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FOSTERING ADVOCACY, COMMUNICATION, EMPOWERMENT AND SUPPORT
(FACES) FOR AFRICAN AMERICAN FAMILIES OF CHILDREN WITH AUTISM: A
PILOT STUDY

BY

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DISSERTATION

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Abstract

Children with autism spectrum disorder (ASD) and their families often face challenges with accessing early intervention and related services. African American children face additional challenges due to disparities in diagnoses and access to services. These disparities present a great need for parent advocacy strategies to combat barriers such as culturally insensitive service delivery and strained parent-professional partnerships. In this sequential mixed methods study, I examined the effectiveness of a six-week parent training intervention (FACES) on strengthening perceptions of advocacy and empowerment among African American parents of children with ASD. Multiple sources of data were collected and mixed to refine the intervention and to assess the effectiveness of FACES. Results indicated that parents' perceptions of their advocacy skills, sense of empowerment, and community support were strengthened following the FACES program. Implications for research and practice are discussed.

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Table of Contents

Chapter 1 Introduction	1
Chapter 2 Review of Literature	9
Chapter 3 Methods	30
Chapter 4 Results	63
Chapter 5 Discussion	91
References	106
Appendix A IRB Approval	117
Appendix B Recruitment Flyer	118
Appendix C Screening Script	119
Appendix D Consent Form	121
Appendix E Data Collection Timeline	123
Appendix F Pre-FACES Focus Group Interview Guide	124
Appendix G Pre-FACES Questionnaire	125
Appendix H Post-FACES Focus Group Interview Guide	126
Appendix I Post-FACES Focus Group Participant Interview Guide	127
Appendix J Example Member Check Summary	128
Appendix K FACES Curriculum Overview	129
Appendix L Training Protocol and Fidelity Checklists	130

Appendix M FACES Formative Evaluation.....	136
Appendix N FACES Summative Evaluation.....	138
Appendix O Family Information Questionnaire.....	142
Appendix P The Everyday Discrimination Scale.....	145
Appendix Q FACES Pre/Post Measures.....	146

Chapter 1

Introduction

Autism and African American Children

The prevalence of autism spectrum disorder (ASD) among 8-year-old children is one in 68 children across racial and ethnic backgrounds (CDC, 2016). European American children however, are 1.2 times more likely to be diagnosed with ASD than African American children (CDC, 2016). Findings indicate that African American children with ASD are often misdiagnosed or go undiagnosed until years after the onset of symptoms (Mandell et al., 2009). Hilton et al. (2010) examined the underrepresentation of African American children in ASD genetic registries, and while their data were not representative of all African American families of children with ASD, they suggest that over half of the probable cases of ASD in African American children remained undiagnosed by the age of 8 years old. Mandell and Novak (2005) suggest that these disparities may be due in part, to the fact that few epidemiologic studies have explored ethnic differences in the symptoms of ASD.

Previous research around ASD has highlighted the importance of early diagnosis and early intervention in addressing the needs of children with ASD (Boyd, Odom, Humphreys, & Sam, 2010). For children with disabilities, including ASD, the early childhood years are critical because early identification increases the likelihood that the child will benefit from interventions and services designed to address his or her needs (Bruder, 2010; Irvin, McBee, Boyd, Hume, & Odom, 2012). While the likelihood of identifying children with ASD during the first 2 years of life has become more promising than in previous years (Boyd et al., 2010), the probability of early ASD diagnoses, however, has not generalized across racial and ethnic groups. African American children are often diagnosed years after the onset of symptoms, and in some cases

remain undiagnosed well into their elementary school years (Hilton et al., 2010; Mandell et al., 2009). Therefore, African American children are not as likely to receive and benefit from the early intervention services that many of their European American peers with ASD benefit from as toddlers.

Problem and Significance

To date, little is known about the experiences of African American parents of children with ASD. Although it is evident that ASD is prevalent among African American children (CDC, 2016), few studies have addressed the degree to which under diagnosis and misdiagnosis affects African American children with ASD and their families (Mandell et al., 2002).

Given the aforementioned dearth of literature, in our previous study (Pearson and Meadan, in press) we interviewed African American mothers of children with ASD about their experiences related to obtaining an initial diagnosis and accessing services for children with ASD. Several categories and themes emerged in the participants' responses that were identified as facilitators or barriers to obtaining early diagnoses and access to services. One barrier that mothers reported was that healthcare providers were often dismissive of their concerns—mothers felt it was very challenging to develop partnerships and communicate effectively with some of the providers. As such, these experiences have, in many cases, driven a wedge between parents and healthcare providers, leaving parents feeling un-empowered and unsure about how to advocate effectively for their children. One parent shared the following regarding her interactions with her child's healthcare provider:

When I would go to visit him [developmental pediatrician] he would just say, 'Oh well. I would recommend this, but you don't have the money for that.' Then he is just like, 'I am just going to give you this literature.' I am just like seriously why do we come here.

Another reported barrier was parents' knowledge of child development and disability. A few mothers indicated that their knowledge of child development was limited because their child with ASD was also their first child. For example, one mother said, "She is my only child. I was a teacher but I worked with kids [ages] five and up. So, if they were walking and talking I could handle that. I wasn't familiar with babies."

Finally, at the end of each interview, mothers were asked, *What recommendations do you have for educators, service providers, and healthcare providers to better serve the needs of African American children with ASD?* Many of the mothers' recommendations were actually for other parents like themselves. The primary emergent theme was a need for parent education and support. One participant said, "Parents not only need to know the resources that are available and how to access them, but they need training themselves." Two other participants shared the following:

I think educating the parent . . . if they just get that education and know that this is going to help—this is to benefit your child, this is the outcome. Especially if they are waiting—if they start seeing things at three and it gets worse by the time they are seven or eight, you have missed all of that.

For me, the biggest thing is to help me to understand or help me to help him; not the generic class, but maybe what your particular child might need. More parent education as far as how to navigate these systems.

These participant recommendations corroborate the previous work of Gourdine, Baffour, and Teasley (2011) and Zuckerman et al. (2013), both of which suggest that African American parents need more opportunities to access information about ASD.

In addition to the barriers and areas of need, participants discussed a number of facilitators that positively shaped their experiences with gaining access to services. Two of the most fundamental ways that mothers were able to gain access to services for their children

included advocacy and communication/partnerships with school-based professionals and other service providers. Parent advocacy was a primary theme that was echoed throughout a majority of interviews as a strategy to provoke action and attention to their child's needs. One mother shared the following: "I do know what he is entitled to. They do the IEP but I do go thoroughly through it. If I don't agree with it, I sit there, take my time, say, 'no, I don't agree with this.'"

In the literature, research around advocacy among parents of children with disabilities is present, though limited. In their work that explored the predictors of parent advocacy, Ewles, Clifford, and Minnes (2014) purported that (a) little is known about the factors that contribute to parent advocacy, and (b) little is known about the factors that increase the likelihood of successful advocacy among parents of children with ASD. Their findings suggest that parents require better education and training to increase their understanding of service delivery for children with ASD, and consequently, their ability to advocate effectively. Efforts to address this need for parent-training have been reflected in a few parent advocacy trainings such as the Special Education Advocacy Training (SEAT; COPAA, 2016), the Volunteer Advocacy Project (VAP; Burke, 2013), and the Latino Parent Leadership Support Project (LPLSP; Burke, Magaña, Garcia, & Mello, 2016).

Though definitions vary, a core theme among definitions of advocacy suggests that it is an active exercise of *empowerment* that contributes to problem-solving and developing solutions (Munro, 1991). Some of the early work around empowerment among parents suggests that it is a central goal in the efforts to access and improve services for children with disabilities (Koren, DeChillo, & Friesen, 1992). Specifically, empowerment refers to an individual's ability to develop a sense of power and demonstrate an ability to influence the environments that affect

peoples' lives (Koren et al., 1992). Therefore, empowerment is viewed as a prerequisite to effective advocacy.

