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Equity and Access to Care: Barriers to Diagnostic and Treatment Services for Black Families of Autistic Youth

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Equity and Access to Care: Barriers to Diagnostic and Treatment Services for Black Families of Autistic Youth

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Abstract

Numerous barriers to diagnostic and treatment access are present for families concerned their child might have autism spectrum disorder (ASD; e.g., long waitlists, limited specialized providers). However, Black families of autistic youth may experience additional racial barriers (e.g.., racial microaggressions, perceived stigma) due to the intersectionality of their child's disorder and their identity as Black Americans, a group that is systematically minoritized in the United States. Despite the importance of early identification and intervention, little research has documented how these barriers to treatment participation may impact perceived treatment effectiveness, treatment satisfaction, and stress among Black families of autistic youth. This proposed study explored the role race-related, structural, and practical barriers to treatment participation play in treatment effectiveness and satisfaction among Black families with autistic youth. Findings from this project will help contribute knowledge essential to creating a healthcare system that is responsive to minority groups and addresses the needs of the Black community.

Keywords: autism spectrum disorder, culture, barriers, treatment, Black families

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Barriers to Diagnostic and Treatment Services for Black Families of Children with Autism Spectrum Disorder

There are a number of barriers that are present for families concerned their child might have autism spectrum disorder (ASD), a neurodevelopmental disorder characterized by restricted interests, repetitive behaviors, and social communication deficits (APA, 2013). These barriers include limited providers trained in ASD diagnostics and treatment, long waitlists, and navigating the extensive list of recommended treatments often prescribed for autistic youth (e.g., social skills groups, physical therapy, speech and language therapy). However, [1]Black families of autistic youth may experience additional barriers (e.g.., racial microaggressions, perceived stigma) due to the intersectionality of their child's disorder and their identity as Black Americans, a group that is systematically minoritized in the United States (Lovelace et al., 2018; Stahmer et al., 2019). These barriers can cause delays in seeking an assessment, receiving an ASD diagnosis, and obtaining treatment. This lag is an urgent health crisis, as research reveals utilizing early intervention services is critical for optimal outcomes in autistic youth (Bruder, 2010; Irvin et al., 2012). At present, little research has documented how these barriers to treatment participation may impact Black families of autistic youth, thus preventing present barriers from being addressed and inadvertently perpetuating racial inequalities.

Once diagnosed, data has demonstrated equivalent prevalence rates of autism spectrum disorder (ASD) across various races and ethnicities (i.e., 1 in 36 children; Maenner et al., 2023); however, clear health care disparities arise for Black families when examining a) the age at which autistic youth receive a diagnosis, b) the length of time between symptom onset and when

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[1] *Note.* The term Black is used to represent participants in the study who self-identified as Black or originating from African descent. The terms Black, people of color, and marginalized groups are used interchangeably.

families receive services, and c) the quality of care received (Lovelace et al., 2018; Mandell et al., 2002). Indeed, Black autistic youth are diagnosed approximately two years later than the national average (i.e., 6 vs. 4 years of age), are often misdiagnosed before receiving an ASD diagnosis, and require more provider visits before receiving a diagnosis (Bruder, 2010; Constantino et al., 2020; Mandell et al., 2007; Sell et al., 2012; Yeargin-Allsopp et al., 2003).

Previous literature has attributed the disparities in diagnostic timing for Black families to differential diagnoses (Pearson, 2015). For example, Black autistic youth are often misdiagnosed with conduct disorder (a disruptive behavior disorder) or adjustment disorder (a traumatic stress disorder; Mandell et al., 2008) and are more likely to be labeled as having disruptive behaviors after receiving an ASD diagnosis (Gourdine & Algood, 2014). The latter suggests that clinicians may be more likely to overlook ASD in Black children, and less likely to recommend further evaluation for autism (Mandell et al., 2009). This delayed access to care for Black families is a major public health concern as early intervention is critical for obtaining optimal treatment outcomes in autistic youth (Bruder, 2010; Irvin et al., 2012), including improvements in disruptive behaviors, verbal communication skills, language development, IQ scores, peer interactions, and parental stress (Bondy & Frost, 1995; Horner et al., 2002; Koegel, 2000; Koegel et al., 2014; Lovaas, 1987; McEachin, 1993).

Once diagnosed, Black families are also at risk for receiving delayed access to treatment services (Burkett et al., 2015; Fisher et al., 2022; Mandell et al., 2007). One major explanation for the delay in accessing diagnostic and treatment services is that Black families of autistic youth report several barriers; these barriers include both practical barriers (e.g. treatment costs, geographical limitations) that can affect treatment participation among all ethnic groups and delay access to early intervention services (Fisher et al., 2022; Smith-Young et al., 2020;

Stahmer et al., 2019) as well as racial hindrances that are specific to groups often marginalized within society (e.g. racial microaggressions, stigma; Blanchett et al., 2009; Broder-Fingert et al., 2020; Gourdine et al., 2011; Khan & Mian, 2020; Lovelace et al., 2018; Pearson & Meadan, 2018; Pearson et al., 2019).

Practical barriers may include stressors and obstacles that compete with access to diagnostic and treatment services such as accessibility, family stress, time limitations, and financial constraints (Smith-Young et al., 2020; Stahmer et al., 2019). For instance, a qualitative study by Lovelace et al. (2018) focused on the experiences of Black mothers with autistic sons; one mother living in an urban area reported that "…They have nice programs but they're always in the suburbs, they're always far out. If you don't have a vehicle, you can't get to them." Likewise, in another study assessing perceptions of access to services among Black caregivers, participants who lived in southern rural areas endorsed challenges accessing services due to limited resources (Pearson & Meadan, 2018). Another key barrier in accessing diagnostic and treatment services is financial and time constraints. Working caregivers with less job flexibility may endorse increased challenges with bringing their child to autism-related services (Stahmer et al., 2019). In addition, families with lower incomes may have less insurance coverage, flexibility to take their child to and from appointments, psychoeducational resources, and financial means to pay for quality specialized care (Mackintosh et al., 2005; Pearson et al., 2020a; Zuckerman et al., 2013). Families also described facing service barriers such as long waitlists that may exacerbate delays in accessing diagnostic and treatment services (Smith-Young et al., 2020; Stahmer et al., 2019). Furthermore, families may face barriers as they navigate the fragmented autism treatment services available, again delaying service access (Brewer, 2018; Goin-Kochel et al., 2008).

Unfortunately, barriers are not limited to practical factors for Black families. Black families of autistic youth report experiencing unique racial barriers such as providers' lack of cultural humility, perceived stigma, and racial bias and discrimination (Blanchett et al., 2009; Broder-Fingert et al., 2020; Gourdine et al., 2011; Fisher et al., 2022; Lovelace et al., 2018; Pearson & Meadan, 2018). The pronounced disparities experienced by Black families of autistic youth may be further exacerbated by structural barriers in place that disproportionately impact people of color in America. Racial barriers often intersect with issues of poverty and equity and may be rooted in systemic racism – "systems that were created to support White families accessing care over people of color" (Broder-Fingert et al., 2020, p.1). Additionally, communities of color also display a long-standing mistrust of research, treatments, and providers due to the historical occurrences of manipulation, stereotyping, and racism encountered in the past (Gourdine et al., 2011).

To better understand the complex nature of cultural barriers faced by Black caregivers of autistic youth, qualitative studies have been used to assess the experiences of Black families seeking treatment services for their autistic child. Across a few qualitative studies, several key racial barriers have been implicated. For instance, Pearson and colleagues (2020a) found that parent denial and limited knowledge of ASD among caregivers and health care providers were common racial barriers that arose among their Black participants. Parental denial may be heightened by perceived stigma, including blame and perceptions from family members and other Black community members (Lovelace & Robertson, 2018; Pearson et al., 2020a; Stahmer et al., 2019). Further, another study indicated that the Black families they surveyed were more likely to believe that they did not need treatment services or professional help to improve mental health problems (Anglin et al., 2008). Black families of autistic youth were also more likely to report that they lacked the adequate knowledge and resources to advocate for their child (Fisher et al., 2022;

Lovelace et al., 2018; Pearson et al., 2020a; Stahmer et al., 2019). Nevertheless, some Black caregivers educated themselves independently about ASD and ASD treatment services so that they could better advocate for their child (Fisher et al., 2020; Pearson & Meadan, 2018).

Racial barriers have also arisen from racial divergence between providers and caregivers (Fisher et al., 2020; Liptak et al., 2008). In some instances, providers may display covert acts of racial discrimination that cause discomfort and hinder Black families from accessing timely diagnostic and treatment services. For example, providers may carry biases such as assuming caregivers are uneducated; consequently, providers then fail to adequately listen when parents state their concerns (Dababnah et al., 2018; Gourdine et al., 2011; Lovelace et al., 2018). In addition, Black families of autistic youth have reported feeling excluded from ASD treatment services and have described a sense of tokenism as they sought services and support (Lovelace et al., 2018). Due to disparities in representation of Black individuals in health care and psychology, culturally matching is not a common opportunity for Black families, even though it may increase healthcare utilization and quality of care for Black individuals (Cabral & Smith, 2011; Fisher et al., 2022; Khan & Mian, 2020; Salsberg et al., 2021; United States Census Bureau, 2015).

Understanding the role of racial and practical barriers to treatment participation is essential to better understand how culture uniquely impacts treatment quality, parental stress, and child outcomes among this group that is systemically marginalized by American society. Given that this study reported on Black families and ASD within this population, it must be noted that the Black community has endured a long history of prior misapplication and misuse of research to reinforce both negative stereotypes about their ethnic group and inequitable care (Kemet, 2019; Thompson et al., 2003). As Black families bear the challenges associated with navigating the health care system to seek services for their autistic child, they may be exposed to additional harms that increase risk for poor mental health outcomes (Murry et al., 2018; U.S. Department of Health and Human Services, 2001). While this is evident, it is important to acknowledge that there are many who are able to exhibit resiliency and maintain a healthy quality of life regardless of the continued barriers they face from a system that was not designed to address their needs (Brown, 2008).

Parents' roles include addressing a child's needs, nurturing their child to grow into the best versions of themselves, and instilling values in their child. While these tasks are already hard and often stressful for caregivers, many parents of autistic youth experience additional stress due to their child's issues with communication, adaptive functioning, disruptive behaviors, emotional reciprocity, need for sameness, and intellectual functioning (Baker-Ericzen et al., 2005; Hastings, 2003; Nik Adib et al., 2019). These additional concerns can interfere with family relationships and detract attention from other priorities; namely, this can precipitate stress proliferation, which can cause additional challenges in other areas of the family’s life including marital tensions and work difficulties (Benson, 2006; Gray, 1998; Iadarola et al., 2019).

Several research studies have demonstrated the pronounced psychological, physical, social, and financial stress caregivers of autistic youth face relative to caregivers of typically developing children, children with other developmental disabilities, and children with chronic conditions (Baker-Ericzen et al., 2005; Blacher & McIntyre, 2006; Hayes & Watson, 2013; Higgins et al., 2005; Nik Adib et al., 2019; Schieve et al., 2007; Sivberg et al., 2002; Weiss, 2002). Caregivers of autistic youth take on a crucial role in navigating the service delivery system to gain quality ASD services. For many caregivers, this is the first time they have had to take on such a huge role advocating for their child among different stakeholders and community members including school educators, therapy providers (e.g. occupational therapist, speech-language therapists, behavioral clinicians), and even family members and friends. While seeking treatment and diagnostic services can exert increasing demands on parents of autistic youth, these difficulties can be exacerbated when structural barriers are present. Moreover, cultural barriers (e.g., racial microaggressions, perceived stigma) can lead to lower treatment-seeking behaviors as well as depression symptoms (Bradford et al., 2009; Gourdine et al., 2011; Nadal et al., 2004). In fact, parental and community perceived stigma can negatively impact caregiver well-being and contribute toward additional parental stress, especially among historically marginalized racial groups (Ilias et al., 2016). Further, Black families may also face additional stressors, including fewer availability of resources, lower support, inequities rooted in structural racism, and racial microaggressions (Fisher et al., 2022; Fu et al. 2014; Kelly et al. 2013; Sue et al. 2008; Sue & Sue, 2013).

Unfortunately, there is limited research on Black families of autistic youth; this disparity in research is especially pronounced as it relates to perceived parental stress and well-being. One study conducted by Williams and colleagues (2018) found that Black families of autistic children in their sample endorsed greater amounts of stress when compared to Euro American families. Additional factors that contribute to parental stress for underrepresented families of autistic children include interference with family relationships and activities, misperceptions and community beliefs, racial/ethnic background acceptance, and parental experience navigating the healthcare system (Iadarola et al., 2019). The increased levels of stress may also impact Black families' treatment seeking behaviors, service engagement, and treatment quality (Gopalan et al., 2010). In fact, a previous study investigating the effectiveness of early teaching interventions for autistic youth demonstrated that greater parental stress impeded the effectiveness of the intervention (Osborne et al., 2008). Investigating parental experiences and barriers as it relates to seeking services for their child and engaging in treatment may potentially provide meaningful clinical implications and insight into enhancing parental experiences and child outcomes for Black families of autistic youth (Smith & Iadarola, 2015).

While preliminary research has identified a range of racial and practical barriers Black families of autistic youth encounter, few studies have prioritized investigating the ramifications of these barriers (e.g., parental stress, treatment effectiveness, treatment satisfaction) on families. Understanding the relation between barriers, parental stress, treatment effectiveness, and treatment satisfaction is obligatory to determine whether our current health care system is providing quality care to Black families of autistic youth. Beyond that, evaluating these factors will demonstrate how these variables may be interrelated and the possible mechanisms contributing to poorer quality care for Black families of autistic youth. Moreover, the findings from this study will educate providers and professionals on the experiences of Black families who utilize their services and highlight ways to meaningfully change our health care system to support Black families of autistic youth.

An emerging body of literature has begun to assess the treatment experience of Black families of autistic youth (Collins et al., 2006' Pearson et al.,2020b), most of which have utilized qualitative study designs. In a small qualitative study investigating parent and professional experiences supporting Black autistic youth, more than half of the parent participants expressed dissatisfaction with the treatment services they received (Pearson et al., 2020a). Pearson and colleagues (2020a) postulated that these feelings may be best explained by cultural discordance between families and the therapists providing the treatment services. Replicated evidence of dissatisfaction of treatment services among minority groups with and without children with special needs suggest minoritized families are more likely to express dissatisfaction with the care they received when family-centered care factors (e.g. trust, respect, listening, collaboration) were not taken into account (Ngui & Flores, 2006). In fact, prior research has indicated that Black families are less likely to receive family-centered care, which is delivered in a manner that establishes a collaborative effort between families and providers while considering the needs and values of the family (Hodgetts et al., 2013; Magana et al.,2015; Montes & Halterman, 2011). Family-centered care has been associated with greater caregiver satisfaction and decreased parental stress among families rather than using patient-centered care alone (Woodside et al., 2001). Collectively these prior findings suggest that promoting the use of family-centered treatments may contribute to bridging the health disparities gap for Black families (Magnusson & Mistry, 2017; Wagner et al.,2022).

In addition to lower utilization of family-centered care for Black families, the generalizability of treatments, assessments, and research remains a problem for groups that are systemically marginalized (Konkel, 2015; Reynolds & Suziki, 2012; Steinbrenner et al., 2022). Child psychological assessments and evidenced-based treatments are normed from predominantly White, non-Latinx families with high-incomes (Reynolds & Suziki, 2012). Homogenous samples are problematic as it adds to the worsening of health disparities between White families and non-White families (Konkel, 2015; Steinbrenner et al., 2022). Certainly, limiting samples to White participants can introduce biases and may contribute to the rise in misdiagnoses, lag in diagnostic times, and delay in access to timely appropriate treatment services for Black families of autistic youth (Reynolds & Suziki, 2012). Of note, treatment efficacy for one subculture does not equate to treatment efficacy among a separate subculture (Bernal & Scharrón-del-Río, 2001; Steinbrenner et al., 2022). Unfortunately, even with the vast literature on the effectiveness of treatments for ASD (e.g. Applied Behavioral Analysis, Early Start Denver Model), there is negligible evidence available on the effectiveness of interventions for Black families of autistic youth which perpetuates lack of treatment access (Smith et al., 2020; West et al., 2016).

In addition to concerns about treatment effectiveness for this population, research has also found that a larger proportion of Black families prematurely drop out of treatment (de Haan et al., 2018). Current ASD research that has successfully represented Black families has failed to examine potential factors that lead to lower retention and engagement for utilizing ASD treatment services. While some models have been created for Black families in mind to increase knowledge of ASD and greater levels of support with success (e.g., the Family Peer Advocate Model; Jamison et al., 2017), the vast majority of studies on treatments for autistic youth fail to even mention racial/ethnic demographic information making outcomes less meaningful and ignoring the unique needs and challenges often faced by families of color (Steinbrenner et al., 2022; Smith et al.,2020; Wong et al., 2014). Neglecting the cultural concerns of Black families of autistic youth and continuing to promote a Eurocentric mentality when treating Black families may lead to low treatment engagement, client discomfort and stress, and less favorable outcomes in mental or behavioral treatment services (Fisher et al., 2022; Huey & Polo 2008; McNeil et al., 2002).

Current Study

The current study will advance the state of science by providing Black parent perspectives of treatment effectiveness and satisfaction for the various treatment models utilized while trying to get services for their autistic child. Moreover, the results from this study contribute toward bridging the research-to-practice-gap for Black families whose voices are vastly underrepresented in autism research; this was done by highlighting the specific barriers and experiences of these families (both racial and practical). Moreover, findings from this study recognize the possible necessity of developing, implementing, and disseminating culturally-sensitive evidence-based interventions to increase engagement, satisfaction, and effectiveness for this population.

Despite important research initiatives that have attempted to identify barriers contributing to the disparities in diagnosis time and treatment access for families of autistic youth (Smith-Young et al., 2020; Stahmer et al., 2019), even fewer studies have assessed the impact of racial and practical barriers to treatment participation experienced by Black families. The current study aims to fill the knowledge gap by assessing both barrier types experienced by Black families during the diagnostic and treatment process, and will evaluate caregiver stress, caregiver-perceived treatment effectiveness, and caregiver satisfaction with the treatment services utilized.

The specific aims of the study are as follows:

1. To determine if practical and racial barriers to treatment participation experienced by Black families of autistic youth correlate with parental stress, treatment effectiveness, and treatment satisfaction.
    a. Hypothesis 1: Families who report greater barriers to treatment on racial and practical barriers will indicate greater parental stress, poorer treatment effectiveness ratings, and poorer satisfaction ratings (Pearson et al., 2020a; Smith-Young et al., 2020).
2. To determine if parental stress mediates the relation between barriers to treatment participation experienced by Black families of autistic youth and parental perceived treatment effectiveness and satisfaction.
    a. Hypothesis 2: Families’ stress levels will mediate the relation between their reported barriers to treatment participation and both parental perceptions of

        treatment effectiveness and satisfaction (Iadarola et al., 2019; Osborne et al., 2008).

3. To gain additional insight and recommendations for improving service delivery into the experiences of Black families of autistic youth while obtaining a diagnosis, accessing services, and engaging in treatment.
    a. Hypothesis 3: Families will report both structural and racial barriers, how barriers impacted their stress, their perceptions of treatment effectiveness, and their level of satisfaction with services during qualitative interviews (Pearson & Meadan, 2018; Stahmer et al., 2019).
4. Exploratory aim: To evaluate if treatment effectiveness ratings and treatment satisfaction ratings differ significantly across multiple evidence-based treatment services for ASD.

Method

Participants

The study recruited Black caregivers of autistic youth ($N = 101$; determined by an a priori analysis, correlational analysis, using G* Power: alpha $p < .05$, power $\beta = 0.8$, and effect size Cohen's $d = 0.3$). For the qualitative portion of the study, semi-structured interviews were conducted during a follow-up with a portion of the sample ($n = 20$). After receiving Institutional Review Board approval, families were recruited through the Simon Foundation's Powering Autism Research (SPARK) database (SPARK Consortium, 2018). SPARK partners with over 30 academic medicine and autism research centers across the United States to identify families of autistic youth and advance foundational research on ASD. The SPARK team invited parents/caregivers of autistic children/dependents who met the following inclusionary criteria: a) a parent or guardian of a child between 10 months old to 20 years, b) The caregiver or child/dependent must have identified as Black or African American, and c) the child must have a diagnosis of ASD and be previously registered through SPARK. For cases of multiplex families, one child/dependent was randomly selected. SPARK sent an invitation email to 562 eligible families that fit the inclusion criteria. Out of those invited, 111 consented to participate in the survey, and 78 consented to participate in the interview. When SPARK reached 101 completed surveys, they deactivated the surveys and turned off reminder emails so no one new would be able to complete the surveys. Parents/caregivers who completed the study surveys were given the option to participate in a follow-up online/phone interview. Once families consented to participate in the interviews, their contact information was shared with the study team via the secure Research Match/Tempus portal. Once 20 interviews were completed, interviews concluded. Families were recruited across the Midwest, Southern, Western, and Northeastern United States. Caregivers who did not speak, write, or comprehend English were excluded from this study. Caregivers completed the consent process prior to being enrolled in and participating in the study.

