

Chapter 1

Study Overview

For many parents, an initial autism diagnosis is the beginning of an uncertain journey fraught with questions regarding life outcomes, therapies, and schooling dilemmas. An initial autism diagnosis may also lead parents to question exactly what autism is. Autism spectrum disorder (ASD) is a neurodevelopment disorder characterized by repetitive behaviors, narrow interests, communication impairments, and impaired social interactions (Centers for Disease Control and Prevention [CDC], 2020; Montes & Halterman, 2011). Children and adults with autism may demonstrate a spectrum of communicative abilities ranging from verbal to nonverbal with challenges making and sustaining eye contact (Seltzer et al., 2003). Some individuals with autism display rigid behaviors with difficulty adapting to daily social changes (CDC, 2010). For families of children with autism, this characteristic often necessitates rigid scheduling of family routines, as variation in scheduling, for some children, can lead to behavioral meltdowns. Physically, some individuals with autism demonstrate clumsy or uncoordinated movements and may engage in repetitive movements, such as arm flapping or rocking. Some fixate on objects, specifically the mechanical functioning of objects, or repetitively spin objects (CDC, 2010). While there is no cure for autism, researchers note that as individuals develop into adulthood, some symptoms may decrease in intensity (Seltzer et al., 2003).

Research confirms an increase in the number of children diagnosed with ASD, with a marked increase between 2002 and 2010 (Baio et al., 2018). Specifically, the rate of children identified with autism remains high, with as many as one in 44 children identified as having autism, with boys

4 times as likely to be diagnosed (CDC, 2022). Findings from Baio et al. (2018) indicate a racial hierarchy in that White children are more likely than Black children to be identified with ASD; Latino children were less likely than White and Black children to be diagnosed with ASD. This data further articulates that Black and Latino children are evaluated and diagnosed at later ages than their White peers.

Despite the growth in the number of autism diagnoses across racial/ethnic populations in the US, the majority of the clinical and practitioner-based research literature on ASD utilizes White families and children, upon which interventions are based (Pierce et al., 2014; Tincani et al., 2009). The additional perspectives of Black families, can, for example, provide additional understandings of familial participation, enhance treatments, and improve outcomes for Black children with ASD, as the condition is not limited to White populations as once believed and still perpetuated throughout the research literature (Dyches et al., 2004; Hilton et al., 2010; Pierce et al., 2014).

Insights into Black family practices, particularly that of mothers, is critical to expanding considerations of why Black families receive later ASD diagnoses and receive ASD-related services at rates much lower than their White counterparts (Dyches et al., 2004; Mandell & Novak, 2005; Mandell et al., 2009). Finally, the perspectives of Black mothers directly challenges long-standing perceptions of autism mothering as the exclusive, albeit contested, domain of White mothers (Douglas, 2014; Mandell & Salzer, 2007). In the next section, I briefly examine how mothers have historically been situated as the cause of their children's autism, beginning with the labeling of autism mothers by medical practitioners and researchers as *refrigerator mothers*.

Refrigerator Mothers: Historical Representations of Autism Mothers

The field of autism was fundamentally shaped by the 1943 publication of Leo Kanner's germinal study "Autistic Disturbances of Affective Contact." The diagnostic of "early infantile autism" emerged from the study, which focused on 11 children with shared behavioral and communicative behavioral patterns. Kanner, an Austrian immigrant, was particularly interested in the lack of social engagement, impaired verbal communication, and physical rocking displayed by study participants. The study

was also important because it not only established autism nomenclature and symptoms but also blamed mothers as the cause of autism (Douglas, 2013, 2014; Kanner, 1943). Kanner based his findings on observations of mothers of the original 11 children in his study, during which he believed mothers exhibited cold, refrigerator-like behaviors that prohibited healthy mother-child bonding (Douglas, 2014; Simpson, 2003).