Communication has been identified as a facilitator for effective partnerships between parents and professionals (e.g., Azad & Mandell, 2015; Pearson & Meadan, in press).

Communication is also one of the recommended practices in effective service delivery for students with disabilities (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). In many cases, effective family-professional partnerships help to facilitate parents' advocacy efforts (Burke & Goldman, 2015; Pearson & Meadan, in press), however, these partnerships require open communication between parents and professionals. Azad and Mandell (2015) suggest that one of the reasons parents and teachers do not bring up concerns regarding children with ASD is because they do not feel well prepared to communicate with each other. Given the importance of communication as a component of effective family-professional partnerships, Azad and Mandell (2015) recommend that future intervention efforts focus on targeting parent-professional communication as one way to better address the needs of children with ASD.

Finally, in regards to advocacy and empowerment among African American families in particular, Whitley, Kelley, and Campos (2011) suggest that the history of social discrimination among this population of caregivers has intensified the need to explore their feelings of empowerment because these sociocultural experiences shape caregiving behaviors. While previous work has explored and highlighted the successes of parent advocacy and empowerment training programs among primarily European American populations (e.g., Goldman, Burke, Mason, & Hodapp, 2016) and among Latino populations (e.g., Burke et al., 2016), no known parent-advocacy training programs have been designed specifically to address the needs of African American parents of children with ASD, to date. A culturally responsive parent-

advocacy training program designed specifically for African American families has the potential to increase parents' knowledge of ASD, strengthen communication and partnerships with professionals, strengthen empowerment, and strengthen parents' advocacy efforts in the ASD community (Pearson & Meadan, in press). Research findings have demonstrated the effectiveness of parent advocacy training programs such as the VAP and LPLSP (Burke, 2013; Burke et al., 2016); however, there still exists a dearth of research that (a) highlights African American parents' experiences with advocating for their children and (b) aims to address the needs related to advocacy and empowerment among African American parents of children with ASD.

Purpose and Research Questions

The purpose of this study was to (a) understand African American parents' experiences with advocacy and (b) to develop and pilot an advocacy and empowerment program entitled FACES (Fostering Advocacy, Communication, Empowerment, and Support) for African American families of children with ASD. This study was guided by the following research questions:

1. What experiences do African American parents of children with ASD have with advocating for services?
2. Does the FACES program increase empowerment in African American parents of children with ASD?
 - 2a. Does the FACES program increase parents' knowledge of ASD?
 - 2b. Does the FACES program increase parents' understanding of and confidence in implementing social communication strategies?
 - 2c. Does the FACES program increase parents' understanding of and confidence in managing behavior?
 - 2d. Does the FACES program increase parent-professional communication and partnership as reported by parents?

- 2e. In what ways and to what extent does the FACES program strengthen parents' perceptions of their ability to advocate effectively for services for their children with ASD?
3. How do African American parents of children with ASD perceive the social validity of the goals, procedures, and outcomes of the FACES program?

Theory of Change

This mixed method study was comprised of pre/post focus groups and pre/post surveys. It predicted that after completing the FACES program, participants would demonstrate three outcomes: the predicted proximal outcomes for parents included (a) increased knowledge of ASD, (b) increased understanding and confidence in implementing social communication strategies, and (c) increased understanding and confidence in managing behavior. The secondary predicted outcomes for parents included (a) strengthened positive perceptions of parent-professional partnerships, (b) strengthened perceptions of empowerment, and (c) strengthened perceptions of their ability to advocate effectively for their children with ASD. The predicted distal outcomes included (a) increased access to services for children with ASD as a result of parent advocacy, (b) improvements in social communication and behavior of African American children with ASD, and (c) improvements in parents' overall satisfaction with their parenting practices and family quality of life. This study will highlight proximal outcomes, only (i.e., parent outcomes). The theory of change is illustrated in Figure 1.

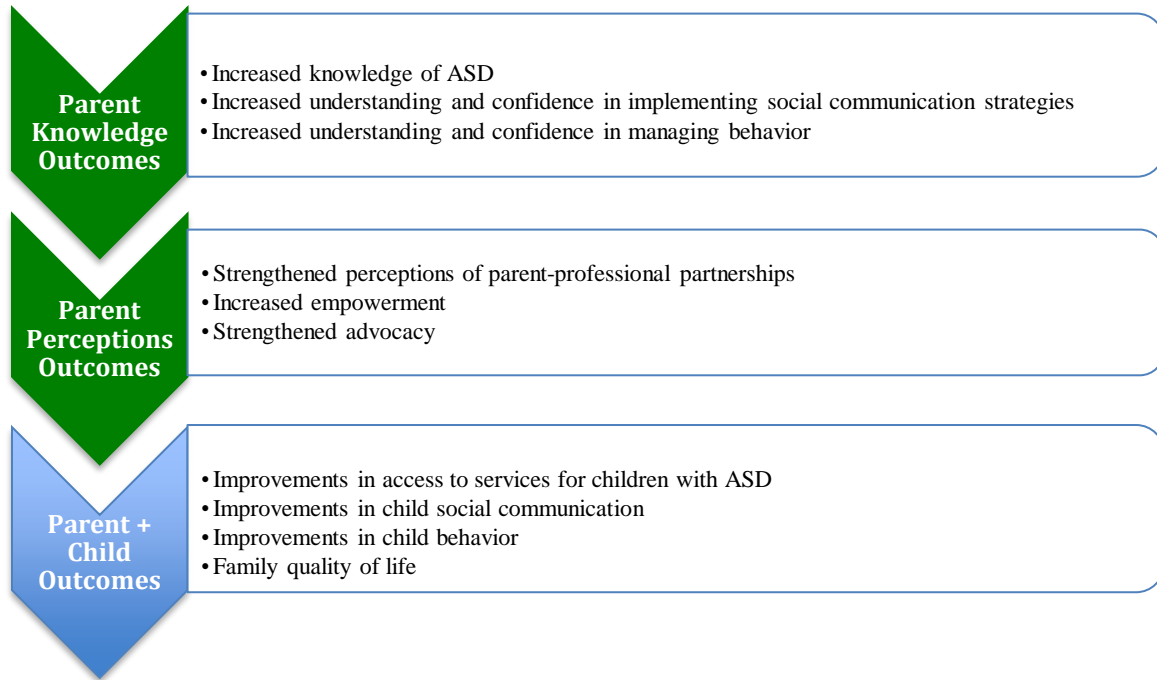


Figure 1. FACES Theory of Change.

As demonstrated in Figure 1 above, I hypothesized that the FACES program would improve parent knowledge outcomes related to ASD, social communication, and behavior management. I also hypothesized that FACES would strengthen parents’ perceptions of outcomes including: empowerment, advocacy, and parent-professional partnerships.

In Chapter 2, I review the literature that informed the development of FACES. In Chapter 3, I describe the methodologies that were employed in this study (e.g., pre/post surveys, pre/post focus groups) and how I mixed the methodologies both for development and evaluation of FACES. In Chapter 4, I present the results of the study. In Chapter 5, I discuss the findings, limitations, and implications of this study.

Chapter 2

Review of Literature

Since the 1980s, the prevalence of ASD among 8-year-old children in the United States has risen from an estimate of one in every 2,000 children to one in every 68 children (CDC, 2016). Given the importance and impact of early intervention on addressing the needs of young children with ASD (Bruder, 2010; Irving et al., 2012), the early childhood years are critical for both identification and for initiating early intervention services (Boyd et al., 2010). However, many African American and Latino children with ASD are not identified until school age or later (e.g., Hilton et al., 2010; Magaña, Parish, & Son, 2015; Mandell et al., 2009). Parents, caregivers, and families (more generally) are key stakeholders in navigating and facilitating the implementation of services for school-age children with ASD (Bruder, 2010; Irvin et al., 2012).

