Associations Between the Content and Level of Parent Concerns Pre-Diagnosis and Timeliness of Autism Screening and Diagnostic Evaluation Among a Diverse Sample of Children in Part C Early Intervention

Kohrissa Joseph

University of Massachusetts Boston

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ASSOCIATIONS BETWEEN THE CONTENT AND LEVEL OF PARENT CONCERNS PRE-DIAGNOSIS AND TIMELINESS OF AUTISM SCREENING AND DIAGNOSTIC EVALUATION AMONG A DIVERSE SAMPLE OF CHILDREN IN PART C EARLY INTERVENTION

A Thesis Presented

by

KOHRISSA JOSEPH

Submitted to the Office of Graduate Studies
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Clinical Psychology Program
ASSOCIATIONS BETWEEN THE CONTENT AND LEVEL OF PARENT CONCERNS PRE-DIAGNOSIS AND TIMELINESS OF AUTISM SCREENING AND DIAGNOSTIC EVALUATION AMONG A DIVERSE SAMPLE OF CHILDREN IN PART C EARLY INTERVENTION

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KOHRISSA JOSEPH

Approved as to style and content by:

Abbey Eisenhower, Associate Professor
Chairperson of Committee

Alice S. Carter, Professor
Member

Laurel Wainwright, Senior Lecturer II
Psychology Department
Member

Sarah Hayes-Skelton, Program Director
Clinical Psychology Program

Laurel Wainwright, Department Chair
Psychology Department
ABSTRACT

ASSOCIATIONS BETWEEN THE CONTENT AND LEVEL OF PARENT CONCERNS PRE-DIAGNOSIS AND TIMELINESS OF AUTISM SCREENING AND DIAGNOSTIC EVALUATION AMONG A DIVERSE SAMPLE OF CHILDREN IN PART C EARLY INTERVENTION

August 2022

Kohrissa Joseph, B.S., Oakwood University
M.P.S., University of Maryland College Park
M.A., University of Massachusetts Boston

Directed by Professor Abbey Eisenhower

Though autism can be diagnosed as early as 18 months for many children, the current average age of diagnosis is between 3 and 4 years old. Children of color are diagnosed even later. Several studies have examined this disparity and have found that one significant contributor is pediatric providers’ screening practices. Though the American Academy of Pediatrics (AAP) recommends autism specific screening at 18- and 24-month well-child visits, many pediatricians report only screening if they are concerned or if the parent mentions a concern. In light of recent findings that Black and Latinx parents may have fewer autism-related concerns than White parents prior to their child’s autism diagnosis, it may be that pediatricians screen children of color less often
due to parents not voicing concerns. Such practices could contribute to delayed screening and diagnosis for children of color. Thus, the current study examined whether the number of parents’ autism-related concerns pre-diagnosis mediates the relation between race and timeliness of autism screening and diagnosis. As a secondary data analysis, this project used data from a screening study implemented at 3 Part C Early Intervention (EI) agencies, including the parents of the 516 children that received an autism diagnosis. EI providers are increasingly being relied upon to screen for autism and in the larger study, it was found that they deviated from the screening protocol, as do pediatricians. As such, it is possible that similar patterns of delayed screening and diagnosis can be observed in the EI settings. It was first examined whether autism related parent concerns predicted timeliness to screening and diagnosis. Fewer concerns predicted greater time to screening and diagnosis. Next, differences in parent concerns across races was examined. Black parents reported fewer concerns than White parents; there were no differences between other racial groups. Finally, a mediation path was analyzed for Black and White parents; concerns mediated the relation between race and timeliness of diagnosis but did not mediate the pathway between race and timeliness of screening. The current study is the first to identify how the number of parents’ autism-related concerns is related to the timeliness of autism screening and diagnosis. It also helps further explore parents’ autism-related concerns, an unstudied contributor to delayed autism diagnosis among Black children. These findings shed light on the importance of how parent concerns are elicited by providers and the need for improved practices both to elicit concerns and ensure timely diagnosis in the absence of parents’ concerns.
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CHAPTER 1
BACKGROUND AND SIGNIFICANCE

While Autism Spectrum Disorder (ASD) can be reliably diagnosed for many children by 18 months (Pierce et al., 2019) and parents report first becoming concerned about the child’s development between 18-24 months on average (Chawarska et al., 2007; Ozonoff et al., 2009), the average age of diagnosis is between 3 and 4 years old (van ’t Hof et al., 2020). Further, children of color are diagnosed even later (Angell et al., 2018). Delayed diagnosis is concerning particularly in light of the missed opportunity for early intervention. Early intervention is associated with better verbal and cognitive skills as well as increased independence (Clark et al., 2018). To aid in the earlier recognition and diagnosis of autism, the American Academy of Pediatrics (AAP) recommended universal autism specific screening at 18 and 24 month well-child visits (Gupta et al., 2007). However, many pediatricians do not follow these recommendations (Arunyanart et al., 2012; Porter et al., 2016; Self et al., 2015). Further, the United States Preventative Services Task Force (USPSTF) has stated that there is not sufficient evidence for the benefits of universal screening in pediatrics, and that best practice may be pediatric providers screening only when parents bring up concerns (Siu, 2016).

The inconsistent screening behaviors of providers and this statement by the USPSTF together pose a challenge for early diagnosis and intervention for ASD and may disproportionately affect children of color. Families from marginalized backgrounds may be especially at risk for continued delayed diagnosis as they already tend to be screened and
diagnosed later (Angell et al 2018; Constantino et al 2020; Valicenti-Mcdermott et al., 2012). Further, recent research has shown that Black and Latinx parents report fewer autism related concerns pre-diagnosis when asked what general concerns they have about their child (Coffield et al., 2020; Donohue et al., 2019). This difference has not been seen on behaviorally anchored screening measures. As the recommendation to screen only when parents bring up concerns is consistent with what some providers report doing (Self et al., 2015), it is important to investigate how parents’ expressed concerns vary across racial and ethnic groups, and whether raising concerns affects overall timeliness of ASD diagnosis.

**Screening in Early Intervention**

As many children on the spectrum receive services through Part C Early Intervention (EI) prior to diagnosis, recent efforts have been made to implement screening at EI agencies. Further, the ongoing relationship between parents and providers in EI agencies allows for more opportunities for surveillance and ongoing conversations between parents and providers about concerns. One study found that screening in the Part C early intervention system contributed to earlier diagnosis for children who typically face delayed diagnosis, including children of color, children from low income families, and children from households where English is not the primary language spoken (Eisenhower et al., 2021; Sheldrick et al., 2019). Importantly, parent and EI provider autism concerns endorsed at screening predicted greater likelihood of referral to and completion of a diagnostic evaluation as well as receipt of an autism diagnosis (Sheldrick et al., 2019). Though the EI context is vastly different from primary care, screening behaviors of EI providers and pediatricians may be similar, as in practice, both often rely on their own discretion when deciding who and when to screen (Self et al., 2015; Sheldrick et al., 2019). Thus,
investigation of how parent concerns may impact providers’ likelihood to screen and timeliness of ASD diagnosis is an important consideration for the EI setting as well.

