

EXPERIENCES OF AFRICAN AMERICAN PARENTS OF STUDENTS WITH  
AUTISM AND SCHOOL PARTNERSHIPS

A thesis submitted to the faculty of  
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In partial fulfillment of  
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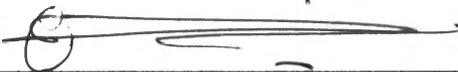
Isabella Chanette Brown  
San Francisco, California

May 2018

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## CERTIFICATION OF APPROVAL

I certify that I have read *Experiences of African American Parents of Children with Autism and School Partnerships* by Isabella Chanette Brown, and that in my opinion this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirement for the degree Master of Arts at San Francisco State University.



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This phenomenological inquiry was aimed at uncovering the experiences of African American parents of school age children on the autism spectrum. The researcher sought to understand how parents navigate school systems and to investigate the potential impact for cultural brokers to enhance school partnerships by using Communities of Practice. Data collection included 11 in-depth interviews with parents (9 mothers and 2 fathers) in 5 school districts and with 6 cultural brokers. Results show that parents face hardships due to isolation, a general lack of knowledge about autism among others in their lives, and inequitable power dynamics between school systems and participants. The outcome of this work suggests ways to address these challenges by enacting measures to increase trust and representation, provide training, and implement use of cultural brokers as a bottom up approach to shifting parent-school power dynamics.

I certify that the abstract is a correct representation of the content of this thesis.



\_\_\_\_\_  
Chair, Thesis Committee

5 / 15 / 2018  
\_\_\_\_\_  
Date

For Mateo Short Pants  
The Guardian of the Garden

## ACKNOWLEDGEMENTS

This master's thesis is a culmination of years of dedication in efforts to better the lives of students and families impacted by disability, including my own. My aspiration is addressing school reform measures to ensure equal legal rights and protections allotted to us all are upheld in educational spaces.

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## Chapter 1: Relevant Literature

African Americans entered America in chains and unlike immigrants, slaves or involuntary nonimmigrant minorities did not arrive with the intent to escape unbearable circumstances in their native land (Ford, 2012; Ogbu & Simons, 1998). Howard Zinn (2003) described the onset of slavery and its effects on this ethnic group as the following: “torn from their land and culture, forced into a situation where the heritage of language, dress, custom, family relations, was bit by bit obliterated except for the remnants that blacks could hold on to by sheer, extraordinary persistence” (p. 26). The aforementioned outlines the historical context of despair and disparity, setting the tone for centuries of staunch disenfranchisement of African Americans in the United States. The vile experiences of African-American families included chattel slavery and the Jim Crow era which mandated restrictions on marriage, voter suppression, derisory employment, insufficient affordable housing, segregated schools and communities, unlawful literacy acquisition, and substandard facilities and efficacious education.

Fortunately, *Brown v. Board of Education* ignited desegregation of public schools in 1954. In this landmark case the Supreme Court unanimously ruled, “separate but equal has no place” in public school spaces. The Equal Protection Clause of the Fourteenth Amendment as well as the due process law under the Fifth Amendment prohibit states from maintaining racial segregation in public education (347 U.S. 483). However, desegregation alone failed to sufficiently improve the quality of education for African Americans (Martin & Varner, 2017). Thus, the overarching web of inequality continued

to rest on the heads of this culture. Additionally, *Brown v. BOE* could have leveled the playing field due to the Supreme Court's landmark decision that separate school facilities are inherently unequal, but many schools were solidly divided by de facto race and class as poverty remained prevalent in the African American communities (Zinn, 2003; Spring, 2000; Kozol, 1991). An abundance of studies show there are lingering inequalities for many African Americans within school systems, such as an overrepresentation in special education and a lack of quality education (Osher, Woodruff, & Simon, 2003; Skiba et al., 2006; McKenna, 2013). A recent study challenges some of the literature on overrepresentation of African American students in special education, which encourages taking a critical look into situations of underrepresentation for some students (Morgan, Farkas, Cook, Strassfeld, Hillemeier, Pun, & Schussler, 2017). Therefore, more attention must be given to the experiences of African American families in American schools.

Inequalities are perpetuated by differences in interpretation of what is important, this is especially relevant for students with disabilities. In a recent qualitative study centered on urban African American parents and family members of children on the autism spectrum, Burkett, et al. (2017) used a nursing and anthropological perspective as a way to explore "caring using a cultural lens" a concept used to find meaning in what is universal and diverse in a culture (p. 497). The findings uncovered two very meaningful themes: respect and faith. Respect for these families meant having respect for their family as a community, their disabled child, elders, and authority figures. Establishing the importance of discipline and how it is handled was also seen as a way of showing respect

– as it is passed down through generations and taught inside the home. Behavior is of considerable importance for these families, but presents challenges for children on the autism spectrum. To combat these challenges it was observed that families created different ways to target behavior problems that addressed respect and limitations due to disability. Families used direct and functional discipline such as “Do this...” or “Stop doing this...” (p. 501). Combinations of corrective methods were used if initial tactics were unsuccessful. It was also observed that families felt effective discipline would lead to positive outcomes for their child on the autism spectrum in spite of their perplexing behaviors. The second theme in this study was centered on faith in God. Faith was seen as believing that their child on the autism spectrum was a blessing from God and participants looked to churches and family for “indigenous” support. Parents in the study felt providing care for their child brought forth spiritual and emotional closeness. According to the study, these families are equipped to provide culturally appropriate care to their children on the autism spectrum. It is suggested that health care field providers decrease disadvantageous ethnocentric attitudes in medical practices in order to better service urban African American families and children on the autism spectrum.

Research in the medical domain points to the need for more thoughtful culturally responsive interactions centered in patience and trust for children on the autism spectrum, their families and caregivers. The need for cultural responsiveness when interacting with African Americans is also noted in the field of education (Gray, 2009). Additional studies in the field of special education are also needed to reveal African American

parental/caregiver views, their understanding of autism, and their view of the role of schools.

It is duly noted that the success of all school age children in learning environments relies heavily on active engagement between caregivers and school communities. As with any relationship, trust forms the basis of meaningful parent-school partnerships. Goddard, Tsahannen-Moran, & Hoy (2001) found that teacher trust in students and parents was tied to poverty or socioeconomic status (SES) and not race. A higher ratio of “poor” students had a lower rating of perceived trust for parents and students by teachers. In turn, social relationships amongst teachers, parents and students were negatively affected by poverty and dissimilarities in culture. The findings of the study reinforce the belief that trust creates ideal conditions for learning in school environments by “enabling and empowering productive connections between families and schools” (p.14). It is also important to note the authors felt trust is acquired when all members of a school community participate in its development: without it students essentially miss out on a critical form of social support. The study urgently calls for expanding methods to improve trusting relationships between teachers, parents and students in urban school settings, as well as the implication of trust as a two-way street.

Finding ways to gain trust from underrepresented ethnic groups, specifically African American parents and caregivers, has presented challenges in fostering long-term advocacy efforts and in maintaining a positive presence in school communities. These challenges in developing efficacious school partnerships and parent advocacy do not

solely rest on the shoulders of low income African American parents in single family homes which are known as disconcerting family systems. On the contrary, participatory action research by Yull, Blitz, Thompson, & Murray (2014) examined building family and school partnerships with families of color. They used critical race theory to uncover how middle class African American parents experience family-school partnerships. Fifteen of the nineteen parents who participated in the focus groups were two-parent homes, and 80% were college graduates. The outcome was once again in line with existing research: families of color felt a lack of cultural awareness and cultural ignorance, isolation, colorblind racism, and identified race as a barrier to effective school engagement.

Systemic barriers of class, race, and Eurocentric belief systems can restrict, limit, and often completely disengage participation and inclusion efforts of African American children and families (Osher, Woodruff, & Sims, 2013). In order to explicitly unveil unfortunate roadblocks in African American engagement in school communities we must explore experiences of White teachers who are largely responsible for educating African American pupils (Soloman, Portelli, Daniel, & Campbell, 2005). It has been observed that these deleterious notions put a strain on parent-teacher and parent-school relationships. In a 2012 study, twenty-six teachers in a predominately White middle school and school district were chosen as participants; 47% of those participants self-reported having had multicultural training, yet personal and professional inexperience was noted as a factor in difficulties tackling matters of race, racism and diversity with

their students (Henfield & Washington, 2012). This study discussed how ignoring concerns regarding racism mirrors systemic power differences in school settings. While several teachers admitted to having uncertainty in their abilities to instruct and bond with students of this ethnic group, they were also aware of the fact that having information about diverse student backgrounds and supplementary training was key in providing positive outcomes for African American students. These students rely on the cultural competency of their teachers in providing fair and supportive environments for learning.

Without shared insights among parents and teachers, where does this leave an African American special education student? Prior research has shown that while students benefit from parent participation in school communities, it is a widely known fact that many African Americans adversely struggle with school engagement efforts (Latunde & Clark-Louque, 2014; Williams, Pemberton, & Dyce, 2012; Latunde, 2009; Harry & Klinger, 2005; Thompson, 2003; Hale, 2001). Advocating for children in special education settings has even greater roadblocks for parent participation than in general education settings (Bezdek, Summers, & Turnbull, 2010). Research points to cultural disconnects between marginalized groups and the school community as a major cause for this ongoing ostensible lack of involvement when it comes to special education (Kalyanpur & Harry, 2012). A diagnosis of autism alone can present difficulty in navigating through educational and social alliances in the community. Membership in a minority group adds a myriad of additional challenges making school partnerships an impossible feat to manage single-handedly.

According to Kayanpur & Harry (2012), special education is a complex macro-system infused with an unknown belief systems, copious technical jargon, and tacit wisdom with which many minority groups are severely out of touch. Minority parents may choose to not show up for Individualized Education Program (IEP) meetings and parent teacher conferences for fear of revealing such deficiencies in their own knowledge and cultural incongruity, often never learned, yet required to meaningfully participate (Kalyanpur, Harry, & Skrtic, 2000). A parent's own level of education comes into question when entering the special education advocacy realm, whereas a post-secondary education is warranted as a prerequisite to fully comprehend fundamental procedural safeguards for IEPs (Gomez Mandic, Rudd, Hehir & Acevedo-Garcia, 2012). The Individuals with Disabilities in Education Act (IDEA) mandated parent-professional collaboration, which includes the expectation of vocal advocacy on the part of parents to seek due process in order to get the services needed for their children when necessary (Turnbull, 2005), but is this a realistic task for most African American parents and guardians to accomplish?

A recent study uncovered how school leaders who were attentive to shaping school culture successfully created and maintained school trust and family engagement (Francis, Blue-Banning, & Turnbull, 2015; Hill & Gross, 2016). In parallel, they found that trusting partnerships between families and professionals could only be centered in trust if members of the school community were equipped with "a sense of belonging and membership for all stakeholders, including school professionals, students, and families"

(p. 291). Another key factor to the success of trust within a school community was having parents as access points in enlisting more families to engage in and contribute to the school. Families bring comfort and ease to other families.

While studies indicate trusting parent school partnerships are exceedingly beneficial to all, a body of research shows constructive school partnerships lowered stress levels, specifically in mothers. Burke & Hodapp (2014) surveyed 965 mothers of students with developmental disabilities. What was observed was that enjoyable parent-school relationships actually decreased stress as a result of “positive” parent-school partnerships. This finding further highlights the significance of meaningful and trusting parent-school initiatives.

Kyzar, Haines, Turnbull, and Summers (2017), have expanded on existing research to provide a comprehensive set of seven partnership principles for school communities: communication, professional competence, advocacy, commitment, equality, and trust. *Communication* focused on paying attention to the depth and frequency of interactions, listening without judgment, using common language and not complex jargon and acronyms, being authentic, and facilitating exchanges of information. *Professional competence* is tied to parent participation, greater involvement from parents, and higher parent approval in special education. Proficiency in professional competence denotes appropriate education for students, professional development, and having high student expectations. *Advocacy* entails proactively working with families with challenges, finding ethical solutions, opportunities for advocacy, win-wins outcomes, alliances, and

discovering and noting issues. *Respect* recognizes honoring cultural diversity (understanding family beliefs), acknowledging child and family strengths, and treating families and pupils with dignity. *Commitment* involves being sensitive to the emotional state of families, having an available and flexible schedule, and assisting families in extraordinary ways. *Equality* is centered in shared power with professionals and families and a feeling of seemingly equal power over student education. The last principal, *trust*, is what holds parent-professional relationships together. Trust is also comprised of good judgment, confidentiality, reliability, and an individual's trust in themselves.