While research findings have demonstrated the importance and positive outcomes of advocacy and empowerment studies among families of other racial and ethnic groups, what we know less about are the needs and experiences of African American parents of children with ASD around advocacy and empowerment. To better understand the need for advocacy and empowerment training for African American parents of children with ASD, it is necessary to first understand the experiences of African American families of children with ASD. It is also critical to (a) understand factors that have contributed to differential diagnoses and access to services among this population, (b) learn more about factors that act as facilitators to obtaining needed services, and (c) gain knowledge of existing parent training models. Differential diagnoses are defined as, “rates and timing of diagnoses of ASD in African American children that are less than, or more delayed than those of European American children” (Pearson, 2015). The length of time to diagnosis among African American children has been attributed to

culturally insensitive service delivery (Gourdine et al., 2011), practitioners' limited knowledge of ASD, and stigma attached to disability in the African American community (Burkett, Morris, Manning-Courtney, Anthony, & Shambley-Ebron, 2015; King & Bearman, 2009; Liptak et al., 2008; Mandell, Novak & Zubritsky, 2005).

We know that families of children with ASD are essential partners in the education process; the roles and importance of family-school partnerships have been highlighted in both legislation (e.g., Individuals with Disabilities Education Act; Every Student Succeeds Act) and professional educational organizations (e.g., Autism Society of America; Council for Exceptional Children). These family-school partnerships can lead to more effective intervention implementation, more positive parent-professional relationships, and more positive child outcomes (Azad & Mandell, 2015). To better understand the needs of families of children with ASD and the importance of advocacy and empowerment among African American parents, this review of literature will focus on: (a) social communication and behavior in children with ASD, (b) available services for children with ASD and their families, and (c) ASD in African American children. Then, I will describe the conceptual model (Figure 2) that led to the development of the FACES program. Using the conceptual model as a guide, the second half of this review will explore (d) empowerment as a prerequisite for advocacy, and (e) advocacy and partnerships as parenting practices that are critical for gaining access to services and supporting the social-communicative and behavioral needs of African American children with ASD.



Figure 2. FACES conceptual model.

Social Communication and Behavior in Children with ASD

Social communication. We know that the core features of ASD include (a) impairments in social communication and social interaction across contexts, and (b) restrictive, repetitive patterns of behavior (CDC, 2016). Researchers have estimated that 25-30% of children with ASD have fewer than 20 functional spoken (or augmented) words (Tager-Flusberg & Kasari, 2013). Moreover, many children with ASD demonstrate a combination of communication challenges (e.g., joint attention, awareness of others) that make it difficult for parents to develop and maintain high quality interactions that influence both the quantity and quality of learning opportunities for their children (Luyster & Lord, 2009; Shire et al., 2015). Researchers from the Marcus Autism Center suggest that even among children with ASD and an IQ above 70, African American children have poorer language and communication skills than European American children. They believe these findings are implications of delayed diagnoses and inaccessibility to early and effective behavioral treatments among African American children with ASD

(Wright, 2016). Given this challenge, it is important that family members understand terminology related to social communication so they are better prepared to collaborate and effectively address it. Although engaging in evidence-based, parent-implemented communication interventions can be challenging, parents are integral in facilitating the development of children's communication skills because they have the unique ability to influence their child over many years (Shire et al., 2015). Therefore, it is important that family members develop an understanding of and confidence in implementing social communication strategies.

Behavior. Behavior is defined as anything a person does that can be observed and measured (Cooper, Heron, & Heward, 2007). Definitions of challenging behavior are varied, however, these behaviors can include, but are not limited to: being withdrawn, aggressive, and hyperactive (Maskey, Warnell, Parr, Le Couteur, & McConachie, 2013). More specifically, researchers define severe challenging behaviors as those that include aggression, self-injurious behavior, and violent tantrums (Durand & Carr, 1989). One of the biggest obstacles that families face when trying to address challenging behavior is the unfamiliarity with the terminology of behavioral interventions. Given this challenge, it is important that family members understand terminology related to challenging behavior and behavior interventions so they are better prepared to collaborate and effectively address it (Meadan, Ayvazo, & Ostrosky, 2014).

To better understand and address challenging behavior, we rely on four key assumptions: (a) human behavior is functional and serves a purpose; therefore, problem behavior also serves a purpose; (b) human behavior communicates; therefore, problem behavior has communicative intent; (c) human behavior is predictable and can be triggered by environmental conditions (e.g., related to context), and (d) human behavior is changeable—if we understand the function,

predictors, and consequences of the problem behavior, we can develop appropriate interventions (Crone & Horner, 2003). In many cases, children with ASD exhibit behavior repertoires that can have negative impacts on family members (Hastings et al., 2005). Therefore, it is critical for family members to have knowledge and understanding of behavior management strategies.

Services for Children With ASD and Their Families

Over the years, the increased prevalence of ASD has heightened the need for more educational and therapeutic services and interventions for individuals with ASD (Wong et al., 2014). In many cases, however, services for individuals with ASD have been described as limited, inaccessible, and costly (Dymond, Gilson, & Myran, 2007; Irvin et al., 2011).

The first component of gaining access to interventions and services begins with a referral for a screening to determine if the child is eligible for further evaluation under the Individuals with Disabilities Education Act (IDEA; Bruder, 2010). Diggle and McConachie (2002) found that although children with ASD can pose significant challenges within their families, when these families have access to and are able to implement early intervention services and practices for their children, it aids in their children's development and progression. Furthermore, families benefit from the support they receive throughout the intervention process (Bruder, 2010).

For families of children with ASD, a number of evidence-based practices have been identified that fall within two classifications: focused intervention practices and comprehensive treatment models (CTMs; Wong et al., 2014). Focused intervention practices aim to achieve specific behavioral or developmental outcomes for children with ASD. Some examples of focused intervention practices include prompting, reinforcement, discrete trial teaching, and peer-mediated interventions. Many of these practices are components of CTMs (Odom, Boyd, Hall, & Hume, 2010).

CTMs are comprised of a set of practices that are designed to achieve broader learning goals, and to address the core deficits associated with ASD (Odom et al., 2010). These types of interventions have been in existence for more than 30 years, although new models continue to be developed. CTMs are typically more intensive (e.g., 25 hours per week), occur over longer periods of time (e.g., one or more years), and they usually have multiple components. Some examples of CTMs include the Lovaas Institute (i.e., applied behavior analysis [ABA]), Treatment and Education of Autistic and Communication Handicapped Children (TEACCH), and the Denver Model (Odom et al., 2010).

In their work on the need for services among parents of children with ASD in Virginia, Dymond et al. (2007) found that of the 886 parents of children with ASD in their study, many of them requested services that mirrored the evidence-based practices described by Wong et al. (2014). The most frequently parent-requested service for ASD was ABA. Other examples of services requested by parents include speech therapy/communication training, respite care, social skills groups, early intervention, sensory integration therapy, and recreational activities. While the types of services requested varied across parents, Dymond and colleagues found that one of the factors that parents believed negatively impacted their ability to obtain services was delayed diagnosis or misdiagnosis of ASD. Therefore, even when services are available for children with ASD, the children are not always eligible for these services due to delayed identification. Given these findings, it is important that family members have knowledge of ASD and services for both children with ASD and their families.

Disparities in Diagnoses

In their most recent community report on ASD, the CDC highlights that while African American children do not have a lower risk of developing ASD than European American

children, the data show that they are less likely to be identified with ASD (CDC, 2016). The exact reasons for this disparity are unknown; however, findings suggest that stigma, lack of access to healthcare services, and low-income may be factors that influence ASD identification in African American children.

