University of Cincinnati

Date: 4/24/2023

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It is entitled:

The impact of race on satisfaction with the diagnostic process of ASD and service utilization

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The impact of race on satisfaction with the diagnostic process of ASD and service utilization

A Dissertation
In the
Department of Psychology
of the College of Arts and Sciences
in partial fulfillment of the requirements for the degree of Doctor of Philosophy

by

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University of Cincinnati
April 2023

Committee Chair: Shari L. Wade, Ph.D.

Abstract

Introduction: Black caregivers report dissatisfaction with the diagnostic process for autism spectrum disorder (ASD), describing delayed referrals, inadequate treatment by service providers, and insufficient information from medical professionals. Families' experiences with the diagnostic process are important to understand, as the diagnostic process is a pivotal time in a child's life that can impact their developmental trajectory and facilitate or hinder access to needed services. The goal of the current study is to examine racial differences in caregivers' perspectives of the diagnostic process and how families' experiences relate to service use.

Participants: We recruited 124 (71%) White/Caucasian and 50 (29%) Black/African American caregivers of children diagnosed with ASD through the Cincinnati Children's Division of Developmental and Behavioral Pediatrics (DDBP).

Measures: We extracted demographic and evaluation characteristics from the medical record. We used participants' addresses to identify neighborhood-level social vulnerability. Caregivers completed surveys, assessing demographic information, which services their child received since the ASD diagnosis, and their experiences with the diagnostic process (e.g., how providers treated them, the amount of information provided). Caregivers could provide comments to expand upon their Likert responses.

Data Analysis: We used generalized linear models to examine the relation between race and satisfaction and the association between race and service utilization, first in unadjusted models. We conducted partially adjusted models, controlling for demographic variables, and fully adjusted models controlling for proxy variables of institutionalized racism such as income, neighborhood vulnerability, and caregiver education level. We examined whether race moderated the association between satisfaction with the diagnostic process and service utilization. We identified qualitative themes from open-text box responses using inductive methods with a diverse team of trained researchers reflecting participants in the diagnostic process (e.g., psychologist, speech therapist, family member).

Results: We did not identify racial differences in families' satisfaction with the diagnostic process or service utilization. Race moderated the association between satisfaction and therapy use ($F(163) = 3.59$, $p = .03$) and between satisfaction and community resource use ($F(169) = 4.76$, $p = .03$). For Black families, there was a positive association between satisfaction and service use. Caregivers who provided comments to expand on their Likert response were generally less satisfied with the diagnostic process. Caregivers described mixed feedback about wait times, their providers, and the information they received. Black families specifically described a power differential between providers and themselves and expressed that culture was not addressed during the diagnostic process.

Discussion: Given the large racial and ethnic disparities, we were surprised to find similarly high levels of satisfaction and service utilization among Black and White families. Future studies employing community-based recruitment methods using a more representative sample can identify whether these patterns persist across different diagnostic settings. We identified that, for Black families, satisfaction impacted service utilization, paralleling previous research suggesting the importance of the quality of care for marginalized families. Families' qualitative feedback sheds light on important changes that could be implemented to improve families' experiences with the diagnostic process.

Acknowledgements

I would like to dedicate my dissertation to my wonderful parents and fiancé, Kyle. Watching my parents engage in meaningful careers dedicated to serving children with autism was inspiring. My mother and father have given me endless support throughout my child and early adulthood, from driving home from work to bring my homework to my high school to editing my term papers in college. They have given me strength, wisdom, and unconditional support. I would not be the woman I am today without them. To my fiancé Kyle, thank you for supporting me through the past 5 years and encouraging me to pursue my dream. Your calming presence and hilarious punch lines have helped me through the long hours of writing throughout graduate school. I am in awe of your patience and dedication to your patients. You motivate me to be a better clinician, researcher, and human.

I am also appreciative of my dissertation committee, Drs. Jastrowski-Mano, and Mitchell, who have taught me in the classroom and mentored me throughout my graduate studies. A special thank you to Dr. Shari Wade, who has served as my mentor throughout graduate school. Your dedication to translating research into programs that will support children and their families is inspiring. I would also like to thank my mentors, Drs. Steph Weber and Jen Smith, for saying "yes and…" to every research idea I propose. Without your support and generosity, this study would not have been possible.

Finally, I would like to thank my friends, who have been by my side during every adventure and difficult moment during my graduate career. To James and Lisa, I cannot even begin to imagine graduate school without my other two musketeers. From our road trips to Disney movie nights, I have belly laughed, felt supported, and knew I was never alone.

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Background

Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by (a) differences in social communication and interactions and (b) restricted, repetitive, and stereotyped behaviors or interests. The prevalence of ASD is increasing, with the most recent CDC estimates suggesting that 1 in 36 children are diagnosed with ASD in the United States, compared to 1 in 88 children 10 years ago (CDC, 2023). Children with ASD often have physical- and mental-healthcare needs that require regularly scheduled visits with one or more neurodevelopmental specialists such as behavior therapists, developmental pediatricians, occupational therapists, and speech therapists (Turcotte et al., 2016). For young children with ASD, early, intensive services are the gold standard of treatment and generally lead to more positive behavioral, social, emotional, cognitive, and language outcomes (Fuller & Kaiser, 2020; Peters-Scheffer et al., 2011; Sutera et al., 2017; Zachor & Ben-Itzchak, 2017).

Despite the benefits of specialized services, research suggests that children with ASD are less likely to have their needs met compared to children with other special healthcare needs (Drahota et al., 2020). National studies have found that nearly one-fifth of caregivers report unmet physical- or mental-healthcare needs for their child with ASD and that one-fourth of children with ASD do not receive needed therapeutic services, such as occupational or speech therapy (Benevides et al., 2016; Karpur et al., 2019). Unmet needs for behavior therapy services may be even greater than for other therapeutic services. A recent study estimated that nearly two-thirds of children with ASD do not receive needed behavior therapy services (Farmer et al., 2014). In addition, even those who are diagnosed early and recommended to receive early intervention services only receive approximately 40% of recommended weekly therapy hours (Yingling & Bell, 2019a).

The reasons children with ASD have unmet physical- or mental-healthcare needs are multifactorial, some of which may be different for Black and White families (Paine et al., 2018; Williams & Sternthal, 2010; Yearby, 2018). Economic and social conditions impact access to and quality of services, particularly for Black families (Cohn & Harrison, 2022; Magnusson & Mistry, 2017; Ziedas et al., 2022). Two important social contributors to health for Black families are institutionalized and personally mediated racism (Jones, 2000).

Institutionalized Racism

Institutionalized racism is defined as racism that is embedded in the laws, regulations, and norms of a society, which leads to unequal access to materials, societal resources (e.g., employment, information, wealth), and social capital for people of color (Golash-Boza, 2016). For example, institutionalized racism contributes to income inequality, in which families of color have substantially less wealth than White families. A recent study found that Black families have on average eight times less wealth than White families (Bhutta et al., 2020). In addition, Black families are more likely to live in areas with less access to healthcare and receive poorer quality care than White families (Drahota et al., 2020; Fiscella & Sanders, 2016). Black children are also more likely to lack insurance coverage (Soylu et al., 2018), be without a primary care provider (Alberto et al., 2019), and experience barriers to accessing medical care (Alberto et al., 2019) than White children.

Institutionalized racism has a significant impact on access to and quality of screening, diagnostic, and therapeutic services for Black children with developmental concerns. Reduced access to primary care providers and limitations of healthcare-provider training and screening tools contribute to delays in screening and diagnosis of Black children with ASD (Alberto et al., 2019; Kalb et al., 2012; Zeleke et al., 2019). Despite national recommendations for ASD-specific screening at 18- and 30-month well-child visits, Black children are screened at later ages than White children (Herlihy et al., 2014; Zeleke et al., 2019). Yet, there are no differences in the age at which Black and White caregivers first notice concerns about their child's development (Jang et al., 2014; Matheis et al., 2017; Rosenberg et al., 2011; Zeleke et al., 2019). In addition, primary care providers report less confidence in assessing symptoms of ASD in Black than in White children (Azim et al., 2020), and ASD screening tools have lower sensitivity and specificity for Black relative to White children (Guthrie et al., 2019; Moody et al., 2017).

Long waiting lists for a developmental evaluation can also delay diagnosis (Pearson & Meadan, 2018). Caregivers have described that financial concerns, limited insurance coverage, transportation costs, and limited flexibility in work schedules serve as barriers to seeking a developmental evaluation (Dababnah et al., 2018; Lovelace et al., 2018; Pearson & Meadan, 2018; Pearson et al., 2020; Stahmer et al., 2019). In qualitative studies, Black caregivers describe that the diagnostic process for ASD is long (Pearson & Meadan, 2018; Stahmer et al., 2019), and a large study found a 3-year delay between the age of first concern and ASD diagnosis among Black children (Constantino et al., 2020). In that study, nearly one-third of participants stated a lack of nearby service providers delayed their child receiving a diagnosis. Nearly half of the participants reported seeing multiple professionals before their child was diagnosed with ASD, and 14% saw six or more specialty care providers before receiving an ASD diagnosis (Constantino et al., 2020).

One factor that can contribute to an increased number of specialty-care visits for Black children during the ASD diagnostic process is misdiagnosis. Black children are commonly misdiagnosed, with symptoms of ASD sometimes misinterpreted as an adjustment or conduct disorder (Mandell et al., 2007; Mandell et al., 2009; Weitlauf et al., 2023). Black children also are more likely to have intellectual disability co-occurring with ASD (Baio et al., 2018; CDC, 2021; Christensen et al., 2016), which suggests that ASD may be underdiagnosed in Black children who do not have an intellectual disability.

Institutionalized racism also impacts access to and quality of treatment services for Black children. The well-documented delays in ASD diagnosis of Black relative to White children have obvious negative implications for the timeliness of treatment-service access (Constantino et al., 2020; Fountain et al., 2011; Valicenti-McDermott et al., 2012). Black children are less likely than White children to participate in early intervention services, and they enter treatment at older ages (Drahota et al., 2020; Feinberg et al., 2011). Institutionalized racism also produces income and education inequality for Black families, which are associated with lower levels of service utilization (Bilaver et al., 2021; Lee McIntyre & Zemantic, 2017). In addition, the structural barriers that impede access to screening and diagnosis continue to exist as families seek needed therapeutic services for their children (e.g., long waiting lists, inflexible work schedules). Further, Black caregivers report a lack of knowledge of available services as another obstacle (Smith et al., 2020). Consequently, Black children are less likely than White children to use outpatient services, including behavior therapy, care coordination, group therapy, occupational therapy, and speech therapy (Bilaver & Havlicek, 2019).

Personally Mediated Racism

Personally mediated racism, like institutionalized racism, is ubiquitous in the United States and impacts service provision and receipt for Black families. Personally mediated racism is defined as prejudice (differential assumptions) and discrimination (differential actions) that can be both intentional and unintentional toward people of color (Jones, 2000). Most Black adults report discrimination in employment, in public settings, while obtaining housing, and in police interactions (Bey et al., 2019; Bleich et al., 2019). Almost all Black adults report exposure to racial slurs and microaggressions (Bleich et al., 2019). Healthcare providers have similar levels of implicit racial bias as the general population, and most Black adults who describe experiencing discrimination in general report repeated occurrences of discrimination by healthcare providers (Maina et al., 2018; Nong et al., 2020).

Similarly, Black caregivers of children with ASD report unequal treatment by healthcare institutions and providers (Angell & Solomon, 2014; Dababnah et al., 2018; Solomon & Lawlor, 2013). Black families report less shared decision making for their child's care than White families (Perez Jolles et al., 2020). Black caregivers also indicate that doctors make assumptions about them based on their race (Dababnah et al., 2018), such as assumptions about their SES and marital status. In several studies, caregivers indicated that providers minimized their concerns about their child's behaviors, and in turn, were less likely to provide referrals for a developmental evaluation (Dababnah et al., 2018; Lovelace et al., 2018; Stahmer et al., 2019). Biases also may contribute to differential access to knowledge about existing resources, as Black families report that they receive less information about available supports and services than White families (Burkett et al., 2015).

Research corroborates caregiver-reported concerns regarding providers' biases. Primary care providers report biased beliefs related to caregivers' knowledge and understanding of ASD symptoms. One study found that providers believe caregivers of Black children have lower levels of ASD knowledge than caregivers of White children (Zuckerman et al., 2013). Providers who believed Black caregivers have lower levels of knowledge were more likely to believe that Black caregivers face barriers to seeking a diagnosis (Zuckerman et al., 2013). Healthcare providers also report concerns about Black families' ability to follow through on service recommendations

(Burkett et al., 2015). Providers' biases about Black caregivers' knowledge and behavior may impact providers' practices, such as decreasing the likelihood of the provider referring Black children for developmental evaluations and increasing the likelihood of the provider minimizing caregiver concerns about their child's development (Dababnah et al., 2018; Lovelace et al., 2018; Stahmer et al., 2019). In addition, in a national survey of developmental behavioral pediatricians, some self-reported underdiagnosing ASD. The most common reason for underdiagnosis was the perception that caregivers did not want a diagnosis (Azim et al., 2020). In the same study, providers reported that nonWhite families were more likely to think that an ASD diagnosis was "a bad thing" than White families. Though providers did not explicitly describe underdiagnosing children of color, their beliefs that minoritized families think ASD is "a bad thing" may influence their willingness to diagnose Black children with ASD.

Personally mediated racism impacts healthcare utilization, provider-family interactions, and trust in healthcare providers. One study described that over one-fifth of Black adults avoided seeking healthcare for themselves and for family members due to anticipated discrimination (Bleich et al., 2019). Similarly, a study in New Zealand found that caregivers' experiences with everyday prejudice and discrimination were associated with decreased child healthcare utilization and reduced satisfaction with their child's healthcare (Paine et al., 2018). Additionally, Maina et al. found that greater implicit bias among providers was associated with lower ratings of patient-centered care (2018). Experiences of discrimination also contribute to medical mistrust (Williamson et al., 2019), which is an important predictor of healthcare utilization (Arnett et al., 2016). Specifically, among Black patients, a study found that perceived racism had both a significant direct effect on satisfaction with care and an indirect effect on satisfaction mediated by cultural mistrust and trust in providers (Benkert et al., 2006). Another study documented that Black caregivers subjected to implicit biases report less confidence in their healthcare provider's recommendations (Penner et al., 2016). Trust of healthcare professionals is crucial, as it is associated with satisfaction with the healthcare system and health outcomes (Birkhäuer et al., 2017).

A lack of culturally responsive care also impacts provider-caregiver interactions (Lin et al., 2012; Magaña et al., 2015; Parish et al., 2012). Culturally responsive care is defined as care that seeks to understand and address a family's background, their belief systems, and the social contributors to health impacting the family, including institutionalized and personally mediated racism (Patneaude & Kett, 2020). Unfortunately, Black families do not often receive culturally responsive care (Magana et al., 2012). In a national survey, Black caregivers of children with ASD and other developmental disabilities were less likely than White caregivers to report their child's healthcare provider listened carefully to them, helped them feel like a partner, spent enough time with their child, and was sensitive to their family's customs and values (Magaña et al., 2015). In general, Black families of children with ASD report greater dissatisfaction with their care than White families (Liptak et al., 2008; Sansosti et al., 2012). The dearth of people of color in the field of developmental disabilities potentially contributes to reduced rates of culturally responsive care. In fact, a recent survey found that only 2% of developmental behavioral pediatricians are Black (Bridgemohan et al., 2018). Although training may increase White providers' ability to deliver culturally responsive care, medical and allied healthcare curricula devote sparse time and attention to antiracism and cultural humility (Khan & Mian, 2020), which prevents providers from learning ways in which to understand and acknowledge families' cultural beliefs and experiences.

Culturally responsive healthcare care is particularly important for Black caregivers, as they report heterogeneous beliefs and knowledge about the causes of ASD. At the group level, Black families may be more likely to believe common misconceptions about ASD, such as poor maternal-child relationships cause ASD or that ASD is not a “real” condition (Castillo et al., 2020). They are less likely to believe in the contribution of genetics as a cause of ASD (Zuckerman et al., 2016). Black caregivers have described stigma and a lack of acceptance of developmental disabilities in their communities (Burkett et al., 2015; Dababnah et al., 2018) and may use spirituality and religion to cope with stigma (Pearson et al., 2021). They may also differ from White families in their experiences with extended families’ involvement in their child’s care (Burkett et al., 2015). Extended family members of some Black caregivers may not accept the child’s ASD diagnosis (Lovelace et al., 2018; Pearson & Meadan, 2018). By contrast, extended family members in other Black families are highly involved in the child’s care (Burkett et al., 2015). Therefore, it is important for healthcare providers to understand and address Black families’ values and beliefs.

Experiences with the diagnostic process

The impact of racism on the diagnostic process for children with ASD and their caregivers is important to understand, particularly as the prevalence of ASD increases. Children can reliably be diagnosed with ASD by 24 months (Hyman et al., 2020). Early diagnosis is critical as it allows children to access intervention services at a younger age, which contributes to better functional outcomes (Fuller & Kaiser, 2020; Peters-Scheffer et al., 2011; Sutera et al., 2017). Not only do early intervention services predict improved outcomes for children with ASD, but also children who are diagnosed at earlier ages are more likely to participate in school-based services and behavioral intervention (Zuckerman et al., 2017). Therefore, the diagnostic process is a pivotal time in a child's life that can impact their developmental trajectory and facilitate or hinder knowledge of and access to needed services.

Unfortunately, in most studies documenting caregivers' experiences with the diagnostic process, caregivers expressed dissatisfaction with the length of the process (Lappé et al., 2018; Lovelace et al., 2018; Pearson & Meadan, 2018; Stahmer et al., 2019), providers' empathy (Coffield et al., 2021; Crane et al., 2016), the explanation of the diagnosis (Kizildag et al., 2022), and the amount of advice and follow up (Crane et al., 2016; Eggleston et al., 2019; Keenan et al., 2010; Moh & Magiati, 2012; Potter, 2017; Sansosti et al., 2012; Weitlauf et al., 2023). In fact, a recent systematic review highlighted that in 75% of the 34 articles reviewed, caregivers generally described dissatisfaction with the diagnostic process of ASD (Small & Belluigi, 2023).