While long-standing castigation of mothers for causing their children's autism can be traced back to Kanner's study, it is important to place such claims into a sociohistorical context. Kanner's work, as noted by Douglas (2014), emerged during the latter portion of World War II, during a time of shifting and unsettling social order. Women, who in the prewar years had primarily occupied domestic roles, now occupied public spaces in the workforce and higher education. As Douglas (2014) argues, these social factors surrounding women filtered into what amounts to Kanner's (1943) chastisement of the mothers in his study, as these women possessed college degrees and worked outside of the home. Kanner's blame of mothers was furthered by Bruno Bettelheim (1959, 1967), who elevated the use of *refrigerator mother* to describe his subjective observation of cold and detached maternal behaviors.

Moreover, as Douglas (2014) notes that in extending autism diagnostic and treatment work to the domestic realm, Kanner (1943) and Bettelheim (1959, 1967) predicated their critiques of refrigerator mothering on social norms of White middle-class mothering. She said, "The refrigerator mother was also an ironically privileged identity (and continues to be today), available only to mothers with temporal, bourgeois, Mother American or Western European mothers. She emerged as part—and perhaps as handmaiden to—the post-World War II reassertion of traditional gender roles and push of white middle-class mothers back into the home" (p. 104). Said otherwise, the refrigerator mother label, under the guise of scientific knowledge, served to send the message that White middle-class women risk harming their children if they opt out of social norms. An autism diagnosis was thus deemed the result of White middle-class women choosing to pursue higher education and employment outside the home (Douglas, 2014). Although Kanner later reversed his views of mothers as the cause of autism, switching instead to biological factors, the damage to White middle-class autism mothers was done and adversely positioned them in opposition to autism experts.

Conversely, Black autism mothers were omitted, overlooked, and invisibilized in the original research that resulted in the refrigerator mother

label, as both Kanner and Bettelheim used only White middle-class families in their samples. The lack of racial diversity in their samples continues to be an issue today, leading autism researchers to publish research based upon the experiences of White middle-class families and furthering the conceptualization of autism as a White condition. For example, a Black mother in the 2003 documentary *Refrigerator Mothers* commented, as cited in Douglas (2014, p. 101), “According to my doctor, my son could not be autistic. I was not White. It was assumed that I was not educated and therefore he was labeled emotionally disturbed.” The mother recognized the double entendre of exclusion by virtue of race and inclusion in the offensive label of refrigerator mother as availed only to White women.

White Warrior Autism Mothers

Given the blame placed upon White mothers and their labeling as refrigerator mothers by autism researchers and medical professionals, it stands to reason that White mothers developed a particular form of autism mothering to directly challenge the refrigerator mother label (Simpson, 2003). According to Chivers Yochim and Silva (2013), *warrior mothers* are middle-class White autism mothers who publicly wage warriorlike fights against systems to win service gains for their children. Warrior mothering stands in direct contrast to negative images of bad mothering associated with refrigerator mothers because the warrior mother demonstrates her “goodness” or the qualities of good mothering by her heightened level of autism advocacy, and her refusal to take no for an answer. Good mothers, such as autism warrior mothers, leverage cultural and social capital to maneuver through systemic red tape, demonstrating that they are knowledgeable about laws and required services. Under the model of autism warrior mothers, White mothers are the holders of knowledge of what is best for their children, including treatments, school placements, and community-based services (Angell & Solomon, 2017; Eyal & Hart, 2010). The inherent knowledge of warrior mothers is in direct opposition to autism mothers from previous generations in that their work contrasts, contradicts, and rarely intersects with that of medical professionals (Douglas, 2013). Autism warrior mothers approach the acquisition of services from an individualized transactional approach, placing emphasis on gains for her child versus collective gains of all families grappling with autism. In these individualized battles, warrior mothers are rewarded by medical

providers and school systems with demanded services (Angell & Solomon, 2017; DeWolfe, 2015).

Images of White warrior autism mothers now proliferate social media through websites, Facebook, and Twitter (Chivers Yochim & Silva, 2013), with actor and comedian Jenny McCarthy as the leading face. In the early 2000s, McCarthy emerged as the face of warrior mothers, authoring books on autism mothering. McCarthy leveraged her celebrity to launch a platform focused on curing and preventing autism, specifically promoting warrior mothers' ability to heal their children. She became the face of the antivaccine movement by attributing the cause of autism to chemicals in vaccines, although this claim has been dismissed as unreliable and scientifically unsound (Chivers Yochim & Silva, 2013). McCarthy's claims of warrior mothers' ability to heal autism drew the ire of the medical community and served to highlight a schism on who possesses autism knowledge: warrior mothers or medical professionals.