Findings have also indicated that socioeconomic status plays a role in the accessibility of healthcare and intervention services for families of children with ASD (Kogan et al., 2009; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Although low socioeconomic status impacts families across racial and ethnic groups, this phenomenon is particularly relevant for African American children. In 2010, 38.2% of African American children under the age of 18 were living in poverty (U.S. Census Bureau, 2013). Research findings, however, indicate that even among African American families who were not living in poverty, children with ASD were misdiagnosed, or diagnosed years after the onset of symptoms (Gourdine et al., 2011; Sansosti, Lavik, & Sansosti, 2012). Recent reports based on presentations from the 2016 International Meeting for Autism Research (IMFAR) corroborated these findings by highlighting the diagnosis gap between African American and Hispanic children, and European American children. Researchers reported that the impact of socioeconomic statuses of European American children is starting to fade, but not among African American children. Researchers suggest that these findings “might mean that some disparities in diagnosis stem from racial differences that are independent of socioeconomic status” (Wright, 2016).

The CDC has emphasized that there is a need to target strategies that increase awareness of ASD among African American (and Latino) families, and to help families address these barriers so that African American and Latino children are evaluated and diagnosed at earlier ages (CDC, 2016). Given the misdiagnoses and late identification of ASD in African American

children (e.g., CDC, 2016; Mandell et al., 2002; Wright, 2016; Yee, 2016), research has pointed to a need for (a) parent training to increase knowledge and awareness of ASD in the African American community and (b) resources to help parents advocate for the services and supports their children need (Azad & Mandell, 2015; Burkett et al., 2015; Pearson & Meadan, in press; Zuckerman et al., 2013).

FACES Conceptual Model

Ecological systems theory. Since the 1970s Bronfenbrenner's ecological framework for human development has shaped how we situate relationships and interactions within both community contexts and broader societal contexts (Bronfenbrenner, 1994). The Ecological Systems theory suggests that different types of environmental systems influence human development, and, these external influences have an effect on the degree to which families are able to foster healthy development of their children (Bronfenbrenner, 1986). Bronfenbrenner's ecological systems theory includes four levels of environmental systems that shape human development: microsystems, mesosystems, exosystems, and macrosystems. Bronfenbrenner described the microsystem as a developing person's immediate environment that includes activities, social roles, and interpersonal relations. Settings for this context can include families, schools, peer groups, and workplace environments. The mesosystem is a collection of microsystems that links two or more settings from the microsystem. The exosystem comprises linkages between two or more settings; however, in the exosystem at least one of the settings is indirectly influenced because the immediate person does not play a role in that setting. The macrosystem comprises the overarching pattern of micro-, meso-, and exosystems; the macrosystem is thought of as the societal blueprint for an individual's culture or subculture (Bronfenbrenner, 1994).

Developed based on the Ecological Systems theory design, the FACES conceptual model seen in Figure 2 includes three systems that, together, influence child-centered outcomes and family quality of life. The outer most layer of the model represents the *intersectionality* of African American parents of children with ASD; I refer to this as the macrosystem. The second layer (i.e., arrows) represents constructs that are fluid, interconnected, and influenced by the relations between multiple settings within the microsystem (e.g., relations between family and school); I refer to this as the mesosystem. Empowerment, partnership, and advocacy represent parenting practices; I refer to this level as the microsystem because parenting practices include both social roles *and* interpersonal relations (Bronfenbrenner, 1994). Two central parenting practices that are critical elements of accessing services for African American parents of children with ASD include advocacy and partnerships (Pearson & Meadan, in press). The core of the model represents African American parents' engagement in practices that promote positive child outcomes, and increased family quality of life. The aim of the FACES conceptual model is to represent through an ecological systems lens, the complexity of identity, ability, advocacy, empowerment, and parenting practices that ultimately shape child outcomes for African American children with ASD.

Identity and intersectionality. The macrosystem of the FACES model is referred to as identity and intersectionality because it forms the blueprint for individuals' culture. Given the identified barriers related to culture, race, and diagnoses of ASD, I have also drawn from a Critical Race Theory (CRT) lens to develop a parent-training program that supports the empowerment of African American parents of children with ASD.

The greater the stigma attached to an ethnic group, the more difficult it is for mainstream professionals to recognize cultural strengths that are different from their own. This has been the case for African Americans, whose loss of their original languages, customs, and

religions rendered them, to all appearances, a group without a culture. (Harry, 2002, p. 132).

Historically, African American students in special education have been overrepresented in learning disability and emotional behavioral categories, and placed in segregated (i.e., self-contained) classrooms. Moreover, Artiles (2011) argues that disproportionality in special education illustrates “an interesting paradox in the racialization of disabilities” because “the civil rights response for one group of individuals (e.g., learners with disabilities) has become a potential source of inequities for another group (e.g., racial minority students) despite their shared histories of struggle for equity” (p. 431). Researchers have noted that the history of these discriminatory practices have had a negative impact on African American parents’ relations with and perceptions of the special education system (Boyd & Correa, 2005). As a result, African American parents have demonstrated a pattern of less participation in special education procedures (Harry, 1992) and less participation in special education advocacy efforts (Harry, Allen, & McLaughlin, 1995).

Critical Race Theory. CRT emerged as a movement in the mid 1970s when lawyers, activists, and scholars realized that many of the advancements of the Civil Rights era were regressing (Delgado & Stefancic, 2012). CRT provides a critical, interdisciplinary analysis of race and racism, and, while the theory has a number of tenets, one of the overarching tenets is that racism is engrained in the fabric and system of the American society (Delgado & Stefancic, 2012). Delgado et al. (2001) argue that intersectionality within CRT highlights multidimensional oppressions, and it also recognizes that race alone cannot account for disempowerment. In other words, “intersectionality means the examination of race, sex, class, national origin, and sexual orientation, and how their combination plays out in various settings” (Delgado et al., 2001, p. 51). The intersectionality of African American parents (e.g., mothers or fathers, single

parents, co-parents, individuals with and without disabilities, colleagues in various work settings) contributes to their experiences, identities, and how they view themselves within the context of an ecological model.

McKay (2010) suggested that for many years, African American community education has extended beyond the formal classroom as a means for adults to counter the master narrative, recover silenced consciousness, and affirm their identities by empowering learners to acquire skills they need to assess and address injustices. In education research, the use of voice is critical because it conveys the participants' thoughts, feelings, desires, and politics (Dei, 2005). It is also important to note that "identities are not only multiple and intersecting, but also gendered, racial, historical, and social constructs" (Berry, Jay, & Lynn, 2010). Similarly, in her work around diverse approaches to parent advocacy, Trainor (2010) discusses the role of cultural and social capital in advocacy approaches, and in gaining access to information. Consistent with the work by Berry et al. (2010) around intersectionality, Trainor suggests that factors such as race/ethnicity, socioeconomic status, and disability interact in unique ways; as a result, those factors that influence parents' approaches to advocacy are often difficult to identify and understand. The FACES model does not operate within a deficit paradigm as it relates to race; rather the underlying foundation for FACES program is a critical theory (i.e., CRT) that highlights the systemic inequalities that perpetuate disparities among people of color. The FACES program is aimed to provide participants with skills (e.g., advocacy, partnerships, resources) that might better equip African American parents of children with ASD to overcome systemic inequality.

Empowerment

Advocacy is an active exercise of *empowerment* that contributes to problem-solving and developing solutions (Munro, 1991). Therefore, it is important to consider the role of empowerment in African American families of children with ASD. Family empowerment has long been viewed as a central goal of the efforts to improve services for children with disabilities and their families (Koren, DeChillo, & Friesen, 1992). Family empowerment emerged as a construct rooted in the consumer, practice, and research communities. Within the consumer movement, empowerment was represented by (a) self-help and self-reliance, (b) a focus on family strengths rather than deficits, and (c) embedding family values within public policies and programs (Koren et al., 1992). Empowerment as a construct is often associated with a development of power and having the ability to influence the environments that affect peoples' lives (Koren et al., 1992).

In many cases, families of color encounter various forms of social stigma and discrimination when navigating the service system. One method to help combat these experiences is through engaging families of color in empowerment practices that could help them recognize their personal strengths and efficacy for positive change in their lives and in their children's' lives (Whitley et al., 2011). Empowerment practices are particularly important for parents of children with disabilities because without parents' involvement, students with disabilities are likely to face both inadequate and inappropriate services (Burke, 2013).