While the literature regarding caregivers' dissatisfaction with the diagnostic process has been well-documented, these studies have been limited by their inclusion of predominantly White, European caregivers. However, qualitative studies have highlighted similar concerns among Black caregivers, who have also reported facing biases during the diagnostic process (Dababnah et al., 2019; Lovelace et al., 2018; Stahmer et al., 2019). In addition, Black caregivers have described that cultural differences between themselves and providers negatively impacted the diagnostic process (Pearson et al., 2020, Stahmer et al., 2019).

Quantitative research can build upon qualitative findings using larger, more representative samples. Most quantitative studies in this area have examined the association between race and the age of diagnosis, demonstrating that Black children are diagnosed later than White children (Constantino et al., 2020; Fountain et al., 2011; Maenner et al., 2020; Valicenti-McDermott et al., 2012). However, no quantitative studies have explored the impact of race and racism on Black families' satisfaction with the diagnostic process. Therefore, the current study examines caregivers' perspectives of the diagnostic process using a large sample of caregivers who present for a developmental evaluation at a large, Midwestern academic hospital. We explored the relation between race and satisfaction with the diagnostic process and the relation between race and service utilization. We used caregivers' qualitative responses to survey questions to contextualize our findings. This research has the potential to allow researchers to understand systems- and provider-level changes needed to improve families' experiences with the diagnostic process and increase service utilization.

In addition, the association between satisfaction with the diagnostic process and service use may be stronger for Black in comparison to White families, given the importance of satisfaction and cultural responsiveness of care to trust in healthcare providers' recommendations and service utilization among Black families (Arnett et al., 2016; Bleich et al., 2019; Paine et al., 2018; Penner et al., 2016). Only one study has examined the impact of satisfaction on service utilization for caregivers of color who have a child with ASD, finding that Latino families were less satisfied with their care, in comparison to White families, which drove lower rates of service utilization for these families (Parish et. al, 2012). Therefore, in this study, we will also examine whether race moderated the relation between satisfaction with the diagnostic process and service utilization to determine whether the association between satisfaction with care and service utilization differs for Black versus White caregivers.

First, we hypothesize that Black families will report less satisfaction with the diagnostic process of ASD than White families. Second, we hypothesize that institutionalized racism, characterized by proxy variables such as income, will be negatively associated with satisfaction with the diagnostic process for Black families. Third, we hypothesize that Black families will use services at lower rates than White families, and this will be partially explained by proxy variables for institutionalized racism. Fourth, we hypothesize that race will moderate the association between satisfaction and service utilization, such that satisfaction with the diagnostic process will have a stronger positive association with service utilization for Black versus White caregivers. Finally, we hypothesize that caregivers' qualitative responses will parallel previous research describing concerns with the wait times, systems-level barriers (e.g., transportation), and providers' communication, and specifically, Black caregivers will describe discrimination and cultural differences between providers and caregivers (Dababnah et al., 2018; Lovelace et al., 2018; Stahmer et al., 2019).

Method

Setting

At Cincinnati Children's Hospital Medical Center (CCHMC), young children with developmental concerns and possible ASD are referred for a multidisciplinary evaluation in one of several models. Children under the age of 3 participate in an "Under 3 Arena" in which they are evaluated by (a) a medical provider (i.e., developmental nurse practitioner or physician), (b) a speech-language pathologist, and (c) a clinical psychologist (i.e., PsyD or PhD). Children aged 3 to 5 participate in a "3 to 5 Arena" model, in which a clinical psychologist and speech-language pathologist conduct the evaluation. Children who are ages 6 and older typically meet with only a psychologist for the evaluation. Evaluating clinicians write a detailed report regarding findings and recommendations for supports and services (e.g., requesting a school-based evaluation to determine whether the child will qualify for an Individualized Education Plan [IEP], speech therapy, behavior therapy). Subsequently, a developmental behavioral pediatrician or psychologist shares the evaluation findings and resources, supports, and services that may benefit the child and family during an appointment referred to as the information sharing session (ISS).

Participants

Participants were eligible to participate in the study if they identified as a White/Caucasian or Black/African American caregiver of a child diagnosed with ASD through the CCHMC Division of Developmental and Behavioral Pediatrics (DDBP). We also included biracial/multiracial caregivers if at least one race was described as Black, African, or African American. We included bi-racial and multi-racial caregivers because they are also exposed to anti-Black institutionalized and personally mediated racism and face reduced access to and quality of health care (Forrester et al., 2019; Franco et al., 2021; Singh et al., 2017). Additional eligibility criteria included being able to read the survey. Caregivers needed to speak one of the following languages to participate: English, Spanish, Nepali, Arabic, or French. However, all participants in the current study spoke English fluently.

We recruited families whose children were diagnosed in 2018 and did not exclude children with co-morbid conditions. We chose the year 2018 to examine both the diagnostic process and subsequent service utilization in the two years following diagnosis prior to the COVID-19 pandemic, which significantly impacted evaluations and treatment service provision. We also wanted to allow families to have time to engage in services, particularly given long waiting lists for ASD-specific services (Yingling & Bell, 2019b). We consulted with a non-profit organization for Black and Brown caregivers of a child with ASD and other developmental disabilities who believed that caregivers would be able to remember and recall details from the diagnostic process in 2018, given its significance and salience to families.

We obtained contact information for all children who were diagnosed with ASD in 2018 from the medical record. From February 2021 to February 2023, we attempted to contact the primary caregiver of each evaluated child to obtain a representative sample of children who present to the division for a developmental evaluation.

Chart Review

The researcher selected variables to extract from the medical record based on their relevance to satisfaction with the diagnostic process. These variables included arena model type, provider names, family address, caregiver language, and the child's diagnoses. We also extracted the number and type of recommendations in the evaluation reports (e.g., recommendation for speech therapy). The researcher met with psychologists (one White psychologist, one Indian psychologist) and Developmental Behavioral Pediatricians (two White pediatricians, one Asian pediatrician, one Latina pediatrician) to seek feedback on potential additional variables for data collection. Based on feedback from the team, IQ/cognitive score was also extracted from the medical record. Additionally, the team suggested ways in which to categorize co-morbid conditions for inclusion in the models. Co-morbid conditions were categorized as emotional or behavioral disorder (e.g., anxiety), delay (i.e., delay in one or more areas) medical condition (e.g., spina bifida, seizures), language disorder (e.g., expressive language disorder), and hearing loss.

Demographic information

Survey questions

After screening families for eligibility, the researcher asked caregivers about their race/ethnicity, their child's race/ethnicity, and their gender. Asking caregivers these questions over the phone allowed participants to describe themselves without being limited to a defined set of response options. Caregivers completed additional demographic questions in REDCap, providing their age, relationship, years of education (on a continuous scale from less than 12 to greater than 16), employment status, marital status, household income, and languages spoken in the home.

Census Tract Data

We extracted the 2018 median household income from the Census Tract, which is a small geographic area of around 4,000 individuals by zip code. We also extracted geographical location (e.g., urban, suburban, rural), Childhood Opportunity Index 2.0 (COI), and Social Vulnerability Index (SVI) scores from the Census Tract Data.

Childhood Opportunity Index. The COI measures and maps the quality of resources and conditions in a child's neighborhood at the census tract level. Domains include measures of the quality of education (e.g., early childhood education centers, third-grade reading and math proficiency, teachers' years of experience), health and environment (e.g., access to healthy food, house vacancy rate, hazardous waste dump sites), and social and economic neighborhood resources and conditions (e.g., homeownership rate, median household income, single-parent households) that matter for a child's healthy development (Noelke et al., 2020). COI scores are percentiles compared to national norms, where lower scores reflect worse childhood opportunities in the census tract.

Social Vulnerability Index. The SVI was developed by the Centers for Disease Control to better understand the social circumstances of communities in the United States (Centers for Disease Control and Prevention/ Agency for Toxic Substances and Disease Registry/ Geospatial Research). The SVI uses U.S. Census data to rank each census tract on 15 social factors. These social factors are grouped into 4 categories, including SES (i.e., below poverty, unemployed, income, no high school diploma), household composition (i.e., older adults in the home, children in the home, persons with a disability in the home, single-parent households), minority status/language, and housing/transportation (i.e., multi-unit structures, mobile homes, crowding, no vehicle, group quarters). The SVI has demonstrated utility in predicting health disparities and identifying under-resourced neighborhoods (Azap et al., 2020; Givens et al., 2021; Yu et al., 2020).

Distance to the hospital. Finally, we used families' zip codes (to protect privacy) to calculate the time it would take to drive to the location of their evaluation in minutes. We used Google Maps to calculate the driving time on a weekday, extracting the driving time between 9 am to 4 pm, which parallels clinic times.

Service receipt

Families selected what services they or their child accessed since receiving the ASD diagnosis, from a list of services typically recommended in evaluation reports (e.g., speech therapy, behavior therapy, caregiver support group, Applied Behavior Analysis [ABA], school services). Caregivers were able to describe any additional services they or their child received that were not provided as a response option.

Satisfaction Survey

The satisfaction questionnaire was developed through an iterative process. The researcher created a team comprised of two White psychology graduate students, a White licensed psychologist, a White developmental behavioral pediatrician fellow, a White speech pathology graduate student, a White epidemiologist, and a Black family member of a child with ASD. The team conducted a careful examination of literature related to caregivers of color's experiences with the diagnostic process. Then, the team drafted questions to assess caregivers' satisfaction with the diagnostic process within DDBP, which was measured on a 7-point Likert scale from "Strongly Disagree" to "Strongly Agree." The team shared the questions with two developmental behavioral pediatricians of color, who provided feedback and made suggestions to modify the survey's content based on their experiences sharing ASD diagnoses with families. They described the aspects of the diagnostic process that they believed to be most important to families (e.g., emotional support, guidance on next steps). The pediatricians suggested changes to the questions about service utilization to improve readability (i.e., dividing service utilization questions into the following categories: therapies, school services, and community resources). They also suggested adding questions about the amount of information received during the ISS (i.e., Did they receive enough information? Did they receive too much information?).

Next, the team presented the survey to the governing board of a non-profit organization for Black and Brown caregivers of children with developmental disabilities. Present at this meeting were four caregivers and two facilitators. The group's facilitators are two qualitative researchers who conducted an ethnographic study that resulted in the caregivers meeting and forming the organization. Caregivers and facilitators gave feedback on the survey's content and wording. For example, caregivers suggested the researchers add a question on how the providers communicated about the diagnostic process itself (i.e., what to expect during the diagnostic process). The group also emphasized the importance of family members being understood during the diagnostic process, which led to the formulation of the question, "I felt understood by the DDBP providers when I talked about my child." Caregivers described that the ISS can be overwhelming, suggesting the importance of providers giving families resources to review following the ISS, when they have had time to process the diagnosis. This led researchers to draft the question: "My provider gave me enough guidance to get me started on next steps (e.g., school, therapy)." The governing board also suggested wording changes to improve the clarity of questions (e.g., reducing the length of sentences).

Finally, the team shared the revised survey with DDBP's Family Advisory Committee, which is comprised of family members of children with ASD and other developmental disabilities. Present at this meeting were eight White caregivers and one Black caregiver of children with developmental disabilities. Caregivers reviewed the survey and provided feedback on content and wording. Caregivers were also asked to describe what each question meant to them, which led to modifications to the survey to improve clarity. For example, caregivers were uncertain whether the question "I was satisfied with the amount of time it took to schedule my initial appointment with the division" referred to the duration of the phone call to schedule the appointment or the wait time between the referral and the initial ASD evaluation appointment. Therefore, the question was modified to: "I was satisfied with the amount of time between the referral to DDBP and my child's first ASD evaluation appointment." In addition, caregivers suggested that researchers give participants the opportunity to provide comments regarding their responses, allowing families to elaborate and document potential heterogeneity in their experiences (e.g., families may describe that they had a positive experience with one provider but a negative experience with another). Caregivers on the Family Advisory Committee also suggested that the research team modify the question, "The providers gave me enough information to understand my child's diagnosis" to "The providers gave me enough guidance and resources to begin to understand my child's diagnosis" to reflect the idea that families learn more information about ASD over time. Additionally, they helped to make wording changes to improve clarity and readability (e.g., changing "perspective" to "point of view", changing when "you had the evaluation" to "your child had the evaluation"). The survey was translated into the four most used languages by caregivers who present to DDBP using Cincinnati Children's translation services: Spanish, Nepali, Arabic, and French. The final questions can be found in Appendix 1.

Recruitment

This study was approved by the CCHMC Institutional Review Board. A racially and ethnically diverse team of multi-disciplinary researchers (i.e., developmental behavioral pediatricians, psychology trainees, speech-language pathology trainees, and family members of children with Autism) recruited families by phone and email identified through patients' electronic health records. If an email was listed in the patient's electronic health record, the research team first emailed families to briefly explain the study and provide contact information. All families were also recruited by phone calls, which we varied in the day of the week and time of day to optimize recruitment. In recruitment calls, we emphasized that we wanted to hear families' voices to be able to improve care for families moving forward. We made efforts to highlight that nothing families share will impact them or their child's care.

Approximately halfway through recruitment, the research team created a video introducing families to the study to increase rapport and trust. The video was sent to families via text and/or can be found at the following link: https://www.youtube.com/watch?v=HTrUK-N5nwA&ab_channel=AllisonFisher. To facilitate survey completion, the researchers also encouraged families to complete the survey over the phone immediately after they consented or during follow-up calls to remind families to complete the survey. After survey completion, we reached out to families who were dissatisfied with the diagnostic process and offered them the opportunity to connect with a family navigator at Cincinnati Children's, who is a family member of a child with a developmental disability trained to support families in navigating their child's diagnosis.

Data Analysis

Demographic information and arena model type were described using means and percentages. We calculated the mean number of services recommended in the evaluation reports in total and by type (e.g., speech therapy, school services, speaking with a social worker) across racial groups. Next, we categorized whether caregivers received the services that were recommended in the evaluation reports. We calculated the proportion of recommended services that the family received in total and by category (i.e., outpatient therapies, school services, community resources). For example, if a family was recommended speech and occupational therapy and received occupational therapy, the proportion of outpatient services received would be considered .50. We assigned numbers based on caregivers' responses to satisfaction questionnaires (1 = strongly agree, 2 = agree, etc.) and averaged caregiver responses across the satisfaction survey (hereafter referred to as "satisfaction").

Factor Analysis

The research team reviewed the structure of the survey questions and discussed categories in which to group caregiver responses. The group concluded that the survey questions logically divided into three categories: provider factors, information provided, and wait times. These factors matched qualitative themes from open-text box responses, which were similarly divided into provider factors, information provided, and wait times. We used R to perform a confirmatory factor analysis (CFA) and chose maximum likelihood because the data were normally distributed. Originally, the model produced a RMSEA greater than .10. We removed the two questions with the lowest factor loadings ("The providers respected my cultural and family values" and "I was satisfied with the written reports"). This choice was also supported by participants' qualitative responses. Although both groups were given the opportunity to respond to this question, only Black participants provided open-text box responses to the question about their cultural and family values being respected. Black participants who provided qualitative responses indicated that culture was not typically discussed, and some of those participants felt they were treated like any other caregiver. Qualitative responses, therefore, suggest that whether or not the provider respected their cultural and family values may factor into their overall impression of their provider less than other factors (e.g., emotional support). Qualitative responses in response to participants' satisfaction with written reports were mixed. Caregivers discussed how they used the reports to support the school's evaluation, how it was written (e.g., well-written, typos), and how the report either facilitated or hindered insurance coverage for services. Therefore, these responses suggest that for some participants, their perception of the written results may relate more to how participants use the report and its quality rather than the information provided in the report. After removing the two questions, the hypothesized model appeared to be a good fit of the data. As a result, we did not modify the loadings or structure (see Table 1 for model indices).

Table 1.

Confirmatory factor analysis including entire sample

	Indices	CFA Criteria	Values
Comparative fit index (CFI)	Discrepancy between the data and the hypothesized model, while adjusting for sample size	above .9 (O'Rourke & Hatcher, 2013)	0.95
Normed Fit Index (NNFI)	Relative reduction in misfit per degree of freedom	above .9 (O'Rourke & Hatcher, 2013)	.93

Root Mean Squared Error of Approximation (RMSEA)	How far our hypothesized model is from a perfect model	less than .1 (Fabrigar et al., 1999)	.098
Standardized Root Mean Square Residual (SRMR)	The difference between the observed correlation and the model implied correlation matrix.	less than .08 (Hu & Benter, 1999)	.041
Factor loadings	The correlation coefficient for the variable and factor	Above 0.3	.51-.91

After confirming the three-factor structure, we identified that two participants were missing data for the question “The DDBP providers respected and valued my opinions and point of view.” Because that variable strongly loaded onto the “provider” factor (.79), we used the average score for the other three variables in that factor to impute a score for the two missing data points. Similarly, one participant did not respond to the question “I was satisfied with the amount of information I received about my child's diagnosis and potential next steps.” Again, we used the average of the three non-missing questions on the “information provided” factor due to the question’s high loading (.85).

We conducted a multigroup confirmatory factor analysis (MG-CFA) to test measurement invariance in the satisfaction survey across Black versus White participants (Sass et al., 2014). We found that when dividing our sample into two groups (i.e., Black, White), the fit parameters decreased, which is expected with smaller sample sizes. However, factor loadings remained high. In testing for measurement invariance, the results provided some evidence of equal item intercepts and measurement invariance, given the small changes in CFI (Table 2).

Table 2.