**Delayed Diagnosis**

The aim of the current study is to examine whether the content and number of parent concerns contribute to delayed diagnosis of autism and whether differences in the content of concerns based on parent race may help explain later diagnosis among children of color. Several known factors contribute to delays in diagnosis including delayed screening, lack of access to diagnostic clinics, and being diagnosed with something other than ASD (Martinez et al., 2018). Despite guidelines by the AAP that suggest general developmental screening at several time points and autism specific screening at 18- and 24-month well-child visits, as well as evidence of decreased delays in diagnosis when screening is done consistently (Martinez et al. 2018), providers do not consistently follow these recommendations. Porter et al (2016) found that only about 63% of pediatric primary care providers report using formal developmental screening tools with their patients. Across several studies, rates of compliance with AAP screening recommendations range from 17%-75% (Arunyanart et al., 2012; Porter et al., 2016; Self et al., 2015). Some providers also report several modifications to the AAP recommendations for ASD screening such as: screening at the 18-month visit but not the 24-month visit, only screening if the child was referred for autism screening, and only screening if the provider was concerned or if the parent voiced a concern (Self et al., 2015).

While there are no specific autism screening guidelines for EI agencies, recent efforts to decrease delays in diagnosis have included investigation of autism screening practices in EI agencies (Eisenhower et al., 2021; Sheldrick et al., 2019). EI providers have reported screening more often for general developmental delays than autism. Further, they have reported infrequent
use of recommended autism screening measures and lack of preparation to speak with families about autism (Pizur-Barnekw et al 2013; Tomlin et al 2013). It is also evident that, similar to pediatricians, EI providers may take liberty in deciding when and how to implement screening practices. For example, in a study introducing an autism screening system in 3 EI agencies, Sheldrick et al (2019) reported that several providers endorsed slowing down the screening process if they thought parents were not ready. It is unknown whether children in these scenarios were diagnosed later on average. Investigation of other factors that may slow down the screening process within EI and how this may impact timeliness of autism diagnosis is warranted.

**Children of Color Diagnosed Later**

Racial and ethnic minority children experience greater disparities in access to an autism diagnosis. They are diagnosed later than their White counterparts (Angell et al 2018; Constantino et al 2020; Valicenti-Mcdermott et al., 2012) and several years after parents endorsed having first concerns about language, behavior, or general development (Constantino et al., 2020; Valicenti-Mcdermott et al., 2012). Interestingly, the prevalence of diagnosed autism has historically been higher among White children than children of color, suggesting that children of color are being missed (Baio et al., 2018). In the Center for Disease Control and Prevention (CDC) monitoring study focused on prevalence rates among school aged children, it has been found that the gap has recently closed for Black children and Asian/Pacific Islander children relative to White children but persists for Latinx children (Maenner et al 2020). This narrowing of the gap in racial disparities in diagnosis suggests that increased attention to disparities in diagnosis may have helped increase rates of diagnosis among children of color. Still, disparities in early diagnosis persist (Constantino et al 2020).
Several factors may contribute to the delayed diagnosis of children of color including screening practices, availability of diagnostic evaluations, and inaccurate diagnosis (Mandell et al, 2007; Carbone et al, 2020; Constantino et al, 2020). One study found that Latinx children are screened for autism in pediatric settings less often than non-Latinx White children (Carbone et al 2020). Further, many Black parents report long wait times to see a provider and also having to see several providers before receiving an autism diagnosis (Constantino et al., 2020). It has also been found that, once evaluated, children of color are less likely to be given an autism diagnosis and have a higher likelihood of being misdiagnosed (Mandell et al., 2007). Further, there is a greater delay from parent’s first concern to receipt of a diagnosis for children of color than for White children, with some suggesting that parents of color may have difficulty expressing concerns to providers or encounter greater barriers to receiving a timely diagnosis (Angell et al 2018). Relatedly, some studies have found that parents of color may wait longer to voice concerns to their child’s pediatric provider due to stigma, mistrust of medical systems of care, and discouragement from seeking services by family and community members (Angell et al 2018). As possible support for the existence of a communication breakdown between parents of color and medical systems of care, one study found that parents of color are less likely to mention concerns to primary care providers, yet speak to school staff about concerns (Zeleke et al., 2019). Lastly, provider bias in screening children of color may contribute to disparities. Providers may screen Latinx children less often due to the belief that Spanish-speaking parents are not able to understand screening tools (Angell et al 2018).

As several studies have shown that parents of color may face unique challenges with accessing diagnosis, particularly in relation to their interactions with primary care providers, Dababnah et al (2018), conducted a qualitative study with 22 female caregivers of Black children
on the spectrum. These parents were interviewed about their experience obtaining a diagnosis for their child from the time of first concerns to diagnostic ascertainment. Three of the themes derived from the interviews include: whether providers listened to parents’ concerns, strained interactions with providers, and stigma in the Black community concerning diagnostic labels. Regarding whether providers listened to parents’ concerns, it was found that when providers did listen and act, the children were diagnosed by age 4 or earlier, similar to findings in a nationally representative sample (Zuckerman et al., 2015). When the provider did not act on the parent’s concerns, the children were diagnosed between 4 and 8 years old. Among the group of parents who reported that their child’s provider did not attend to their concerns, some sought intervention independently or persisted in asking their provider for a referral. Of note, the parents who persisted in asking for a referral all came from educationally and financially privileged backgrounds, suggesting that higher SES may be a protective factor for parents of color facing challenges getting their child a diagnosis. Similarly, several studies have found that children of color with highly educated parents are diagnosed earlier (Angell et al 2018). Dababnah (2018) also found that strained interactions with providers include parents perceiving that the provider’s failure to provide a referral for their child was based on racial bias. Lastly, it was found that stigma in the Black community includes resistance of an autism or special needs label and encouragement from friends and family members to pray or increase discipline with child in lieu of seeking evaluation and services. Indeed, these qualitative findings may offer support to previously mentioned findings that suggest parents of color may be apprehensive to share concerns with their PCP for several reasons. Further investigation of the communication breakdown between parents of color and providers and its contribution to delayed detection of autism among children of color is warranted.
Parent Concerns and Race

Studies have shown that, among parents of children later diagnosed with ASD, there is no difference between racial/ethnic groups in the age at which parents first became concerned about the child’s development (Jang et al., 2014). However, most studies have not examined the content of these first concerns. Thus, while there may be no difference in the child age of these initial concerns, which include both general developmental and autism specific concerns, the nature of the concerns may vary. Indeed, recent studies have found differences in the content of parental concerns of Black parents and Spanish-speaking parents of children later diagnosed with autism, with both groups expressing fewer ASD-related concerns than White and English-speaking parents respectively. Importantly, these studies determined parent concerns by coding parents’ responses to an open-ended question about the general concerns they had about their child. In both studies, these questions were asked after autism specific screening but prior to the child receiving a diagnosis (Coffield et al., 2020; Donohue et al., 2019). Prior to the child’s diagnosis with autism, Black parents were found to have fewer social, RRB and overall ASD-related concerns than white parents, though there was no difference in the prevalence of non-ASD-related concerns (Donohue et al., 2019). In a similar study, focused on Latinx and non-Latinx families and Spanish speaking and English-speaking families, no difference was found when grouping participants based on race. However, it was found that, prior to diagnosis, Spanish-speaking parents reported general developmental and ASD-related concerns less often than primarily English-speaking parents (Coffield et al., 2020).

Though differences in concerns based on parent race have been found when probing in an open-ended format (Coffield et al., 2020; Donohue et al., 2019) and not on screening measures (Jang et al., 2014), differences in concerns may also emerge in probes done through a
questionnaire format. Blacher et al. (2019) found that, when asked to endorse specific concern categories such as depressed/anxious, motor skills, etc., Latinx mothers endorsed a smaller number of total concerns than white mothers. Additionally, Latinx mothers endorsed fewer concerns than White mothers in two ASD-related characteristics; “difficulty with transitions” and “social skills” and some characteristics related to compliance and disruptive behavior, but did not differ in their frequency of endorsing concerns related to temperament, “ritualistic behaviors”, “peculiar interests”, eating, motor skills, and speech, (Blacher et al., 2019).