Previous work around empowerment defines empowerment practice as “a method to help marginalized families gain a sense of control over their life circumstances” (Whitley et al., 2016, p. 383). Empowerment practice helps reduce the feeling of powerlessness that inhibits marginalized families from taking appropriate action to resolve problems. When parents feel

empowered they are more likely to advocate for their children and families' needs. On the other hand, when parents feel powerless and defeated they are unable to advocate successfully for their children and families. Exploring empowerment among African American caregivers is particularly important because of the social injustices that make them more susceptible to vulnerability as caregivers (Whitley et al., 2011).

In our previous study (Pearson & Meadan, in press), each of the 11 participating mothers completed the revised Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) prior to completing their interviews. Findings indicated that the overall family empowerment scores ranged from 57.0 to 135.0 (highest possible total score) and the average *total* empowerment score across the sample was 108.36. Similarly, the median total empowerment score was 109.0. The descriptive statistics from the FES indicate that parents' perceptions of empowerment were considerably high, though their experiences with advocacy as documented through qualitative data, were varied.

During the interviews, some participants used a large number of "I" and "we" statements that strongly emphasized their sense of empowerment as it related to obtaining services for their children. One participant scored the maximum score of 135 on the revised Family Empowerment Scale. During the interview, she shared experiences that demonstrate, qualitatively, a strong sense of family empowerment:

My husband and I, we've definitely learned that *we* are going to be our daughter's biggest advocate. We really come in the leadership roles and *we* are the ones who are going to make the decisions for our daughter. I think if *we* weren't pushing and pulling and letting them know what we expect, I don't think they would do as much as they do. *They know we have the expectation and we know our rights and we know what our daughter needs.*

Other participants shared experiences that reflected much lower empowerment. One of the participants had a total empowerment score of 57 on the FES. In reference to her experiences

with educators and administrators during her son's IEP meetings she said, "Sometimes I am just there as a formality I think, because *I have no clue what they are talking about.*" She went on to explain:

Usually I just kind of sit there and they say, "well this is what we are going to offer him. This is how it's going to be." A lot of times I have no clue what they are talking about; sometimes it makes me feel like I don't know my own child because *I don't know what he needs. I don't know how he learns.*

Many mothers scored greater than 100 on the FES; during the interviews, these parents were also more likely to share their positive experiences with advocating for their children's needs. Conversely, mothers who scored below 100 on the FES were more likely to identify challenges with parent-professional partnerships, and limited knowledge of ASD as barriers to their ability to advocate effectively. These findings, along with the highlighted importance of empowerment in the literature, indicate that African American parents of children with ASD can potentially benefit from training that focuses on increasing their perceptions of empowerment.

Parenting Practices

Advocacy. Given the complexity of ASD, and the challenges of accessing early intervention, school-based services, and other related services, children with ASD demonstrate a great need for parent advocacy (e.g., Cohen, 2009; Mueller & Carranza, 2011; Wright & Taylor, 2014). Families from underrepresented backgrounds present an even greater need for parent advocacy because they are often combating additional barriers such as low socioeconomic status and inadequate and culturally insensitive service delivery (Mandell et al., 2007).

In the early literature, advocacy was described as speaking and acting on behalf of another person or a group of people to help address their needs (Wolfensberger, 1977). More specifically, effective advocacy has been defined as "a non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction

and contribute creative solutions to problems existing in human service systems” (Munro, 1991, p. 1). A more recent definition of advocacy specific to ASD describes it as “any action taken by a parent on behalf of their child or other children with ASD to ensure adequate support, proper level of care, and basic human rights” (Ewles et al., 2014, p. 74). Finally, the Council of Parent Attorneys and Advocates (COPAA) defines advocates as individuals who actively negotiate for the needs of others (COPAA, 2016).

Advocacy in special education can include a number of activities performed by parents on behalf of their children (Burke & Hodapp, 2016). IDEA legislation includes requirements that educators form partnerships with parents and assist them in (a) understanding the nature of their child’s disabilities and needs, (b) communicating effectively and working collaboratively with special education and related service team members, and (c) participating in the development of and decision-making processes for individualized education programs (IEP; IDEA, 2004).

In our previous study, participants discussed a number of facilitators that positively shaped their experiences with gaining access to services (Pearson & Meadan, in press). Two “facilitating” approaches that have been identified as effective strategies for gaining access to services include advocacy and partnerships/communication. One of the most fundamental ways that mothers were able to gain access to services for their children was through advocacy. Parent advocacy was a primary theme that was echoed throughout a number of interviews as a strategy to provoke action and attention to their child’s needs. One mother shared the following:

We were able to advocate to get her [instructional assistant] to continue to be with our daughter and we even had to be specific in what we wanted to put in her IEP. They didn’t want to put personal aid. They wanted to put classroom aid and we had to say, “I am sorry, we weren’t born yesterday. We know the difference and we want a personal aid who is specifically for our daughter not somebody that you can pull and do whatever you need.”

Existing advocacy training models. Three examples of current special education advocacy training models include the Special Education Advocacy Training (SEAT; COPAA, 2016; Wheeler & Marshall, 2008 as cited in Burke, 2013), the Volunteer Advocacy Project (VAP; Burke, 2013), and the Latino Parent Leadership Support Project (LPLSP; Burke, Magaña, Garcia, & Mello, 2016). The SEAT project began in 2005 with a purpose of developing curriculum to train special education advocates to better meet the needs of individuals with disabilities and their families. The SEAT training was piloted in three different areas across the country and included competencies such as an introduction to special education advocacy, foundation of special education law, principles and components of special education law, practicing advocacy with ethics and integrity, skills of a special education advocate, conflict resolution in special education, and the business of advocacy. The SEAT curriculum is comprised of 115 hours of classroom instruction and at least 40 hours of field experiences (COPAA, 2016). Findings from the SEAT training indicate that (a) the rigor and time commitment may discourage underrepresented groups from participating and (b) more formative and summative evaluations are needed to examine the effectiveness of the SEAT trainings (Burke, 2013).

The VAP was developed to address the need for special education advocates across the state of Tennessee, and was adapted to meet the needs of families in Tennessee based on the Parent Leadership Support Project (PLSP). The VAP is unique in that one criterion for admission is that each graduate from the project must agree to advocate for four additional families of students with disabilities at no charge. The VAP training teaches participants about federal and state laws, timelines associated with evaluations, IEPs, procedural safeguards, and eligibility requirements. In addition, participants learn about ways to engage in effective

communication approaches with schools, and they also learn about effective modes of providing emotional support for parents of children with disabilities (Burke, 2013). The VAP is delivered during 40 hours of face-to-face training, in addition to take-home readings and homework assignments. Preliminary findings from the VAP study indicate that parents demonstrated significant improvements in both their perceptions of special education knowledge and advocacy skills (Burke, Goldman, Hart, & Hodapp, 2016).

Finally, the LPLSP is an advocacy training for Spanish-speaking families of children with ASD. The LPLSP was developed based on the VAP, and adapted to meet the needs of Latino parents of children with ASD. The LPLSP is a 36-hour training that is delivered across nine training sessions. The trainers for the LPLSP include an attorney and an advocate, both of whom are also parents of children with ASD. The findings from this study indicated that, based on high participant attendance, low attrition, and participant satisfaction (based on formative and summative evaluations), the LPLSP was feasible for Latino families of children with ASD. Following the training, preliminary findings indicated that the LPLSP group demonstrated significantly greater knowledge of special education and significantly greater levels of family empowerment than did the control group (Burke et al., 2016).