Procedures

Caregivers completed a battery of questions to assess demographic information, parental stress, racial and practical barriers to treatment participation, treatment utilization history, treatment effectiveness, and treatment satisfaction. Families were recruited by SPARK through email. Interested participants clicked a link which directed them to the study consent and survey via an internal, secure SPARK website. Average survey duration was 30 minutes. All participants were confirmed for meeting the inclusionary criteria. Once all survey respondents were collected, researchers in the present study then received the deidentified data from the SPARK research team. All families who completed the questionnaire were emailed a $75 Amazon gift card from SPARK.

At the end of the survey, participants were asked if they were interested in being contacted for a follow-up, semi-structured interview over the phone or online. Interested families completed an online authorization form and their contact information was shared with the study team via a secure portal. Twenty caregivers were randomly selected to participate in the interview. Interviews were conducted using Cisco Webex software and recorded and transcribed verbatim for data analysis procedures. Verbal informed consent was obtained from each participant and each confirmed that they were in a safe, secure location before beginning their interview. Average interview duration was 40 minutes. All families who participated in the interview were given a $50 electronic Amazon gift card from SPARK.

Measures

Copies of measures and the qualitative interview guide are available for review (see Appendix A-G).

The Family Background Questionnaire was derived from a similar study assessing barriers among African American families of autistic youth (Pearson & Meadan, 2018). The questionnaire was slightly adapted for the present study to include additional questions pertaining to the child (see Appendix A). The questionnaire includes items such as parent's age, gender, marital status, level of education, and family income. The questionnaire also includes items regarding the child, such as child age, age of diagnosis, who diagnosed the child with autism, child gender, and the total number of children in the household.

The Barriers to Treatment Participation Scale-Expectancies (BTPS) is a measure used to assess individuals' or caregivers' barriers when seeking and accessing mental health services

(Kazdin et al., 1997). This 44-item measure uses a 5-point Likert scale ranging from *Never a problem* (0) to *Very often a problem* (5). The BTPS has adequate psychometric properties with an internal consistency reliability score of 0.86 (Kazdin et al., 1997). The scale's items and instructions were slightly modified to evaluate for current rather than expected experiences (see Appendix B). The BTPS includes four subscales: Stressors and Obstacles that Compete with Treatment (20 items), Treatment Demands and Issues (10 items), Perceived Irrelevance of Treatment (8 items), and Problematic Relationship with the Therapist (6 items). The summation of scores represents the total set of practical barriers to treatment participation. The second section of the measure (i.e., the Critical Events Scale) was omitted for this study as it has not been normed.

The Racial Barriers to Treatment Participation Scale (RBTPS) was developed to assess racial barriers to treatment participation and to better serve the study population (see Appendix C). The racial barriers used in this scale were gathered from an in-depth literature review specific to barriers to treatment experienced by Black families and Black families of autistic youth (Blanchett et al., 2009; Broder-Fingert et al., 2020; Burkett et al., 2015; Cuccaro et al., 2007; Cuevas, 2013; Gourdine et al., 2011; Leong & Kalibatseva, 2011; Lovelace et al.,2018; Mandell et al., 2002, 2007, 2009; Pearson & Meadan, 2018; Pearson et al., 2019; Stahmer et al., 2019). These barriers were then translated into items for this scale (e.g., stigma, perceived microaggressions, denial, and culturally unresponsive treatment).

The items in the Racial Microaggression subscale in the CBTPS were derived from the Racial Microagressions in Counseling Scale. The measure has shown psychometric support with a reliability coefficient of 0.85 and was predictive of lower satisfaction ratings and health outcomes (Constantine, 2007). The second section of the measure (the Critical Events Scale) was omitted for this study. The Racial Barriers to Treatment Participation Scale consists of 29 items scored on a 5-point Likert scale (0 = *Totally Disagree*, to 5 = *Totally Agree*). The scale includes three subscales: Racial Microaggressions (10 items), Family and Community Beliefs (10 items), and Treatment (9 items). The following items were reverse coded (e.g. 11-12, 14-16, 21, 23-24, 26). The summation of scores represented the total set of racial barriers to treatment participation.

Parental stress was measured using the Parental Stress Scale (Berry & Jones, 1985). Previous studies have used this measure to assess parental stress for parents of children with and without clinical difficulties (see Appendix D). The Parental Stress Scale has shown adequate psychometric support with a reliability coefficient of .83. The 18-item scale assesses positive (e.g. personal growth, emotional benefits) and negative (e.g. demands, restrictions) components of parenthood. The scale was administered on a 5-point Likert scale (1 = *Strongly Disagree* to 5 = *Strongly Agree*). The following items were reverse coded (e.g. 1-2, 5-8, 17-18).

Parents reported on their overall perceptions of treatment efficacy for their autistic child using a 4-point Likert scale (1 = *Child improved dramatically* to 4 = *Child became worse*) in the Parent-Reported Treatment Efficacy Ratings Scale. This instrument development was based on a prior study investigating the effectiveness of treatments and therapies for autistic youth (Goin-Kochel et al., 2008). The questionnaire in the present study was modified to assess overall treatment efficacy among participants (see Appendix E). Due to the preliminary nature of this proposed project, additional components of the measure were used for exploratory analyses.

The questionnaire also included efficacy ratings for endorsed treatment services. The treatment services were listed in a close-ended format. They consisted of Applied Behavioral Analysis (ABA), Occupational Therapy, Physical Therapy, Behavioral Parent Training , Speech and Language Therapy, and an open-ended response option for families to indicate any other service not specified that they have received. The following services were used because they were the most commonly used treatment services for autistic youth indicated by prior literature (Goin-Kochel et al., 2008). Parent efficacy ratings for specific treatment services were scored on a 4-point Likert scale (1 = *Child improved dramatically* to 4 = *Child became worse*). The items were reverse coded so that greater treatment effectiveness scores were represented by higher numbers.

Parental perceived treatment satisfaction was measured on a 5-point Likert scale (1 = *Very Satisfied*, to 5 = *Very Dissatisfied*) in response to the question stem, 'Are you happy with the overall treatment services received by your child?' Due to the preliminary nature of this proposed project, additional components of the measure were used for exploratory analyses (see Appendix F).

The questionnaire also included treatment satisfaction ratings for endorsed treatment services. Treatment satisfaction ratings for specific treatment services were on a 5-point Likert scale (1 = *Very Dissatisfied*, to 5 = *Very Satisfied*) in response to the question stem, 'Are you happy with the treatment received by your child at…' followed by the specific services mentioned earlier (e.g., ABA, Speech and Language Therapy). The items were reverse coded so that greater treatment satisfaction scores were represented by higher numbers.

Following the initial assessment battery, families indicated their interest in being contacted for a qualitative interview. Semi-structured interviews were conducted during a follow-up with a portion of the sample (*n* = 20). The participants for this portion of the study were invited at random out of those who consented to be contacted. The interview questions asked about family experiences obtaining an initial ASD diagnosis, accessing treatment services, and families' recommendations to professionals to better serve Black children of autistic youth (e.g. 'What obstacles have you encountered while trying to get services?' 'Do you believe being Black has had an effect on your experience, and if so how?'). The interview included additional probes to be used by the interviewer based on the information the caregiver disclosed. The questions were based off of prior qualitative research assessing barriers experienced by Black families of autistic youth (Lovelace et al., 2018; Pearson & Meadan, 2018; Pearson et al., 2019; see Appendix G). Interviews were conducted using Cisco Webex software, recorded, and transcribed verbatim.

Analytic Strategy

The goals of Aim 1 were to determine if practical and racial barriers to treatment participation experienced by Black families of autistic youth correlated with parental stress, treatment effectiveness, and treatment satisfaction. Pearson correlations were calculated to examine the relations among practical barriers to treatment participation, racial barriers to treatment participation, parental stress, treatment effectiveness, and treatment satisfaction. Overall barriers to treatment participation were represented by the summation of the RBTPS and the BTPS scores. To interpret the correlations, the classification of the correlation coefficient *r*, according to Hinkle and colleagues (2003) was adopted. Further, multiple linear regression analyses were conducted to determine if practical and racial barriers to treatment participation predicted parental stress, treatment effectiveness, and treatment satisfaction. Family demographic variables were included (annual household income, caregiver highest level of education) as covariates.

The goal of Aim 2 was to determine if parental stress mediated the relation between barriers to treatment participation experienced by Black families of autistic youth and parental perceived treatment effectiveness and satisfaction. Mediation analyses were going to be conducted using the PROCESS function via SPSS statistical software, Version 24.0 (IBM Corp., Armonk, NY). The mediating role of parental stress was going to be tested in the following variable associations:

a. Practical barriers to treatment participation X treatment satisfaction
b. Practical barriers to treatment participation X treatment effectiveness
c. Racial barriers to treatment participation X treatment satisfaction
d. Racial barriers to treatment participation X treatment effectiveness

An error probability of $p < .05$ was planned to be used as the statistically significant level.

The goal of Aim 3 was to gain additional insight and recommendations for improving service delivery into the experiences of Black families of autistic youth while obtaining a diagnosis, accessing services, and engaging in treatment. An iterative approach was used to generate themes among the interview data. The coding system was developed by researchers using conventional content analysis to identify emergent themes throughout the interviews (Hsieh & Shannon, 2005). After multiple coordinated meetings to collaborate on the themes that emerged and eliminate redundant themes, a consensus was reached on the final coding scheme. The interviews were coded by two researchers using the final code scheme as a codebook, and reliability was assessed for at least 80% inter-coder percent agreement for 25% of the data. Intercoder agreement between two graduate researchers was 96.65%. The QSR N*Vivo 11 coding software was used to analyze the data throughout the coding process.

The goals of Aim 4 were to evaluate if treatment effectiveness ratings and treatment satisfaction ratings differ significantly across multiple evidence-based treatment services for autistic youth. Analyses conducted in Aim 4 were exploratory in nature. Frequency of treatment service use was reported. Due to the ordinal responses of the treatment effectiveness and satisfaction scales, and failing to meet assumptions for normal distribution, nonparametric tests (Wilcoxon Signed Rank Test) were conducted to compare reported treatment effectiveness and reported treatment satisfaction across endorsed treatment services.

Results

Data was analyzed using IBM SPSS Statistics. Demographics for caregivers and their children are presented in *Table 1*. Caregivers were largely mothers (91.1 %), of African-American origin. Income and educational level were fairly equally distributed. The mean age of the children was 9 years, and most were male (76.2%). The mean age of the caregivers was 39.5 with the youngest caregiver 22 years of age, and the oldest caregiver 64 years of age. Caregivers were married (55.4%), in a relationship with a partner (11.9%), divorced (10.9%), or single (19.8%). The families resided in urban (38.6%), rural (18.8%), and suburban (42.6%) areas with an average of 2 other kids living in the household.

Aim 1

The first aim of this study was to investigate the relationship between practical and racial barriers to treatment participation, parental stress, treatment effectiveness, and treatment satisfaction experienced by Black families of autistic children. Pearson correlations were calculated (Table 2). Means and standard deviations are presented in *Table 3*. The results of the Pearson correlation test showed that racial barriers to treatment was positively correlated with parental stress ($r = 0.388$, $p < .001$) and practical barriers to treatment ($r = 0.605$, $p < .001$), and negatively correlated with perceived treatment effectiveness ($r = -.217$, $p = .029$) and perceived treatment satisfaction ($r = -0.358$, $p < .001$). Results revealed that practical barriers to treatment was positively correlated with parental stress ($r = 0.560$, $p < .001$) and negatively correlated with perceived treatment effectiveness ($r = -.378, p < .001$) and perceived treatment satisfaction ($r = -0.418, p < .001$). Further, parental stress was negatively correlated with perceived treatment effectiveness ($r = -.215, p = .031$) and perceived treatment satisfaction ($r = -.251, p = .012$). Perceived treatment effectiveness and perceived treatment satisfaction were positively correlated ($r = 0.624, p < .001$).

All assumptions were met for the multiple regression analyses on parental stress, practical barriers to treatment, and racial barriers to treatment. The results of the regressions are summarized in *Table 4 and Table 5*. Findings indicated that the family demographic covariates did explain significant variance in parental stress (F (2, 97) = 7.410, $p = .001$). Controlling for caregiver educational level and family annual income, perceived practical barriers to treatment was found to be associated with parental stress, significantly accounting for 29% of the variance in parental stress, $R^2\Delta = 0.29$, $F\Delta(1, 96) = 48.248$, $p < .001$. The overall model accounted for 42.3% of the total variance in parental stress $F(3, 96) = 23.429$, $p < .001$. Similarly, controlling for caregiver educational level and family annual income, perceived racial barriers to treatment was found to be associated with parental stress, significantly accounting for 11% of the variance in parental stress, $R^2\Delta = 0.11$, $F\Delta(1, 96) = 13.952$, $p < .001$. The overall model accounted for 24.3% of the total variance in parental stress $F(3, 96) = 10.25$, $p < .001$.

Next, multiple regression analyses were conducted on racial barriers to treatment, practical barriers to treatment, treatment effectiveness, and treatment satisfaction. Our data was negatively skewed and kurtotic for treatment effectiveness and treatment satisfaction scores, indicating more positive reports of treatment effectiveness and satisfaction. The values for skewness and kurtosis between -2 and +2 were considered acceptable in order to prove normal distribution (George & Mallery, 2010). All of the skewness and kurtosis scores fell in between the accepted values. The Shapiro-Wilk test was significant ($p < .05$) suggesting that treatment effectiveness and satisfaction were not normally distributed. Additional visual inspections of histograms and normality plots further suggested nonnormality. Taken together, it was determined that the treatment effectiveness and satisfaction scores were not normally distributed. Therefore, transformation procedures were conducted. Overall treatment effectiveness and satisfaction scores were log transformed. The Shapiro-Wilk test was significant ($p < .05$), indicating no change in normality after long transformation. Due to the asymmetric spread of treatment effectiveness and treatment satisfaction scores, an ordinal regression analysis was conducted to investigate whether family factors (e.g. caregiver education level, family income), racial barriers, and practical barriers to treatment predicted treatment effectiveness and satisfaction. In the analyses, both the Pearson chi-square test, test of parallel lines, and the deviance test were non-significant, suggesting good model fit. Together, the predictors accounted for a significant amount of variance in perceived treatment effectiveness, likelihood ratio $\chi^2(4) = 18.282$, $p = .001$. Only practical barriers to treatment, $\beta = -.029$, SE = .010, $p = .003$, and caregiver education level, $\beta = .238$, SE = .116, $p = .041$, significantly independently predicted treatment effectiveness. This indicates that caregivers who experience a greater number of practical barriers are more likely to report reduced treatment effectiveness and caregivers who have a higher education level are more likely to report greater treatment effectiveness. When taken together, racial and practical barriers to treatment, caregiver education level, and family income accounted for a significant amount of variance in perceived treatment satisfaction, likelihood ratio $\chi^2(4) = 22.287$, $p < .001$. Only practical barriers to treatment, $\beta = -.020$, SE = .008, $p = .019$ significantly independently predicted treatment satisfaction. This indicates that caregivers who experience a greater number of practical barriers are more likely to report reduced treatment satisfaction. Results are shown in *Table 6.*

Aim 2

The second aim of this study was to assess if parental stress mediated the relation between barriers (practical and racial) to treatment participation experienced by Black families of autistic youth and parental perceived treatment effectiveness and satisfaction. As determined by previous analyses, all assumptions were not met to conduct a mediation analysis. Treatment effectiveness and satisfaction are not normally distributed. Therefore, a mediation analysis was not conducted at this time.

Aim 3

The goal of the third aim of this study was to gain additional insight into the experiences of Black families of autistic children as they navigated the diagnosis and treatment journey and to hear recommendations for improving service delivery for families. The qualitative results generally aligned with the findings from the quantitative findings. Three primary themes arose: a) Barriers, b) Facilitators, and c) Recommendations. Within these primary themes, additional subthemes emerged that further elucidated the experiences of Black caregivers of autistic youth as they navigated the diagnostic and treatment process (*Figure 1)*.

Barriers

Caregivers who provided their narrative identified several barriers that negatively impacted their overall experience, mental health, quality of care, and access to care. These barriers stemmed from 1) Caregivers, Family, and Community Members; 2) Systemic Sources, and 3) Providers and Professionals.

As a part of their lived experience obtaining an autism diagnosis and accessing treatment services, Black caregivers of autistic youth reported experiencing barriers within themselves as well as from family and community members. These barriers included a) denial, b) fear, c) mental health challenges, d) blame, e) poor knowledge about ASD, and f) lack of support. For many families, the first step in their journey was identifying that their child had autism. Many families indicated noticing signs of autism before receiving an evaluation, while others grappled with the diagnosis after receiving an evaluation. Denial was identified as an initial part of the process for many caregivers, and with denial, came ignoring, and for some, attempts to "fix" autism. One mother stated:

"I was not ready. I poured myself, for the next year, I poured myself into 'I'm going to fix him, I'm going to make him better'... I mean, I did everything. I took him back to that same clinic a year later, and I wanted them to test him again, and for them to tell me he was all better. And they tested him again, and they told me that he had made some progress, but he still had autism."

Although all of the caregivers who interviewed were mothers, they indicated that many of their child's fathers also had a hard time understanding the diagnosis. Many mothers attributed their partner's denial to wanting their child to be what they perceive as normal, and some even indicated receiving blame.

"I really got some typical feedback from his dad, like, 'There is nothing wrong with him.' I don't know why men do that…men typically are in denial more, a lot of time the mother gets blamed right, for those types of things."

Some caregivers who had older children even reported that the children themselves experienced denial when being told about their diagnosis. One mother with a daughter diagnosed later in life, indicated that her daughter chose not to identify as autistic:

"She doesn't want to be identified anymore now that she's older as being on the spectrum, so she spends a tremendous amount of energy masking. And so she doesn't want to socialize with other people with the diagnosis of autism or anything."

Upon receiving the diagnosis and coming to realization that they would be raising a child who must navigate a world that has historically discriminated against people of color and people with disabilities, many caregivers were stricken with fear. Caregivers in particular spoke about the realities of raising a Black autistic male, and fear surrounding potential interactions with police.

"I think even if your child doesn't have autism, just a male child who is Black or Hispanic or of any color, you are hypersensitive to the things that could go wrong. What occurs when your child is autistic there is fear that something will happen, and they won't understand him because he's autistic. His behavior will be misinterpreted and that can cause something bad. You know that's the biggest fear, especially with a male child."

In addition to experiencing denial and fear, caregivers identified that a significant obstacle in their journey to receiving a diagnosis was poor knowledge about autism. For caregivers, families, and community members, their knowledge of autism was associated with poor a prognosis, beliefs that autism is caused by bad parenting, vaccines, and so forth. For many families, autism was a relatively new or even an unknown diagnosis.

"When they finally said they believed that she had autism, she had gone through an intense evaluator process, with IQ tests and all kinds of testing, and she came out of it with a

diagnosis of autism, and it turned us inside out because... the diagnosis of autism is permanent. She didn't understand any of it, and I didn't want to explain it to her because I didn't understand it myself."

Poor knowledge about autism exacerbated community stigma and blame from family and community members. One mother described:

"Yes, the process was, it was awful for me, as a Black female. Taking my son to church, and having members of my church say, 'Nah, he's a bad kid.'... it was culturally hard, and you don't talk about these kinds of things you know in our community. And sometimes there are people that would say, 'don't get therapy' or 'we go pray about it, and God is going to take care of everything.' And then I had to break away from that and say, 'No God is giving me the resources.'"

In addition to coming to terms with a newly acquired diagnosis, some families reported experiencing several outside stressors (e.g., job displacement, family illness, personal illness, traumatic event, taking care of multiple children), which further hampered their experience navigating diagnostic and treatment services and their overall mental health. Throughout their journey, caregivers indicated experiencing anxiety, depression, and high amounts of stress. Many mothers shared the experience of feeling as if they were alone throughout this process, including feeling unsupported by family members and professionals. One mother stated:

"His father isn't a big help at all. He doesn't help at all... He was against me coming to therapy from the beginning, so is his mother too. So I faced a lot of adversity when it comes to getting help."

Many participants disclosed facing barriers that were closely tied to systemic forces that negatively impacted their experience navigating diagnostic and treatment services. For the purposes of this study, systemic barriers were characterized by factors, policies, and practices of the system as a whole (not tied to a particular individual) that resulted in unequal treatment or exclusion. These systemic barriers fell under the following themes: a) Black and White Disparities, b) Black Visibility, c) COVID-19, d) Geography, e) Hidden Support, f) Insurance and Finances, and e) Long Waitlists. More than half of the sample described that they experienced differential treatment compared to their White counterparts within the healthcare system. Caregivers indicated that white families had more access to quality resources. Further, Black caregivers felt that they had to advocate significantly more for their children than their white counterparts to be taken seriously. One mother indicated:

"It's really bad with our Black boys. And it's both frustrating, you know, that you always gotta have proof, you always gotta have paperwork. And cause we literally have white counterparts that we know whose kids are autistic too, and we'll just ask questions and they don't have to do the same thing… and you're like what, wait a minute, and that's when you realize it is race."