Multigroup confirmatory factor analysis

			White	Black	Configural Invariance	Metric Invariance	Scalar invariance
Comparative fit index (CFI)	Discrepancy between the data and the hypothesized model, while adjusting for sample size	above .9 (O'Rourke & Hatcher, 2013)	.94	.81	.892	.887	.885
Root Mean Squared Error of Approximation (RMSEA)	How far our hypothesized model is from a perfect model?	less than .1 (Fabrigar et al., 1999)	.11	.20	.15	.15	.14
Standardized Root Mean Square Residual (SRMR)	The difference between the observed correlation and the model implied correlation matrix.	less than or equal to .08	.044	.08	.06	.08	.08
Factor loadings	The correlation coefficient for the variable and factor	Above 0.3	.53-.93	.56-97	n/a	n/a	n/a
Change in CFI?	Testing for measurement invariance	<.01 (Cheung & Rensvold, 2002)	n/a	n/a	n/a	.005	.002

Control variables

We selected potential control variables based on their theoretical significance to the diagnostic process. For example, families may be more overwhelmed if they have visits with a greater number of providers (captured through Model Type). In addition, single caregivers may face additional barriers throughout the diagnostic process (e.g., seeking childcare for other children). Potential control variables included the number of providers, caregiver's marital status, child's co-morbid conditions (e.g., genetic condition), and child's sex. We used bivariate correlations to determine whether any of the potential control variables were associated with satisfaction or service use among Black and White caregivers.

Institutionalized racism

In several large-scale studies, segregation, income, education, and neighborhood factors have been used as a proxy for institutionalized racism and may be more robust predictors of adverse health outcomes than health risk behaviors (e.g., diet, exercise, alcohol consumption) for Black adults (Simons et al., 2018; Simons et al., 2021). Therefore, we examined several variables as a proxy for institutionalized racism, including caregivers' years of education, household income, caregivers' employment status, geographical location (i.e., Appalachian vs. non-Appalachian, rural vs. non-rural), SVI scores, COI scores, and child age at the evaluation. We also used IQ as an institutionalized racism proxy variable, hypothesizing that differences in IQ between Black and White children are related to institutionalized racism, as Black children with ASD are far more likely to be diagnosed with intellectual disability than White children, likely due to underdiagnosis of Black children with ASD without intellectual disability (Baio et al., 2018; CDC, 2023). Racial differences in IQ are also likely related to biases in test construction (Olson & Jacobson, 2015).

Variables in the models

For Aim 1, we retained control and institutionalized racism proxy variables in the models if they were significantly associated with satisfaction for Black or White caregivers. For Aim 2, we retained control and institutionalized racism proxy variables in the models if they were significantly associated with service utilization for Black or White caregivers. For Aim 3, we retained control and institutionalized racism proxy variables in the models if they were found to be associated with service utilization after backward elimination in Aim 2.

***Aim 1*: Does race predict satisfaction with the diagnostic process?**

To address Aim 1, the researcher conducted separate unadjusted Generalized Linear Models (GLM) examining the relation between race and satisfaction total score and race and domain scores (Table 3). Next, the researcher conducted partially adjusted models controlling for factors that are unrelated or less related to institutionalized racism. We used backward stepwise regression to eliminate non-significant variables ($p > .10$). A partially adjusted model allows researchers to begin to quantify the impact of institutionalized racism and its consequences (e.g., implicit/explicit biases) on caregivers' satisfaction with the diagnostic process. We hypothesize that differences between Black and White families' satisfaction with the diagnostic process, after control variables are entered are largely related to the impacts of institutionalized and personally mediated racism. Finally, fully adjusted models included factors unrelated to institutionalized racism (control variables) and factors related to institutionalized racism. In fully adjusted models, we also examined the interaction effects of race and institutionalized racism proxy variables. This allows us the opportunity to explore the intersection between systemic factors and race (Adkins-Jackson et al., 2022). By controlling for many factors related to institutionalized racism, we can begin to understand the impact of personally mediated racism on caregivers' satisfaction with the diagnostic process, should differences be identified. Therefore, we hypothesize that racial differences in the fully adjusted models are related to personally mediated racism and lack of culturally responsive care for Black families. Backward stepwise regression was used to eliminate non-significant variables ($p > .10$) in the models.

Aim 2: **Does caregiver race predict entry into services?**

To address Aim 2, the researcher conducted separate unadjusted GLM examining the relation between race and the proportion of recommended services received (e.g., family received 60% of services recommended in evaluation reports) and receipt of recommended services by category (i.e., what percentage of recommended outpatient therapies were received; what percentage of recommended community services were received). Logistic regression was used to examine the relation between race and the likelihood of recommended school service receipt (i.e., did a family receive school services if recommended in the reports). We used Odds ratios to capture the effect size in the logistic regression.

Next, the researcher conducted partially adjusted models controlling for factors that are unrelated or less related to institutionalized racism. We used backward stepwise regression to eliminate non-significant variables ($p > .10$). Finally, fully adjusted models included factors unrelated to institutionalized racism and factors related to institutionalized racism. Backward stepwise regression was used to eliminate non-significant variables ($p > .10$) in the models. In all models, we used the False Discovery Rate (FDR), which is a less stringent correction, to adjust for multiple comparisons and maintain power. Results are reported using FDR-corrected p-values.

Table 3

Potential control and institutionalized racism proxy variables.

Unadjusted models	Variables added to partially adjusted models with control variables	Variables added to fully adjusted models with proxy variables for institutionalized racism[a]

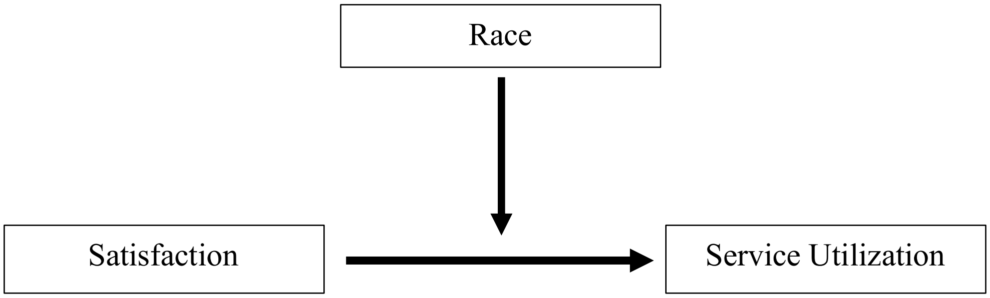
• Race	• Model type • Caregiver marital status • Co-morbid conditions • Child sex • Time since evaluation	• **Time driving to evaluation location** • **Age at evaluation** • **Years of education** • **Household income** • Employment status • Geographical location (e.g., rural, suburban) • **SVI Housing/transportation** • SVI Socioeconomic status • SVI Household composition • SVI Minority language • COI Health and Environment • COI Socioeconomic status • **COI Education** • IQ/cognitive score • **Insurance**
Aim 1 outcome variables: total satisfaction score, satisfaction domain scores		
Aim 2 outcome variables: percentage of recommended services received (total), percentage of recommended outpatient services received, percentage of recommended community services received, receipt of recommended school services (y/n)		

[a] Also examined the interaction between race and institutionalized racism proxy variables.
Bolded variables were associated with outcome variables and included in one or more models.

Aim 3: **Does race moderate the association between satisfaction and service utilization?**

To test whether the association between satisfaction with the diagnostic process and service utilization is moderated by race, we ran a linear regression in which service utilization was regressed onto satisfaction scores, race, and an interaction term (created by multiplying race and satisfaction; Figure 1). We first centered satisfaction to avoid issues of multicollinearity. We examined service utilization by the proportion of recommended services received total and by category. Statistical analysis was conducted using PROCESS (Hayes, 2017). In our models, with our sample of 124 White and 50 Black/African American caregivers, we had sufficient power (>.80) to detect medium effects, with up to six predictor variables entered into each model.

Figure 1.
Proposed model to examine whether satisfaction with the diagnostic process moderates the association between race and service utilization.



***Aim 4.* Examine open-text box ("qualitative") responses from Black and White participants**

We examined participants' qualitative descriptions of their responses to survey items line-by-line. The research team was comprised of a Black mother of a child with Autism, an Indian school psychology trainee, an Indian developmental behavioral pediatrician, a White speech-language pathology trainee, and two White psychology trainees. The research team had worked closely together over the previous year, developing significant trust and respect to allow for differing opinions and dissent. Because the team is comprised of diverse disciplines, each team member brought a unique perspective to the coding. Team members first examined the data independently and came together to code responses through group discussions until consensus was reached (Hemmler et al., 2022). We first categorized Black families' responses into "positive" or "negative," when applicable. We further categorized responses into themes of each participant's response using a consensus-based inductive method, iteratively updating the coding structure. For example, several families discussed wanting specific guidance on which treatment recommendations to pursue, which was coded as "Need more guidance and direction." Next, coders reviewed the codebook to categorize codes into subcategories (axial coding; Thomas & Harden, 2008) and combined some codes into higher-level themes, across satisfaction survey questions. For example, caregivers described that both the information about the diagnosis and treatment recommendations were not tailored to their unique child, which was grouped together as a “Lack of individualized care.” We engaged in member checking with our team member, Ms. Larkin, who is a Black mother of a child with ASD and a governing member of a nonprofit organization for Black and Brown caregivers, Autism and We. She confirmed that identified themes matched her own experiences and/or the experiences of other caregivers served by Autism and We. Her input was particularly helpful for themes that researchers may have otherwise thought to be off topic. For example, when asked about their experiences with providers at Cincinnati Children’s, some Black caregivers compared positive experiences with their providers at Children’s to mistreatment by providers at other institutions. Ms. Larkin described that it is important for us to contextualize caregivers’ opinions of their care at Cincinnati Children’s with this information.

To reduce burden on the research team, the two White psychology trainees categorized White participants’ responses into themes using the same methodology. All themes are presented by race to compare and contrast the experiences of Black in comparison to White caregivers.

Results

Background characteristics

Please note, we will be using the term “Black” to describe Black and African American participants across studies to be as inclusive as possible. Out of the 389 children who were Black or White and were evaluated in 2018, primary caregivers for 174 (44.7%) completed the satisfaction survey (50 [29%] Black caregivers and 124 [71%] White caregivers; See Tables 4 & 5). Nineteen (11%) caregivers completed the survey by phone, and there were no differences in the mean satisfaction between those who completed the survey by phone in comparison to those who completed it online (t(173)=1.46, p = .15). The time from diagnostic evaluation to study participation was significantly longer for Black caregivers (M = 4.2 years, SD = 0.44 years) than White caregivers (M = 3.9 years, SD = 0.39 years), t(171) = 3.6, p < .001. This likely reflects the effectiveness of the research video we sent to participants halfway through recruitment. Across both groups, the time from diagnostic evaluation to study participation ranged from 2.5 to 5.1 years.

Table 4.

Race and ethnicity of Black caregivers and their children

Race & Ethnicity	
Caregiver-reported race	
African American	24 (48%)
Black	19 (38%)
Biracial	3 (6%)
Multiracial	1 (2%)
African	3 (6%)
Perceived race[a]	
Black[b]	27 (54%)
African American	16 (32%)
African	1 (2%)
Bi-racial	2 (4%)
Bi-racial/African American	1 (2%)
Indian	1 (2%)
Person of interest[c]	1 (2%)
Prefer not to answer	2 (4%)
Ethnicity	
Non-Hispanic	17 (34%)
African American	11 (22%)
Black	11 (22%)
African	3 (6%)
American	3 (6%)
Ethiopian	2 (4%)
Jamaican	2 (4%)
Person of color	1 (2%)

Child race	
African American	24 (48%)
Black	19 (38%)
African	3 (6%)
Biracial	3 (6%)
Multiracial	1 (2%)

[a]What would others perceive your race to be? [b]One person wrote Black and African American; [c]Participants did not further expand on what this means to them.

Table 5.

Race and ethnicity of White caregivers and their children

Race & Ethnicity	
Caregiver-reported race	
White	84 (67.7%)
Caucasian	40 (32.3%)
Child race	
White/Caucasian	121 (97.6%)
Hispanic	1 (0.8%)
Spanish/Mixed	1 (0.8%)
N/A	1 (0.8%)
Ethnicity	
Not Hispanic	46 (37.4%)
White	43 (34.6%)
American	10 (8.1%)
German	8 (6.5%)
European	4 (3.2%)
German/Irish	2 (1.6%)
Bulgarian	1 (0.8%)
Eastern European	1 (0.8%)
English	1 (0.8%)
English/German	1 (0.8%)
Greek	1 (0.8%)
Hispanic	1 (0.8%)
Irish	1 (0.8%)
Jewish	1 (0.8%)
Middle Eastern	1 (0.8%)
Did not respond/not sure	2 (1.6%)
Child race	

White	112 (90.3%)
Bi-racial	9 (7.3%)
Black/African American	2 (1.6%)
Middle Eastern	1 (0.8%)

Most caregivers (*n*=150, 86.2%) were mothers (See Table 6). The mean age of caregivers who completed the survey was 38.1 years old (*SD* = 7.2). Approximately one-quarter (*n*=42, 24.1%) had a high school education equivalency or less. Seventy-eight caregivers held full-time jobs (44.8%), and 58 (33.3%) caregivers stayed home to care for one or more children. The median family income was $72,126.

Children were on average 3.2 years old (Median age = 3 years, *SD* = 1.6) at the time of the evaluation. Most participants were evaluated by a multidisciplinary team (*n*=168, 96.6%). Seventy-nine children were evaluated by a speech-language pathologist and a DBP, followed by developmental testing with a psychologist ("Under 3 Arena"). Sixty-four children (36.8%) underwent an evaluation with a speech-language pathologist and psychologist, typically on the same day ("3-5 Arena"). Fewer families (*n*=25, 14.4%) consulted initially with a DBP, followed by a second visit in which the child was evaluated by a speech-language pathologist and psychologist. Only six children were evaluated by just a psychologist (3.4%; "6 and Over Model").

We did not have access to the amount of time families waited between the referral and their first autism evaluation appointment; however, the median wait time between the first evaluation appointment and the ISS was 27 days. The mean wait time was 49 days (*SD* = 64), skewed higher due to large outliers, which likely represent families who needed to reschedule their ISS multiple times.

Table 6.

Sample demographic characteristics by race.

	Black (*n*=50)	**White** (*n*=124)	**Cohen's** ***d/Phi*[a]**	***p***
Child demographics				
Child gender, n (%)				
Male	42 (84%)	97 (78.2%)	0.07	.39
Female	8 (16.0%)	27 (21.8%)		
Caregiver demographics				
Relationship to child, n (%)				
Mother	46 (92.0%)	104 (83.7%)		
Father	4 (8.0%)	10 (8.1%)	.16	.64
Adoptive parent	0 (0.0%)	4 (3.2%)		
Grandmother	0 (0.0%)	3 (2.4%)		
Legal guardian	0 (0.0%)	3 (2.4%)		
Number of siblings, N (%)				
0	16 (32%)	37 (30.8%)		
1	20 (40%)	41 (34.2%)	.13	.45
2	11 (22%)	33 (27.5%)		
3+	3 (6%)	9 (7.2%)		
Sibling with Autism (yes), N (%)	3 (9.0%)	11 (9.2%%)		
Age, M (SD)	36.40 (6.88)	38.32 (8.41)	-0.33	.06
Gender, n (%)				
Female	46 (92.0%)	110 (88.7)	0.049	.51
Male	4 (8.0%)	14 (11.3%)		
Relationship status, n (%)				
Single	23 (46.0%)	12 (9.7%)	**.10**	**< .001**
Married/living with a partner	14 (28.0%)	94 (75.8%)		
In a committed relationship	7 (14.0%)	10 (8.1%)		
Divorced	6 (12.0%)	6 (4.8%)		
Other	0 (0.0%)	2 (1.6%)		
Family Structure, N (%)				
Mother & Father /Two caregiver household	24 (48%)	97 (80.8%)	**.39**	**< .001**
Single Mother / Single Father	25 (50%)	15 (12.5%)		
Other (e.g., grandparents, legal guardian)	1 (2.0%)	8 (6.5%)		
Education, n (%)				
High school degree or less	15 (30.0%)	27 (21.8%)		
Some college	23 (46.0%)	41 (33.1%)	0.087	.25
Bachelor's degree	9 (18.0%)	31 (25.0%)		
Advanced degree	3 (6.0%)	25 (20.2%)		
Occupation status, n (%)[b]				
Full-time	21 (42.0%)	57 (46.3%)	.19	.098