To my knowledge, no studies have sought to examine the early parental concerns of Asian or Asian American parents of autistic children. However, one study focused on expectations of school-related skills, verbal assertiveness, compliance, politeness, emotional maturity, instrumental independence, and social skills among Japanese and U.S. mothers and found some differences in the timing of expectations of certain skills. Japanese mothers expected mastery of emotional maturity, compliance, and social courtesy earlier than U.S. mothers (Hess et al, 1980). Another study comparing parent and teacher perspectives of ADHD in Korea and the U.S. found that Korean parents had greater concerns about academic achievement and U.S. parents had greater concerns about child behavior (SeokYoung, 2011). As similar research has not been conducted specific to autism-related concerns, the current study will examine the autism-related concerns of Asian American parents in an exploratory manner.

Taken together, these findings suggest that certain concerns may be less salient for parents of different racial/ethnic backgrounds relative to White parents and that differences in language may also contribute to the expression of concerns. The cause(s) of these differences is unclear, particularly for Latinx families in which the difference could be due to language, culture, or both. Though the reasons behind differences in expressed concerns are unknown,
these factors are important to consider in terms of how providers probe for concerns. Providers should be made aware that families from different racial/ethnic backgrounds and families who primarily speak a language other than English may not initiate conversation of certain concerns and may express concerns differently. In a system where providers rely on parents to voice concerns before implementing screening and referrals, these families may be overlooked. If providers are to rely on parent report of concerns before initiating screening, they should ask targeted questions that elicit concerns about specific behaviors. Further, one study found no differences across racial/ethnic groups in parent concerns on autism screening measures (Jang et al., 2014). Though replication is needed to solidify this finding, this initial study suggests that following the AAP’s universal screening recommendations may eliminate the potential for these families to be overlooked.

**Specific Aims**

Overarching aim: To determine whether, among a racially diverse sample of children receiving Part C Early Intervention (EI) services and who later received a diagnosis of autism, the number of parents’ autism-related concerns pre-diagnosis predicts the timeliness of autism screening and diagnosis, and, if so, whether the presence of fewer autism-related concerns among Black, Latinx, and Asian parents partially accounts for the delayed screening and diagnosis of their children.

1. To determine whether the number of parents’ autism-related concerns pre-diagnosis (retrospectively ascertained at an autism diagnostic evaluation based on parents’ responses to a question about their concerns prior to EI) predicts the timeliness of autism screening and diagnosis.
Hypothesis: Among children who later received a diagnosis of autism, children of parents who had fewer autism related concerns pre-diagnosis will have greater delays in first-stage screening and diagnosis after initiating Part C Early Intervention services.

2. To determine whether there are differences across racial groups in the number of parental autism-related concerns prior to autism diagnosis.

Hypothesis: Black and Latinx parents will have fewer autism related concerns compared to White parents. It will also be examined in an exploratory manner whether Asian American parents differ from other racial groups in the number of autism-related concerns pre-diagnosis.

3. To determine whether the number or presence of parents’ autism-related concerns pre-diagnosis partially mediates the relation between parent race and delayed screening and diagnosis for children of parents of color.

Hypothesis: Racial groups will differ in the timeliness of their screening and diagnosis, and the number of parents’ autism-related concerns pre-diagnosis will partially mediate this relation between parent race and timeliness of autism screening and diagnosis.

   a. Prior to testing the mediation in hypothesis 3, I will first determine whether race is associated with timeliness of screening and diagnosis.

Hypothesis: In line with existing research on health disparities in screening and diagnosis, I expect that children of Black and Latinx parents will have greater delays in screening and diagnosis compared to children of White parents. It will also be examined in an exploratory manner whether children of Asian American parents will differ from other racial groups in the timeliness of screening and diagnosis.
b. Finally, if all of the three individual paths are supported (H1: concerns to timeliness; H2: race to concerns; and H3a: race to timeliness), then I will evaluate whether the number or presence of parents’ autism-related concerns pre-diagnosis partially mediates the path from race to timeliness of autism screening and diagnosis for both children of Black parents and children of Latinx parents (vs. White). This would be the final step in assessing an overall mediation effect. Hypothesis: I expect that, for both children of Black and Latinx parents, the effects of race (Black vs. White and Latinx vs. White) on the timeliness of both screening and diagnosis will be partially mediated by their parents’ number of autism-related concerns prior to diagnosis. The mediation path for the children of Asian American parents will be examined based on the results of exploratory analyses of the three individual paths (H1, H2, and H3a).
CHAPTER 2
RESEARCH DESIGN AND METHODS

Participants

Participants in the current study (N = 516) are a subset of participants from the larger ABCD Early Screening study, a HRSA- and NIH-funded study aimed at targeting disparities in Autism Spectrum Disorder (ASD) diagnosis and intervention for children marginalized along the lines of race, income, and English language proficiency. Screening and diagnostic evaluations were conducted in English and Spanish. ABCD participants were young children receiving Part C Early Intervention (EI) services at three agencies within the Boston Circle of Promise, a region identified for needed interventions targeting health disparities: 43.4% of participants were at agency 1, 40.7% at agency 2, and 15.9% at agency 3. As part of an ongoing EI-university partnership, these EI-enrolled children were screened for autism using a multi-stage screening process in 2013-2019. The current study includes the 516 participants from this larger ABCD sample who went on to receive a diagnosis of autism through the ABCD Project.

Within this sample, 80.2% of the children were male. The average child age at initial screening and diagnostic evaluation was 24.55 months (range: 12-35 months; SD=5.06) and 27.68 months (range: 14-39 months; SD = 4.93) respectively. The average child developmental quotient (DQ) was 67.90 (range: 45.0-96.0; SD=10.41). Among responding parents, 84.2% were female. Relationship to child was assessed and parents reported the following: 84.5% biological
mother, 13.9% biological father, 0.4% grandmother, 0.2% adoptive mother, 0.2% foster mother, 0.2% grandfather, 0.2% foster father, and 0.4% other. In terms of English proficiency, 47.2% reported having “poor”, “fair”, “good” or “very good” English proficiency and 52.8% reported having “excellent” proficiency or being a native speaker. Most parents (89.2%) reported that at least one caregiver within the household had at least a high-school education and 57.5% reported household income equal to or below 185% of the state poverty level. Both parent and child race were assessed based on an open-ended item that was later aggregated into groups; parents reported child race as Latinx (45.3%), Black (19.4%), White (15.5%), Asian (4.8%), and Multi-Racial/Ethnic (3.9%). Parents reported their own race as Latinx (45.9%), Black (19.8%), White (16.7%), Asian (4.8%), and Multi-Racial/Ethnic (3.3%); another 3.5% of parents and 2.9% of children were from other racial groups for which we had less than 50 participants. Another 6.0% of parents either did not respond to the question of parent race/ethnicity or provided unclear responses that could not be coded and were not aggregated; the same for 8.1% of child race/ethnicity responses. A summary of participant demographics are displayed in Table 1.

