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The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum.

By

ELIZABETH HOLLIDAY MORGAN
DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

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In

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Approved:

Dr. Aubyn Stahmer, Chair

Dr. Maciel M. Hernández

Dr. Lauren Lindstrom

Dr. Maisha Winn

Dr. Sally Rogers

Committee in Charge

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CONTENTS

DEDICATION AND ACKNOWLEDGEMENTS.....	IV
ABSTRACT.....	V
INTRODUCTION	1
REFERENCES FOR INTRODUCTION.....	6
STUDY 1: NARRATIVES OF SINGLE, BLACK MOTHERS USING CULTURAL CAPITAL TO ACCESS AUTISM INTERVENTIONS IN SCHOOLS ABSTRACT.....	10
NARRATIVES OF SINGLE, BLACK MOTHERS USING CULTURAL CAPITAL TO ACCESS AUTISM INTERVENTIONS IN SCHOOLS	11
CULTURAL CAPITAL AND AUTISM PARENT ADVOCACY	13
METHOD.....	16
COLLABORATORS.....	17
PROCEDURE	18
MEASURES.....	20
DATA COLLECTION AND ANALYSIS	21
FINDINGS.....	22
COLLABORATOR PROFILES	23
CROSS-CASE DOMINANT CULTURAL CAPITAL THEMES.....	30
CAPITAL FACILITATORS	31
EMERGING THEME: GENERATIONAL RESISTANCE CAPITAL.....	32
DISCUSSION.....	33
REFERENCES FOR STUDY 1.....	37
STUDY 2: THE DEVELOPMENTAL PROCESS OF PARENT ADVOCACY FOR BLACK MOTHERS OF CHILDREN ON THE AUTISM SPECTRUM ACROSS THREE STATES: PORTRAITS OF BLACK MOTHER ADVOCATES ABSTRACT.....	42
THE DEVELOPMENTAL PROCESS OF PARENT ADVOCACY FOR BLACK MOTHERS OF CHILDREN ON THE AUTISM SPECTRUM ACROSS THREE STATES: PORTRAITS OF BLACK MOTHER ADVOCATES	43
BLACK BOX OF AUTISM PARENT ADVOCACY	44
DISPARITIES ARE RED FLAGS FOR INSTITUTIONAL RACISM	45
UNDERSTANDING ADVOCACY DEVELOPMENT FOR BLACK ASD MOTHERS.....	46
RESEARCH METHODOLOGY AND METHODS TO UNCOVER BLACK BOX	47
METHOD.....	49
RESEARCHER POSITIONALITY.....	51
COLLABORATORS.....	51
PROCEDURES.....	51
MEASURES.....	53
INTERVIEW PROTOCOLS	53
DATA COLLECTION AND ANALYSIS	54
FINDINGS.....	57
SUMMARY OF PHASES OF ADVOCACY DEVELOPMENT.....	58
I. TRUSTWORTHY AGENTS OF SUPPORT	59
II. ADVOCACY VALUE SYSTEM DEVELOPMENT.....	65

III. POSITIVE ADAPTION.....	71
DISCUSSION.....	80
IMPLICATIONS.....	84
REFERENCES FOR STUDY 2.....	85
CONCLUSION	96
APPENDICES	98

Dedication and Acknowledgements

This dissertation is dedicated to my mother, my grandmother, and all of the mothers that poured into me and into others for generations. It has been a beautiful struggle to uplift the voices of those of us that have been silenced for too long.

I must thank my God, my husband, and my children for being with me throughout this process and never leaving my side. I also need to thank my community, the many scholar friends that I have met along the way that have helped to shape and mold me into the scholar I am today. My Xavier University crew, Attiyya, Sonata, Danielle, and Fatmata; you believed that I would be “Dr. Beth” over 20 years ago; I will always value your sisterhood. My Harvard homies, Keishana, Hope, and Brian; you are not only my friends, but you are also my family. To the students, parents, and teachers that I have been honored to work with during my 16+ years career as an educator. It is your example of perseverance and determination that paved the path to get me here. To my countless colleagues over the years at UC Davis: MIND/CEDD, AUCD, Los Rios Community College, and SCOE what a privilege it has been to work with you all. To my Qual Scholars/FYD writing group, your brilliance sharpened my scholarship, but your friendship improved my life. Thank you to my formal advisors and informal advisors, there are too many to list, but your mentorship is valued and appreciated. Last, thanking my research assistant team, Aziza Litterjohn, Efren Rodriguez, Felipe Avila, and Jamie Bolander, your commitment to this project really made such a difference. Permission has been granted for use of published study 1 “Narratives of Single, Black Mothers using Cultural Capital to Access Autism Interventions in Schools by publisher Taylor & Francis.

“It's the possibility of having a dream come true that makes life interesting.”

— Paulo Coelho, The Alchemist

Abstract

While Autism research is interdisciplinary, a review of the research offers a monocultural understanding of how autism impacts family development. Most studies use a homogenous population sample of White middle-class families and/or omit intersectional factors such as race and developmental disability in both the design and analysis of the study. Additionally, while the literature on the effects of parental advocacy on the diagnosis and treatment of children on the autism spectrum does offer a more nuanced perspective of the role and identity of such parents, it does so with the exclusion of race and gender from much of the analyses. The experiences of Black mothers of children with Autism are either absent or presented from a deficit point of view ignoring the long-standing advocacy work from this population. Therefore, if we are to better understand the differences in experiences that produce advocacy development for Black parents of children on the autism spectrum, additional studies are needed. Consequently, using a Critical Race Theoretical (CRT) framework, we conducted critical empirical investigations with the aim to explore and understand the pathway to becoming *autism parent advocates* for populations with intersectional oppressed identities such as race, gender, and class. The first study conceptualized types of resources (i.e., community cultural wealth) that Black mothers of Autistic children (N=5) used to navigate school systems. Published in the *British Journal of Sociology of Education* (Morgan & Stahmer, 2021), we found that Black mothers were more likely to use advocacy to navigate special education systems when schools engaged in family-centered practices. The second study explored the variables associated with *parent advocacy development* in Black mothers (N=7) of children on the autism spectrum across three states: California, Pennsylvania, and New York. Findings include three key phases of development that

occur over time for Black mothers to cultivate the advocacy for their children and for families they coach in their communities.

Introduction

In 1943, Dr. Leo Kanner diagnosed the first children in the United States with the disability we know as Autism Spectrum Disorder (ASD) (Angell & Solomon, 2014; de Wolfe, 2013, Silverman, 2011; Zarembo, 2011). Although it has been 80 years since the first diagnosis, the role of parental advocacy in obtaining an ASD diagnosis and treatment for autistic children remains significant (Angell & Solomon, 2014; Silverman, 2011; Zarembo, 2011). Research indicates that multiple factors contribute to children being diagnosed during early development and treated within the first year of diagnosis, but the most critical factor is a powerful parent advocate, also known as an ‘autism parent’ (Angell & Solomon, 2014; Gourdine et al., 2011; Harstad et al., 2013; Hassrick, 2019; Wilson, 2015). The term ‘autism parent’ or ‘ASD parent’-- a label first documented in the unpublished ethnography dissertation that explained the complex identities of parents of children on the autism spectrum (de Wolfe, 2013) -- is used throughout the text to describe the autism parent population. Black parents of children on the autism spectrum also share the identity of advocate, but because of the social construct of race and other intersectional variables, the course to becoming a powerful advocate can look different (Burkett et al., 2015; Lovelace et al., 2018; Morgan & Stahmer, 2021; Pearson & Meadan, 2021; Stahmer et al., 2019; Wilson; 2015). To better understand the issues that affect the advocacy development of Black parents of children on the autism spectrum, we need critical empirical investigations to explore and understand the pathway to becoming autism parent advocates for populations with intersectional oppressed identities (impacted by racism, sexism, classism) or what Annamma & Hardy call, “multiply marginalized” populations, such as Black women (Annamma & Handy, 2020).

The two papers that comprise this dissertation share one primary goal: to use a critical theoretical framework to investigate advocacy development for Black mothers of children on the

autism spectrum. Although there have been studies on autism parenting and the skills, stresses, and challenges that are associated with the parenting experience at various phases of development for the child (Hassrick, 2019; Pellecchia et al., 2018; Trainor, 2010), we have limited understanding of the resources, strategies, and pathways for effective advocacy for Black autism parents.

Two major unanswered questions surround the impetus of these papers. First, what resources and in which context are Black autism mothers able to advocate for autism services for their children when in schools? Using a Critical Race Theoretical (CRT) framework, the first study conceptualizes types of community cultural wealth (i.e., non-dominant cultural capital) that Black mothers expressed during semi-structured interviews which asked about experiences of challenge and triumph in navigating schools' systems for supports and services for their autistic children. We collected narratives of five single Black mothers to get a better understanding of what and how mothers overcame the barriers and secured services for their Black autistic children. Using a thematic analysis, we coded interviews for several domains of cultural capital found in the literature, including *aspirational, familial, social, linguistic, resistant, navigational, motherhood, and Black cultural capital* (Carter, 2003; Lo, 2016; Yosso, 2005). Mothers in the study predominately provided examples of *resistant* and *navigational* capital. Black mothers were more likely to use their capital to affect services for their children when schools engaged in family-centered practices. This study has been published in the *British Journal of Sociology of Education* (Morgan & Stahmer, 2021).

For the second question, what key experiences, stressors, perceptions, and resources influence positive adaption and advocacy development for Black mothers of autistic children? Using CRT, a critical methodological framework, paired with the qualitative method of

Portraiture (Lawrence-Lightfoot & Davis, 1997), the second study investigates variables associated with parent advocacy development in Black mothers of children on the autism spectrum across three states: California, Pennsylvania, and New York. To better understand the pathway to positive adaption for Black Mothers, the Double ABCX developmental model was applied to understand key resources, stressors, and perceptions before and after the autism diagnosis that influenced the development of advocacy for Black mothers (Weber, 2011). The ABCX model is a formula used in family stress research to help explain factors in families that help them recover from a crisis while predicting the variables to be them to adapt to the crisis (Weber, 2011). The *A* in the model represents the crisis-precipitating events or stressors, the *B* represents the family's crisis-meeting resources, the *C* represents the interaction and perception or representation that the family makes of the crisis and the *X* represents the actual crisis (Weber, 2011). This study used liberating methodologies to co-construct portrait narratives of seven mothers to illustrate the resources they used to navigate service-delivery systems (e.g., early intervention, special education) after their child's diagnosis and discuss how those resources contributed to their advocacy development. The results indicate: (1) Black mothers discuss using internal resources (i.e., non-dominant cultural capital) to navigate service-delivery systems before and after their child's diagnosis (Yosso, 2005); (2) Black mothers describe disseminating advocacy strategies (e.g., being persistent, not taking no for an answer, and keeping detailed records) to parents they coach.

Narrative inquiry and a phenomenological qualitative method of portraiture were used in both dissertation studies to approach the construction and analysis of interviews that were collected from Black mothers of children on the autism spectrum. We selected qualitative methods to conduct these studies to provide more depth to the data obtained and to unearth the

thoughts, feelings, and opinions of study collaborators. We used semi-structured and open-ended interview questions to allow for relationship building and social reciprocity between the researcher and collaborators (Esterberg, 2001). In line with CRT principles of challenging the dominant ideology and emphasizing the centrality of experiential knowledge, participants in both of the studies are called “collaborators”. This was done to confront the hierarchical power dynamics involved in social science research and to reimagine and redesign empirical investigations that recognize the value of partnership and collaboration in conducting high-quality qualitative inquiries (Ladson-Billings, 2000; Ladson-Billings, 2015; Lawrence-Lightfoot, 1994; Lawrence-Lightfoot & Davis, 1997). Due to the intersectionality of race, gender, and class of our study collaborators, this approach was necessary to obtain a detailed snapshot of their lives and advocacy development (Crenshaw, 1989). This is particularly important for studies involving Black women because of harm, in the form of historical trauma and erasure, that institutions of higher learning and research have perpetuated against us (Du Bois, 2008; Lawrence-Lightfoot, 1994; Zurberi, 2001).

Collaborator Demographics

We collected multiple individual interviews (Study 1: $N = 5$; Study 2: $N = 28$) from Black mothers that lived in cities in the three states of California, New York, and Pennsylvania to get their perspectives on advocating for assessments and services for their children on the autism spectrum over time. In both studies, a family demographic questionnaire added to the analysis of interviews by providing an understanding of the family structure and educational and economic resources. An additional survey, the Community Cultural Capital questionnaire which was adapted from a multi-site randomized control trial study, was added to collect self-reports of types of capital they felt they had (Morgan, 2020) from each study participant (Study 1: $N = 5$;

Study 2: $N = 7$). Because this is a qualitative dissertation, both survey questionnaires were used to triangulate interview data and allow for a deeper understanding of what tools and resources mothers had to support their advocacy development. Using multiple units of analysis to study a cultural phenomenon such as parent advocacy development provides a “thick description” (Geertz, 1988) and allows for a more in-depth understanding of the details that go into mothers developing advocacy.

In both studies, we found that advocacy development for Black mothers included many key social agents of support and networks, personal attributes, and resilient responses to stressors and hardships before and after their child’s diagnosis which produced an advocacy value system. This value system became the foundation for their drive to secure supports and services not only for their own children, but for other children in their communities. However, we are left with more interesting questions as to what types of interventions will create the systems-level changes to facilitate marginalized groups of people to activate their advocacy which will ultimately inform my scholarship and career as an academic. The findings from this dissertation will provide a rationale for future studies that investigate parent involvement and access to intervention for autistic children, and will be of interest for researchers, organizations, and agencies that truly seek to do work that creates change and is thoughtfully inclusive of factors that impact multiply marginalized populations.

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Study 1: Narratives of Single, Black Mothers using Cultural Capital to Access Autism Interventions in Schools Abstract.

Abstract: Lack of access to autism treatment has deepened the disparities for Black children with ASD. Limited resources and lack of advocacy skills in Black families are reasons given for these service gaps but the identification of mechanisms that support Black families access to treatment for their children has yet to be investigated. This paper explores the forms of cultural capital single Black mothers use to advocate for their children with autism in schools in the United States. Using a Thematic Analysis, interviews were coded for several domains of cultural capital found in the literature, including *aspirational, familial, social, linguistic, resistant, navigational, motherhood, and black cultural capital* (Carter, 2003; Lo, 2016; Yosso, 2005). Mothers in the study predominately provided examples of *resistant* and *navigational* capital. Additionally, mothers were more likely to use their capital to impact services for their child, when schools engaged in family-centered practice.

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This is an Accepted Manuscript version of the following article, accepted for publication in British Journal of Sociology of Education. Elizabeth Holliday Morgan & Aubyn C. Stahmer (2021) Narratives of single, black mothers using cultural capital to access autism interventions in schools, British Journal of Sociology of Education, 42:1, 48-65, DOI: [10.1080/01425692.2020.1861927](https://doi.org/10.1080/01425692.2020.1861927). It is deposited under the terms of the Creative Commons Attribution-Non-Commercial License (<http://creativecommons.org/licenses/by-nc/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

Narratives of Single, Black Mothers using Cultural Capital to Access Autism Interventions in Schools

The U.S. Centers for Disease Control reports 1 in 54 children has autism spectrum disorder (ASD); (CDC, 2020), making it a considerable public health concern. However, there are large disparities in the early identification of autism and access to care. Although Black¹ children are just as likely to have ASD as their White counterparts (Daniels & Mandell 2013; Yeargin-Allsopp et al., 2003), Black children with autism are diagnosed 1.6 – 5 years later (Mandell et al., 2007; Mandell et al. 2009). Black children with ASD are also almost three times more likely to initially be misdiagnosed (Mandell et al., 2009). Multiple studies have concluded that early autism detection and treatment leads to better outcomes in cognitive and language abilities (Rogers & Vismara, 2008), yet many Black children are identified after the window of early intervention closes. Once diagnosed, Black families regardless of socioeconomic status or educational attainment, have reduced access to intervention services (Gourdine & Algood, 2014; Longtin & Principe, 2016).

Accessing high-quality diagnostic and intervention services for autism has historically required a high degree of parent advocacy (Lord & McGee, 2001). Parental advocacy in the U.S. during the 1970's and 80's was the mainspring behind the inclusion of children on the autism spectrum in schools (Silverman, 2011). U.S. Federal legislation in the Individuals with Disabilities Education Act 2004 (IDEA, 2004) mandates that schools treat parents as equal

¹ The authors capitalize the word “Black” when that term is used to designate ethnicity and race. Per the American Psychological Association Manual Style (6th edition), Section 3.14, p.75, “racial and ethnic groups are designated by proper nouns and are capitalized: Black and White”. The lead author also prefers to use Black because it functions as a unifying term for the descendants of the African diaspora including people within the African-American, African, Afro-Caribbean, and Afro-Latinx heritages.

partners in all phases of educational assessment, planning, and treatment of their children who receive special education services, making the ability to advocate critical to service access. Parents were given rights to advocate for access to autism services for their children, however, the most empowered and visible parent advocates were White Americans.

Research on mothering children with disabilities and the social constraints prescribed on mothers is rooted in unequal gender roles and nurturing responsibilities (Green, 2007; McKeever & Miller, 2004). The experience of mothering children with disabilities includes calling on intermediaries who have influence to utilize cultural capital on their behalf to obtain access to supports and services for their children, yet many investigations exclude the experience of Black mothers. Research on Black mother relationships with special education settings provides evidence that Black mothers do not receive the same level of participation and partnership as their White parent counterparts (Stanley, 2015). Black families report distinct stereotypes and prejudices that serve as barriers for Black mothers during the Individualized Education Program (IEP) process including being described as ‘adversarial, dysfunctional, uncaring’ and being told their input during meetings is an ‘untrustworthy source of information’ (Stanley, 2015). Providers also report challenges partnering with families of color, including distrust and cultural mismatching (Harry, 2002; Rao, 2000). As a Black woman with a son on the autism spectrum, the lead author also experienced disempowerment during IEP meetings. Her positionality within the context of her child’s schools required her to state her academic knowledge as an autism researcher and use her skills as an educator to validate her positions and level the scales of delegitimizing treatment. This led to her interest in conducting the current study to understand how this experience manifests itself in advocacy strategies for other Black mothers. We suggest one way to support Black families may be to conduct phenomenological investigations to better

understand the experience of Black mothers of children with disabilities and the roles of cultural capital in autism parent advocacy when intersectional domains of identity such as race, gender, and class are factors.