Part-time	6 (12.0%)	13 (10.6%)		
Multiple part-time	0 (0.0%)	3 (2.4%)		
Contract	2 (4.0%)	1 (0.8%)		
Unemployed	3 (6.0%)	4 (3.3%)		
Unable to work	3 (6.0%)	1 (0.8%)		
Stay-at-home caregiver	14 (28.0%)	44 (35.8%)		
Other	1 (2.0%)	0 (0.0%)		
Public insurance status, n (%)	37 (74.0%)	48 (38.7%)	**-0.32**	**< .001**
Caregiver-reported income (current, N (%))				
Under $30,000	23 (46.0%)	24 (20.0%)		
$30,000-$59,000	12 (24.0%)	22 (17.9%)	**.34**	**< .001**
$60,000-$99,999	8 (16.0%)	16 (13.0%)		
$100,000 or more	7 (14.0%)	58 (47.2%)		
Median income (2018, M [SD])	$50,039.9 (32,590.5)	$85,731.8 (32,590.5)	**-1.12**	**< .001**
COI Z-score, M (SD)	27.7 (27.97)	63.6 (28.6)	**1.35**	**< .001**
Socioeconomic status	29.7 (30.0)	66.4 (27.1)	**1.30**	**< .001**
Health & Environment	23.5 (23.3)	50.8 (21.3)	**1.50**	**< .001**
Education	36.6 (23.5)	58.5 (27.1)	**.88**	**< .001**
SVI Z-score, M (SD)	.61 (.26)	.32 (.27)	**1.14**	**< .001**
Socioeconomic status	.61 (.28)	.35 (.27)	**.94**	**< .001**
Housing and disability	.53 (.25)	.49 (.28)	**.51**	**< .001**
Transportation	.52 (.25)	.35 (.27)	**.67**	**< .001**
Minority and language status	.53 (.21)	.25 (.20)	**1.40**	**< .001**
Distance from the hospital, M (SD)				
Miles to evaluation location	16.9 (38.7)	24.1 (17.4)	.29	.09
Time to evaluation location (minutes)	25.3 (35.0)	32.6 (16.8)	.31	.06
Pre-Evaluation Service Utilization				
Therapies prior to evaluation, *n* (%)				
Speech	25 (50.0%)	58 (46.8%)	-.02	.77
Occupational Therapy	13 (26.0%)	50 (40.3%)	.14	.06
Physical Therapy	7 (14.0%)	16 (12.9%)	-.015	.85
Early Intervention	22 (44.0%)	61 (49.2%)	.054	.47
Preschool	19 (38.0%)	51 (41.1%)	.021	.77
Individualized education plan	16 (32.0%)	39 (31.5%)	-.005	.94
Evaluation Characteristics				
Age at evaluation (months, *M [SD]*)	41.1 (17.7)	42.5 (19.7)	-0.07	.33
Cognitive z-score, *M (SD)*	-2.3 (.86)	-1.8 (1.3)	**-0.40**	**.006**
Vineland Total Score, *M (SD)*	68.8 (11.0)	69.0 (9.8)	-0.07	.69
Days between evaluation and feedback, *M (SD)*	52.8 (75.6)	50.0 (76.4)	0.07	.71
Co-occurring diagnoses, *n* (%)^c				
Hear	0 (0.0%)	2 (1.6%)	.068	.37
Delay	38 (76.0%)	79 (63.7%)	-.12	.12
Behavioral or emotional diagnosis	3 (6.0%)	20 (16.1%)	.14	.07

Medical condition	1 (2.0%)	7 (5.6%)	.079	.30
Language disorder	15 (30.0%)	40 (32.3%)	.022	.77

[a] Cohen's D used for continuous variables and Phi used for categorical variables.
[b] one caregiver did not disclose employment status; number of siblings was missing for four participants, relationship to the child was missing for one participant, gender was missing for one participant; [c] Hear = hearing diagnosis, such as mild conductive hearing loss; Delay = Developmental delay in one or more areas; Behavior or emotional diagnosis, such as Attention-Deficit/Hyperactivity Disorder, Adjustment disorder, disruptive behavior disorder; Medical conditions such as Spina Bifida, seizures, Fragile X syndrome; Language disorder such as mixed-receptive expressive language disorder

Survey Completers and non-completers

We did not have access to the caregivers' race for those who did not complete the survey. Therefore, we compared survey completers and non-completers based on the child's race in the medical record. Out of all children who were evaluated in 2018, the proportion of caregivers who completed the survey were more likely to have Black children than White children (X(1) = 10.13, *p* < .001; See Table 7).

Table 7.

Comparison of completers and non-completers by race

	Black Children	**White Children**
Completers	50 (53%)	124 (42%)
Non-completers	44 (47%)	168 (58%)
Total evaluated in 2018	94 (24.4%)	292 (75.6%)

Comparing completers vs. non-completers with Black children, there were no differences in demographic, socioeconomic, evaluation (e.g., cognitive, adaptive scores), or pre-evaluation service utilization characteristics. Comparing completers vs. non-completers with White children, caregivers who completed the survey had higher median incomes (Completers: *Mdn* = $87,477, *SD* =$32,035; Non-completers: *Mdn* = $75,628, *SD* = $28,112) and lower levels of vulnerability on the SVI (Completers: *M* = .29, *SD* = .25; Non-completers: *M* =. 37, *SD* = .26) and COI (Completers: *M* = .017, *SD* = .03; Non-completers: *M* = .008, *SD* = .03) in comparison to the median income and SVI/COI scores of non-completers (*t*(285) = 2.6 - 3.3, *p* = .001 - .01, Cohen's *d*s = .28-.40).

Because we used the race of children to compare completers vs. non-completers, it is important to note that of completing White caregivers, 10 (7.5%) of their children were categorized as Black in the medical record. Also notably, the race of some children may be inaccurate in the medical record, making it an imperfect proxy for caregiver race. Among completers, two Black children were misidentified as "White" by the medical record, and one White child was misidentified as "African American" by the medical record.

Identifying co-variates and testing the assumptions of regression

In both satisfaction and service utilization models, we identified multi-collinearity between median income, SVI SES, and COI SES (VIF > 4). Because childhood opportunity and social vulnerability are broader neighborhood-level factors, we chose to retain median income in the models. We also identified non-constant error variance for insurance status and education level of the primary caregiver (heteroscedasticity). Therefore, we used a heteroscedastic-consistent standard error estimate across models (Hayes, 2007).

All other assumptions of regression were met: 1) there appears to be a linear relation between predictors and dependent variables (i.e., satisfaction, service utilization), 2) the residuals are random and independent, 3) there is constant variance of residuals for the predictor variables at different levels of the dependent variables (aside from insurance status and education), and 4) the errors are normally distributed.

Please see Tables 8 and 9 for predictor variables significantly correlated with the total satisfaction score and total service utilization. All other demographic variables (e.g., gender) and institutionalized racism proxy variables (e.g., geographical location, cognitive score) were not associated with outcome variables.

Table 8.

Correlations between potential predictor variables and satisfaction

Potential co-variate	Included as a co-variate?	Correlation with satisfaction: Black families	Correlation with satisfaction: White families	Significant difference in correlation coefficient b/w[a] Black and White Caregivers	Correlation with satisfaction: Total Sample
Caregiver years of education	Yes	.20, $p > .05$	**.21, $p = .02$**	N	**.17, $p = .03$**
Insurance status (t-test)	Yes	M(public) = 1.70 M(private) = 1.99	M(public)= 1.79 M(private)= 2.00	N	**M(public) = 1.75** **M(private) = 2.00**
Median Income	Yes	**.31, $p = .03$**	.17, $p > .05$	N	**.21, $p = .006$**
COI Education Domain	Yes	.20, $p > .05$	**.23, $p = .02$**	N	**.23, $p = .003$**
Age at evaluation	Yes	-.015, $p > .05$	**.19, $p = .04$**	N	.14, $p > .05$
SVI SES	No	**-.22, $p = .02$**	**-.28, $p = .05$**	N	**-.24, $p = .001$**
COI SES	No	**.21, $p = .02$**	.20, $p > .05$	N	**.21, $p = .006$**

[a] b/w = between

Table 9.

Correlations between potential predictor variables and total service utilization

Co-variate	Included as a co-variate?	Correlation with service utilization: Black families	Correlation with service utilization: White families	Significant difference in correlation coefficient b/w Black and White Caregivers	Correlation with service utilization: Total Sample
Caregiver years of education	Yes	.20, $p > .05$	**.18, $p = .04$**	N	**.18, $p = .05$**

Median Income	Yes	.15, *p* > .05	**.28, *p* = .001**	N	**.25, *p* =.001**
COI Education Domain	Yes	-.08, *p* > .05	**.21, *p* = .02**	N	**.16, *p* = .03**
Time driving to site of evaluation (minutes)	Yes	**.28, *p* =.048**	-.11, *p* > .05	**p = .02**	.03, *p* > .05
SVI Housing and transportation	Yes	-.07, *p* > .05	**-.29, *p* = .001**	**p = .03**	**-.25, *p* =.001**
SVI SES	No	-.02, *p* > .05	**-.24, *p* = .008**	N	**-.19, *p* =.01**
COI SES	No	.03, *p* > .05	**.21, *p* = .02**	N	**.15, *p* = .05**

Table 10.

Satisfaction scores by question and race

Satisfaction scores [a]	**Black**	**White**
Provider factors		
The providers explained the diagnostic process.	1.72 (.83)	1.99 (1.31)
I felt understood by the DDBP providers when I talked about my child.	1.98 (1.38)	1.90 (1.20)
The DDBP providers respected and valued my opinions and point of view.	1.89 (1.20)	1.85 (1.11)
I felt emotionally supported by my providers.	2.42 (1.75)	2.37 (1.55)
I had the opportunity to ask questions about the diagnosis.	1.82 (1.04)	1.73 (.99)
Provider total	1.97 (.99)	1.97 (.97)
Information provided		
I was satisfied with the recommendations, resources, and referrals I received.	2.18 (1.37)	2.57 (1.69)
I was satisfied with the amount of information I received about my child's diagnosis and potential next steps.	2.08 (1.38)	2.51 (1.68)
My providers gave me enough guidance and resources to begin to understand my child's diagnosis.	2.12 (1.27)	2.38 (1.59)
My providers gave me enough guidance and resources to get me started on next steps (e.g., school, therapy).	2.25 (1.56)	2.48 (1.62)
Information total	2.16 (1.25)	2.49 (1.50)
Wait times		

I was satisfied with the amount of time between the referral to DDBP and my child's first Autism evaluation appointment.	2.32 (1.62)	2.75 (1.78)
I was satisfied with the amount of time between my child's first evaluation appointment and receiving the official diagnosis at the Information Sharing Session (ISS).	2.26 (1.60)	2.32 (1.54)
Wait total	2.16 (1.25)	2.54 (1.46)
Other		
My providers respected my cultural and family values.	1.84 (.82)	1.71 (.94)
I was satisfied with the written results (the reports).	2.18 (1.12)	2.12 (1.23)

[a] Survey items were rated on a 7-point Likert scale (1 = Strongly agree to 7 = Strongly disagree)

Overall, both Black and White families were satisfied with their care throughout the diagnostic process (Table 10). Regarding provider factors, 44 (88%) Black families and 109 (88%) White families were satisfied or very satisfied with their provider or providers (See Figure 2). Very few families were dissatisfied or strongly dissatisfied with their providers (2 [4%] Black families and 4 [(3%] White families). Families were also relatively satisfied with the information provided; 41 (82%) Black and 86 (69%) White families agreed or strongly agreed that they were satisfied with the information that was provided (See Figure 3). By contrast, 2 (4%) Black families and 10 (7.8%) White families disagreed or strongly disagreed. Regarding wait times, 38 (76%) Black and 80 (65%) White families agreed or strongly agreed that they were satisfied with wait times for the first evaluation appointment and between the first evaluation appointment and the ISS, when they received the official diagnosis (See Figure 4). However, 5 (10%) Black and 12 (10%) White families were dissatisfied or strongly dissatisfied with the waiting times.

Figure 2.

Averaged satisfaction score of provider domain by race

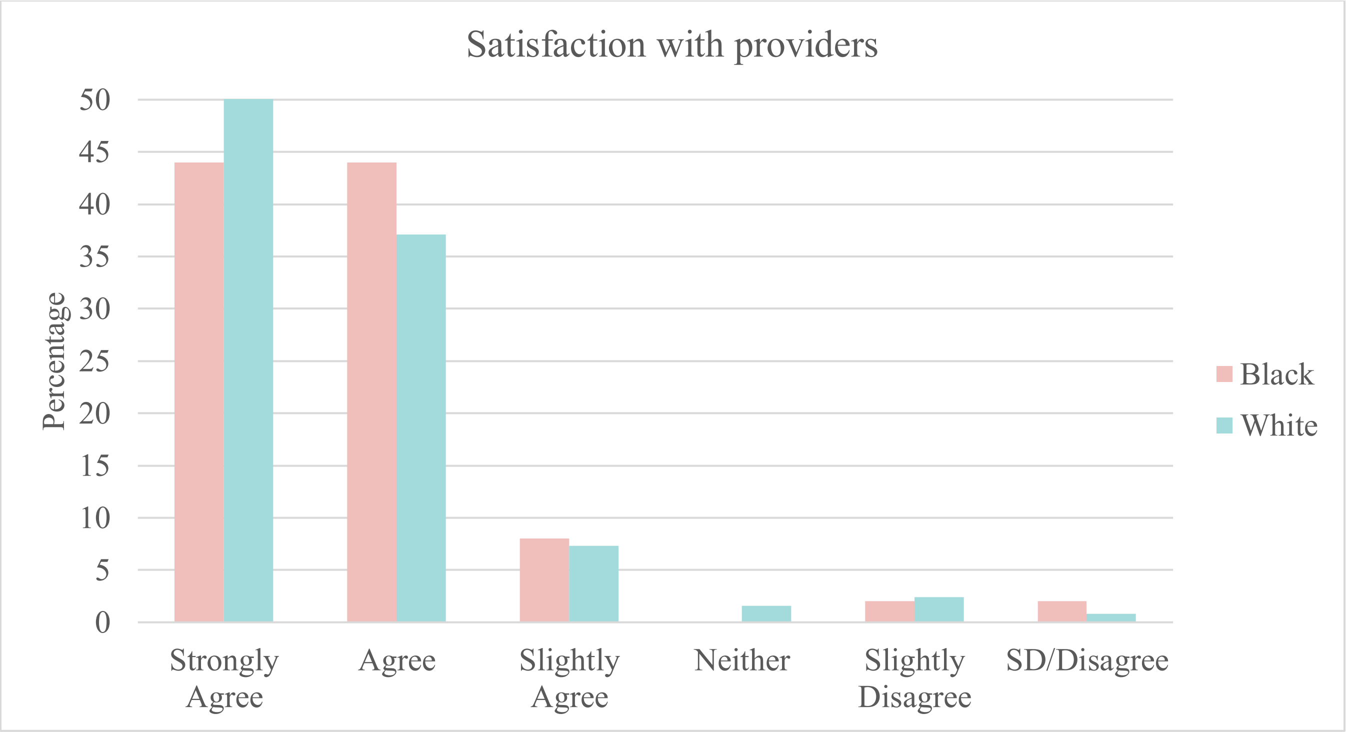


Figure 3.

Averaged satisfaction score of information provided domain by race

Figure 4.

Averaged satisfaction score of wait times domain by race

Aim 1: Does race predict satisfaction with the diagnostic process?

Unadjusted satisfaction models. In unadjusted models, there were no differences between Black and White responses regarding the total satisfaction score (*t*(173) =.90, *p* = .37), provider factors (*t*(173) = .008, *p* = .99), information provided (*t*(173) = 1.4, *p* = .18), or wait times (*t*(173) = .99, *p* = .32).

Partially adjusted satisfaction models. We did not examine partially adjusted models because demographic factors (e.g., child sex, caregiver marital status) were not associated with satisfaction for Black or White families.

Fully adjusted satisfaction models. In the fully adjusted model predicting satisfaction, race, insurance status, education level of the caregiver, median income, child's age at evaluation, and all interaction terms were removed from the models. Only educational opportunities at the neighborhood level (e.g., teacher experience, 3rd grade reading and math proficiency, high school graduation rate) continued to predict satisfaction with providers (*t*(173) = 2.66, *p* = .009, partial eta squared = .04). For every 25% increase in opportunity, satisfaction increased by 0.18 points. Only educational opportunities at the neighborhood level continued to predict satisfaction with the information provided (*t*(173) = 2.00, *p* = .006, partial eta squared = .05), such that for every 25% percentage increase in opportunity, satisfaction with the information provided increased by 0.33 points. For wait times, only median income predicted satisfaction (t(173) = 2.79, *p* = .006, partial eta squared = .04). For every income increase of $20,000, satisfaction with wait times increased by 0.17 points. Only neighborhood-level educational opportunities predicted total satisfaction scores (*t*(173) = 3.06, *p* = .003, partial eta = .05), with satisfaction increasing by 0.25 points for every 25% increase in opportunity.

Average service utilization by race

Table 11.

Services received prior to the evaluation

Service	Black	White	Effect Size	P-value
Therapies				
Speech	25 (50.0%)	59 (52.4%)	.022	.45
Occupational Therapy	13 (26.0%)	51 (41.1%)	**.14**	**.043**
Physical Therapy	7 (14.0%)	16 (12.9%)	.015	.51
Early Intervention	22 (44.0%)	62 (50.0%)	.054	.29
Preschool	19 (38.0%)	50 (40.2%)	.021	.46
IEP	16 (32.0%)	39 (31.5%)	.005	.54

Prior to the evaluation in DDBP, approximately half of the children received speech therapy, and a little over one-third of the children were enrolled in preschool (Table 11). During the ISS, more than half of the participants were recommended to receive four or more therapeutic services, most commonly ABA (*n*=139, 79.9%), speech therapy (*n*=109, 62.6%), behavior therapy (*n*=97, 55.7%), and group therapy (*n*=87, 50%; Table 12). Most families were recommended to receive one or more community resources (*n* = 138, 79.3% recommended the County Board of Developmental Disabilities, *n* = 107, 61.1% recommended Ohio Autism Scholarship) and to receive in-school services (*n* = 154, 88.5%). There were no differences in the number or type of recommendations by race.

Table 12.

