns they reported on their children differed by parent reported race. Additionally, the relations between parental belief or concern and clinical judgment of ASD severity were also moderated by parent reported race. Our first finding was that parental belief of their child having ASD (before the evaluation) was highest amongst White parents, followed by multiracial or other, Black/African American, and finally Hispanic parents. Asian parents endorsed the lowest belief in their child having ASD. The discrepancy between White and Asian parents' beliefs in ASD was large – 80% versus 41%. This finding is striking given that Asian children had the highest ADOS-2 severity scores as rated by clinicians. Research suggests that stigma against ASD is greater among Asian families, which may contribute to this discrepancy (Liao, Lei, & Li, 2019; Seung, 2013).

We also found that White parents had longer responses when describing concerns about their children. The word count was progressively lower in Asian, Hispanic, and Black/African American families. White parents also endorsed significantly more themes (i.e., concerns) compared to Black/African American and Asian parents. It is possible that the non-White families in our study had shorter responses/fewer themes because they felt like they would not be heard by predominantly White clinicians. A systematic review in health communication suggested that Black patients experienced poor communication quality, information-giving, and patient engagement compared to White patients. Further, racial concordance between patients and physicians was associated with better communication outcomes and treatment adherence (Shen et al., 2018). In ASD specifically, when parents raise child concerns, they are often met with reassuring/passive responses from providers (Zuckerman, Lindly, Sinche, 2015). Dadabnah et al (2018) reported that parents of children with ASD feel like racial bias impacts their interactions with primary healthcare providers. A history of negative interactions with providers may have made Asian, Hispanic, and Black/African American families hesitant from sharing more of their concerns.

We also found associations between parental beliefs and clinical judgment, and this association was moderated by parent reported race. When White parents believed their children had ASD, those children had *lower* ASD severity as rated by clinicians. There was no association between parent belief of ASD and clinician-observed ASD severity for

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Black/African American, Hispanic, and Asian families. Our findings are consistent with studies showing that White parents report more concerns about ASD compared to other racial groups (Blacher et al., 2014, 2019). One probable reason for this finding may be structural racism (Bailey et al., 2017; Broder-Fingert, Mateo, & Zuckerman, 2020). Research has shown that racial/ethnic minority communities have systematically lower access to high-quality healthcare and have worse healthcare outcomes compared to White communities. This is true regardless of education or income (Williams et al., 2016), suggesting that racism and provider bias may play a role (Jones & Mandell, 2020). As a result, White parents may have more knowledge/awareness of ASD, perhaps due to greater medical literacy or engagement in health services (Burkett et al., 2015; Jones & Mandell, 2020). If parents are less likely to believe their children have ASD, access to care may be averted or delayed, placing racial/ethnic minority children with ASD at a disadvantage relative to White children.

We also found that the most prevalent themes reported by parents were related to communication, social, and emotional/behavioral needs (Zablotsky et al., 2017). Black/African American parents reported fewer concerns about cognition, emotions/behaviors, sensory needs, social skills, and ASD-specific RRBs. However, they reported more concerns related to communication. In Hispanic families, parents were less concerned about sensory needs and ASD-specific RRBs, and more concerned about communication compared to White parents. For Asian parents, children's emotions/behaviors and ASD-specific RRBs were less concerning relative to White parents. Parents of multiracial or other children reported more concerns about motor skills and communication compared to White parents.

It is noteworthy that communication emerged as a primary concern for Black/African American, Hispanic, and multiracial or other parents. Both Black/African American and Hispanic children had lower language abilities compared to White children, suggesting that parents were adequately detecting these delays. Research has shown that minority toddlers with ASD have lower scores on language, communication, and gross motor skills than non-minority children (Tek & Landa, 2012). It is possible that communication may serve as an umbrella term for parents, encompassing other related concerns, such as social skills and cognition. This may reflect differences in developmental literacy or in the words used to describe symptoms of ASD. Research indicates that socio-demographic differences (e.g., race, income) correspond to lower levels of health literacy (Zuckerman et al., 2013, 2017). Targeted approaches to increasing screening and surveillance for ASD in underserved populations should focus on communication concerns which may be a vehicle through which parents convey ASD symptomatology.