Advocacy in African American families. Family and professional partnerships are one of the recommended practices in effective service delivery for students with disabilities (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Findings have indicated that advocacy efforts are often facilitated by effective family-professional partnerships (Burke & Goldman, 2015; Pearson & Meadan, in press). Few studies however, have explored the advocacy efforts among African American parents of children with disabilities. To my knowledge, only one study to date has explored the advocacy efforts of African American mothers of children with

disabilities. In her qualitative inquiry (i.e., semi-structured interviews), Stanley (2015) explored the advocacy experiences of low-income African American mothers of children with disabilities in rural special education. Based on the interview data from 12 African American mothers who participated in the study, Stanley found that mothers defined advocacy as something that (a) begins early, (b) looks different, (c) includes locating and utilizing community resources, (d) includes ongoing communication within schools, (e) is doing what it takes, and (f) is being visible. The mothers often identified educator and administrator characteristics that made them feel more empowered to advocate. Overall, mothers believed that it was the open communication, validation of feelings, care, and mutual trust that facilitated their advocacy efforts (Stanley, 2015).

Partnerships. Given the nature and impact of ASD on individuals' functioning in both home and school environments, parent participation in both educational planning and service delivery is critical (Azad & Mandell, 2015). Azad and Mandell classify family-school partnerships as those that include parents in service delivery, parent-professional partnerships, family-centered care, family centeredness, and family/parent involvement.

In a study that measured the quality of healthcare relationships among families of children with ASD and developmental disabilities, Magaña et al. (2015) found that African American and Latino parents were less likely than European American parents to report that their healthcare provider was sensitive to their family's customs and values, less likely to listen carefully to their concerns, and less likely to help them feel like a partner. African American mothers in particular, have suggested that partnership and open communication are the most important ingredients in special education advocacy (Stanley, 2015). Partnerships were also a key facilitator that emerged in our previous study around African American parents' experiences

obtaining diagnoses and gaining access to services for their children with ASD (Pearson & Meadan, in press). Findings from this study indicated that the development of collaborative partnerships between the parents (i.e., mothers) and educators, service providers, and healthcare providers was a facilitator for gaining access to services. Of the 11 mothers who participated in this study, six discussed the partnerships they developed and the impact that these partnerships had on their experiences. One participant said, “I appreciate the fact that they actually listen to us as parents because we have earned their respect; because we are educated and we are well-informed, they listen.”

Another participant shared her experiences with a teacher who did not have any previous experience teaching children with ASD. Over time however, she was able to develop a partnership with him that led to more collaboration and positive outcomes. She said:

The teacher he tried . . . he went to different seminars about autism. So, he was trying to educate himself. He tried his best and even I would meet up with him. He would text me all the time and I would text him. And, when J [child’s name] forgets his homework he takes a picture of it and text it to me. (Pearson & Meadan, in press)

Implications

Based on the findings of this review of literature, we know that African American children are less likely to be diagnosed with ASD than European American children (CDC, 2016), more likely to have poorer language and communication skills than European American children, and more likely to face delayed diagnoses, even across socioeconomic statuses (Wright, 2016). Moreover, minority families often miss out on treatments and, in many cases, are left out of autism research (Yee, 2016). Findings related to racial and ethnic disparities in autism research indicate that there are broad socioeconomic, cultural, and language barriers that limit minority families’ participation in studies and navigation of treatment options (e.g., Hilton et al., 2010; Wright, 2016; Yee, 2016). Based on these findings, future studies should (a) implement

new methods of recruiting and retaining minorities in research, and (b) develop better screening, support, and treatment programs to help bridge the gap between minority and majority populations in autism research.

In terms of parent advocacy and empowerment, findings indicate that (a) parent education and training programs are vehicles that can contribute to increased feelings of control and support for parents of children with ASD (Meadan, Halle, & Ebata, 2010), and (b) parent-advocacy trainings have been successful in increasing advocacy, knowledge, and empowerment among both minority (Latino) and non-minority populations (Burke et al., 2016). Therefore, there is a need for research that evaluates potential solutions for effective parental advocacy and involvement for children with disabilities (Burke, 2013). One such resource might include intervention studies that are designed to address barriers that parents of children with disabilities face in advocating for their children.

To date, there are no advocacy and empowerment trainings designed to meet the unique needs of African American parents of children with ASD. However, given the feasibility and effectiveness of parent advocacy training programs such as the LPLSP (Burke et al., 2016), we know that parent-training interventions designed to address the specific needs of culturally diverse populations can increase parents' feelings of empowerment and knowledge of advocacy skills. We also know that the most effective parent-training interventions are often those that include a combined focus on changing children's behavior *and* parents' well being (Meadan et al., 2010). Therefore, given the need for increased availability of and access to support services for minority families of children with ASD (Mandell & Salzer, 2007; Meadan et al., 2010; Pearson, 2015), the FACES program has the potential to fill an area of need. The FACES program has the potential to (a) increase knowledge and awareness of ASD in the African

American community and (b) serve as a resource to help parents feel more empowered to advocate for the services and supports their children need most.

Chapter 3

Methods

Overview

The purpose of this study was to (a) better understand experiences related to advocacy and empowerment among African American parents of children with ASD, and (b) develop and pilot the FACES (Fostering Advocacy, Communication, Empowerment, and Support) Program.

This study was guided by the following research questions:

1. What experiences do African American parents of children with ASD have with advocating for services?
2. Does the FACES program increase empowerment in African American parents of children with ASD?
 - 2a. Does the FACES program increase parents' knowledge of ASD?
 - 2b. Does the FACES program increase parents' understanding of and confidence in implementing social communication strategies?
 - 2c. Does the FACES program increase parents' understanding of and confidence in managing behavior?
 - 2d. Does the FACES program increase parent-professional communication and partnership as reported by parents?
 - 2e. In what ways and to what extent does the FACES program strengthen parents' perceptions of their ability to advocate effectively for services for their children with ASD?
3. How do African American parents of children with ASD perceive the social validity of the goals, procedures, and outcomes of the FACES program?

I hypothesized that the FACES program would (a) improve parent knowledge outcomes related to autism, social communication, and behavior management, and (b) strengthen parents' perceptions of empowerment, advocacy, and parent-professional partnerships. I employed a complementary, sequential mixed-methods design (Greene, 2007) to address the research questions. The two different research methodologies employed in this study included pre-post

intervention surveys, pre-post intervention focus groups, formative and summative evaluations, and participant testimonials. The purposes for mixing methods in this study included *development, complementarity/initiation, and triangulation*. The pre-intervention focus group data and formative evaluation data were mixed during data collection and used for further development and refinement of the FACES training to meet the specific needs of this cohort of participants. Following the program, the post FACES survey data, post FACES focus group data, and participant testimonials were mixed during analysis and interpretation to address the research questions (Greene, 2007). In Figure 3, I highlight the scope of this mixed methods design based on the research questions and corresponding data sources.

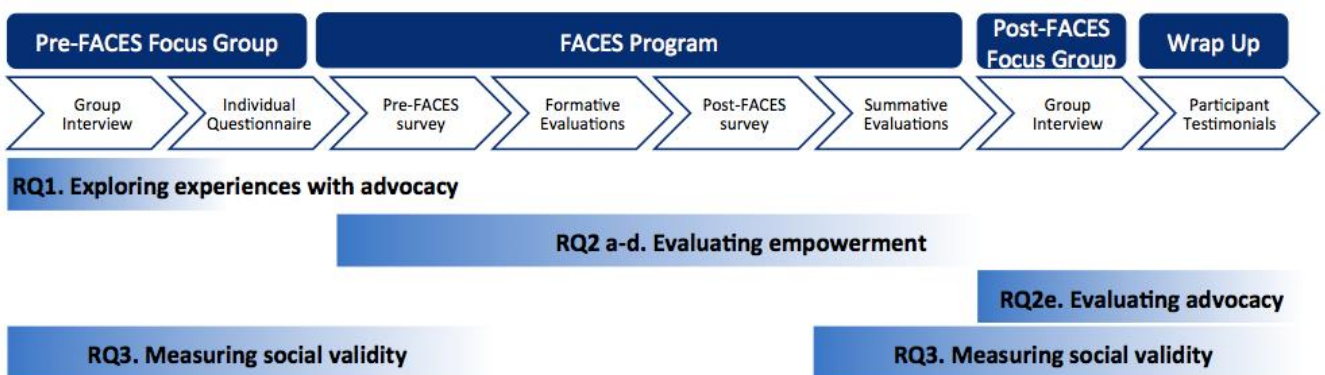


Figure 3. Scope of data collected.