Therapeutic services received following the evaluation

Service	Black (*n* = 50)	White (*n* = 124)	Effect Size	P-Value
Therapies, N (%)				
Speech				
Recommended (yes)	34 (68.0%)	75 (60.5%)	.07	.39
Received if recommended (yes)	29 (85.0%)	64 (85.3%)	.001	1.0
Occupational Therapy				
Recommended (yes)	17 (34.0%)	46 (37.1%)	.029	.73
Received if recommended (yes)	16 (94.0%)	41 (89.1%)	.075	.55
Physical Therapy				
Recommended (yes)	1 (2.0%)	5 (4.0%)	.05	.68
Received if recommended (yes)	1 (100.0%)	2 (100%)	-	-
Behavior Therapy				
Recommended (yes)	21 (42.0%)	76 (61.3%)	**.18**	**.028**
Received if recommended (yes)	3 (14.0%)	33 (43.4%)	**.25**	**.02**
Group Therapy				
Recommended (yes)	22 (44.0%)	65 (52.4%)	.08	.40
Received if recommended (yes)	0 (0.0%)	12 (18.5%)	**.23**	**.03**
ABA Services				
Recommended (yes)	40 (80.0%)	99 (79.8%)	.002	1.0
Received if recommended (yes)	6 (15.0%)	27 (27.3%)	.13	.19
Early Intervention				
Recommended (yes)	10 (20.0%)	24 (19.4%)	.007	1.0

Received if recommended (yes)	7 (70.0%)	16 (66.7%)	.032	1.0
Total number of therapeutic services recommended	3.56 (1.67)	3.81 (1.71)	.15	.39
Community resources				
Ohio Autism Scholarship				
Recommended (yes)	32 (64.0%)	75 (60.4%)	.03	.73
Received if recommended (yes)	2 (6.0%)	12 (16.0%)	.13	.22
Board of Developmental Disabilities				
Recommended (yes)	40 (80.0%)	98 (79.0%)	1.0	N
Received if recommended (yes)	20 (50.0%)	42 (42.8%)	.065	.46
Connect with social work				
Recommended (yes)	49 (98.0%)	121 (97.5%)	.013	.68
Received if recommended (yes)	12 (24.4%)	23 (19.0%)	.061	.41
Connect with family Support Professionals				
Recommended (yes)	19 (38.0%)	50 (40.3%)	.021	.87
Received if recommended (yes)	4 (21.0%)	10 (20.0%)	.012	1.0
Total number of community resources recommended	3.26 (1.19)	3.21 (1.24)	.041	.80
School services				
Recommended (yes)	43 (86.0%)	104 (83.9%)	.027	.73
Received if recommended (yes)	42 (95.4%)	96 (87.3%)	.084	.27

Note. Families may not have been recommended a service if they were already receiving that service at the time of the evaluation.

For total service use, 38 (76%) Black and 85 (69%) White families used 50% or fewer recommended services (Figure 5). Regarding therapies, 35 (78%) Black and 72 (72%) White families used 50% or fewer recommended therapeutic services (e.g., speech, occupational, physical therapy; Figure 6). For community resources (e.g., Ohio Autism Scholarship, board of disability services), 43 (91%) Black and 101 (89%) White families used 50% or fewer of the recommended community resources (see Figure 7). Almost all families (42 (95.4%) Black families and 96 (91.4%) White families) received recommended school services (Figure 8).

Figure 5.

Percentage of services recommended in evaluation reports that families reported receiving.

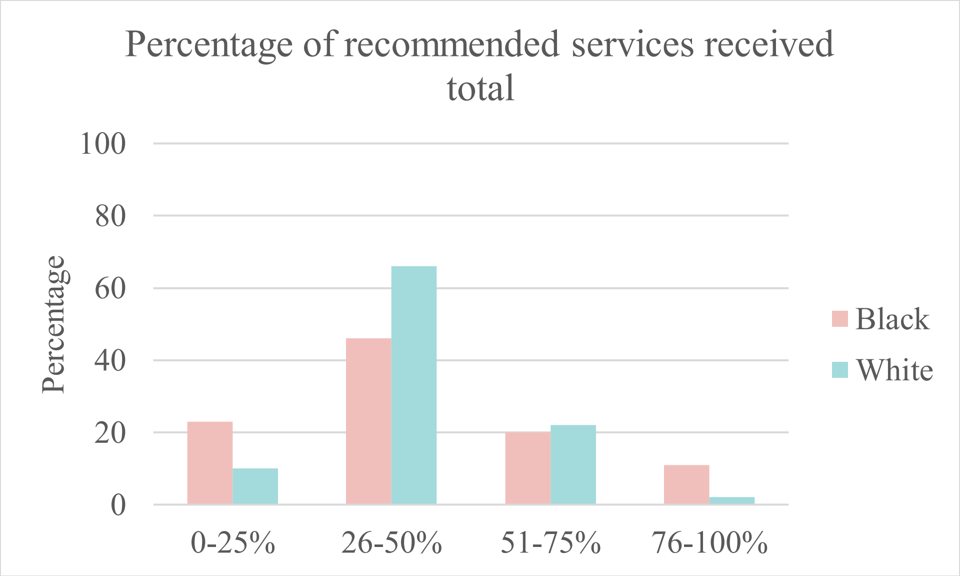


Figure 6.

Percentage of therapies (e.g., speech, behavior) recommended in evaluation reports that families reported receiving.

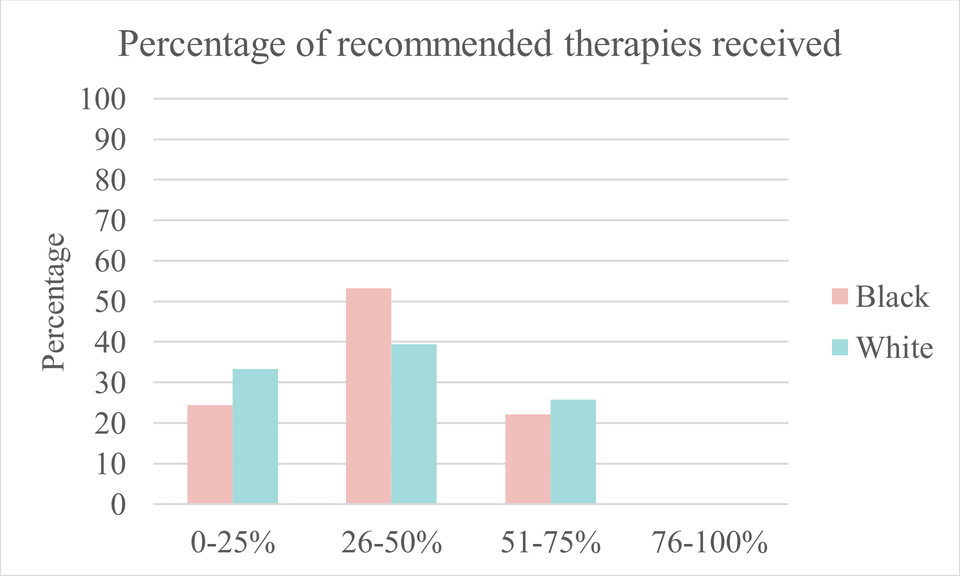


Figure 7.

Percentage of community resources (e.g., board of developmental disabilities services, Ohio Autism scholarship) recommended in evaluation reports that families reported receiving.

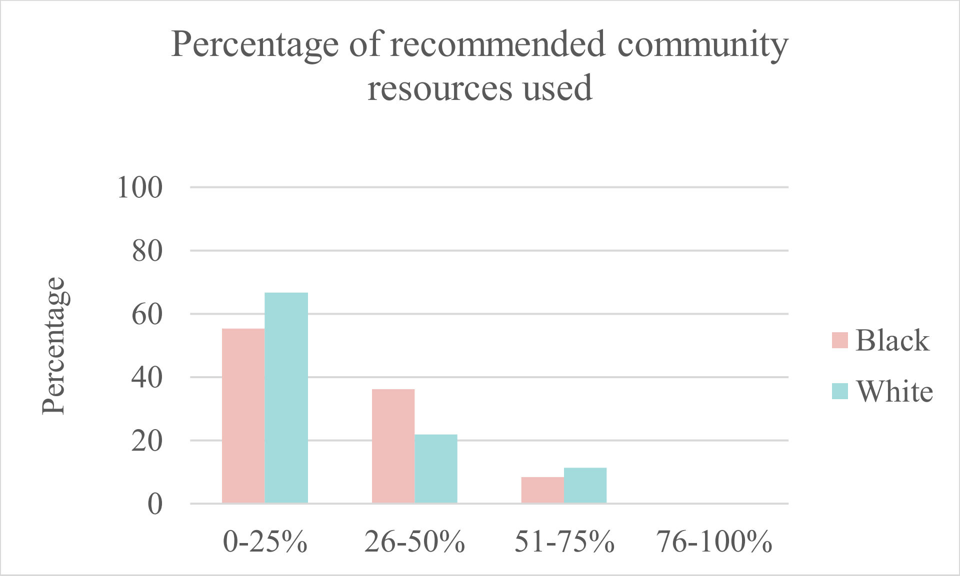
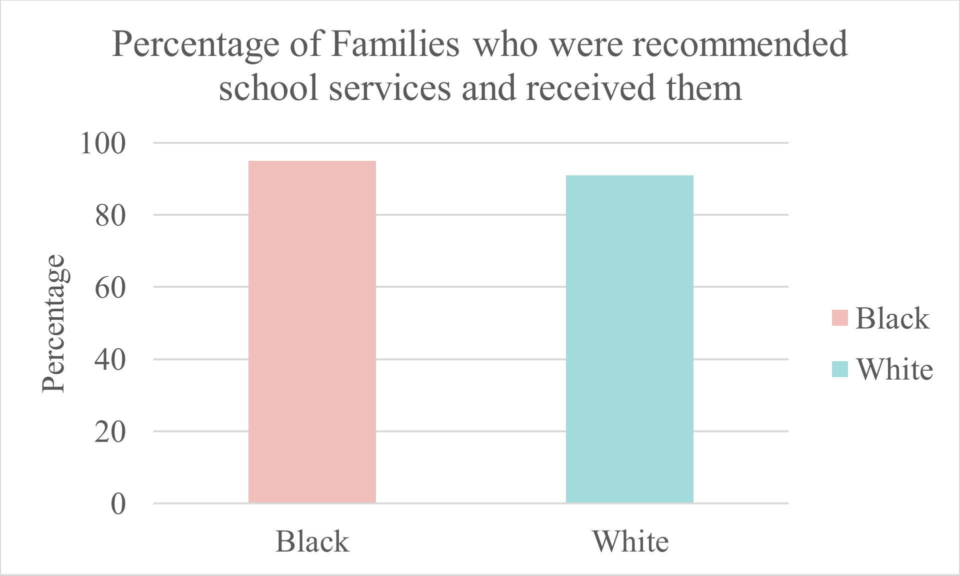


Figure 8.

Percentage of families who received school services, if recommended in evaluation reports.



***Aim 2:* Does caregiver race predict entry into services?**

Unadjusted service utilization models. In unadjusted models, total service use (*t*(173) = .59, *p* = .59), therapeutic services received (*t*(169) = 1.67, *p* = .20), community resources received (*F*(173) = -.54, *p* = .59), and receipt of school services (X(1)=0.94, *p* = .33) did not differ by race.

Partially adjusted satisfaction models. We did not examine partially adjusted models because demographic factors (e.g., child sex, caregiver marital status) were not associated with service use for Black or White families.

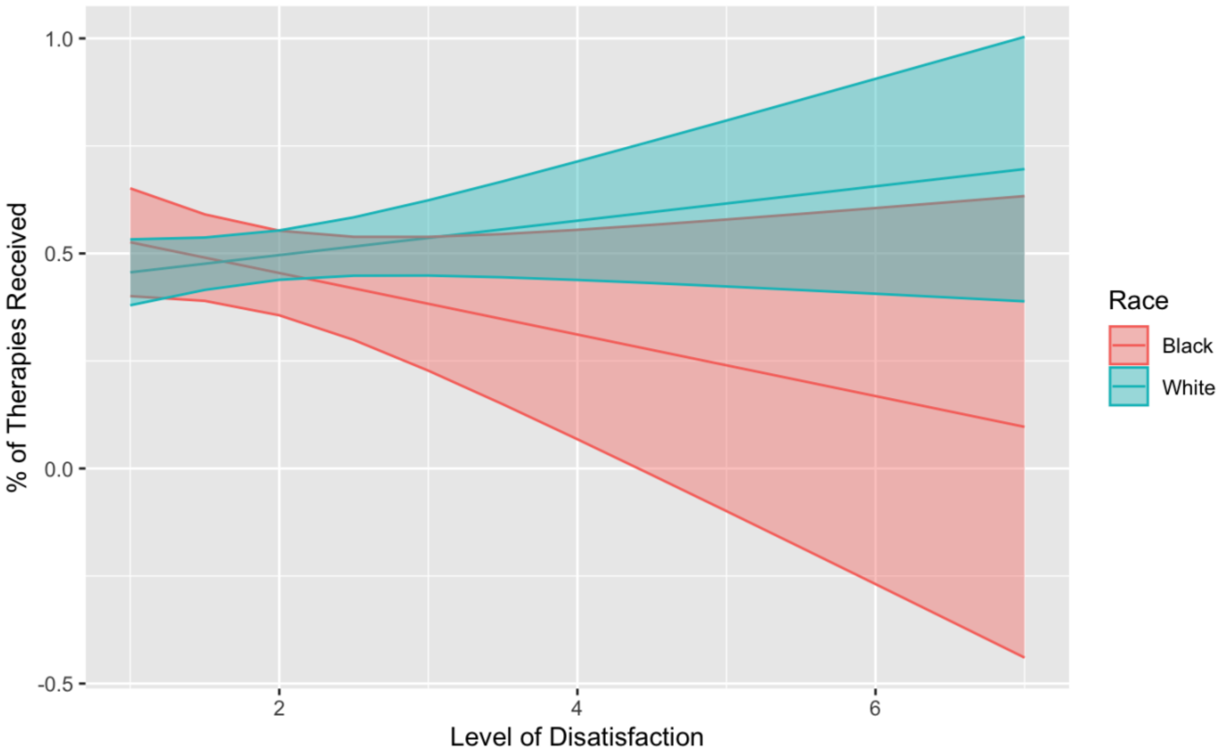
Fully adjusted service utilization models. Using backward elimination, there were no significant predictors of total service use, use of community resources, or use of school services. Regarding therapeutic service use, families with a higher median income were more likely to use a greater percentage of recommended services (*t*(167) = 2.61, *p* = .04, partial eta squared = .04). For every increase in median income by $20,000, there was a 2% increase in the percentage of recommended therapies received.

Aim 3: Does race moderate the association between satisfaction and service utilization?

Race did not moderate the association between satisfaction and total service use, *F*(170) = 1.96, *p* = .16. However, race significantly moderated the association between satisfaction and therapy service use, *F*(163) = 3.59, *p* = .046 (Figure 9). When decomposing the interaction, greater satisfaction was marginally associated with a greater percentage of therapeutic service utilization among Black families, *B* = -.061, *t*(163) = -2.56, *p* = .08. Among White families, there was no association between satisfaction and service utilization, *B* = .034, *t*(163) = 1.26, *p* = .21. Race also moderated the association between community resources and satisfaction, *F*(169) = 4.76, *p* = .046 (Figure 10). For Black families, there was a positive association between satisfaction and community resource utilization, *B* = -.062, *t*(169) = -2.19, *p* = .03. There was no association between satisfaction and service utilization for White families, *B* = 0.021, *t*(169) = 0.97, *p* = .33. Because nearly all families used recommended school services (90%), we did not examine whether race moderated the association between satisfaction and service utilization.

Figure 9.

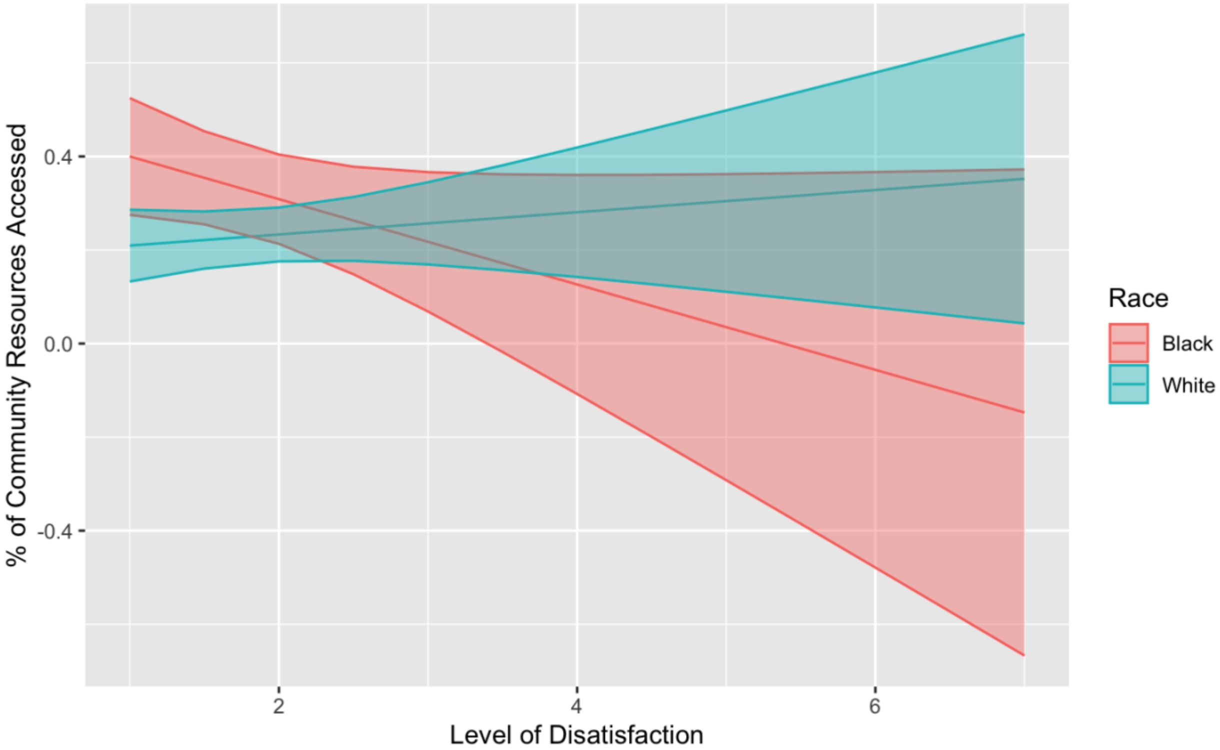
Race as a moderator of satisfaction on therapeutic service utilization



Note. 1 = High level of satisfaction; 7 = High level of dissatisfaction

Figure 10.