Finally, for Hispanic families, there was a positive association between the parents' endorsement of the ASD social communication theme and clinicians' observed severity. When Hispanic parents reported concerns related to social communication, those children had higher CSS scores compared to Hispanic parents who did not report social communication concerns. Parental concerns about "eye contact" and "not responding to name" were associated with clinician reported severity scores, highlighting the importance of following up on these critical concerns, especially from Hispanic families. Hispanic/Latinx families are described to be collectivistic in nature, placing high value on family

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relationships (Ruiz, 2005). When Hispanic parents reported that their children were not maintaining eye contact or responding to their name (qualities impacting family relationships), not only did those children get an ASD diagnosis, but clinicians rated those children to be more severe in their ASD symptomatology. In raising knowledge/awareness of ASD in Hispanic families, it may be particularly salient to spotlight characteristics of early social communicative deficits.

## Limitations

In our study, ethnicity and race were viewed as one variable because that is the way it is presented in EHR. We did not have more granular information on ethnicity and culture, and how these related to race. We acknowledge that many groups are not monolithic (e.g., Mexican-vs. Puerto Rican), and more research is needed to examine how within group heterogeneity may influence parents' beliefs and concerns. However, our study included Asian families, who are often excluded from studies examining race. Additionally, we had a large sample of Black/African American families, who are often underrepresented in research. We did not have information on children's IQ or other characteristics (e.g., adaptive functioning). We also controlled for age in our analyses. In future studies, it will be important to examine the potential interaction effects between child's age and race/ethnicity on parental beliefs and concerns.

Nonetheless, our sample included children with confirmed ASD diagnosis using the gold standard ADOS-2 and team-based clinical judgment. Given that the current study uses clinic data, the providers were clinically trained on the ADOS-2, and not research reliable; therefore we do not have inter-rater reliability. We also did not have clinician demographic data to explore implicit biases. We hope that through future investigations we can collect this data and examine whether clinician factors (e.g., race) moderate the association between parental concerns, child race, and clinical judgment of ASD severity. We limited our sample to families who were obtaining their first ASD evaluation based on parent report; however, there was no way to confirm that this was actually true. We also used a single dichotomous question to code for parental belief and a single open-ended response to code for parental concerns. In some cultural groups, there may be reluctance to go against professional judgments. We recognize that to adequately gauge parental perspectives, a more comprehensive approach is needed. Finally, there is a possibility of selection bias toward families with access to web-based portals, given that both belief and concern items were captured through our online system.

## Implications

Studies of ASD often rely on parent report to screen for an ASD-specific sample. If White parents believe their children have ASD, this may influence how they complete standardized measures. Moody and colleagues (2017) have urged the field to move toward ASD screeners that perform equally well across different racial groups. Our findings suggest that focusing on communication concerns may allow studies to be more inclusive of Black/African American and Hispanic families.

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Clinically, if White parents think their children have ASD, they may be more likely to schedule appointments and follow-through with the diagnostic process compared to non-White families. Azad et al. (2019) showed that Black families were less likely to keep their initial appointment at an ASD clinic. The extent to which families utilize services has meaningful implications for children. In the present study, when White parents believed their children had ASD, those children actually had lower ASD severity scores, suggesting that the limited services available may be utilized *more* by *less* severe White children. Our findings indicate that more targeted, culturally-informed awareness campaigns are needed.

In public health, large-scale surveillance studies (e.g., Autism and Developmental Disabilities Monitoring network) often rely on chart reviews to estimate the number of children with ASD (Rice et al., 2007). The most recent CDC report (2018) suggested that estimates of ASD were higher for White children compared to Black/African American children (Baio et al., 2018). Both groups were more likely to be identified compared to Hispanic/Latinx children. Our results suggest that greater beliefs of ASD in White families may be one probable reason underlying this discrepancy. Nevertheless, this is the first study of its kind to leverage the rigor of both quantitative and qualitative methods to describe how race may influence parental beliefs and concerns during the diagnostic process. Collectively, our findings show that there is a subjective element to the ASD diagnostic process that is influenced by the innate characteristics that people bring to that process.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgements:

We thank the patients of Kennedy Krieger Institute's Center for Autism and Related Disorders for agreeing to contribute de-identified data for the purposes of advancing research and science.