Race also impacted how families perceived the services and supports they interacted with, in particular, many families expressed feeling like the spaces they were in lacked Black visibility, including visibility of Black professionals, Black families, and Black autistic youth. In some cases, caregivers reported that the lack of representation made them feel tokenized and unsupported and that finding Black support groups was a huge challenge:

"My son was in a support group, and he was the only Black kid in the support group and we got him there because his therapist got us in there, but the only Black, or even child of color in the group. And he didn't have an issue with race or anything, but I asked if he was

comfortable, and he said ‘mmm not so much,’ and like why have him somewhere he’s uncomfortable.”

The effects of the COVID-19 pandemic further exacerbated the structural and systemic barriers that Black families faced, especially families navigating the health system. Nearly all caregivers discussed that the pandemic negatively impacted their access to services, mental health, financial resources, and child functioning. One mother shared:

“When we were in lockdown our services stopped. So, he wasn’t getting services through the district and he wasn’t getting the in-home services through our insurance. And just the pandemic itself increased his anxiety. We have yet to get that under control.”

Caregivers indicated that access to care was further impacted by geographical barriers, financial barriers, and long waitlists. Caregivers described that for services, one “downside is the distance.” Others stated that some services had waitlists up to 2 years long, and insurance and access to financial resources played a crucial role in their access to quality services. Service access was dependent on insurance types, child diagnoses, and state policies. One mother shared how the waitlist was substantially different when she switched insurance companies, and how having private insurance decreased access to some services:

“What I did find is when I’m on Medicaid and had public insurance, the doors open for him. He gets disability, he gets all the speech and OT therapies he needs. Verses when I’m with private, they don’t offer autism services and I have to pay out of pocket.”

While gathering the resources to best advocate for their child and provide them with the care and support they needed, some caregivers noted that there were many hidden supports within the system. Caregivers felt that families have the right to access these supports but that people may not know about them because they are not shared publicly.

"They don't know about the resources; they don't know that you can get free diapers for your child if they are not potty trained. I've told his doctors that he is not potty trained and not one of them have ever told me that he's able to receive training pants for free. I didn't know that, so that's something I had to go find out on my own, and that's something somebody in the medical field should definitely know."

Providers and professionals played a critical role into the experience of Black families as they navigated the diagnostic and treatment system. For some, providers and professionals acted as advocates. However, for many caregivers in the study's sample, barriers related to treatment from providers and professionals were the most impactful. These barriers fell under the following themes: a) Lack of Humility, Compassion, Patience, and Understanding; b) Poor Knowledge of Autism; c) Multiple Diagnoses; d) Multiple Providers; e) Racism and Microaggressions; f) Treatment Not Helpful; g) Assumptions; and h) Unfair Treatment from School. The most prevalent barrier that families experienced (as evidenced by how many times it was references during the interviews) was lack of humility, compassion, patience, and understanding from professionals. Caregivers discussed feeling unheard by professionals, invalidated, dismissed, and ultimately unseen.

"I tried to get social security for her and she was denied by that. The judge literally told me, 'it sounds like she just needs a spanking.' I couldn't believe it."

Additionally, when given the diagnosis, caregivers indicated that providers and professionals often times delivered the diagnosis without compassion, understanding, or empathy. One mother described:

"I received his diagnosis after two visits, and the doctor that diagnosed him was considered the Cadillac of doctors, very old-school, very prestigious doctor. But she has a child

on the autism spectrum. She gave us a folder, she said 'your son has autism, it's important to get him involved in ABA therapy and have conversations with the school…', I think because she was so experienced with giving a diagnosis, there was less of a lens of empathy and more of a lens of business."

Caregivers postulated that some of their negative interactions with providers and professionals were due to a lack of provider knowledge about autism. In some cases, caregivers indicated that they had to teach multiple providers and professionals about autism and their child's needs. In addition, some families received other diagnoses related to attention, behavior, and sensory dysfunction before getting an autism diagnosis. One caregiver shared not getting an autism diagnosis until her eighth appointment with providers:

"They diagnosed him with ADHD and they said 'do you want to give him Ritalin?' and I said 'he's two and a half there is no way. You people are crazy.' So then about a year later, the second time I went to [testing place], they did a whole bunch of testing and they said he has obsessive compulsive disorder, and telomere biology disorder, and auditory processing disorder and decoding issues and memory issues, all these things but never autism. So they kept him, and they did testing every year. On the eighth year, the final appointment, they discharge at 8, they said 'you don't want to give him medication for ADHD, he is going to be fine, he will probably be a rocket scientist or entrepreneur, he'll be fine.'

In addition to feeling a lack of compassion from professionals and providers, some caregivers reported experiencing blatant racism and racial microaggressions from the professionals they interacted with. One mother shared:

"When my son was 3, we were in a situation, for whatever reason I had to take him to the Social Security Office and I had to speak with one of their doctors, this old white man. This man,

he asked me how many children I had, I have 4, and then he asked me 'do all my kids have the same father?"

In addition, after receiving an autism diagnosis, caregivers also recounted that some professionals also made assumptions about their child based on their autism diagnosis, including assumptions about their abilities and cognitive skills. For instance, one mother recalled:

"She even called us in because she didn't believe me when I said how good he was doing, and his teacher got angry and she was like, 'okay but why won't you believe her, he is one of our best kids here, super smart.' And so after a few weeks she was just like, 'so he really is smart.' And she just didn't believe me, it was like she counted him out from day one basically."

Although most of the caregivers in the sample had positive experiences with the treatment services they used, some caregivers found that treatment was not helpful, which may or may not been influenced by the pandemic. One mother recalled her experience with ABA,

"I've only done ABA, but it happened during the COVID lockdown, so I don't think it that it's a fair representation of it; however, I really feel like it's ABA or nothing. Like that's what I really feel like. That's all you get. It was very intrusive to have someone at your home for 4 hours a day 5 days a week cuz they have a minimum…like on top of everything being too much, it's too much."

Nearly half of the caregivers discussed the impact of the school system, specifically unfair treatment by school professionals, negligence, and lack of preparation for college. One mother explained,

"Three study halls, they gave up on her… I think they push our kids through, and I think the kids who are children of color in this area, if they can't play sports and they have any kind of difficulties, they are just pushed through, just shoved right through…. Child cannot read, she's

21… they just blow them off and tell them any kind of stuff, they just wanna get them through as quietly as they can."

Facilitators

Caregivers also discussed facilitators that positively propelled their journey and increased their access to resources and support. Facilitators fell under the following themes: a) Acceptance, b) Advocacy, c) COVID-19, d) Peer and Community Support, e) Police Aids, f) Positive Experience with Treatment, and g) Prior Experience and Knowledge. Prior to accessing treatment services, one of the most influential facilitators was acceptance of the autism diagnosis from caregivers and family members. For many, their journey to finding quality services did not start until caregivers were able to transition from denial to acceptance. One mother indicated,

"But then for a long, many years, it's like okay I need my son to function outside in the world. I don't want no special treatment, no special nothing. And what I learned, and it took me years to learn this, that he was special needs. And once I accepted that… 'what did I do wrong, oh we should've never gotten the shots,' all those things, the blame, and trying to fix him, it kinda went out the window and I shifted to how do we function in his normal and not our normal."

Caregivers also reported that advocacy was a facilitator integral to receive care for their child across settings. Advocacy included gathering the knowledge, doing the research, asking the questions, being persistent with requests, having support from family members, advocating for other families with similar experiences, and having providers and professionals as advocates for their child. In many cases, without advocacy, caregivers reported that their child's needs were neglected. Learning to become a self-advocate and gaining support from providers and professionals were key advocacy methods to enhance the experience of Black families of autistic youth. One caregiver shared, *"I know the psychologist who diagnosed him, she was at one point, she was pushing, because like I said we started to notice some changes in his school behavior, and so she was like if you if you get push back, I would love to fight with you."*

For many caregivers, they were better able to advocate for their child when they were privy to previous knowledge about autism and the service systems from their professional experience, or experience learned from family members and peers. For instance, one mother stated:

"I have two people, one was actually my mother-in-law and the other was a close friend of the family, and they both ended up working with children who were autistic. And so they said, you might want to get him checked out."

In addition to having supportive advocates, families discussed that having peer and community support, specifically support from caregivers going through similar experiences and living in communities with autism-friendly and sensory-friendly facilities, was key.

"I am actually involved in my sorority and my sorority sisters are extremely helpful and supportive, and the current church I attend, they have a special needs ministry."

As mentioned previously, caregivers in this study reported fears regarding raising a Black autistic child and the potential risk of interacting with law enforcement officers. To mitigate their fears and prepare their child for interactions with police, caregivers discussed using aids. For instance, several caregivers discussed setting up meetings with local police officers, putting autism bumper stickers on their cars, or reviewing scripts with their children. One mother shared,

"Well, one of the first things we did is register with our local police department and fire department that [child's name] was on the spectrum. And in the beginning he did elope, so that also meant that they needed to be aware of him and who he was and how he is. There is also a

police officer who has a child on the spectrum and he does talks and trainings throughout our state. I mean, this police officer is white, his child is white, and he admits, even with that, he wouldn't want most of his fellow officers to engage with his son in a crisis."

Although many families reported experiencing barriers as a result of the COVID-19 pandemic, some families reported positive experiences from the pandemic. In particular, some caregivers indicated that their child appeared to be less stressed and happier during periods of social isolation.

"For my daughter I think well you know she's really not a social person so she really liked the distant learning you know and she liked the fact that she didn't have to go...she was the only one that really liked it."

Nearly all the families that participated in the interview described at least some positive perceptions of the treatment services they utilized; specifically, they indicated that the treatments were helpful and that they had a good relationship with the professionals providing the treatment. One caregiver said,

"We did some speech pathology and that was pretty good because she has a lisp, and it was really pronounced, and it's a little less pronounced now. She was with a very, very good psychologist who worked with her for a couple of years, and she did make great strides."

Recommendations

At the end of the interviews, caregivers provided considerations and recommendations for providers and professionals to better improve the experience of Black families of autistic youth as they navigate the diagnostic and treatment process. The following themes were identified: a) Increased Collaboration; b) Greater Humility, Compassion, and Understanding; c) Increased Support after Diagnosis; d.) More Black Professionals and Providers; e) More Services and Supports for Older Autistic Youth; f) More Back Support Groups; g) More Trainings about Autism for Professionals; h) Greater Access to Parent Trainings; and i) Police Trainings. The primary recommendation that arose from caregivers was greater humility, compassion, and understanding among providers and professionals. One mother pleaded,

"I would say for them to be more understanding and at least try to listen to what Black families are trying to communicate to them. Some people they might not be as knowledgeable as I was so what I'm trying to say is, no matter what words or references they are using, I would say for providers to try and understand."

After receiving the autism diagnosis, many caregivers described feeling unsupported. Thus, nearly half of the caregivers recommended that providers and professionals give additional support to Black families after delivering the diagnosis. Additionally, caregivers discussed wanting support from other caregivers who had shared their experience. One caregiver shared an idea about incorporating peer support for families,

"What needs to happen are volunteers, paid volunteers, when there is a Black family that's going to receive a diagnosis, ask somebody else to be there. Ask me to come, and after they get this diagnosis they're going to be crying….and 'oh my God what am I going to do?', and I would be like 'hey I got you, and let me tell you, you're going to get through this….it's going to be okay.' And when people that look like you are able to tell you that it's going to be okay, you believe it."

Other support related recommendations included having access to more Black parent support groups to learn from other caregivers.

"I think we do need more of our own support groups because a lot of times when you get the diagnosis, your family isn't gonna rally around you."

Additionally, caregivers discussed the importance of having more Black professionals within the service system. One mother stated,

> *"I would just say try to hire more people of color. Like, if that was, like an initiative or something, just trying to get more, because it would be nice for us, you know, a client to see their therapist, or at least more therapists in the building that look like them."*

Other recommendations provided by caregivers were increased supports for older autistic youth as they transition to adulthood. For example, one mother stated, "there is nothing really in that teen group and that's such a vital point." Another caregiver said, "She needs a therapist who can help her transition into adulthood, and she doesn't get services like that…" On top of supports, parents provided recommendations to increase access to parent trainings, police trainings, and professional or provider trainings to learn about autism and advocate for autistic families. One mother said,

> *"I don't know how doctors get training after they get their Ph.D., I know they go to conferences and stuff like that, so maybe more opportunities for them to learn about autism. Cause they just don't know a lot for them to be in the middle to be dealing with as many autistic children as they do."*

Aim 4

The last aim of this study was to determine what treatments Black caregivers of autistic children were participating in and to evaluate if their perceived treatment effectiveness ratings and perceived treatment satisfaction ratings differed significantly across the services they utilized. On average, families endorsed using three treatment services, with one being the lowest number of treatments used in the sample and seven being the highest number of treatments used in the sample. The most frequently endorsed treatment service was Speech and Language

Therapy (85.1%), followed by Occupational Therapy (76.2%), ABA (62.4%), Behavioral Parent Training (39.6%), and Physical Therapy (32.7%). The treatments that caregivers endorsed using in the open-ended response were categorized accordingly: Social Skills Training, Play Therapy, Feeding Therapy, Medication, Neurofeedback, Talk Therapy, School Therapy, and Music Therapy. Reports and frequencies are presented in *Table 7*.

Overall, caregivers in the sample reported positive perceptions of the treatment services used (see *Table 7* and *Table 8*). Greater than 70% of the sample reported that their child improved from the treatment services used; less than 16% reported no noticeable changes in their child, and less than 2% indicated that their child got worse from the treatment services. Treatment efficacy ratings were most positive for Speech Therapy, followed by Occupational Therapy, Behavioral Parent Training, Physical Therapy, and Applied Behavioral Analysis. Greater than 60% of caregivers indicated being happy with the treatment services used, less than 25% indicated being neither satisfied nor dissatisfied with treatment, and less than 14% reported being dissatisfied with the standard treatments used. For treatment satisfaction ratings, caregivers were the most satisfied with Speech Therapy, followed by Physical Therapy, Behavioral Parent Training, ABA, and Occupational Therapy. Further tests were conducted to assess differences between how caregivers perceived the usefulness of treatment and how happy caregivers were with treatment. Although caregivers appeared to express greater effectiveness with treatment than satisfaction, Wilcoxon Signed Rank Test revealed no significant differences between treatment effectiveness and satisfaction ratings for ABA ($t = 122.5$, $z = -1.392$, $p = .164$), Occupational Therapy ($t = 249.5$, $z = -1.675$, $p = .094$), Physical Therapy ($t = 63.00$, $z = 0.179$, $p = 0.858$), Behavioral Parent Training ($t = 25.00$, $z = -0.265$, $p = 0.791$), and Speech Therapy ($t = 205.5$, $z = -1.196$, $p = .055$). See *Table 9.*

Discussion

The purpose of this study was to highlight the unique experiences of Black families with autistic youth as they navigated the diagnostic and treatment process. Specifically, the study explored the relation between practical and racial barriers, caregiver stress, and perceived treatment effectiveness and satisfaction. Of note, current literature has previously highlighted the barriers that Black families of autistic children face as they seek out diagnostic and treatment services; however, present research lacks insight into the differential effects of both racial and practical factors on parental stress and treatment quality (Bishop-Fitzpatrick & Kind, 2017; Smith et al., 2020). This is the first study that has used quantitative and qualitative methods to document the experiences of Black caregivers of autistic youth in treatment.

The first goal of this study was to explore the relation between racial barriers, practical barriers, parental stress, treatment effectiveness, and treatment satisfaction. The findings confirmed significant correlations between barriers, caregiver stress, and perceived treatment quality. Specifically, greater experience of barriers was associated with greater caregiver stress, and more negative perceptions about treatment effectiveness and satisfaction.

Further analyses confirmed that racial barriers and practical barriers arose as independent predictors of parental stress (while controlling for family income and caregiver education level). Although prior studies have showed the impact of caregiver income and education level on parental stress (Yan, 2022), this study suggests that independent from family income and education level, Black caregivers are experiencing additional barriers that heighten their stress levels. These findings are in line with current literature that emphasizes the impact caregiving an autistic child has on parental stress (Kim et al., 2020), and the unique stressors Black caregivers experience that effect their stress levels (Kim et al., 2020; Williams et al., 2019).

Next, two regression analyses were conducted to determine factors contributing to Black caregivers' perceptions of a) treatment effectiveness b) and treatment satisfaction. From these analyses, it was determined that practical barriers to treatment and caregiver education level independently predicted treatment effectiveness. Finally, practical barriers to treatment was the only factor that significantly predicted treatment satisfaction. There is a vast literature on practical barriers to treatment for families of autistic youth (; Martinez et al., 2018; Straiton et al., 2021), but a dearth of research remains that explores the unique views of Black families and how these barriers contribute to treatment experiences.

Racial Barriers

Caregiver Stress

Several studies have demonstrated that caregivers of neurodivergent youth are vulnerable to greater amounts of stress compared to neurotypical caregivers (Barroso et al., 2018). In the present study, several clear racial barriers originated from caregiver reports. Specifically, families noted that racial microaggressions from professionals and family and community autism stigma were common concerns. This is partially supported in other research on stress among historically underrepresented groups with autistic children. Specifically, family misconceptions of ASD, difficulties navigating the service delivery system, and culture have all been shown to be contributors to caregiver stress (Iadarola et al, 2019). However, the present study expanded on previous research by highlighting unexplored racial barriers that increased caregiver stress including poor inclusivity and representation of Black individuals, fear that their child faces risk of prejudice and discrimination, and poor connection to other Black families who share similar experiences.

Autism stigma was a prevalent contributor to parental stress for caregivers in this sample. Negative beliefs about autism were cited from family and community members such as attributing autism to caregiver competence in parenting and holding beliefs that autism is something that can be cured or fixed. Upon receiving a diagnosis, many caregivers entered a state of denial. Denial included the idea that they can “fix” autism by participating in a handful of treatment services to make things better. Unfortunately, this increased stigma, denial, and parental stress because their expectations were not being met (Mitter et al., 2019). Once caregivers were able to enter a state of acceptance that their child was autistic and everything that came with it, many described feeling more empowered and relieved. This finding was echoed in other studies where Black caregivers reported lack of autism acceptance was common in their community (Burkett et al., 2015; Rivera-Figueroa et al., 2022; Stahmer et al., 2019). Although caregivers eventually were able to feel relief after accepting their child as autistic, many still had to grapple with negative beliefs and misconceptions from family and community members.

Misconceptions about autism can expand to a family’s support system or community. Unfortunately, caregivers reported dealing with a lack of acceptance from family and community members fueled by poor understanding of autism and cultural beliefs. Indeed, community stigma can lead to increased feelings of shame, denial, loneliness, and decrease help-seeking behaviors for Black caregivers (Pearson et al., 2022; Stahmer et al., 2019). Family and community stigma can worsen parental stress via two potential pathways. First, stigma can lead to a lack of intervention for child mental health needs (Zuckerman et al., 2018), which can lead to an increase in challenging behaviors, a decline in socio-emotional functioning, and overall augment parental stress. Second, family, friends, and community members (e.g., church members, national panhellenic sorority members) play a critical role in the experience of Black families

(Burkett et al., 2015; Stahmer et al.,2019). If caregivers are receiving blame, negative beliefs, and ultimately poor acceptance from these groups and individuals who they would typically turn to for social support, they will have fewer social resources, which are critical to alleviating stress and increasing resilience in Black families. Caregivers urge family member and community members to respond to their concerns with a compassionate rather than a critical lens (Drame et al., 2020). When Black caregivers of autistic youth have a strong village of support a (e.g., family members, peers, community members, teachers, and professionals; Rivera-Figueroa et al., 2022; Stahmer et al., 2019) that offers commitment, a nonjudgmental listening ear, support, and collaboration, they feel more confident, and in turn less stressed about the challenges they may face across the home, school, and community settings (Drame et al., 2020).

Other studies have highlighted the impact that difficulties with the medical system and diagnostic process have on parental stress of Black caregivers (Williams et al., 2019). Black families with autistic youth experience greater amounts of stress compared to Eurocentric caregivers, which may be moderated by levels of acculturation (Williams et al., 2019). In other words, the study demonstrated that caregivers who were less acculturated to American Euro-centric values, customs, and beliefs were more likely to use religion to cope and were susceptible to experiencing greater amounts of stress (Williams et al., 2019). Although levels of acculturation were not studied in the present study, many caregivers reported distress while navigating the diagnostic and treatment process and reported using adaptive (“God is giving me the resources”) and maladaptive (“Don’t go to therapy, go pray about it”) religious coping messages.