Race as a moderator of satisfaction for community resource utilization

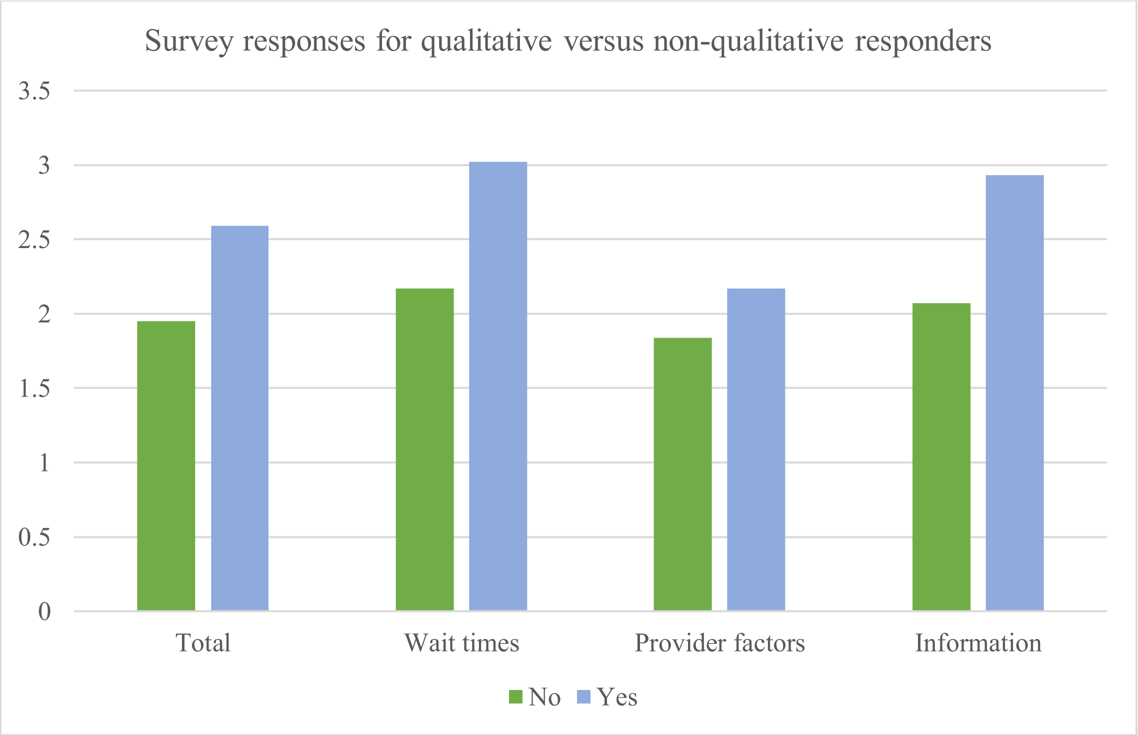


Note. Level of satisfaction: 1 = High level of satisfaction; 7 = High level of dissatisfaction

Aim 4: Examining qualitative survey responses

Figure 11.

Survey responses for qualitative versus non-qualitative responders



Note. No = Did not provide qualitative response. Yes = Did provide qualitative response.

Eighty-one (46.6%) caregivers gave one or more qualitative responses in open text boxes (17 [34.0%] Black families, 54 [43.5%] White families). There were no differences in the proportion of While versus Black families who provided qualitative responses. Regarding demographic characteristics, there were no differences in child (e.g., cognitive scores, gender) or caregiver characteristics (e.g., relationship to child, relationship status). Participants who gave qualitative responses had higher median income (*M* = \$82,137.41, *SD* = \$36,018.74) than those who did not (*M*= \$71,228.57, *SD* = \$33,520.71; *t*(171)=-2.04, *p* = .04, *Cohen's d* = .32). Similarly, those who gave qualitative responses had higher median education (*M*=15 years, *SD* = 1.90) levels than those who did not (*M*= 14 years, *SD* = 1.79; *t*(172) = 4.17, *p* <.001, *Cohen's d* = .64).

Those who gave qualitative responses in one or more open-text boxes had lower total scores on the satisfaction survey and by domain (M_{diffs} = .55-1.25, *t*(172) = 3.61-5.77, *p* < .001, Cohen's *d* = .59-.96). There were some discrepancies between families' written response and their Likert scale responses to survey questions. Of the negatively coded written responses about their provider(s), 17 (31%) selected a positive Likert response (i.e., “Slightly Agree,” “Agree,” “Strongly Agree). For example, one mother who “Agreed” that her provider explained the evaluation process to her wrote, “Never mentioned the word autism during the evaluation. It felt like an elephant in the room.” Another family who indicated they “Agreed” they were satisfied with the information they received wrote, “It felt standard. They told me to follow up with them and the school who would cater to his disability. I had to do it on my own. I found a school that was for special needs children. I was new to being a father of two and in the special needs field, it was chaotic to navigate that during COVID.” Of the negatively coded written responses about the information provided, 45 (43%) families selected a positive Likert response. Regarding wait times, of the written responses that were categorized by coders as “negative,” 10 (20%) families provided a positive Likert response. For example, one family who indicated they “Slightly Agreed” that they were satisfied with the wait time shared, “It's hard to wait even a minute after an evaluation like that. It was horrible to wait a few weeks though.”

Some caregivers described **general negative impressions** of the diagnostic evaluation (Table 13). Caregivers with negative impressions indicated that they did not like their providers, appointments were not family-centered, multiple visits were set up to increase financial gain for the hospital, the evaluation was not helpful, and they felt discouraged after the evaluation process. However, some Black and White caregivers felt the evaluation was a helpful and positive experience. Caregivers with a **positive impression** indicated that they were satisfied with their providers, were able to obtain an evaluation for their child at a young age, their provider used caregiver-friendly language, and that they felt comfortable and satisfied with the diagnostic process.

Provider factors

In response to the question, “My providers explained what to expect during the evaluation process,” Black and White families expressed concerns that they **did not receive enough information.** Some families described that providers did not mention the evaluation would be assessing for symptoms of ASD. One caregiver wished providers would have explained the timeframe of the evaluation: “I wished they would have told me how long it would take to complete all pieces. Speech was scheduling 6 - 7 months out, which is hard to hear when a provider just told you they suspect that your child has Autism.” By contrast, a few Black and White families reported **satisfaction with their providers’ explanation of the evaluation process.**

Some caregivers described that they **felt heard, understood, and respected** during the evaluation: “Providers always made me feel heard, and I never thought I was being disregarded.” Of those responses, a few Black families compared the high quality of care they received at Cincinnati Children’s to **poorer care at other institutions**. For example, one mother shared she received two incorrect diagnoses before her child was ultimately diagnosed with ASD at Cincinnati Children’s. “At [outside institution], they said nothing was wrong. Then in a year, we took him to [other outside institution], and they said ‘no’ nothing is wrong. The whole time, I was telling my pediatrician ‘Something is wrong.’ So, finally we were sent to Cincinnati Children's. We felt more heard when we went to Cincinnati Children's.”

Other Black and White families described that their **concerns were dismissed,** or they **felt unheard** during the evaluation. These caregivers expressed that providers did not listen to caregivers’ perspectives of their child’s behavior and development. For example, one mother stated, “They acted as if I didn't know anything, and they knew everything and they didn't want me to chime in. You're here to listen to us.”

Some Black and White families were concerned about **the accuracy of the evaluation.** For a few families, their child underwent one or more previous evaluations at Cincinnati Children’s or another institution before being diagnosed with ASD, which led to confusion. Other families felt the evaluation results were not accurate, though these families did not explain why. Some Black and White caregivers felt uncomfortable with the **pace of the appointments** themselves, indicating that the **appointments felt rushed.** This may have impacted their trust in the providers’ interpretations: “I actually feel more time needs to be spent with the patient to get to know them. It felt rushed and like they just looked to check a few boxes and move on.”

Caregivers described that the diagnostic process is emotionally overwhelming. Black and White families reported mixed experiences regarding **emotional support** from providers during the diagnostic process. Some families shared that providers were understanding, kind and sympathetic: “The doctor was very compassionate and understanding while giving me the news.” Other families felt like “just another number,” that providers did not leave space for processing, and that the appointment felt “clinical.”

Black families specifically discussed concerns related to the **power differential** between providers and themselves. Some caregivers shared that they did not think to question their child’s diagnosis or the provider’s opinions. Additionally, one mother shared concerns about asking providers for support: “Sometimes I'm scared to ask for help and fear that somehow it can be [turned] around as me being incapable of taking care of my child.”

Although Black and White families were both asked about providers respecting their cultural and family values, only Black families provided qualitative responses. Some caregivers described that **culture** was not addressed during the diagnostic process. A few families indicated they felt like they were treated the same as all other families. One caregiver reported that her culture was affirmed, and another family reported it is important to consider cultural conceptualizations of ASD and the level of acceptance among family members. This mother expressed, “The other part is understanding parents' level of acceptance. Parents may not be ready to accept this. One parent may be on board, but another may not. And what about others in that child's village? I think it expands a bit more broadly.”

Information provided

Both Black and White families spoke to the **challenges of processing the diagnosis during a single visit**. Families felt that they had difficulty taking in new information and needed time to process before being able to ask questions. Some White caregivers also described that their child’s presence at the ISS negatively impacted their ability to be forthcoming and process the diagnosis. Additionally, Black and White caregivers spoke to the **loneliness** that can accompany processing an ASD diagnosis. For example, one mother shared, “There's also a feeling of loneliness. I didn't know anyone else that has experienced this diagnosis. I didn't have a shoulder to tap on.”

Qualitative responses regarding the information provided during the ISS were overwhelmingly negative. Black and White caregivers described that they **needed more guidance and direction** regarding what services and supports their child needed. One mother shared, “They did give me some information […] However, there wasn't a clear direction of what to do.” Another caregiver stated: “They gave me resources BUT I had to hunt everything down. I had no idea where to start. I feel like if a kid is sick- you get clear instructions. Like call this doctor or take this med. It was like here is a bunch of suggestions- best of luck. Again, we felt lost and more confused."

Caregivers expressed that being provided with an **overwhelming amount of information** prevented them from understanding specific next steps: "We received a TON of information, but it was almost too much. I wish there was a time where we received the diagnosis then time to decompress, then a 'planning' period with a social worker or other planner. There was A LOT of information, but it was so much that it was overwhelming, and we could not dial into a path."

Similarly, Families discussed **not receiving individualized care that was tailored to their child or family.** For example, Black and White caregivers described wanting information about their child's specific presentation, "The information we received about the diagnosis was that he was 'mild to moderate.' That was the only thing we were told. I understand autism is a spectrum, but it gave more questions than answers." Families also wanted recommendations that were specific to their child, "I was hoping there were more specifics to help my kid's issues versus a very broad spectrum autism diagnosis because they all so different."

Caregivers also reported **needing more information about supports and services**, including what services were available, the purpose of each service, and how to obtain services. One caregiver indicated that families need additional guidance, "Not just handing you paperwork. They should explain each program and each resource. Explain the terminology like HSA waivers. They just give you numbers to call and people to email." Families specifically reported needing more information about school services, including the IEP process, schools for children with ASD, and private school options. As a result of limited guidance, caregivers needed to **do their own research** to understand their child and how to proceed.

Some resources provided to caregivers were **outdated or not relevant** for the child and family. For example, one caregiver shared being given outdated organization information: “All of the ABA providers listed were out of business or didn't answer/respond.” Other caregivers indicated that materials and suggestions did not meet their needs or values. For example, one caregiver expressed, “I personally don't believe ABA should be recommended due to its history and experiences of actual autistic former participants.”

While many families expressed dissatisfaction, some shared they were **satisfied with the information they received**. For example, one mother shared she was satisfied with the written resources, “They gave me a packet of a lot of resources when he was diagnosed and that was so helpful.” A few caregivers expressed facilitated families’ entry into services. Additionally, a few caregivers mentioned their providers' responsiveness to their questions.

Some families **wanted additional follow up** to support caregivers’ emotional needs, reassess their child’s needs, and discuss next steps. Importantly, some White families who participated in a follow-up appointment called a “Therapeutic Programming Session” described **benefiting from follow-up care**: “We had an appointment where he was evaluated by multiple therapists and that appointment was incredibly helpful. At the time we were dealing with a lot of elopement (child running away).”

Caregivers were specifically asked about their satisfaction with the written report detailing assessment results and diagnostic findings. In qualitative responses, caregivers were more likely to report **concerns with the report.** Some Black and White caregivers shared they did not receive the written reports from the evaluation. Others described their insurance company did not accept the documentation in the report about the child’s diagnosis and service needs. Caregivers also indicated that the report contained mistakes such as grammatical errors and hard-to-read figures. Those who were **satisfied with the written reports** expressed that the reports helped their child receive services, allowed families to see their child's progress, and supported IEP planning.

Though we did not specifically ask families about their experiences accessing services, caregivers spontaneously commented about their experiences. Some families reported **difficulty accessing services**, which was more prevalent among Black families. Families described the limited availability of services, which are often only offered during traditional work hours. By contrast, some White families reported **ease in accessing services**. These families indicated they were immediately placed into services. For example, one mother stated, "They helped me sign up for [Ohio Early Intervention] and everything was smooth sailing after that."

Wait times

Black and White caregivers commonly described concerns about the **wait time for their first evaluation appointment,** frequently describing that they waited months between their referral and first appointment. A few caregivers expressed that waiting for the appointment led to significant stress: "When your primary care provider gives you the referral and it takes months for that [appointment] and then another month for the diagnosis - you're coping with a lot of stress & worry."

Black and White caregivers also described **dissatisfaction with the time between their first evaluation** and receiving the **official diagnosis at the Information Sharing Session (ISS).** One mother shared her experiences advocating to move the process forward, "If I did not call scheduling every day, asking if there were any cancellations, we would still be waiting to complete all the evaluations. If a parent does not have resources to advocate for their child, there will be a big gap in time before they get those results." Both Black and White caregivers commented that the entire process was long because it involved multiple appointments. Interestingly, some caregivers noted that although they waited a few months for appointments, they were **satisfied with the wait time** because they **expected** it to be long or because their child was already enrolled in services. By contrast, a few Black families specifically discussed that waiting for the evaluation appointment and results **delayed** their ability to enroll their child in **needed services.** A few caregivers indicated that the **process moved quickly**, with some stating that cancellations and knowledge of the department facilitated the process.

Family strengths

Finally, the **strength and resilience** of families were clear in their open-text responses. Families described how they advocated for their child and conducted their own research to identify the next steps. One father shared, “I've made it my number one mission [to figure out how to support my child] and it's my reason to live.” Another mother described the way in which the lack of support facilitated her growth as an advocate: “I felt and still feel it was like ‘here is your diagnosis, good luck!’ With that said, I understand that each child on the spectrum presents differently and there is no one size fits all remedy. Looking back, as frustrated as I was at my perceived lack of guidance to jumpstart our autism journey, it forced me to be scrappy and taught me how to advocate for my child.”

Table 13.

Endorsed themes by race

Theme	Theme	Black	White
General	General negative impression	X	X
	General positive impression	X	X
Provider Factors	Did not receive enough information about evaluation	X	X
	Satisfaction with explanation of evaluation process	X	X

	Felt heard/respected	X	X
	Poorer care at other institutions	**X**	
	Concerns were dismissed/felt unheard	X	X
	Concerns about accuracy	X	X
	Appointments were rushed	X	X
	Lack of emotional support	X	X
	Felt emotionally supported	X	X
	Power differential between providers and caregivers	**X**	
	Culture	**X**	
Information provided	Challenges with processing diagnosis in a single visit	X	X
	Alone to process diagnosis	X	X
	Need more guidance and direction	X	X
	Overwhelming amount of information	X	X
	Need additional support in understanding services	X	X
	Had to research on own	X	X
	Lack of individualized care	X	X
	Irrelevant and outdated resources	X	X
	Wanted more follow- up	X	X
	Follow-up care was helpful		**X**
	Concerns with report	X	X
	Satisfaction with report	X	X
	Difficulty accessing services	X	X
	Ease of accessing services		**X**
Wait times	Long wait time for first appointment	X	X
	Long wait time for Information Sharing Session (ISS)	X	X
	Wait time met expectations	X	X
	Process delayed entry into services	**X**	
	Process moved quickly	X	X
Strength and resilience		X	X

Discussion

Quantitative

We found that most families were satisfied with the ASD diagnostic process at a large academic medical center, and there were no differences in families' satisfaction by race. After their child was diagnosed with autism, most families reported receiving speech and occupational therapy. Most families also received school-based services at their child's local school district. Utilization was lower for other recommended services. We identified that race moderated the associations between satisfaction and therapy use and satisfaction and community resource use, such that there was a significant positive association between satisfaction and service use for Black families.

Qualitative

Less than half of families provided written feedback to survey questions, and those who responded were generally less satisfied with the diagnostic process. However, we did identify that some families who wrote in negative responses selected positive Likert options to the quantitative survey questions (i.e., "Strongly Agree," "Agree," "Slightly Agree"). Families who gave qualitative feedback described mixed experiences with their providers, the information provided, and wait times. Families who were satisfied shared their providers were supportive and open, they received an appropriate amount of information to pursue next steps, and they did not wait long. Those who were dissatisfied did not feel supported by their providers, desired more information about supports and services tailored to their specific child's needs, wanted additional follow up to help them identify and follow through with next steps, and experienced a lengthy diagnostic process. Black families specifically described a power differential between providers and themselves and expressed that culture was not addressed during the diagnostic process.

Main Findings

Lack of racial differences in satisfaction.

The impact of socioeconomic factors on satisfaction. We did not identify racial differences in satisfaction with wait times, providers, the information provided, or the total satisfaction score. Additionally, race did not interact with institutionalized racism proxy variables to predict satisfaction with the diagnostic process. Therefore, in our study, the impact of socioeconomic factors did not differentially impact Black versus White caregivers. Rather, in fully adjusted models, neighborhood-level educational opportunities on the childhood opportunity index (COI), which measures factors such as the quality of early childhood centers, years of teacher experience, and high school completion rate, were associated with satisfaction with providers and the information provided. Median income was associated with satisfaction with wait times. Our findings parallel previous research suggesting the SES of families is positively associated with satisfaction with the diagnostic process (McCrimmon & Gray, 2021). Perhaps families of higher SES had primary care providers who were more responsive to their concerns and referred them for a developmental evaluation earlier. Additionally, families of higher SES may have already completed other evaluations (e.g., speech language, occupational therapy, physical therapy) and/or enrolled their children in therapeutic services and were, therefore, less impacted by waiting for the official diagnosis (Irvin et al., 2012; Nguyen et al., 2016).