Funding: Preparation of this article was supported in part by a grant from the National Institute of Mental Health (7K23MH119331–02; PI: Azad).

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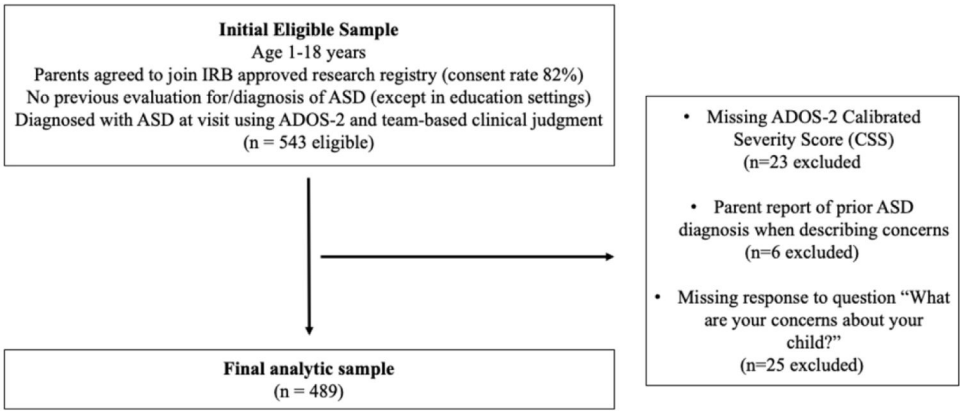


**Figure 1:**

Eligibility criteria for study sample. Children in our sample could have other, non-ASD diagnoses. Families did not have to be English-speaking.

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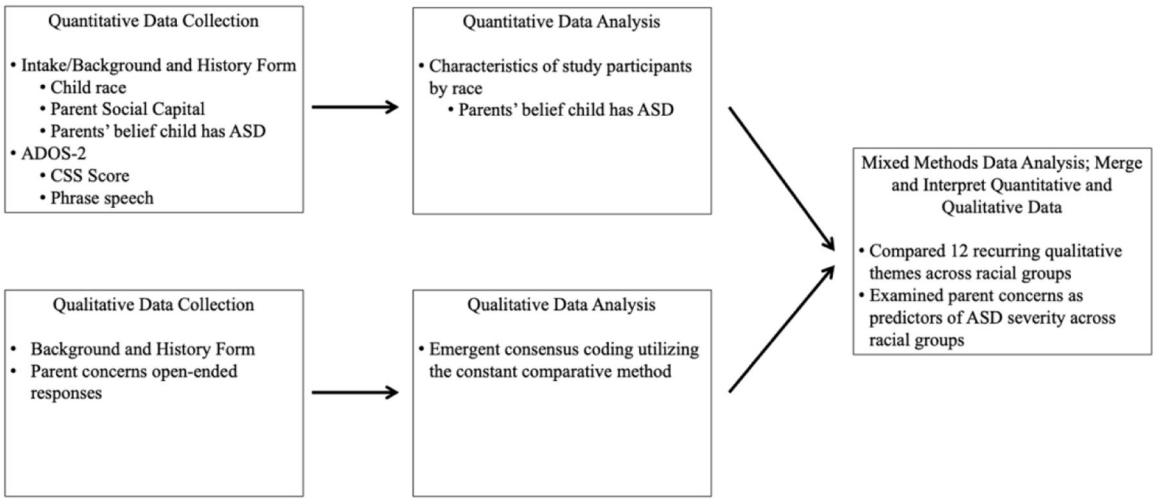