Embracing these parent partnership principals is key to accessing meaningful parent involvement and equitable assembly between parents, students, and professionals. The findings in a mixed methods study by Louque and Latunde (2014) support this claim. They utilized surveys and post survey interviews to analyze the perceptions, experiences, and feelings of African American parents of typical school age children in their educational environments. One hundred and thirty participants completed the survey, which led to interviews with ten female parents. The results of this study revealed African American parents had a multiplicity of ways of engaging in their children's education. Ninety four percent of the participants frequented their child's school; one of the top reasons for visits was to observe interactions between the children, their children's peers and teachers. Parents noted their visits were "pleasant because school staff greet and welcome them" (p. 7). The more involved parents were in the specifics of their child's academic work the more they engaged with other parents. However, 50.8%

of families never attended school board and site council meetings. An unfortunate barrier to attendance by African American families was meeting times. This points to the fact that a magnitude of families in this ethnic group miss out on vital opportunities to make a difference in decisions affecting their children's broader academic trajectories. As mentioned, African American parents who have children with disabilities have even greater challenges with engagement in school communities. However, studies show this can be accomplished when approached nontraditionally.

A promising framework for enhancing trusting partnerships and knowledge sharing between perceived experts [teachers and school administrators] and perceived novices [parents and caregivers] is communities of practice. A community of practice is an alternative to typical top down knowledge sharing models. Historically, marginalized ethnic groups, especially African Americans, face systemic barriers and are at a disadvantage, failing to benefit from and fully participate in educational spaces. The origin of communities of practice is based on a theoretical structure that utilizes both a broad and dynamic elucidation of knowledge (Wenger, 1998). A community of practice is defined as '...groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis' (Wenger, McDermott, & Snyder 2002, p. 4).

The essential components of the community of practice theoretical model are: *a joint enterprise (domain of knowledge), mutual engagement (a community of people), and a shared repertoire (shared practice)* (Wenger, 1998). A joint enterprise or domain

generates the identity of the group and establishes common ground in that all members have a collective goal that acts as the motivating force in the community of practice. ‘The domain inspires members to contribute and participate, guides their learning, and gives meaning to their actions’ (Wenger et al., 2002, p. 28). Mutual engagement or community forms the social fabric of learning. ‘A strong community fosters interactions and relationships based on mutual respect and trust. It encourages a willingness to share ideas, expose one’s own ignorance, ask difficult questions, and listen carefully’ (Wenger et al., 2002, p. 28). Shared repertoire or practice is particular knowledge developed, shared, and maintained by the community, Wenger describes shared repertoire as ‘a set of frameworks, ideas, tools, information, styles, language, stories, and documents that community members share’ (Wenger et al., 2002, p. 29).

When parents and educators engage with each other as a community of practice, they are likely to solve and address problems with regards to the needs of the student with disabilities (Mortier, Hunt, Leroy, Van de Putte and Van Hove, 2010). Specifically for African American families this framework holds promise. A study by Fairfax (2016), noted change can occur using community of practice in conjunction with the Afrocentric paradigm for further development of African American interests. He warns that without the use of community of practice “community intervention is fragile and substandard” (p. 79). There is marked success in school settings when leaders work to find solutions in equitable partnerships with African Americans. Cooper, Riehl, and Hasan (2010), examined how a parent coalition convened to examine the “status quo” and furthering

steps toward change in their school. With the use of a cultural broker (a type of intercessor or liaison who assists in creating new connections between groups), African American parents along with teachers and school leaders “engaged in reciprocal learning, formed new identities and relationships, and forged ahead with a type of powerful collaborative activism” (p.781). Additional research is needed to explore how African American parents in partnership with professionals can form systems of change using the community of practice framework to transform existing school-centered philosophies about learning and community engagement in scholastic environments.

This study seeks to fill the void where there is a need for more information related to African American parent interpretation of autism within their families and community, how they currently navigate through special education, and how their views and experiences impact existing partnerships within school communities. Another aim of this work is to explore how parent school partnerships for African American families in special education can be improved and what culturally attuned communities of practices can look like. This study will also examine whether cultural brokers are able to enhance trusting partnerships within special education contexts and the greater school community for African Americans. In addition, this research will to expand on the emerging literature on African American families.

## Chapter 2: Methodology

### Methodological approach

The objective of this work is to uncover the lived experiences of African American parents of autistic students in their families and community, understand how African American families navigate their educational spaces, and gain insight into whether cultural brokers can enhance these partnerships using the Communities of Practice framework. In order to address the specific aims and nature of this study, qualitative research is the most appropriate methodological approach. The intention of qualitative research in scholarship points to the National Research Council's target to yield guided knowledge centered on "what is happening?" and "why is it happening?" (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005). Brantlinger, et al (2015) argue that the nature of qualitative studies addresses "attitudes, opinions, and beliefs" of (p.196) of individuals involved in special education. The author anticipates that this study will uncover attitudes, opinions and beliefs about parent-school partnership and autism in the African American community.

Qualitative research is a "systematic approach to understanding qualities, or the essential nature, of a phenomenon within a particular context" (Brantlinger, et al. 2005, p.195). Characteristics of qualitative research are denoted by Creswell (2013) as: 1) the researcher discloses their experiences, 2) horizontalization (e.g., relevant quotes related to the topic are listed, equal value in terms of the expressions of the group are given,

relevant topics are grouped into units of meaning), 4) the researcher pens textual descriptions and along with “ad verbatim” quotes, 5) the structural description is written by the researcher, conclusively, 6) the research identifies the essence of the phenomenon rendering the textual and structural examination (p. 106).

This purpose of this study aligns with the purpose of phenomenological inquiry or phenomenology. Specifically, phenomenological inquiry or phenomenology describes and understands the essence of lived experiences of individuals who have also experienced a particular phenomenon (Creswell, 1998; Padilla-Diaz, 2015). However, due to time constraints and the small scope of this work, the author will not be able to engage in-depth phenomenological, methods, such as full immersion into the world of the participants. Rather, for the purpose of this research the author will use a generic qualitative research methods to collect and analyze the data to illuminate the phenomenon under studied (Lichtman, 2014). The researcher will investigate: the understanding and exploration of the experiences of African American families with children on the autism spectrum within the scope of their communities and parent-school partnership. This study will also examine the possibility of enhancing these relationships through the social learning framework found in CoP and its cultural broker concept. Therefore, gaining insight into the experiences of participants who fit the cultural broker role is congruent with the overall principal aspirations of this work.

## **Parents of autistic students**

### **Recruitment criteria**

Purposeful selection or purposive sampling (Palys, 2008) was used as it denotes particular settings, persons, or activities that are deliberate and essential in providing evidence pertinent to questions and goals that would otherwise be unfounded (Patton, 1990; Maxwell, 2013). In essence, as conveyed by Miles and Huberman (1994), the selection of participants is directly driven by the research questions. For the purpose of this study, it was essential for participants to meet the following criteria: a) the participant must identify as an African American parent or guardian of a child on the autism spectrum, b) the parent either previously acquired an IEP for their child, or was presently working toward obtaining an IEP due to autism like behaviors or characteristics consistent with the Diagnostic and Statistical Manual of Mental Disorders fifth edition or DSM-5 (pg. 50-51):

“persistent deficits in social communication and social interaction across multiple contexts, restricted, repetitive patterns of behavior, interests, or activities, symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life). Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning, these disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual

disability, social communication should be below that expected for general developmental level”, (DSM5, 2013).

### **Recruitment stages**

This study used two types of recruitment methods: snowball sampling and convenience sampling. The snowball method consists of asking individuals who were previously identified as participants to identify like individuals for consideration (Patton, 1990; Miles & Huberman, 1994; Lichtman, 2013; Maxwell, 2013). This was ideal for locating seemingly out of reach and rare participants for this study. However, this recruiting method did not fulfill the recruitment process. In turn, two recruitment phases were employed in order gain the desired sample size of 11. First, the researcher sent individual emails to two special education colleagues and had a discussion with a university special education professor about recruitment. These efforts led to six parent participants (4 mothers and 1 couple). While scheduling interviews with each of the first five families, the researcher inquired if they were aware of other potential parents who mirrored the characteristics of the sample.

Convenience sampling was employed to complete the recruitment process. This type of sample is defined as participants who are likely to participate (Maxwell, 2013; Miles & Huberman 1994; Patton, 1990). The researcher contacted a colleague and two of her own family members to inquire if they had any knowledge of parents who were members of their school communities who fit the criteria to enroll in the study; two participants were acquired during this recruitment phase (3 mothers). Another special

education colleague created a Facebook post detailing requirements for participants and successfully located the last two parents needed for this sample (1 couple). There were persistent challenges during the process of recruitment, as many attempts were needed to secure participants; this was due to the specific participant characteristics.

### **Participant Demographics**

A total of 11 parents participated in this project. The following table represents demographic information about the parent participants. There were seven mothers and two couples (one married and the other in a domestic partnership). All parent participants have diverse educational backgrounds: high school graduate (n 5), bachelors degree (n 4), and masters degree in special education along with teaching credentials (n 2). They resided in two different counties and their children attend/previously attended school in five urban public school districts in the Bay Area.

One participant has an adult son who has aged out of receiving special education services. The age of each participant's child, IEP eligibly, and classroom designation are also represented in Table 1.

Participant	Education	Occupation	Age of Child	IEP Eligibility	Classroom Designation
Ali & Lisa	Diploma/ Some college	Retail Manager & Facility Manager	4	Autism	Non-public school
Sheri	Bachelors	Tech Company Project Manager	8	Autism	Fully included
Val & Ron	Bachelors Bachelors	Financial Planner	8	Autism	Fully included
Wilma	Masters	Special Education Teacher	8	Speech & Language	Fully included
Lauren	Diploma	Homemaker/part-time at school site worker	9	Autism	Special Day Class
Karen	Masters	Special Education Teacher	15	Autism	Special Day Class
Sarah	Diploma	Operations Clerk	16	Autism	Special Day Class
Brenda	Diploma	Unemployed	16	Autism	Special Day Class
Sandy	Bachelors	Real Estate	26	Autism	Four year university

Table 1: Parent Participant Demographics

It is important to note demographic data from the 2014-2015 school year in each of the parent participants' school districts. African American students made up only 10.9 to 26.7 percent of the student body population in the parent participant school districts. However, 53.5 to 79.2 percent of the teachers identified as White, whereas a mere 5.6 to 18.7 percent of teachers identified as African American. Table 3 also indicates the

number of African American students on the autism spectrum in respective school districts (Educational Data Partnership, 2018; California Department of Education Data Quest, 2018).

School District	African American Students	Autistic African American Students	White Teachers	African American Teachers
A	18.4%	25	56.9%	9.8%
B	26%	50	79.2%	5.6%
C	26.7%	202	53.5%	18.7%
D	18.8%	30	69.1%	6.6%
E	10.9%	49	54.7%	9.7%

Table 2: Participant School District Demographics.

### Cultural brokers

#### What are cultural brokers?

Cultural brokers have unique roles in the social learning framework of CoP in that they can garner multi-membership or occupy multiple positions within their communities (as trusted members of families and school communities). Etienne Wenger (1998) defines *brokering* as “connections provided by people who can introduce elements of one

practice to another.” (p. 105). He further argues that, multi-membership allows cultural brokers to compile information and act as agents for change using boundary objects which are, “artifacts, documents, terms, concepts, and other forms of reification around which communities of practice can organize their interconnections.” (p. 105).