Regarding providers and the information provided, families in neighborhoods with higher educational opportunities had higher quality and a greater number of early childhood centers. Early childhood centers in well-resourced areas may have facilitated the diagnostic process and supported families with obtaining in-school services and pursuing other supports and services for their children. This could result in caregivers already being knowledgeable about the information provided to them following their child’s diagnostic evaluation. Further, the quality of in-school services may be higher in areas of greater educational opportunities on the COI. As such, families may be more satisfied with their children's in-school service support and subsequently reflect more positively on their experiences with the diagnostic process.

The association between SES factors and satisfaction highlights that systemic inequality, which drives SES disparities, negatively impacts the diagnostic experiences of families of lower SES and those who live in socially vulnerable areas. However, effect sizes were small in the current study.

Examining lack of racial differences in satisfaction. As described above, we did not identify racial differences in families' satisfaction with the diagnostic process. A lower percentage of White families were satisfied or very satisfied with wait times and the information provided, but this was not statistically significant. Only two previous studies have examined the association between race or ethnicity and satisfaction with the diagnostic process. One study conducted in the U.S. did not identify racial and ethnic differences in overall satisfaction (Jashar et al., 2019). However, racially and ethnically minoritized families were less likely to report that the diagnostic visits met their evaluation and recommendation needs. In this study, approximately 76% of participants were White, and researchers combined the experiences of different racially and ethnically minoritized groups (Jashar et al., 2019). The other study was conducted in New Zealand and did not identify differences between the satisfaction of New Zealand European families compared to Māori and Pacific Islander families (Eggleston et al., 2019). In Eggleston et al., only 10% of families identified as Māori or Pacific Islander (2019). Therefore, with limited existing research, we are unable to form conclusions about the association between race and satisfaction with the diagnostic process across studies.

Still, we were surprised that satisfaction was not lower for Black families than White families, given the large racial disparities in the quality of care for racially and ethnically minoritized children (Drahota et al., 2020; Fiscella & Sanders, 2016). In previous qualitative studies, Black caregivers have reported negative experiences with the diagnostic process that may parallel negative experiences of White families (e.g., long wait times, minimization of concerns, communication challenges); however, Black caregivers have also described experiencing discrimination during the diagnostic process (Dababnah et al., 2018; Lovelace et al., 2018; Stahmer et al., 2019; Weitlauf et al., 2023) and have expressed that cultural differences between providers and caregivers negatively impacted their experiences (Pearson et al., 2020; Stahmer et al., 2019; Weitlauf et al., 2023). In a national survey of caregivers of children with developmental disabilities, Black caregivers were less likely than White caregivers to report their child's healthcare provider listened carefully to them, engaged in collaborative care, spent enough time with them, and were sensitive to their family's values and customs (Magaña et al., 2015). Other studies have identified Black caregivers of children with ASD are less satisfied with their child's care in comparison to White families (Colic et al. 2022; Zeleke et al., 2019). Previous research suggests that Black caregivers are also more likely to experience barriers that impact the diagnostic process, including lower levels of insurance coverage (Flores & Lin, 2013; Soylu et al., 2018), problems finding specialty care providers (Flores & Lin, 2013), and limited time with the child's primary care provider (Alberto et al., 2019; Flores & Lin, 2013). In addition, Black children are also diagnosed later (Baio et al., 2018), underdiagnosed (CDC, 2023), and sometimes misdiagnosed (Mandell et al., 2007; Weitlauf et al., 2023).

Some Black families did express dissatisfaction with the diagnostic process, which may reflect our efforts to build trust and rapport with participants. However, the number of Black caregivers expressing discontent was small. One explanation for the findings in the current study is that Black families may have been hesitant to be forthright in their responses. Many Black families do not trust researchers and medical providers, due to exploitation and mistreatment by researchers and the healthcare system (Gluck et al., 2018; Scharff et al., 2010; Tamlyn et al., 2023; Williams et al., 2013). For the current study in particular, Black families may worry that responding negatively to survey questions about their experiences with the diagnostic process may lead to retaliation against them or influence their children's care (De Brún et al., 2017; Nooruddin et al., 2020; Smith & Fortunato, 2008; Williams et al. 2013).

Previous research has demonstrated establishing personal relationships with minoritized families before and during the research process can foster trust, which leads to a greater willingness to engage in challenging conversations (Antoine-LaVigne et al., 2023; Gluck et al., 2018; Shaw et al., 2009; Tamlyn et al., 2023). Though a diverse team of researchers, including two Black caregivers of children with ASD, recruited families in the present study, we did not establish relationships with participants before asking them personal questions about their experiences with their children's care. We also recruited families from an academic medical center, which could have reduced trust in the research study. Caregivers may see researchers as representing the healthcare institution that they distrust (Sankaré et al., 2015).

Another possibility is that families who had negative experiences were less likely to respond to our survey (Fauth et al., 2013). Families may be less willing to re-engage with an institution with which they had negative experiences. Again, this may be particularly true for Black families, who have been exploited by research experiments and the healthcare system (Gluck et al., 2018; Shaia et al., 2020; Tamlyn et al., 2023).

Likely in combination with reduced trust, we may not have identified racial differences in satisfaction due to high levels of overall satisfaction with the diagnostic process. Cincinnati Children's has been consistently ranked one of the top three children's hospitals in the country by US News (Harder, 2023). In fact, Black families in our study compared the high quality of care they received at Cincinnati Children's to poorer care at other institutions. Additionally, between 2013 and 2015, the division underwent significant quality improvement efforts to reduce wait times and increase access for children under the age of 3 undergoing an ASD evaluation (Williams-Arya et al., 2019). These efforts reduced the total cost of the evaluation and mean wait time from referral to diagnosis from 139 days to 29 days, improvements that were maintained over the following 2 years. Therefore, the division's efforts to improve the diagnostic process may have contributed to increased satisfaction across racial groups in our study. Furthermore, Cincinnati Children's is a large well-resourced hospital. Families can receive follow-up care for their child (e.g., speech therapy) at the diagnosing institution, which may have facilitated connection to services, leading families to feel more positive about their providers and the information they received about supports and services.

In previous studies, the age of ASD diagnosis predicted satisfaction with the diagnostic process (Guillon et al., 2022; Sansosti et al., 2012) and perceived support with their child's diagnosis (Tait et al., 2016). In the current study, we may not have identified racial differences in families' experiences in part because there was no difference between the age at evaluation among Black relative to White children.

Further, our study focused only on the developmental evaluation itself. Much of the dissatisfaction about providers described in previous studies is related to how primary care providers responded to caregivers' concerns about their children's behaviors or development (Boshoff et al., 2016; Crane et al., 2016; Guillon et al., 2022; Hidalgo et al., 2015; Ryan & Salisbury, 2012; Sansosti et al., 2012). Families have described feeling dismissed or unheard, which delayed referrals for a developmental evaluation. Across racial groups, caregivers may be more satisfied with their developmental evaluation providers, who have specialized training in diagnosing ASD, as opposed to their primary care providers, who families and providers themselves have described as having less knowledge about ASD (Fisher et al., 2022; McCormack et al., 2021).

Lack of racial differences in service utilization

The impact of socioeconomic factors on service utilization. Median income in fully adjusted models predicted therapeutic service utilization, which parallels findings in previous studies (Lee McIntyre & Zemantic, 2017; Singh & Bunyak, 2019). Lower family income can directly impact service use through financial barriers but can also be a proxy for other factors that may impede service use, such as inflexible work schedules, lack of childcare, limited insurance coverage, and significant family stressors (Singh & Bunyak, 2019). Notably, though median income significantly differed across race, race did not predict service use in the current study. Moreover, the impact of socioeconomic factors did not impact Black caregivers more than White caregivers regarding service use. The impact of socioeconomic factors on both satisfaction and service use was small and may not be clinically meaningful. The limited impact of SES and vulnerability on our outcome variables may be due to our use of broad neighborhood-level SES variables. Future studies can examine more proximal consequences of structural inequality such as social capital or the underlying causes of disparate healthcare access (e.g., health literacy, knowledge of available services, transportation; Henning-Smith et al., 2013; Pickard & Ingersoll, 2015; Stormacq et al., 2019). Examining the impact of these factors and their intersection with race can provide us with a more comprehensive understanding of the impact of socioeconomic factors and institutionalized racism on service use (Adkins-Jackson et al., 2021)

Examining lack of racial differences in service utilization. The lack of racial differences in service utilization conflicts with previous research indicating that Black children enter into services later and use fewer services than White families (Bilaver & Havlicek, 2019; Bilaver et al., 2021; Yingling & Bell, 2019). Previous studies have identified that in comparison to White children, racially and ethnically minoritized children are less likely to use outpatient services (Bilaver & Havlicek, 2019; Bilaver et al., 2021), specialty services (Broder-Fingert et al., 2013) and publicly funded community interventions such as early intervention and ABA (Zuckerman et al., 2017). This was particularly surprising as Black families in our study had greater levels of social vulnerability and lower household incomes on average, with medium to large effect sizes. Therefore, Black families may have had to overcome additional barriers compared to White families to access similar levels of services.

As described above, families may receive services at the diagnosing institution, potentially reducing the impact of structural inequality on families' service utilization. In our study, nearly three-quarters of all Black families used public insurance in comparison to 40% of White families. Policies and practices, such as Home and Community Behavioral Health Service waivers, which cover in-home and outpatient services for children with disabilities, and Medicaid expansion, may have supported service utilization for families with public insurance (Griffith et al., 2017; LaClair et al., 2019; Velott et al., 2015). In fact, a recent national study found that having public insurance was associated with a large reduction in unmet needs for children with complex behavioral health needs (Graaf & Snowden, 2020).

Furthermore, across racial groups, families were satisfied with the information they were provided, which may support greater service utilization among all families in our sample. A previous study described that caregiver knowledge of services partially mediated the association between SES and service use (Pickard & Ingersoll, 2015), suggesting that increased awareness may mitigate some barriers to service use. Similarly, the high level of global satisfaction with the diagnostic process may have contributed to greater rates of service utilization among Black children, as we identified a significant positive association between satisfaction and service use among Black families. In our study, approximately 50% of families were evaluated before age 3 and 70% before age 4, which may have also promoted greater service use. Early diagnosis increases entry into early intervention and early childhood education, during which providers can facilitate connection to other needed services (Zuckerman et al., 2017). Additionally, we assessed for service utilization, on average, 4 years after the diagnostic process, giving ample time for all families to access needed services.

Race moderated the association between satisfaction with the diagnostic process and service utilization

We identified that race moderated the association between satisfaction with the diagnostic process and service use, such that greater satisfaction was associated with greater community resource and therapy service use among Black, but not White, families. Therefore, satisfaction may be particularly important for Black families, who have been mistreated by the healthcare system and frequently face discrimination in their everyday lives and by healthcare providers (Bey et al., 2019; Bleich et al., 2019; Maina et al., 2018). Positive healthcare experiences can facilitate trust in providers and their recommendations, particularly during an emotionally laden and challenging time for caregivers (Abel & Efird, 2013; Haywood et al., 2014). However, at all levels of satisfaction, service utilization did not differ between Black and White families. The lack of racial differences in service use across levels of satisfaction may be due to the small number of dissatisfied families in our study and the significant variation in service use among dissatisfied families. Therefore, moderation results should be interpreted cautiously. Future studies could examine whether results are replicated with a larger sample, including other variables that may also be important to service utilization, such as trust in the recommendations, transportation, and flexibility in caregivers' schedules (Henning-Smith et al., 2013; Pickard & Ingersoll, 2015; Stormacq et al., 2019). In a future study, we could explicitly ask caregivers if their experiences with the diagnostic process influenced their service utilization, which could provide us with greater insight into caregivers' perspectives.

Additional findings

Service utilization

Most families used 50% or fewer recommended therapeutic services. In total, families were recommended to pursue three or more types of therapeutic services. Low rates of service utilization may be at least in part related to how reports were written. Reports tend to be created off existing templates; therefore, some families may have been offered or recommended services that their child did not need or could be addressed at home or in school. Additionally, reports may include all services that *could be* helpful, which families can then prioritize based on their own goals, perceptions of need, time, and resources.

Families in the current study were more likely to prioritize speech and occupational therapy. Of those recommended group and behavior therapy, only 14% and 37%, respectively, used these services, and these services were used less often by Black relative to White families. For group therapy, Black children were less likely to use group therapy, regardless of whether they were provider- or self-referred. For behavior therapy, Black children who were recommended to participate in behavior therapy did so less often than White children. Black caregivers may have been satisfied with their children's behavior and peer social skill support in the school environment. It is also possible that Black families more frequently face systemic barriers to behavior and group therapy receipt, such as a lack of representation among participants in groups (Smith et al., 2020). Stigma against behavioral health services may also reduce behavior and group therapy use (Dababnah et al., 2018; Jon-Ubabuco & Dimmitt Champion, 2019).

Though most families were recommended to receive ABA, less than one-quarter of children, across racial groups, participated in ABA therapy. Rates of participation in our study are similar to those in previous studies (Lee McIntyre & Zemantic, 2017). Low rates of ABA utilization could be related to several factors including a low supply of certified providers (Zhang & Cummings, 2019), challenges with insurance coverage (Douglas et al., 2017), time and cost of ABA services (Singh & Bunyak, 2019), and negative opinions about ABA (Leaf et al., 2022).

Children were also recommended, on average, two or more community resources. Most families were recommended to pursue the Ohio Autism Scholarship and services through the board of developmental disabilities, and nearly all families were recommended to meet with a Cincinnati Children's social worker. Around half of the families reported accessing services through their county's board of developmental disabilities, whereas fewer than one-half reported accessing other community resources. Lower rates of community service use may be due to a lack of referrals, not qualifying for county disability services, and a lack of awareness about these resources (Todorow et al., 2018). Less than one-third of children used the Ohio Autism Scholarship, which subsidizes the cost of private special education dedicated to serving the unique needs of children with ASD, likely because they instead accessed school services through their local school district. Almost all families accessed in-school services through their child's local school district. This finding matches previous studies suggesting high rates of in-school service use (Lee McIntyre & Zemantic, 2017).

Although some children may not need *all* the services they were recommended, some children in our sample may not be receiving needed services. In a previous national study, approximately 25% of caregivers reported unmet need for one or more therapeutic services (Benevides et al., 2016), and approximately 20% described one or more unmet healthcare needs in general (Karpur et al., 2019). Unlike with previous studies, with our sample, we did not assess caregivers' perceptions of unmet needs. Future studies could assess perceived service needs from providers, caregivers, and based on standardized reports of the child's speech, activities of daily living, and behaviors to better understand service use and unmet needs in this population.

Qualitative feedback

Notably, a minority of participants were only slightly satisfied with the diagnostic process (11% wait times, 8% provider factors, 13% information provided), and some families were slightly to strongly dissatisfied with the wait times (11%), their providers (1%), and the information provided (8%). The specific concerns of these families are likely captured in qualitative themes, described below, as caregivers who provided comments tended to be more dissatisfied with the diagnostic process. Still, the mean difference in scores between those who provided qualitative responses and those who did not was less than one point for each satisfaction domain and the total score. Importantly, the average score among those who provided qualitative responses did not surpass 3.0, which corresponds to the Likert response "I was slightly satisfied." Also of note, many families who provided negatively coded comments "agreed" that they were satisfied with the diagnostic process on the Likert scale. Therefore, it is likely that the survey questions do not capture the nuanced experiences of families. Families may be more willing to provide constructive feedback when given the opportunity to comment, rather than "Agreeing" or "Disagreeing" with a statement.

Themes and clinical implications

Qualitative themes regarding the diagnostic process were not representative of all participants' experiences. Still, it is important to consider the clinical implications of identified themes, especially as most themes were described by both racial groups.

Provider factors

Though some families reported that providers used accessible and thorough communication, others described they did not understand all evaluation procedures. Caregivers in previous studies have indicated providers' use of medical and technical jargon impeded their understanding of the diagnosis (Blanche et al., 2015; Coffield et al., 2021; Jegatheesan, 2009). Additionally, in one study, Latinx caregivers described feeling concerned that the evaluation was based largely on the caregivers' report, suggesting a mismatch between caregivers' expectations and the evaluation procedures (Coffield et al., 2021).

In the current study, some caregivers felt their concerns were heard and respected, while others felt providers did not listen to their concerns. Likely, as a result, some caregivers questioned the accuracy of their child's diagnosis. To ameliorate communication challenges, providers should validate and address caregivers' concerns in the context of the diagnostic process. Providers can receive additional training in patient- and family-centered care, which involves partnering with patients to ensure they are involved in all aspects of their care and engaging in shared decision making tailored to patients' beliefs, preferences, and values (Goldfarb et al., 2017; Kouo et al., 2022). Education and interventions to promote patient- and family-centered care have been effective in improving families' satisfaction with care and healthcare knowledge (Gallo et al., 2015; Goldfarb et al., 2017). In addition, employing a "teach back" method, in which the caregiver is prompted to 'teach-back' to a provider the information conveyed, can improve communication between providers and caregivers and help align understanding and expectations (Griffey et al., 2015).

Although some caregivers felt emotionally supported by providers, other caregivers indicated they felt alone in processing the diagnosis and described a lack of emotional support, paralleling previous research (Carlsson et al., 2016). In previous studies, caregivers have expressed that the diagnostic process is an emotionally overwhelming and challenging experience (Boshoff et al., 2016; Coffield et al., 2021), underscoring the importance of emotional support from providers. Providers can also connect families with peers, who have shared experiences and can support one another in processing the diagnosis (Makino et al., 2021).