Positioning the Social Context of Black Motherhood In the Black family unit, the mother has long been a cornerstone. Black mothers are commonly decision-makers, leaders, and activists both in the home and community (Landry, 2002). Black mothers have shouldered the burden of protecting their children from institutionalized racism (Elliott & Reid 2016), while engaging in activities that ensure the survival of members in the community (Collins, 1994). Black women face obstacles associated with gender inequality and racial domination in tandem, as they have the double burden of fighting daily battles associated with race and gender that cannot be teased apart but exist together in a complex synergistic existence (Simien, 2004). Black mothers who have children with ASD carry multiple layers of obstacles when confronted with opposition which may affect their advocacy development; these mothers potentially have to deal with the many “isms” (i.e., sexism, racism, classism) associated with the intersectionality of gender, class, and race, as they develop the advocacy strategies needed to fight for their children (Collins, 1989; Crenshaw, 1989). Thus, being a Black woman in the U.S. means race and gender are always salient factors during interactions with male-dominated (patriarchal) and/or anti-Black spaces such as schools (Collins, 1994; hooks, 1981). Schools tend to reproduce and maintain social inequalities by continually rewarding people who possess a particular capital associated with White, middle-class, values and norms and thus can be oppressive spaces for Black mothers and their children (Blum, 2015; Lareau, 2011; Lareau & Horvat, 1999).

Cultural Capital and Autism Parent Advocacy

Sociologists have defined a person's social assets, such as their education, style of speech, and intellect, as cultural capital (Bourdieu, 1973). Bourdieu's theory of Social Reproduction designates three forms of cultural capital as a model for explaining intergenerational transmission of power and status: the embodied, objectified, and institutional states (Bourdieu, 2018). Whereas objectified and institutionalized forms of capital materialize in cultural goods (e.g. commodities, intellectual property, and educational degrees), the embodied state is the fundamental foundation for all other forms of capital, manifesting in the long-lasting possessive embodiment of cultural capital accumulated over time. Although Bourdieu's usage of the concept was related to the field and does not equate to deficit in a normative way, his theoretical conception of capital as embodied resources serves as seminal work.

For decades, cultural capital was exclusively associated with White culture, but Tara Yosso's work on Community Cultural Wealth allows a better understanding of how cultural capital relates to the embodied forms of cultural capital within Communities of Color Based on a Critical Race Theory (CRT) framework, Yosso used Community Cultural Wealth to re-conceptualize traditional interpretations of cultural capital to describe the cultural wealth, or funds of knowledge, that many communities of color possess. Cultural wealth is translatable into cultural capital but is not traditionally valued in educational settings (Moll, 2019; Yosso, 2005). CRT is a transdisciplinary, methodological paradigm that offers a framework to recognize, investigate, and transform the social structural aspects of society that maintain social stratification between subordinate and dominant racial, ethnic, gender, and economic groups (Delgado, 2002). According to Solórzano and Delgado (2001), the CRT model comprises five elements:

(A) The centrality of race and racism and their intersectionality with other forms of

subordination.

- (B) The challenge to dominant ideology.
- (C) The commitment to social justice.
- (D) The centrality of experiential knowledge.
- (E) The transdisciplinary perspective.

In the current study, we use the CRT Community Cultural Wealth Model to frame the forms of cultural capital that Black mothers use to navigate, survive, and thrive in social atmospheres that are oppressive and not built with them in mind. When Black single mothers engage with special education systems, they run into intersectional obstacles that require they employ multiple advocacy strategies or use multiple forms of cultural capital to overcome. Yosso's Community Cultural Wealth Model illuminates the cultural resources that constitute capital in marginalized communities and may help researchers understand how to leverage strengths found in communities of color to support their advocacy (see Table 1 in [Appendix A](#) for detailed definitions). The Community Cultural Wealth Model deconstructs cultural capital, into six types which include (Yosso, 2005):

- (a) Aspirational: the ability to maintain hopes and dreams in oppressive environments.
- (b) Linguistic: the intellectual and social skills attained through communication experiences in more than one language and/or style.
- (c) Familial: the cultural knowledge from family or kin that carries a sense of community, memory, and cultural intuition.
- (d) Social: the networks of people and community resources.
- (e) Navigational: the ability to navigate systems not built with a marginalized population of people in mind.

(f) Resistant: the ability to oppose and challenge inequality.

Based on the specific tasks and skills needed for Black mothers to develop an advocacy strategy for their children, two additional types of cultural capital, Black cultural capital (Carter, 2003) and Motherhood capital (Lo, 2016), become important. Motherhood capital originates from a study of 25 monolingual low-income Mexican immigrant mothers that used their influence in schools and medical settings to be mother advocates for their children (Lo, 2016). Black cultural capital is described as the knowledge and dual possession of cultural capital and non-dominant cultural capital and the ability to fluidly utilize the capital in the appropriate social context, also known as code-switching (Carter, 2003), (see [Appendix A](#): Table 1 for list and definitions).

An empirical investigation of the cultural capital resources that facilitate Black mother advocacy strategy may provide information about how to address the current dilemma of the disparities in accessing ASD interventions. The objectives of this paper are to (1) examine the types of cultural capital that Black mothers identify as important when advocating for their children, and (2) identify potential barriers and facilitators to active engagement in educational systems for Black mothers.

Method

The study design involves a qualitative analysis of five in-depth, semi-structured interviews with single Black mothers of children with ASD about tools and assets they possess that might translate into strong advocacy strategy. Qualitative in-depth interview methods are a useful approach to research in this population because it allows an understanding of the intersectionality and complexities of a social phenomenon that occurs in the lives of Black mothers (Timmermans & Tavory, 2012). CRT is the theoretical framework used to formulate the

study therefore the authors used a transformative (critical) paradigm epistemology of acknowledging the social and historical interactions and the need to address issues of power and trust. A CRT methodological framework and theoretical application of Cultural Capital and Community Cultural Wealth Model provided the grounding for interview analysis to identify the cultural resources that Black mothers used to engage in advocacy with school systems (Yosso, 2005).

The reflexivity and positionality of the lead author being a Black mother of a child on the autism spectrum allowed for high-quality data to be collected as each of the mothers knew they were speaking to a person that empathized, understood, and was a part of their in-group (Hsiung, 2010; Milner, 2007). In addition to the principal investigator, the research team consisted of three female researchers. Two undergraduate research assistants participated in coding transcripts, identified as a Black and a White woman.

Collaborators

A purposeful sampling of single Black mothers provided a focused investigation of resources Black mothers own without the influence of additional caregivers in the home. Purposeful sampling is commonly used to identify and select information-rich cases related to the area of interest (Palinkas et al., 2015). For this study, the inclusion criteria are: (1) Mother of a child between the ages of 7 and 17 years of age with a medical diagnosis or school classification of ASD. The age limits are set to ensure that participating mothers have had substantial experience and interactions with special education and other service delivery systems. (2) Self-identifying as Black or African American. We allowed for this distinction to include the diversity of cultural experiences within the Black community, including people who identify as a part of the African diaspora. (3) English-speaking. (4) Qualifying as single; we

solicited single mothers in order to understand the individual internalized cultural capital domains that were most dominant and being utilized while advocating for Black autistic children. This includes individuals Non-married and/or not having other adult partners living in the home. Additionally, this includes individuals who do not have a partner outside of the home who consistently provides capital as a resource, an appropriate categorization given that many Black adolescents live in single-parent homes as a result of having parents who were never married or became divorced (Hetherington et al., 1998). The average age of the five mothers was 47 years old. They all had some college education with a majority having a four-year degree. All but one was active in a parent support group for children with disabilities. Children ranged in ages from 7 to 14.5 years and all primarily placed in a special education classroom for children with autism (see [Appendix B](#) for Table 2 with caregiver demographics). Collaborators received a small gift card as compensation for their participation in the study.

Procedure

Recruitment included sending informational fliers to local parent support groups for Black families of children with developmental disabilities and on Facebook groups (e.g., ASD Mocha Moms). All interviews took place at a university in Central Valley California and lasted approximately 90 minutes. Collaborators completed a demographic questionnaire before the interview. All mothers were informed and aware of the lead author's social positioning and ingroup status as a Black ASD mother which we suggest assisted in the facilitation of high-quality data collection. All interviews were audio-recorded and transcribed for coding. We recruited and interviewed until we reached saturation in common themes.

A semi-structured interview protocol was used to gather information about the key non-dominant cultural capital domains that the mothers used in their interactions with service

intervention systems (i.e., early intervention and special education). Our additional questions focus on understanding the mother's first experiences after their child's diagnosis and their recollection of the process to obtain services and supports during that time. We created a semi-structured interview protocol (see [Appendix C](#)) using questions drawn from the literature to gather information about the key Community Cultural Wealth Cultural Capital domains that the mothers used in their experiences with service intervention systems (i.e., early intervention and school systems). Additional questions focused on understanding the mothers' first experiences when their child was diagnosed and what they could remember about how they obtained services and supports during that time. The topics addressed include:

1. Personal resources and strengths that have proven helpful when advocating for their child with ASD
2. Experiences and examples of advocacy they used as a model in advocating for their child
3. Words of advice or wisdom that they would share with another Black mother who had just received an ASD diagnosis for their child
4. Invitation to tell anything else they wanted us to know (See Table 3, [Appendix C](#) for interview guide)

We used in-depth ethnographic interviews of participating Black mothers with children on the autism spectrum to allow a deeper understanding of their experiences and non-dominant domains of cultural capital when navigating service delivery systems. We decided to use this methodology because semi-structured and open-ended interview questions allow for social reciprocity and relationship building between researcher and informants (Esterberg, 2001). Due to the intersectionality of gender, class, and race identities, we desire a detailed snapshot of these

families' lives as they ultimately impact child outcomes (Crenshaw, 1989). Expressly, four kinds of information can only be captured during in-person interviews when the interviewer has room to view the non-verbal and nuanced communication of the participant. These include the honorable, the schematic, the visceral, and meta-feelings which are harbored in the emotional landscape within cultural research (Pugh, 2013).

In-person interviews took place in a private room at the University of California campus and were conducted in a secured setting to establish trust and privacy. We aimed to conduct in-depth ethnographic semi-structured interviews that lasted for 60 – 90 minutes each. Participation was completely voluntary, and collaborators had the right to end participation at any time without risk of losing their gift.

Measures

The *Community Capital Parent Questionnaire* (designed for the study) is a 10-item scale that will assesses collaborators' community cultural capital levels on a 1-5 Likert-Type scale. We formulated these items from past qualitative research on non-dominant cultural capital (Carter, 2003; Lo, 2016; Yosso, 2005). We used this tool for data analysis to correlate levels of non-dominant cultural capital with demonstrations of advocacy in their interviews in parent collaborators ([See Appendix D](#)).

A demographic survey, designed for the study, was a three-section demographic questionnaire that collected personal information to better understand certain background characteristics of collaborators.

Section One: Gathers collaborators' information including age, highest education level completed, current employment status/occupation, race, ethnicity, income, number of children or

family members with autism other than child that fit criteria for project, and level of participation in parent support groups for families of children with disabilities.

Section Two: Collects information on the collaborators' child with autism including gender, grade, age of diagnosis, number of years it has been since they were first diagnosed, and type of schooling placement child is in (e.g., autism-only disability classroom in public school).

Section Three: Collects information about collaborators' household, including number of people (children and adults) who live in the home, family household income, status of supplemental income assistance, medical insurance status, and geographic location of their primary residence (e.g., urban, suburban, rural).

Data collection and analysis

The CRT methodological framework challenges the paradigms on race, gender, and class by recognizing these factors as a foundational and a central theme in societal constructs that have major impacts within historically disenfranchised people, like Black people, in the United States (Bell, 1992a; Omi & Winant, 1993). We use CRT to interpret and analyze interview data in the context of the Black mother advocate experience within school intervention systems to give voice to the repressed Black parent experience, unearthing the challenges and stories of resilience. CRT provides a method for interpreting the impacts of social structures and institutions on ASD Black families and illuminates their stories and journeys. During the analysis of the interviews, we used CRT to interpret the impacts that social structures and institutions have on the lives of the Black mothers of children with ASD; a journey currently hidden behind the dominant, White and middle-class, narratives in the literature. CRT can be used to analyze both reasons these stories have traditionally been absent in the literature, and how institutional racism can result in nuanced advocacy based on context for Black mothers.

A multistage process of thematic coding was followed to analyze interview data (Miles et al., 2018). First, we listened to and read transcripts simultaneously to confirm accuracy. Next, we developed broad descriptive codes and definitions based on non-dominant cultural capital literature and began initial data coding. We assigned codes (e.g., Aspirational Capital) to individual passages of text. After completing one round of coding, the research team discussed the addition of emerging codes that came from key topics in the interview data. Coding was conducted in pairs with the lead author coding all interviews. Disagreements were discussed and coders came to consensus (Nowell et al., 2017). During the third stage of analysis, we developed five in-depth narrative profiles for each participant using field notes and coded interview data. The profiles included detailed descriptions of the mother participant, her family network, and her experiences supporting her child with autism in schools. A cross-analysis of all interviews was used to confirm and document patterns related to spaces and environments in which single Black mothers were able to exercise their cultural capital to create opportunity for increased services and supports for their child with autism in schools (Alverson et al., 2019; Miles et al., 2018).

Findings

The interviews of single Black mothers provided in-depth perspectives of their experiences interacting with school systems and intervention teams for their children with ASD. All five mothers expressed a myriad of challenges related to communication with school and intervention staff at various points in their child's development. Findings are discussed in three parts: (1) participant profiles, including the experience of initial diagnosis and introduction to services and as well instances of the expressed advocacy that it took to secure services, (2) cross-case dominant cultural capital themes, (3) emergent themes that arose from cluster coding.

Collaborator Profiles

Evelyn. A tall woman with bold features was middle-aged, yet her hazel bronze skin gave her a youthful glow. Her responses were succinct, poignant, and powerful as she told stories describing the cultural capital she used to advocate for her son in school. Evelyn was a divorcee and mother of two boys. Her oldest was a college sophomore and her youngest was 14 years old with ASD. After his diagnosis, she admitted feeling the pressure to give up her voice and allow the many new interventionists that were experts in her son's life to take over and lead his intervention management. Evelyn herself did not graduate from college until her early forties; thus, the education and pedigree of these experts felt intimidating. Her insecurities were bolstered when she felt shut out of conversations regarding her son's intervention plan. In this quote Evelyn describes her experience of stepping into her role as an advocate for her son:

And I will tell you this. That's what came through the years in the journey of standing up to people in a room that don't look like you. It requires you to use the knowledge you have. It requires you to use the understanding you have. It requires you to realize that you got this. You know what's best for your child. When you're in the initial IEP, you're the one running that ship. And once you take that wheel, things run a little differently.

Evelyn learned to follow her instincts, which she admits was hard because she did not have many peers as role models. She educated herself and found parents from various parent support groups to be mentors, although frequently, she was the only Black mother in the group. It took her a few years, but she soon found her voice. When asked what she does when she is told “no”, this question made her perk up in her seat. She took a slightly different tone of voice to explain that she did not allow “no” to cause her to be emotional; instead, she found the power to set her

emotions aside for a moment to become “*stronger than superwoman*” to advocate for her son. In this story, Evelyn gives an example of advocating for her son during an IEP:

I would say I've had a couple of services that were wrongfully terminated because of Thomas. And I think it was discrimination because of his size and his ethnicity...I think those are the times we have to regroup. Because I truly find in these situations as being an African American woman, they're expecting truly a different response from me. So at that time [transition IEP from junior high to high school] I happened to turn to the specialist who was handling the meeting. And said, "Okay, I'm done!" She goes, "Well, what does that mean?" I said, "You guys will find a placement of my choice where he'll go and pay for it." And she looked at me. I said, "If I can't find suitable [placement] for what you have here in this district and she's [school administrator] clearly telling me that he's not wanted, that there's a problem. There was a different change then, after that, because they weren't expecting that.

Evelyn is now a full-time home health care worker for her son and spends most of her free time supporting other families who have children with developmental disabilities.

Mae. Mae grew up in the segregated South of the U.S. in the 1960s². She wore a pair of colorful plastic framed glasses that sat neatly on the bridge of her caramel nose. She had three children; her two oldest were approaching adulthood when her now 13-year-old with ASD was born. Before being diagnosed with ASD at six years old, her youngest son was diagnosed with severe Attention Deficit Hyperactivity Disorder (ADHD) at three after being expelled from his preschool. Mae never felt that the ADHD diagnosis was sufficient, so for three years she pressed

² U.S. history includes a time period after the emancipation (1897-1965) that denied Black Americans basic civil rights through the enforcement of “Jim Crow” Segregation Laws.

her doctors and the school district for additional testing. This is an account of her advocating to her pediatrician:

They said no, that they was going to stay with the original diagnosis. Anyway, we're fussing with the doctor, and kind of getting smart with her and telling her, basically, "You can go with anything that you want to go with, but I am going to get him tested. You just can make this easy with me, otherwise, I'm coming through a backdoor, but I'm going to have this test done because I know something is wrong. If you so sure that the other diagnosis is correct, then, why won't you just let me have the test to prove that you're right and that I'm wrong and stuff?" Finally, she decided, just for whatever reason, that she'd give me the authorization I needed to go and have him tested.

Although Mae's son showed a strong ability to achieve academically, he was placed in a self-contained special classroom with other developmentally disabled children until his seventh-grade year. Mae described her struggle to convince the IEP team that he belonged in a general education setting. This is Mae's account of an exchange she had with her son's IEP team while advocating to provide him an opportunity to be educated in the least restrictive environment (LRE) and include him in a general education setting with typically developing peers during his middle school years:

I went there, and I hand my list out, and I started telling him I wanted him to be in just one regular class at this point. As I was talking to him and they was kind of starting to knock me back a little bit, "Well, what if he fail?" Instead of my answer being then that I'm afraid he fail, What if he fail? So what? If he fails, he fails, but he failed knowing that we gave it a try, [better] than not never knowing that

you gave it a try, and then he succeed at a lower level, which still can be a failure.

No, let us, don't worry about him failing. Let him do the best that he can.

Mae worked full time but found time to take part in support groups, connecting with other parents. She found that networking with other ASD families that were cultural matches to her was an important step in her advocacy journey.

Wilma. Wilma was a teacher by training and mother of five children ranging from college age to her youngest who was seven with ASD. It was her youngest son's preschool teacher that first mentioned developmental concerns while attempting to expel him from their preschool center. When Wilma went to her pediatrician the doctor did not listen to her concerns. In time, her son began to demonstrate self-injurious behaviors and would leave marks on himself. When Wilma tried to seek services from medical or school providers, she was told that all that could be done was to give her a speech evaluation for her son. This is an account of Wilma advocating for a comprehensive evaluation for her son:

Because someone I knew told me, "You need to ask for an evaluation. That's the only way to get the services that you need." Then when I did that they said, "Well, we can do a speech evaluation, but that's about it." "I was like, "Oh, okay. Let's do the speech evaluation for a kid that's hurting himself, constantly crying and beating up his family and destroying property." It just kind of seemed like they wanted to do things in a certain way, and I was like, "My son needs help now. He needs a special kind of help. We need to know what he has, what's going on

Because of her training as a general education teacher, she had some exposure in the U.S. special education evaluation process and therefore wrote a letter to the principal of her son's elementary school asking for a comprehensive psychoeducational evaluation. Once her son was officially

diagnosed, they placed him in 40 hours a week of services at a behavioral center for children on the autism spectrum. He has remained in a similar classroom to this day. Although Wilma was college-educated, possessed a teaching credential, and had strong communication skills she expressed feeling disempowered and lost in terms of how to navigate the complexities of service interventions for her son. She states, *'I kinda felt like I was powerless but yet I had a voice and I had some validity in what I was saying.'* Wilma was one of two mothers interviewed that went through the courts to exercise their parental right to be full partners in their child's special education process. Wilma won her case against the school district and when asked, she felt that her voice was finally heard and validated when she utilized the legal system and exercise her parental rights. Wilma lived far from support groups that included other Black mothers, so she sought a group that had virtual participation options. Wilma participated in support groups because she valued the information that other Black mothers of children on the autism spectrum provided. She especially valued receiving their input on ideas of how to support her son in accessing services when she *'hit a wall'* in her personal advocacy efforts.