This mistrust of the medical system may also be intertwined with health literacy. Research on nonautistic samples have demonstrated the interconnectedness of family income and caregiver education level on access to care, health literacy, and systemic racism (Hodgkinson et al., 2017; Loyd et al., 2019; Muvuka et al., 2020). Indeed, families of autistic youth with lower income may have lower health literacy, including less knowledge about available service options, while families with higher incomes may be more inclined to initiate the research and gather the knowledge needed to be effective advocates for their children (Pickard & Ingesoll, 2016). Nearly 80 million adults in the United States have minimal health literacy, which may be aggravated among historically marginalized communities (Kutner et al., 2006; Schillinger et al., 2021). Limited health literacy can lead to obstructed treatment service use, which can potentially generate further frustration and stress among caregivers of autistic youth (Lindly et al., 2022). The intersection of limited health literacy and poor culturally responsive care may exacerbate caregiver distress. Families who are not privy to the resources and information they have rights to are more likely to come across barriers that impede their child's level of care when encountering professionals who neglect certain areas of care (Drame et al., 2020). This is particularly relevant in the schools, where caregivers express feeling like they have to conform to white-middle class norms in order to be seen (Drame et al., 2020).

Furthermore, caregivers in this sample reported feeling stress outside of the medical setting. Indeed, given the pervasiveness of racism within American society, many caregivers reported concerns about their child's safety being Black and autistic within the U.S. Black individuals, especially Black autistic males, are at risk for encountering threatening interactions with law enforcement officers (GBD 2019 Police Violence US Subnational Collaborators, 2021; Hutson et al., 2022). Autistic youth contact with law enforcement officers ranges from 6 to 21 percent (Rava et al., 2017; Tint et al., 2017; Turcotte et al., 2018), while Black youth are nearly four times as likely to face threat from law enforcement officers (Hyland et al., 2015). Nelson pronounced "Race and disability morph into one another to construct the perfect criminal who is perceived as requiring the use of disciplinary force and punishment" (Nelson, 2016, pg. 618). Although the risk that Black men face has been recognized globally, less political and legal attention has been paid toward reducing risk for Black autistic males – with only a small number of cases recognized on a national level: Stephon Watts, Elijah McClain, Ricardo Hayes (Baragona, 2021; Chicago Reader, 2021; The Associated Press, 2018). Many caregivers in this study indicated taking steps to reduce the likelihood of their child being harmed by police (e.g., autism bumper sticker, autism label on their license, meeting with local police officers, practicing scripts with their child).

Treatment Effectiveness, and Satisfaction

Across the literature specific to Black families with autistic youth, there has been a reoccurring theme of stereotyping, discrimination, and racism among professionals (Broder-Fingert et al., 2020; Gourdine et al., 2011; Jones et al., 2020; Lovelace et al., 2018). Indeed, greater than 50% of African Americans experience racial discrimination on a regular basis, with Black youth experiencing incidents of racial discrimination approximately five times a day (English et al., 2020; Lee et al., 2019). Racial microaggressions, a covert form of racism, also negatively impacts the psychological well-being of Black individuals, and can lead to increased psychological distress and potentially post-traumatic stress (Torino et al., 2019).

In this study, many caregivers described experiencing racial microaggressions from professionals when obtaining an autism diagnosis, during which professionals often made assumptions about their family. Several caregivers also discussed feeling ignored, invalidated, and invisible to professionals, which many caregivers attributed to the color of their skin. Discrimination, microaggressions, and racism was reflected across several studies assessing the barriers experienced by Black families of autistic youth (Burkett et al., 2015; Drame et al., 2020; Lovelace et al., 2018; Pearson et al., 2020a). Many Black families alluded to the fact that they had to arrive at professional appointments and meetings with all of the necessary knowledge and information in hand in order to be heard and respected – working harder than their white peers to avoid being dismissed. This experience was echoed across other Black caregivers of autistic youth, in which some caregivers indicated that they were even encouraged to code switch, assimilate to white norms, and mask their true selves to be accepted (Drame et al., 2020). Malia, a mother of an autistic child summarized this experience in a book documenting the narratives and experiences of Black autistic youth along their journey: "You have to act, *speak*, and look a certain way in order to get help. That's not right. They get paid to help, but [Black parents] are supposed to make them feel more comfortable before they can help you" (Drame et al., 2020, pg. 101).

While it was hypothesized that racial barriers would play a role in treatment effectiveness and satisfaction, outcomes from this study did not indicate that it was a significant independent predictor. This may be explained by the following: First, as part of the qualitative narrative that caregivers provided, a majority of the racial microaggressions and perceived racial discrimination experienced by families occurred during the diagnostic process rather than with their treatment providers. This is reflective in prior literature highlighting the barriers and racism Black families face as they seek a diagnosis (Lovelace et al., 2018; Pearson et al., 2020a). Second, as a part of this study, the question of interest was whether racial barriers impacted overall treatment effectiveness and satisfaction. Thus, families may have experienced racial barriers in certain treatment services, which may not have hampered their overall perceptions of service usefulness and satisfaction. Similarly, caregivers could have experienced racial barriers with a particular provider or place, prompting them to switch to a different provider or place, in which their positive experiences and reduction of racial barriers with the new place superseded their overall perceptions of the service. One of the limitations of this study is it captured the retroactive reports of caregiver's treatment experience and current levels of parental stress, thus, ratings of parental stress, racial barriers, treatment effectiveness, and treatment satisfaction could have certainly been heightened if ratings were captured in the moment. Despite this limitation, the findings of this study in conjunction with the narratives told from families demonstrate the lingering impact that racial barriers can have on the experience of Black families of autistic youth.

Practical Barriers

Caregiver Stress

Practical barriers that have been associated with caregiver stress in prior research include but are not limited to geographical location, long waitlists, and treatment costs (Brewer, 2018; Pearson & Meadon, 2018, Smith-Young et al., 2020; Stahmer et al., 2019). The results of this study corroborate those barriers, and further elucidate the effects of additional practical barriers on parental stress. These factors included caregiver work inflexibility, children having trouble understanding treatment, and treatment being more work than expected. Timing of access to care may play an important role in experienced barriers and caregiver's perceived stress as well. Petrongolo (2014) hypothesized that during a critical period (i.e., 6 months after the initial autism diagnosis) families who were able to receive support services and experience minimal barriers to treatment care were likely to experience less psychological stress. In the present study, most caregivers (79.8%) were able to access treatment less than a year after being diagnosed with autism despite the pronounced number of barriers and stress experienced. The influence of the critical period may be more impactful for caregivers who receive an autism diagnosis beyond the national average diagnostic age (e.g., 4 years of age). As part of the qualitative portion of the study, caregivers who had children diagnosed with autism later in life reported challenges with finding care for their child. Practical barriers may also be worsened for Black families living in rural or underresourced communities where access to quality care may be less accessible (Mello et al., 2016; Stanley, 2015). In fact, in a cross-sectional study examining geographical barriers as it relates to racial disparities in access to autism resources, areas that had the largest proportion of Black autistic youth had the lowest number of autism resources (Liu et al., 2023).

Adams and Young (2020) conducted a systematic review of perceived barriers of accessing psychological treatment for mental health problems for autistic youth. From their review of 12 qualitative and quantitative papers, caregivers identified the follow barriers: costs of services, provider not accepting insurance, treatment too far or lack of transportation, provider lack of knowledge about autism, and dissatisfaction with the provider. As a part of the qualitative findings, families also echoed these barriers and added that there are many hidden supports for families of autistic youth. Currently, the average yearly cost of care for autistic individuals is approximately $6,500 for children ages 0-5 years, $9,050 for youth ages 6-17, and $13,600 for autistic individuals who are 18 and older (Buescher et al., 2014). Although recent changes in mandated insurance policies have increased access to treatment and diagnostic services for some, insurance and treatment cost barriers still remain among families from higher socioeconomic backgrounds and families from lower socioeconomic backgrounds (Mandell et al., 2016; Pickard & Ingersoll, 2016). Given the financial demands of raising an autistic child, caregivers must also manage working their job and taking their children to and from appointments. This can be more challenging for families who have more job inflexibility and less social support and can lead to increased caregiver stress (Houser et al., 2014). Providing caregivers of autistic youth with job-protected paid leave may bolster caregiver employment support so parents do not have to choose between their family's financial security and their child's improvement (Houser et al., 2014).

Caregivers also reported limited autism knowledge among providers and professionals. Poor professional autism knowledge has been widely documented across the literature among primary care doctors, teachers, and mental health practitioners (Aylward et al., 2021; Elder et al., 2016; Gómez-Marí et al., 2021; Maddox et al., 2019; McCormack et al., 2020). Poor knowledge about autism among professionals may worsen diagnostic delays and perpetuate additional caregiver stress and non-affirming care for neurodiverse individuals (Aylward et al., 2021). Furthermore, if professionals lack important information on autism to take care of their child, caregivers may be forced to educate professionals on autism, which can add unwarranted burden onto caregivers and increase their stress. Although caregivers are the experts on their children, it should not be their responsibility to educate professionals on autism. These findings highlight the importance of the role providers play in shaping the experiences of Black caregivers as they engage in treatment services. Specifically, providers can invoke meaningful change within the service delivery system by implementing strategies to reduce the logistical barriers that impede families from participating in treatment (e.g., providing travel vouchers, telehealth sessions, childcare), participating in trainings about ASD, setting clear expectations for treatment for children and parents, and practicing flexibility for the families they serve to reduce feelings of caregiver stress.

An emerging body of literature has been dedicated to exploring adaptive coping methods that ameliorate stress in Black caregivers of autistic youth including coping strategies such as family resilience (e.g., family resources, perceived social support, parenting efficacy), religious support, and planful problem solving (Kim et al., 2020; Lewis et al., 2022; Williams et al., 2019). The Black Family Stress and Coping Model developed by Murry and colleagues (2018) provides an important framework that considers socio-historical proponents of stress (e.g., racism, discrimination) and strength-based protective factors (e.g., optimism, kindship support, spirituality) to conceptualize stress in Black families. This model aligns with the types of supports and recommendations caregivers in this study expressed needing, for instance, increasing access to parent support groups with other Black caregivers of autistic youth to expand support. Initiatives, supports, and interventions should be implemented throughout the diagnostic and treatment process to bolster these cultural protective factors and mitigate stress in Black caregivers. One mother in this study advocated for having peer supports from other Black caregivers of autistic youth after receiving the autism diagnosis. Other methods to reduce parental stress and reduce the burden of practical barriers on families may be to assist families with planning the next steps after they receive a diagnosis, include all relevant family members in the diagnostic and treatment process, promote caregiver self-care practices rather than emphasizing the notion that Black mothers need to be the “strong Black women,” and facilitate an environment in which caregivers can authentically voice their concerns and needs, regardless of the race of the professional with whom they are working (Lewis et al., 2022; Morgan & Stahmer, 2020; Nichols et al., 2015; Wallace-Watkin et al., 2022).

Treatment Effectiveness and Satisfaction

Findings from the present study also demonstrated the impact practical barriers to treatment had on treatment effectiveness and treatment satisfaction. Previous research on this topic by Pearson and colleagues (2020a) used qualitative interviews to investigate the experience of Black parents of autistic youth. In this study, more than 50% of the parent participants expressed dissatisfaction with the treatment services they received. Pearson and colleagues (2020a) hypothesized that these findings may be best explained by cultural discordance between families and therapists providing the treatment services and poor autism training among professionals on how to support families of autistic youth. Furthermore, prior research suggests that minoritized families are more likely to express dissatisfaction with the care they receive when family-centered care factors (e.g., trust, respect, listening, collaboration) are not taken into account in treatment services (Ngui & Flores, 2006). This aligns with the top recommendation provided by caregivers in this study: increased humility, compassion, and understanding from professionals. This suggests that facilitating a collaborative family-centered treatment environment is pertinent to enhance the quality of care for Black families of autistic youth. Limited access to quality care for Black families of autistic youth may be further impacted by insurance barriers and minimal access to affordable therapies and services (Wallace-Watkin et al., 2022; Weitlauf et al., 2023).

Contrary to previous literature, caregivers in this sample mostly reported positive experiences of the treatment services they used, and practical barriers rather than racial barriers were shown to significantly influence caregiver perceived treatment effectiveness and satisfaction. While findings were unexpected, it is possible that responses were impacted by the COVID-19 pandemic in which many caregivers of autistic children have endorsed greater amounts of stress and disruptions in treatment services (Wang et al., 2021). As part of the qualitative exploration of this study, one mother reported that during the COVID-19 pandemic, “getting care was a struggle.” This experience was replicated in a study conducted by Ferguson and colleagues (2022) in which families reported lower satisfaction with services delivered via telehealth compared to services delivered in person. In addition, caregiver stress has been shown to play a significant role in caregiver perceived treatment satisfaction (Ferguson et al., 2022). Practical barriers could have certainly been intensified by the pandemic and negatively impacted treatment satisfaction and effectiveness. First, staff shortages among treatment services could have limited the flexibility of treatment services and minimized efficient communication between families and professionals (Spain et al., 2021). Second, engaging autistic children in services and incorporating traditional aspects of treatments may have been more difficult during telehealth sessions or socially distanced in person sessions (Spain et al., 2021). Third, due to racial and structural inequities, Black individuals have been profoundly impacted by the pandemic, with increased marital challenges, deaths, illnesses, and financial hardships, which in accumulation can increase parental stress and reduce family engagement in treatment services (Abrams et al., 2022; Baweja et al., 2022; Karpman et al., 2020; Kullar et al., 2020). These barriers may be further pronounced in those living in rural areas with techno-geographical disadvantages and fewer available proximal services (Ramirez et al., 2021).

Although practical barriers to treatment did arise as a predictor of perceived treatment effectiveness and treatment satisfaction, caregivers were generally happy with the services they used and found them helpful for their child. Service utilization patterns among the caregivers in this study are described below.

Service Utilization

The literature on ASD tends to focus almost exclusively on white individuals (Steinbrenner et al.,2022). For this reason, another goal of this study was to thoroughly examine the types of treatment services Black families of autistic youth are utilizing and to explore whether caregiver perceptions of effectiveness and satisfaction differed between the services endorsed. In our sample, the majority of caregivers reported using Speech and Language

Therapy, followed by Occupational Therapy and Applied Behavioral Analysis. Behavioral Parent Training and Physical Therapy were utilized the least out of the standardized treatment services provided. These rates are consistent with Goin-Kochel's (2006) study that assessed treatment efficacy ratings among a large sample of caregivers with autistic children; Goin-Kochel and colleagues found that 84.1% of families tried Speech and Language Therapy, followed by Occupational Therapy (75.4%). Similarly, in this study, Physical Therapy was among the services least utilized (30.5%; Goin-Kochel et al., 2006). The patterns of service use seem to be parallel to the prevalence of comorbid concerns among autistic youth. Delays in speech and language skills (92.4%) are the most common symptom presentations in autistic individuals with even greater language deficits demonstrated in Black autistic youth (Parmegianni et al., 2019; Cuccaro et al., 2007). For this reason, it is not surprising that Speech Therapy and Occupational Therapy arose as the most utilized service among Black caregivers across studies (Goin-Kochel et al., 2006; Lee McIntyre & Zemantic, 2017). Further, motor skill challenges are often overlooked among autistic youth (Zampella et al., 2021), and may be targeted using Physical Therapy.

Despite recent advances in the growth of Behavioral Parent Training programs for autistic youth and their families (Postorino et al., 2017), less than 40% of Black caregivers reported using Behavioral Parent Training programs compared to nearly 50% in other autism represented samples (Goin-Kochel et al., 2006). This may be attributed to a) less access to family-centered care (care engaging families or parents as partners) among Black caregivers of autistic youth despite reported benefits (Montes & Halterman, 2011; Wagner et al., 2022), b) less utilization of Behavioral Parent Training programs due to the limited number of providers trained in autism to deliver such programs (Sanders et al., 2009), and c) demands of Behavioral Parent Training programs being too great when in combination with other barriers to treatment participation (e.g. job inflexibility, limited time, stigma; Postorino et al., 2017; Stahmer et al., 2019; Straiton et al., 2021). Although Behavior Parent Training Programs were among the least utilized services, many caregivers expressed wanting access to more parent training programs, especially ones that were congruent with their cultural values and experiences. One mother stated: "I've met so many parents, everybody doesn't know, even myself, how to deal with an autistic child." Findings from a study conducted by Straiton and colleagues (2021) indicate that providers play a pivotal role in access to parent training programs; indeed, provider training, competency, and ability to engage caregivers in parent trainings influence access to parent training programs.

Despite increased practical and racial barriers experienced throughout the diagnostic and treatment process, a majority of caregivers in this sample reported positive treatment efficacy ratings (>70%) and positive treatment satisfaction ratings (>60%). These optimistic ratings equate with caregiver treatment efficacy ratings (>70%) provided in previous studies (Goin-Kochel et al., 2006), indicating that Black caregivers of autistic youth are engaging in services that they find useful and valuable in addressing their child's needs and concerns. Caregivers from this sample generally reported greater dissatisfaction with treatment compared to negative reports of treatment effectiveness, although no significant differences were apparent.

Although it is important to understand how effective treatment is for Black caregivers of autistic youth, it is just as imperative to assess how happy caregivers are with treatment, which may potentially influence parental stress and treatment engagement (Prakash, 2010). In the current study, less than 14% of caregivers expressed dissatisfaction with the treatments they utilized. Moreover, treatment efficacy and satisfaction ratings did not differ significantly between the different services utilized. In a sample of majority Black caregivers of autistic children, treatment satisfaction was variable across service type, with speech services having the greatest reported satisfaction (Pearson et al., 2020b). Conversely, in a study examining the experience of Black caregivers of autistic youth engaging in treatment services for their child,, more than 50% of the parent participants expressed dissatisfaction with the treatment services they received because of increased racial discordance between caregivers and providers and poor perceived autism knowledge among professionals (Pearson et al., 2020a).

Given the considerable disproportionate impact the COVID-19 pandemic has had on communities of color and lower income communities, it is important to discuss these findings in light of the significant global event (Kantamneni, 2020). Although the present study did not specifically query about treatment efficacy and satisfaction reports during the pandemic, the pandemic could have certainly influenced caregivers' retrospective reports of treatment satisfaction and effectiveness. The pandemic drastically altered access to autism treatment services as well as the way in which treatments were provided, often transitioning service delivery from in-person to telehealth methods (Ameis et al., 2020). Further, as a result of COVID-19, many treatment services were temporarily discontinued while families suffered from disruptions in their routine and emotional and behavioral challenges (Nonweiler et al., 2020; White et al., 2021). Ferguson and colleagues (2022) surveyed caregivers of autistic youth on their satisfaction of treatment services during the pandemic and found lower reports of treatment satisfaction for ABA, Speech and Language Therapy, and Occupational Therapy when delivered via telehealth. Among those services, ABA demonstrated the highest satisfaction ratings across telehealth and in-person delivery mediums.

Contrary to findings suggested from Ferguson and colleagues, in the current study, ABA had one of the highest dissatisfaction ratings among the standard treatment services utilized, with

Speech and Language Therapy demonstrating the highest satisfaction ratings. ABA has recently been deemed a more controversial autism treatment service in light of some troublesome findings. Indeed, recent literature has been published highlighting a significant portion of autistic samples experiencing posttraumatic stress from undergoing ABA treatment (Kupferstein, 2018). Increased neurodiversity advocacy has targeted the harmful effects of ABA due to the treatment's efforts to make neurodivergent youth appear neurotypical, thus devaluing the uniqueness and acceptance of autistic youth (Chapman & Bovell, 2022). As discussed earlier, for Black families, dissatisfaction with ABA and other treatment services may also be attributed to racial barriers. In fact, a meta-analysis of the efficacy of psychotherapy youth interventions demonstrated that psychotherapies were less effective in states with higher anti-Black racism (Price et al., 2022). Recognizing the magnitude of impact that racial barriers have on treatment quality for Black families, emerging initiatives in the ABA community have been piloted to provide care that respects and values the Black community (Čolić et al.,2021; Kaiser et al., 2022).

Limitations

The present study provides a much-needed examination into both racial and practical barriers Black families of autistic youth experience while navigating the diagnostic and treatment process. Further, utilizing a mixed-method approach, we were able to determine the effect these barriers had on parental stress, perceived treatment effectiveness, and perceived treatment satisfaction. This study illuminated the continued racial disparities, racism, and discrimination prevalent in our society and health system. However, the present study was not without several potential methodological weaknesses. First, the families recruited as a part of this study were connected to SPARK, a well-organized network of medical centers designed to diagnose autism and connect families to research. Thus, some of the findings from this study may not generalize to families of autistic youth who are self-diagnosed or do not have a formal diagnosis, have fewer resources and connections, and who are distrustful of research. It is recommended that future studies make efforts to seek perspectives from Black caregivers of autistic youth who may be less inclined to participate in research and families who were not able to obtain a formal diagnosis. Further, researchers should seek perspectives about services from Black autistic youth to gain better insight into creating and delivering services that respect the needs and values of Black autistic youth.