**Figure 2:**
Mixed-method processes of data collection, analysis, and integration.

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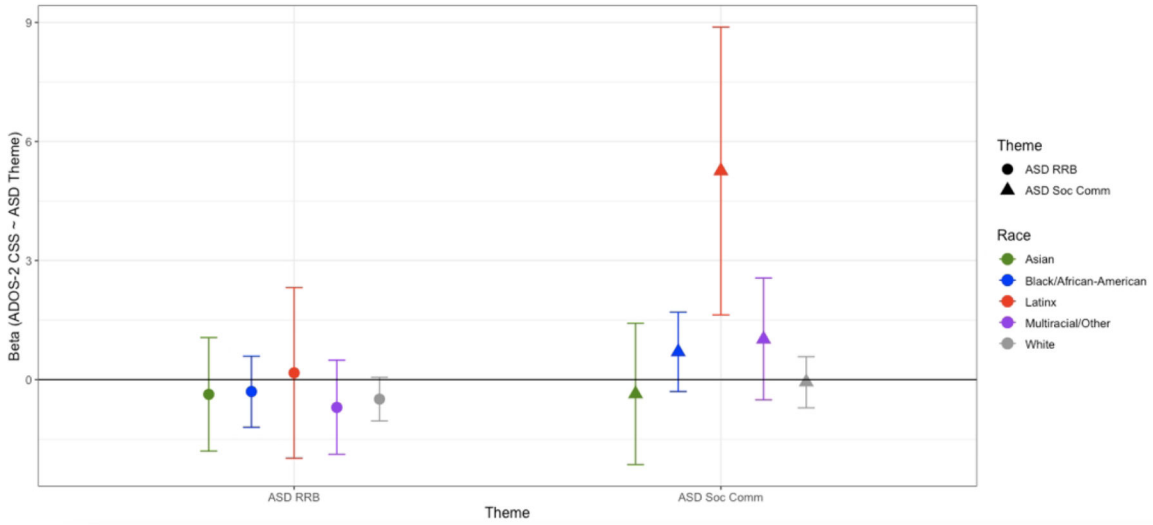


**Figure 3:**

Multivariable linear regression modeling risk of ADOS-2 calibrated severity score given endorsement of parental concern ASD-specific themes (restricted/repetitive behaviors or social communication), stratified by child race, adjusted for parental education, marital status, insurance, child age, and parental concern word count.

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**Table 1**

Characteristics of Participants by Child Race (N = 489)

| | | Asian (n = 49) | Black/African American (n = 110) | Hispanic (n = 31) | Multiracial/Other (n = 65) | White (n= 234) | Chi-square/F-value (P-value) |
|---|---|---|---|---|---|---|---|
| | | Mean (SD) or % | | | | | |
| Age (years) at ADOS-2 | | 4.1 (2.2) | 5.3 (3.3) | 4.4 (3.2) | 4.8 (2.9) | 6.1 (3.6) | 5.5 (< .001) |
| Child sex | Male | 73.5 | 82.7 | 83.9 | 83.1 | 77.4 | 3.1 (.51) |
| Parental Education | High school | 15.2 | 33.6 | 46.7 | 39.7 | 15.2 | |
| | Trade school | 8.7 | 34.6 | 6.7 | 20.6 | 8.7 | 45.3 (< .001) |
| | Bachelor | 32.6 | 18.7 | 26.7 | 25.4 | 32.6 | |
| | Graduate | 43.5 | 13.1 | 20.0 | 14.3 | 43.5 | |
| **Parental Sex** | Female | 71.1 | 90.2 | 90 | 82.5 | 93.8 | 5.0 (<.05) |
| Marital Status[a] | Married/Together | 83.0 | 50.5 | 71.0 | 65.6 | 72.0 | 24.2 (< .01) |
| Insurance | Commercial | 57.1 | 68.8 | 31.2 | 67.7 | 62.5 | |
| | Medical Assistance | 41.4 | 31.2 | 68.8 | 32.3 | 37.5 | 50.8 (< .001) |
| Parental Belief Dx[b] | | 40.8 | 67.3 | 61.3 | 73.8 | 80.3 | 34.2 (< .001) |
| Parental Concern - Word count | | 26.3 (30.7) | 21.2 (24.3) | 26 (39.3) | 39.2 (56.8) | 42.4 (51.9) | 5.1 (< .001) |
| Referral Source | Other | 6.1 | 11.8 | 6.5 | 6.2 | 12.0 | |
| | Peds | 40.8 | 37.3 | 58.1 | 40.0 | 40.6 | 7.7 (.46) |
| | Specialty | 53.1 | 50.9 | 35.5 | 53.8 | 47.4 | |
| Receiving Intervention[c] | | 50.0 | 58.7 | 61.3 | 56.9 | 64.2 | 4.1 (.40) |
| Phrase speech | | 24.3 | 44.8 | 39.3 | 55.2 | 63.1 | 25.3 (< .001) |
| ADOS-2 CSS Scores | | 7.8 (1.8) | 7.7 (1.9) | 7.2 (2.0) | 7.1 (2.1) | 7.2 (2.0) | 2.1 (.08) |

Note.