In the current study, Black families reported a power differential between themselves and providers. Providers are inherently in a position of authority in their role as healthcare providers, who are responsible for promoting the health and well-being of children. This power differential is intensified for marginalized families, especially Black families, who face structural barriers to accessing healthcare, personally mediated racism in their everyday lives and interactions with healthcare providers, and a lack of cultural matching with healthcare providers (Benuto et al., 2020; Fiscella & Sanders, 2016; Salsberg et al., 2021; Serchen et al., 2020).

Black caregivers also expressed that culture was not addressed during the diagnostic process. A few of these families indicated that they were treated like all other patients in DDBP, and one caregiver described that it was important for providers to address culture in the diagnostic process. Previous research suggests that culturally responsive care is positively associated with families' healthcare experiences, and addressing culture in healthcare interactions improves health outcomes and reduces health disparities (Alizadeh & Chavan, 2016; Curtis et al., 2019). Education on cultural humility should be incorporated into all levels of providers' training (Luquis & Pérez, 2021). Providers need to educate themselves on anti-racism and social justice to bring awareness to their implicit and explicit biases, as well as the impact of institutionalized racism on healthcare access and delivery (Valdez, 2020). In addition, to increase caregivers' voice in healthcare interactions, shared decision making tools should be used throughout the process (Sheldrick et al., 2019). Caregivers need greater opportunities for provider-caregiver cultural matching by increasing diversity in the healthcare field. Healthcare organizations can implement diversity, equity, and inclusion initiatives to increase mentorship, hiring, and retention of racially and ethnically minoritized individuals. However, systemic changes are also needed to improve the accessibility of education and training for students of color (Aylward et al., 2021).

Information provided

Likert scale responses suggest most families were satisfied with the information they received. Families who were dissatisfied indicated they needed more guidance and direction on next steps, received an overwhelming amount of information that was difficult to process, and received information that was not tailored to their child or was outdated. This adds to previous research suggesting the importance of support, guidance, and future planning to caregivers (Keenan et al., 2010) and that families need more tailored information about supports and services (Carlsson et al., 2016; Hennel et al., 2016; Moh & Magiati, 2012).

For families who need additional support processing the diagnosis or identifying next steps, a follow-up appointment could be offered, which would allow families to ask additional questions and refine future planning (Carlsson et al., 2016). In addition, family navigators, who are family members of children with ASD, can support caregivers through the diagnostic process by helping them identify and address barriers to care, supporting families' understanding of assessment results, and facilitating connection to resources and services (Feinberg et al., 2016). Family navigation services using cultural matching have been shown to reduce disparities and improve family satisfaction with the diagnostic process (DiGuiseppi et al., 2020; Feinberg et al., 2016; Feinberg et al., 2021; Iadarola et al., 2020). In addition to family navigator services, providers can review the assessment results and emphasize the need for resources and services in a way that is culturally responsive, accessible for families, and devoid of medical or technical jargon (Zuckerman et al., 2014). Caregivers' responses to needs assessment tools can also be used to guide clinical care. One such tool is the Family-Centered Autism Navigation interview, which assesses if families understand their child's diagnosis, experience barriers to service use, know which next steps to take, feel confident in advocating for their child, and know other families with the same diagnosis (Pizur-Barnekow et al., 2021).

Wait Times

Approximately 20% of families were dissatisfied with wait times. In their qualitative comments, families described that the diagnostic process was lengthy and emotionally challenging, and some Black families indicated that the process delayed service receipt. Previous quantitative studies have reported that families wait anywhere from 8 months to over 2 years from the age at which they first bring up concerns to their child's primary care provider to when their child is diagnosed (Becerra-Culqui et al., 2018; Moh & Magiati, 2012; Sansosti et al., 2012; Zuckerman et al., 2017). There is a dearth of providers who can diagnose ASD, leading to long waiting lists (Aylward et al., 2021; Broder-Fingert et al., 2020; Drahota et al., 2020). One solution to the lack of specialty care providers is the Project Extension for Community Healthcare Outcomes (ECHO) framework. The ECHO framework was developed to connect providers in service deserts to interdisciplinary teams of experts in ASD to increase local providers' knowledge of ASD and provide collaborative guided practice (Mazurek et al., 2017). This framework has been used to allow primary care providers to diagnose children with ASD (Mazurek et al., 2019). Psychologists can also be integrated into primary care practice to assist with the screening and identification of ASD to ameliorate practical barriers, improve ease, and reduce wait times for a developmental evaluation (Hine et al., 2020). In conjunction with the solutions described above, telehealth assessment can be leveraged for developmental evaluations to reduce practical barriers and wait times (Alfuraydan et al., 2020; Bridgemohan et al., 2018).

Limitations

This study should be interpreted within the context of its limitations.

Limitations to the survey and variables collected

Though we developed the survey through an iterative process that included participants in the diagnostic process (e.g., psychologists, speech pathologists, families), we did not engage in a formal cognitive validation, which may impact the validity and comprehensibility of the survey. In the MG-CFA, some of the fit parameters (e.g., RMSEA, CFI) for Black participants were slightly below the "acceptable" range, likely related to the small sample size ($n = 50$). In a recent systematic review, researchers suggested using a sample size of 120 for a three-factor model, though the needed sample size may be reduced for surveys with strong factor loadings such as ours (Wolf et al., 2013). The sample size is particularly impactful for the RMSEA value (Kenny et al., 2015), which in our models was only acceptable when examining the entire sample. In fact, Kenny et al. found that the RMSEA value often falsely indicated a poor fitting model when the degrees of freedom ($df = 41$ in our sample) and sample size are small (2015).

Sample size impacts the CFI less; across Black participants, the CFI was .81, suggesting a lower fit in comparison to the survey fit for White participants. Positively, the factor loadings were high across the entire sample and by subgroups. We also demonstrated good evidence for metric invariance, suggesting we likely measured the same construct, satisfaction, across Black and White caregivers.

In addition to survey and demographic characteristics, we limited the number of questions on the satisfaction survey to reduce the burden of participation. For example, we only asked one question about families' culture: "My providers respected my cultural and family views." A large body of literature suggests cultural differences between Black and White families in the conceptualization of autism, their children's care, and treatment planning (Bazzano et al., 2012). Black families often report religious coping and beliefs that ASD is God's will or a blessing (Burkett et al., 2017; Llorens et al., 2015; Williams et al., 2019). Extended family members may also be involved in the child's care (Burkett et al., 2017; Stahmer et al., 2019), and some Black families prefer to include extended family members in the diagnostic process (Stahmer et al., 2019).

Previous studies have also described that different family members may have conflicting views of the child or disability in general, which may impact the diagnostic process (Llorens et al., 2015; Lovelace et al., 2018; Pearson & Meadan, 2018; Stahmer et al., 2019). Black families have highlighted the importance of providers respecting caregivers' beliefs, values, and parenting abilities (Pearson & Meadan, 2018; Stahmer et al., 2019). Though one family in the current study described the importance of providers addressing cultural conceptualizations of ASD, we did not specifically ask families about how providers did or did not address these cultural factors. We also did not explicitly ask about families' experiences of racism during the diagnostic process. Future studies that involve building personal relationships with marginalized families can better understand the impact of cultural differences and discrimination on families' experiences with the diagnostic process and subsequent service use.

Although no caregivers openly disagreed with the diagnosis, a few spontaneously described that they were concerned about the accuracy of the evaluation results. We did not explicitly ask caregivers about their acceptance of their child's ASD diagnosis, which may impact families' satisfaction with the diagnosis process. Previous studies suggest that acceptance of their child's diagnosis impacts knowledge of ASD-related services, service utilization, and caregiver and child outcomes (Da Paz et al., 2018; Di Renzo et al., 2020; Gordillo et al., 2020). Future studies could examine the interactions between race, culture, and acceptance on families' experiences and service utilization.

We did not require participants to provide qualitative responses to their survey questions, which contributed to a negative response bias in qualitative feedback. Previous studies have suggested participants are more willing to put forth additional time and effort when their experiences are negative (Poncheri et al., 2008; Zhou et al., 2017). This may also demonstrate a cognitive tendency in which families pay greater attention to and are more impacted by negative aspects of healthcare experiences (Poncheri et al., 2008). Future studies could ask participants to respond to the survey questions and provide feedback to researchers in semi-structured interviews to gain in-depth feedback from all participants. This could enhance our understanding of the specific behaviors of providers or aspects of the diagnostic process that improved or negatively impacted families' experiences.

Though our set of potential predictors was theory-driven, we used backward regression to examine the association between demographic and evaluation characteristics and satisfaction and service utilization. We only included variables in the models if they were significantly associated with our outcome variables (i.e., satisfaction, service use) for Black or White families. Therefore, we may have not included variables that are significant predictors when the full set of variables is included. In addition, backward elimination increases the likelihood of identifying spurious and non-meaningful findings (Smith, 2018). However, our findings match previous literature about the association between socioeconomic factors and satisfaction and service utilization (Eggleston et al., 2019; Hidalgo et al., 2015; Morin et al., 2022; Sansosti et al., 2012)

Limitations to sample

Almost half of the families whose children received an ASD diagnosis at Cincinnati Children's in 2018 participated in our survey. When comparing Black children whose caregivers participated to those who did not, we did not identify any differences in demographic (e.g., income, child age at evaluation) or evaluation characteristics (e.g., diagnoses received, cognitive score, recommendations). However, the average age at the time of the evaluation among Black children was around 3.5, which is younger than in previous studies and may have increased families' satisfaction with the process in the current study (Constantino et al., 2020).

We also identified that, proportionally, caregivers of Black children were more likely to participate than caregivers of White children. We made concerted efforts to recruit Black caregivers by 1) using accessible and transparent communication, 2) increasing the ease of participation (e.g., the survey could be completed in less than 15 minutes over the phone, text, or email), 3) varying the time and day in which we called, texted, and emailed participants, 4) building a diverse team of researchers to recruit Black participants, and 5) creating an introduction video to facilitate rapport and increase trust in our research study. Additionally, because we started our recruitment efforts by first contacting caregivers of color, we recruited Black caregivers over a longer duration.

Further, we did not recruit a representative sample of White participants. When comparing caregivers of White children who participated to those who did not, caregivers in our study had higher median incomes and lived in less socially vulnerable neighborhoods. Previous studies have suggested that greater socioeconomic status is associated with greater satisfaction with the diagnostic process and service utilization (Eggleston et al., 2019; Hidalgo et al., 2015; Morin et al., 2022; Sansosti et al., 2012); therefore, the satisfaction ratings and service use of White caregivers may be inflated in our study. Although families who participated did not differ on any other demographic or evaluation factors in comparison to those who did not participate, there may be other differences between participants and non-participants that drove these families' lack of participation (e.g., lack of trust in research, dissatisfaction with care, less engagement in services, using services at outside organizations, perceptions of disability).

Because we only recruited families of children who were ultimately diagnosed with ASD, we are also missing the perspective of families with children who were potentially misdiagnosed with a diagnosis other than ASD. However, we are likely capturing the perspectives of some caregivers of children who were misdiagnosed at a previous evaluation and given an ASD diagnosis at the 2018 evaluation. Several families in our study were evaluated and not diagnosed with ASD at Cincinnati Children's before 2018, and a few families described experiences of misdiagnosis at other institutions in their qualitative comments. We are also missing the perspective of families who did not engage in a developmental evaluation at all. Families who have had previous negative experiences with healthcare providers, stigma against developmental disabilities, or experience significant barriers to healthcare access may not seek out a developmental evaluation (Bleich et al., 2019; Paine et al., 2018). Therefore, we cannot understand racial differences in these families' experiences.

Additionally, we did not include families who were diagnosed at locations other than Cincinnati Children's, such as private practices and community mental health agencies, or families who were diagnosed by primary care providers. According to the National Survey of Children's Health, about 50% of children receive a diagnosis from a provider other than a psychologist, neurologist, or psychiatrist, with 21% receiving a diagnosis from their primary care provider (Emerson et al., 2016). As such, we are only including the perspectives of families diagnosed by a psychologist, neurologist, or developmental behavioral pediatrician whose role is to diagnose ASD. Families outside of Cincinnati Children's are more likely to be diagnosed by psychologists or pediatricians whose practice focuses on a broader range of conditions and presenting concerns. In future research, we can examine the experiences of children who were diagnosed in different locations by different specialty providers to determine how diagnostic practices impact satisfaction.

Though the study focused on the experiences of Black and White caregivers, we are missing the perspective of other racial and ethnic groups and linguistically diverse individuals. Finally, due to the small sample size, we were unable to examine differences in the experiences of families who identify as Black, bi-racial, and African. Colorism, experiences of discrimination and systematic racism against people with darker skin tones, is prevalent in everyday life and the healthcare system, which may impact families' experiences with the diagnostic process (Slaughter-Acey et al., 2019; Stamps et al., 2022). Further, caregivers who identify as African may have different experiences due to the intersection of their nationality, skin tone, race, and lived experiences (Asante et al., 2016).

Limitations to the findings

We did not examine the dose or timing of services; therefore, we do not know the impact of satisfaction on the number of hours in therapy or how quickly families entered into services following the diagnosis. We also did not assess the quality of care, which is disparate between Black and White families (Leigh et al., 2016; Magaña et al., 2015; Zeleke et al., 2019). We are limited by caregivers' retrospective reports of satisfaction and service utilization in the current study. As mentioned above, responses to the satisfaction survey in our study may be positively biased as families are far removed from their child's diagnostic process and have been engaged in several services. Similarly, families may have conflated their experiences with the diagnostic process with more recent healthcare experiences. We are also uncertain about the accuracy of caregivers' reports of their child's service engagement. Caregivers may not always understand the terminology used to describe treatments, which can impact their knowledge and recall of therapeutic services their child has received.

Future directions

Future research could interview *all* families or a representative subset of families in greater depth to better understand specific practices that enhanced or were detrimental to caregivers' satisfaction. Future research studies could also recruit families diagnosed in different locations (i.e., not just Cincinnati Children's) by engaging with community partners and forming relationships with caregivers to increase trust in research. In future studies, reciprocal relationships should be established with participants, such that participation benefits both the researcher and the "participants" (Ware & Myrick, 2023). For example, we could provide caregivers with information about ASD, supports, and services. We could also give *all* participants the opportunity to connect with Cincinnati Children's family navigators for support and to navigate current concerns. Finally, we could follow families prospectively through the diagnostic process to reduce recall bias.

Conclusion

We identified that standard practices at a large, well-resourced, highly rated children's hospital are effective and well-received by many, but not all families. It is likely that efforts made by the institution to reduce wait times and improve families' experiences were generally effective and benefitted a larger number of families. Notably, we did not identify racial differences in families' satisfaction with the diagnostic evaluation. We identified that race moderated the association between satisfaction and therapy use and satisfaction and community resource use, such that there was a significant positive association between satisfaction and service utilization for Black families. Some families provided negative qualitative feedback, which has important clinical implications. Embedding psychologists in primary care, training primary care providers to diagnose ASD, and implementing telehealth assessments can reduce wait times. Offering a second feedback session with families or connecting caregivers with family navigators can increase emotional support, support understanding of the diagnosis, and refine treatment planning.

Dissemination Plan

We first plan to disseminate the results of this project to our community partner, Autism and We, a nonprofit organization to support Black and Brown caregivers. We are working to format the presentation to be accessible and understandable to caregivers of differing health literacy. We will present results to the governing board of Autism and We for guidance in interpretation and suggestions for next steps. We have also contacted other community organizations, such as "Our Tribe," a grassroots initiative to support Black families of children with ASD and the Family Advisory Committee, which is comprised of family members of children with ASD and other developmental disabilities. After receiving feedback, we plan to present the results of the project to DDBP's Anti-Racism Committee, a committee dedicated to improving knowledge about health inequity and racism and promoting equitable healthcare practices within the division. We will then present the results to the division at large and the Ohio Psychological Association. We will engage in conversations with DDBP providers on ways to improve the diagnostic process for all families. We also plan to publish our findings in a research journal.

Appendix 1.

The first part of this questionnaire asks about your experiences with your child's ASD evaluation process in the Division of Developmental Behavioral Pediatrics (DDBP) at Cincinnati Children's. We want to know about your experiences from the time your child was referred to DDBP to when your child had the ASD evaluation.

My providers explained what to expect during the evaluation process.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I was satisfied with the amount of time between the referral to DDBP and my child's first ASD evaluation appointment.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I felt understood by the DDBP providers when I talked about my child.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

The DDBP providers respected and valued my opinions and point of view.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree

- Strongly disagree

The following questions ask about the appointment during which you and your provider talked about the findings from the evaluation(s) and your child's diagnosis of ASD. This appointment is called the "Information Sharing Session (ISS)."

I was satisfied with the amount of time between my child's first evaluation appointment and receiving the official diagnosis at the Information Sharing Session (ISS).

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I was satisfied with the recommendations, resources, and referrals I received.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I was satisfied with the amount of information I received about my child's diagnosis and potential next steps.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

[if they endorsed that they slightly disagreed to strongly disagreed that they were satisfied with the amount of information provided]
I received too much information about my child's diagnosis and potential next steps.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree

- Strongly disagree

[if they endorsed that they slightly disagreed to strongly disagreed that they were satisfied with the amount of information provided]
I did not receive enough information about my child's diagnosis and potential next steps.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I had the opportunity to ask questions about my child's diagnosis.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

My providers gave me enough guidance and resources to begin to understand my child's diagnosis.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

My providers gave me enough guidance and resources to get me started on next steps (e.g., school, therapy).

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

I felt emotionally supported by the provider(s) during the evaluation process.

- Strongly agree

- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

The provider(s) respected my cultural and family values.

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

After the Information Sharing Session (ISS), did you read or look through the written results (the reports)?

- Yes
- No

Please estimate the number of times you read through or looked at the written results (the reports).

- Once
- A few times
- Many times
- I still look at it frequently

I was satisfied with the written results from the evaluation (the reports).

- Strongly agree
- Agree
- Slightly agree
- Neither agree nor disagree
- Slightly disagree
- Disagree
- Strongly disagree

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