**Procedures**

The larger ABCD Project’s multistage screening process included two standardized questionnaires at Stage 1, followed by a play-based observational screening tool at Stage 2 for those screening positive at Stage 1, and a diagnostic evaluation for those screening positive at Stage 2. In line with a universal screening model, all study-eligible, EI-enrolled children at our three partnering EI agencies were to receive Stage 1 screening. Children were advanced to Stage 2 if they received an elevated score on the screeners or if either a parent or Early Intervention Provider (EIP) expressed concerns about ASD; children were referred for a diagnostic evaluation if they received an elevated score at Stage 2 or if the parent or EIP continued to have ASD.
concerns. Stages 1 and 2 screenings were conducted by EIPs during their regularly occurring EI sessions. EIPs had autonomy over if/when screenings were conducted and referrals made and were encouraged by the research team to refer onward for Stages 2 and the diagnostic evaluation if any of the screening criteria were met. EIP’s at Agencies 1 and 3 implemented universal screening while half of the EIP teams at Agency 2 conducted universal screening and half only screened when concerned about ASD. A licensed clinical psychologist supervised the diagnostic evaluation and assigned ASD diagnoses at a university and offered diagnostic feedback, as well as informing families that they were now eligible for ASD-specific Part C EI services, which were only eligible to children with an ASD diagnosis.

**Measures**

Demographic surveys were typically completed independently by parents and developmental history interviews were administered to parents by licensed psychologists during the diagnostic evaluations, as part of broader information-gathering. The developmental history interview and other interactions with the parents were conducted in English or Spanish depending on parent preference.

**Demographics.** Demographic characteristics, including parent and child race and ethnicity, parent relationship to child, parent education, income and household size, and parent English proficiency, were determined through parent-reported questionnaires during diagnostic assessments.

Parent race and ethnicity, rather than child race and ethnicity, were used for all analyses as it more closely reflects our conceptualization of the impact of race on parental concerns in this study. Consistent with existing research, parent race is particularly important in predicting health disparities in access to care for marginalized children (Manning et al., 2011). Parent race and
ethnicity were assessed with open-ended questions, in which parents were asked to state, in their own words, the race(s) and ethnicity/ies they identify with; This open-ended approach has been shown to more accurately capture self-identified race than close-ended multiple-choice items (Eisenhower et al., 2014). These were then coded by a team of researchers into aggregate categories: Black, Latinx, Multi-Racial/Ethnic, White, Asian, and n<50 for racial/ethnic groups that include fewer that 50 participants.

Parent-reported household income on an eight-point scale, along with household size, were used together to determine whether the family earned at or below 185% of the state poverty level; this dichotomous variable (above versus below 185% of the poverty level) was used as our income variable in analyses. For those missing the parent income and household size data (13.6%) needed to determine whether the family earned 185% of the state poverty level, we relied on parent report of public (versus private) insurance to indicate that families earned < 185% of the state poverty line when this data was available (10.3% of the sample).

To assess English proficiency, parents were asked to rate their ability to speak English on a scale of 1 (poor) to 5 (excellent) if English was not their first language. For the present study, a score of 5 was given to parents that endorsed English as their first language, and data for all participants was evaluated on a 5-point scale. Data were missing for 7.2%. To assess parent education, parents were asked to report their level of education on a range from 8th grade or less to professional degree. For the present study, parent education was collapsed across the entire household as a dichotomous variable reflecting whether or not at least one parent had a high school education or more. Data were missing for 4.7%. Parent relationship to child data were missing for 3.9%.
**Parent Concerns.** In a developmental history interview during the diagnostic evaluation, parents were asked questions about their child’s general development. For the current study, we utilize parent’s responses to the following questions to assess their concerns about their child’s development: “Before your child started with Early Intervention, was there anything you were concerned about in terms of his/her development?” If concerns were endorsed, parents were asked, “What were you concerned about?” Responses to both questions were recorded verbatim.

Using an adaptation of the coding schema reported in Donohue et al (2019), which was modified from Ozonoff et al. (2009), parent responses to the concern questions were coded based on three concern categories that map onto the DSM-5 categorizations of autism characteristics—speech/communication, restricted and repetitive behaviors (RRB), and social—as well as parents’ use of the autism label (e.g., “I think my child may be autistic”). Speech and communication were coded separately in this study as many children enter EI for speech production related concerns. Combining these general speech concerns with communication concerns could lead to less variability in the overall concern variable. The coding schema is presented in Table 2. A score of 1 was coded for each of the 5 categories a concern was endorsed in, and, post-coding, a total concern score was derived by summing the number of categories endorsed (6-point scale of 0-5). Coding was conducted by three researchers and reliability analyses were conducted on 20% of the data. The average Cohen’s kappa across all three coders for each concern category ranged from moderate to strong as follows: .928 for speech, .663 for communication, .821 for RRB, .868 for social, and 1.00 for autism label. Consensus coding by the three researchers was used to resolve discrepancies. A clinical psychologist and expert in autism diagnosis was consulted when discrepancies could not be resolved by the three coders.
Child Developmental Functioning. Prior to beginning EI services, children were assessed for eligibility using the Battelle Developmental Inventory-2 (BDI-2). The BDI-2 is a standardized assessment of developmental and functional skills in young children across 5 domains- motor, adaptive, cognitive, personal-social, and communication. As the parent concern variable is based on parents’ concerns at the onset of EI services, this early assessment of child functioning, administered at the start of children’s EI services is temporally relevant to these early parental concerns. The total score reliability coefficients range from .98-.99, with comparable performance of 4 of the 5 domains (the adaptive domain fell below .80). Test-retest reliability above is .80 for the 5 domains and total score. The test has moderate to high correlations with several different assessments of child development (Newborg, 2005). The total developmental quotient (DQ) score was used as an assessment of child developmental functioning and included as a covariate where relevant. For 45 participants (8.7% of the sample) for whom BDI-2 DQ was unavailable, composite scores from the Mullen Scales of Early Learning (MSEL), which was administered at the diagnostic evaluation, were used. The MSEL is a widely used measure of developmental functioning for infants and toddlers. Internal consistency for individual scales ranges from .75 to about .80 and test-retest reliability ranges from .70-.80. It is also highly correlated with several developmental and language assessments for infants and toddlers (Mullen, 1995). Within the present sample, MSEL composite scores and BDI-2 total DQ were moderately significantly associated for the 461 participants that had both measures (r=.403, p<.001). Controlling for the time between the BDI-2 administration and the MSEL administration, the correlation remained moderately significant (r=.417, p<.001).

Timeliness of Screening and Receipt of a Diagnosis. Timeliness of screening was calculated as the time elapsed between the date at which the child became eligible for initial
screening and the date of initial screening, in days. Timeliness of diagnosis was calculated as the time elapsed between the date of eligibility for initial screening and the diagnostic evaluation in days. Date of eligibility for the initial screening was either the date at which the child turned 14 months or, for children > 14 months, the date at which the child entered EI or the study onset, whichever was later. Date of EI entry was derived from the date of the BDI-2 (91.3%) when available or based on parent report of age at EI entry or date of EI entry (7.8%), or date they first started seeing their case coordinator (0.58%). For a few participants (1.9%), the time elapsed between eligibility for stage 1 screening and the screening produced a negative value, suggested data entry errors or that the child was screened prior to eligibility (e.g., before the official study start date or before turning 14 months). For these participants, the number of days elapsed was recorded as 0 if the difference was within 60 days; all others were considered missing data.
CHAPTER 3
RESULTS

Preliminary Analyses

All data were analyzed using SPSS 28.0 statistical package. Descriptive statistics were examined for each of the independent, dependent, and potential control variables. For the continuous variables, boxplots were used to assess for outliers and variables with outlier values were changed to one point above the highest non-outlier value. Next, means, standard deviations, and skewness and kurtosis were assessed. A frequency analysis was run for the parent concern variable to examine the distribution of the number of concerns, a 6-level variable (0-5 concerns). The proposed criteria for sufficient variability, fewer than 90% of participants represented at each level of concerns, was met. The mean number of concerns was 1.04 (range: 0-4; SD=.723). A z-score version of the parent concern variable was used for main analyses.