Josephine. Josephine was a cosmetologist by training and a self-made woman. She was a mother of two sets of twins, with one of her youngest being diagnosed on the autism spectrum shortly before her second birthday. She described the layers of crisis that she was in while her daughter was diagnosed and how at the time, she could not be an effective advocate because she was in "survival mode". *'My mom passed away in April and my dad in June. So, she got diagnosed, and I had just ended a relationship that year as well.'* She described how her instinct was to do the only thing she knew how to do which was to go back to work and press forward without allowing herself the time to process the emotions surrounding the diagnosis:

I had nowhere to go, so I went to work. I think after the appointment I went right back to work. I dropped her off then I went to work. Then I think I decided to like... like I didn't accept it. So... I don't know if I didn't accept it because I didn't... I had so much other stuff to deal with.

Josephine discussed how she did not know how to help her child and felt she initially failed her, explaining that she knew nothing about ASD and only knew one person who had a child on the spectrum. Her daughter would engage in self-injurious and dangerous behaviors such as running away from her in public (i.e., eloping) or having uncontrollable tantrums in stores, which caused Josephine to withdraw from most activities outside of the home. A traumatic event during a trip to the grocery store in which her daughter was almost hurt became a pivotal moment for Josephine:

At that point, nothing else was important, and that's when everything just changed for me, because I'm like "I'm gonna lose my child if I don't get it together." I had on heels; you know what I'm saying. I couldn't catch her. So, I was just like this isn't important anymore. It just wasn't important. She was important. So that's when it kind of flipped.

Josephine began to educate herself by picking up any pamphlet and book on ASD that she could find. She started to participate in parent support groups and ask any parent of a child with ASD who would talk to her about what they did to help their child. One of Josephine's most positive interactions was with her daughter's teacher who was an American Sign Language (ASL) interpreter and was excited when Josephine mentioned to her, she thought her daughter could start using ASL to communicate:

So when I brought the idea to her [teacher] that's when I found out she was an interpreter. And she was so cool she would send me videos of her working with Zora and we were just in constant contact with each other. We would email each other in the beginning of the day, and at the end of the day.

Josephine felt that her child's classroom teacher provided her with positive interactions and receptiveness to her ideas, however, receptiveness was rare in her experiences with other professionals. Josephine exclaimed that mostly when she communicated her visions and hopes for her child, professionals disregarded her, saying 'good luck with that'. While this was discouraging for Josephine, it did not stop her from quitting her job and committing her attention to providing care for her children but especially for her daughter with ASD. She now feels that it is her duty to help other parents by actively taking part in groups and events that let her reach other families and give them hope.

Henrietta. Henrietta held a master's degree and worked full-time for the local college. She had a brilliant smile that beautifully contrasted her deep chocolate skin tone. Her only child was diagnosed on the spectrum shortly before he was three. Henrietta admitted to guilt because she was not the one who recognized and sought intervention for her child. It was her mother, who recognized that her grandson was not keeping up with his developmental milestones. Thus, Henrietta brought her mother to the autism evaluation as she was most fit to answer questions regarding his behaviors and development. Once Henrietta received the evaluation that led to a diagnosis of ASD she felt she was not prepared to parent a child with developmental disabilities and found herself often aggravated with the process, stating: "*and it's so much information that you're trying to take in at one time. And you're there for hours, you get tired*" As a result, there were times in her son's life that he received no services or school intervention. It should be noted

that Henrietta was also the only mother who did not actively belong to a parent support group for children with disabilities and did not keep an ongoing relationship with other parents of children with disabilities. She spoke of consulting a professional advocate to help her navigate special education meetings:

I ended up getting an advocate, which for the most part until the end was really good. And she did a great job, so there was some stuff that I could do that I didn't know about. So, we got...the school did pay for an outside evaluation.

Cross-Case Dominant Cultural Capital Themes

During the interviews, each participant provided examples that fit all eight non-dominant cultural capital domains. Collaborators most consistently mentioned examples that fit two prevailing forms of cultural capital: Resistant and Navigational Capital. The mothers consistently shared stories involving Resistant Capital, represented by stories of needing to fight to have their children diagnosed and receive services. The following is an illustration of one mother, Mae, using Resistant Capital during a discussion with a teacher from her son's school:

But instead of me buying into what you saying to me, and letting you talk down to me, even though I realize that what you are doing. I'm going to go a different route and stuff to get to you and let you know you don't have a fool sitting here. I'm not your fool. I'm not your uneducated dummy.

Navigational capital was the second most common community capital resource reported. The following quote depicts Evelyn's description of how she used navigational capital:

I think it was harder because I haven't seen a lot of single Black women out there...It required me to remove myself out of that grief state and realize I have to find out, I have to figure out what is gonna benefit my son.

Capital Facilitators

Each mother possessed many domains of non-dominant cultural capital, but the findings support the notion that a supportive social context is a key ingredient that facilitates Black mothers in effectively utilizing their cultural capital. For instance, when mothers told stories about feeling respected, an important element in agency delivery of family-centered care, they also talked about being more able to use their voice to advocate for their child (Wilson & Dunst, 2005). Mothers told stories about being respected on their child's intervention team and with their child's classroom teachers, and as a result, being able to utilize their cultural capital resources. This is an account, from Mae describing her experience of feeling respected and empowered during an IEP:

It was just a whole different outcome [vs. previous IEP where mother felt disregarded and disenfranchised], because I didn't go in there. I wasn't fussing. I wasn't arguing. But I was going in there to make a point. And that's what I did.

However, when IEP teams were contentious, and mothers felt unvalued, their cultural capital domains were not as useful in producing more services, (i.e., additional assessments, and inclusion options for their children). In these instances, many mothers expressed the need to engage in actions that demonstrated resistance capital but due to an unsupportive social context their capital was not useful, as shown in Wilma's account:

She didn't know that I was a former teacher, and not an idiot...I just went, "Oh, you want to play that game? Okay... It was like every time something came up I had to ask for a meeting...We'd sit around and talk about what's happening, but nothing would be done about it. There wouldn't be any solutions that would take care of the issue.

The mothers' stories yielded suggestions to improve engagement strategies that school staff could use with Black children and families. Such suggestions included the need for additional training programs for schools to engage Black families and build relationships. In this account, Evelyn discussed the change in her son's teacher when he decided to partner with her:

And that's why some teachers are just phenomenal...they just realize that [they will need to do more to partner with Black families] and teaching our children, every day's going to be different, and each day I'm going to have to go over and above what I might normally do.

Emerging Theme: Generational Resistance Capital

The development and evolution of a coding system by a research team can produce a rich and rigorous interpretation and understanding of the data (Weston et al., 2001). During the third phase of analysis, a theme surfaced that we coined *Generational Resistance Capital*. We coded and defined this theme when collaborators connected their perseverance to advocate for their children to historical accounts of resistance from their family or community members. It contains the notion they find the strength to press forward from the roots of the struggles from their ancestors. This capital is related but distinct from familial capital because it references a historical knowledge based in resistance and opposition to discriminatory treatment based on race, class, and/or gender. Examples of this capital included one from Henrietta discussing how she learned not to tolerate racial discrimination she felt she received in schools from a story she knew about her mother:

And my mother was raised in that time where you had the different "white water" and the "colored water"[Jim Crow Segregation]. She was raised in that era. It

was not something that was tolerated for her [her mother refused to accept being treated unequally].

In this account, Evelyn discussed how her mother modeled how to demand respect from people she perceived held prejudicial ideas against Black women. She states:

I was blessed to be raised by a strong, Black single woman. And she made sure no matter what, when she walked in the room, you knew. You knew who she was and you're going to treat her as such.

Discussion

The current study sought to include a dimension—the role of mothering a child with a disability - as an additional identity to the discourse of Black feminist intersectionality. The intersectional experience of being a Black woman in America is a social quagmire producing layers of opposition in environments that were historically created for White men, such as schools. When Black women have children with ASD, in efforts to advocate and become champions for their children to access needed services and supports, they must engage in systems that are structurally and systemically racist, sexist, and ableist. The current study shows that Black mothers in their roles as advocates for their children benefit from cultural capital resources in interactions with service delivery systems. It is also important to note that Black mothers draw upon these resources to fight the obstacles associated with navigating oppressive spaces in other contexts.

Black mothers described consistent challenges interacting with “experts” around obtaining an autism diagnosis and appropriate services, including extensive examples of racial prejudice leading to misdiagnosis, deferred diagnosis, and poor service quality. These mothers discussed the constant need to defy and contest the decisions of autism experts in order to

express their “professional parental” expertise and to advocate for access to necessary services (Rogers, 2011, p. 570). Additionally, a majority discussed the important role of peer parents of children with disabilities in developing and helping to mold their advocacy strategies.

As the mothers described their experiences, the importance of cultural capital became apparent. Most specifically, mothers actuated resistance capital to advocate for their children’s access to quality services, and often felt the need to argue against the expert recommendations in pursuit of individualized services for their child. Black mothers may feel the need to be more outspoken in their requests for services because of implicit biases seen in service providers (Gullo et al., 2018). Additionally, they highlighted the importance of navigational capital, which can support understanding the complex service systems required for children with autism.

Although their stories expressed less emphasis on the use of familial capital, they did discuss learning from their parents and grandparents about the need for resistance capital. The generational translation of values and traditions has been an attributed function of the family unit (Moore & Berchmans, 1996), but the concept of transmission of advocacy strategy and resilience from one generation to another is a newer concept. This new idea that communities that have experienced oppression and hardship develop survival strategies that have been passed down through generations will benefit from future research investigations of evidence of *Generational Resistance Capital* across family multi-generational groups that include a child with a disability. This type of capital may support advocacy strategies for Black mothers of children with autism and other disabilities.

Mothers also reported examples that indicate an interaction between their cultural capital and advocacy strategies and the service context. Several mothers reported feeling more empowered when service providers used family-centered care strategies. One example is the openness of

Josephine's daughter's teacher to partnering with her and hearing her ideas about using ASL to support her daughter's ability to communicate. The need for school policy to be more family-centered and culturally responsive is supported by comparing the experiences of mothers who received family-center care juxtaposed with those who did not.

This study does include some limitations. The mothers in the study had some college education which could have influenced their experience navigating educational systems. Additionally, collaborators come from one geographic area of the United States. Potentially different types of cultural capital may be highlighted by Black mothers living in other states and abroad.

Understanding the assets and internal resources that Black mothers own dismiss the myths about their lack of advocacy skills and instead requires a look at the institutional barriers in our schools and intervention systems that limit them, and perhaps other parents, from exercising their power and voice. Recommendations for improving access might include schools creating culturally relevant parent support groups to promote cultural matching of peer groups to help model advocacy strategies. Additionally, cultural competence and humility training for ASD service providers in schools could reduce implicit bias and encourage family-centered practice.

This research adds to the current literature regarding mechanisms leading to service disparities for children with autism. Examining the assets and cultural capital resources that communities of color possess and bring to interactions with service delivery systems may lead to the development of novel interventions to address barriers in the interface of Black families with a child with disabilities and service delivery systems (i.e., school systems, early intervention, and medical). In the current study, a voice that has been silenced for far too long has

here been recognized for its strength and endurance. Indeed, we hope that this study will stimulate researchers and policy makers to study the assets and internal resources that families within communities of color possess and work to improve current research designs and ultimately ameliorate service delivery systems and interventions for all families of children on the autism spectrum.

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Study 2: The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum Across Three States: Portraits of Black Mother Advocates Abstract

Abstract: In this exploratory transformative study, the qualitative method of Portraiture (Lawrence-Lightfoot & Davis, 1997) is used to recognize the characteristics associated with parent advocacy in Black mothers of children on the autism spectrum across three states: California, Pennsylvania, and New York. This study used liberating methodologies to co-construct portrait narratives of seven mothers to illustrate the resources they used to navigate service-delivery systems (e.g., early intervention, special education) after their child's diagnosis and discuss the development of their advocacy skills. The results of this study found: (1) Black mothers discuss using internal resources (i.e., non-dominant cultural capital) to navigate service-delivery systems (medical and schooling systems) before and after their child's diagnosis (Yosso, 2005). (2) Black mothers describe disseminating advocacy strategies to parents they coach.

The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum Across Three States: Portraits of Black Mother Advocates

In 1943 child psychiatrist, Dr. Leo Kanner published the history-altering and seminal paper entitled “Autistic Disturbances of Affective Contact” which established autism as a diagnosis. Kanner’s paper described his observations of eleven minors he described as having a limited ability to generalize or engage in spontaneous activity, engaging in stereotypic repetitive behaviors, and as distinct from children diagnosed as mentally retarded because of their unquestionable endowment of “cognitive potentialities” (Grinker, 2008; Kanner, 1943). All eleven children were from white middle-class two-parent family groups whose parents used their social capital to dispute their child’s previous mental retardation diagnosis (Eyal, 2013). Diligently, these autism parents used every resource they had to advocate for a second evaluation and resisted previous expert assessments that disputed their child’s potential (Kanner, 1943). The parents located Dr. Kanner and sought out his expertise because they were seeking a diagnosis that gave their family hope. This was likely due to the belief at the time that autism was a mental illness with restorative potential whereas mental retardation was inborn with no hope for treatment (Eyal, 2013). The advocacy shown by these parents demonstrated the formation of the identity of the autism parent, with the activism of vigorous campaigning to bring about political and social change as the bedrock of its essence (Ryan & Cole, 2009).

In this exploratory study, we examine the characteristics associated with parent advocacy development in Black mothers of children on the autism spectrum. We interviewed seven (7) parent peer coaches from a larger multi-site study in which peer coaches supported low-income, culturally, and linguistically diverse families soon after receiving an autism

diagnosis for a child in their care. The primary aim of the current study is to understand the types of resources (i.e., cultural capital) parent coaches use to advocate for their children and if they promoted the use of similar strategies for families they coached.

Black Box of Autism Parent Advocacy

While much research confirms the importance of parental advocacy for children on the autism spectrum (Canter, 2004; Hiatt-Michael, 2004; Hyatt, 2004; McCloskey, 2010), only a few have endeavored to understand the variables involved in the development of that advocacy (Hassrick, 2019; Horvat et al., 2003; Lareau, 2011; Trainor, 2010). These studies have investigated the role of social capital, which sociologists have defined as: relationships with influential people that provide helpful and useful resources and knowledge as key to activating formal and informal advocacy for parents of autistic children navigating service systems (Bourdieu, 1977). Formal advocacy includes safeguards and rights that federal legislation under the Individuals with Disabilities Education Act (IDEA, 2004) provides caregivers of children with disabilities from 0-21 years of age (Reiman et al., 2010). Informal advocacy includes the parent's regular inclusion and participation in decision-making with service providers professionals (i.e., teachers, doctors, therapists) to influence the emergent learning and skill development of their children (Hiatt-Michael, 2004; McCloskey, 2010).

The need to understand variables involved in parent advocacy is critical for fostering autism parent advocacy development. However, the literature only tells one side of the story as most studies have homogenous samples of White families and children. This leaves us to wonder, what are the experiences of families of color, specifically Black families, and what is necessary to activate the development of their advocacy? These unknown variables and processes have led to a lack of understanding about the pathway and process to advocacy

development for Black ASD parents, therefore leading to an uncertainty on how to engage and support Black families of children on the autism spectrum. This lack of knowledge has helped to further the gaps in service and deepen the disparities for Black autistic children.

Disparities are Red Flags for Institutional Racism

Although the CDC reports that we will diagnose 1 in 54 children with autism spectrum disorder, there are large disparities in access to early diagnosis and intervention services (CDC, 2020; Mandell et al., 2002). Black children are diagnosed with ASD 1.6 – 5 years later than White children (Mandell et al., 2009), and are also three times more likely to be misdiagnosed (Mandell et al., 2007). Additionally, families of Black autistic children are less knowledgeable about evidence-based autism intervention services and advocacy even when socioeconomic status and education are controlled for (Gourdine et al. 2011; Longtin & Principe, 2016). Examples of systemic and institutional racism include, but are not limited to, instances when Black mothers contact educators and pediatricians for guidance on how to help their children that are demonstrating developmental concerns but are often dismissed or ignored (Harry, 1995; Pellecchia et al., 2018; Skiba et al., 2008; Stahmer et al., 2019). Despite these obstacles, there are Black mothers that advocate for diagnosis and intervention for their own and other children in their communities.

In the cases when families have multiple barriers to accessing ASD interventions due to intersectional oppressions such as racism, sexism, and classism demonstrated through socioeconomic limitations and institutionalized bias; families often rely on familial support as well as cultural and spiritual traditions and beliefs to overcome the stressors of the recent diagnosis (Cartledge et al., 2002; Longtin & Principe 2016; Xu, 2007). Furthermore, previous studies have also found that race and SES influence a family's access to intervention services

and are highly contingent on the parent's academic attainment and possession of cultural capital (Lareau & Weininger, 2003; Trainor, 2010). Therefore, to better understand the issues that affect Black autism parent advocacy development, we need critical empirical investigations to explore and understand the pathway to becoming autism parent advocates in multiply marginalized populations, such as Black women (Annamma & Handy, 2020).