What sets a cultural broker apart from a novice member of group within a school community is simply unfamiliarity with the way in which to meaningfully engage in the particulars of a school environment. Cultural brokers are masters of the “nuances and the jargon” (Wenger, 1998, p. 104) that entrench school communities. Cultural brokers know how to navigate through and with these established school wide internal systems. They are involved in translation, coordination, and alignment between perspectives of each group.

### **Cultural broker recruitment**

The recruitment of cultural brokers was conducted during parent interviews using the snowball method as previously described. During parent interview discussions, parents indicated details about advocating for their child and others who have done so on their behalf. They spoke openly about how advocates impacted their lives and/or school communities. The researcher then asked parents who fit the role of a cultural broker to participate in a future focus group or forward the contact information of an individual the researcher noted as a cultural broker to contact for recruitment. This process led to five cultural brokers. All five potential cultural brokers were sent recruitment letters by email.

The sixth cultural broker was enrolled when an existing cultural broker participant notified the researcher by email of a school administrator who was interested joining the study and shared her contact information.

### **Cultural broker demographics**

All six cultural brokers identify as African American. Collectively, they have a total of over 90 years of experience in the field of education between them and 31 years of special education experience. They work in or with school systems (administrators, teachers, college prep program director) and in the business realm as a financial planner. Three of the participants are both parent participants and cultural brokers. In terms of education: one of the focus group participants had earned a doctorate, four had master degrees (two were also credentialed special education teachers), and one had a bachelors degree. Table 3 represents the demographics of the focus group participants.

Participant	Education	Occupation	Years in current field	Child in SPED
Millie	Masters	Principal of large public school	20 years	No
Cheryl	Masters	Coordinator of educational services (former public school principal)	18 years	No
Wilma	Masters	Special education teacher	9 years	Yes
Karen	Masters	Special education teacher	22 years	Yes
Val	Bachelors	Financial consultant	12 years	Yes
Janet	Doctorate	Program director	Over 22 years	No

Table 3: Focus Group Participant Demographics

The focus group participants all showed their vision and dedication to improving the lives of African American children with disabilities in various ways. The participants may advocate for families and children as members of IEP teams and Student Study Teams (SSTs), hold training workshops about the IEP process for families in their community, conduct an ability awareness presentation, tour an alternative school site with a family, intervene during an IEP meetings and remind parents of their child's right to a quality education and receiving services, inform or remind members of their school staff about the importance of cultural competency, and empower students with tools toward self advocacy.

### **Researcher reflexivity**

It is important to note that this researcher does identify as African American, as well as a parent of a teenager on the autism spectrum. She is a product of a public and parochial school education in two Bay Area school districts. After graduating from Merritt College with an associate of arts degree in Legal Studies, the author of this work was awarded a bachelor of arts in Family and Consumer Sciences from San Francisco State University. The mission of this dynamic program at San Francisco State University is centered in “empowering individuals and strengthening families, communities, and the institutions which serve them, with a commitment to social justice and a goal of improving the quality of life within a dynamic and diverse global environment.” Through her course of study, the author’s purpose and intention to achieve a lifelong goal of helping others by addressing the challenges individuals with disabilities, specifically autism, was reignited. Autism is not seen by the research through a deficit lens. Therefore, throughout this work she has chosen not to use clinical terminology (i.e., ASD) when referring to individuals or groups in this study.

One of the most important aims of this study is to unveil the authentic experiences of the participants while highlighting a need for change and intervention for this population. The researcher has immense benevolence, compassion, and a deep understanding surrounding this area of research due to her experiences as an African American mother of a son on the autism spectrum. Thus, the participant interviews conducted by the researcher are very candid and display a great deal of vulnerability that

in most cases only a trusted investigator who developed a high level of rapport with participants could successfully deliver. The author also feels strongly about using the lens of DisCrit (Disability Studies and Critical Race Theory) to analyze the findings. This theoretical framework is centered in the intersectionality of race and disability and gives voice to marginalized populations.

The researcher also believes it is of great importance to address ways to increase knowledge sharing opportunities for African American parents who have children with disabilities in their school and greater communities which is a very limited subset the field of educational research and school reform. This study has been developed as an attempt to fill that void.

### **Data collection**

#### **Parent and cultural broker interview protocol development.**

Two different types of data collection instruments were used as conduits to this qualitative study: in depth semi-scripted interview and focus group. These methods are the bases for exploring the shared meaning of participant experiences in their own contexts (Seidman, 1998). They also aid in identifying problems and real issues participants face (Lichtman, 2014). Semi-scripted interview questions allow researchers to making slight adjustments to prearranged sets of questions during individual interviews based on their responses (Lichtman, 2014). Focus groups utilize interactions between participants to produce insights that would likely be much more difficult to

access outside of the group dynamic; these interactions within the group center on topics initiated by the researcher/moderator (Morgan, 1997).

Interview questions emerged from the phenomenological conceptual framework informed by existing literature on parent-school partnerships, the social learning theory CoP, and efforts to expand limited literature on African Americans and autism. The interview protocol (refer to Appendix A) consists of eight questions consistent with the concept of warming participants up to have an in depth discussion by commencing with an easy question about their familial leisure activities, followed by more weighted questions that are centered specifically in topics found in the research questions (Maxwell, 2013), such as, *what do you feel is important for your child and does your school community share those views?* In addition, questions concerning the representation of autism, the IEP process, positives and negatives within school systems, advocates, and the need for support for these families were solicited. The inquiry ended by asking if parents had anything else to add to the discussion.

The cultural broker questions (refer to Appendix B) were designed to ascertain what they experience as advocates for African American families and children and how they can enhance trusting partnerships between parents and special educators with the same type of structured semi-scripted questions.

The researcher's first drafts of the interview questions were discussed with a senior professor in the Special Education Department. Revisions were made with the

goals of the study in mind and the final protocol was preserved. Below are questions presented to parents during their interviews.

1. Please state your name, child's age, and a fun activity or outing you like to do as a family.
2. Your child has been diagnosed as being on the autism spectrum, what do you feel is important for your child and does the school community share your views?
3. How do you feel about the representation of autism in the African American community?
4. Does your child have an IEP? If so, can you remember how you went about obtaining it?
5. Can you describe two instances of disconnect/distrust between you and the school? What made this happen? What could have made a positive difference? Now, can you give two examples of positive interactions?
6. Who were the key people/advocates for you and your child? How have they made a difference?
7. Do you feel there is a need for more support (help or assistance) for African American parents of children with autism/on the autism spectrum in navigating through parent-school partnerships? If so, what would that look like?
8. Is there anything else you would like to add?

Table 4: Parent interview questions

### **Procedures for conducting parent interviews**

Once all 14 participants were secured, parent participants were contacted by phone and email to schedule in depth semi-scripted interviews during the most convenient locations and times. Parents were given two copies of the informed consent document. The researcher gave participants an opportunity to read, discuss key points (such as confidentiality, complete anonymity, and the expected time commitment), and offered to answer any questions regarding the study prior to signing. The additional copy

was reserved for their records. For interviews conducted online and by telephone, consent forms were sent via email or U.S. mail along with self-addressed stamped envelopes for returning the signed copy to the researcher. Questions regarding consent were discussed prior to the interview. Scheduling and the informed consent process took up to ten minutes. Six interviews were conducted face to face, whereas the researcher met participants at their home, a coffee shop near their place of employment or a private conference room inside of a local public library. Two interviews were held by telephone and one interview was conducted online using Zoom Video Communications™. Parent interviews were conducted from June and October and were 60 to 120 minutes in duration.

The researcher recorded all nine interviews using an electronic audio recording device to ensure accuracy and integrity of interview data with the expressed permission of each participant. Within a period of one week and a half the recordings were transcribed verbatim. After the researcher transcribed the interviews, all of the participants were contacted to review their responses in order to ensure their words, feelings, and thoughts were accurately represented. Nine of the 11 (82%) parent participants were available to contribute to this measure. The questions in Table 4 represent the final version of the semi-scripted protocol presented during parent interviews.

### **Procedures for conducting cultural broker focus group interview**

The researcher contacted focus group participants by phone and email to schedule the focus group. The most convenient times and locations were surveyed. However, the demands of the focus group participant schedules did not allow for a collective meeting. As a result, an online Zoom Video Communications™ meeting was arranged. An email comprised of a link to the meeting and other specifications was sent. The informed consent forms were handled in the same fashion as online and telephone parent interviews. Coordinating the meeting and sending out the consent form took up to twenty minutes. The focus groups were conducted during the months August and September. 180 minutes was the duration of both groups. The following are questions presented to cultural brokers.

1. Please state your name, if you have a child in special education, and a fun activity or hobby you like to do on your days off?
2. Think back to when you took on your first advocate role. How did it happen that you became an advocate for African American families?
3. Describe situations when you felt an educator, school administrators, or other members of the school system were not taking the concerns of African American families seriously? How did this make you feel?
4. How do you support African American families in advocating for the needs of their child(ren)?
5. Do you feel there is a need for more support (help or assistance) for parents with school age children on the autism spectrum in navigating and enhancing parent-school partnerships? If so, what would that look like?
6. Do you have ideas or suggestions for African American families to gain more power or cultural capital in coming together with SPED case managers,

principles and school district representatives?

7. Is there anything you would like to add?

Table 5: Cultural broker focus group interview questions

The focus groups consisted of two sessions. Each session was recorded using an electronic audio recording device. Transcriptions of all interviews and focus groups were created using secure audio recordings to ensure the accuracy and integrity of the interview data. The researcher transcribed all interviews.

### **Data analysis procedures**

The generic approach, as previously defined, utilizes the researcher's experiences into the iterative (repetitive) process of systemic qualitative research (Marshall & Rossman, 2016; Rossman & Rallis, 2012).

In accordance with Lichtman's (2014) outline of the generic data analysis process, the researcher will discuss the steps taken in the analysis procedure. Once all verbatim transcriptions of audio recordings were completed, the researcher utilized the raw data to perform a line-by-line analysis. This first cycle of data analysis led to 235 codes, refining that high number of codes brought that number down to 195. Field notes were also used to highlight significant descriptors that were reflective of all parent and cultural broker experiences during data collection. Throughout this phase, the researcher sought an in

depth understanding of each African American parent with a child on the autism spectrum and each cultural broker in the focus group.

Next, significant descriptive statements were used to identify clusters of meaning (Creswell, 2012). The researcher contacted participants for member checks at this juncture. Participants were asked to verify responses and update the researcher if any answers to the interview questions changed since the last interview. Two participants gave the researcher feedback to clarify their responses and added more detailed information to clarify three areas of their interview data. These additional notes were handwritten and added to the transcribed data. Further sorting of 195 codes resulted in 135 codes.

The final step was to form themes using textual descriptive statements to provide a narrative describing participants experiences. The researcher continued to revisit focus group and parent participant data to form structural descriptions or significant statements used to describe the contexts or where the phenomenon was experienced. At this stage, the researcher met with an assistant professor, an experienced qualitative researcher, to discuss categories that emerged from the clusters of meaning. This discussion led to the further refinement of 135 codes to 95 categories, then 35 categories. Ultimately, seven themes, as indicated in the tables below, emerged as the essence of the phenomenon. Tables 6, 7, and 8 identify each theme as it relates to participant data and the research questions.

**I. Experiences of African American parents of autistic children in their family & community**

Themes	Participant Responses									
	Ali & Lisa	Sheri	Val & Ron	Wilma	Lauren	Karen	Sarah	Brenda	Sandy	Focus Group
<b>i. Isolation</b>	X	O	X	O	O	X	X	X	X	-
<b>ii. Unfamiliar disability</b>	X	X	X	X	X	X	X	X	X	-

Legend: **X** The participant did feel a sense of isolation as a result of their autistic child and/or autism was an unfamiliar disability to their family members and/or community.

**O** The participant did not feel a sense of isolation from their community and/or family or that autism was an unfamiliar disability to their family members and/or community.