Second, the study's sample was largely African American caregivers (68.3%) and children (67.3%). It is possible that a portion of the sample may have experienced additional barriers due to the amount of time they have lived in the U.S. For example, 12.8% of caregivers identified as being of a different nationality, meaning that in addition to racial barriers and practical barriers, they may have also had to overcome cultural barriers or prejudice related to issues such as speaking English as a second language or speaking with an accent (Lim et al., 2020). In a study examining the experiences of Somalian caregivers of autistic youth, caregivers emphasized the impact of cultural and beliefs on their understanding of autism (Fox et al 2017). Future research may benefit from exploring the unique experiences of Black families with autistic children not born in the United States, and their perceptions of accessing diagnostic services and care.

Third, some of the reports provided by families were retroactive reports, which possibly limited response accuracy. For example, caregiver reports on treatment satisfaction may look different 1-day post-treatment vs 3-years post treatment. Fourth, although the Racial Barriers to Participation Scale was created by the researchers based on empirical evidence for Black families of autistic youth, it was not a validated, psychometrically supported scale. Therefore, future research may benefit from standardizing the measure or developing another measure with more empirical support. Furthermore, measures used to assess treatment effectiveness were based on parental report rather than behavioral progress monitoring, clinician report, or behavioral observations. Although the qualitative results provided helpful insight to the qualitative findings, it would have also been helpful to know with whom families experienced reported racial microaggressions (e.g., primary care doctor, community members, school professionals, psychologists) to further target increasing cultural humility in specific settings.

Implications and Future Directions

Notwithstanding these limitations, this study does have several practical implications and directions for future research. Given the impact of racial and practical barriers to treatment on caregiver stress, greater efforts are needed to monitor and mitigate caregiver stress in treatment and collaborate with Black families to work to reduce experienced barriers (e.g., the Autism Parenting Stress Index, a brief stress measure; Silva & Schalock, 2012). Moreover, cultural components of stress should also be taken into account when monitoring stress (e.g., stigma, racial microaggressions, poor family support).

Practical barriers (e.g., geographical barriers, treatment cost) further impacted the perceived treatment effectiveness, perceived treatment satisfaction, and parental stress of Black autistic caregivers. Greater efforts and strategies need to be prioritized among policy makers and professionals to improve the care of Black autistic families (e.g., flexible appointments, public transportation vouchers, community initiatives that offer treatment and assessment resources in under-resourced areas; Rivera-Figueroa et al., 2022). New areas of research have emerged on leveraging telehealth services to improve access to treatment and assessment services. One particular example is the development of a device that utilizes caregiver questionnaires, home videos, and provider questionnaires to develop algorithms that assists with an efficient diagnostic process (Megerian et al., 2022). As we progress towards more digitized forms of service delivery, it is still imperative to provide humanized and culturally responsive levels of care.

The results of the study emphasize the lack of culturally responsive care received by Black caregivers of autistic youth from providers and professionals especially within the diagnostic process. This may be attributed to poor knowledge about autism or lack of cultural humility. There is, therefore, a benefit for mandatory trainings in cultural humility, family-centered care, and autism for professionals who diagnose, treat, and serve autistic youth (e.g., primary care doctors, psychologists, therapists, school providers). Trainings should include psychoeducation, experiential learning, as well as consultation from autism experts and advocates, including autistic individuals (Gillespie-Lynch et al. 2017). Future research should explore the effects of utilizing these forms of culturally responsive autism trainings on the quality of care for Black families.

Advocacy played a critical role in facilitating access to resources and improving quality of care for the caregivers in this sample. Although having the tools to advocate for their child was necessary for most caregivers, many indicated wanting greater advocacy efforts from providers and professionals with whom they interacted. Building the cultural capital (e.g., aspirational, familial, social networks) of Black families of autistic youth and empowering them to navigate the diagnostic and treatment systems that they interact with (e.g., medical system, mental health system, school system, economic system) to mitigate parental stress, increase family resilience, and improve treatment quality is essential (Morgan & Stahmer, 2020).

One method to increase cultural capital is to provide parent training programs. Embedded within these programs for caregivers of autistic youth should be lessons to increase the skills and tools needed to provide quality care for their child, increase access to resources, and address behavioral concerns. Furthermore, professionals within these systems should garner the necessary tools and resources to better advocate for the families they serve. Work done to enhance collaboration between caregivers and professionals has already produced promising findings. Indeed, the Fostering Advocacy, Communication, Empowerment, and Supports (FACES) is a workshop conducted with parents, providers, and educators to increase partnerships, help families learn about autism resources in their community, and assess the needs of underserved families in the community (Pearson et al, 2020b). Similarly, Mind the Gap, a peer-mediated intervention for caregivers of autistic youth has been piloted with caregivers of autistic youth who live below the federal poverty line and includes modules on topics related to education about autism, navigating the service delivery system, stigma, challenging behaviors, anxiety and acceptance, living a healthy lifestyle, and working with providers (Iadarola et al., 2020).

Another important area for support lies within the Black community. Families within the sample discussed how stigma and family rejection of autism yielded increased stress and delayed their efforts to get help for their child. Garnering a supportive network of family members, peers, professionals, and community members (familial and social capital) to reduce caregiver stress. Partnerships with Black community centers or in institutions where autism stigma may be salient is an important next step. For instance, Johnson and Van Heck (2015) successfully piloted a training that provided Black church leaders within inner cities with knowledge about signs of autism and autism resources using culturally tailored materials. Additionally, increasing Black autistic visibility within the Black community to normalize concerns may be another avenue to increase awareness. For example, the Disney Channel (a television program for children and families) recently aired an episode of *The Proud Family: Louder and Prouder*, where a Black family reacted to receiving an autism diagnosis (Essence Magazine, 2023). The episode provided an accurate reality of the internal experience of most Black families when receiving a diagnosis: denial, confusion, and eventually acceptance. More research is needed to address the implications and recommendations raised by the caregivers in this study to create programs, resources, and a system of care that is responsive to the needs and values of Black families of autistic youth.

Conclusion

Ultimately, the purpose of this study was to amplify the voices and experiences of Black families with autistic youth. Black caregivers of autistic youth are still encountering a number of racial and practical barriers when seeking treatment and diagnostic services for their children. Despite increased autism awareness and acceptance, stigma is still an apparent barrier within the Black community. Furthermore, despite increased efforts across industries to practice cultural humility and provide equitable treatment after events of widespread anti-Black violence, covert and overt forms of anti-Black racism is still prevalent among the professional community providing services to Black autistic youth. These barriers negatively impact caregiver stress and may also impact caregiver perceived treatment quality (although caregivers largely liked treatments and thought they were effective in this sample). The narratives told by caregivers further elucidate the tumultuous experiences of Black caregivers as they seek diagnostic and treatment services for their children. An experience that may be worsened by family, professional, and systemic barriers, and can be improved by advocacy, acceptance, peer and community support, and increased knowledge. Black families of autistic youth call for increased compassion, support, training, and humility among professionals who serve autistic youth.

References

Abrams, E. M., Greenhawt, M., Shaker, M., Pinto, A. D., Sinha, I., & Singer, A. (2022). The COVID-19 pandemic: Adverse effects on the social determinants of health in children and families. *Annals of Allergy, Asthma & Immunology*, *128*(1), 19–25. https://doi.org/10.1016/j.anai.2021.10.022

Ameis, S. H., Lai, M.-C., Mulsant, B. H., & Szatmari, P. (2020). Coping, fostering resilience, and driving care innovation foric people and their families during the COVID-19 pandemic and beyond. *Molecular Autism*. https://doi.org/10.1186/s13229-020-00365-y

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders, 5th ed*. Arlington, VA: American Psychiatric Association.

Anglin, D. M., Alberti, P. M., Link, B. G., & Phelan, J. C. (2008). Racial differences in beliefs about the effectiveness and necessity of mental health treatment. *American Journal of Community Psychology, 42*(1-2), 17-24. https://doi.org/10.1007/s10464-008-9189-5

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., Kurzius-Spencer, M., Zahorodny, W., Robinson Rosenberg, C., White, T., Durkin, M. S., Imm, P., Nikolaou, L., Yeargin-Allsopp, M., Lee, L. C., Harrington, R., Lopez, M., Fitzgerald, R. T., Hewitt, A., Pettygrove, S., Constantino, N. J., Vehorn, A., Shenouda, J., Hall-Lande, J., Van Naarden Braun, K., & Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C.: 2002)*, *67*(6), 1–23. https://doi.org/10.15585/mmwr.ss6706a1

Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, *30*(4), 194–204. https://doi.org/10.2511/rpsd.30.4.194

Baragona, J. (2021), "MSNBC host chokes up while reading Elijah McClain's last words", MSNBC Host Chokes Up While Reading Elijah Mcclain's Last Words, available at: https://www.msn.com/enus/news/crime/msnbc-host-chokes-up-while-reading-elijah-mcclain-s-last-words/ar-AANZGcG (accessed 24 January 2022).

Barroso, N. E., Mendez, L., Graziano, P. A., & Bagner, D. M. (2018). Parenting stress through the lens of different clinical groups: A systematic review & meta-analysis. *Journal of Abnormal Child Psychology*, *46*(3), 449–461. https://doi.org/10.1007/s10802-017-0313-6

Baweja, R., Brown, S. L., Edwards, E. M., & Murray, M. J. (2022). COVID-19 pandemic and impact on patients with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *52*(1), 473–482. https://doi.org/10.1007/s10803-021-04950-9

Benson P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, *36*(5), 685–695. https://doi.org/10.1007/s10803-006-0112-3

Bernal, G., & Scharrón-del-Río, M. R. (2001). Are empirically supported treatments valid for ethnic minorities? Toward an alternative approach for treatment research. *Cultural Diversity & Ethnic Minority Psychology*, *7*(4), 328–342. https://doi.org/10.1037/1099-9809.7.4.328

Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*(3), 463–472. https://doi.org/10.1177/0265407595123009

Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(11), 3380–3391. https://doi.org/10.1007/s10803-017-3251-9

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, *50*(Pt 3), 184–198. https://doi.org/10.1111/j.1365-2788.2005.00768.x

Blanchett, W. J., Klingner, J. K., & Harry, B. (2009). The intersection of race, culture, language, and disability: Implications for urban education. *Urban Education, 44*(4), 389–409. https://doi.org/10.1177/0042085909338686

Bondy, A. S., & Frost, L. A. (1995). Educational approaches in preschool: Behavior techniques in a public school setting. In E. Schopler & G.B. Mesibov (Eds.), *Learning and cognition in autism* (pp. 311–338). New York: Plenum Press.

Bradford, L. D., Newkirk, C., & Holden, K. B. (2009). Stigma and mental health in African Americans. In R. L. Braithwaite, S. E. Taylor, & H. M. Treadwell (Eds.), *Health issues in the Black community* (p. 119–131). Jossey-Bass/Wiley.

Brewer A. (2018). "We were on our own": Mothers' experiences navigating the fragmented system of professional care for autism. *Social Science & Medicine (1982)*, *215*, 61–68. https://doi.org/10.1016/j.socscimed.2018.08.039

Broder-Fingert, S., Mateo, C. M., & Zuckerman, K. E. (2020). Structural racism and autism. *Pediatrics*, *146*(3), e2020015420. https://doi.org/10.1542/peds.2020-015420

Brown, D. L. (2008). African American resiliency: Examining racial socialization and social support as protective factors. *Journal of Black Psychology, 34*, 32 - 48. https://doi.org/10.1177/0095798407310538

Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for their future. *Exceptional Children*, *76*, 339–355. https://doi.org/10.1177/001440291007600306

Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, *168*(8), 721–728. https://doi.org/10.1001/jamapediatrics.2014.210

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of Autism and Developmental Disorders*, *45*(10), 3244–3254. https://doi.org/10.1007/s10803-015-2482-x

Campbell, K. (2016, December 9). Wait time for child autism assessments “completely unacceptable.” CBC News. http://www.cbc.ca/news/canada/prince-edward-island/pei-autism-wait-times-1.3890512.

Cabral, R. R., & Smith, T. B. (2011). Racial/ethnic matching of clients and therapists in mental health services: a meta-analytic review of preferences, perceptions, and outcomes. *Journal of Counseling Psychology*, *58*(4), 537–554. https://doi.org/10.1037/a0025266

Cauce, A. M., Domenech-Rodríguez, M., Paradise, M., Cochran, B. N., Shea, J. M., Srebnik, D., & Baydar, N. (2002). Cultural and contextual influences in mental health help seeking: a focus on ethnic minority youth. *Journal of Consulting and Clinical Psychology*, *70*(1), 44–55. https://doi.org/10.1037//0022-006x.70.1.44

Chapman, R., Bovell, V. (2022). Neurodiversity, advocacy, anti-therapy. In: Matson, J.L., Sturmey, P. (eds) *Handbook of autism and pervasive developmental disorder*. Autism and Child Psychopathology Series. Springer, Cham. https://doi.org/10.1007/978-3-030-88538-0_6

Chicago Reader (2015), Black, autistic, and killed by police, retrieved from: https://chicagoreader.com/news-politics/black-autistic-and-killed-by-police/ (accessed 05 March 2023).

Christensen, D. L., Bilder, D. A., Zahorodny, W., Pettygrove, S., Durkin, M. S., Fitzgerald, R. T., Rice, C., Kurzius-Spencer, M., Baio, J., & Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among 4-year-old children in the Autism and Developmental Disabilities Monitoring Network. *Journal of Developmental and Behavioral Pediatrics*, *37*(1), 1–8. https://doi.org/10.1097/DBP.0000000000000235

Čolić, M., Araiba, S., Lovelace, T. S., & Dababnah, S. (2021). Black caregivers' perspectives on racism in ASD services: Toward culturally responsive ABA practice. *Behavior Analysis in Practice*, *15*(4), 1032–1041. https://doi.org/10.1007/s40617-021-00577-5

Collins, A. L., Ma, D., Whitehead, P. L., Martin, E. R., Wright, H. H., Abramson, R. K., Hussman, J. P., Haines, J. L., Cuccaro, M. L., Gilbert, J. R., & Pericak-Vance, M. A. (2006). Investigation of autism and GABA receptor subunit genes in multiple ethnic groups. *Neurogenetics*, *7*(3), 167–174. https://doi.org/10.1007/s10048-006-0045-1

Conner, K. O., Copeland, V. C., Grote, N. K., Rosen, D., Albert, S., McMurray, M. L., Reynolds, C. F., Brown, C., & Koeske, G. (2010). Barriers to treatment and culturally endorsed coping strategies among depressed African American older adults. *Aging & Mental Health*, *14*(8), 971–983. https://doi.org/10.1080/13607863.2010.501061

Constantine, M. G. (2007). Racial microaggressions against African American clients in cross-racial counseling relationships. *Journal of Counseling Psychology, 54*(1), 1–16. https://doi.org/10.1037/0022-0167.54.1.1

Cuccaro, M. L., Brinkley, J., Abramson, R. K., Hall, A., Wright, H. H., Hussman, J. P., Gilbert, J. R., & Pericak-Vance, M. A. (2007). Autism in African American families: Clinical-phenotypic findings. *American Journal of Medical Genetics*, *144B*(8), 1022–1026. https://doi.org/10.1002/ajmg.b.30535

Cuevas, A. G. (2013*). Exploring four barriers experienced by African Americans in healthcare: perceived discrimination, medical mistrust, race discordance, and poor communication.* (Publication No. 10.15760/etd.615) [Masters Theses, Portland University]. PDX Scholar.

Dababnah S., Shaia W. E., Campion K., Nichols H. M. (2018). “We had to keep pushing”: Caregivers’ perspectives on autism screening and referral practices of Black children in primary care. *Intellectual and Developmental Disabilities, 56*(5), 321–336. 10.1352/1934-9556-56.5.321

Davenport, M. A., Romero, M. E., Lewis, C. D., Lawson, T., Ferguson, B., Stichter, J., & Kahng, S. (2021). An initial development and evaluation of a culturally responsive police interactions training for Black adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Advance online publication. https://doi.org/10.1007/s10803-021-05181-8 de Haan, A. M., Boon, A. E., de Jong, J., & Vermeiren, R. (2018). A review of mental health treatment dropout by ethnic minority youth. *Transcultural Psychiatry*, *55*(1), 3–30. https://doi.org/10.1177/1363461517731702

Drame, E., Adams, T., Nolden, V., Nardi, J. (2020). *The Resistance, Persistence and Resilience of Black Families Raising Children with Autism*. Peter Lang Publishing Group.

Elder, J. H., Brasher, S., & Alexander, B. (2016). Identifying the barriers to early diagnosis and treatment in underserved individuals with autism spectrum disorders (ASD) and their families: A qualitative study. *Issues in Mental Health Nursing*, *37*(6), 412–420. https://doi.org/10.3109/01612840.2016.1153174

English, D., Lambert, S. F., Tynes, B. M., Bowleg, L., Zea, M. C., & Howard, L. C. (2020). Daily multidimensional racial discrimination among Black U.S. American adolescents. *Journal of Applied Developmental Psychology, 66*, 101068. https://doi.org/10.1016/j.appdev.2019.101068

Essence Magazine (2023, February 7). 'The Proud Family: Louder And Prouder' Dedicates Episode To Autism Awareness. Retrieved from: https://www.essence.com/health-and-wellness/proud-family-autism-episode/

Ferguson, E. F., Jimenez-Muñoz, M., Feerst, H., & Vernon, T. W. (2022). Predictors of satisfaction with autism treatment services during COVID-19. *Journal of Autism and Developmental Disorders*, *52*(8), 3686–3697. https://doi.org/10.1007/s10803-021-05232-0

Fisher, A. P., Lynch, J. D., Jacquez, F. M., Mitchell, M. J., Kamimura-Nishimura, K. I., & Wade, S. L. (2022). A systematic review examining caregivers' of color experiences with the diagnostic process of autism spectrum disorder. *Autism,* 13623613221128171. Advance online publication. *https://doi.org/10.1177/13623613221128171*Fox, F., Aabe, N., Turner, K., Redwood, S., & Rai, D. (2017). “It was like walking without knowing where I was going”: A qualitative study of autism in a UK Somali migrant community. *Journal of Autism and Developmental Disorders, 47,* 305–315. https://doi.org/10.1007/s10803-016-2952-9.

Fu, M., Shen, Y.C., & Marquez, G. (2014). Personal adjustment of ethnic minority populations across the life span by gender as measured by stress and coping. In F. T. L. Leong, L. Comas-Díaz, G. C. Nagayama Hall, V. C. McLoyd, & J. E. Trimble (Eds.), *APA handbooks in psychology®. APA handbook of multicultural psychology, Vol. 2. Applications and training* (pp. 107–118). American Psychological Association. https://doi.org/10.1037/14187-006

GBD 2019 Police Violence US Subnational Collaborators (2021), “Fatal police violence by race and state in the USA, 1980-2019: a network meta-regression”, *The Lancet, Vol. 398* No. 10307, pp. 1239-1255.

George, D., & Mallery, P. (2010) *SPSS for windows step by step: A simple guide and reference 17.0* Update. 10th Edition. Pearson: Boston.

Gillespie-Lynch, K., Bublitz, D., Donachie, A., Wong, V., Brooks, P. J., & D'Onofrio, J. (2017). "For a long time our voices have been hushed": Using student perspectives to develop supports for neurodiverse college students. *Frontiers in Psychology*, *8*, 544. https://doi.org/10.3389/fpsyg.2017.00544

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2009). Parental reports on the efficacy of treatments and therapies for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 3*(2), 528- 537. https://doi.org/10.1016/j.rasd.2008.11.001

Gómez-Marí, I., Sanz-Cervera, P., & Tárraga-Mínguez, R. (2021). Teachers' knowledge regarding autism spectrum disorder (ASD): A systematic review. *Sustainability*, *13*(9), 5097. MDPI AG. Retrieved from http://dx.doi.org/10.3390/su13095097

Gopalan, G., Goldstein, L., Klingenstein, K., Sicher, C., Blake, C., & McKay, M. M. (2010). Engaging families into child mental health treatment: Updates and special considerations. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 19*(3), 182–196.

Gourdine, R. M., Baffour, T. D., & Teasley, M. (2011). Autism and the African American community. *Social Work in Public Health*, *26*(4), 454–470. https://doi.org/10.1080/19371918.2011.579499

Hastings R. P. (2003). Child behaviour problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, *47*(Pt 4-5), 231–237. https://doi.org/10.1046/j.1365-2788.2003.00485.x

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism: The International Journal of Research and Practice*, *9*(2), 125–137. https://doi.org/10.1177/1362361305051403

Hinkle E. D., Wiersma, W., & Jurs G. S. (2003). *Applied statistics for the behavioral sciences, 5th ed.* Boston, Mass: Houghton Mifflin.