McCarthy's popularity also speaks to discourses and imagery surrounding autism warrior mothers who have formulated identities and support groups across social media (Angell & Solomon, 2017). While warrior moms share knowledge via social media and support groups, what tends not to filter into the discourse are issues of race and class as it relates to familial supports and services. In their study of Los Angeles-based Latino autism parents, Angell and Solomon (2017) found that while participants attempted to utilize warrior mother advocacy strategies, their actions did not necessarily yield positive outcomes. Their findings thus highlight the presumption of race and class neutrality in the imagery of warrior mothers, leaving mothers of color invisibilized in the realm of autism advocacy, fueling the belief that mothers of color do not fit the tightly prescribed image of autism fighters (Angell & Solomon, 2017). And, due to the focus on White autism warrior mothers, Black autism mothers' conceptualizations of their mothering roles is under-researched.

Black Family Perspectives on Autism

Research on Black families of children with ASD highlights levels of distrust of medical providers and educational services, with Black parents believing behavioral and social supports do not meet their culturally based needs (Carr & Lord, 2012; Delgado Rivera & Rogers-Atkinson, 1997; Leininger, 1991; Leininger & McFarland, 2006). Interactions between Black parents

and autism professionals may highlight long-standing tensions between Blacks and members of the medical community (Washington, 2006). Routine appointments may then be viewed as intrusive and an opportunity to judge Black parents, in particular lower-income parents, making them feel uneasy and subject to condemnation. For example, Sousa (2015) describes the surveillance of mothers of special needs children including judgments of the mother's advocacy and caring by service providers. Families in need of systemic assistance must submit themselves to the scrutinizing judgment of service providers in order to receive services. Such service-contingent judgments are filtered through cultural lenses, meaning providers' determinations are mitigated by perceptions of social class, race, and immigrant status (Alston & Turner, 1994; Gourdine et al., 2011; Morgan & Stahmer, 2020). As noted in Sousa's (2015) case study of maternal involvement and family income levels, low-income mothers also described strategies of engagement with their children's development, despite systemic and institutional rebuttals. Broader inclusion of families of color can serve to offer more detailed understandings of how race, class, gender, and culture intersect to shape outcomes of individuals with ASD.

The research literature examining the absence of Black families from ASD research often conflates race with culture (Ennis-Cole et al., 2013). It is important to note that culture is not synonymous with race but instead more narrowly represents a worldview or lenses by which families determine values, childrearing practices, and traditions (Brown & Rogers, 2003). King and Mitchell (1995) describe Black cultural ethos as a worldview emphasizing collectivism and as spiritual and holistic. Black culture affirms individual personhood while simultaneously respecting collective experiences, knowledge, and being. Communal values and orientations, along with spirituality, serve as a buffer for societal micro- and macroaggressions targeting Black lives by the larger society. A Black cultural ethos, according to King and Mitchell (1995), builds knowledge collectively through the spoken word, thus solidifying socially constructed knowledge.

The research on the impact of culture on ASD is relatively scant beyond that which explores the impact of race on age of diagnosis, classification of symptoms, and access to care (Mandell et al., 2009; Montes & Halterman, 2011). Pierce et al. (2014) conducted a literature review of three ASD journals examining the inclusion of race and ethnicity. The review yielded low results and limited descriptions of participants' race/ethnicity, with only 72% of journals featuring research that included race

or ethnicity. The researchers further noted that studies that did include race/ethnicity provided limited details on participant recruitment and included small sample sizes that limited generalizability (Pierce et al., 2014). It should also be noted, however, that the existing literature largely does not distinguish between the implications of race and culture, meaning a treatment of them as two separate concepts is needed. Said otherwise, theories of expertise must account for the impact of culture; as Collins (2000) argues, culture undergirds knowledge production because it is situated knowledge. Such theories of expertise, within the current corpus of autism research, however, rarely account for social contexts including issues of race, class, and gender.