- N/A (data for this section was collected from parent participants only)

Table: 6 Research question one themes

**2. Parent-school partnership experiences of African American parents of autistic students and cultural brokers.**

Themes	Participant Responses									
	Ali & Lisa	Sheri	Val & Ron	Wilma	Lauren	Karen	Sarah	Brenda	Sandy	Focus Group
<b>iii. Empowering experiences</b>										
Being in the loop	X	X	X	X	X	X	X	X	O	-
Opportunities for growth	X	X	O	X	X	X	X	X	X	-
<b>iv. Disempowering experiences</b>										
Substandard services	X	O	X	X	X	X	X	X	X	X
Communication	X	X	X	X	X	X	X	X	X	X
Issues with school district	X	O	X	O	X	X	X	X	X	X

Legend: **X** The participant did feel their child received substandard services, they experienced tense and disproportionate communication, had issues with their school district since their child became school age, were in the loop (in terms of communication), and their child’s school community offered opportunities for growth.

**O** The participant did not feel they received substandard services, tense and disproportionate communication, had issues with their school district at any time or their child was not presented with opportunities for grow within their school community.

- N/A (data for this section was collected from parent participants only)

Table 7: Research question two themes

**3. Needs and desired support for African American parents to enhance parent-school partnership experiences.**

Themes	Participant Responses									
	Ali & Lisa	Sheri	Val & Ron	Wilma	Lauren	Karen	Sarah	Brenda	Sandy	Focus Group
<b>v. Specifically designed help in schools/districts</b>	X	X	X	X	X	X	X	X	X	X
<b>vi. Create measures to improve autism awareness/acceptance</b>	X	X	X	X	X	X	X	X	X	X
<b>vii. Develop ways to increase representation and trust</b>	X	X	X	X	X	X	X	X	X	X

Legend: **X** The participant did feel African Americans parents would benefit from school communities offering explicit help, training and more cultural awareness.

**O** The participant did not feel African Americans parents would benefit from school communities offering explicit help, training and more cultural awareness.

Table 8: Research question three themes

## **Data analysis credibility procedures**

In an effort to reduce possible bias, Brantlinger, et al (2005), points to explicitly disclosing personal attributes and view points as a solution to improving validity.

### **Member checks**

#### **First level**

Parent participants were contacted for member checks once all interviews were conducted. These participants were asked to verify responses and update the researcher if any answers to the interview questions changed since the last interview. Two out of the 11 participants gave the researcher feedback to clarify their responses and added more detailed information to clarify three areas of their interview data. Nine out of the eleven parents were able to take part in this part of the study, while two parents were not.

The focus group session included an assistant moderator who procured notes that documented main points discussed by the group. At the completion of the group discussion a member check was performed by the assistant moderator, whereby the focus group members were provided with a summary of their responses to each question. Thus, ensuring the main points they conveyed were understood accurately and truthfully (Lichtman, 2013). When asked if the information recited was in line with their responses; all (100%) of the group members agreed that the assistant moderator accurately captured the essence of their responses.

### **Second level**

Nine parent participants listened to the researchers summary of the main points they made during the interviews and gave feedback and provided additional data they felt was more in tune with their own experiences.

### **Methodological triangulation**

This study used both semi-scripted parent interviews and focus group discussion. Another aspect of combining data to increase validity relates to three different participant experiences: families, cultural brokers, and a non-parental cultural broker. These data sources reported on the same phenomenon. In addition, the presence of an assistant moderator and experienced qualitative researcher strengthened the design of this study (Thurmond, 2001).

### **Collaborative work**

A senior university professor assisted in the design and revision efforts of the semi-scripted interview questions for both the parent participants and the focus groups. Working collaboratively was intended to: decrease subjectivity, bias, and to ensure this work is not centered in the sole interpretation of the author. In addition, Lichtman (2014), alludes to the contribution of collaboration with other researchers as a way to increase reliability in qualitative studies.

**Interrater reliability**

The concept of interrater reliability relates to the level of agreement between raters, add to overall triangulation (Lichtman, 2014). An experienced special education graduate school peer coded a verbatim transcript of a parent interview. Upon completion, the researcher and aforementioned graduate student discussed interpretation of the raw data of one parent interview. We were 92.8% were in agreement of the 52 out of 56 codes that emerged independently. In addition, the process of reducing codes to categories and to themes was done in consultation with an assistant professor at the university.

**Thick description**

Thick description, according to Clifford Geertz (1973), is a detailed description of actual behavior so insightful one can recognize essential patterns and context that inform meaning. The researcher used descriptions and quotes from both the in-depth parent interviews as well as the cultural broker focus groups to describe the context, detail, emotion, and webs of social relationships participants and their children experience.

### Chapter 3: Results

The first objective of this study was to gain insight into the experiences of African American parents with children on the autism spectrum within their family and communities. Secondly, the researcher sought to discover what these parents are currently experiencing when navigating their existing school communities, examine and identify ways to enhance parent-school partnerships in special education and the greater school community using elements of the communities of practice framework. A third objective was to explore how African American parent-school partnerships in special education can improve with the presence of cultural brokers. This research will expand on the emerging literature surrounding African American families and autism.

The results of this study will be discussed and organized in three topics whereas data emerged through an inductive analysis related to the following seven themes:

- 1) Autism and in the African American family and community
  - i. *Isolation*
  - ii. *Unfamiliar disability*
- 2) African American parents of autistic children within their school community
  - iii. *Empowering experiences*
  - iv. *Disempowering experiences*
- 3) Desired support for African Americans and role of cultural brokers within parent-school partnerships.
  - v. *Specifically designed help in schools/districts*
  - vi. *Create measures to improve autism awareness/acceptance*
  - vii. *Develop ways to increase representation and trust*

### **Autism in the African American family and community**

A primary focus of this work was to explore how participants feel about the representation of autism in their own families and their greater community. The experiences pointed to a general absence in understanding and/or familiarity of characteristics associated with this disability, as well as an impending fear of individuals who were significantly impacted by autism.

**Isolation.** Six of the nine parent participants experienced isolation in their role of parenting an autistic child. Parents felt little or no visibility in their communities and families. However, parent philosophies surrounding isolation varied, but the general feeling was a lack of membership in their extended families and community. The data showed many parents experienced intermittent feelings of sadness and abandonment from extended family members. In addition, these participants had little involvement and/or interaction with members of their community.

It's kind of complicated in my biological family because my main support system was my mom who passed away...my mom raised my sister who has autism. Now I am raising my sister who is a young adult with autism and we don't see much of the family come around for hardly much of anything. (Karen)

Karen also revealed how she feels regarding alienation and exclusion. She sorrowfully recounted, "maybe painful and sad some times, but we keep it moving." Karen's experiences point out the layers of complexity in her life as a caregiver.

In another example, Brenda, who also has a teenage son, similarly described isolation as ostracism from extended family members. She unpacks her discontentment with one tearful statement, “It is sad that you cannot call a family member to watch your kid for you for a couple of hours.” During her interview, Brenda took a few minutes to recover from the assessment of her situation.

In their communities, the data described how they experienced autistic children and their families as essentially disregarded.

I don't see anybody in this community really looking out for us and [our] autistic kids. I can't even find my son a decent camp...I don't see anything for these African American autistic kids. I don't...where are the little programs for autistic kids? How come we don't have programs? How come we always [have to] stay in the shadow? Bring us out too. I don't feel like they [are] doing anything. (Brenda)

Through her experiences she felt autistic African American children in her community were kept in the dark or isolated. This data uncovered her desperation for inclusion and respite throughout her narrative. Other parent participants echoed this perception along with a yearning for change.

Sarah shared another example of how parents may feel isolated in their community. Her fears were centered on individuals outside of her immediate family and how they were unable to understand her largely nonverbal son during communicative interactions. Sarah sites “trust issues” and her son’s unconventional communication methods as reasons for appearing unmotivated to participate in support groups (in person and social media).

I've always been told, reach out – there are groups on social media...you can always go out and find a support group. Me, personally, I guess I just don't push myself to look for outside support besides my family. I have big trust issues when it comes to (my child) and it's mainly because of his speech...when it comes to the community or church or that type of support or representation; it's not there for me... (Sarah)

The need for support outside of Sarah's family is outweighed by the discomfort of the unknown. In turn, the data showed support outside of the family unit was inaccessible to some participants. In contrast, church was the exception to this phenomenon. Two participants shared that their church communities were very supportive of their autistic children.

Ali and Lisa felt the grips of isolation in the greater community as they attended an autism event at a highly acclaimed academic institution. An older white male seemed bewildered by their mere presence at an event in which well over two hundred people were in attendance. According to Ali and Lisa they were the only African American couple in attendance. They elaborated on their encounter:

Lisa: [An older] Caucasian male came up to us and was like, "I never see you, so you guys, get like, you guys get this, you guys have this, I've never seen like a...

Ali: He was basically saying...he didn't know there was autism in the African American community. He's never seen any [one], but this is a conference with about two hundred – three hundred people. We were the only black couple there, period. This was at Stanford. (Ali and Lisa)

These participants wondered why more African American parents were not in attendance. They also felt this individual's ignorance was baffling. Ali and Lisa received information about the autism event through a staff member in their child's state run early intervention

program. They noted that information regarding similar conferences and other potential resources for parents and caregivers do not trickle down to African American communities.

**Unfamiliar disability.** All parent participants revealed their families and/or communities were largely unaware of autism or how characteristics of autism may impact individuals. When face to face with autistic children, family members often denied the existence of the disability. Cultural broker participants also experienced a lack of knowledge in the African American community with respect to autism. During interviews parents voiced feelings of frustration and disappointment.

Wilma, a special education teacher and mother of a second grader, articulated concerns of parents of autistic students who reside at her school site and members of her community. She believed that many African Americans have not accepted autism as a disability for people of color because they were not included in the conceptualization of autism.

Black and Brown people have not been in the spaces that create the diagnosis. They [have to] trust the diagnosers, right? They trust the professionals who are coming up with these things and what they have to say about their children – “that’s a White kids’ disorder” because there is something about autism...I feel so glad to talk about some of this. There has been a culture of acceptance around autism for White people and not for Black people. (Wilma)

Her experiences in the field suggest marginalization profoundly affects African American individuals having access to conceptualizing autism and other disabilities. Her

experiences as an educator in the field of special education with connections to parents and their unique perceptions of disability within this ethnic group provides greater depth as to why autism is unfamiliar in African American communities.

Karen, who also has dual roles of caregiver and educator in the field of special education concurs regarding limitations to knowledge in these communities. She stated, “I feel like African American families don’t really quite know what to do when they encounter a student with autism.” She aptly expressed the sentiments of other parents regarding their experiences of African American families’ challenges with understanding autism.

Sandy’s experiences demonstrate another example of the confusion and apprehension extended family members can experience. She exhaustively detailed their inquiries regarding the enigmatic mystery of autism in past experiences.

This was all something that was extremely confusing to the African-American community...the fact that I can be me, Sandy, this militant kind of person who is obviously well educated could produce a child with a very handsome man who I was married to – that was now considered autistic was baffling to everybody around me...African American neighbors [in the] community? I think it was a lot of awe, if you will, as to what it was... (Sandy)

When Sandy’s son was enrolled in elementary school, she recalled, “there was no representation of autism in the African American community.” Parents of the youngest children in the study, echoed Sandy’s twenty-three year old statement.

The data shows an undeniable yearning for more information and understanding about autism; its origin and symptoms in the African American community. Val, described a link between higher education and acceptance of autism in her extended family.

Family members don't perceive it in the same way, if they're not educated. My husband's family – they are in education. His aunt was director of social workers for Detroit public schools so she really knows this. She helped us be an advocate for him, but my family is military-based, so they either ignore it or they give him more of a diagnosis than what he has so they speak to him as if he doesn't understand English or something or he's really behind when that's not the case. You know, they don't understand autism. (Val)

Val's experiences with her family are common among participants in this study. Many participants reported family members were unaware the broad definition of autism as well as nuances about this disability such as, autism has spectrum or array of distinguishing markers that may or may not be present in other autistic individuals. Unknowingly placing unreasonable expectations on autistic children was another area parents felt led to isolation. They felt individuals outside of their immediate families routinely misunderstood their children.