Understanding Advocacy Development for Black ASD Mothers

We applied the Family System Theoretical (FST) approach of the Double ABCX model to understand the process of positive adaptation and advocacy development for Black mothers of autistic children (Cox & Paley, 2003; Fingerman & Bermann, 2000, Manning, 2011). The Double ABCX model is a long-standing FST model used to understand the adaptation process that families experience when in crisis (Toliver, 2015; Weber, 2011). The *A* in the model represents the crisis-provoking events or stressors, the *B* represents the family's resourcefulness and crisis-meeting resources, the *C* represents the perception or representation that the family makes of the crisis and the *X* represents the crisis (Weber, 2011). Diagnosis of a child with a developmental disability such as ASD can be considered a crisis; therefore, the model's application is used to uncover the key stressors, resources, and perspectives that contribute to a family's capacity to adapt to this new aspect of their child's identity (Xu, 2007). Theoretically, utilizing Double ABCX module allows for an analysis of key characteristics that occur over time that allow for healthy adaptive outcomes for Black mothers of children with ASD, (See [Appendix E](#), Model 1 for application of the Double ABCX model for Black mothers of children on the autism spectrum). In this exploratory study, we examined the characteristics associated with parent advocacy development in Black mothers of children on the autism spectrum applying the developmental model of the Double ABCX model to explore the experiences (stressors,

resources, and perceptions) mothers had over time to understand their pathway to advocacy development._

Research Methodology and Methods to Uncover Black Box

Critical Race Theory (CRT) draws from and covers a wide-ranging literature base within law, education, sociology, ethnic studies, history, and women's studies. CRT offers a framework to recognize, investigate, and transform the social structural aspects of society that maintain the social construct of race, the social stratification between subordinate and dominant racial, ethnic, gender, and economic groups, and the ongoing oppression of subordinate groups (Delgado-Bernal, 2002; Matsuda et al., 1993; Tierney, 1993). CRT evolved from Critical Legal Studies, which focused on the persistent and inherent problems within the law—especially Civil Rights Law—critically examining the law's connection to the maintenance of racial social stratification and subordination of people of color (Bell, 1992a; Bell, 1995). CRT provides an intersectional framework to support our understanding of the development of advocacy for Black mothers of children on the autism spectrum. Given the myriad of overlapping intersections such as race, gender, class, and disability that commonly occur in and impact Culturally and Linguistically Diverse families' experiences, researchers must consider the impact of intersectionality for Culturally and Linguistically Diverse families of children on the autism spectrum. The CRT framework is comprised of five elements: (A) The centrality of race and racism and their intersectionality with other forms of subordination, (B) the challenge to dominant ideology, (C) the commitment to social justice, (D) the centrality of experiential knowledge, (E) the transdisciplinary perspective (Solórzano, 1998; Solórzano & Yosso, 2001; Yosso, 2005).

Conducting qualitative semi-structured interviews allows for a deeper understanding of the individual pathways of Black mother advocacy development to make connections across the

interviews to find themes that tell the authentic story of Black mothers. This is a part of the methodology of CRT and the intersectional sibling of CRT: Dis/Crit (disability studies and critical race theory) (Annamma & Handy, 2020; Connor et al., 2016) of acknowledging the intersectional experience of race, gender, class, and disability through centralizing the stories from Black mothers to learn the impacts of systemic and institutional bias (i.e., racism, sexism, classism, and ableism) have impacted their advocacy development. CRT's Tenet 1: the intercentricity of race and racism with other forms of subordination and Tenet 4: Centrality of experiential knowledge is central in this pursuit, acknowledging and accounting for the role of social systems of oppression and how they impact every aspect of development for the family, mother, and child (Solórzano & Bernal-Delgado, 2001).

We utilize the methods and principles of the phenomenological method of Portraiture to collect and analyze the data (Lawrence-Lightfoot & Davis, 1997). We chose this method because it allowed for the researcher to delve into the social relations, history, and political context of their collaborators (Harding, 2006). Studies that utilize a Portraiture methodology seek to understand what informs a practice that is labeled successful (i.e., successful advocacy). This method allows for the collaborators and the researcher to co-construct a picture of what successful advocacy looks like from their own vantage point. Thus, the Portraiture methodology allows for a "thick description" of the data (Geertz, 1988). Portraiture is a form of layered qualitative inquiry that allows the researcher to conduct in-depth interviews over time and incorporates observations, document and abstract analysis, and maps the context to explore and understand the individual's story to capture more universal themes. Portraiture is unique and different than traditional social science investigations in its resistance to being deficit-based but instead focusing on the goodness of the stories (Lawrence-Lightfoot; 2005). Portraiture principles include: (1) listening

FOR the story not just TO the stories told, (2) listening for the nuances of “goodness”, and (3) allowing the researcher to be completely in the process to uncover the complex answers to questions that only the collaborator can answer. The objective of this study and research is to make a deeper impact and reach other families, providers, and researchers that need to experience these stories for the betterment of their life and work-- which demonstrates commitment to social justice (i.e., CRT Tenet 3), the use of an inter and trans-disciplinary perspective (i.e., CRT Tenet 5), and commitment to sharing findings that are accessible beyond the reach of the academy and works to build community (i.e., Portraiture principle 5; Watson, 2019; Yosso, 2005).

Method

This study investigated the internal resources that Black mothers use in their advocacy work (Dababnah et al., 2018; Lovelace et al., 2018; Matias & Allen, 2013; Rogers, 2017; Solorzano & Yosso, 2001) using the method of portraiture (Lawrence-Lightfoot & Davis, 1997). The primary aim of this study was to demonstrate the use of qualitative methods that heal and give agency (i.e., “liberating methodologies”) to Black mothers of children on the autism spectrum through the illustration of the resources they used to navigate service-delivery systems to learn how those resources contributed to their advocacy development (Lawrence-Lightfoot & Davis, 1997; Watson, 2019).

As part of a larger study, we recruited peer coaches across four study sites: Los Angeles, CA; Sacramento, CA; Rochester, NY, and Philadelphia, PA. These four sites are part of the Autism Intervention Research Network on Behavioral Health (AIR-B) project, a federally funded research network committed to improving outcomes for children with autism and their families. One focus on the AIR-B III multisite project was to support families of children recently

diagnosed with ASD who experience income-based disparities across all four sites in accessing services for their child; this involved testing a peer coaching model called Mind the Gap (MTG). The AIR-B project followed a community-partnered participatory research (CPPR) model (Jones & Wells, 2007) and included a high degree of engagement with community stakeholders (e.g., service providers, parents of children with ASD, parent advocates, educators) in the design of the research and intervention objective development. Community stakeholders gave the suggestion to incorporate the use of Parent Peer Coaches to help reduce barriers to engagement with the intervention. Parent peer coaches were recruited at each site through existing partnerships with local community organizations and through referrals from service intervention providers and parent advocacy groups. We based the eligibility for the peer coach position on (1) having a child age 8 years or older with a diagnosis of autism provided at least 5 years prior, (2) previous experience working with other parents, (3) evidence of understanding the service system in their local area, and (4) fluency in English and/or Spanish. All peer coaches were chosen via interview with the research team. Across the four sites, we recruited 25 parent peer coaches and trained them to become Mind the Gap (MTG) peer coaches. MTG Peer coach training consisted of four sessions of 3–4-hour small group training on the MTG coaching materials, procedures, and active listening and communication strategies to use with mentee families. Three out of the four MTG sites had peer coaches that identified as Black women ($N = 7$) across three of the four sites. The lead PI included a permission to contact form into the studies' approved IRB documents and distributed to the Sacramento, Rochester, and Philadelphia MTG research coordinators to give to the seven Black MTG peer coaches to consider participation in the new study. A study flier and a link to a recording of the principal investigator of the project explaining the study and her ingroup connection as being a Black mother of a child on the autism

spectrum was also sent to the MTG research coordinators to distribute to the mothers (Morgan, 2020b)

Researcher Positionality

Similar to the first study, the reflexivity and positionality of the lead author being a Black mother of a child on the autism spectrum allowed for in-group status with collaborators (Hsiung, 2010; Milner, 2007). Besides the principal investigator, the research team comprised one undergraduate and three bachelors level scholars that possessed various intersectional identities. One Latino male who was a family member of a disabled person. A White female who felt connected to interviews stating that “*despite our differences, I did feel like I was able to resonate with some of the participant’s stories and experiences, for example learning to find hope through spirituality*”. A Black woman stated that she could “*relate to the mothers’ strong will to figure things out and become an advocate for themselves and loved ones*” because of her own experiences advocating in educational and health care settings. And last, a self-identified homosexual cisgender male that comes from a family that immigrated to the United States from Colombia who felt his life experience was opposite of the mothers but said “*it was a privilege to hear their stories and to understand their struggles*”.

Collaborators

Study 2 included seven (7) collaborators (see Table 2), who met the following *Criteria for inclusion*: (1) Parent of a child who has a medical diagnosis or school classification of autism or autism spectrum disorder (ASD). (2) Proficient English speaker. (3) Has been assigned at least 1 AIR-B MTG family to coach over the last 3 years. (4) Identify as Black or African American, (see [Appendix F](#) for collaborator demographics).

Procedures

We used a qualitative phenomenological framework, Portraiture, to collect and analyze the interview data (Lawrence-Lightfoot, 2005; Lawrence-Lightfoot & Davis, 1997). Portraiture methods are similar to ethnography, but distinct in the approach and level of engagement that the researcher (portraitist) takes part in data collection. Through the careful process of listening for the story and being completely committed to unearthing answers to complex questions and guarding against simplistic, fatalistic, or pessimistic inquiries the researcher honors the participant's experiences and seeks to validate their stories through looking for nuances of goodness (Watson, 2019). Through the use of the Portraiture method, the researcher can delve into the social relations, history, and political context of the mother's advocacy (Harding, 2006), allowing for the product of a collaborative qualitative inquiry that works to disrupt the power dynamics that are inherent in the research and liberate the voices of a traditionally marginalized group of ASD parents.

We conducted four (4) in-depth semi-structured interviews each of with seven (7) Black mother peer coaches for a total of 28 (60 – 90 minute each) in-depth, ethnographic, semi-structured interviews (Esterberg, 2001). During each interview we collected participant observation field notes and responses to object-interviews (Nordstrom, 2013) to allow for a deeper understanding of their experiences and developmental processes involved in their advocacy journey. Object-interviews are a post-structural exercise used in qualitative inquiry to shift the focus from traditional participant-centered interviews into a space of collaboration between persons and objects to link events, emotions, and ancestors to their personal narrative. *“The object-interview shifts the interview from a subject-centered conventional qualitative interview into a space in which both subjects and objects produce knowledge about family”* (Nordstrom, 2013, p. 238). Prior to the interviews, we asked collaborators to find two artifacts

(i.e., documents, photographs, textiles, or objects) that have significance to them, that represent to them (A) their experience of advocating for their child with ASD or that represent where they draw their strength from to advocate for their child and (B) their experience of advocating for other families that they have coached or represent what they think their role as a peer coach (Nordstrom, 2013).

Measures

The *Community Capital Parent Questionnaire* (see description from Study 1, p. 24-25).

The *Demographic survey* (see description from Study 1, p. 24-25)

Interview Protocols

Two semi-structured interview protocols further divided into two sections (Part A and Part B, See [Appendix G](#) for complete interview guide) were created using questions to gather information about their developmental process, and key resources that collaborators used over time to advocate for their children and to teach advocacy to families they coached. Based on dominant themes discovered in Study 1, items on the interview guide were written to obtain more information about the mothers' social/friendship network (social capital), their experience navigating service delivery systems (navigational capital), family/kinship supports (familial capital), and adversarial experiences they had in the past that contributed to their advocacy development (resistance and generational resistance capital). Other topics included:

1. Types of stressors, perceptions, and resources that the mother possessed before and during the time of her child's autism diagnosis.
2. Types of stressors, perceptions, and resources that the mother developed or maintained after the time (or currently) of her child's autism diagnosis.

3. Examples of healthy adaptation and positive identity perception of herself and her child.
4. Examples of coaching strategy and lessons of advocacy skills that mothers intentionally taught to families they coached.

Data collection for this study occurred in 2020, which was during two major world crises: the COVID-19 pandemic and the racial reckoning uprising and protest that occurred after murders of Black citizens by police and White domestic terrorists in the killings of George Floyd, Breonna Taylor, Ahmaud Arbery, and Daniel Purdue. These incidents occurred in the same cities of some of the collaborators, producing anxiety and anger that mothers needed to process during the course of our interviews. Thus, additional questions were added to the interview guide to get more insight to how these events impacted Black families and their children on the spectrum.

Data Collection and Analysis

We utilized the methodology of Portraiture to collect and analyze the data (Lawrence-Lightfoot & Davis, 1997). We chose this methodology because it allows for the researcher to delve into the social relations, history, and political context of their collaborators (Harding, 2006) which is essential for intersectional qualitative research (López et al., 2018). Studies that utilize a Portraiture methodology seeks to understand what informs a practice that is labeled successful (i.e., successful advocacy), using this method allows for the collaborators and the researcher to co-construct a picture of what successful advocacy looks like from their own vantage point. Thus, the Portraiture methodology allows for a “thick description” of the data (Geertz, 1985). Interviews were audio-recorded, transcribed, and de-identified. Although the principal investigator had previously met with and conducted home visits with collaborators based in

California to provide an introduction to the study objectives, the COVID-19 pandemic required a change in plans for in-person interviews to become virtual interviews. During each virtual interview, jottings and notes were taken to observe the home environments that collaborators conducted their interviews (Pugh, 2013; Sacha, 2017).

A precoding process was implemented to identify deductive and inductive codes from each transcribed interview. Deductive concepts from the protocol and inductive concepts from the transcripts were identified and summarized into a database format. Data analysis included a summary memo of each concept across collaborators allowed for systematic summaries of responses and the extraction of main ideas and topics which were used to create a codebook (Boyatzis, 1998). A codebook was created representing common themes in advocacy resources, strategies, and processes across all collaborators based on advocacy mothers used for themselves and taught to their mentees. A codebook was created including 3 primary codes and 11 sub-codes. Primary codes included: *Community Cultural Capital (CCC)*, *Advocacy Development (AD)*, and *Coaching Advocacy (CA)*. Sub-codes for CCC included: *Social Friendship Capital*, *Navigational Capital*, *Familial Capital*, *Generational Resistance Capital*, and *Resistance Capital*. Sub-codes for AD included: *Pre-Diagnosis Stressors*, *Pre-Diagnosis Perceptions*, *Post-Diagnosis Stressors*, *Post-Diagnosis Perceptions*, and *Positive Adaptation*. There were no subcodes for *Coaching Advocacy (CD)* (see Table 6, [Appendix H](#) for complete codebook). For each primary-code and sub-code, multiple examples were pulled from the database as examples to support training for Inter-Rater Reliability (IRR). The criteria for the application of each code were identified by using detailed inclusion and exclusion criteria. A team of undergraduate Research Assistants (RAs) were trained on the codebook and began reading interview transcripts to look for themes in the data and code during facilitated

team meetings (Glasser & Strauss, 1967; Tavory & Timmermans, 2009). During RA training a review of codebook wording of inclusion and exclusion criteria was conducted and small revisions of the codebook were done to improve and clarify wording. The final codebook was established to use for IRR testing.

In order to achieve IRR, each coder was required to successfully pass two tests with 75% agreement between their codes and the principal coder (principal investigator was principal coder; Wongpakaran et al., 2013). Each IRR test included 20 lines from study transcripts that were representative of all codes in the codebook to ensure that coders had reliability across all codes. Twenty percent of the total word count of all transcripts (3 transcripts) were coded with two or more coders who had achieved IRR. Consensus coding was applied for disputed codes and a final master transcript was created for each double coded transcript and entered into the qualitative software (Nowell et al., 2017). Data analysis of all coded data was conducted to identify dominant themes, trends, and processes. Qualitative theorists suggest and encourage the use of a qualitative data analysis software, especially in handling large qualitative datasets (Berg, 2001; Jones, 2007; Kelle, 1997; Krueger, 1998; Miles & Huberman, 1994). The software package chosen for the current study included the Computer-Assisted Qualitative Data Analysis Software (CQDAS) named Nvivo. Nvivo is one of the most popular qualitative software packages used to conduct code-and-retrieve and theory-building analysis of datasets (Azeem et al., 2012). A total of 84 items of data were entered into Nvivo under the file categories of: Artifacts (14 items), Field Notes (28 items), Interviews (28 items), and Surveys (14 items) and coded using the codebook. Coded interview data was analyzed within the Nvivo qualitative software to find dominant themes and perform a word similarity cluster analysis to understand the relationships between the codes, (see [Appendix I](#) for cluster analysis). Nominal

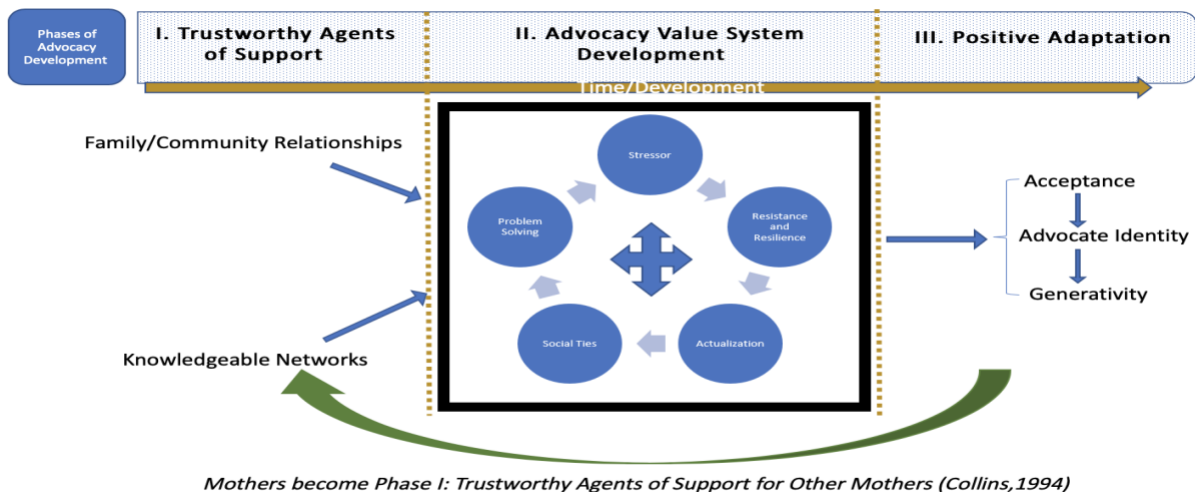
brainstorming protocols were implemented over a series of research team meetings to apply theory and to interpret the findings (Tague, 2005). Portraits of successful advocacy development were made for three (3) of the seven (7) collaborators. The process of selecting mother’s portrait was based on two key factors: First, the artifact the mother chose to share and how it related to a central finding. Second the presence of dominant themes of codes (i.e., cultural capitals) that were coded for the mother across all four of her interviews and the connection to the central findings. Once portraits were constructed, the principal investigator met with each mother to review and engage in member checking strategies to get input and make amendments to the portrait if needed (Harper & Cole, 2012).

Findings

The findings for this study are broken down into three categories to better understand the key factors involved in positive adaptation and advocacy development for Black ASD mothers:

- I. Trustworthy Agents of Support
- II. Advocacy Value System Development
- III. Positive Adaptation (see Figure 3 below and [Appendix K](#) for larger view).

Figure 4: Phases of Black ASD Mother Advocacy Development.



The three categories were formulated through running a code category cluster analysis in NVivo of all coded data using a Pearson correlation coefficient analysis that generates a diagram that clusters codes together if they have many words in common forming a dendrogram or cluster map (see Figure 2 in [Appendix I](#)). The clusters were then theoretically interpreted and assigned stages of advocacy development according to the ABCX model, see figure 4 in [Appendix J](#).

Summary of Phases of Advocacy Development

The first phase includes the identified “Trustworthy Agents of Support” that collaborators spoke of during their interviews. This category included people who were considered significant agents of support both pre-and-during the diagnosis for the mother’s autistic child. Such agents included the maternal grandmother of the child, trusted service providers, and older children who gave emotional or practical supports for the mother. These were significant social agents in the mother’s lives that were there for them and gave them the foundation for their advocacy development. These agents held various relationships over the mother’s life, but all fostered trusted relationships that the mothers referenced during their interviews as key to their advocacy development.