FACES Program Development

Theoretical frameworks. In developing the FACES program, I drew from two theoretical frameworks to inform the scope, structure, sequence, and rationale for the intervention. These two frameworks were Adult Learning Theory and Sociocultural Theory. All FACES participant activities were designed with adult learning principles *and* sociocultural learning theory in mind.

Adult learning theory. Adult learning has been defined in the literature in a number of ways. One definition suggests that adult learning is, “change in behavior, a gain in knowledge or

skills, and an alteration or restructuring of prior knowledge” (Hoare, 2006, p. 68). Other researchers define adult learning as a collection of methods and theories for optimal learning conditions (e.g., Trotter, 2006).

In their review of 79 studies, Trivette, Dunst, Hamby, and O’Herin (2009) coded each study based on the presence of six characteristics of adult learning (introduce, illustrate, practice, evaluate, reflect, master). They suggest that all six adult-learning characteristics are important and associated with positive learner outcomes. In addition, they argued that the more adult-learning characteristics that are included in efforts to teach adults new skills, the more likely these efforts will produce positive outcomes.

Consistent with these adult learning characteristics, the FACES program included (a) *introductions* to new material, knowledge, or practices (e.g., mini lectures with PowerPoint presentation), (b) demonstrations or *illustrations* of the use of the material, knowledge, or skill(s) (e.g., videos, modeling), (c) activities that engaged the learners in the implementation or use of the material, knowledge, or *practice(s)* (e.g., case scenarios, group discussions, think-pair-share), (d) opportunities for participants *to evaluate the outcomes* of the application (e.g., formative evaluations and discussions), (e) opportunities for participants to *reflect* on their learning experiences (e.g., group discussions, think-pair-share), and (f) activities that engaged the participants in *self-assessment* of their knowledge and skills (e.g., multiple choice questions about covered content; formative evaluations).

Sociocultural theory. The second theoretical framework that I drew from in developing the FACES program was the sociocultural theory. Vgotsky and colleagues during the 1920s and 1930s first explored sociocultural approaches to learning and development. Sociocultural approaches are based on three concepts: (a) human activities take place in their cultural context,

(b) human activities are mediated by language and other symbol systems, and (c) human activities can be best understood when investigated in their historical development. Moreover, learning must be situated within cultural-historical context—adult development cannot be understood apart from this because people are not separate from, but a part of the contexts in which they live (John-Steiner & Mahn, 1996).

Within the context of adult learning, pedagogy that is rooted in sociocultural theory emphasizes (a) learners as active participants, (b) observation, collaboration, questioning, and scaffolding, and (c) reflection and discussion (Baumgartner, 2001). Sociocultural theory provides an important theoretical base for the FACES program because a critical part of this program is to provide a space for participants to not only gain knowledge of specific strategies and skills, but also to provide a space for social interactions where participants can engage with each other, share knowledge of resources, share experiences, help brainstorm, and troubleshoot challenges related to their experiences as parents of children with ASD through critical reflection and discussion (Baumgartner, 2001). Together, the adult learning theory and sociocultural theory provide an explanation of *how* we engaged the participants in adult learning, and *why* learning within this cultural context was important.

Researcher reflexivity. As a researcher, it is important to understand the degree to which one's knowledge, background, and experiences can impact the collection and interpretation of data. It is also important for researchers to acknowledge and self-disclose their assumptions, beliefs, values, and potential biases when conducting qualitative research (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Therefore, my background and experiences related to this study are noted here.

My experiences to date have primarily been with diverse families of children with ASD. I have worked in home, school, and community settings as an ABA therapist and program consultant for children with ASD and their families for 6 years. In addition, it is critical for me to consider the intersectionality of my own identity (African American, woman, ABA therapist, etc.) and any potential biases that might have influenced data collection and interpretation (Berry, Jay, & Lynn, 2010). To address the possibility of researcher bias, I kept detailed field notes throughout the research process (i.e., training sessions, focus groups), and I engaged in regular debriefings with the research team to better reflect on the data collection process and my interpretation of the data as it relates to any potential biases.

The research team. The culturally, ethnically, and linguistically diverse research team was comprised of myself, my advisor (Dr. Hedda Meadan), and two graduate student assistants from the Department of Special Education at the University of Illinois. All research team members completed University of Illinois Institutional Review Board (IRB) trainings and were approved as co-investigators on this project prior to data collection.

Participants and Settings

This study was approved by the IRB at The University of Illinois (see Appendix A). The criteria for selecting participants were as follows: (a) a parent or guardian who had a child (ages 3-14) with a primary diagnosis of ASD (verified by the Social Communication Questionnaire), (b) *both* parents/guardians and the child identified as African-American, and (c) at least one parent from each family was willing to participate in the six-week FACES program and complete pre/post focus groups and surveys. Given the complexities of emerging adulthood for teenage mothers (Akella & Jordan, 2011), one exclusion criterion required that participants not be teen mothers (i.e., < 20 years) at the time of the study.

Recruitment. I aimed to recruit African American parents of children with ASD from diverse socioeconomic and educational backgrounds. From August 2016 until October 2016, participants were recruited through local and statewide agencies and community organizations (e.g., parent support groups), in addition to social media sites. Recruitment flyers were disseminated in both electronic and hard copy format (Appendix B). I also employed a *selective* snowball sampling technique (i.e., chose a representative selection of participants to recruit/recommend other individuals who might also meet inclusion criteria).

Phone screening. After identifying parents who were interested in participating, I followed up with them to provide detailed information about the study and to conduct an inclusion phone screening (see Appendix C). During the phone screenings, ASD diagnoses were confirmed by using the Social Communication Questionnaire (SCQ; Berument, Rutter, Lord, Pickles, & Bailey, 1999). The SCQ is a 40-item screening tool for ASD, to be completed by parents, based on the revised Autism Diagnostic Interview (Lord et al., 1994), and has been used widely in both research and practice and has demonstrated sensitivity over time (Chandler et al., 2007). Questions on the SCQ are related to reciprocal social interactions, language and communication, and repetitive and stereotyped patterns of behavior. The SCQ has strong reliability ($\alpha = .90$) and satisfactory differentiation of ASD diagnostic criteria and other diagnoses. The SCQ was not a pre-post measure and was used for screening purposes only. The SCQ was administered via phone and all children ($N= 8$) of participants in this study met the cutoff score of 15.

If, during the screening, parents met all criteria and still expressed interest, I explained that their participation in the study was completely voluntary, any information they shared would be kept confidential, and they could choose to withdraw from the study at any time, for any

reason. Participants were also informed that data collection would include videotaping of the training sessions and audiotaping of the focus groups. Each phone screening took approximately 20 minutes to complete.

Participants. In total, 17 parents contacted me to express interest in the study. All 17 parents participated in the inclusion screening and met inclusion criteria. Thirteen parents enrolled in FACES (i.e., completed the screening and agreed to participate) and began the study (i.e., gave consent). Of the 13 participants who began the study, 10 participants completed all of the study requirements (see Figure 4). All participants provided written consent (see Appendix D) prior to participation. Given the nature of this mixed methods pilot study, all sources of data from all participants were included in the analyses.