### **African American parents of autistic children within their school community**

The experiential inquiry in this section is centered in data exploring the experiences of participants in their respective school communities.

## **Empowering experiences**

**Being in the loop.** eight of 11 parents described occasions when they experienced instances of positive communication within their school communities. When educators listened to and addressed the concerns of parents and students, parents felt important and seen as equals by teachers and support staff. The data showed effective communication was advantageous to them and their children with special needs. Parent participants felt it was of considerable importance when knowledge was openly shared about what had occurred during their child's school day, related to interventions that were working, and tips for forging through difficulties with their school districts.

Ron and Val appreciated when their teacher emailed them. "I like that she emailed me...she explained to me he was falling behind on his reading which was unlike him." Other parents specially Sarah, preferred phone calls to communicate with her child's teachers. "I can say that they will keep me informed. They have no problem with calling me [if] (my son) is acting out or [to say] we have this to offer...[the calls are] usually from a teacher."

Ali and Lisa, beamed while sharing their feelings about a teacher they considered an ally, "The teacher he had for the last two years was literally everything...she was on our side...she worked for the district or whatever, but she was on our side." According to these participants, the teacher generously shared information and resources about ways to be more successful in advocating for their son in IEP meetings. Ali and Lisa described

the educator's level of involvement and interaction with her students, as "going above and beyond. She was the best case scenario; that is a teacher you want."

Participants also reported the importance of instructional aides and how they have the potential of becoming vital players in their child's academic spaces. Ron and Val expressed how much they appreciated frequent input through journaling their son's aide consistently provided, "Mr. O is fantastic. Everyday I get about a paragraph on what he did for math and science. He sat in [classes] for math and science and that helped a ton."

Wilma's interview provided an example of the effective communication she experienced with an administrator. The principal initiated conversations to address general concerns regarding her son's previous teacher. He informed her that he had comprised a class list and was looking into who would be the best fit for her son, "that went a long way with me." Wilma revealed. Participants reported a renewed enthusiasm in their school environment when made aware that their feelings and opinions truly mattered to their school community.

Ali and Lisa shared how a positive experience they encountered impacted the outcome of their initial IEP meeting, "they definitely changed a lot of his goals on his IEP...they worked with us. I felt like we were being heard. It was a great experience." This category uncovered ways parents had positive experiences engaging with school staff in an array of communicative modes and dimensions.

**Opportunities for growth.** Nine of the 11 parent participants had experienced the benefits having a say in the decision-making process for a change in school and/or classroom placements, as well as in the selection of a new teacher. When parents learned of administrators strategically planning for their children's needs, they again felt heard and looked forward to future collaboration. As a result of a meeting between Wilma and the school principal about selecting the appropriate teacher for her son, she shared, "his first grade teacher was really great, he was also a drummer...(my son) was specifically put into his class and they worked really well together." Wilma's husband is a musician and her son loved to drum and communicate using his voice to create rhythmic sounds. She felt he benefited from the placement and had a positive and successful relationship with a perfectly matched teacher.

Child centered interventions gave parents insight into their child's needs; they reported feeling hopeful about their child's futures when independence was a classroom/school community focus. Lauren's example was centered on a teacher who assisted her in potty training her son. She explained this challenge, "We were struggling with potty training him and this one teacher...[declared] I'm going to help get him potty trained and she was like tomorrow bring him underwear." Lauren's revelation that a teacher had successfully accomplished something no one else was able to do because of her child's unique needs. This was a celebrated milestone for her entire family.

In another example, Sheri described how her son benefited from an area inside of his classroom that his teacher created for taking breaks. A designated area where he could

sit and read train (his special interest area) magazines. She shared how this small, but meaningful intervention provided him with a quiet space to reset when he felt overwhelmed. The reading materials he received were a much higher level, which allows the benefits of exposure to more advanced vocabulary.

The data showed participants were pleased when their child was given opportunities for growth and independence and when teachers could see their children from a positive and strength-based perspective. They were also excited when the school community showed a vested interest in the futures of the children. Sandy described her son's third grade teacher as an African-American male and recounted, "he was the one that made us aware of how (my son) was trying to communicate with us through his art. He is the reason (my son) is at SAE (School of Audio Engineering) today." Sandy also shared her son has earned an associate degree and is currently working toward a bachelors in animation and multimedia art.

### **Disempowering experiences**

**Substandard services.** In special education, related services typically go hand and hand with the onset of a child's diagnosis and his or her IEP. The data showed many participants must vehemently and zealously advocate for their child to receive services that are routinely granted to other autistic students. The services in question could be, but are not limited to speech and language therapy, occupational therapy, assistive

technology, one-to-one instructional aide, transportation to and from school facilities, and a variety of accommodations and/or modifications to core curriculum.

Ten of the 11 parents and the cultural brokers felt their children or children in their school community were not receiving the quantity and quality of related service(s) or instruction they should. Data showed a lack of structure and consistency in classrooms, and an overall need for more educator and instructional aide training in autism was reported. Participants also felt the role of an instructional aide was seemingly unclear. Brenda, for example, was very distraught when speaking about the need for sign language proficiency in the instructional aide's role. Noting the staff was not familiar with signs a student would use to communicate basic needs. As a result, there have been instances when her teenage son arrived home from high school in clothing soaked in urine, Brenda said, "We don't need a babysitter. We need you guys to participate and help us make them grow. Why I'm sending him there [to school] with an aide and he's coming back wet?"

The data that revealed a main concern conveyed by participant was directed at teachers and instructional aides who did not devote the time to develop meaningful and worthwhile relationships with their children. Some participants felt their child's academic and social emotional progress was unknown when reconnoitered their classrooms and met with teachers and support staff.

The first meeting with the second grade teacher, she says, "He's still reading at level C and I think that's where he was when he left here." And the reading tutor

he goes for pullout with says, “No, I tested him this morning and he’s at D”. So yeah I kinda made a physical movement that was like, here we are again, you don’t know my child and that’s a problem. (Wilma)

The data showed participants expressed high levels of dissatisfaction when their child’s academic needs are chronically unknown. They also felt teachers and instructional aides were complicit in the district’s mistreatment of their children which the data shows is typically created from a cultural of a lack of accountability/unawareness.

Participants reported the aforementioned issues as the cause of long standing distrust and tension between families and school communities/districts. Ron and Val provided an example of the problem of high turnover in teachers in their school community, “Last year I think they changed teachers a lot.... he had five teachers within the school year.” Inconsistency within their school community was an ongoing issue for this family; Val’s frustration was noted as she uttered the following, “They implemented the iPad and him having a corner for a sensory break. That was great, [it] lasted for maybe a month...how can you expect him to be consistent, if you’re not?” Data points to fears participants face regularly that the needs of their children will not met in their respective classrooms. Lisa shared her observation of her son’s school site: “I’m peeping through the window and I’m seeing that there’s no structure and there’s really nothing going on. My child is like banging, like on the ground with a hammer, doing nothing, absolutely nothing.”

The data presented participants having clear expectations for their child's school environment and educators. Based on the experiences Ron and Val shared, they ultimately feel their child has been set up for academic failure. Reinforcing this position, Val states, "It's like if I don't come in there and do your job then my son is not going to read."

The school staff failing to read and/or refusal to follow the recommendations for services and address behavior needs found in their child's IEP also a serious concern for other participants. In turn, they felt school staff was not prepared to address the documented needs of their students.

If you do not read the child's file then you are going automatically assume there is always a problem with the student and that is a problem...the teachers wouldn't read his file so I would have to go to the school...and be like if you would read his IEP and what's on file, you would understand the way he acts and why he acts out. (Lauren)

Lauren become frustrated when called to her son's school to intervene when school staff feels they are ill equipped or untrained to handle challenging situations. She felt that if they had read the supports and recommendations delineated in the IEP, they could curb their need to summon her to school for assistance in performing their job duties.

In contrast, Brenda shared her observation of her son engaged in academic work inside of his classroom for the very first time (he is a junior in high school). She revealed, "I really never saw my son sit down with a pen in his hand doing something so I have to [say] hats off to the [teacher] this year." The aforementioned example demonstrates how

long parents may wait for improvements in her child's services or academic programs to occur. Nonetheless, parent concerns regarding services extend beyond the classroom.

The data showed how poor quality services and support for the participants were also apparent when transportation was provided by district to and from school placements. Sheri, was visually frustrated while sharing her example of a disturbing transportation issue. Her son, (a kindergartener at the time) was "taking the bus to his afterschool program which was probably five miles away, maybe less than that and the bus system was not organized. It would take an hour and a half maybe two hours [for him to arrive]." Sheri felt fearful and frustrated when she received calls from the aftercare provider inquiring about her son's whereabouts and she had no knowledge of his location.

Ali and Lisa also had a transportation issue during the summer where temperatures reached 104 degrees, but their son's bus was without a functioning air conditioning system. The students were forced to remain onboard for almost three hours. These participants were outraged to learn the school he was transported to that day had shut down. In turn, ill equipped with plan for an alterative location for students, the decision was made to leave the children on the bus.

**Tense and infelicitous communication, actions and lacking cultural awareness (competence and humility).** All participants felt several members of their school community failed to communicate with them in effective and respectful ways.

They reported atmospheres void of culturally responsiveness in their school communities. The data showed how participant words and actions were often misinterpreted and misconstrued by members of their school communities. Resulting in parents feeling unwelcome beyond the gates of their child's school. Parents expressed that their experiences in many cases felt toxic and hurtful, and in turn, they some may have shut down and were visually upset when engaging with personnel who lack cultural awareness. They were spoken to in unpleasant ways when reaching out to staff to discuss various topics. Such as, reporting the needs of their child, reporting how their child was treated unfairly or was underserved, and when other disagreements with the school staff surfaced. Sandy expressed what was seemingly the most extreme instance of infelicitous communication.

Probably the biggest assumption as an African-American was that I was violent and I would do or say something that was uncontrollable. For example, whenever we set a [IEP] meeting where they felt like they were going to tell me something that didn't jive or go with what I was requesting - that was within my rights. They would make sure that the police were there or some sort of security was there...I would have to say to the lady who was the director...you just had an appointment with a white family and I didn't see the security person in that meeting. (Sandy)

She felt there was no justification for the stereotypes placed upon her and asked why police were present in her IEP meeting. She recalled attending all of her school meetings as a businesswoman; dressed impeccably and with glamorously styled hair. She expressed her dismay at being treated with censure, "to lump me in that whole category

and you've [the school staff] seen me in a business suit with my high heels and my briefcase.”

Participants reflected on their school communities that have staffed their customer service positions with individuals who believed in acting and operating on negative stereotypes. These staff members may be the first, and sometimes, only representatives who consistently interacted with parents in culturally unresponsive ways, even when they were provided training.

There are customer service positions everywhere and I would say that it happens frequently because often times they hold that same position (perceptions) as the team members (teachers, school administrators, and service providers)...we are in investing in diversity or investing in being responsive...you cannot assume that one person is like everyone. Yet, that is what happens. So if someone has encountered an experience here at the front office around one parent that may live in a specific section of town who they've already seen negatively and another person who comes in the door, from that part of town is seen as the same; that is unfortunate. It is something that every day is an uphill battle to fight. (Cultural broker)

Cultural brokers also felt that in addition to the front office staff, White teachers were unaware of exactly how to intervene when inappropriate racially based slang was used by African American students in her school site. She said, “We had the N-word discussion and White teachers were afraid to say anything about using the N-word [even when] other students were uncomfortable, but they were excusing it because culturally they assumed it was okay.”

This cultural broker reflected on what she felt about the cause of White teachers overlooking African American students use of racial slang in school settings, she explained that it was around, “guilt and dismissal because of ignorance about how to engage or intervene or interact with other cultures and specifically black or brown people from specific white teachers...white administrators because of fear.” This fear she spoke of is centered in either making people feel uncomfortable or not knowing exactly what to do or how it should be handled.

Participants felt that there was insufficient attention placed on the value of cultural differences. They also thought there was an inability of school and district staff to demonstrate cultural responsiveness. A cultural broker revealed, “what seems to be missing is that cultural relevance piece where a lot of people who are sitting at the table are not able to communicate with families of color.”