While shifts in autism research now recognize families as a valuable source of knowledge, such expertise still primarily relies upon studies of White families, namely those from middle- to upper-class backgrounds, and provides limited insights on socialization and adaptation to ASD within families of color (Connors & Donnellan, 1998; Dyches et al., 2004; Mandell & Salzer, 2007; Myers et al., 2009). The need for ASD research on families of color is further compounded by glaring discrepancies in access between White and Black families to diagnosis and interventions. Black families receive diagnosis at later ages, an average of 1.5 years behind their White peers (Mandell & Novak, 2005). Additionally, rates of misdiagnosis of Black children with ASD are higher than any other demographic group (Mandell & Novak, 2005). Thus, the combination of later diagnosis and higher rates of misdiagnosis impacts long-term outcomes for Black youth with ASD. For example, a longitudinal study of mental health and health care for young adults with ASD demonstrated that Blacks have higher rates of limited care (Roux et al., 2015). Black young adults with ASD are more likely to lack transitional services (including vocational programs) and experience higher rates of unemployment and poverty, (Roux et al., 2015; Shattuck et al., 2012). Such outcomes further necessitate research on Black families caring for children with ASD.

Finally, it is important to highlight some particularities of experience relevant to Black families at the intersection of race, class, gender, and autism. Said otherwise, the matrix of oppression and privilege for Black families may necessitate different types of familiar practices or mothering that are currently under-researched. For example, families of children with ASD may focus social skill development on safety strategies, particularly as it relates to instances of elopement (Solomon & Lawlor, 2013). Nearly half of all children with ASD wander from school and home, necessitat-

ing police involvement in a third of all elopement cases (Anderson et al., 2012). For Black families, however, the involvement of law enforcement in cases of elopement could compound already nebulous community-police relationships and national tensions around policing practices.

An examination of social skills strategies among Black families of children with ASD could provide insights on the intersection of race, class, gender, and disability within Black cultural communities, further expounding cultural ways of “taking care of one’s own” (King, 2001; King, 2002; Morris, 1992; Pruchno et al., 1997). Burkett et al. (2015) explored culturally situated caregiving practices among Black families, looking specifically at how cultural care informs health care for Black children with ASD. For example, Burkett et al. (2015) and Burkett et al. (2016) highlighted Black families demonstrating care through watchful behaviors. While the families described ASD-related safety concerns, the study explored familiar protective behaviors in relation to health care settings. Parents in the study were aware and concerned about the intersections of race, disability, and gender. While research has documented significant differences in ASD diagnosis for Black children with ASD, there exists a need to better understand what happens within Black families post diagnosis (Ennis-Cole et al., 2013). Specifically, given the cultural implications racial injustice in the US has had upon Black family socialization practices, what do these practices entail among families of Black males with ASD?

Black Mothers and Sons

This study examines the relationships of Black mothers and sons with autism, specifically examining how Black mothers socialize their sons. I chose to focus on Black mothers and sons with autism for several reasons. First, the majority of Black children are currently raised in single-mother-headed households, according to the Casey Foundation’s 2015 Kids Count Report. This fact coupled with societal positioning of mothers as primary caregivers provides the backdrop for this study. Second, Black mothers practice gender-specific childrearing practices, largely shaped and influenced by intersections of race, class, and gender (Boyd-Franklin & Franklin, 2000; Bush, 2004; Gantt & Greif, 2009; Mandara et al., 2010). For example, Collins notes that Black women socialize their children with safety in mind, with protective actions framed by marginalized positionality (2000). She explains that Black women have been in the American

workforce since enslavement and, thus, subjugated to objectification, sexual abuse, and other hegemonic forms of oppression. Black women who worked in close proximity to White families or men socialized their daughters to protect them against workplace sexual abuse due to their own experiences in White-dominated spaces.