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[a] Parents were classified as being married/living together, or divorced/separated/widowed/never together, or other;

[b] Parent believes child has ASD, prior to diagnosis;

[c] Child receives behavioral, mental health, or educational services at intake

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**Table 2**

Codebook with Examples of Parent Concerns

| Theme | Definition (or concerns related to…) | Examples |
|---|---|---|
| Academic | learning, learning disability, academic skills, or school success | • "He needs more assistance in his classes than the rest of the children in his classes do."<br>• "Windows of opportunity for learning and engagement present challenges." |
| Atypical behaviors | atypical and repetitive behaviors | • "She has some unusual behaviors such as hand flapping and running back and forth while humming."<br>• "Makes strange expressions when staring at subjects." |
| Emotional/behavioral | internalizing/externalizing behaviors, and ability to express, understand, or regulate emotions | • "Has a very difficult time understanding and processing his emotions."<br>"Throws objects around and sometimes at people." |
| Cognition | attention, concentration, executive functioning, and inflexible thinking | • "Slow cognitive processing"<br>"Remaining focused and engaged with tasks such as doing puzzles." |
| Communication | verbal and nonverbal communication, not specific to social situations | • "Regression in speech, almost never talks at all anymore." "No pointing." |
| Developmental | skills being lower than peers or siblings, and comments about diagnosed/suspected developmental delays | • "Developmentally behind others his age."<br>• "Always had issues with being behind in milestones." |
| Health | physical health | • "She has two eye conditions."<br>• "Sleep issues." |
| Life skills | ability to independently carry out activities of daily living | • "I have concerns that he will be very behind with life skills…such as putting shoes on/off, brushing teeth..."<br>• "Delays in the areas of self-help." |
| Motor skills | fine/gross motor skills or body movements | • "Poorly developed fine motor skills and limited gross motor skills."<br>• "Wobbly and uncoordinated movements." |
| Seeking diagnostic clarity or resources | seeking diagnostic clarity or additional resources (e.g., academic supports/therapy) | • "Just want to get a definitive diagnosis so if needed any accommodations can be made for him at school."<br>• "Want to make sure he is getting the support he needs." |
| Sensory | sensory sensitivities | • "Sensitive to light and noise."<br>• "Fidgets in her clothes and lately will demand to wear loose fitting clothing to school instead of other jeans or pants." |
| Social | social and play skills | • "She has trouble making and keeping friends because she does not understand social cues."<br>• "Doesn't play with other children." |

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**Table 3**

Qualitative Themes Stratified by Child Race

| | Asian (n=49) | Hispanic (n=110) | Black/African American (n=31) | Multiracial/Other (n=65) | White (n=234) |
|---|---|---|---|---|---|
| | | | Mean (SD) or % | | |
| Academic | 4 (8.2%) | 16 (14.5%) | 5 (16.1%) | 9 (13.8%) | 40 (17.1%) |
| Atypical behaviors | 3 (6.1%) | 19 (17.3%) | 6 (19.4%) | 12 (18.5%) | 43 (18.4%) |
| Emotional/behavioral | 17 (34.7%) *a | 13 (41.9%) | | 28 (43.1%) | 135 (57.7%) |
| Cognition | 16 (32.7%) | 6 (19.4%) | | 11 (16.9%) *a | 79 (33.8%) |
| Communication | 37 (75.5%) * | 81 (73.6%) *a | 24 (77.4%) *a | 45 (69.2%) *a | 111 (47.4%) |
| Developmental | 4 (8.2%) | 8 (7.3%) | 3 (9.7%) | 6 (9.2%) | 23 (9.8%) |
| Health | 5 (10.2%) | 9 (8.2%) | 2 (6.5%) | 5 (7.7%) | 34 (14.5%) |
| Life skills | 6 (12.2%) | 13 (11.8%) | 3 (9.7%) | 16 (24.6%) | 47 (20.1%) |
| Motor skills | 3 (6.1%) | 4 (3.6%) | 2 (6.5%) | 11 (16.9%) *a | 17 (7.3%) |
| Seeking diagnostic clarity or resources | 10 (20.4%) | 9 (8.2%) | 2 (6.5%) | 12 (18.5%) | 36 (15.4%) |
| Sensory | 4 (8.2%) | 9 (8.2%) *a | 1 (3.2%) *a | 12 (18.5%) | 46 (19.7%) |
| Social | 25 (51.0%) | 44 (40.0%) *a | 20 (64.5%) | 26 (40%) *a | 134 (57.3%) |
| ASD-specific themes † | | | | | |
| ASD theme – RRB | 13 (26.5%) | 23 (20.9%) | 7 (22.6%) | 26 (40.0%) | 107 (45.7%) |
| ASD theme – Social Communication | 41 (83.7%) | 30 (96.8%) * | | 52 (80.0%) | 184 (78.6%) |
| Number of codes | 4.2 (2.6) *a (2.5) *a | 4.4 (2.3) | | 4.3 (2.7) *a | 5.6 (3.6) |
| Number of themes | 3.8 (2.0) a (1.7) *a | 4.0 (1.4) | | 4.2 (1.9) | 4.4 (2.2) |