Hodgetts, S., Nicholas, D., Zwaigenbaum, L., & McConnell, D. (2013). Parents' and professionals' perceptions of family-centered care for children with autism spectrum disorder across service sectors. *Social Science & Medicine (1982)*, *96*, 138–146. https://doi.org/10.1016/j.socscimed.2013.07.012

Hodgkinson, S., Godoy, L., Beers, L. S., & Lewin, A. (2017). Improving mental health access for low-income children and families in the primary care setting. *Pediatrics, 139*(1). https://doi.org/10.1542/peds.2015-1175

Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W., & Reed, H. K. (2002). Problem behavior interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disorders*, *32*(5), 423–446. https://doi.org/10.1023/a:1020593922901

Houser, L., McCarthy, M., Lawer, L., & Mandell, D. (2014). A challenging fit: Employment,childcare, and therapeutic support in families of children with autism spectrum disorders. *Journal of Social Service Research,40*, 681–698. doi:10.1080/01488376.2014.930944

Hsieh, H. F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Huey, S. J., Jr, & Polo, A. J. (2008). Evidence-based psychosocial treatments for ethnic minority youth. *Journal of Clinical Child and Adolescent Psychology*, *37*(1), 262–301. https://doi.org/10.1080/15374410701820174

Hutson, T.M., McGhee Hassrick, E., Fernandes, S., Walton, J., Bouvier-Weinberg, K., Radcliffe, A. and Allen-Handy, A. (2022), "“I'm just different–that's all–I'm so sorry … ”: Black men, ASD and the urgent need for DisCrit Theory in police encounters", *Policing: An*

International Journal, Vol. 45 No. 3, pp. 524-537. https://doi.org/10.1108/PIJPSM-10-2021-0149

Hyland, S., Langton, L., & Davis, E. (2015). Police Use of Nonfatal Force, 2002-11. Washington DC: US Department of Justice, Office of Justice Programs, Bureau of Justice Statistics.

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, S., Hauptman, L., Hassrick, M., Crabbe, S., Vejnoska, S., Morgan, E., Nuske, H., Luelmo, P., Friedman, C., Kasari, C., Gulsrud, A., Mandell, D., Smith, T. (2020). Mind the gap: an intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. Pilot Feasibility Studies, 7;6:124. doi: 10.1186/s40814-020-00662-6.

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, *65*(1), 20–30. https://doi.org/10.1080/20473869.2017.1347228

Ilias, K., Liaw, J. H., Cornish, K., Park, M., & Golden, K. J. (2017). Wellbeing of mothers of children with "A-U-T-I-S-M" in Malaysia: An interpretative phenomenological analysis study. *Journal of Intellectual & Developmental Disability, 42*, 74 - 89. https://doi.org/10.3109/13668250.2016.1196657

Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders, 6*(1), 565-572. https://doi.org/10.1016/j.rasd.2011.07.018

Jamison, J. M., Fourie, E., Siper, P. M., Trelles, M. P., George-Jones, J., Buxbaum Grice, A., Krata, J., Holl, E., Shaoul, J., Hernandez, B., Mitchell, L., McKay, M. M., Buxbaum, J.

D., & Kolevzon, A. (2017). Examining the efficacy of a family peer advocate model for Black and Hispanic caregivers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*(5), 1314–1322. https://doi.org/10.1007/s10803-017-3045-0

Johnson N, & Van Hecke A (2015). Increasing autism awareness in inner-city churches: A brief report. *Journal of Pediatric Nursing*, 30(6), e69. 10.1016/j.pedn.2015.04.008

Jones, D. R., Nicolaidis, C., Ellwood, L. J., Garcia, A., Johnson, K. R., Lopez, K., & Waisman, T. (2020). An expert discussion on structural racism in autism research and practice. *Autism in Adulthood*, *2*(4), 273–281. https://doi.org/10.1089/aut.2020.29015.drj.

Khan S., Mian A. (2020). Racism and medical education. *The Lancet Infectious Diseases, 20*(9), 1009. https://doi.org/10.1016/S1473-3099(20)30639-3

Kaiser, K., Villalobos, M. E., Locke, J., Iruka, I. U., Proctor, C., & Boyd, B. (2022). A culturally grounded autism parent training program with Black parents. *Autism*, *26*(3), 716–726. https://doi.org/10.1177/13623613211073373

Kantamneni N. (2020). The impact of the COVID-19 pandemic on marginalized populations in the United States: A research agenda. *Journal of Vocational Behavior*, *119*, 103439. https://doi.org/10.1016/j.jvb.2020.103439

Kazdin, A. E., Holland, L., Crowley, M., & Breton, S. (1997). Barriers to Treatment Participation Scale: Evaluation and validation in the context of child outpatient treatment. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *38*(8), 1051–1062. https://doi.org/10.1111/j.1469-7610.1997.tb01621.x

Kelly, S., Maynigo, P., Wesley, K., & Durham, J. (2013). African American communities and family systems: Relevance and challenges. *Couple and Family Psychology: Research and Practice, 2*(4), 264–277. https://doi.org/10.1037/cfp0000014

Kemet S. (2019). Insight Medicine Lacks - The continuing relevance of Henrietta Lacks. *The New England Journal of Medicine*, *381*(9), 800–801. https://doi.org/10.1056/NEJMp1905346

Kim, I., Dababnah, S., & Lee, J. (2020). The influence of race and ethnicity on the relationship between family resilience and parenting stress in caregivers of children with autism. *Journal of Autism and Developmental Disorders*, *50*(2), 650–658. https://doi.org/10.1007/s10803-019-04269-6

Koegel L. K. (2000). Interventions to facilitate communication in autism. *Journal of Autism and Developmental Disorders*, *30*(5), 383–391. https://doi.org/10.1023/a:1005539220932

Koegel, L. K., Koegel, R. L., Ashbaugh, K., & Bradshaw, J. (2014). The importance of early identification and intervention for children with or at risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, *16*(1), 50–56. https://doi.org/10.3109/17549507.2013.861511

Konkel L. (2015). Racial and ethnic disparities in research studies: The challenge of creating more diverse cohorts. *Environmental Health Perspectives*, *123*(12), A297–A302. https://doi.org/10.1289/ehp.123-A297

Kullar, R., Marcelin, J. R., Swartz, T. H., Piggott, D. A., Macias Gil, R., Mathew, T. A., & Tan, T. (2020). Racial disparity of coronavirus disease 2019 in African American communities. *The Journal of Infectious Diseases*, *222*(6), 890–893. https://doi.org/10.1093/infdis/jiaa372

Kupferstein, H. (2018), "Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis", *Advances in Autism*, Vol. 4 No. 1, pp. 19-29. https://doi.org/10.1108/AIA-08-2017-0016

Kutner, M., Greenberg, E., Jin, Y. and Paulsen, C. (2006) The health literacy of America's adults: Results from the 2003 national assessment of adult literacy (NCES 2006- 483). US Department of Education, National Center for Education Statistics, Washington DC.

Lee, R. T., Perez, A. D., Boykin, C. M., & Mendoza-Denton, R. (2019). On the prevalence of racial discrimination in the United States. PLOS ONE, 14(1), e0210698. https://doi.org/10.1371/journal.pone.0210698

Lee McIntyre, L., & Zemantic, P. K. (2017). Examining services for young children with autism spectrum disorder: Parent satisfaction and predictors of service utilization. *Early Childhood Education Journal*, *45*(6), 727–734. https://doi.org/10.1007/s10643-016-0821-y

Leong, F. T., & Kalibatseva, Z. (2011). Cross-cultural barriers to mental health services in the United States. *Cerebrum: The Dana Forum on Brain Science*, *2011*, 5.

Lewis, E. M., Dababnah, S., Hollie, K. R., Kim, I., Wang, Y., & Shaia, W. E. (2022). The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children. *Autism*, *26*(8), 2015–2025. https://doi.org/10.1177/13623613211070865

Lim, N., O'Reilly, M., Sigafoos, J., Lancioni, G. E., & Sanchez, N. J. (2020). A review of barriers experienced by immigrant parents of children with autism when accessing services. *Review Journal of Autism and Developmental Disorders, 8*(3), 366–372. https://doi.org/10.1007/s40489-020-00216-9

Lindly, O. J., Cabral, J., Mohammed, R., Garber, I., Mistry, K. B., & Kuhlthau, K. A. (2022). "I Don't Do Much Without Researching Things Myself": A mixed methods study exploring the role of parent health literacy in autism services use for young children. *Journal of Autism and Developmental Disorders*, *52*(8), 3598–3611. https://doi.org/10.1007/s10803-021-05240-0

Liu, B. M., Paskov, K., Kent, J., McNealis, M., Sutaria, S., Dods, O., Harjadi, C., Stockham, N., Ostrovsky, A., & Wall, D. P. (2023). Racial and ethnic disparities in geographic access to autism resources across the US. *JAMA Network Open*, *6*(1), e2251182. https://doi.org/10.1001/jamanetworkopen.2022.51182

Lovaas O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, *55*(1), 3–9. https://doi.org/10.1037//0022-006x.55.1.3

Lovelace, T., Robertson, R.E., & Tamayo, S. (2018). Experiences of African American mothers of sons with autism spectrum disorder: Lessons for improving service delivery. *Education and Training in Autism and Developmental Disabilities, 53*, 3-16. https://www.jstor.org/stable/26420423

Loyd, A. B., Hotton, A. L., Walden, A. L., Kendall, A. D., Emerson, E., & Donenberg, G. R. (2019). Associations of ethnic/racial discrimination with internalizing symptoms and externalizing behaviors among juvenile justice-involved youth of color. *Journal of Adolescence, 75*, 138–150. https://doi.org/10.1016/j.adolescence.2019. 07.012

Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2006). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities, 12*(1), 41–52.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2019). “I wouldn’t know where to start”: perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism, 1362361319882227*. https://doi.org/10.1177/1362361319882227.

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., Nguyen, R. H. N., … Shaw, K. A. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C. : 2002)*, *72*(2), 1–14. https://doi.org/10.15585/mmwr.ss7202a1Magnusson, D. M., & Mistry, K. B. (2017). Racial and ethnic disparities in unmet need for pediatric therapy services: The role of family-centered care. *Academic Pediatrics*, *17*(1), 27–33. https://doi.org/10.1016/j.acap.2016.06.010

Mandell, D. S., Barry, C. L., Marcus, S. C., Xie, M., Shea, K., Mullan, K., & Epstein, A. J. (2016). Effects of autism spectrum disorder insurance mandates on the treated prevalence of autism spectrum disorder. *JAMA Pediatrics*, *170*(9), 887–893. https://doi.org/10.1001/jamapediatrics.2016.1049

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American*

Academy of Child and Adolescent Psychiatry, *41*(12), 1447–1453. https://doi.org/10.1097/00004583-200212000-00016

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *37*(9), 1795–1802. https://doi.org/10.1007/s10803-006-0314-8

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, *99*(3), 493–498. https://doi.org/10.2105/AJPH.2007.131243

Martinez, M., Thomas, K. C., Williams, C. S., Christian, R., Crais, E., Pretzel, R., & Hooper, S. R. (2018). Family experiences with the diagnosis of autism spectrum disorder: System barriers and facilitators of efficient diagnosis. *Journal of Autism and Developmental Disorders*, *48*(7), 2368–2378. https://doi.org/10.1007/s10803-018-3493-1

McCormack, G., Dillon, A. C., Healy, O., Walsh, C., & Lydon, S. (2020). Primary care physicians' knowledge of autism and evidence-based interventions for autism: a systematic review. *Review Journal of Autism and Developmental Disorders, 7*(3), 226–241. https://doi.org/10.1007/s40489-019-00189-4

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, *97*(4), 359–391.

McMiller, W. P., & Weisz, J. R. (1996). Help-seeking preceding mental health clinic intake among African-American, Latino, and Caucasian youths. *Journal of the American Academy of Child & Adolescent Psychiatry*, *35*(8), 1086–1094. https://doi.org/10.1097/00004583-199608000-00020

McNeil, C. B., Capage, L. C., & Bennett, G. M. (2002). Cultural issues in the treatment of young African American children diagnosed with disruptive behavior disorders. *Journal of Pediatric Psychology*, *27*(4), 339–350. https://doi.org/10.1093/jpepsy/27.4.339

Megerian, J. T., Dey, S., Melmed, R. D., Coury, D. L., Lerner, M., Nicholls, C. J., Sohl, K., Rouhbakhsh, R., Narasimhan, A., Romain, J., Golla, S., Shareef, S., Ostrovsky, A., Shannon, J., Kraft, C., Liu-Mayo, S., Abbas, H., Gal-Szabo, D. E., Wall, D. P., & Taraman, S. (2022). Evaluation of an artificial intelligence-based medical device for diagnosis of autism spectrum disorder. *NPJ Digital Medicine*, *5*(1), 57. https://doi.org/10.1038/s41746-022-00598-6

Mello, M. P., Urbano, R. C., Goldman, S. E., & Hodapp, R. M. (2016). Services for children with autism spectrum disorder: Comparing rural and non-rural communities. *Education and Training in Autism and Developmental Disabilities, 51,* 355–365. http://www.jstor.org/stable/26173863

Montes, G., & Halterman, J. S. (2011). White-Black disparities in family-centered care among children with autism in the United States: Evidence from the NS-CSHCN 2005-2006. *Academic Pediatrics*, *11*(4), 297–304. https://doi.org/10.1016/j.acap.2011.02.002

Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities*, *89*, 10–21. https://doi.org/10.1016/j.ridd.2019.03.001

Morgan E. H., Stahmer A. C. (2020). Narratives of single, black mothers using cultural capital to access autism interventions in schools. *British Journal of Sociology of Education*, 42, 48–65. https://doi.org/10.1080/01425692.2020.1861927

Murry, V. M., Butler-Barnes, S. T., Mayo-Gamble, T. L., & Inniss-Thompson, M. N. (2018). Excavating new constructs for family stress theories in the context of everyday life experiences of Black American families. *Journal of Family Theory & Review, 10*, 384–405. https://doi.org/10.1111/jftr.12256

Muvuka, B., Combs, R. M., Ayangeakaa, S. D., Ali, N. M., Wendel, M. L., & Jackson, T. (2020). Health literacy in African-American communities: Barriers and strategies. *Health Literacy Research and Practice*, *4*(3), e138–e143. https://doi.org/10.3928/24748307-20200617-01

Nadal, K. L., Griffin, K. E., Wong, Y., Hamit, S., & Rasmus, M. (2014). The impact of racial microaggressions on mental health: Counseling implications for clients of color. *Journal of Counseling & Development, 92*(1), 57–66. https://doi.org/10.1002/j.1556-6676.2014.00130.x

Nelson, C. A. (2016). Frontlines: Policing at the nexus of race and mental health, *Urban Law Journal*, *43* (3), 615-684. Page 618.

Nichols T., Gringle M., Pulliam R. (2015). “You have to put your children’s needs first or you’re really not a good mother”: Black motherhood and self-care practices. *Women, Gender, and Families of Color*, 3, 165–189. https://doi.org/10.5406/womgenfamcol.3.2.0165

Nik Adib, N. A., Ibrahim, M. I., Ab Rahman, A., Bakar, R. S., Yahaya, N. A., Hussin, S., & Wan Mansor, W. N. A. (2019). Perceived stress among caregivers of children with autism spectrum disorder: A state-wide study. *International Journal of Environmental Research and Public Health*, *16*(8), 1468. MDPI AG. http://dx.doi.org/10.3390/ijerph16081468

Nonweiler, J., Rattray, F., Baulcomb, J., Happé, F., & Absoud, M. (2020). Prevalence and associated factors of emotional and behavioural difficulties during COVID-19 pandemic in children with neurodevelopmental disorders. *Children, 7*(9), 128. https://doi.org/10.3390/children7090128

Ngui, E. M., & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: The roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*, *117*(4), 1184–1196. https://doi.org/10.1542/peds.2005-1088

Office of the Surgeon General (US), Center for Mental Health Services (US), & National Institute of Mental Health (US). (2001). *Mental Health: Culture, race, and ethnicity: A supplement to mental health: A report of the Surgeon General*. Substance Abuse and Mental Health Services Administration (US).

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*(6), 1092–1103. https://doi.org/10.1007/s10803-007-0497-7

Ozonoff, S., Heung, K., Byrd, R., Hansen, R., & Hertz-Picciotto, I. (2008). The onset of autism: Patterns of symptom emergence in the first years of life. *Autism: The International Journal of Research and Practice, 1*(6), 320–328. https://doi.org/10.1002/aur.53

Ozonoff, S., Iosif, A. M., Baguio, F., Cook, I. C., Hill, M. M., Hutman, T., Rogers, S. J., Rozga, A., Sangha, S., Sigman, M., Steinfeld, M. B., & Young, G. S. (2010). A prospective study of the emergence of early behavioral signs of autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, *49*(3), 256–66.e662.

Parmeggiani, A., Corinaldesi, A., & Posar, A. (2019). Early features of autism spectrum disorder: a cross-sectional study. *Italian Journal of Pediatrics*, *45*(1), 144. https://doi.org/10.1186/s13052-019-0733-8

Pearson, J.N., & Meadan, H. (2018). African American parents' perceptions of diagnosis and services for children with autism. *Education and Training in Autism and Developmental Disabilities, 53*, 17-32.

Pearson, J. N., Meadan, H., Malone, K. M., & Martin, B. M. (2020a). Parent and professional experiences supporting African-American children with autism. *Journal of Racial and Ethnic Health Disparities*, *7*(2), 305–315. https://doi.org/10.1007/s40615-019-00659-9

Pearson, J. N., Traficante, A. L., Denny, L. M., Malone, K., & Codd, E. (2020b). Meeting FACES: Preliminary findings from a community workshop for minority parents of children with autism in central North Carolina. *Journal of Autism and Developmental Disorders*, *50*(1), 1–11. https://doi.org/10.1007/s10803-019-04295-4

Petrongolo, M. (2014). Stress in mothers of newly diagnosed children with autism spectrum disorders: Barriers to care, use of support services, and child behavior. *PCOM Psychology Dissertations*. 300. https://digitalcommons.pcom.edu/psychology_dissertations/300

Pickard, K. E., & Ingersoll, B. R. (2016). Quality versus quantity: The role of socioeconomic status on parent-reported service knowledge, service use, unmet service needs, and barriers to service use. *Autism, 20,* 106–115. https://doi.org/10.1177/1362361315569745

Postorino, V., Sharp, W. G., McCracken, C. E., Bearss, K., Burrell, T. L., Evans, A. N., & Scahill, L. (2017). A systematic review and meta-analysis of parent training for disruptive behavior in children with autism spectrum disorder. *Clinical Child and Family Psychology Review, 20*(4), 391–402. https://doi.org/10.1007/s10567-017-0237-2

Prakash B. (2010). Patient satisfaction. *Journal of Cutaneous and Aesthetic Surgery*, *3*(3), 151–155. https://doi.org/10.4103/0974-2077.74491

Price, M. A., Weisz, J. R., McKetta, S., Hollinsaid, N. L., Lattanner, M. R., Reid, A. E., & Hatzenbuehler, M. L. (2022). Meta-analysis: Are psychotherapies less effective for Black youth in communities with higher levels of anti-Black racism? *Journal of the American Academy of Child and Adolescent Psychiatry*, *61*(6), 754–763. https://doi.org/10.1016/j.jaac.2021.07.808

Ramirez, A. V., Ojeaga, M., Espinoza, V., Hensler, B., & Honrubia, V. (2021). Telemedicine in Minority and Socioeconomically Disadvantaged Communities Amidst COVID-19 Pandemic. *Otolaryngology, 164*(1), 91–92. https://doi.org/10.1177/0194599820947667

Rava, J., Shattuck, P., Rast, J., & Roux, A. (2017). The prevalence and correlates of involvement in the criminal justice system among youth on the autism spectrum. *Journal of Autism and Developmental Disorders, 47*(2), 340–346. https://doi.org/10.1007/s10803-016-2958-3

Reynolds, C. R., & Suzuki, L. A. (2013). Bias in psychological assessment: An empirical review and recommendations. In J. R. Graham, J. A. Naglieri, & I. B. Weiner (Eds.), *Handbook of psychology: Assessment psychology* (pp. 82–113). John Wiley & Sons, Inc.

Rivera-Figueroa, K., Marfo, N. Y. A., & Eigsti, I. M. (2022). Parental perceptions of autism spectrum disorder in Latinx and Black sociocultural contexts: A systematic review. *American Journal on Intellectual and Developmental Disabilities*, *127*(1), 42–63. https://doi.org/10.1352/1944-7558-127.1.42

Salsberg, E., Richwine, C., Westergaard, S., Portela Martinez, M., Oyeyemi, T., Vichare, A., & Chen, C. P. (2021). Estimation and comparison of current and future racial/ethnic representation in the US health care workforce. *JAMA Network Open, 4*(3), e213789. https://doi.org/10.1001/jamanetworkopen.2021.3789

Sanders, M. R., Prinz, R. J., & Shapiro, C. J. (2009). Predicting utilization of evidence-based parenting interventions with organizational, service-provider and client variables. *Administration and Policy in Mental Health*, *36*(2), 133–143. https://doi.org/10.1007/s10488-009-0205-3

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, *119 Suppl 1*, S114–S121. https://doi.org/10.1542/peds.2006-2089Q

Schillinger D. (2021). Social Determinants, Health Literacy, and Disparities: Intersections and Controversies. *Health Literacy Research and Practice*, *5*(3), e234–e243. https://doi.org/10.3928/24748307-20210712-01

Sell, N. K., Giarelli, E., Blum, N., Hanlon, A. L., & Levy, S. E. (2012). A comparison of autism spectrum disorder DSM-IV criteria and associated features among African American and white children in Philadelphia County. *Disability and Health Journal*, *5*(1), 9–17. https://doi.org/10.1016/j.dhjo.2011.08.002

Shaia, W. E., Nichols, H. M., Dababnah, S., Campion, K., & Garbarino, N. (2020). Brief report: Participation of Black and African-American families in autism research. *Journal of*

Autism and Developmental Disorders, *50*(5), 1841–1846. https://doi.org/10.1007/s10803-019-03926-0

Silva, L. M., & Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders, 42* (4), 566-574. doi: 10.1007/s10803-011-1274-1.