The second phase includes a bundle of related variables that when brought together form a cycle involved in the development of an “Advocacy Value System” in mother collaborators. These variables included stressors that happen before and after the child’s diagnosis which included trying to get their voices heard by clinicians to get the diagnosis to securing services and supports after their children were diagnosed. The response to these stressors involved mothers demonstrating acts of active resistance and resilience to navigate oppositional agencies, policies, and people. Many experiences had favorable outcomes and produced a buffer of positive experiences and resilience in mothers allowing them to build a

sense of self-actualization while reinforcing their agency and competency to advocate for their children. Often times mothers found allies and strong partners in service delivery agencies and organizations (i.e., case workers, teachers, other parents are support groups) who equipped them to handle the next stressors that came their way. The variables involved in the “advocacy value system” have a relationship to one another but were not always used in a linear manner. They served more as resources that the mother commonly pulled upon to advocate for her children in response to a stressor. A simplified example of this process includes a mother receiving an ASD diagnosis for their child (stressor) and in response, doing her research and calling upon knowledgeable friends to help her understand how to advocate for her child (resources).

The last and final phase is “Positive Adaptation” and is a response to the first two phases of advocacy development for Black autism mothers. This output from the first two categories involves the mother developing a healthy adaptation consisting of acceptance of her child and self, the development and pride in her advocacy identity, and a sense and need for generativity or to pass on to other parents. The process cycles back with the mothers becoming a part of the first phase of development for other mothers by becoming a key agent of support for others in her community.

In the next three sections of the paper, the three phases of advocacy development will be further explained and given evidence from the data to substantiate the model. Each stage is also followed by portraits to that further elaborate the process of development for three mother collaborators involved in the study:

I. Trustworthy Agents of Support

A major theme of mothers having key agents of support that serve as trusted confidants and role models were salient in the interviews. The presence of people such as the mother’s

mother or maternal grandmother of the child was the most dominant reference as the most trustworthy agent of support pre- and post-diagnosis across all of the collaborators. The mothers of the mothers interviewed not only provided emotional, but also practical supports as demonstrated in these accounts from Faith:

And my mom showed me the way how to be strong and how to get things that I need and just don't sit back and think it's gonna come to you. You have to go out and get it” and “I believe me personally, I just had a strong background. So my grandmother and my mom, again, like they were so strong. You know, I really didn't see too much weakness in them. So it's like I have to be strong like them. I have to, you know, represent my family just like they represented.

It was also apparent from the data that the many of the mothers' mothers were also knowledgeable about school and medical systems and give critical insight to how to navigate these systems.

There was also evidence that service delivery providers who had cultural connections made a difference for mothers during and after their children were diagnosed. For example, Trust stated that she had a social worker assigned to her through with her Medicare Health Insurance Program who played a significant role in her advocacy development. This key agent of support had the title of a Medicare Service Coordinator and in addition to being a licensed social worker, was a Black mother of a child on the autism spectrum. Her name was Rockie, and she was with the mother, Trust, from the time her twin boys were diagnosed at 3 years old until she retired over 10 years later. Rockie gave explicit instruction on what needed to be done and connected Trust with all the key people and agencies which whom she needed to start services quickly. When it came to the IEP process it was Rockie that handled all the details, even the

transportation to the meeting, and sat in the meeting with the mom to help her get all the supports that her sons needed. When asking Trust why she believed that she was able to easily find appropriate support for her two sons on the spectrum, she stated that she thinks that it was easier for her to have faith in the people on her son's intervention team because she had Rockie in her life. Not only was Rockie knowledgeable and able to identify with her as being a mother of children on the autism spectrum but she and Rockie also shared a cultural understanding of one another because they both were Black women. Trust states in one of her interviews “*Rockie was awesome because it was more than just being a Medicaid service coordinator. She was also a woman of color, and she also had a child with autism. So therefore, the relation was awesome because everything I went through, she had already gone through*”.

A common theme of the importance of the mother-daughter relationship dominated the data with every collaborator mentioning their mother as a key agent of support. When coding the data the collaborators would mention their mothers as role models and examples of resilience which were commonly coded under the community cultural capitals of familial capital and generational resistance capital. This is Hope’s account for how her mother taught her how to advocate and stood in the gap when she was not able to advocate for her son Elijah:

My mom just kind of. You know, she's kind of built a life for herself, honestly, like I have a lot of respect for her. Just because, you know, she has shown up and that's been a large portion of why the advocacy for us for Elijah has been monumental, because we've had access to her really being a resource for us and advocating when I couldn't, when, you know, when his brothers and sisters couldn't, when his cousins couldn't.

The following portrait of Ola gives an account of the teacher role that the maternal grandmothers held for their daughters or what Dr. Alma Flores calls mother-daughter pedagogy (Flores, 2019). This is Ola's portrait of how her mother supported her advocacy development for her son Carmelo.

A portrait of trustworthy agents of support.



Description of Object or Artifact: Statue of a young Black woman dressed in a white and blue nurse's uniform. She is holding a clipboard in her left hand that is located near her waist with her right hand holding a pencil and next to her chin indicating a thoughtful stance. She has her eyes lowered to read the contents on the clip board and her face is relaxed. She has black thick hair that is neatly combed back and tucked into her nurse's cap that sits at the midline of her head with her bangs exposed in the front.

Ola and Carmelo.

Standing at 5'9" in her quaint two-bedroom first-floor apartment, Ola appeared to be a towering woman. She parted her thick black hair down the middle, which allowed her long sister-lock braids to cascade down her broad brown arms and back. We conducted the interviews in her living room which comprised a dark brown velvet couch with several colorful blankets draped over back seat cushions, a large wood and glass coffee table, a standard-sized television stand in the corner, and one hundred framed pictures meticulously hung on all four of the eggshell matte painted walls. The picture frames held cherished pictures of Ola's family members, such as her late mother. But most were pictures of her two sons, her eldest, King and

her youngest Carmelo, who was on the autism spectrum. It was apparent that her children were Ola's world, and when I asked about her journey in advocating for her son Carmelo, she referenced the pictures behind her saying:

There's a story behind it [points to all the pictures on the walls]. The story came from after King left for school [King chose a college that was away from Ola's city]. It was a hard struggle. I was an empty nester and I was going through my stuff and found the school pictures that I bought each year in a box. And I was truly missing King. And I went through and I put up 100 frames in my house...And it goes back to me doing it all alone. I put each picture in the frame and put them up, I had to figure out where I was mentally and how I was dealing with the situation, I remember thinking, 'man, I don't remember that'. So to have these pictures up helps me to see that I tried to do different things the best I can for my kids. So it kinda gives me that encouragement because I don't think about it, or I don't remember doing that. I feel I did something right and continue to keep both my children engaged.

Keeping a child on the autism spectrum “engaged” requires an enormous amount of advocacy. Keeping a Black child with autism engaged and included in school takes double the advocacy and what Ola describes as “divine intervention”. Ola presented a porcelain statuette of a young Black nurse as her artifact for the object-interview portion of our time together. She explained [see picture of artifact above]:

This statue represents my advocacy for Carmelo because it was the closest thing I have that I think represents the essence of my mother. My mother demonstrated perseverance through the years. She was a poor girl growing up in New York

City and put herself through nursing school through great opposition. In fact, she was rejected from her top choice in nursing schools because she was Black. She showed me how to overcome because she overcame so many different things with adversity in her job, in getting her education which showed me how to become an advocate for myself. She was the one that showed me the ropes. So that was my rock. My mother was a single mom, a Black single mom taking care of her children just like I am.

The artifact Ola carefully chose represented her mother and the advocacy that she learned from her mother both implicitly and explicitly. The face of the nurse statuette looked regal, wise, compassionate, intelligent, and steadfast, all qualities of a powerful mother advocate. Ola's mother taught her how to talk and advocate to health professionals long before they diagnosed Carmelo to be on the autism spectrum. Ola described how her mother always taught her to be attentive and ask questions and believe that her ideas were valid. Ola explained that she used this knowledge when she was navigating services and supports for Carmelo's school intervention plan (IEP) through the years because she knew her voice mattered and that "*there is no such thing as a stupid question*".

Carmelo started receiving autism intervention just three months after he was diagnosed at 2 years old. Given the research on the many challenges and disparities in receiving early intervention services for Black children in California, this was remarkably fast (Montiel, 2014). Ola's humility would not allow her to take an ounce of credit for this but gave honor to her mother's guidance and "*God's Favor*". She discussed getting a lot of advice from her mother right after they diagnosed Carmelo, which she knew was helpful in securing services faster. She also credits the clinician that diagnosed her son for being honest and personable. She

acknowledged that he did not give her the run-around like most parents she knew that had negative experiences and instead listened to her concerns and gave Carmelo the ASD diagnosis that helped Ola secure services quickly.

So he [diagnosing clinician] did kind of prepare me for the blow [information that Carmelo was on the autism spectrum]. [He] prepared me in how he labeled him [Carmelo]. I mean, he labeled him moderate to severe. He said, I'm not necessarily saying that he is, he says, I am giving him this diagnosis so you won't have to enter into politics and this will avoid you having to deal with any politics. And I will tell you, I'm grateful to God for that because I did not have any of the challenges that most parents did because of how he worded the report and how he explained it to me.

Ola's portrait of her advocacy journey exudes confidence. Her style of advocacy resembled the statuette of the Black nurse she presented at the top of the interview. She was calm, consistent, present, patient, and thoughtful. This was evidence that the skills to advocate were not lacking but that other key stakeholders, mentors, and cultural brokers such as her mother and the diagnosing clinician were necessary to ignite and fan the flame of her power.

II. Advocacy Value System Development

The intersectional effects of racial bias and gender discrimination are stressors and hardships Black women overcome daily (Crenshaw, 1995). The stressors associated with having a child with a developmental disability start with the awareness of delay in developmental milestones such as talking, walking, or engaging in socially reciprocal interactions but continue to mount as mothers reach out to professionals for help and are often dismissed or ignored (Harry et al., 1995; Stahmer et al., 2019). Even after they were able to advocate for a ASD diagnosis

collaborators expressed further stressors as professionals still refused to respect them. This is an account from Ola discussing one of her experiences:

And it was just really, really hard and an obstacle that I had as the doctor telling me that, oh, it's just kind of blown it off. Well, we got him to a dialogue where he felt that I was questioning him as a doctor and how he went through, you know, I was in the medical this and that. And, you know, and I think that it's been a big experience throughout this journey is it happens later on in life because it feels like, well, now, you know, your child's older and I know you got the knowledge, but that doesn't mean just because your child got a diagnosis that you don't know your child.

The stressors of not being believed or listened to when they expressed concerns to professionals activated the enactment of resources as demonstrated through several forms of community cultural wealth (i.e., resistance capital, navigational capital, social capital). This is an instance of Elizabeth discussing the amount of persistence she had to have in order to have her daughter assessed for autism “*As I did with everything, I kept going back. I kept records. I talked to them, I said there are some things that are not right so go on in and observe her.*” These stressors were compounded with personal and familial stressors such as divorce/separation from spouses, death of family members, and personal sickness and disability. But through it all the mothers expressed a process of navigating from one stressor to another through enacting strategic skills, communication patterns, and social ties. This is Sarge’s account for her own experience of acquiring a disability and how her advocacy for her son Mister came from her understanding of what it felt like to be ostracized from society:

So I want you to know that as a person as well with disabilities, multiple disabilities, I actually had an experience where I know what it's like to be disabled. And I know what it's like to be treated like you're not included as part of this society. And I never in my wildest imagination thought that this would happen to me. But it did. And I was so like overwhelmed that the fact that they were pinpointing me, that I just I just couldn't fathom not being an advocate and not being able to express what it's like to have a disability.

The following portrait of Nandi gives an account of how she faced multiple stressors (pre-and-post stressors) that supported her advocacy development for her twin sons Hayden and Kerwin to develop an advocacy value system and become an autism parent advocate.

Portrait of advocacy value system development.



Description of Object or Artifact: a black silver pair of grooming clippers with black electrical cord wrapped around the bottom. Held upright in the right manicured hand of the mother advocate Nandi. The background is of a large world map with the continents Africa, Australia and Asia visible.

Nandi, Hayden and Kerwin.

Nandi had a flawless gingerbread mocha complexion. Her shiny lip gloss popped on her perfectly full lips. Her hair was shaved on the sides with a thick, natural style on the top. She had shades of blond highlights on the top of her combed out natural hair puff, but the roots were

a deep brunette. On her face sat a stylish pair of purple plastic framed glasses. She wore big tear drop silver hoops for earrings and had showed off her manicure that she did herself, but it appeared to be professionally done. One look and you could tell she took a lot of pride her appearance and presentation. She also sat in a room that had resembled a classroom. Nandi stated that she was in her basement, and that she was turning it into a space that her 17-year-old twin son Hayden could do his distance learning due to COVID-19 restrictions that she hoped will help with the distractedness he naturally has. Her name, Nandi, came from a movie about an African warrior, Shaka Zulu, and later found that it meant “sweet” in Zulu which is a tribe in South Africa. In the neighboring country of Zambia, it is also known to be a Zulu word to mean “Queen”. Nandi was born and raised in the Caribbean and she stated that her thick rich accent was initially a hinderance in her being able to advocate for her two teenaged sons on the autism spectrum because she felt that no one could understand her when she talked. For Nandi, the process of becoming an advocate was not easy; she had the additional intersectional identity of being an immigrant and found that in addition to the obstacles that other Black women faced, she also had the microaggressions of anti-immigrant and xenophobic attitudes that were common of the times which caused additional stress.

Nandi’s artifact to demonstrate her advocacy for her children were a pair of black corded hair clippers. This object is common in many Black households, due in large part because Black men will often use these to groom their facial hair. Black men often use these clippers instead of razors to shave their mustaches, beards, goatees because razors often cause bumps on their sensitive, melanated skin. This is Nandi’s account for why she felt these clippers represented her advocacy for her children.

I almost teared up thinking about how clippers represent us because my boys were younger, of course. They didn't want to get a haircut, but I knew that they needed a haircut. And because of the behaviors, I didn't want to go to a barber shop, and again, it goes on because of the judgments and the questions and the stares, and so I decided to start cutting their hair myself. I have no experience at all with cutting hair or barbering, but I decided we're going to start this. And it was hard at first. It was really hard keeping them still tried not to mess their hair up and getting them just to sit still and not damaging them or anything. But over time, it became easier and easier. They became more and more tolerant of it. And it made me realize that they can learn because they learned to sit still, they know what was coming. And they know what was expected of them... But in thinking about it, the Clippers kind of showed me that together we can learn and grow and tolerate what comes with perseverance. We can get through this and can learn and grow... And together we can do it...So this represents like an evolution of what we were and where we are now.

Nandi's clipper representation foreshadowed the collaborative nature and advocacy style that she learned to foster. She liked working with other people to help and appreciate the contributions they brought to her sons' intervention team. She had many great experiences with teachers and service professionals and found great allies in people that she did not think she would be able to partner with. One such person included a White female speech language pathologist (SLP) that was assigned to her sons during the time they were in early intervention. Initially, this same therapist refused to come to Nandi's home without another person to support her because she judged the part of town that Nandi's family home was located to be "unsafe".

This SLP was a young white woman and had a straight forward “tell it like it is” approach to communicating with families. Nandi enjoyed this type of communication and ended up creating a strong relationship with the therapist, so much so that the SLP advocated for her and her sons in venues that her family was being discriminated against such as in this instance during an IEP.

There was a time when the boys were really young and we had to go to the city, to the city for, you know, because, of course, they were the purse strings [the location where the decision makers that allocated funds were housed]. So we went in for a meeting. But for some reason, their dad and I were late getting to that meeting and all the therapists were there, along with the representative from the city. And the chair of the meeting, she said, oh, where are these people coming from? So the therapist told them they're coming from the city and city of Rochester, she said. Oh, they're not going to come. So now we didn't know all of this happened.

She said they're not gonna come. They're coming from the city and they're not going to show up. Let's just continue with the meeting. But the therapist said she had to tell them no. These parents will be here. And she said, like just after she said that, we showed up when she told us after the meeting that that's what the lady said. And she told me that those people from the city didn't care about their kids. So she had to the advocate on our behalf saying, no, they will be showing up. It's not because they're from the city. They will be here. And we just need to wait for them. But that was kind of some example of like some prejudice that we weren't privy to at the time, but she later told us what happened.

Nandi had such a beautiful disposition on life that it made her interesting and admirable. She had many hurts and life had dealt her a hard hand on more than one occasion, but she was

unshakable. She had a strength that came from her softness and authenticity. She did not profess to have all the answers or even know any of the answers and was honest about times and places that she could do better but that did not impact her value or how she showed up for herself and her family. She obviously took care of herself. She paid attention to the style of her hair and make-up. Every time we met, she had a new hair style and a new fabulous pair of big, dangly earrings on that gave expression of her personality and uniqueness. She didn't allow for herself to get lost in her identity of being a mother, a daughter, an ex-wife, a friend, an ASD mother, a Black person, a woman. She was Nandi and was all of those things but also so much more, she was an advocate.

Nandi exemplifies the special type of advocacy that takes place when pressure is always high. She had many stressors, related to her sons and non-related but she always pulled upon her resources which included her own resourcefulness, intelligence, humor, her social network of family, and trusted interventionist to be relentless until she got what her sons needed. In time, Nandi's advocacy strategies became second nature as she developed from an advocacy novice to an advocacy expert.

III. Positive Adaption

Mother collaborators expressed acceptance of their autistic children and themselves as being advocates for their children. This included having a positive identity as an advocate and an expressed need or obligation to share her experiences and skills with other parents to help them become advocates for their own children. For some of them the process involved in this healthy adaptation started with the feelings and emotional relief they felt when they received the ASD diagnosis and finally had a name of the disability that they had intuition was impacting their children *"I was actually relieved. And I know a lot of parents don't feel that way. But it was*

like when you know what it is, that you can form a course of action. And that made me feel empowered” (Hope). With diagnosis, the common theme of intense feelings of worry and concern for their children’s welfare quickly followed. This led many mothers to proactively seek support and knowledge from the internet and from trusted agents of support in their lives. The process of developing positive adaption started with these basic emotions which all included statements of their acceptance of their children on the autism spectrum and acceptance of their roles as advocates for their children. This is an account from Sarge as she told a story of her advocating for her son Mister in the community:

And I say and what you need to understand is that we need a better concept of acceptance for our children. You know, these are precious, intelligent children, just like your son or your daughter or, you know, and I just start to point to people and they would like because I wanted them to see they're no different than your children that you say are alright. We all had a diagnosis of some kind. We all do have our idiosyncrasies that we deal with constantly. So you need to understand that some of us may need just a little bit more support.