Prior to main analyses, data were analyzed for the level of missingness. Little’s Missing Completely at Random test was statistically significant, X²=234.63, df=135, p=.000. We used listwise deletion for all variables, even for variables missing > 5% of data (child age at Stage 1 missing 5.2%, English proficiency missing 7.2%, timeliness to Stage 1 missing 5.6%, and parent concerns missing at 9.3%). Other primary variables missing data but less than 5% include time to diagnosis (0.58%), and the number of days elapsed between study start and date of eligibility (0.39%). As parent concerns and timeliness to Stage 1 were key variables and were missing at > 5%, differences in demographic or developmental factors between those missing and not missing
these data were examined. Those missing parent concerns data were higher in English proficiency [M(SD) of 4.34(1.15) vs. 3.80(1.44)], had lower child DQ (M=68.31, SD=11.96 vs. M=67.85, SD=10.25), and were more likely to be from EI Site 1 (50.0%) or 2 (47.9%) versus Site 3 (2.1%) compared to those not missing parent concerns; the two groups did not differ on parent or child sex, race/ethnicity, poverty level, education, parent relationship to child, child age at stage 1 or diagnostic assessment, child timeliness to stage 1 screening or diagnosis, language of diagnostic evaluation, or level of parent concerns. Further, there was a difference in number of days elapsed between study start and eligibility for stage 1 screening for those missing (M=140.87, SD=132.88) and not missing (M=897.06, SD=511.74) parent concern data; t(512)=10.09, p<.001. As parent concern data was missing more often for participants that became eligible earlier on, and for those not at Site 3, it is likely that missing concern data was due to administration factors early in the study implementation rather than parent or child characteristics or other key variables.

Those missing timeliness to stage 1 data were more likely to be children for whom race was not aggregated (93.1% vs. < 0-3.4% missing across all other race groups), to have female parents providing study data (84.2% vs. 15.8% male parents), and to be from EI Site 1 (43.4%) or 2 (40.7%) versus Site 3 (15.9%) than those not missing timeliness to stage 1 data; the two groups did not differ on child sex, parent race/ethnicity, education, poverty level, parent relationship to child, language of diagnostic evaluation, child age at stage 1 screening or diagnosis, child DQ, English proficiency, timeliness to stage 1 screening or diagnosis, parent concerns, or the number of days elapsed between the study start date and date of eligibility. These results were such that proceeding with listwise deletion appeared appropriate.
Relations between the independent and dependent variables and parent race, income, caregiver education level, English language proficiency, child developmental functioning (DQ), EI agency, time elapsed between study start date and child eligibility for screening, and language of the diagnostic assessment were examined to determine whether they should be entered as covariates in the main analyses. Time elapsed between study start date and date of eligibility was assessed as a potential covariate as EI providers may have had an adjustment period to implementing screening into their practice, and language of assessment was considered as a covariate because there were fewer available Spanish language evaluations which may have impacted timeliness to diagnostic evaluation for families that requested a Spanish language evaluation. Variables that were associated with both independent and dependent variables were covaried in subsequent analyses.

English proficiency was associated with parent concerns (r=.153, p=.001) and parent race [F(3,432)=54.35, p<.001]: parents with greater English proficiency reported more concerns and were more likely to be White [English proficiency M (SD) = 4.94 (0.29)] or Black [4.49(0.98)] than Asian [3.64(1.15)] or Latinx [3.15(1.53)]. As this is an expected finding, English proficiency will not be used as a co-variante in main analyses. Child DQ was positively associated with timeliness to stage 1 (r=.281, p<.001), timeliness to diagnosis (r=.306, p<.001), and concerns (r=-.098, p=.033). Caregiver education was associated with timeliness to Stage 1 [t(465)=.821, p=.007] and parent race [x²(3, n=446)=23.55, p<.001]. Income was associated with timeliness to stage 1 [t(478)=-2.69, p=.002], timeliness to diagnostic evaluation and parent race [x²(3, n=438)=38.34, p<.001]. As such, DQ was covaried in analyses for Aims 1 (concerns predicting timeliness to stage 1 screening and diagnosis) and 3B (concerns mediating the relation between race and timeliness) and both caregiver education and poverty status were covaried in
Aims 3A (race predicting timeliness to stage 1 screening and diagnosis) and 3B. All other potential covariates (child age at stage 1 screening and diagnosis, number of days elapsed between study start date and child eligibility for stage 1 screening, child and parent sex, language of diagnostic evaluation, child race, parent relationship to child, and EI site) were not associated with both an independent and dependent variables and were therefore not co-varied in subsequent analyses.

**Analyses of Specific Aims**

**Specific Aim 1:** To determine whether the number of parent autism-related concerns pre-diagnosis (retrospectively ascertained at an autism diagnostic evaluation based on parents’ concerns prior to EI) predicts the timeliness of autism screening and diagnosis.

Hierarchical linear regression analyses were conducted to examine whether number of autism-related concerns predicted timeliness of screening and timeliness of diagnosis, respectively. Two separate regression models were run: one for timeliness to screening and one for timeliness to diagnosis. For both analyses, the child DQ covariate was entered into Step 1 and the number of autism-related concerns was added in Step 2. For the regression predicting timeliness to stage 1 screening, in Step 1, higher DQ predicted shorter time intervals [$R^2=.070, F(1,439)=33.01, \beta=.264, p<.001$]. In Step 2, parents’ number of autism-related concerns predicted timeliness to stage 1 above and beyond DQ [$R^2_{\text{change}}=.054, F(1,438)=27.03, \beta=-.233, p<.001$], accounting for 5.4% of the variance; when parents had more autism-related concerns, the time elapsed to screening was shorter. Both DQ ($\beta=.243$) and autism-related concerns ($\beta=-.233$) remained significant in the final model [$R^2=.124, F(2,438)=30.10, p<.001$].

For the regression predicting timeliness to diagnosis, in Step 1, higher DQ significantly predicted shorter time intervals [$R^2=.094, F(1,465)=48.47, \beta=.307, p<.001$]; consistent with the
finding for time to screening. In Step 2, parents’ number of autism-related concerns predicted timeliness to diagnosis above and beyond DQ \( R^2 \) change=.066, \( F(1,464)=36.60, \beta=-.259 \) p<.001, accounting for 6.6% of the variance; when parents had more autism-related concerns, the time elapsed to diagnosis was shorter. Both DQ (\( \beta=.281 \)) and autism-related concerns (\( \beta =-.259 \)) remained significant in the final model \( R^2=.161, F(2,464)=44.39, p<.001 \). The results of these two regressions support hypothesis 1; a greater number of parent autism concerns was associated with shorter time elapsed from eligibility to screening and from eligibility to diagnosis.

**Specific Aim 2.** To determine whether there are differences across racial groups in the number of parental autism-related concerns prior to autism diagnosis.