Similarly, Black mothers have long feared for the safety and survival of their sons, particularly in light of systems of oppression that serve to target and marginalize Black men (Alexander, 2010; Bush, 2000a, 2000b; Collins, 2000; King & Mitchell, 1995; Yancy et al., 2016). Historically, Black mothers feared threats to sons' physical, economic, and psychological well-being from those functioning under the auspices of law and forces outside the law (Alexander, 2010). The story of Emmett Till, a Chicago Black teen killed by White men after being falsely accused of making sexual advancements toward a White Mississippi store owner's wife, attests to the historically based fears Black women hold about their sons' safety. In the case of Till, the White perpetrators were never convicted, thus supporting long-held notions that justice is meted out quite differently for Whites involved in racial crimes toward Blacks.

The fears of Black mothers for the safety of Black male children have been further heightened by stereotypical portrayals of Black males as loathsome violent criminals who pose threats to the general public. According to Kunjufu (1985) and Noguera (2008), Black boys, in the minds of Whites, shift from innocuous boys to public menaces by age 9, when they begin to enter adolescence. The power of racialized imaging, for example, was used strategically to ignite race-based fears of White voters in the 1988 presidential election (King & Mitchell, 1995). More recently, examples abound of how racial profiling extends to the attire of Black men, criminalizing them, as demonstrated in the killing of Trayvon Martin, a Florida teen killed by an overzealous neighborhood watcher. Martin's killer, George Zimmerman, believed the teen's hoodie denoted a criminal presence (Yancy et al., 2016). He was subsequently acquitted of charges related to the killing of Martin.

Finally, Black mothers are aware that law enforcement interaction is not a matter of *if*, but a matter of *when* in the US. Black males including Tamir Rice, Michael Brown, and Philando Castile were killed by law enforcement despite being unarmed. Specifically, Black males are disproportionately killed by law enforcement across the country. According to the *Washington Post* tracker, in 2016, 963 people were killed by police; 222 Black men were among those killed. Black males were 3 times more

likely to be killed by police than any other group. By 2021, 5 years after the *Post* began collecting data on police shootings, the newspaper reported that 1,636 Black males died by the hands of police nationally. The *Post* also highlighted that Black males represented 34% of unarmed individuals killed by police, a figure disproportionate to 6% of the US population. Additionally, the numbers do not account for those killed while in police custody or by means other than shootings. The dangers faced by Black males at the hands of law enforcement have been further punctuated by social media video postings of police interactions gone awry.

The criminalization of Black men also has far-reaching consequences with high rates of incarceration due to a variety of factors, including federal drug policies and the “school to prison” pipeline correlating school failure to imprisonment (Alexander, 2010; Green et al., 2006; National Association for the Advancement of Colored People [NAACP], 2016). Blacks are incarcerated 6 times more than Whites and now constitute over half the national incarcerated population, with over 1 million Blacks behind bars (NAACP, 2016). The majority of this population is Black males. Thus, Black mothers have ample reasons to be concerned about the safety and survival of their sons (Green et al., 2006; King & Mitchell, 1995).

Intersectionality Theory and Motherwork

Intersectionality is grounded in Black feminist theory, which honors Black women’s intellectual tradition, validates their worldview, and describes how Black women collectively develop ways of knowing (Collins, 2000). The theory provides a framework to understand how power, privilege, and oppression are shaped by multiple forces. Collins and Bilge (2016), elaborating upon the theory, describe intersectionality as:

A way of understanding and analyzing the complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other. (p. 12)

Thus, intersectionality provides a means of examining how autism mothering is a politicized space in which mothers and autistic children are positioned within a complex matrix of power, privilege, and oppression impacting access and services.