The data points to a need for a shift or an overhaul in the way African American parents and students in academic spaces were being serviced and communicated with. Wilma presents a well-articulated example of where she believed these culturally profound problems in school communities and districts may stem from.

If you are not aware of what your schema is walking in the door, like what your biases are, what your...experiences and [are] clear with yourself, what your life looks like outside the doors of the school/practice that you come into - you're bringing all of that in with it's "isms", phobias, all that stuff...it may, you may think you're operating from a compassionate, supportive, social justice oriented space, but really some of those things are racist. (Wilma)

Participants want their concerns surrounding cultural disconnect to become centrally recognized and thus, lead to solutions that are put into place, “[African American parents] don’t feel like they feel for no reason.” Wilma’s example identifies her understanding and frustration when wrestling with the systematic underpinnings keeping African American parents largely absent from school community engagement:

I do feel like the system is set up – I don’t know, it’s unfortunate. I feel like Black people always feel like we just have to do okay and get along, in a system that’s not set up for us to do well in or get along well in and while there are plenty of well meaning White people the system has well been established. (Wilma)

Participants felt members of their school communities and/or districts, created discomfort, distress, and awkwardness in their failure to understand African American cultural differences and see strengths. The data shows participants had the desire to feel understood, competent, and to be perceived in a positive light.

Parents discussed experiencing the feeling of disrespect as shocking phenomenon. The manner in which staff communicated with them in meetings was astonishing. During Karen’s interview she exclaimed, “How they talk to you! I’ve had to go there [address the undesirable behavior] with a couple of people where I’m like, look, I don’t know who you think you’re talking to.” Additionally, Val added she was often scolded when advocating for her son. The response she received in speaking to her child’s teacher is an example, “[the teacher said] Watch your tone, it’s just a bit aggressive and I feel like you’re coming down on me.” [Val responded] Well, I am upset because you send me an email

and you say you want him to read this type of book without pictures and I go in his book bin [at school] and that is all he has [inside of the book bin].”

Parents were also perplexed when serious issues such as their child’s need for reading support were communicated to them in an inappropriate manner. For example, Wilma’s former teacher sent a crumpled tiny note home saying not to forget something trivial, then added, “and I’m also very concerned that (your child) is severely behind (in reading)...it was a very serious matter that she was bringing up on this little crumpled paper.” Parents felt their children deserved more effort from school staff when essential information needed to be conveyed to them with regard their child’s academic progress.

Participants expressed additional concerns in experiences centered in classism. School staff made assumptions about the educational levels of parents. Sandy recalled, “A lot of them [school staff] assumed I didn't know what they were talking about when they would explain what was going on in terms of my son. It was assumed that I was not educated off the bat.” Cultural broker participants shared similar experiences while in IEP meetings with African American parents. Cheryl, a cultural broker shared her experience in meetings, she stated, “Nine times out of ten the assumption when an African-American parent is coming in is they are uneducated, maybe don't care, their child is receiving services because they're trying to collect SSI (Supplemental Security Income), and all of the other stigmas.” Parent participants felt they are often not seen or assessed as competent individuals. This makes parent involvement challenging as Wilma pointed out during her interview.

Participants described how poor communication in their school communities has lasting adverse impacts on children and parents. An example from Ron and Val further explained how their final IEP of the school year never took place. They are perpetually tasked with reminding the case manager to schedule their meetings. Val stated they are working parents who, “do not have time to follow up on the follow up...we did not have a final IEP meeting. I sent her my schedule, she asked me to send it again.” They further explained there was a risk of putting the outcome of the meeting in the hands of the school staff member. In turn, the meeting never took place. Many participants felt that when it came to communication, especially when topics were seen as negative they were often overlooked and disregarded.

**Issues with the school district.** Nine out of 11 parent participants and cultural brokers described experiences dealing with school district practices they described as nocuous. Parents reported urgent requests for related services were routinely tabled, stalled, and ignored indefinitely. This data uncovers the myriad of challenges parents face due to inaction from school districts unless a crisis surfaces. The negative experiences parent participants are forced to grapple with at the hand of their districts were said to have induced numerous hardships and distress. This resulted feelings of frustration, distrust, and widespread anguish.

[She said] “You know they have him in the wrong class.” I said, wow, well he has been in the wrong class for two years. Thank you for bringing that to my attention. So from there [my son] went to four schools until we finally got him in the right place...it took them four years to get it together. (Brenda)

Brenda discovered this error when casually conversing with a district staff member. She also shared her son was initially diagnosed with an intellectual disability, but it was later concluded he indeed had autism. Due to this oversight, she reported the need to be vigilant in her communication with the school and district going forward to prevent this type of irreversible mistake.

Sarah who described her teenage son as having emerging verbal communication skills shared the next example. Her narrative relates to the broader issues facing parent participants when advocating for their children's needs.

We've tried sign language and he's like, "No." He wants to talk so I would ask for more. Why can't we get more speech therapy? Is there any way we can get more? It was always, "Well, this is the amount that they [the school district] is willing to give us." I could never get more speech therapy and that was all the way through elementary. It was the representative from the school district as well as...the teacher...it was both of them. They were working together. (Sarah)

The data revealed that participants were told that budget constraints drive the decisions for granting related services, not eligibility. Sarah also reported her continual requests services were met with underhanded and mendacious responses from the district. She believed that as a largely nonverbal student, her son would justly benefit from speech and language therapy as a pullout service (when service is provided outside of a traditional classroom environment).

I was told that because his classes were mainly speech based, that was another reason we could not get speech therapy outside of the classroom. That still didn't

sit well with me...I finally let that go, now the occupational therapy...to this day I still ask for it. I am told that it's not a service that the school district pays for.  
(Sarah)

She continued, "When I ask for a service I really feel we need that service. My son has really come a long way. I still feel like he could be a little further, but it's always what the school district can pay for, what's allowed, and what's not allowed." Sarah went on to describe an alarming situation when her district refused to provide a one-on-one aide for her son, which resulted in him eloping. She was terrified. "In middle school...he would walk away or he'd have a melt down or something like that. I was always told that he didn't need a one-on-one until one day (her child) walked off and he was gone." After many painstaking hours her son was located in another city by the Sherriff's department and local police officers.

Participants shared their experiences of irascibility as the deceitful practices and unreliable information passed on to them concerning their children from school districts. Ron and Val reported having knowledge that school districts are underfunded, but shared, "parents get tired of this, they sue...the system does not work unless you fight and when you're tired of fighting – that's really the only alternative." The data points to parents who have negative experiences with districts feel they unjustly face constant adversity for what they are theoretically legally conceded through their child's IEP.

Some African American single parents are faced with hardships that may become intensified with the systematic oppression. In turn, some may work multiple jobs and are unable to fully participant in their child education, even if they want to do so.

We are just systematically oppressed as a culture, as a society as African-Americans. Most of us have to work one or two jobs summer from single families single-parent families and the parent doesn't have the resources to be as involved as maybe even they desire. (Cultural broker)

As mentioned above, data shows poverty is reality for some of the parents in this study. Lauren shared her example, “people tell them go sign up for SSI for your child to help with the income, to help support the child because you know nowadays everything is so freaking expensive you gotta have everybody come stay with you to so everything can get paid or you are just living check to check.” As a result of such hardships, participants revealed parents often do not have a link to resources or the funds to take advantage of external interventions, tutoring, and other services to assist their child.

**Desired support for African Americans parent-school partnerships.**

Data indicated three types of desired support: designing specialized help in schools and/or districts, creating measures to improve autism awareness and developing ways to increase representation and trust.

**Specifically designed help in schools/district for African American families.**

All participants felt the need for support groups and clubs specific to the culturally unique needs of African Americans. Because African American programs are rare, every participant believed that commissioned groups are needed in order to address ways for families to become equitable players in parent-school partnerships. Sheri agreed with this sentiment, shared her school community does not have any meetings or groups for

African American parents to come together. She revealed, "I think that would help bridge the gap...on a voluntary basis; like our own little PTA."

Cultural brokers felt the most essential piece in cultivating parent school partnerships is creating momentum for parents to come together. They felt unifying was the first step in order to ensure African American parents create change. "I wish there was some way to get [African American] parents to come together and advocate as a whole because I think that's where we would start to see a change." Cultural brokers, as well as parents felt coming together with "like minded" individuals tackling similar challenges to compare needs, strategize, and meet with stakeholders would culminate a shift in the systemic problems African American parents regularly encounter. However, Sandy thought ensuring full participation from parents called for recruitment efforts through highly publicized ways. Such as, utilizing billboards and telephone hotlines was ideal. Participants revealed the potential to increase cultural capital in African Americans by uniting with common goals, "Imagine the power this group of parents sitting in a room who share similar concerns and being able to make suggestions and network with one another."

In addition to school sites, cultural brokers believed district level parent support was more appropriate than aforementioned individual school and support groups meetings.

Parent support should be offered...[at the] district level because generally at the site you have such a small number of students that say fit under the autism

spectrum that it will probably be more beneficial for all of the families and the children should get to be able to get together and have someone speak to them about how to support their children not only in learning on the education side but also socially. (Cultural brokers)

This example also suggests multi-purpose meetings for parents. Cultural brokers recommended avenues for parents connect and receive training from a district representative.

A desire for social connections was present in parent participant data as well. Parents felt coming together for social activities on the weekend would establish a sense of community for both them and their child(ren), especially when they experienced isolation from their extended families and greater community. Karen gave an example of the need for developing social networks is greater for families when their kids are young. She thought having specific dates and times on Saturdays to meet at a park or museum to support one another was ideal. Many parents agreed that spending even a small period of time together was advantageous, even to bring a group together once a week. Cultural brokers added addressing the needs of families with the least amount of disruption to their lives was ideal.

Participants also discussed how much more they would benefit from receiving information and resources to better advocate for their child. Based on the data participants would ultimately benefit from school staff providing comprehensive, specific, and detailed advice and/or training in all aspects in addressing the needs of their

children. Written instructions, directions, and/or other documents distributed to Sarah from her school staff did not provide her with the appropriate level of access to the information. She needed addition help beyond the words written in the document and that verbal communication would work best. Sarah suggested that schools should do more than hand parents papers and turn them away. Participants expressed a desire to reach a full understanding of what is required of them and/or their child before feeling pressured to move on from a conversation or meeting with school staff.

[A parent said] what do you want me to do? Give me the tools so that I can support him in that way.” And so we talked about that question...the question of how to enhance the partnerships...there is a need for us to be doing that parent advocacy work. (Cultural broker)

Participants also shared that many school communities have the resources to provide support to parents. Her site has a Counseling Enriched Class or CEC this type of program that offers workshops, but she was unable to recall when they offered it to special education families. The participant recalled informing her special education staff, “We need to have a parent workshop. These families need to know how at home they can support their children so they are doing the work we do all day, they are able to grow their kids too.” Participants felt that pinpointing where and when school communities can assert their efforts in developing these opportunities for African American parents is vital in increasing parent membership and trust. The data revealed that developing ways to assist parents in IEP meetings was the most necessary component of any parent training

as the stakes are highest in these meetings. Ali and Lisa felt IEP meetings moved at an inappropriately speedy pace. According to participants when this occurs, many African American parents become unaware of what is transpiring within the framework of said meetings.

Lauren provided an example of how parent educational levels can impede parent participation in IEP meetings in addition to vernacular pace, “Some parents read at a second grade level and don’t know how to read the IEP and [remaining engaged in] what is going on.” Participants wanted help understanding the IEP process. They wanted step-by-step instructions starting with how IEP process works, how to read an IEP, what information and knowledge is needed prior to the meetings, and clear definitions of the programs and services offered to students on the autism spectrum. Another fundamental, but crucial area of knowledge for parents is the terms or jargon that fills the space of those meetings. A focus group participant shared an example why parent training surrounding the terminology spoken during IEP meetings is important, she said, “We speak in these [terms] FAPE and the LREs and there’s so much – [of this specific] language. To be clear on that it’s almost like a handbook should be created that’s digital that can be accessible through Facebook...”