An ANOVA was run with parent race, a categorical variable with 4 groups-Black, Latinx, White, and Asian, as the IV and parents’ number of autism-related concerns as the DV. Participants that did not fall within these 4 racial groups (N=52) were not included in analyses beyond Aim 1 as there was no hypothesis for how parent concerns may vary between these groups and other racial groups. As Levene’s test found unequal variances between groups (p=.012) and the groups had unequal sample sizes, the Brown Forsythe test was used. Race was significantly associated with parent concerns, \( F(3,241.41)=3.03, \ p=.03, \eta^2=.021 \).

Games-Howell post-hoc analyses revealed that White parents (n=75, M=.264, SD=1.09) had significantly greater concerns than Black parents (n=95, M=-.155, SD=.98), with no differences between other racial groups. These results supported the hypothesis that Black parents reported fewer autism related concerns than White parents did pre-diagnosis, but did not support the hypothesis that Latinx parents would have fewer autism related concerns than White parents. It also provided clarity on the exploratory analysis for differences in concerns between
Asian parents and White, Black or Latinx parents; Asian parents within this sample did not differ in concerns from parents in these racial groups.

**Specific Aim 3.** To determine whether the number of parents’ autism-related concerns pre-diagnosis partially mediates the relation between race and timeliness of screening and diagnosis for children of parents of color.

As differences in parent concerns were only found between Black and White parents (aim 2), differences in timeliness were only assessed for these two racial groups. SPSS PROCESS macro model 4 was used to examine the full mediation model (aim 3b) as well as all paths in the model, which included the impact of race on timeliness to stage 1 screening and diagnosis (aim 3a). Bootstrapping analyses were conducted with 5,000 samples and based on a 95% confidence interval. For the mediation model with timeliness to screening, child DQ, parent education, and household income were entered as covariates. The total effect of parent race on timeliness to screening was non-significant [Effect=-17.07, CI(-39.39, 5.25), p=.133] as was the indirect effect [Effect=-4.45, CI(-12.26, .49)]. For the mediation model with timeliness to diagnosis as the outcome, child DQ and household income were entered as covariates. The total effect of parent race on timeliness to diagnosis was non-significant [Effect=-24.02, CI(-57.41, 9.38), p=.157]. However, there was a significant indirect effect of parent race on timeliness to diagnosis by way of parents’ autism-related concerns [Effect=-10.02, CI(-22.70, -.54)]. As the confidence interval does not include 0, it can be concluded that the effect of parent race on timeliness to diagnosis by way of parent concerns is different from 0 and accounts for 41.7% of the variance in timeliness to diagnosis. Research suggests that a significant total effect need not be a prerequisite for testing an indirect effect, substantiating the report of this significant indirect effect (Rucker et al., 2011).
CHAPTER 4

DISCUSSION

Receiving a timely autism diagnosis is important in ensuring that children receive early access to autism-specific services; however, families of color experienced greater delays in diagnosis than White families. The number of autism-related concerns parents have early on, prior to diagnosis, may be one factor that accounts for differences in the timeliness of autism screening and diagnosis. The present study investigated whether parents’ early autism-related concerns mediate the relation between parent race and the timeliness of screening and diagnosis for young autistic children, in the context of a multi-stage screening and assessment protocol for children receiving Part C EI services that was designed to address health disparities in ASD diagnosis. I first sought to establish whether the number of autism-related concerns parents had about their child at the time the child began EI services predicted how quickly their child went on to receive autism screening or a diagnosis of autism. As hypothesized, fewer parental autism-related concerns predicted a greater time elapsed from eligibility to both screening and diagnosis. Next, differences in parental concerns between racial groups were examined. As hypothesized, at a diagnostic evaluation prior to receiving an ASD diagnosis, Black parents reported that they had fewer autism-related concerns at the time of EI entry than White parents. As shown in Table 3, 24.2% of Black parents reported 0 autism concerns as compared to 14.7% of White parents that reported 0 autism concerns. While Black parents appeared more likely than White parents to have 1 autism concern (61.1% vs. 53.3%) they were also less likely to report 2 (12.6% vs.
25.3%) or 3 (1.1% vs. 6.7%) autism concerns. In contrast with our hypotheses, there was no difference in the number of concerns reported between Latinx and White parents. Further, no differences were observed between Asian parents and parents of any other race, which was examined as an exploratory aim. Lastly, the mediation path was examined. In contrast to our hypotheses, race did not predict timeliness to screening or diagnosis. Further, concerns did not mediate the relation between race and timeliness to screening. However, concerns did mediate the relation between race and timeliness to diagnosis, consistent with our hypothesis.

Several prospective studies have found that parents’ autism-related concerns prior to autism diagnosis predict whether children later receive an autism diagnosis (Hess & Landa, 2012; Ozonoff et al., 2009; Richards et al., 2016; Sacrey et al., 2015). Ozonoff et al. (2009), the study that originated the concerns coding protocol used in the present study, prospectively followed younger siblings of autistic children and a comparison group of younger siblings of non-autistic children from infancy through 36 months when diagnostic outcome was evaluated. Parents were asked about their developmental concerns at study intake then again when their child was 6, 12, and 18 months. This study found that at 12 and 18 months, parents of children who were later diagnosed with autism had more autism-related concerns than parents of children who were not diagnosed later, and the number of concerns predicted who would go on to receive a diagnosis. Parent concerns were also significantly associated with measures of development and autism characteristics, further suggesting that parent report of autism characteristics is reliable. While this and other similar studies examined how parental concerns predicted whether children received a diagnosis, the current study found that the number of parental autism concerns predicts how quickly a diagnosis is received. The current study also found that parents’ autism concerns predicted how quickly an autism screening was obtained, a topic that no known
previous studies have investigated. Given that receiving an autism screening increases the likelihood that a child will receive a diagnostic evaluation for autism (Zwaigenbaum & Maguire, 2019), this is an important finding.

The present study, which took place in the Part C EI context, replicated previous research conducted with children in the pediatric context, which focused on children screened for autism at well-child visits then further assessed after a positive screen (Donohue et al., 2019). In this study, parents were asked to list any developmental concerns they had prior to receiving the results of their child’s autism screening, finding that Black parents reported fewer concerns than White parents. Consistent with the study by Donohue and colleagues, Black parents reported fewer autism-related concerns than White parents pre-diagnosis. Though the reasons behind this difference have not been examined, this is important when considering factors that may contribute to delayed screening and diagnosis for Black children. Importantly, this is not to say that the onus of responsibility for delayed screening and diagnosis among Black children rests on their parents. Rather, these findings should serve as evidence for the importance of screening providers’ (EI, pediatricians, etc.) knowledge of these differences among racial groups and impact how parent concerns are elicited by providers. For instance, providers should be encouraged to ask parents directly about various developmental aspects that are relevant to autism instead of asking a general question of whether parents have any concerns about their child’s development or relying on parents to mention specific concerns. Importantly, the present study relied on parent-reported concerns to an open-ended question of the developmental concerns in an interview format, which may reflect the concerns they would mention to a provider spontaneously when asked a general question without any additional prompting.
Psychoeducation from providers around autism may also help to elicit and increase parents’ autism-related concerns, as might the level of trust and comfort between parents and pediatricians and other providers. Psychoeducation would provide parents with important information about development and early signs of autism characteristics that may be otherwise overlooked. In terms of trust between parents and providers, previous research suggests that Black parents often have weaker parent-provider relationships, reporting perceived racism and mistrust of healthcare providers (Angell et al., 2018; Dababnah, 2019). It is possible that, in the present study, Black parents may have had weaker parent-provider relationships with PCPs and other providers who typically contribute to the screening and diagnostic process as compared to White parents, accounting for their fewer autism related concerns.