Note.

* P-value < .05 for chi-square test for difference in theme proportion between children belonging to column race/ethnicity versus White children. Differences in number of codes and themes were compared using t-test. Blue and orange cells denote values that are significantly lower or higher, respectively, relative to values among White children.

† Qualitative codes for parental responses to major concerns categorized as an ASD-specific theme (restricted/repetitive behaviors or social communication).

[a] Remained significant after adjusting for age.

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**Table 4**

Multivariable Linear Regression Modeling Risk of ADOS-2 CSS Score given Parent Belief of ASD, Stratified by Child Race

| | Beta (95% CI) | | | | |
|---|---|---|---|---|---|
| | **Asian** | **Black/African American** | **Hispanic** | **Multiracial/Other** | **White** |
| Parent Belief | 0.2 (−1.0 , 1.5) | 0.1 (−0.7 , 0.9) | −0.3 (−1.9 , 1.3) | −0.9 (−2.1 , 0.2) | −0.8 (−1.4 , −0.1) * |
| Parent Education: Trade (ref: high-school) | 0.1 (−2.3 , 2.5) | −0.1 (−1.0 , 0.7) | −1.9 (−5.5 , 1.6) | 0.9 (−0.8 , 2.6) | 0.1 (−0.6 , 0.8) |
| Parent Education: Bachelor (ref: high-school) | 0.3 (−1.7 , 2.2) | −0.8 (−1.9 , 0.3) | 0.2 (−1.8 , 2.2) | 0.6 (−1.1 , 2.3) | 0.0 (−0.6 , 0.7) |
| Parent Education: Graduate (ref: high-school) | −0.3 (−2.3 , 1.7) | −0.6 (−2.0 , 0.7) | 0.7 (−1.4 , 2.8) | 0.4 (−1.5 , 2.3) | −0.9 (−1.7 , 0.0) * |
| Marital Status: Not Together (ref: together) | −0.4 (−2.6 , 1.8) | −0.7 (−1.5 , 0.1) | −0.8 (−2.8 , 1.2) | −0.7 (−2.2 , 0.8) | −0.1 (−0.7 , 0.5) |
| Marital Status: Other (ref: together) | 1.7 (−2.6 , 5.9) | 0.0 (−1.9 , 1.9) | 0.5 (−4.5 , 5.5) | --- | −2.4 (−4.4 , −0.5) * |
| Insurance: Medical Assistance (ref: commercial) | 0.9 (−0.9 , 2.7) | 0.6 (−0.2 , 1.4) | 1.8 (−0.2 , 3.8) | 0.7 (−0.5 , 1.8) | −0.1 (−0.7 , 0.5) |
| Insurance: Other (ref: commercial) | --- | --- | --- | --- | 0.2 (−1.3 , 1.7) |
| Child age (years) | −0.1 (−0.4 , 0.2) | −0.1 (−0.2 , 0.0) * | −0.1 (−0.3 , 0.2) | −0.2 (−0.4 , 0.0) | −0.1 (−0.2 , 0.0) * |

Note.

* P-value < .05 for adjusted regression estimate