Cultural brokers felt offering parents trainings using multiple modes of media was a way to ensure they have access to information that is more suitable for their needs. Parents also shared that learning how to effectively advocate for their children is crucial, as well as making sure the school staff is implementing the accommodations and support

outlined in their IEP. They felt very strongly about support for IEP meetings going beyond training, they also thought having advocates present in their meetings who could check for understanding, fairness, and to ensure their legal rights were not violated.

**Create measures to improve autism awareness.** All participants felt there was a need for individuals to gain more knowledge about autism in their school communities. Participants felt if teachers, support staff, administrators, students, and other parents were more informed; they would in turn be more understanding and empathetic toward the experiences of autistic students. They believed if school provided autism centered training and there was more awareness it would drastically improve the daily lives of their children and typical peers.

The data pointed to ways limited of knowledge surrounding autism was problematic. A cultural broker noted that in her own experience; there are a limited number of autism specialists in the field who are employed by districts. Many participant experiences pointed to the need for more staff related training, "I had to help the [general education] teacher...she never had a kid with autism in her class. She was not familiar with the disability, she did not have any training or skill set on how to deal with kids that have [it]." Val revealed how surprising it was for her to find teachers who had never been tasked with providing instruction to students with autism or who were not equipped with any previous knowledge of the disability who were assigned to educate her son. Many participants shared that they depend on their school staff to help their children, but wondered how this is possible with little or no training? Val felt once her son is mature

enough to explain autism to others he can handle it, but “right now the school system should help provide some education, the teacher should know [more].”

Participants also felt that along with school staff, peers would also benefit from more awareness around autism. Participants underlined many of the challenges their children face at the hands of their peers such as bullying, and that social interactions would improve if there was more information provided to other members of their school community. Brenda observed a group of peers at her son’s school, “being very mean to kids [with autism] on the courtyard” so she immediately took her concerns to the principal. Brenda and Val felt an appropriate time for peer autism awareness training is during school-wide assemblies and like events.

Families of peers make up the largest part of the school community. Participants felt these parent’s voices and actions can reinforcement the importance of autism awareness in their children and school staff. Parents felt there was a need to bring information to parents because they typically have no idea children in their child’s classrooms have autism and struggle socially. Val spoke of a conversation she had with another mom during a fieldtrip whereas she confided in her about the challenges her son had with peers as an autistic student. According to Val, this parent was very saddened by what her son was experiencing and wanted know how she could help. Participants felt support groups and PTAs would reduce stigma and empower those with autism and their families, as well as provide opportunities for networking.

**Develop ways to increase representation and trust within the African**

**American community.** All of the African American parents and the cultural brokers in this study reported the need for representation in their respective school communities. The data collected during participant interviews demonstrated that parent-school relationships are built and remain centered in trust. African American parents reported wanting to be seen as a priority to their school communities and districts. In order to achieve this, participants felt there was a need for parents to have trusted individuals readily available to support their needs. A cultural broker said the key is, “someone on-site who they know they can go to, who they trust.” That is a big part, whether it was last year's teacher or principal...a team/community liaison. They further explained that it is critical for this trusted person to be housed on the school site for parents to consistently have access to their insight, knowledge and genuine camaraderie.

Ali and Lisa expressed, “I think it’s easier to get these things out if you’re talking to somebody that is African American as I am.” This points to a higher level of comfort that is present for these parents when there is representation. Participants experienced feeling unwelcome in common areas of their school sites, such as the front office.

Let's be honest that's a lot of times where the buck stops and where the gate is closed and parents shut down and they walked out or they feel like I don't even want to deal with anybody in there [the office] or the exact opposite and they snap you know they go off and start yelling they use some profanity depending on the person. (Cultural brokers)

Parents felt they were routinely blamed for outbursts or for disgruntled feelings against school staff, but they reported they were often met with contempt at the door even before a verbal exchange occurred.

Participants felt adjusting hiring practices to increase the representation of African American staff members increased levels of trust in the community. Parents also reported the need for more African American teachers and instructional aides. A cultural broker in the focus group said, “I watched [the family’s] shoulders go down when they walked into the classroom that their child would be [enrolled] in and there was an African-American woman who was an aide in this classroom.” This showed that trust and representation goes hand in hand.

Data indicated the importance of African American parents communicating their needs in order to be more understood in their communities.

I feel like a part of what is going to be most critical is to make the needs of parents like us and communities like ours is making our needs known...educating people about what we need and try to remedy some of the issues that were dealing with in special education. (Cultural brokers)

This basic premise is often missing in school communities. The specific needs of African American parents and autistic students are often unsolicited in school spaces and go largely unknown. Cultural broker participants felt African Americans should begin to embody more grassroots types of action toward change in order to “get the ground shifting.”

#### **Chapter 4: Discussion**

This study sought to describe the experiences of African American parents of autistic children within their families, communities, and school community. Another aim was to identify and examine the possibility of enhancing parent-school partnerships in special education and the greater school community using elements of the social learning framework, communities of practice and cultural brokers. The researcher also aspired to expand on emerging literature centered on African American families and autism. The findings pointed to a multitude of challenges African American parents of autistic children can face daily within extended family, their own community, academic environments, and the community at large. The findings also included suggestions for changes based on the unique perspectives of these African American parents and African American cultural brokers.

The first research question was designed to gain an understanding of the parental experiences of autistic African American children within their family and community. The data indicated that parents felt isolated and that autism was an unfamiliar disability in their communities. Social isolation is defined as a deprivation of social connection. This occurs when individuals, groups, or cultures lose or do not have communication or cooperation with one another. The evidence of social isolation is present when the quantity and quality of interaction is below a person's own specific standards (Zavaleta, Samuel, & Mills, 2017). Bronfenbrenner's Ecological Systems Theory (1979) shows the

all-encompassing experience of isolation African American parents were confronted with as it extends to each of the levels.

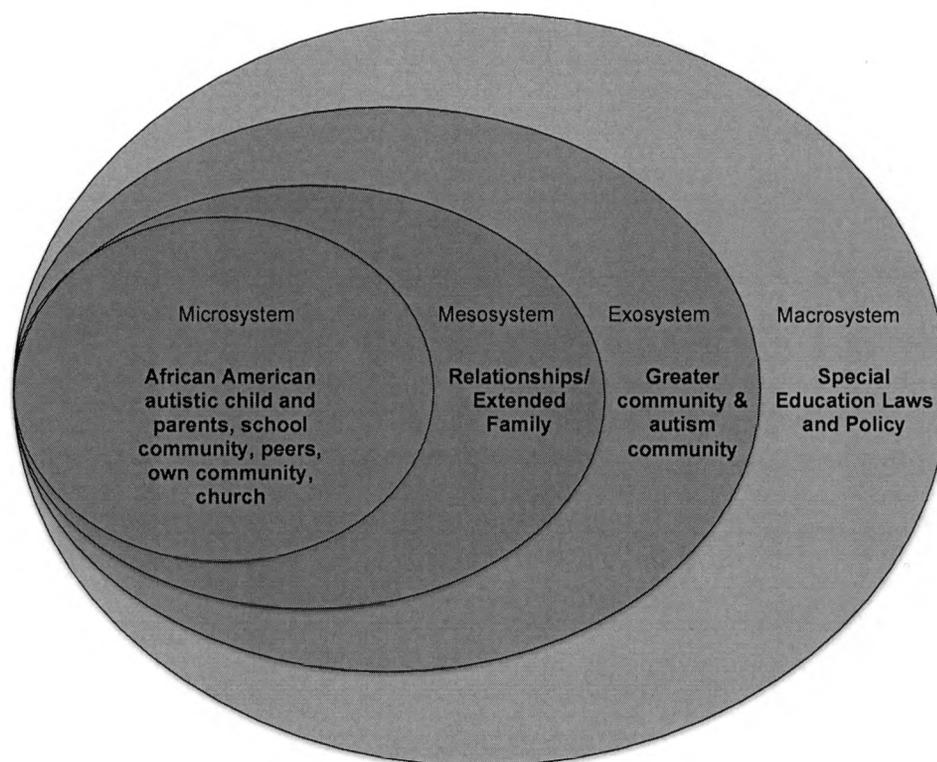


Fig 1. The ecological model: A framework for understanding the challenges African American parents of autistic students.

At the level of the microsystem and mesosystems, the results showed that many parents did not typically interact with extended family members once becoming a parent or caregiver to an autistic child, and thus experienced an inability to reach out to family members for respite purposes.

All parent participants experienced that autism and autistic characteristics were a largely unknown phenomenon in both their family and the larger communities. Family members typically denied the existence of autism or the presence of any disability. As a result, atypical behaviors in the child were ignored, misunderstood, seen as ephemeral or the result of fleeting temperamental moods that required discipline and correction. Some of these autistic children were even feared by their extended families. Two recent studies of African American mothers of autistic children indicate parallel findings concerning family and communities. Their findings supported the fact that African American parents were negatively impacted by disconnects from normative ethnocentric social systems (Lovelace, Robertson, & Tamayo, 2018; Person & Meadan, 2018).

Similarly, at the level of the exosystem, there was a strong feeling of isolation among the participants. They discussed their discomfort when their ethnicity or cultural identities is not represented in support groups and educational settings. This created limited access in utilizing said support groups and other forms of assistance. Also within the school communities there was a strong sense of distrust and loneliness; parents felt out of touch and underrepresented. This finding echoes the work of Gay (1993) about the importance of cultural representation.

Parents were disconnected from existing systems of support at the macro-level as well, such as Special Education Law and Policy. As is the case with other minorities, vital information does not reach them or they do not have the resources and supports (time, money, expertise and experience in successful advocacy) needed to fully activate

them (Kalyanpur, Harry & Skrtic, 2000; Gomez Mandic, Rudd, Hehir & Acevedo-Garcia, 2012). Lacking the advocacy skills to ensure that IDEA and other protections for children with IEPs were honored and maintained presented serious challenges for both parents and their children's futures. This finding supports earlier research on challenges for minority families due to unquestioned cultural premises in the special education system and its underlying assumption of strong advocacy by the parents (Turnbull, 2005; Losen & Welner, 2002).

The findings of this study and existing literature continue to underscore how African American parents who have autistic children experience multilayered social isolation (Yu, 2017b). Participants were not seen as enmeshed in the array of social systems that typically lead to the best possible outcomes for them or their children. Rather, parents were typically disconnected from their extended families, and from their school, with communication being limited and discordant.

The second research question in this study was aimed at uncovering the experiences of African American parents of autistic students in their school communities. Parents felt it was of great importance to receive feedback about their child's progress through information shared by teachers and instructional aids on a regular basis. Parents also appreciated collaborating with teachers to develop IEP goals. Parents were pleased when their school communities provided their children with opportunities for growth. These kinds of positive actions and interactions with school staff were considered empowering.

Findings also uncovered how all parents encountered negative and disempowering experiences (undesirable and detrimental interactions with school staff) in their school communities. African American parents in this study were often met with adverse communication, were denied related services or were recipients of poorly delivered services. Parents felt districts intentionally and routinely engaged in acts of wrongdoing against their children which caused a great deal of needless stress and had long standing negative effects. Another area of discontent was evident when school communities were devoid of cultural responsiveness. This study also found participants subjected to racist, negative stereotypes. As a result, parents legitimately felt unwelcome in their own educational spaces.

These findings support what we know from the literature about the positive effects of meaningful, robust, and equitable parent-school partnerships (Kyzar, Haines, Turnbull, & Summers, 2017; Francis, et al, 2016; Louque & Latunde, 2016; Burk & Hodapp, 2014; Rodriguez, et al, 2014; Mortier, Hunt, Desimpel & Van Hove, 2009; Goddard, Taschannen-Moran, & Hoy, 2001). Moreover, the aforementioned literature emphasizes that without these relationships children with special needs are missing out on much needed collaboration efforts to fully support their needs. Longstanding barriers reflected in the data in this study (i.e. lack of relatable information concerning IEP jargon, power imbalances with school staff and district administration, limited parent engagement due to challenges with transportation, financial hardships, other familial responsibilities, and differences in cultural norms) can impede parent engagement

(Schultz et al, 2016; Kalyanpur, Harry, & Skrtic, 2000; Ong-Dean, 2009). The data herein, and previous research, have indicated even greater challenges for immigrant and nonimmigrant minority parents in both general education and special education (De Gaetano, 2007; Harry, 2002; Gay, 1993; Ogbu & Simons, 1998).