Altogether, these findings serve as evidence for the importance of ongoing conversations between parents and providers to close the gap in concerns between Black and White parents and reduce disparities in diagnosis. A prime opportunity for such conversations is during universal screening for autism. Though universal screening at well-child visits has been suggested by the AAP, it is not followed by many PCPs, and it is not yet supported by the USPSTF (Siu, 2016). If universal screening is utilized as suggested by the American Academy of Pediatrics (AAP), differences in parent concerns may not impact timeliness to diagnosis as there are no known differences in parent report on screening measures by race (Jang et al., 2014). Further, the screening process should include discussions with parents about the results and should provide a platform for parents to share their concerns through conversation and careful interviewing skills of the screening provider. Of note, many EI referrals likely derive from well-child visits; as such, dialogue between parents and PCPs during these visits may help parents identify and continue to formulate their concerns and understandings of their child’s development.
While aspects of parent-provider interactions may be one cause of differences in concerns between Black and White parents, some studies have found that parents’ knowledge about autism may be another factor. For example, it has been found that lesser knowledge of autism in Black communities is one factor that is associated with disparities in care (Rivera-Figueroa et al., 2022), this may be one contributor to fewer autism related concerns among Black parents. Future research should examine whether lesser autism knowledge is associated with fewer autism concerns among Black parents.

A lack of differences in parent concerns between Latinx and White parents was inconsistent with the hypothesized outcome. No differences were found between Asian and other parents as well. Previous research has identified fewer reported general developmental and autism related concerns among parents whose primary language was Spanish (Coffield et al., 2020). Research also supports that lesser English proficiency is associated with difficulty navigating systems of care and delayed diagnosis (Zuckerman et al., 2014). As both Latinx and Asian parents in this study reported significantly less English proficiency than Black and White parents, it remains to be investigated whether there are differences in concerns for these racial groups based on English proficiency, as race in particular was not associated with differences. Future studies should examine whether English proficiency is associated with parent concerns and, consequently, timeliness to autism screening and diagnosis.

Inconsistent with previous research and the hypothesized outcome, race did not predict timeliness to screening or diagnosis. However, it must be noted that this particular sample is within the unique context of a universal, multi-stage screening protocol in EI settings designed to eliminate race-based disparities in diagnosis, and recent analyses using quasi-experimental econometric analyses comparing the three study site partner screening agencies with comparable
non-study agencies found no differences in timeliness to diagnosis by race (Sheldrick et al., 2022). As such, this outcome, though promising, may not be replicable in community settings without such a universal, multi-stage screening protocol. Still, poverty level was associated with a greater time to screening and parent education to both screening and diagnosis even within this study geared toward eliminating such disparities. This suggests that beyond race/ethnicity, these demographic factors should be given special attention in their contribution to disparities in screening and diagnosis, consistent with previous research (Angell et al., 2018; Thomas et al., 2012).

The mediation model, in which parents’ autism-related concerns mediated the association between race and timeliness was significant for timeliness to diagnosis. The number of concerns held by Black and White parents mediated the impact of race on the timeliness of diagnosis, in that fewer concerns among Black parents explained the relation between their race and slower timeliness of diagnosis. This finding is important in our ongoing work to understand and explain racial disparities in timeliness of autism detection: parents’ number of autism concerns differs by race and, in turn, is linked to speed of diagnosis.

Meanwhile, the number of concerns held by Black and White parents did not mediate the impact of race on timeliness of screening. This pattern of results, mediation for diagnosis but not screening, was unexpected given that the number of parental autism concerns for the full sample predicted timeliness to both screening and diagnosis. It may be that concerns more heavily played into decisions around diagnostic appointments than around screening; while screening occurred during regularly occurring EI sessions, diagnostic appointments occurred off-site and thus required a more proactive, intentional decision to attend. Black parents with fewer autism concerns may have been more amenable to screening despite fewer autism concerns but had less
urgency to secure a diagnosis or may have had difficulty finding time for an additional appointment. Additionally, factors outside of concerns and race may have impacted timeliness of screening. These may include contextual or systemic factors such as agency practices and provider preferences around when to screen.

**Strengths and Limitations**

The present study has several strengths. This is the first study to examine whether parents' autism-related concerns predict timeliness to autism diagnosis. This is also the first study to examine whether these concerns mediate the relation between race and timeliness of screening and diagnosis. Further, the sample was relatively large and consisted of participants with diverse demographic backgrounds across race/ethnicity, English proficiency, income, and education. Another strength is the interview method we employed to elicit parent developmental concerns. This allowed parents to speak in greater length and provided the opportunity for interviewers, or parents, to ask clarifying questions if needed.

The present study also has several limitations. First, parent concerns were ascertained retrospectively at the diagnostic evaluation. It is possible that, while these retrospective concerns were intended to assess parents’ concerns at the time of EI entry, they may be affected by shifting cognitions over time. Namely, their concerns may have shifted while their child was in EI due to communication with providers as well as due to the several autism screening assessments administered throughout the study protocol, biasing their recall of initial concerns. Indeed, a subset of these parents noted in qualitative interviews that ongoing conversations with their child’s EI provider throughout the screening process aided their meaning making process prior to the autism diagnosis (Mackie et al., 2021). Further, several of the reporting parents are not the biological parents of the participants; a small group (n=6) were adoptive, foster parents,
or grandparents. It is unclear whether respondents, whether biological parents or not, were the primary caregivers when the children started EI and throughout the study process. Thus, parent concerns obtained at the diagnostic evaluation may not be representative of the initial concerns that may have had the most impact on timeliness to screening and diagnosis for some participants.

Parents in the present study may not be representative of parents in a typical community setting. As previously mentioned, families in this study were being served by EI agencies that were offering a universal, multi-stage screening protocol designed to increase timeliness of screening and diagnosis; most EI agencies do not have such a screening protocol. Additionally, parents with children enrolled in EI may be different from parents not receiving EI in that they may generally have greater concerns as these parents successfully obtained services for their children due to developmental delays; thus, these findings may look different if examined among parents of children not receiving EI services or screened in pediatric settings.

**Clinical Implications**

Previous research has established that children of color receive screening and diagnosis later than White children. Though this is well-established, the contributing factors, likely multi-pronged, are unclear. It is thus important to begin to understand what the contributing factors might be. This study sought to uncover whether parent concerns may be one factor that contributes to delayed autism screening and diagnosis for children of color. Importantly, although universal autism screening has been recommended by the American Academy of Pediatrics (Gupta et al., 2007), many PCPs do not follow the recommended protocol, often relying on parents to mention concerns before deciding to screen. In the present study conducted in EI settings, EI providers also had autonomy in deciding when to screen, though they were
encouraged to screen all children as soon as they were eligible (14 months). Further, the
USPSTF has not provided backing for universal autism screening, stating that there is no
evidence for its necessity and suggesting that providers only screen when parents voice concerns.
It is possible that the combination of these factors—the statement by the USPSTF, inconsistent
autism screening by providers, and fewer reported autism-related concerns among Black parents-
amay contribute to delayed screening and diagnosis for Black children. Black autistic children
are less likely than their White autistic peers to have a PCP, and their parents more likely to
report that their PCP does not spend enough time with their child (Magaña et al., 2015).
Providers should be made aware of these differences and encouraged to employ universal
screening and have ongoing conversations with parents about developmental concerns to help
eliminate differences in concerns by race as well as the chance that fewer parental concerns leads
to delayed screening and diagnosis for Black children. Providers should be taught to ask specific
questions to elicit autism related concerns when speaking with parents from different racial
backgrounds and with lower English proficiency. This clear communication between parents and
providers could eliminate the impact of potential racial/ethnic differences in what concerns are
reported in an interview format and strengthen the parent-provider relationship, which in and of
itself may be a contributing factor in how parents come to realize developmental delays. In fact,
parents of color are less likely to report their developmental concerns to PCPs (Zeleke et al.,
2019) and more likely than their White counterparts to endorse that their providers are not
sensitive to their familial values (Magaña et al., 2015). Training for providers in cultural
humility-working across differences-may help facilitate a relationship of trust between parents of
color and PCPs.
Table 1. Demographic variables.