This acceptance was a sense of pride for the mothers and was commonly associated with a spiritual connection to their faith and purpose in life. The acceptance grew as they began to feel more confident during their interactions with autism providers on their child’s team and became most salient as they grew into their Advocacy Identity as they proselytize inclusion and acceptance for their children within their extended family networks and community. This is an account from Elizabeth as she discussed how she fought against stigma of disability in her own family to make sure that her daughter, Felicia, was included in family activities:

So I had to tell all of the parents, look. You need to talk to your kids because nobody's going to be treating Felicia like this. Felicia is a part of this family. And if it had been up to them initially in the beginning, they would have hidden her because...she [family member] didn't want to accept that she [Felicia] had a disability. They didn't want to accept that they [Felicia and other people in the family] have a disability because [puts up air quotes] 'we don't have that in our family' But you have that in all families.

The final stage involved in the positive adaptation was generativity. Generativity is a concept first coined by Erik Erikson to describe a phase in psychosocial development that commonly takes place during middle adulthood (approximately 40 to 65 years of age) as people strive to nurture and create a legacy for themselves and make positive impacts in the lives of other people (Erikson, 1950; Slater, 2003). This was expressed with the mother collaborators of this study through their expressed desires to educate their community members about autism and advocacy strategy. This led to their interest in becoming peer coaches in the MTG study. This also led to them forming their own support groups and non-profit organizations for Black families of children with disabilities. This is an account from Sarge:

You know, so then the discovery was. Well, if I've never heard of it and I'm Black, then how many other people that are Black have never heard of autism? And that really began my journey. So I found out that there are not a lot of people that are in our community that even have resources that identify what autism is. None of the school districts here had information on autism. None of the teachers in our school system really were identifying kids that may have autism. And so, oh, my

God, I made a pledge right then and there. We're going to have to do something about this. We're going to have to spread this information, because I found that it affects more Black children than anything. And so and especially young men at that time, it was men or young boys that were was affected. And I just I just jumped off the plane without a parachute. Wherever it takes me, I'm going.

Sharing capital with other families.

As mothers experienced multiple encounters with stressors over time, they employed multiple community cultural wealth resources and a repertoire of successful advocacy experiences to build upon their advocacy identities and values. They discovered their “go to” tools and strategies that they could count on when hardships or obstacles arose and they began to feel equipped to handle everything that came their way. This is an example of the confidence that was formed from years of successful advocacy from one of Hope’s interviews:

So at all times, it was just me and my son. I was advocating for him, giving him everything he needed. And every time someone told me no. I kept on pushing. I kept on pressuring people to help me, help him. And I succeeded majority of the time maybe 99 percent out of 100 percent (laughs) I succeeded because I didn't stop. And it was like, I'm not going to ever give up on you, I'm gonna keep on going.

Once the mothers found the strategies that worked for them, they were eager to tell other parents how to use similar tactics to advocate for their own children. In this quote, Elizabeth discussed her experience providing coaching advocacy for a family in her community.

And I just gave her some ideas of more things to do. Like, you know, she kept talking she didn't have money and she wanted to go swimming in that kind of stuff.

And I said, well, you really should be eligible for disability. So you should go through that process so you have money to help him do the things that he needs to do and buy the supplies for him that you need there. And I said, if you need assistance with that, you just need to talk with your early intervention specialist, and they will help you work through the process if it's something that they could do, and they will be able to help you more because they are already in the system. So, you know, the system works. So was directing her to different organizations.

The following portrait of Trust gives an account of how she developed positive adaptation to become a parent peer coach for the other families of children on the autism spectrum.

Portrait of positive adaption.



Description of Object or Artifact: a wooden puzzle piece in the shape of a bottom of a dog's mouth. It included the nose, mouth, and tongue of a blue colored cartoon Blue from the children's cartoon Blue's Clues. The puzzle was made for small children or people with fine motor difficulties because it is large and has a large wooden knob for easy gripping.

The puzzle is in the left hand of mother advocate Trust who held in in front of her chest.

Trust, Traders, and Manny.

Trust was a 49-year-old widow and mother of three children. Her oldest daughter was completing a degree in religious studies in a university hundreds of miles away from their family home in a northeast state of the U.S. and her two twin boys, Manny and Traders,

were handsome nineteen-year-old autistic young men. Trust had a smile that was wide and beautiful, showing her perfectly placed white teeth next to her hickory walnut brown skin. In her hand she held her personal study Bible which is given as the source of her strength and wisdom. The Bible had a black leather cover with worn off gold letters on the spine. It was thick and flimsily due to the large amount of handling that it received. She smiled when she picked it up and used both hands as she proclaimed its authority in her life. I noticed that her fingernails were not manicured but were neatly filed and healthy, not polished but feminine and classy, just like Trust. Her laugh was remarkable and one of the most memorable attributes about her. It was powerful and peaceful at the same time. Like a waterfall, her laugh poured out of her mouth but came from a deep place and landed in joyous cacophony for those in her presence, holding traces of happiness and pain in every deep chuckle which resonated with my own experiences of being a Black autism parent. Trust always seemed secure and very consistent in the way she operated her life. She appeared to thrive in order, as her home appeared orderly and set up with intentionality. Plaques, pictures, and awards were hung carefully on the hallway walls. The kitchen had magnets with inspirational quotes, and cooking utensils hung on the wall near the stove. The qualities that were observed in Trust were admirable, but she was humble and did not give herself credit for the opportunities her advocacy provided for her boys. She became a peer coach for other families because she hoped to be a support to another family and teach them the value of being genuine, reliable, and resourceful.

The puzzle piece that Trust brought for her object-interview to describe her advocacy for other families explained more about how she came to understand the importance of giving back and helping others in her community:

I thought a puzzle piece because what I notice is for each person I talked to, I was a link, I was like that middle person. They needed one, two and three or whatever. After I sat with them and spoke of them, I noticed what was missing and what was needed. So therefore, if I of course, if I had it, I was able to give it to them. Even if I didn't have it, I had a link to someone else who did have it. I would contact that person. They will give me the information and I will relay it back to the client. So I consider myself a puzzle piece. Because I was able to get them what they needed.

Trust described her advocacy identity which such gravitas and sincerely felt that she was the only person that could do what was necessary to take care of her children's needs, saying "I am it". This may be because she did everything for them and, since her husband's passing, was the only person that could advocate for them. She discussed how this advocacy identity required superhero powers and how she felt she had to be several people at one time, recalling a situation where one of her sons ran into the street and she instantly had to become "He-man, She-Ra, and the Hulk at one time" to make sure that he was safe. Now that her husband is gone, she was truly "it" or as she said "I'm It! I'm the one!". This phrase is something that she had repeated several times in our discussions. Her description of being "it" sounds like both a symbol of pride and pain. This quote comes from Trust recalling an episode that she needed to turn into several people in order to support one of her children in crisis:

My kids are dominant, they're boys and they're big and they're gung ho. "I want this' [using her hands to grab]. I am like, no you can't have that. So therefore sometimes, I have to be physical. I'm He-Man, She-Ra, both mixed together. Hulk. I mean, I have to train them. I have to mentally transition into somebody else.

Seriously when they're a flight risk. So I had to put up a six-foot fence, because when they jumped the fence, I had to turn into Marian Jones. I was oh, Zoom cars all backed up in the street. He's standing there like a deer in headlights. And then you have a transition again. If I run, he's going to run. So now I have to stop. Tiptoe slowly step, step, grab and then you turn to somebody else again. You are screaming at the top of your lungs getting in a house. That transition is something else. I mean, in terms of like four different people in the minute. Thank God my husband was alive at the time, he ran them in the house. Now, you are sitting on the step. And you crying because you can't believe what just happened.

This story is an example of Trust showing positive adaptation in her acceptance of her children, their abilities and challenges, and her own advocacy identity. And with this acceptance and advocacy identity came a need for her to give back and help another family. This is Trust's account to her experience of being a peer coach for the first time:

I was glad to be able to help people, even though I personally, when I learned about support groups and things like that, I went to them myself. But being a peer coach, I went directly to the people. They didn't have to go. They probably went to some things, but they were blessed because I was able to come to them directly to their home or wherever we decided to meet. And I was glad to help. I didn't realize that at the time, but I was kind of a relief because I saved them time and I was glad to be able to share what I knew.

She hoped that she helped to make her mentee families feel comfortable and safe with her. She was passionate about doing everything she could to make families feel that they could trust her in order to help them reduce their anxieties. Trust emphasized how important it was to listen to

families, especially Black families because they likely had negative interactions with care providers and had learned to distrust systems of care. This is a quote about her experiences coaching Black families:

The first one and the last one were both also Black. And that was an instant connection. But of course, we're not necessarily going to run to you, you really need to get to know the person. Then you realize that, OK, we have more in common besides our skin color. So once you find out what's more, you know what their needs are. Oh, OK. Oh, here I've been there. I can help with that. I can help with that. I can help with that.

When asked her advice on how providers can gain trust, she stated that she thinks having people like peer coaches that are friendly and relatable is important. She also stated that if providers wanted to reach families of color, they needed to make sure that some of the peer coaches were cultural matches because some families will need to see representation to trust them. When asked what should be done if there were not cultural matches, she said “*find some*”. This refers to practices to ensure diverse personnel especially for agencies that are servicing minoritized and marginalized populations. She discussed how the delivery of the message is just as important as the messenger; therefore, making sure that practitioners know how to read the needs and wants of families is key. Trust believed that it is a key skill to be able to think first and know how to interact with people, especially if they have experienced generational medical and academic trauma. The most important skill is knowing how to listen first and then figure out how to support their individual needs. Trust’s portrait is one of a strong warrior mother advocate, one that is affirmed and accepting in herself and her children, one that is dedicated to helping other mothers.

Discussion

The primary aim of this study was to understand the types of resources (i.e., cultural capitals) parent coaches use to advocate for their children, and we found evidence to support that mothers used a variety of community cultural capitals in both advocating for their children but also in promoting the use of similar strategies for families they coached. The mothers pulled from the support and wisdom they found in their capital as family and generational resistance capitals to find the strength to overcome the stressors and hardships associated with navigating service delivery systems. Accounts of key social agents of support such as the mother's mother were found in all seven of the study collaborators interviews, shedding light of the significance of the mother-daughter relationship throughout the life course for the mothers in the study. The mother's mothers were role models and taught them to navigate through a society that is derogatory and demeaning toward Black women. Ola and Hope both referenced that they learned to be assertive and have their voice heard through careful observation of their mothers who were college educated women in powerful career positions. Their mothers taught them how to be proactive and set themselves and their children apart from stereotypes when they interacted with society. Acknowledging that race is always a factor and that if their Black autistic kids were going to have a chance at opportunity that it would be up to them to advocate and fight for their rights.

This advocacy meant developing a value system of advocacy that involved pulling upon many more community cultural wealth capitals to develop relationships with gatekeepers of knowledge and influence within schools, agencies, and parent support groups to become allies in their child's intervention team. Advocacy also consisted of mothers having to do hours of research and investigation on their own to uncover information on how to support their child's needs. They learned from their agents of support in their lives that they would have to "*figure it*

out” and not expect anyone or any institution to be forthcoming with information and resources. There is a long history of Black women having to make “something out of nothing” in the United States. Because Black women have a multiply marginalized, intersectional existence in society, the tradition has been for us to have make the impossible possible through creativity, grit, and determination. A Black woman is always discerning if she is being treated unfairly due to her skin color or because of her gender or because of both or neither. There is a constant struggle to see multiple angles and trying to determine if a space or person is safe. Excess mental and emotional energy goes into this enervating process that it can leave very little space for other important factors like self-care. But yet, mothers in the study found their identities as advocates to be places of power and pride and relished in the expertise they had acquired as being the person that knew their children and their needs the best. In the process of advocacy value system development many of the mothers (Ola, Hope, Elizabeth, Sarge, and Nandi) discussed developing vision statements or vision boards for their children which they used to think about ways that they could envision their children thriving. They shared these statements with their children’s intervention team to encourage a team commitment to implementing the interventions that will get them closer to the vision. They also shared these statements with people on their child’s team to directly dispel the myths associated with Black parents being unengaged and Black children being destined to fail. The mothers in the study knew that these thoughts were not uncommon, and they were determined to resist any force that would seek to destroy their children’s character and future opportunities.

A second aim of this study was to learn more about the developmental process of advocacy development for Black autism mothers. We found information to support developmental theories on the significant roles of mothers and mothering throughout the lifetime

as a key to healthy attachment and identity development. We also found that the “black box” of advocacy contained a variety of variables that required the use and pulling upon community cultural wealth capitals in both linear and non-linear ways to build up experiences that produced favorable outcomes and experiences for the mother and child. Over time these experiences accumulated to develop a positive adaptation which was demonstrated through a strong acceptance of their autistic children and themselves as being autism parent advocates. In this area, Elizabeth exemplifies her acceptance of her child and her role as an advocate:

Because then if you know your kid, then you know what he can do. And you can't put limitations on him just because he's got a certain label. Yes. Don't, don't. Don't focus on the label. Focus on what you want your child to do, where you want your child to go.

Their pride in their identities as advocates caused them to want to help others therefore attracting them to become peer coaches for other families. The common motivation for becoming a peer coach was to give other parents, specifically other Black mothers, the support and information they would need to become strong advocates for their children much like how they felt their mothers and other key community members had done for them. Many stated they became peer coaches so they could tell other mothers they were not alone and could give them the confidence to develop their own advocacy despite the many systemic barriers and obstacles. This is Nandi giving an example of the type of advice she gives to families:

I really think my advice will be applied to all mothers at some level. But I would say be persistent. Try to do some independent research. And find other mothers that could help support you. Other mothers with kids on the spectrum, preferably Black mothers with kids on the spectrum that can help. And not be intimidated by

degrees or education or your perceived notion of what somebody knows that you might not know.

They took on what Black Feminist theorist, Patricia Hill Collins, calls “other mothering” or “Motherwork” which is described as a long-standing tradition for Black women since we were taken and enslaved during the Colonial times. This tradition involved being a nurturer and protector of children in our communities and having a deep connection to how one child’s detriment is a detriment to the entire community.

“I use the term motherwork to soften the dichotomies in feminist theorizing about motherhood that posit rigid distinctions between private and public, family and work, the individual and the collective, identity as individual autonomy and identity growing from the collective self-determination of one’s group. Racial ethnic women’s mothering and work experiences occur at the boundaries demarking these dualities. ‘Work for the day to come’ is motherwork, whether it is on behalf of one’s own biological children, children of one’s racial ethnic community, or children who are yet unborn” (Collins, 1994).

Mothers spoke about knowing that they only had a small window of opportunity to really help families so they would need to be strategic and listen to them to gain the relationship based on trust so that providers would respect her opinion and expertise. They thought of their coaching services as being a life-preserver for parents that were in a sink or swim situation. The greatest challenges occur when when families face dozens of sink-or-swim situations all at once, which is the case for many Black families due to systemic and institutional racism, as can be found in to low-wages jobs, joblessness, and housing and/or food insecurity. Mothers spoke about how they could relate to the myriad and multiple stressors that many of the families they

coached faced because they themselves lived through similar situations and tried to use these experiences, and the battle wounds they acquired, to gain creditability with families to help them find them a way to the shore and have space to breathe.

Implications

The importance of people, specifically people that earned the mother's trust, over the lifespan was apparent from the data of this study. The people that had the greatest impact were those that provided emotional support but also had insight in how to navigate systems and gave direct instructions on what the mothers needed to do to access supports for their children because they themselves had medical or educational backgrounds. Implications include designing interventions that pull upon the strengths of communities such as targeted outreach to grandparents and influential community members to help spread autism intervention awareness and evidence-based practice implementation knowledge.

There is a need to address the historical trauma that research institutions (i.e., universities and government agencies) and medical systems have inflicted on Black children and families in the past and how as researchers, clinicians, and educators we inherit the burden of making amends for the institutions we represent. This requires doing the work and sifting out practice, policy and procedures that discriminate against Black families and children and replacing them with family-centered, culturally and linguistically relevant and sensitive practice policy and procedures. In the words of the late civil rights activist, John Lewis it is time for us as autism providers to get into "good trouble".

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Conclusion

The process to developing parental advocacy for Black women has not been studied well. In fact, we know so little about it is almost like a “black box” of unknown information that needs to be understood and unpacked. In the two empirical investigations that comprised this dissertation we learned about the many resources and attributes of community cultural wealth that Black mothers were able to pull upon to successfully advocate for supports for their children in schools and in the community. By using a CRT framework to conduct these investigations we were able to find wider social justice implications of the research and amplifying the voices of the mothers and their experiences. For instance, mothers expressed pride in their Blackness yet also discussed the deep concern they had for themselves and their children’s safety due to anti-Black violence. Mothers expressed fear for their Black autistic sons because they recognized that American society’s fear of Black men has led to countless recent deaths, as Ola so poignantly stated:

As a Black mother raising a young Black boy. There we go out every day and there's things that can occur. You need to be willing to defend him in that. And that's what I mean by that. As my son, oldest son says, he has a target on his back every day he leaves his house.

We know that the intersection of race and disability is not recognized in the news articles of these murdered Black men but as mothers we recognize the patterns, mannerisms, and temperament that resemble our own children’s (Artiles et al., 2016; Tincani et al., 2009). We see those Black men murdered and bodies left on the street and can see shadows of our own children.

This work attempts to expand the knowledge of ASD families with intersectional identities (race, gender) by focusing on their assets, rather than deficits, creating a portrait of

advocacy and resilience for us to learn from. This work also makes way for future critical investigations involving the role of spirituality and advocacy for Black mothers of autistic children, the history of disability in the Black community and how stigma of disability impacts acceptance for Black parents of autistic children and last the impacts of the double Pandemic (COVID-19 and Racial Reckoning Movement) on Black families of children with developmental disabilities.