Sivberg B. (2002). Coping strategies and parental attitudes, a comparison of parents with children with autistic spectrum disorders and parents with non-autistic children. *International Journal of Circumpolar Health*, *61 Suppl 2*, 36–50. https://doi.org/10.3402/ijch.v61i0.17501

Smith, T., & Iadarola, S. (2015). Evidence base update for autism spectrum disorder. *Journal of Clinical Child and Adolescent Psychology*, *44*(6), 897–922. https://doi.org/10.1080/15374416.2015.1077448

Smith-Young, J., Chafe, R., & Audas, R. (2020). "Managing the wait": Parents' experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. *Health Services Insights*, *13*, 1178632920902141. https://doi.org/10.1177/1178632920902141

Spain, D., Mason, D., J Capp, S., Stoppelbein, L., W White, S., & Happé, F. (2021). "This may be a really good opportunity to make the world a more autism friendly place": Professionals' perspectives on the effects of COVID-19 on autistic individuals. *Research in Autism Spectrum Disorders*, *83*, 101747. https://doi.org/10.1016/j.rasd.2021.101747

SPARK Consortium (2018). SPARK: A US cohort of 50,000 families to accelerate autism research. *Neuron*, *97*(3), 488–493. https://doi.org/10.1016/j.neuron.2018.01.015

Stahmer, A. C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities*, *6*(4), 752–773. https://doi.org/10.1007/s40615-019-00575-y

Stanley, S. L. G. (2015). The advocacy efforts of African American mothers of children with disabilities in rural special education: Considerations for school professionals. *Rural Special Education Quarterly, 34,* 3-17. https://doi.org/10.1177/875687051503400402

Steinbrenner, J. R., McIntyre, N., Rentschler, L. F., Pearson, J. N., Luelmo, P., Jaramillo, M. E., Boyd, B. A., Wong, C., Nowell, S. W., Odom, S. L., & Hume, K. A. (2022). Patterns in reporting and participant inclusion related to race and ethnicity in autism intervention literature: Data from a large-scale systematic review of evidence-based practices. *Autism*, *26*(8), 2026–2040. https://doi.org/10.1177/13623613211072593

Straiton, D., Groom, B., & Ingersoll, B. (2021). A mixed methods exploration of community providers' perceived barriers and facilitators to the use of parent training with Medicaid-enrolled clients with autism. *Autism*, *25*(5), 1368–1381. https://doi.org/10.1177/1362361321989911

Sue, D. W., Capodilupo, C. M., & Holder, A. M. B. (2008). Racial microaggressions in the life experience of Black Americans. *Professional Psychology: Research and Practice, 39*(3), 329–336. https://doi.org/10.1037/0735-7028.39.3.329

Sue, D. W., & Sue, D. (2013). *Counseling the culturally diverse: Theory and practice* (6th ed.). Hoboken, NJ: John Wiley & Sons.

The Associated Press (2018). Video shows 2017 shooting of unarmed autistic man by police, AP NEWS, available at: https://apnews.com/article/shootings-north-america-us-news-il-state-wirepolice-243563ab47104b0996ed57216e6bbfcb (accessed 21 January 2022).

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorders*, *37*(10), 1902–1912. https://doi.org/10.1007/s10803-006-0323-7

Thompson, H. S., Valdimarsdottir, H. B., Jandorf, L., & Redd, W. (2003). Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: Differences across African American, Latina and Caucasian women. *Patient Education and Counseling*, *51*(3), 217–227. https://doi.org/10.1016/s0738-3991(02)00219-7

Tint, A., Palucka, A. M., Bradley, E., Weiss, J. A., & Lunsky, Y. (2017). Correlates of police involvement among adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-017-3182-5

Torino, G. C., Rivera, D. P., Capodilupo, C. M., Nadal, K. L., & Sue, D. W. (Eds.) (2019). *Microaggression theory: Influence and implications.* New York: John Wiley & Sons.

Turcotte, P., Shea, L. L., & Mandell, D. (2018). School discipline, hospitalization, and police contact overlap among individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(3), 883–891. https://doi.org/10.1007/s10803-017-3359-y

U.S. Census Bureau. (2015). American Community Survey 1-Year PUMS file. Retrieved from www.census.gov/programs-surveys/acs/data/pums.html . "Other" racial/ethnic groups included American Indian/Alaska Native, Native Hawaiian/Pacific Islander, and people of two or more races. U.S. doctorate holders included individuals in the workforce with a doctoral/professional degree in any field. Total may not sum to 100 percent due to rounding.

Wagner, S., Rubin, I. L., & Singh, J. S. (2022). Underserved and undermeasured: A mixed-method analysis of family-centered care and care coordination for low-income minority families of children with autism spectrum disorder. *Journal of Racial and Ethnic Health Disparities*, *9*(4), 1474–1487. https://doi.org/10.1007/s40615-021-01086-5

Wallace-Watkin, C., Sigafoos, J., & Waddington, H. (2022). Barriers and facilitators for obtaining support services among underserved families with an autistic child: A systematic qualitative review. *Autism*, *0*(0). https://doi.org/10.1177/13623613221123712

Wang, L., Li, D., Pan, S., Zhai, J., Xia, W., Sun, C., & Zou, M. (2021). The relationship between 2019-nCoV and psychological distress among parents of children with autism spectrum disorder. *Globalization and Health*, *17*(1), 23. https://doi.org/10.1186/s12992-021-00674-8

Weiss M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism: The International Journal of Research and Practice*, *6*(1), 115–130. https://doi.org/10.1177/1362361302006001009

Weitlauf, A. S., Miceli, A., Vehorn, A., Dada, Y., Pinnock, T., Harris, J. W., Hine, J., & Warren, Z. (2023). Screening, diagnosis, and intervention for autism: Experiences of Black and multiracial families seeking care. *Journal of Autism and Developmental Disorders*, 10.1007/s10803-022-05861-z. Advance online publication. https://doi.org/10.1007/s10803-022-05861-zWest, E. A., Travers, J. C., Kemper, T. D., Liberty, L. M., Cote, D. L., McCollow, M. M., & Stansberry Brusnahan, L. L. (2016).

Racial and ethnic diversity of participants in research supporting evidence-based practices for learners with autism spectrum disorder. *Journal of Special Education, 50*(3), 151–163. https://doi.org/10.1177/0022466916632495

White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernoia, B., Xiao, S., et al. (2021a). Brief report: Impact of COVID-19 on individuals with ASD and their caregivers: A perspective from the SPARK cohort. *Journal of Autism and Developmental Disorders, 1*(10), 3766–3773. https://doi.org/10.1007/s10803-020-04816-6

Williams, T. V., Hartmann, K., Paulson, J. F., Raffaele, C. T., & Urbano, M. R. (2019). Life after an autism spectrum disorder diagnosis: A comparison of stress and coping profiles of African American and Euro-American caregivers. *Journal of Autism and Developmental Disorders*, *49*(3), 1024–1034. https://doi.org/10.1007/s10803-018-3802-8

Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, *45*(7), 1951–1966. https://doi.org/10.1007/s10803-014-2351-z

Woodside, J., Rosenbaum, P., King, S., & King, G. (2001). Family-centered service: Developing and validating a self-assessment tool for pediatric service providers. *Children's Health Care, 30*, 237-252. https://doi.org/10.1207/S15326888CHC3003_5

Yan, H. X. (2022). Race, socioeconomic status, and mothers' parental stress. *Society and Mental Health*, *12*(2), 99–118. https://doi.org/10.1177/21568693221091690

Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of autism in a US metropolitan area. *JAMA*, *289*(1), 49–55. https://doi.org/10.1001/jama.289.1.49

Zampella, C. J., Wang, L. A. L., Haley, M., Hutchinson, A. G., & de Marchena, A. (2021). motor skill differences in autism spectrum disorder: A clinically focused review. *Current Psychiatry Reports*, *23*(10), 64. https://doi.org/10.1007/s11920-021-01280-6

Table 1

Demographic Information of Caregivers and their Children.

Variable		Total *N*=101	Mean	Range [Min, Max]	SD
		***N* (%)**			
Location	Rural	19 **(18.8%)**	-	-	-
	Urban	39 **(38.6%)**	-	-	-
	Suburban	43 **(42.6%)**	-	-	-
Child age, in years		99	9.19	[2, 20]	4.869
Caregiver age, in years		100	39.65	[22, 64]	8.53
Number of Children in House		101	2.21	[1, 6]	1.169
Child gender	Female	24 **(23.8%)**	-	-	-
	Male	77 **(76.2%)**	-	-	-
Caregiver Race/Ethnicity					
	African American	69 **(68.3%)**	-	-	-
	Multiracial	15 **(14.9%)**	-	-	-
	Latinx	1 **(1.0%)**	-	-	-
	African	6 **(5.9%)**	-	-	-
	Caribbean	6 **(5.9%)**	-	-	-

	Other	7 **(6.9%)**	-	-	-
Child Race/Ethnicity	African American	68 **(67.3)**	-	-	-
	Multiracial	30 **(29.7%)**	-	-	-
	Latinx	1 **(1.0%)**	-	-	-
	African	5 **(5.0%)**	-	-	-
	Caribbean	2 **(2.0%)**	-	-	-
	Other	2 **(2.0%)**	-	-	-
Income	<20,000	17 **(16.8%)**	-	-	-
	21,000-35,000	15 **(14.9%)**	-	-	-
	36,000-50,000	19 **(18.8%)**	-	-	-
	51,000-65,000	9 **(8.9%)**	-	-	-
	66,000-80,000	8 **(7.9%)**	-	-	-
	81,000-100,000	13 **(12.9%)**	-	-	-
	101,000-130,000	13 **(12.9%)**	-	-	-
	131,000-160,000	2 **(2.0%)**	-	-	-
	Over 161,000	5 **(5.0%)**	-	-	-
Relationship Status	Married	56 **(55.4%)**	-	-	-

	Divorced	11 **(10.9%)**	-	-	-
	With Partner	12 **(11.9%)**			
	Single	20 **(19.8%)**			
Caregiver Gender	Female	92 **(91.1%)**	-	-	-
	Male	8 **(7.9%)**	-	-	-
	Other	1 **(1.0%)**	-	-	-
Caregiver Relationship	Mother	91 **(90.1%)**	-	-	-
	Father	7 **(6.9%)**	-	-	-
	Grandparent	3 **(3.0%)**	-	-	-
Education Level	Some High School	2 **(2.0%)**	-	-	-
	GED Diploma	6 **(5.9%)**	-	-	-
	High School	19 **(18.8%)**	-	-	-
	Trade or Vocational	11 **(10.9%)**	-	-	-
	Associate degree	10 **(9.9%)**	-	-	-
	Some College	18 **(17.8%)**	-	-	-
	Four-Year Degree	10 **(9.9%)**	-	-	-
	Some Graduate School	5 **(5.0%)**	-	-	-

Graduate/Professional Degree	19 **(18.8%)**	-	-	-

Table 2

Correlation Analysis of Barriers, Parental Stress, Treatment Effectiveness and Satisfaction

Variable	1	2	3	4	5
1. Parental Stress	-	-			
2. Racial Barriers	.388**	-			
3. Practical Barriers	.560**	.605**	-		
4. Perceived Treatment Effectiveness	-.215*	-.217*	-.378**	-	
5. Perceived Treatment Satisfaction	-.251*	-.358*	-.418**	.624**	-

**Correlation is significant at the <.001 level.

*Correlation is significant at the <.05 level.

Table 3

Descriptive Statistics of Study Variables

Variable *N*=101	Mean	SD	[Min, Max]
Parental Stress	40.42	12.23	[19,63]
Racial Barriers	65.29	18.38	[32,115]
Practical Barriers	81.85	29.11	[44,165]
Treatment Effectiveness	3.40	.584	[2,4]
Treatment Satisfaction	3.18	.984	[0,4]

Table 4

Multiple Linear Regression Analysis of Parental Stress, Family Demographic Factors, and Practical Barriers to Treatment

Variable	t	p	β	F	R^2	ΔR^2
1. Family Demographic Factors		.001	-	7.410	.133	.133
Caregiver Education Level	1.682	.096	.202	-	-	-
Family Income	1.700	.092	.204	-	-	-
2. Practical Barriers and Covariates	-	<.001	-	23.429	.423	.290
Caregiver Education Level	1.968	.052	.193	-	-	-
Family Income	1.888	.062	.186	-	-	-
Practical Barriers	6.946	<.001	.539	-	-	-

Table 5

Multiple Linear Regression Analysis of Parental Stress, Family Demographic Factors, and Racial Barriers to Treatment.

Variable	t	p	β	F	R^2	ΔR^2
1. Family Demographic Factors		.001	-	7.410	.133	.133
Caregiver Education Level	1.682	.096	.202	-	-	-
Family Income	1.700	.092	.204	-	-	-
2. Racial Barriers and Covariates	-	<.001	-	10.250	.243	.110
Caregiver Education Level	1.645	.103	.185	-	-	-
Family Income	1.499	.137	.169	-	-	-
Racial Barriers	3.735	<.001	.335	-	-	-

Table 6

Ordinal Regression Analysis of Family Demographic Factors, Racial and Practical Barriers to Treatment, and Treatment Effectiveness and Satisfaction.

Domain (Predictor)	B	*SE*	Exp(B)	*p*	95% CI of Exp (B)	Chi-Square
1. Treatment Effectiveness				.001		18.282
Caregiver Education Level	.238	.1163	1.268	.041	1.010-1.593	4.180
Family Income	-.101	.1100	.903	.356	.728-1.121	.8530
Practical Barriers	-.029	.0100	.972	.003	.954-.990	8.971
Racial Barriers	$2.77E^{-5}$	.0142	1.000	.998	.973-1.028	.000
2. Treatment Satisfaction				<.001		22.287
Caregiver Education Level	.155	.1100	1.168	.140	.950-1.434	2.176
Family Income	-.098	.1040	.907	.344	.740-1.111	.896
Practical Barriers	-.020	.0085	.981	.021	.964-.997	5.351
Racial Barriers	-.026	.0135	.975	.058	.949-1.001	3.589

Table 7

Frequencies of Caregiver Ratings of Treatment Effectiveness for Treatments (N = 101).

Treatment Name	Tried it	Child Improved Dramatically	Child Improved Somewhat	No Noticeable Effect	Child Became Worse
Speech and Language	86 (85.1%)	48 (55.8%)	30 (34.9%)	8 (9.3%)	0 (0%)
Occupational Therapy	77 (76.2%)	31 (40.3%)	35 (45.5%)	11 (14.3%)	0 (0%)
ABA	63 (62.4%)	25 (39.7%)	27 (42.9%)	10 (15.9%)	1 (1.6%)
BPT	40 (39.6%)	7 (17.5%)	7 (67.5%)	6 (15.0%)	0 (0%)
Physical Therapy	33(32.7%)	12 (36.4%)	16 (48.5%)	5 (15.2%)	0 (0%)
Talk Therapy	7(7.9%)	2 (28.6%)	3 (42.9%)	1 (14.3%)	1 (14.3%)
Play Therapy	2 (2.0%)	0 (0%)	1 (50.0%)	1 (50.0%)	0 (0%)
Social Skills Training	4 (4.0%)	1 (25.0%)	3 (75.0%)	0 (0%)	0 (0%)
Medication	2 (2.0%)	1 (50.0%)	1 (50.0%)	0 (0%)	0 (0%)
Feeding Therapy	3 (3.0%)	1 (25.0%)	0 (0%)	2 (75.0%)	0 (0%)
School Therapy	5 (5.0%)	2 (40.0%)	2 (40.0%)	1 (20.0%)	0 (0%)
Music Therapy	3 (3.0%)	2 (66.7%)	0 (0%)	1 (33.3%)	0 (0%)
Neurofeedback	2 (2.0%)	0 (0%)	1 (50.0%)	0 (0%)	1 (50.0%)

*Note*s. Caregivers utilized multiple treatment services so treatment frequencies do not add up to 100. Applied Behavioral Analysis (ABA), Behavior Parent Training (BPT)

Table 8

Frequencies of Caregiver Ratings of Treatment Satisfaction for Treatments (N = 101).

Treatment Name	Tried it	Very Satisfied	Slightly Satisfied	Neither Satisfied or Dissatisfied	Slightly Dissatisfied	Very Dissatisfied
Speech and Language	86(85.1%)	49 (57.0%)	22 (25.6%)	7 (8.1%)	6 (7.0%)	2 (2.3%)
Occupational Therapy	77 (76.2%)	35 (46.1%)	22 (28.9%)	12 (15.8%)	5 (6.6%)	2 (2.6%)
ABA	63 (62.4%)	30 (47.6%)	18 (28.6%)	6 (9.5%)	5 (7.9%)	4 (6.3%)
BPT	40 (39.6%)	11 (27.5%)	21 (52.5%)	6 (15.0%)	2 (5.0%)	0 (0%)
Physical Therapy	33(27.5%)	17 (51.5%)	10 (30.3%)	4 (12.1%)	1 (3.0%)	1 (3.0%)
Talk Therapy	8 (7.9%)	5 (62.5%)	0 (0%)	2 (25.0%)	1 (12.5%)	0 (0%)
Play Therapy	2 (2.0%)	0 (0%)	1 (50.0%)	0 (0%)	1 (50.0%)	0 (0%)
Social Skills Training	4 (4.0%)	2 (50.0%)	1 (25.0%)	0 (0%)	0 (0%)	1 (25.0%)
Medication	2 (2.0%)	1 (50.0%)	1 (50.0%)	0 (0%)	0 (0%)	0 (0%)
Feeding Therapy	3 (3.0%)	2 (66.7%)	0 (0%)	1 (33.3%)	0 (0%)	0 (0%)
School Therapy	5 (5.0%)	3 (60.0%)	2 (40.0%)	0 (0%)	0 (0%)	0 (0%)
Music Therapy	3 (3.0%)	3 (100%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Neurofeedback	2 (2.0%)	1 (50.0%)	1 (50.0%)	0 (0%)	0 (0%)	0 (0%)

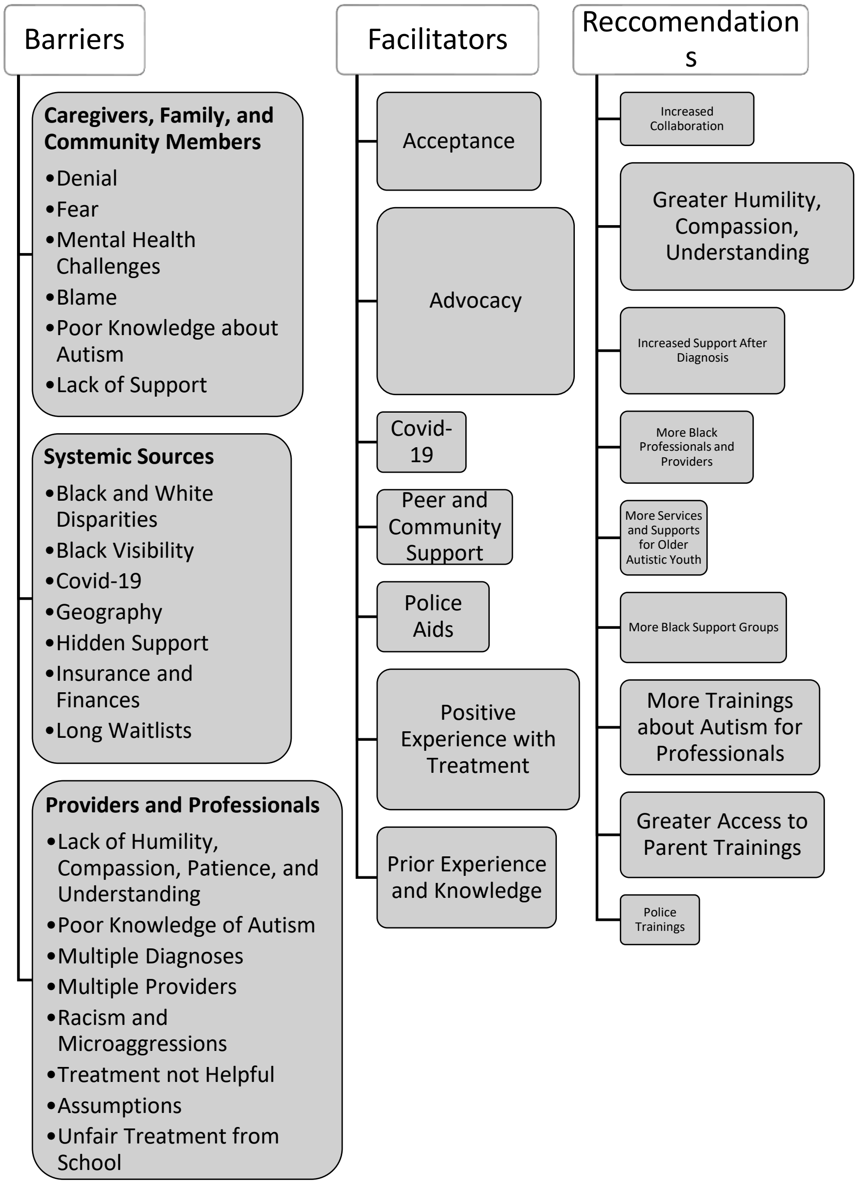
Notes. Applied Behavioral Analysis (ABA), Behavior Parent Training (BPT