<table>
<thead>
<tr>
<th>Child Variables</th>
<th>Overall Sample (N=516)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percent or Mean (SD)</td>
</tr>
<tr>
<td><strong>Sex (%male)</strong></td>
<td>80.2%</td>
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<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>4.8%</td>
</tr>
<tr>
<td>Black</td>
<td>19.4%</td>
</tr>
<tr>
<td>Latinx</td>
<td>45.3%</td>
</tr>
<tr>
<td>White</td>
<td>15.5%</td>
</tr>
<tr>
<td>Multi-Racial/Ethnic</td>
<td>3.9%</td>
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<tr>
<td>Groups with N&lt;50</td>
<td>2.9%</td>
</tr>
<tr>
<td>Missing or not aggregated</td>
<td>8.1%</td>
</tr>
<tr>
<td><strong>Developmental Quotient (DQ)</strong></td>
<td>67.90 (10.41)</td>
</tr>
<tr>
<td><strong>Age in months at Stage 1 screening</strong></td>
<td>24.55 (5.06)</td>
</tr>
<tr>
<td><strong>Age in months at diagnostic assessment</strong></td>
<td>27.68 (4.93)</td>
</tr>
<tr>
<td><strong>Parent Variables</strong></td>
<td></td>
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<tr>
<td><strong>Gender (%female)</strong></td>
<td>84.2%</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>4.8%</td>
</tr>
<tr>
<td>Black</td>
<td>19.8%</td>
</tr>
<tr>
<td>Latinx</td>
<td>45.9%</td>
</tr>
<tr>
<td>White</td>
<td>16.7%</td>
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<tr>
<td>Multi-Racial/Ethnic</td>
<td>3.3%</td>
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<tr>
<td>Groups with N&lt;50</td>
<td>3.5%</td>
</tr>
<tr>
<td>Missing or not aggregated</td>
<td>6.0%</td>
</tr>
<tr>
<td><strong>U.S. Born Status (%born outside of the U.S.)</strong></td>
<td>47.6%</td>
</tr>
<tr>
<td><strong>Education (% at least 1 caregiver in household has HS education)</strong></td>
<td>89.2%</td>
</tr>
<tr>
<td><strong>Household income (% at or below 185% of state poverty level)</strong></td>
<td>57.5%</td>
</tr>
<tr>
<td><strong>English proficiency</strong></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>9.0%</td>
</tr>
<tr>
<td>Fair</td>
<td>15.0%</td>
</tr>
<tr>
<td>Good</td>
<td>35.3%</td>
</tr>
<tr>
<td>Very good</td>
<td>47.2%</td>
</tr>
<tr>
<td>Excellent or native</td>
<td>52.8%</td>
</tr>
<tr>
<td>Relationship to child</td>
<td></td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>Biological mother</td>
<td>84.5%</td>
</tr>
<tr>
<td>Adoptive mother</td>
<td>0.2%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>0.4%</td>
</tr>
<tr>
<td>Foster mother</td>
<td>0.2%</td>
</tr>
<tr>
<td>Biological father</td>
<td>13.9%</td>
</tr>
<tr>
<td>Grandfather</td>
<td>0.2%</td>
</tr>
<tr>
<td>Foster father</td>
<td>0.2%</td>
</tr>
<tr>
<td>Other</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

**Table 2.** Parent autism-related concerns coding scheme.

<table>
<thead>
<tr>
<th>Autism Concern</th>
<th>Description</th>
<th>Examples</th>
<th>% Reported in Overall Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech/Language</td>
<td>Related to speech production/vocalizations (including babbling) and comprehension (receptive language); uses gestures instead of speech; language problems</td>
<td>“Has very few words”; “lost words”; “speech delay”</td>
<td>65.8%</td>
</tr>
<tr>
<td></td>
<td>No use of gestures; reciprocity (e.g., understanding and knowing how to respond; back and forth conversation; intentionality of communication); concerns about hearing; parent just says “communication”; forming sentences/expressing oneself; difficulty requesting/not requesting</td>
<td>“Not requesting”; “communication”; “how hard it is for him to communicate what he wants and needs”</td>
<td>10.9%</td>
</tr>
</tbody>
</table>

35
Restricted and repetitive behavior

- Restricted and repetitive behaviors in sensory, motor, or object use;
- Excessive mouthing;
- Sensory sensitivity;
- Echolalia; scripted speech

Social

- Diminished social interest/engagement;
- Play; social/emotional reciprocity (e.g., reciprocity in interactions such as with play and emotionality);
- Response to name;
- Shyness/social hesitancy;
- Eye contact; following gaze or point of others;
- Social, functional, or symbolic play

Autism label

- Mentioned autism

8.1%

“Sensitive to loud noises”; “flapping”; “piles up objects”

17.5%

“Does not interact with other children”; “doesn’t make eye contact”; “not responding”

2.6%

“Similar symptoms of ASD”; “cousin mentioned ASD symptoms she was exhibiting”

Table 3. Percent concerns and mean timeliness to screening and diagnosis by parent race.

<table>
<thead>
<tr>
<th>Number of Autism-Related Concerns Reported by Parent</th>
<th>Asian (N=23)</th>
<th>Black (N=95)</th>
<th>Latinx (N=218)</th>
<th>White (N=75)</th>
<th>Overall Sample (N=468)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Concerns</td>
<td>8.7%</td>
<td>24.2%</td>
<td>20.2%</td>
<td>14.7%</td>
<td>20.1%</td>
</tr>
<tr>
<td>1 Concern</td>
<td>78.3%</td>
<td>61.1%</td>
<td>59.2%</td>
<td>53.3%</td>
<td>58.3%</td>
</tr>
<tr>
<td>2 Concerns</td>
<td>13.0%</td>
<td>12.6%</td>
<td>18.3%</td>
<td>25.3%</td>
<td>18.4%</td>
</tr>
<tr>
<td>3 Concerns</td>
<td>0.0%</td>
<td>1.1%</td>
<td>2.3%</td>
<td>6.7%</td>
<td>3.0%</td>
</tr>
<tr>
<td>4 Concerns</td>
<td>0.0%</td>
<td>1.1%</td>
<td>0.0%</td>
<td>0.0%</td>
<td>0.2%</td>
</tr>
</tbody>
</table>
Mean # of Days to Screening (SD) (n=25) (n=96) (n=224) (n=80) (n=487)
Mean # of Days to Diagnosis (SD) (n=25) (n=102) (n=235) (n=86) (n=513)

Note. Mean # of Days refers to the number of days elapsed between the date at which the child became eligible for screening and the date at which the screening or diagnosis occurred.

This table reflects concerns and timeliness for the four racial groups included in aims 2 and 3 and the overall sample which includes all other groups (e.g. multi-racial/ethnic).

**Figure 1.** Mediation Model (aim 3).
REFERENCES


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