Douglas (2014) elaborates on how intersectionality impacts autism mothering and describes it as a space complicated by perceptions of mothers' identity, agency, and authority: "[Intersectionality pushes one to] think anew about some of our most intimately experienced ways of being together—as mother and autistic child—as not simply natural, nor a straightforward matter of disability or maternal oppression, but as interpretive and political sites replete with lessons about power, difference, and forms of agency within late modern life" (p. 2). Intersectionality is needed to disrupt renderings of autism mothers as exclusively White and middle class, thereby invisibilizing the particularity of experiences faced by autism mothers of color. Said otherwise, the matrix of autism and mothering is not race neutral, with race serving as a key determinant of oppression and/or privilege (Douglas, 2014; Angell & Solomon, 2017). For example, at the matrix of autism mothering, White autism warrior mothers encounter "disability and maternal" oppression while simultaneously exercising political power and agency to the exclusion and marginalization of Black autism mothers. Thus, intersectionality illuminates how one group of mothers can denounce ableism, decry autism discrimination, and concomitantly center themselves as the essentialized authorities on autism mothering.

Intersectionality disrupts the one-size-fits-all narrative of autism mothering and speaks to why a study examining the experiences of Black autism mothers is needed. On the surface, middle-class mothers with health insurance and high levels of educational attainment should possess valuable forms of social capital needed to access and navigate social, behavioral, and health systems. A singular lens of class, however, does not account for the disparities in autism services received by Black families, as research examining Black autistic children's health outcomes attests to racial discrimination when pursuing critical autism services (Broder-Fingert et al., 2020; Constantino et al., 2020; Stahmer et al., 2019). Class and educational status do not buffer Black autism families from anti-Black racism in service delivery and access. Thus, intersectionality provides a means of understanding the complexities of power, privilege, and access at the matrix of intersecting identities for Black autism mothers (Annamma et al., 2013; Carastathis, 2014; Combahee River Collective, 1979; Crenshaw, 1991).

An examination of Black autism mothers' intersectionality also requires a framework to better conceptualize maternal approaches at the matrix of oppression. Collins (1994) conceptualizes motherwork as a political form of mothering situated in the sociopolitical contexts of Black life in America. She elaborates:

Issues of survival, power and identity—these three themes form the bedrock of women of color's motherwork. The importance of working for the physical survival of children and community, the dialectical nature of power and powerlessness in structuring mothering patterns, and the significance of self-definition in constructing individual and collective racial identity reveals how racial ethnic women in the United States encounter and fashion motherwork. (p. 374)

Motherwork is concerned with the survival of Black children because their physical and socioemotional safety is at risk across oppressive systems in the US. Those engaged in motherwork do not see themselves as powerless but are instead driven by the need to protect Black children's self-worth and survival. Black mothers are empowered by resistance, determination, and an unwillingness to accept social injustices because they understand their children's fate is contingent upon their actions (Harry et al., 2005; Terhune, 2005). In the face of systemic oppression, motherwork's identity focus ensures that Black children have a sense of wholeness and know themselves. Black mothers understand that self-knowledge is tactical when countering pervasive negative imagery, adultification, and criminalization of Black children (Alexander, 2010; Dumas & Nelson, 2016; Heitzeg, 2016). Thus, motherwork provides a theoretical lens to analyze Black autism mothers' multisystem advocacy for the collective well-being of their sons given their position at the intersecting matrix of race, class, and gender.

Study Purpose

This study draws upon intersectionality theory to better understand how race, class, gender, and autism (functioning here as a disability), categories of primary social status, coalesce in the lives of individuals with ASD. In this study, perspectives of Black mothers are analyzed to better understand family-situated ASD practices through the lenses of race, class, gender,

and disability. The perspectives of Black mothers, a largely invisibilized population in the ASD literature, were examined to better understand how race, class, gender, and disability intersect in their parenting practices (Collins, 1986; Dyches et al., 2004; Mandell & Salzer, 2007). Black mothers of sons with ASD provide a particular angle on intersectionality, given the historical and contemporary threats to the social, economic, and emotional well-being of Black males (Collins, 2000; King & Mitchell, 1995). The study posed the question: How do Black mothers of sons with ASD equip and prepare them to confront race, class, gender, and disability?

Study Methodology

The study employed a phenomenological strategy of inquiry to better understand the phenomena of being Black, female, and classed raising sons similarly labeled as Black, male, classed, and autistic. Qualitative methods lend themselves to better understanding how participating mothers describe and articulate the ways in which race, class, gender, and disability shape Black mothers' parenting practices of sons with ASD.