Table 9

Wilcoxon Signed Rank Tests: Comparison of Treatment Effectiveness and Treatment Satisfaction

Treatment Type (*N*)	*Asym. Sig (2-tailed)*	T	z
Applied Behavioral Analysis (*62*)	.164	122.5	-1.392
Speech Therapy (*86*)	.055	205.5	-1.196
Physical Therapy (*33*)	.858	63.0	0.179
Occupational Therapy (*77*)	.094	249.5	-1.675
Behavioral Parent Training (*40*)	.791	25.0	-0.265

Figure 1 Barriers, Facilitators, and Recommendations Experienced by Black Families of Autistic Youth



APPENDIX A

Family Background Questionnaire

	Response Options
Caregiver Gender	Male Female Other Prefer not to answer
Relationship to Child	Mother Father Grandparent Aunt Uncle Step mother Step father Foster parent or guardian Other
Caregiver Age	0-99 years
Caregiver Race/Origin	Black-African American Black-Multiracial Black-African Black-Latinx Black-Caribbean
Marital Status	Single Cohabitating Partner Married Divorced Widowed
Based on the pictures below, choose which geographical image best fits your location	Urban Rural Suburban

	 Urban, suburban and rural communities
Highest Level of Education	Did not attend high school Some high school GED Diploma High school graduate Trade or vocational school (after high school) Associate Degree (two-year degree) Competed some college Baccalaureate Degree (four-year degree) Some graduate school Graduate/professional degree (M.D., Ph.D., M.A/M.S., M.B.A., etc.)
Annual Family Income	Less than $20,000 $21,000-$35,000 $36,000-$50,000 $51,000-$65,000 $66,000-$80,000 $81,000-$100,000 $101,000-$130,000 $131,000-$160,000 Over $161,000
Total # of children in the household	Range (>0)
Child Gender	Male Female Trans-male Trans-female Agender Nonbinary Gender fluid Intersex
Child Race/Origin	Black-African American Black-Multiracial

	Black-African Black-Latinx Black-Caribbean
Child current age	Range (0-20)
Who first noticed symptoms of autism in your child?	Pediatrician Child Psychiatrist Child Psychologist Pediatric Neurologist School professionals Me Another caregiver Family members or friends Other (Open-ended) Unsure
How old was your child when a professional first suggested that your child might have autism	Range (0-20)
Who diagnosed your child with autism?	Pediatrician Child Psychiatrist Child Psychologist Pediatric Neurologist Occupational Therapist Other (Open-ended)
Child Age of Diagnoses	Range (0-20)
How old was your child when they first received any professional or educational services for autism?	Range (0-20)

APPENDIX B

Parent Version of the Barriers to Treatment Participation Scale– (BTPS)

Below is a list of statements that some parents have about seeking psychological help, counseling, or advice for their child or adolescents. For each item, please check a box to indicate how much you agree with the statement.

	Totally disagree	Somewhat disagree	Neutral	Somewhat agree	Totally agree
I. *Stressors and Obstacles That Compete With Treatment*					
1. We do not have transportation (car, truck, taxi) to travel to treatment	☐	☐	☐	☐	☐
2. My child is involved in other activities (sports, clubs, music lessons) that would make it hard to come to a session	☐	☐	☐	☐	☐
3. Scheduling appointment times for treatment is difficult	☐	☐	☐	☐	☐
4. Treatment conflicts with other activities in which I am involved	☐	☐	☐	☐	☐
5. I experience too much stress in my life to participate in treatment	☐	☐	☐	☐	☐
6. My personal health problems or illness stops me from getting treatment for him or her	☐	☐	☐	☐	☐
7. My child's health problems or illness stops me from getting treatment for him or her	☐	☐	☐	☐	☐
8. Crises at home gets in the way	☐	☐	☐	☐	☐
9. Treatment adds more stress to my life	☐	☐	☐	☐	☐
10. Bad weather prevents us from coming to treatment	☐	☐	☐	☐	☐
11. My time is limited; I don't have time for the assigned work	☐	☐	☐	☐	☐
12. My child is never home long enough to do the homework assigned	☐	☐	☐	☐	☐

13. Family health problems or illness in our home stops me from getting treatment for my child	☐	☐	☐	☐	☐
14. Getting a babysitter so I can come to treatment with my child is a problem	☐	☐	☐	☐	☐
15. Parking at the treatment agency stops me from getting treatment for my child	☐	☐	☐	☐	☐
16. Members of my family stop me from getting treatment for my child or they disagree with me about whether we should come to treatment at all	☐	☐	☐	☐	☐
17. I am too tired after work to go to sessions	☐	☐	☐	☐	☐
18. My job schedule is too hectic	☐	☐	☐	☐	☐
19. Treatment takes time away from spending time with my children	☐	☐	☐	☐	☐
20. I have trouble with other children at home, which makes it hard to come to treatment	☐	☐	☐	☐	☐
II. Treatment Demands and Issues					
21. My child refuses to go to the sessions	☐	☐	☐	☐	☐
22. Treatment takes too long (too many weeks)	☐	☐	☐	☐	☐
23. Treatment cost too much	☐	☐	☐	☐	☐
24. Billing is a big hassle	☐	☐	☐	☐	☐
25. Information we get from treatment (handouts, referral information) is confusing for me or my child	☐	☐	☐	☐	☐
26. My child has trouble understanding treatment	☐	☐	☐	☐	☐
27. Treatment is more work than I thought it would be	☐	☐	☐	☐	☐
28. The atmosphere at the clinic makes appointments uncomfortable	☐	☐	☐	☐	☐
29. I don’t have a say in my child’s treatment	☐	☐	☐	☐	☐
30. The work assigned to me as part of this treatment is difficult	☐	☐	☐	☐	☐
III. Perceived Irrelevance of Treatment					

31. Treatment is not necessary	☐	☐	☐	☐	☐
32. Treatment is not what I expected	☐	☐	☐	☐	☐
33. I lose interest in coming to sessions	☐	☐	☐	☐	☐
34. Treatment becomes less important as it goes on	☐	☐	☐	☐	☐
35. Treatment does not focus on my child's life and problems.	☐	☐	☐	☐	☐
36. Treatment "brings out" new or different problems in my child	☐	☐	☐	☐	☐
37. My child's behavior will improve on its own; treatment is not needed	☐	☐	☐	☐	☐
38. Treatment does not work	☐	☐	☐	☐	☐
IV. *Problematic Relationship With the Therapist*					
39. I don't have a good relationship with the therapist	☐	☐	☐	☐	☐
40. I have to give too much personal information to the therapist	☐	☐	☐	☐	☐
41. The therapist is not confident that treatment will work	☐	☐	☐	☐	☐
42. The therapist questions my ability to carry out treatment programs at home	☐	☐	☐	☐	☐
43. The therapist does not support me or my efforts	☐	☐	☐	☐	☐
44. The therapist does not call enough	☐	☐	☐	☐	☐

APPENDIX C

Racial Barriers to Treatment Participation Scale

THE STATEMENTS BELOW ARE INTENDED TO REPRESENT SOME SITUATIONS THAT MAY HAVE OCCURRED OVER THE COURSE OF OBTAINING TREATMENT SERVICES FOR YOUR CHILD. AS WELL AS SOME BELIEFS THAT SOME BLACK PARENTS MAY HAVE AS THEY SEEK SERVICES FOR THEIR CHILD. FOR EACH ITEM, PLEASE CHECK A BOX TO INDICATE HOW MUCH YOU AGREE WITH THE STATEMENT.

	Totally Disagree	**Somewhat Disagree**	**Neutral**	**Somewhat Agree**	**Totally Agree**
I. Racial Microaggressions					
1. My provider avoided discussing or addressing racial issues in our session(s).					
2. My provider or therapist sometimes was insensitive about my cultural group when trying to understand or treat my concerns or issues (e.g., “You should disengage or separate from your family of origin if they are causing you problems.”).					
3. My provider or therapist seemed to deny having any cultural biases or stereotypes (e.g., “I’m not racist because some of my best friends are Black.”).					
4. My provider or therapist may have thought at times that I was overly sensitive about racial issues (e.g., “Don’t be too sensitive about the racial stuff. I didn’t mean anything bad/offensive.”).					
5. My provider or therapist at times seemed to over-identify with my experiences related to my race (e.g., “As a gay person, I know just what it’s like to be discriminated against.”)					

6. My provider or therapist at times seemed to have stereotypes about my racial group, even if he or she did not express them directly (e.g., “I know that Black people are very religious” and “Did you grow up in the inner city? or “You are so articulate.”).					
7. My provider or therapist sometimes seemed unaware of the realities of race and racism (e.g., “When I look at you, I don’t see color.” Or “Everyone can succeed in this society, if they work hard enough.”).					
8. My provider or therapist at times may have either overestimated or underestimated my capabilities or strengths based on my racial group membership (e.g., “I’m sure you can cope with this problem as a strong Black woman” and “Black people are so cool.”).					
9. My provider or therapist sometimes minimized the importance of racial issues in our session(s) (e.g., “I’m not sure we need to focus on race to understand your child’s behavior).					
10. My provider or therapist may have offered help that was inappropriate or unneeded based on my racial group membership (e.g., “I don’t usually do this, but I can waive your fees if you can’t afford to pay for counseling.”)					
II. Family and Community Beliefs					
11. I know a lot about my child’s disorder.*					

12. I know a lot about treatment services for my child’s disorder.*					
13. I believe my child’s behavior will improve on its own; treatment is not needed.					
14. I trust the health professionals providing the treatment services.*					
15. I trust the treatment services provided. *					
16. Members of my family or friends agree with me about whether we should come to treatment.*					
17. My family or friends blame me for child’s behavior problems.					
18. I believe faith plays a stronger role in my child’s well-being than treatment services.					
19. I fear my child faces risk of prejudice and discrimination.					
20. Treatment was worse than what I expected it to be.					
III. *Treatment*					
21. The treatment environment was inclusive of my race (e.g. People of color on their website, handouts, waiting room magazines, treatment materials).*					
22. I felt rushed, like I wasn’t getting enough treatment time or time to talk to my provider.					
23. It seemed like my provider was knowledgeable about the problems my child was facing. *					
24. I understood all the terms and language my child’s providers and therapists used.*					
25. I would prefer if my child’s provider was Black, like me.					
26. I have connections to other Black families going through the same thing. *					
27. I needed to educate myself; no community resources or educational resources were provided to me.					

28. I was afraid or too shy to ask my child’s therapist or provider questions.					
29. My child was misdiagnosed previously.					

**items reverse coded*

APPENDIX D

Parental Stress Scale

	Strongly Disagree	**Disagree**	**Undecided**	**Agree**	**Strongly Agree**
1. I am happy in my role as a parent.*					
2. There is little or nothing I wouldn't do for my child(ren) if it was necessary.*					
3. Caring for my child(ren) sometimes takes more time and energy than I have to give.					
4. I sometimes worry whether I am doing enough for my child(ren).					
5. I feel close to my child(ren). *					
6. I enjoy spending time with my child(ren). *					
7. My child(ren) is an important source of affection for me. *					
8. Having child(ren) gives me a more certain and optimistic view for the future.*					
9. The major source of stress in my life is my child(ren).					
10. Having child(ren) leaves little time and flexibility in my life.					
11. Having child(ren) has been a financial burden.					
12. It is difficult to balance different responsibilities because of my child(ren).					
13. The behaviour of my child(ren) is often embarrassing or stressful to me.					

14. If I had it to do over again, I might decide not to have child(ren).					
15. I feel overwhelmed by the responsibility of being a parent.					
16. Having child(ren) has meant having too few choices and too little control over my life.					
17. I am satisfied as a parent.*					
18. I find my child(ren) enjoyable.*					

APPENDIX E

Treatment Effectiveness Ratings

Overall Treatment Effectiveness		**Child improved dramatically**	**Child improved somewhat**	**No noticeable effect**	**Child became worse**
How would you rate your child's overall improvement for the treatment services you have used?					
Service Utilization	**Tried it**	**Child improved dramatically**	**Child improved somewhat**	**No noticeable effect**	**Child became worse**
Applied Behavioral Analysis (ABA)	☐				
Occupational Therapy	☐				
Physical Therapy	☐				
Behavioral Parent Training	☐				
Speech and Language Therapy	☐				
Other	☐				
*Open ended branched question for services selected: How long were you using this service (in months)?					

APPENDIX F

Treatment Satisfaction Ratings

Overall Treatment Satisfaction	**Very Satisfied**	**Slightly Satisfied**	**Neither Satisfied or Dissatisfied**	**Slightly Dissatisfied**	**Very Dissatisfied d**
Are you happy with the overall treatment services received by your child?	☐	☐	☐	☐	☐
Service Utilization: Are you happy with the treatment received by your child at….					
Applied Behavioral Analysis (ABA)	☐	☐	☐	☐	☐
Occupational Therapy	☐	☐	☐	☐	☐
Physical Therapy	☐	☐	☐	☐	☐
Behavioral Parent Training	☐	☐	☐	☐	☐
Speech and Language Therapy	☐	☐	☐	☐	☐
Other (Open ended)	☐	☐	☐	☐	☐

APPENDIX G

Semi-Structured Interview Questions

1. INTRODUCTION TO STUDY

2. Tell me about the concerns you were trying to address with the treatment services you sought for your child with ASD.

3. Please tell me about your experiences with obtaining an initial diagnosis of ASD.
(Probes):
    - How long did it take to receive a diagnosis?
    - How old was your child when they were diagnosed?
    - Number of visits/providers
    - Was your child ever diagnosed with something else prior to receiving an autism diagnosis?
    - Perceived knowledge of providers
    - Your knowledge of ASD and how it influenced your interactions with professionals
    - Perceived cultural responsiveness
    - How did your family and friends respond to his/her diagnosis?
    - How did you respond to his/her initial diagnosis?

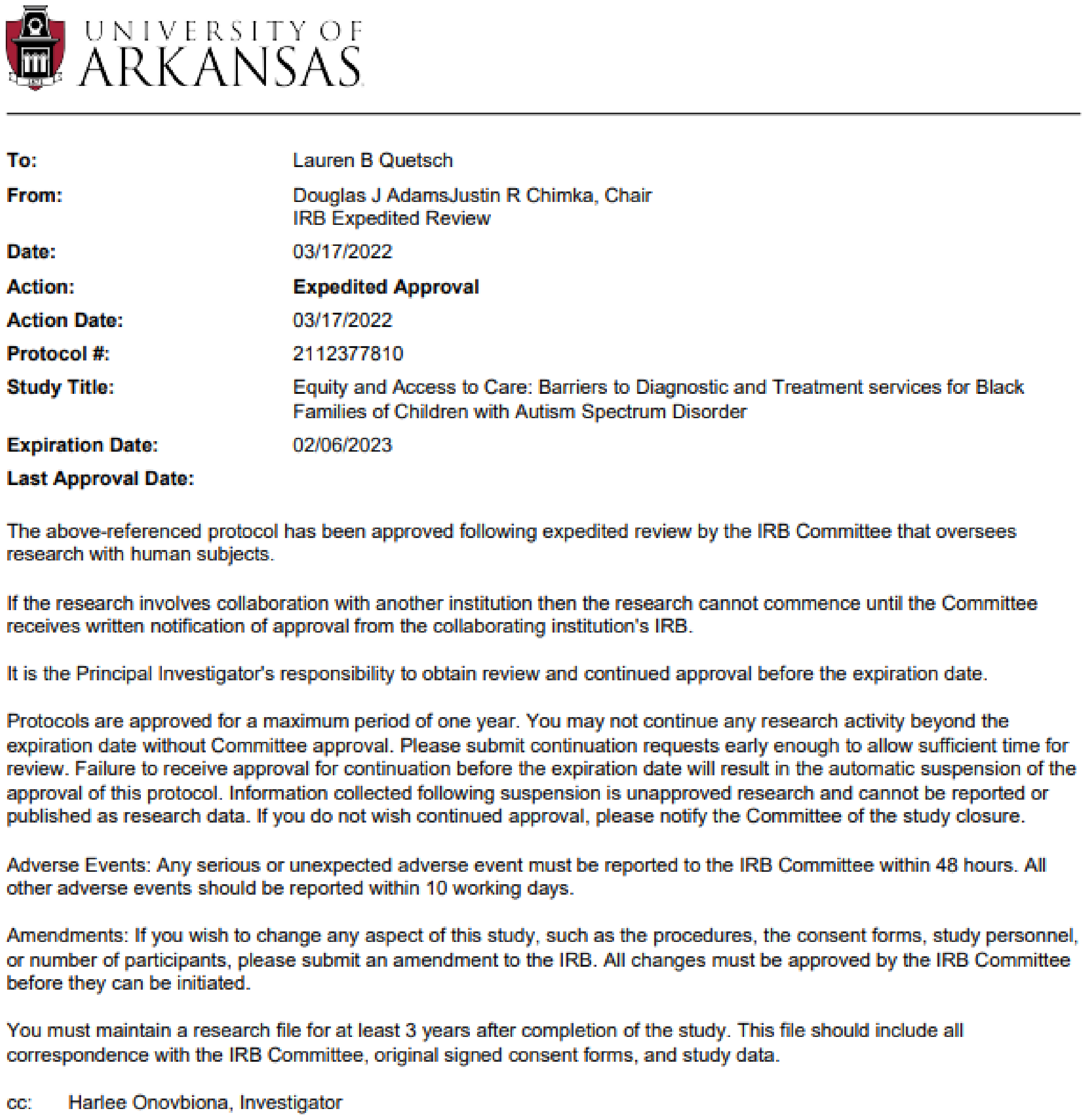
4. Please tell me about your experiences with accessing treatment services for your child.
(Probes):
    - How long did it take to access services?
    - What services has your child had so far?
    - Were the providers receptive to your needs and concerns?
    - What services have been the most and least helpful and why?
    - What challenges have you encountered while trying to get services? Why do you think you encountered those obstacles?
    - How have the obstacles you have encountered influence your stress levels and well-being?
    - Perceived cultural responsiveness?
    - Do you feel like you have adequate support? (e.g. from providers, family, friends, community)

5. What have your experiences been like as the parent of a child with ASD?
(Probes):
    - How has the pandemic affected your experience receiving treatment services or caring for your child with ASD?
    - Do you believe that being Black has had an effect on your experience, and if so how?
    - How has having a Black child with ASD affected your interactions with law enforcement?
    - Do you think there are any types of services or supports missing for Black families that have children with ASD? What type and how would they be beneficial?

6. What recommendations do you have for providers, educators, or other professionals to better serve the needs for Black families of children with ASD?
    - Is there anything you wish you had more of or less of during the process?

7. Is there anything else you would like to add?

APPENDIX H



UNIVERSITY OF ARKANSAS

To:	Lauren B Quetsch
From:	Douglas J AdamsJustin R Chimka, Chair IRB Expedited Review
Date:	03/17/2022
Action:	**Expedited Approval**
Action Date:	03/17/2022
Protocol #:	2112377810
Study Title:	Equity and Access to Care: Barriers to Diagnostic and Treatment services for Black Families of Children with Autism Spectrum Disorder
Expiration Date:	02/06/2023
Last Approval Date:	

The above-referenced protocol has been approved following expedited review by the IRB Committee that oversees research with human subjects.

If the research involves collaboration with another institution then the research cannot commence until the Committee receives written notification of approval from the collaborating institution's IRB.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date.

Protocols are approved for a maximum period of one year. You may not continue any research activity beyond the expiration date without Committee approval. Please submit continuation requests early enough to allow sufficient time for review. Failure to receive approval for continuation before the expiration date will result in the automatic suspension of the approval of this protocol. Information collected following suspension is unapproved research and cannot be reported or published as research data. If you do not wish continued approval, please notify the Committee of the study closure.

Adverse Events: Any serious or unexpected adverse event must be reported to the IRB Committee within 48 hours. All other adverse events should be reported within 10 working days.

Amendments: If you wish to change any aspect of this study, such as the procedures, the consent forms, study personnel, or number of participants, please submit an amendment to the IRB. All changes must be approved by the IRB Committee before they can be initiated.

You must maintain a research file for at least 3 years after completion of the study. This file should include all correspondence with the IRB Committee, original signed consent forms, and study data.

cc: Harlee Onovbiona, Investigator