Appendices

<u>Appendix A</u>	Study 1	Table 1, <i>Community cultural wealth and non-dominant cultural capital definitions</i>
<u>Appendix B</u>	Study 1	Table 2, <i>Caregiver Demographics</i>
<u>Appendix C</u>	Study 1	Table 3, <i>Black ASD Moms Interview Guide</i>
<u>Appendix D</u>	Study 1 & 2	Parent Questionnaire, <i>Community Cultural Capital Measure/Scale</i>
<u>Appendix E</u>	Study 2	Figure 1, <i>Double ABCX model for Black mothers of children on the autism spectrum</i>
<u>Appendix F</u>	Study 2	Table 4, <i>Caregiver Demographics</i>
<u>Appendix G</u>	Study 2	Table 5, <i>Black Mother Parent Coach Interview Guide</i>
<u>Appendix H</u>	Study 2	Table 6, <i>Black Mother Parent Coach Codebook</i>
<u>Appendix I</u>	Study 2	Figure 2, <i>NVivo word similarity cluster analysis</i>
<u>Appendix J</u>	Study 2	Figure 3, <i>Codes within Phases of Advocacy Development Model</i>
<u>Appendix K</u>	Study 2	Figure 4, <i>Phases of Advocacy Development Model</i>

Appendix A

Table 1

Community cultural wealth and non-dominant cultural capital definitions

Name of Capital	Definition
<i>Aspirational Capital</i>	Aspirational capital refers to the ability to maintain hopes and dreams for the future, even in the face of real and perceived barriers. This resiliency is evidenced in those who allow themselves and their children to dream of possibilities beyond their present circumstances, often without the objective means to attain those goals. [Yosso, 2005]
<i>Familial Capital</i>	Familial capital refers to those cultural knowledges nurtured among familia (kin) that carry a sense of community history, memory and cultural intuition. This form of cultural wealth engages a commitment to community well-being and expands the concept of family to include a broader understanding of kinship. [Yosso, 2005]
<i>Social Capital</i>	Social capital can be understood as networks of people and community resources. These peer and other social contacts can provide both instrumental and emotional support to navigate through society's institutions. In Communities of Color, social capital is used to give information and resources they gained through these institutions back to their social networks. Creating the tradition of 'lifting as we climb' [Yosso, 2005]
<i>Linguistic Capital</i>	Linguistic capital includes the intellectual and social skills attained through communication experiences in more than one language and/or style. This repertoire of storytelling skills may include memorization, attention to detail, dramatic pauses, comedic timing, facial affect, vocal tone, volume, rhythm and rhyme. Linguistic capital also refers to the ability to communicate via visual art, music or poetry. [Yosso, 2005]
<i>Resistant Capital</i>	Resistant capital refers to those knowledges and skills fostered through oppositional behavior that challenges inequality. This form of cultural wealth is grounded in the legacy of resistance to subordination exhibited by Communities of Color... Therefore, transformative resistant capital includes cultural knowledge of the structures of racism and motivation to transform such oppressive structures. [Yosso, 2005]
<i>Navigational Capital</i>	Navigational capital refers to skills of maneuvering through social institutions. Historically, this infers the ability to maneuver through institutions not created with Communities of Color in mind. Navigational capital thus acknowledges individual agency within institutional constraints, but it also connects to social networks that facilitate community navigation through places and spaces including schools, the job market and the health care and judicial systems. [Yosso, 2005]

<i>Motherhood Capital</i>	Motherhood capital is described as “the mothers’ interactional styles and knowledge that signal to institutional gatekeepers their deep caring for and intimate understandings about their children. [Lo, 2016]
<i>Black Cultural Capital</i>	Black Cultural Capital refers to the skills that Black/African Americans have acquired that allows them to move through in-group and out-group interactions with people within and outside of their race. It includes the ability to code-switch, recognize and understand different social norms, customs, styles in cultures and the skills to adapt to fit themselves into various social interactions. [Carter, 2003]

Appendix B

Table 2

Caregiver Demographics

Name	Age	Education	Employment	Child Age	Income	Child Placement	Cultural Capital (greatest to least coded)
Evelyn	52	College Graduate	Full Time IHSS * worker for child	14	\$40-49K	SPED Classroom	Resistant, Navigational, Black Cultural Capital, Linguistic, Motherhood, Aspirational, Familial, Social
Mae	55	College Graduate	Full Time work outside of home	13	\$80-89K	GE/SPED Classroom Split	Resistant, Navigational, Black Cultural Capital, Aspirational, Social, Familial, Linguistic, Motherhood
Wilma	39	College Graduate	Full Time IHSS worker for child	7	\$30-39K	ASD Classroom	Resistant, Navigational, Social, Black Cultural Capital, Social, Aspirational, Linguistic, Familial
Josephine	42	Two Year Degree	Full Time IHSS worker for child	10	\$30-39K	ASD Classroom	Navigational, Resistant, Social, Black Cultural Capital, Aspirational, Familial, Linguistic, Motherhood
Henrietta	45	College Graduate	Full time work outside of home	10	\$50-59K	SPED classroom	Resistant, Navigational, Black Cultural Capital, Social, Aspirational, Linguistic, Motherhood

*IHSS-In Home Support Services; State funding available for families to are caretakers for disabled children in California.

Note: names of collaborators have been changed for anonymity.

Appendix C

Table 3

Black ASD Moms Interview Guide

Agenda and Questions
Welcome and General Housekeeping Items and Forms
Review Purpose of Study, Start Recording.
Introduction of Researcher – Ask informant to tell a little about themselves and what they like most about their child with ASD?
First Concerns and First Steps
<ol style="list-style-type: none"> 1. <u>Think back to the time after your child was diagnosed with ASD. How did you go about getting services at that time?</u> 2. <u>What (if anything) got in the way of getting the diagnosis and/or access to services?</u> 3. <u>What and who was helpful in getting these services? (probe: Do feel that you were an advocate for your child during this time? Why or why not?)</u>
Cultural Capital and Special Education Services Questions
<ol style="list-style-type: none"> 4. <u>What are your relationships with your child’s primary therapist and teachers like? (probe: Have you ever stayed in touch with one of your child’s past teachers or therapists in order to ask for advice or get information? If so, can you tell more? Can you tell about an experience that you found communicating with your child’s teachers or therapist challenging?) [Social capital]</u> 5. <u>Do you feel like you know who you can go to for good information and advice about ways to have a successful (IEP/504/IPP) meeting for your child? Why or why not? (probe: Is asking for accommodations and services during (IEP/504/IPP) an easy thing to do for you? Why or why not?) [Navigational capital]</u> 6. <u>Do you believe that your child’s ASD diagnosis will keep them from achieving good things in his/her life? (probe: Despite the fact your child’s diagnosis, do you still have high hopes and dreams for your child? Can you tell about one big dream you have for them?) [Aspirational capital]</u> 7. <u>When you are in an (IEP/504/IPP) meeting for the child do you think you are able to effectively communicate and get your points across? [probe: Can you tell about an instance that you felt you were able to have a positive interaction with your child’s teacher or therapist. What made that interaction positive? Was it anything that you said that helped it to stay positive? [Linguistic capital]</u> 8. <u>Who do you go to for emotional support? (probe: Do you have people in your life that you can count on for support when the journey gets difficult? Who are they? What do they do for you? [Familial capital]</u> 9. <u>Do you think that children with ASD should have the same rights as all other children? Why or why not? (Probe: Do you believe that all children with ASD should be fully included? Have you done anything to make sure that your child has not been discriminated against or excluded because they have ASD?) [Resistance capital]</u> 10. <u>Would you say that you have a deep and intimate understanding of your child’s needs? Do you feel that when you communicate this knowledge about your child that you can strongly advocate for your child and members of his (IEP/504/IPP) team listens? Can you give an example of this? [Motherhood capital]</u>

11. Would you agree that you are able to communicate fluently with other members of the Black community? Do you communicate in a similar manner with people that are not in the Black community? (probe: Would you say that you are able to easily turn on and off the different communication styles easily? Can you give an example of you doing this when supporting your child with ASD?) [Black cultural capital].
12. What skill do you use the most in advocating for your child during (IEP/504/IPP)s? Where there a personal skill set or knowledge based that you found helpful to use when you are advocating for your child?
- i. How did you learn those skills?
 - ii. Who taught them to you?
 - iii. How long did it take you to learn them?
 - iv. When do you find that they are needed?
 - v. Do you use these skills and/or knowledge base in any other areas of your life?
 - vi. Have you ever used these skills or knowledge and it did not work? What did you do? Why do you think they didn't work?

13. Mother wit

Imagine that you had a magic telephone that would allow you to talk to every Black mother right after they received an autism diagnosis for their child. What would you tell them? What is one of the first things they should do to help their child thrive at school and in the community? What skills or resources would you tell them they need to utilize to do this? What about your experience with service delivery agencies (school, regional centers) taught you these lessons?

Appendix D

Parent Questionnaire

Community Cultural Capital Measure/Scale

Community Capital Scale

Completed by: Mother **Date completed:** ___ / ___ / ___

Office use only

ID: _____

Read each statement and place an “X” in the box corresponding to how you feel each statement applies to you. Please check the box next to the question if you feel that the wording of the question is concerning. We will ask for your input on checked boxes after you have completed the questionnaire.

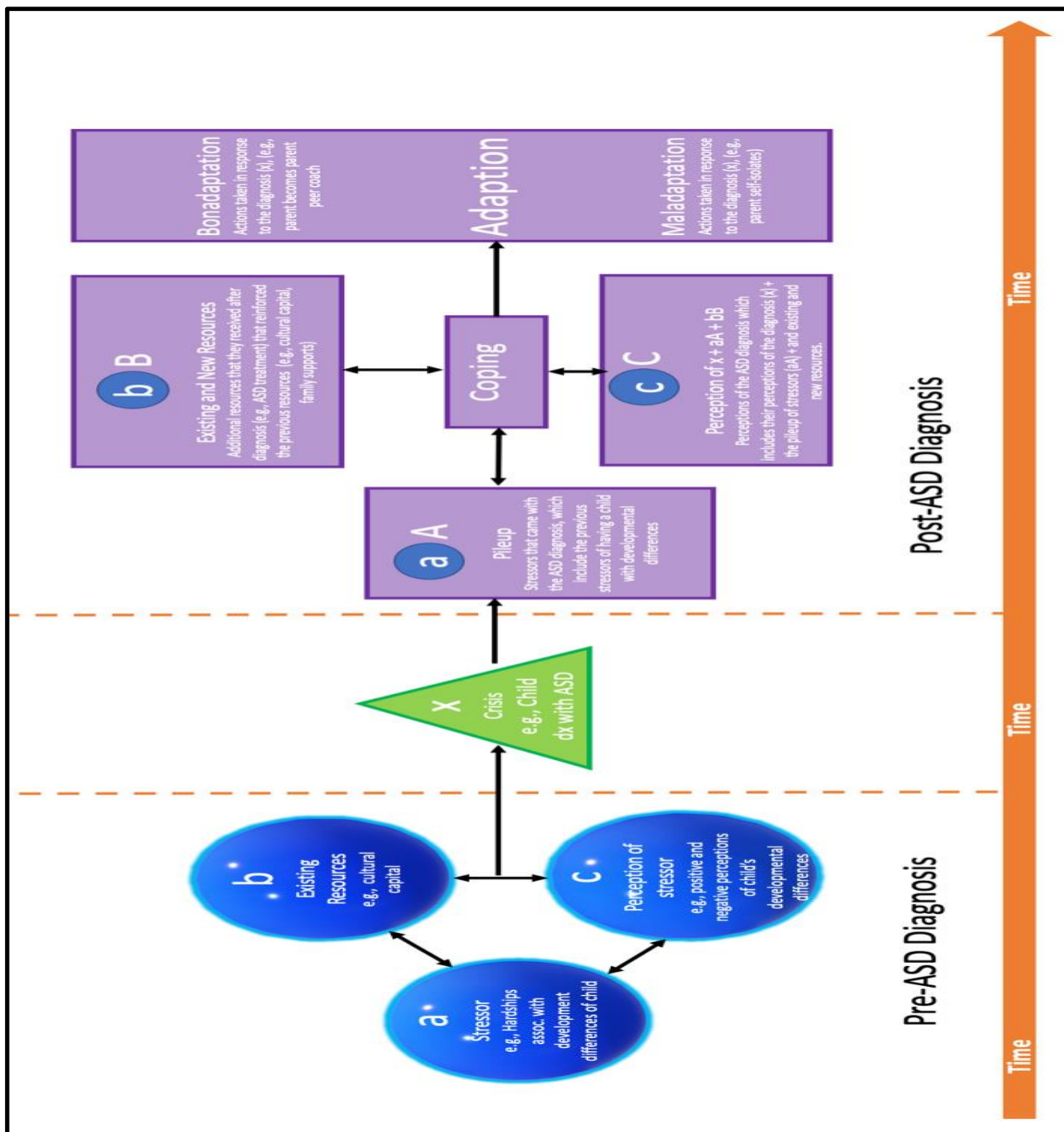


	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree	<u>Concerning Language?</u>
1. I have high hopes and dreams for myself.						
2. People tell me that I am a good communicator.						
3. I avoid people that don't respect me.						
4. Professionals listen to me when I tell them about my child.						
5. I can get through tough situations.						
6. I believe that labels (e.g., diagnosis, gender race/ethnicity etc.) cannot keep people from achieving.						
7. When I face challenges, I use my family and community for emotional support.						
8. I won't go along with the crowd if it does not work for me or my family.						
9. People in my community have different ways of communicating with each other than people outside of my community. I know how to communicate and act in both communities.						
10. I have a strong social network of friends that gives me information and opportunities that most people don't have.						

Appendix E

Figure 1

Double ABCX Model Framework for MTG Parent Peer Coaches adapted from Weber (2011)



Appendix F

Table 4

Collaborator Demographics

Name*	Age	Education	Employment	Child Age	Income	Age of child Diagnosis	Time from Diagnosis to Treatment
Ola	54	Bachelor's Degree	Employed Part-Time	18	\$40-49K	2 years old	Less than 3 months
Hope	48	Bachelor's Degree	Employed Full-Time	20	\$100K or more	7 years old	2+ years
Elizabeth	76	Bachelor's Degree	Retired	9	\$50-59K	2.5 years old	Less than 3 months
Trust	49	Bachelor's Degree	Employed Full-Time	19	\$20-29K	3 years old	3 to 6 months
Nandi	47	Some College	Unemployed	17	\$10-19K	1.8-year-old	Less than 3 months
Sarge	61	Vocational Certificate	Employed Part-Time	14	\$50-59K	3 years old	3 to 6 months
Faith	46	Associates Degree	Employed Part-Time	19	\$20-29K	3 years old	3 to 6 months

*Mothers self-assigned pseudonyms for themselves, children, and significant people in their portrait.

Appendix G

Table 5

Black Mother Parent Coach Interview Guide

Agenda and Questions for Interview 1
Welcome, Review Purpose of Study, have collaborators take demographic questionnaire, start Recording. Start conversation with question about how recent health care crisis has impacted them and their family.
<p style="text-align: center;">Section 1A:</p> Object Interview Question (collaborators were asked to bring an artifact that they feel represents their experience of advocating for their child to the first interview) Can you share with me the artifact that you chose to bring to the interview? How does this represent your advocacy? Where Does Your Advocacy Come From Questions: <ol style="list-style-type: none">1. What aspects of your parenting would you say you were most confident about and had the highest self-esteem in doing BEFORE your child was diagnosed? If so, describe what you did.2. Can you tell the story of the day your child was diagnosed with ASD?<ol style="list-style-type: none">a. How did you handle being told about this new diagnosis?b. How did you cope with the news? (Prompt: Did you journal or talk to a friend?)3. After your child was diagnosed, how were you able to secure services for them?<ol style="list-style-type: none">a. What and who was helpful in getting these services?b. Do feel that you were an strong advocate for your child during this time? Why or why not?)4. What aspects of your parenting would you say you were most confident about and had the highest self-esteem in doing AFTER your child was diagnosed with autism?<ol style="list-style-type: none">a. Can you describe the types of family support you had after the diagnosis for caring for your child that you found helpful?b. Can you describe the types of community or agency support you had after the diagnosis for caring for your child that you found helpful?c. What supports and challenges you faced after the diagnosis that taught you how to advocate for your child?
<p style="text-align: center;">Section 1B:</p> Imagine that you could go on a vacation from your job of being a parent of your child with autism for an entire year! All you had to do was come up with a job description to find a person that had similar qualities as you to fill your shoes while you were away, how would you write up the job description? <ol style="list-style-type: none">a. What types of attributes would they need to have?b. How should that person interact with your child?c. How should that person interact with your community? Cultural Capital Questions: <ol style="list-style-type: none">1. Who are the people you go to for information to help your child? (probe: Have you ever stayed in touch with one of your child’s past teachers or therapists in order to ask for advice or get information? If so, can you tell more? [Social capital])

2. How did you figure out how to navigate service delivery systems (school, early intervention, medical, etc.) that lead to accessing services for your child? (probe: Is asking for accommodations and services during (IEP/504/IPP) an easy thing to do for you? Why or why not?) [Navigational capital]
3. Who do you go to for emotional support? (probe: Do you have people in your life that you can count on for support when the journey gets difficult? Who are they? What do they do for you? [Familial capital]
4. Have you done anything to make sure that your child has not been discriminated against or excluded because they have ASD?) [Resistance capital]*

Agenda and Questions for Interview 2

Review and summarize what we discussed in the first interview and explain the purpose of the second interview. Start Recording.

Section 2A:

Object Interview Question (collaborators were asked to bring an artifact that they feel represents their experience of advocating other families that they have coached) Can you share with me the artifact that you chose to bring to the interview? How does this represent your experience in coaching other families?

How Have You Used Your Advocacy for Your Child/Family Questions?

1. Think back to the time after your child was first diagnosed with ASD. What (if anything) got in the way or were barriers of getting the diagnosis and/or access to services?
2. Can you remember a time that you had to assert yourself and communicate to someone of your child's intervention team (e.g., teacher, interventionist, doctor) that your concerns or ideas would not be ignored? Can you tell the story?
3. When you communicate during your child's intervention meetings (IEP/504/IPP/Medical) do you feel that your ideas heard? What do you do to make sure they are heard and respected? What do you do when you feel they are not heard or respected? Can you give an examples?
4. What skill do you use the most in advocating for your child during (IEP/504/IPP)s? Where there a personal skill set or knowledge based that you found helpful to use when you are advocating for your child?
 - i. How did you learn those skills?
 - ii. Who taught them to you?
 - iii. How long did it take you to learn them?
 - iv. When do you find that they are needed?
 - v. Do you use these skills and/or knowledge base in any other areas of your life?

Section 2B:

Imagine that you had a magic telephone that would allow you to talk to every Black parent right after they received an autism diagnosis for their child. What would you tell them? What is one of the first things they should do to help their child thrive at school and in the community? What skills or resources would you tell them they need to utilize to do this? What about your experience with service delivery agencies (school, regional centers) taught you these lessons?

Peer Coaching Questions

1. What was most appealing to you about becoming a parent peer coach for recently diagnosed families of children on the autism spectrum?
2. What do you think you brought to (or taught) your parent mentees?
3. What do you think you took away (learned) from your parent mentees?
4. What is a skill or strategy that you wished all of the parent mentees your supported could learn from you? Why do you think it's important that they know this skill or strategy? ASD parent mentees could learn from you?
5. Is there anything else you want to tell me about your experiences as a parent of a child with ASD or as a peer coach?