Study Participants

Participants included Black mothers from Western, Central, and Westchester County, New York. The remaining mothers hailed from different regions of the US, including Texas, Virginia, and North Carolina. The 14 participating mothers were recruited by a variety of strategies. First, I engaged mothers I knew through my social networks. I am a member of a historically Black sorority, and I used that network as well, as it provided local, regional, and national recruitment pools. My sorority sisters then reached out to members of other historically Black sororities for possible study participants. This process yielded the majority of study participants. The second recruitment strategy included identifying Black church congregations in Western and Central New York. I emailed and called churches from the largest Christian denominations, including African Methodist Episcopal (AME), Baptist, and Pentecostal. Announcements were placed in church bulletins with study details and my contact information. A third strategy utilized social media. I asked sorority sisters and friends, who I knew had large numbers of followers on Instagram, Twitter, and

Facebook, to post study details on their pages. I also created a Twitter account with the intent of recruiting participants.

Study participation was determined by a variety of criteria. First, participants were required to be Black women, with no limitations placed on ethnic identification. While I recognize that White women are mothers of Black sons with autism, the study focus was specifically on women who identified as Black. The standpoints of Black women present, as Collins (1986) argues, unique perspectives at the nexus of race, class, gender, and other common social indicators. Collins elaborates by saying: “Black women possess a unique standpoint on, or perspective of, their experiences and that there will be certain commonalities of perception shared by Black women as a group . . . living life as a Black woman may produce certain commonalities of outlook. In other words, Black feminist thought contains observations and interpretations about Afro-American womanhood that describe and explain different expressions of common themes” (p. 16). Thus, I was very purposeful in delineating participation to Black women who mother sons with autism. Participants included a representation of diasporic cultures, as some mothers identified as Caribbean, African, and Afro-Latino. A second criterion was mothering a Black son with ASD. Participants identified sons as having a spectrum of ASD diagnoses, as some mothers identified their sons’ diagnosis as Asperger’s, high functioning, or low functioning. I am aware that these terms may connote ableism to some readers, positioning autistic people along a continuum of normalcy (Botha et al., 2021). Participants’ usage, however, is reflective of language used when they received their sons’ initial diagnosis. BAMS’ use of outdated autism descriptors may also reflect how Black mothers are over-excluded from autism communities. Participants also described comorbid conditions of attention-deficit hyperactivity disorder (ADHD), OCD, and Tourette’s syndrome. Participants mothered sons who were verbal, nonverbal, and minimally verbal. BAMS’ terminology may be at odds with the autism community but is also a reflection of how Black autism mothers are positioned as outsiders among autism researchers and service providers.

In seeking participants, I did not specify income levels, as I wanted a cross-section of Black mothers to determine how categories of primary status played out in their mothering of sons with ASD. The participant group was comprised of middle-class mothers, all of whom had education levels beyond high school; all were college educated with some holding graduate degrees including doctorates. Study criteria did not specify mar-

ital status, as my focus was exclusively upon the participating mothers. Most participating Black mothers, however, were married at the time of data collection. Study criteria also did not specify a religious preference for participants, although most professed Christian beliefs that they exercised in different ways and varying degrees. The fact that all study participants are educated, middle class, and Christian does not preclude diverse perspectives of Black women with multifaceted identities at these shared intersections. For example, participants identified as middle class but represented a broad income spectrum within that classification.

Data Collection Methods

This study utilized a variety of data collection methods in an effort to generate rich descriptive data. Prior to all interviews, participants were asked to complete a participant demographic form. The demographic form functioned as a means of organizing critical demographic details related to participants and their families. Participants were asked to provide a self-selected pseudonym for themselves and their son(s). Demographic questions ranged from age, occupation, number of children, and number of children with autism. The second section of the demographic form focused upon participants' son(s) with ASD. Questions posed covered: age of diagnosis, current age, ability to verbally communicate, additional medical conditions, and safety concerns.