For participants in this study, the aforementioned disparities were strongly experienced as racial issues, which align with similar research by Yull, et al (2014; Osher, Woodruff, & Sims, 2013). Hence, the racial inequality parents encountered in school communities indicated the need to look at the ongoing reasons African American parents have difficulty fully and influentially engaging in colonized academic spaces (Leonardo, 2009; Du Bois, 1935). One theme that stood out in the data was the lack of trust that the parents in this study had in the school system as a space where their children would receive the education and supports and services they need to grow and be successful. This lack of trust was based in a history of negative experiences they encountered over the years. In addition, Ogbu and Simmon's (1998) Cultural Ecological Theory of Minority Schooling, indicates that involuntary minorities feel a strong lack of trust in *white institutions* such as courts, schools, and government due to a history of oppression. At the nucleus of this issue rests historic systemic ideologies centered in racism and ethnocentrism that have only been mitigated through policy and law, but never successfully eliminated (Meier & Rutherford, 2017; Ladson-Billings & Tate, 2016; Ripper, 2016; Fitzgerald, 2015; Kayanpur & Harry, 2012; Leonardo, 2007). Evidence of infractions and blatant denial of the rights of African American and other students of

color in special education school systems, even when mandated by IDEA, reflects a resistance to changing negative perceptions of these students (Bronfenbrenner, 1967) that date back to the period following the *Brown v. Board* decision of 1954 in both general education and special education spaces (Losen & Orfield, 2002; Turnbull, 2005).

The findings of this research can be understood within a framework of Disability Studies and Critical Race Theory (DisCrit). In education, DisCrit highlights systems where race, racism, dis/ability and ableism are built into the interactions, procedures, discourses, and institutions of education (Connor, Ferri, & Annamma, 2016, p. 14). “DisCrit seeks to understand ways that macrolevel issues of racism and ableism, among other structural discriminatory processes, are enacted in the day to day lives of students of color with dis/abilities” (p.15). This study presents a DisCrit perspective because it focuses in on the multidimensional identities of race and disability. Additionally, it gives voice to a marginalized population on a topic that has received little attention in the literature. It considers legal and historical aspects of disability in that it delineates how parents and their children are denied legal rights, services, interventions, and are grossly underserved in public education spaces, even when formally diagnosed and granted related services through a legally binding IEP. A DisCrit perspective also supports activism and resistance. The proposed measure of introducing the framework of communities of practice as a grassroots movement includes a bottom up approach to take action and to alter the power dynamics of historically disenfranchised parents and students.

The third research question sought to uncover what the desired support for African American parents with autistic children navigating through parent school partnerships encompassed and how cultural brokers could enhance these partnerships. Data from both parents and cultural brokers uncovered what would providing support on their behalf in school communities entail. Trust and representation were of the utmost importance and were a perceived starting point in developing extensive meaningful relationships with school staff and districts. A persistent narrative among parents and cultural brokers was how much more prepared parents would be in advocating for the needs of their children if they were provided with explicit instruction in every aspect of the IEP process and interventions. They wanted access that allowed for full engagement in meetings, trainings, and any decisions concerning their child in way that may have been different from current Eurocentric norms that were deeply embedded in educational spaces. Training for teachers, aides, administrators, peers and their parents was seen as a desired area of need, so that autistic students were not singled out and harshly disciplined in school communities.

Cultural brokers felt a community liaison was the key to addressing the needs of parents in real time and to working toward establishing trust, and building bridges to connect African American families to the greater school community. These brokers, using a grassroots type of approach, knew what was needed to ensure change. They knew that providing support and specialized training was key, but also realized that through a Community of Practice, all players - parents, teachers, aides, district staff and experts

(aka cultural brokers) - have the ability and right to participate equally in moving toward the shared goals (Ishimaru, Torres, Salvador, Lott, Williams, & Tran, 2016; Rossetti, Sauer, Bui, & Ou, 2017).

Comparable literature addressing the benefits of establishing communities of practice in inclusive special education settings calls attention to the ability to eliminate barriers to parental engagement through its “transformative quality that allows members to adapt their existing frames of reference, assumptions and theories, and to integrate them into their identities” (Mortier, 2018, p. 13). The data revealed by cultural brokers in this study, as well as in Mortier’s paper, addresses the importance of preparing teachers to become members of communities of practice with parents to develop supports for the students. It is the integrated knowledge of the school staff, the student, peers, and other parents in the community that creates positive student outcomes. Trust and access are at the core of parent-school partnerships for participants (Francis, et al, 2016). Schools have typical hierarchical structures; power is rather formal and centralized, so negotiation can be limited to key authority figures (Laluvein, 2010). However, Laluvein (2010) and Mortier (2018) point to the importance of trust and how it emerges through repetitive “social interactions and takes root” as individuals come to know each other. This familiarity and membership is central to communities of practice and to structuring the aforementioned power struggle.

African American parents in this study expressed a desire to be better informed by pertinent literature addressing how best to support their autistic child’s needs and to

improve overall quality of life outcomes. Connecting the dots for parents and working toward closing the knowledge gap through the concepts of *mutual engagement* and *shared repertoire* as members of an active community of practice is where the cultural broker's role comes into play. There is notable success in community partnerships for African American parents when utilizing this social learning framework along with cultural brokers (Fairfax, 2016) in general and special education settings (Cooper, Riehl, & Hasan, 2010). Furthermore, the potential role of cultural brokers and their ability to create and maintain connections in a social learning dynamic is viewed as the starting point for achieving the goal of engaging African American parents in special education settings.

### **Limitations of this study**

The first limitations in this study were attributed to the small sample size and location of participants. These shortcomings were due to the narrow reach of recruitment, limited number of autistic children within a concentrated geographical range, and the time constraints of this study. In addition, three participants had dual roles as both parent and cultural broker. However, this research provided rich and new data for the field, but it cannot be generalized due to the sample size.

Another existing limitation was that all participants were parents of male students. Autistic female students who identified as African American could potentially have varying experiences within general education and special education milieus.

The last limitation is based on a female dominant sample demographic. This study was comprised of only two male parents. However, the two male participants shared that they have significantly and consistently been involved in their child's education and overall growth and development.

### **Recommendations**

Consistent with the experiences described by participants, the following recommendations are suggested:

- (1) Autism awareness in African American communities. It would be beneficial to African American students and their parents if more members of their community were knowledgeable about autism and characteristics that may be present in autistic individuals. Many religious spaces are the pillars of their communities; equipping them with information to share with their members is a way to address this need. Other community spaces such as libraries and community recreation centers are ideal spaces for community forums for sharing information about autism.
- (2) Autism centered training. Parents are calling for teachers, aides, and all parties in school communities to gain knowledge and expertise in autism centered training to become better prepared to educate their children. In addition, providing training that engages the entire school community (i.e. all school meetings and assemblies) would have the most impact is recommended. This could provide an

opportunity for removing stigma associated with autism, which in turn could promote and support inclusion and acceptance of autistic African American students. School wide communities embracing neurodiversity may also create much needed change toward respecting all differences.

- (3) Trust and representation. It is imperative that changes are made in hiring practices to bring more African American individuals into key roles within school systems in order to create more trust and equality in school communities. Many participants and prior research concludes student success in classrooms increase when teachers represent their own ethnicity (Egalite, Kisida, & Winters, 2015).

It is also vital for school districts to impose policies and require oversight to enforce the implementation of IEP recommendations, revisiting how teachers and school staff are trained in supporting autistic students and creating ways to ensure equality in services and support.

Implementing Cultural Humility training would be pertinent in providing immediate relief to African American parents and children faced with school sites and districts devoid of cultural awareness and competence. Cultural Humility incorporates a lifelong commitment to self-evaluation and self-critique, to address power imbalances (Tervalon & Murray-Garcia, 1998). This concept “is best defined not as a discrete end point but as a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves” (p. 118).

(4) Power imbalances within parent-school partnerships and limited parental advocacy efforts. It is recommended that schools hire or provide training to existing school staff to form viable Communities of Practice and to utilize cultural brokers to connect parents and caregivers in and around advocacy training. This can be done by providing and sharing the tools to better understand the practices of schools and districts in relation to IEP meetings (laws and disability policies to ensure they are familiar with their rights). There should also be increased opportunities for African American parents to support each other in facilitated support groups. First, school communities must survey the particular needs of their parents and offer options for participating outside of ethnocentric norms (online meetings that are cell phone accessible, attending meetings through social media forums like Facebook or other popular sites) (Williams, Pemberton and Dyce, 2012). African American parents must be seen using a strengths-based lens by members of their school communities (Mortier, 2010, Cooper, Riehl & Hasan, 2010).

### **Future research**

The results of this study present the rationale and momentum for addressing the unique needs of African American families based on what was uncovered herein. Future research will focus on: (1) replicating this study with more African American parents and cultural brokers to support the current findings; (2) discovering what teachers and school communities need in order to provide more equitable education environments for African

American autistic pupils and parents; (3) analyzing alignment of cultural brokers with parents to form active communities of practice and actualizing equity for African American families in school systems; (4) conducting additional research addressing the areas of autism centered training, representation, cultural competence and cultural humility, and increasing parent advocacy.

### **Conclusion**

The significance of this study, despite any limitations, rests in the value of the results and the inclusion of the unique voices of African American mothers, two fathers, and cultural brokers as participants in research of this nature. It is one of the first studies providing insights into the experience of African American families with children with autism in their communities. This work pushes forward the narrative reiterating a necessity for school/district staff to improve their efforts to build trust, increase representation, and acknowledge the impact of turning a blind eye to inequality and cultural unawareness for African American parents and students. This study also presents compelling evidence from African American parents, which supports their insistence that school communities that do not typically invest the time and effort needed to meet their unique needs must be addressed. The lived experiences of these parents justifies the need to shift the blame from African American parents, which would be a move in the right direction for increasing and sustaining new connections centered in trust and collaboration (Nussbaum, 2013; Nussbaum, 1997). This study offers additional evidence for the need to engage in communities of practice and to pursue the involvement of

cultural brokers as ways to empower parents, and to create spaces of trust that will result in appropriate supports and services for students with autism in their school communities.

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### **Appendix A: Parent Participant Interview Questions**

1. Please state your name, child's age, and a fun activity or outing you like to do as a family.
2. Your child has been diagnosed as being on the autism spectrum, what do you feel is important for your child and does the school community share your views?
3. How do you feel about the representation of autism in the African American community?
4. Does your child have an IEP? If so, can you remember how you went about obtaining it?
5. Can you describe two instances of disconnect/distrust between you and the school? What made this happen? What could have made a positive difference? Now, can you give two examples of positive interactions?
6. Who were the key people/advocates for you and your child? How have they made a difference?
7. Do you feel there is a need for more support (help or assistance) for African American parents of children with autism/on the autism spectrum in navigating through parent-school partnerships? If so, what would that look like?
8. Is there anything else you would like to add?

### **Appendix B: Cultural Broker Focus Group Interview Questions**

1. Please state your name, if you have a child in special education, and a fun activity or hobby you like to do on your days off?
2. Think back to when you took on your first advocate role. How did it happen that you became an advocate for African American families?
3. Describe situations when you felt an educator, school administrators, or other members of the school system were not taking the concerns of African American families seriously? How did this make you feel?
4. How do you support African American families in advocating for the needs of their child(ren)?
5. Do you feel there is a need for more support (help or assistance) for parents with school age children on the autism spectrum in navigating and enhancing parent-school partnerships? If so, what would that look like?
6. Do you have ideas or suggestions for African American families to gain more power or cultural capital in coming together with SPED case managers, principles and school district representatives?
7. Is there anything you would like to add?