You have answered all the questions I have prepared but I want to make sure that you have an opportunity to tell me whatever you want me to know? Is there anything else you feel you need to say? *

**At the end of each interview (1 & 2) collaborators will be emailed an electronic gift card and asked to complete the proof of gift card receipt.*

Appendix H

Table 6

Black Mother Parent Coach Codebook

Code	Top-Code/Sub-Code Name	Description	Inclusion Criteria	Exclusion Criteria
#1	Community Cultural Capital: <i>Social Friendship Capital (1.1)</i>	This code is found when mothers express a social connection that gave them insight, advice, or modeled behaviors that opened up doors for services and supports for their children that they would not have had without this connection.	When mention of any service providers such as SLPs, OT, RN, Drs, State or Federal agency Medicaid service provider or other Special Education professionals or ABA vendors that gave parent direct tips, ideas, or insight on how to access services and supports for their children. This can include parents of children on the autism spectrum and support groups that they participated in the past.	Exclude if the parent mentions that this person only gave them social emotional support. Also exclude if the two parents are peers (have children at the same age or level of development). <i>Code as Community Cultural Capital Familial Capital if these are mentioned.</i>
#2	Community Cultural Capital: <i>Navigational Capital (1.2)</i>	This code is found when mothers tell stories or demonstrate instances that they had to figure out ways to access supports and services for their children. This includes when they use strategy to overcome obstacles and barriers that kept her child from having access to services and supports.	When mother gives examples of using such resources as books, pamphlets, the internet, accessing Family Resource Center/Parent Training and Information Centers/Disability Organizations, learning special education, state and federal laws so they can access their parental rights. Also include when mothers describe navigating social support systems such as Medicaid/Medical, Social Security (SSI), and other intervention systems.	Exclude when mother mentions being Black or that her race or gender were factors that caused her to have to come up with a strategy to overcome an obstacle associated with gaining access to services and supports for her child. <i>Code Community Cultural Capital Resistance Capital if this is mentioned.</i> Exclude when mothers mention people in their social network that they brought into meetings or received information from that helped them navigate a system. Code Community. Code <i>Cultural Capital_ Social friendship Capital</i> if this is mentioned.

#3	Community Cultural Capital: Familial Capital (1.3)	Code with mothers discuss family members (mother, father, siblings, aunts, uncles, grandparents) and when they have a person that was a friend, but they made to be like a family member (kin) that has been a social emotional support. Also, code when mothers mention these people have been role models or have friendship with them, they feel is pivotal in them getting through tough situations.	Include when this person gives good advice and serves as a backup parent or extra eyes for the mother for the child on the spectrum. This person is either direct family or a close peer meaning that they are around the same age or have children the same age or developmental level.	Exclude when this person(s) is a part of an agency or organization (i.e., Medicaid service worker, ABA vendor) or if they are non-peers and family members that have given the parent insight into ways to access services and supports that opened doors for them. Code <i>Cultural Capital Social Capital</i> if this is mentioned.
#4	Community Cultural Capital: Generational Resistance Capital (1.4)	Code when mother mentions a story or example of them learning to advocate from examples of people within their communities (i.e., their family members) overcoming discrimination and oppression based on their race, class, or gender which gave them a sense of purpose and pride of being a Black woman.	Include when they give these example people overcoming discrimination and oppressive systems (i.e., racism, classism, sexism, ableism). Include when mother refers to an “ism”. Code when mother was told stories of these oppressions or intentionally told not to believe that they are inferior in order to prepare them for life (survival skill).	Exclude when there is no mention of oppression or discrimination based on social system (racism, classism, sexism, ableism, etc.). Code as <i>Community Cultural Capital_Resistance Capital</i> when mentioned.
#5	Community Cultural Capital: Resistance Capital (1.5)	Code when mother tells stories or gives examples of her resisting or push back at ASD professionals (OTs, SLP, Teaches, Medical Doctors, Early Interventionist, district special education staff) when they told the mother something that they did not personally believe about their child.	Include when mothers would not take no for an answer and persisted to find the supports and resources, they knew they needed. Include when they mother gives examples/stories of preparing to have conflict or needing to implement advocacy strategies to advocate for their child because someone that was on the intervention team told them “no” or did not believe or respect their ideas/options about their child.	Exclude when mother mention social systems of oppression (sexism, classism, racism) experienced by family or community. Code as <i>Community Cultural Capital Generational Resistance</i> if mentioned.
#6	Advocacy Development: Pre-Dx Stressors (2.1)	Code when mother mentions hardships and stressors that she experienced prior to or at the point their child was diagnosed. Also, code when	Include stories or instances when mother discusses her journey of obtaining the autism diagnosis for her child and the barriers and challenges, she faced. Also	Double Code: when mother mention stressors associated with fighting against social systems of oppression (racism, sexism, classism), code

		<p>the mother discusses resources such as skills or strategy that she used prior and during her child's diagnosis.</p>	<p>include information about specific advocacy skills and strategy (organization, communication, relationship skills) she used to get the diagnosis for her child.</p> <p>Include mentions of mother's concerns about child's development. Include stressors such as Financial (e.g., loss of job), relational (e.g., separation or divorce from spouse, death of family member), health/physical (e.g., physical or mental disability) that existed before and during the time of the child's diagnosis.</p>	<p><i>Cultural Capital Resistance Capital</i> if mentioned.</p> <p>Double Code: when mother mentions skills used to advocate for her child's diagnosis or services due to previous experiences, jobs, experiences she had, when this is mentioned code as <i>Cultural Capital Navigational Capital</i>.</p>
#7	Advocacy Development: Perceptions Pre-Dx (2.2)	<p>Code when mother talks the metacognition (feelings, thoughts, ideas and perceptions) she experienced prior to and during the time of her child's ASD diagnosis.</p>	<p>Include when mother discuss her perceptions, feelings, ideas about autism and disability before and during the time of her child's initial diagnosis. Can also include her perceptions of having a child demonstrating atypical development and stigmas associated with it.</p>	<p>Exclude when mother mentions perceptions after the time of her child's diagnosis, in this case code as <i>Advocacy Development Perceptions Post-Diagnosis</i>.</p> <p>Double Code: when mother mentions family and friends being a support for them prior and during diagnosis, code <i>Community Cultural Capital Familial Capital</i> in this case.</p> <p>Double Code: when mother mentions ASD clinicians or service providers (I.e., Pediatricians, SLPs) that gave the parent information or ideas that allowed them to get diagnosis or services for their child, code <i>Community Cultural Capital Social Capital</i> in this case.</p>

				Double Code: when mother discusses the exact resources and strategies, she used to navigate service systems, code <i>Community Cultural Capital Navigational Capital</i> in this case.
#8	Advocacy Development: <i>Post-Dx Stressor (2.3)</i>	Code when mother mentions hardships, stressors that she experienced post/after her child's diagnosis. Also, code when the mother discusses resources such as skills or strategy that she acquired after child diagnosis that supported her advocacy development.	<p>Include stories or instances when mother discusses her journey to secure services and the barriers and challenges, she faced. Also include information about specific advocacy skills and strategy (organization, communication, relationship skills) she used to secure services for her child after diagnosis.</p> <p>Include stressors such as Financial (e.g., loss of job), relational (e.g., separation or divorce from spouse, death of family member), health/physical (e.g., physical or mental disability) that existed at any point <u>after</u> her child's diagnosis.</p>	<p>Exclude when mother discusses her experience in acquire ASD Diagnosis, code <i>Advocacy Development-Pre-Dx Perceptions of Stressor</i> in this case.</p> <p>Double Code: when discusses using disability parent support groups and agencies she was connected with post-diagnosis to secure services, also code as <i>Community Cultural Capital Social Capital</i> in this case.</p> <p>Double Code: when mother mention stressors associated with fighting against social systems of oppression (racism, sexism, classism), also code <i>Cultural Capital Resistance Capital</i> if mentioned.</p> <p>Double Code: when mother mentions skills used to advocate for her child's diagnosis or services due to pervious experiences, jobs, experiences she had, when this is mentioned also code as <i>Cultural Capital Navigational Capital</i>.</p>

#9	<p>Advocacy Development: Perceptions Post-Dx (2.4)</p>	<p>Code when mother talks the metacognition (feelings, thoughts, ideas and perceptions) she experienced after her child's ASD diagnosis.</p> <p>This code is used when mother discusses her perceptions of her experience of being an advocate for her child and her identity and role as an advocate.</p>	<p>Include when mother discuss her perceptions, feelings, ideas about autism and disability after and her child's diagnosis. This can include current perceptions of acceptance of her child and herself.</p> <p>Can also include her perceptions of having a child on the autism spectrum how she handles stigma from family and community members.</p>	<p>Exclude when mother mentions perceptions before or during the time of her child's diagnosis, in this case code as <i>Advocacy Development Perceptions Pre-Diagnosis</i>.</p> <p>Double Code: when mother mentions family and friends being a support for them after the diagnosis, also code <i>Community Cultural Capital Familial Capital</i> in this case.</p> <p>Double Code: when mother mentions ASD clinicians or service providers (i.e., Pediatricians, SLPs) being critical in giving them information or ideas that allowed them to get diagnosis or services for their child, also code <i>Community Cultural Capital Social Capital</i> in this case.</p> <p>Double Code: when mother discusses the exact resources and strategies, she used to navigate service systems, also code <i>Community Cultural Capital Navigational Capital</i> in this case.</p>
#10	<p>Advocacy Development: Positive Adaption (2.5)</p>	<p>Code when mother mention their motivation to becoming a parent coach.</p>	<p>Include when mother expresses instances where she mentions her desire to not only advocate for her own child but for other kids and families in her community</p>	<p>Exclude when mother mentions her acceptance or perception of child's disability, in this case code, <i>Advocacy Development Post-Diagnosis Perceptions</i>.</p> <p>Exclude when mother mentions and stressors (i.e., financial, mental, health/physical) that exist as a result of her child's ASD diagnosis., in this case code <i>Advocacy</i></p>

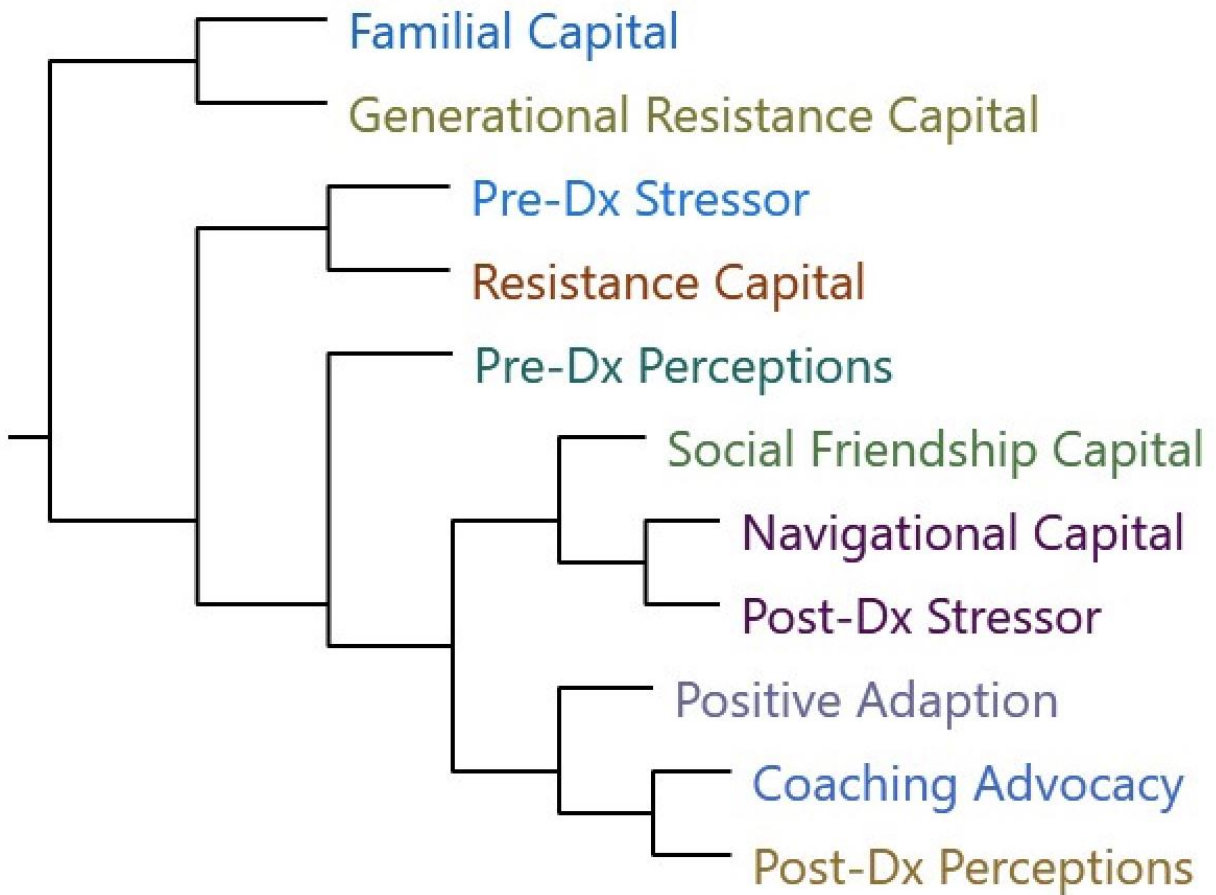
				<i>Development Post Dx Stressor.</i>
#11	Coaching Advocacy (3.0)	Code when mother discusses specific strategies they used when coaching other families.	<p>Include social-emotional support they provided to families (e.g., I would listen). Also, include types of resources and supports they used to coach families and types of resources and supports the advocated for families to access (e.g., connect them with support group or provider).</p> <p>Also, include advice that she would give newly diagnosed families (both Black families and in general) about ways to adapt and accept to the ASD diagnosis.</p>	<p>Exclude when mother discusses advice she gave as a peer coach to other families that is not a specific strategy or resource but is more a pep talk that included her process of understand her own role of a parent advocate, in this case include as <i>Advocacy Development Perceptions Post Dx.</i></p>

Appendix I

Figure 2

NVivo Word Similarity Cluster Analysis

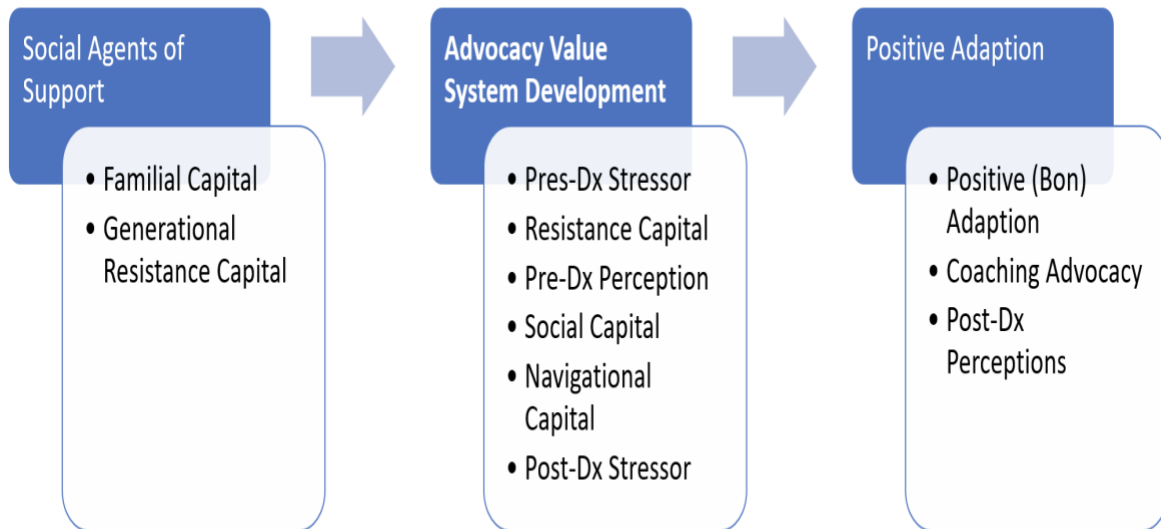
Items clustered by word similarity



Appendix J

Figure 3

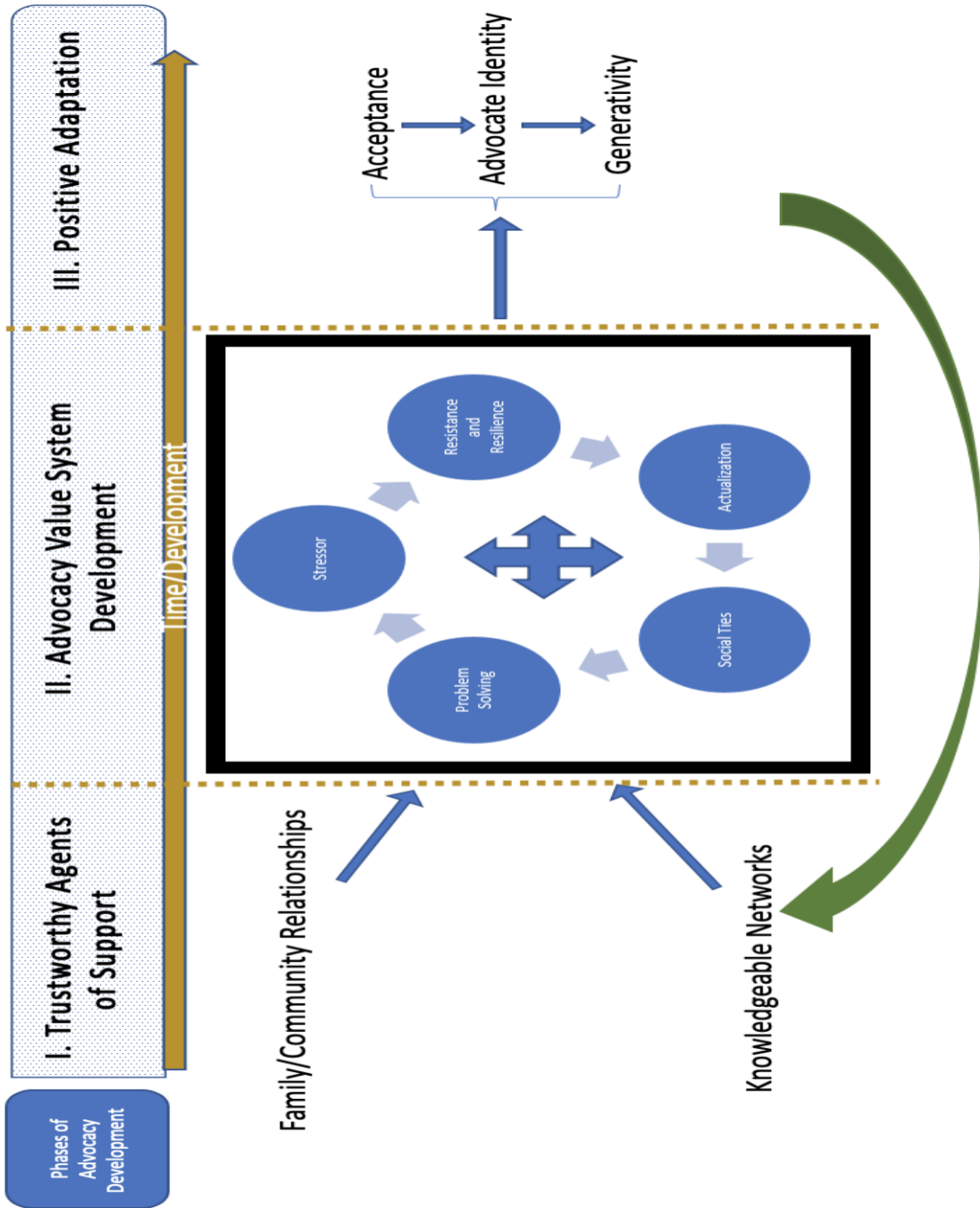
Codes within Phases of Advocacy Development Model



Appendix K

Figure 4

Phases of Advocacy Development Model



Mothers become Phase I: Trustworthy Agents of Support for Other Mothers (Collins, 1994)