Family constellation diagrams were distributed to participants at the same time as the demographic forms. The diagram was created to provide a visual representation of participants' familial constellations and community support systems for their son(s) with autism. The diagram is a bullseye with the child at the center. Participants were asked to indicate family and others who provide social supports for their sons by adding their names and descriptive titles reflecting the relational connection. Those with closer relationships to the son(s) were asked to be placed in proximity to the center of the bullseye. The diagram is situated in Afrocentric research methods (King & Mitchell, 1995) and acknowledges the communal nature of Black families, which includes fictive kin (Boyd-Franklin, 2003; Burkett et al., 2016; Burkett et al., 2015; Stack, 1974).

All participants completed individual interviews that took place at cafés, a classroom on a college campus, or an office. Four interviews

occurred over the phone¹ due to distance and travel limitations. The interview protocol, overall, sought to better understand how BAMs make sense out of mothering Black males who happen to have autism. The protocol included questions focused on their sons' initial ASD diagnosis and their sons' personality and social challenges. Questions then shifted to focus upon mothers' perspectives on raising a Black male with ASD and their opinions on what ASD providers, educators, and law enforcement need to know in order to provide culturally responsive services. Specifically, I asked participants what and how they taught their sons given the intersection of race, class, gender, and autism. Mothers were also asked about family support systems and self-care. All individual interviews lasted 60 to 90 minutes and were professionally transcribed. While the initial research plan called for a small group conversation with BAMs assembled in one location, this proved daunting and did not occur due to scheduling.

Data Analysis

Several rounds of data analysis occurred, utilizing both manual coding and electronic coding by means of Atlas.ti qualitative analysis software. Data analysis began prior to the first interview by virtue of a priori coding then progressed to several rounds of open coding as data collection occurred (Saldana, 2016). While the analytical software allowed me to better view the progression of smaller codes to the formulation of larger codes, I ultimately utilized manual coding as a means of organizing BAMs' thoughts into categories. Once these categories were organized, I returned to individual transcripts to ensure the inclusion of BAMs' voices across categories. The process then resulted in study themes presented here as chapters.

On a more personal note, the process of data analysis also served as an analytical process for me. For example, when participating mothers cried, I felt their emotions, as I did when they expressed frustrations. The more I interviewed and communicated with the participating mothers, the more I realized that the process uncovered feelings and experiences I closely held and had only expressed to myself in writing, as journaling was a space to process my own thoughts. Journaling allowed me to make

1. Data collection began in 2017, when videoconferencing was not yet widely accessible. Thus, details on all participants' physical appearances were not available.

sense of being Black, a mother, classed, gendered, and raising a Black son with autism and led me to realize that I was simultaneously interviewing mothers and posing similar questions to myself. The “I am Caleb’s mom” narratives that appear at the start of each chapter are those journal entries and they bring an autoethnographic element to the study. The refrain of being Caleb’s mom developed organically as a pronouncement of my maternal pride and protectiveness. Readers will see the connections between my autoethnographic narratives and data from participating mothers. This organization creates a collective voice of Black mothers of sons with ASD, while including my own.

In the following chapter, participating Black autism mothers are introduced in detail to familiarize readers with the mothers and sons. My hope is that readers will connect with the contexts of BAMs’ lives to gain a better understanding of mothering at the intersection of race, class, gender, and autism through the standpoint of BAMs. This intersection will be revisited across the chapters with regard to BAMs’ process of seeking autism diagnosis for their sons and the resulting processes of accepting the diagnosis. The analysis presented then shifts to specifically consider how BAMs mother at the intersection of race, class, gender, and autism with regard to their fears, hopes, and long-term goals for their sons. In articulating long-term outcomes for their sons, however, BAMs employ discursive resistance when advocating for their sons in various social spaces, including schools and churches. I then delve into the advocacy of BAMs, specifically connecting the fight for dignity and resources with a larger mission. In doing so, mothers share advocacy strategies they breathe into their sons, specifically, holding high expectations for sons, despite autism. Finally, BAMs offer medical, educational, and human service providers’ culturally responsive suggestions and strategies for serving Black autism families. I then conclude the book with suggestions for future research and practice for Black autism parents and those involved in providing autism services to Black autism families.