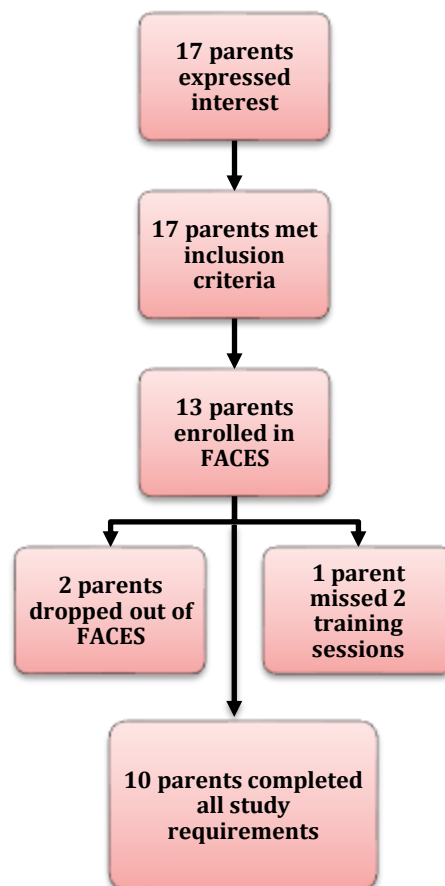


Figure 4. Participant recruitment, inclusion, and retention.

Of the 10 parents of children with ASD who completed all study requirements and met criteria for data analysis in this study, seven participants were mothers, two participants were fathers, and one participant was a grandmother. Participant ages ranged from 36 years to 63 years (mean age = 46.6 years). Eight participants were married (the two father participants were married to two of the participating mothers), and two participants were not married. Based on the seven participants who reported their income, the annual family income (AFI), ranged from \$34,500 to \$165,000 (mean AFI = \$78,357). Additional participant information, including participant scores from the Everyday Discrimination Scale, is presented in Table 1. Note that Alicia, Deborah, and Marva were not included in data analysis because they did not meet the study requirements (e.g., missed more than one FACES session, did not watch the missed session(s) online, did not complete the post-FACES survey).

Children. Of the eight children whose parents participated in the study, seven were male (87.5%) and one was female (12.5%). The children's ages at the time of the study ranged from 3 to 11 years (mean age = 8.25 years). The children's ages at the time of ASD diagnosis ranged from 3 to 10 years (mean age = 5.86 years).

FACES Guests. In addition to the parents who attended the training regularly, four individuals attended at least one FACES session as a guest. Guests included two grandmothers (i.e., Catherine's mother and Marva's mother) and two fathers (i.e., Mary's husband and Alicia's husband). Guests provided informed consent, engaged in group activities and discussions, and completed formative evaluations following the session(s) they attended.

Table 1

FACES Participants

Participant number	Relationship to child	Caregiver age	Marital status	Education	Employment	Family income	# of children	Other children with disabilities	Child gender	Child age	Age at diagnosis	EDS score ^c
Phoebe ^a	Mother	43	Married	A.A.	At home mom	\$34,500	1	No	Male	7	6	45
Luke ^a	Father	36	Married	B.A.	Computer technician	\$34,500	1	No	Male	7	6	41
Janice ^b	Mother	46	Married	B.A.	Accountant	\$100,000	2	No	Male	11	9	44
Chris ^b	Father	48	Married	B.A.	Social worker	\$100,000	2	No	Male	11	9	45
Violet	Grandmother	63	Widowed	Some college	Retired	----	2	Yes	Male	9	--	--
Erika	Mother	50	Single	Some college	Supervisor	\$67,500	1	No	Female	8	6	40
Catherine	Mother	47	Married	B.A.	Healthcare	\$47,000	3	No	Male	11	3	44
Nanci	Mother	39	Married	Some college	Service rep	----	1	No	Male	3	3	45
Tamryn	Mother	48	Married	Some college	At home mom	----	2	No	Male	10	--	45
Mary	Mother	46	Married	Some college	Account executive	\$165,000	2	No	Male	6	4	45
Alicia ^d	Mother	35	Married	B.A.	Community organizer	\$48,000	1	No	Male	3	3	
Deborah ^e	Mother	48	Divorced	M.A.	Teacher	\$85,000	2	Yes	Male	8	4	
Marva ^e	Mother	36	Married	Some college	Safe passage supervisor	\$30,000	2	No	Male	8	3	--

^aParent dyad. ^bParent dyad. ^cEveryday Discrimination Scale; Range 9-45, where lower scores reflect higher perceptions of everyday discrimination. ^dMissed two FACES sessions; completed all other study requirements. Not included in survey data analysis; ^eMissed three or more FACES sessions; did not complete post FACES survey. Not included in survey data analysis.

Settings. All trainings and focus groups were held in group meeting rooms at public libraries in a large Midwestern urban area. The location for each session rotated between three library branches (all within a seven mile radius), depending on the availability of the meeting rooms. Each library provided free and ample parking (e.g., lot or street), and was within one block of public transit systems (e.g., bus or train).

Procedures and Instruments

To investigate African American parents' experiences advocating for services for their children with ASD (RQ1), I conducted pre-intervention focus group interviews with the participants (Krathwohl, 2009). To examine the effectiveness of the FACES program (RQ2), I employed pre and post FACES surveys. Finally, I assessed the social validity (RQ3) of the FACES program through post-intervention focus groups, formative evaluations, summative evaluations, and participant testimonials.

On or before the day of the pre FACES focus group, each participant provided informed consent, and completed the demographic questionnaire, Everyday Discrimination Scale (EDS), and pre FACES survey via UIUC Google form or hard copy, depending on participant preference. During sessions 1-5, participants completed formative evaluations at the conclusion of each training session. On the last day of the FACES program, participants completed the post FACES survey, the summative evaluation, and recorded their testimonials (see Figure 5 for an overview of the study procedures). Participants received a \$75 stipend upon completion of *all* study components (i.e., \$25 following the pre-intervention focus group, \$25 following the six-week intervention, and \$25 following the post-intervention focus group). I collected all data (with the help of two graduate student assistants) between September and December 2016 (see Appendix E for data collection timeline).

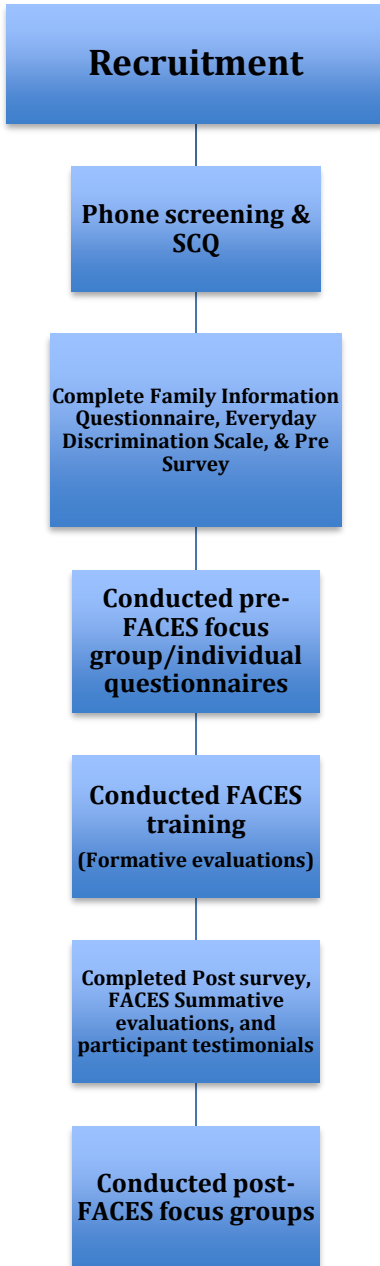


Figure 5. FACES study flowchart.

In the next section I describe the data collection and data analysis procedures for the focus groups. Then, I describe (a) the FACES program design and measures, (b) data analysis procedures, and (c) the procedures for mixing methods.

Data Collection: Focus Groups and Testimonials

One pre-FACES and two post-FACES focus groups were conducted. Additionally, participants recorded testimonials, following the program. The purpose of the pre-FACES focus group was to better understand African American parents' experiences and needs related to advocating for their children with ASD (RQ1), and to further develop the training program. The primary purpose of the post-FACES focus groups and testimonials was to assess the social validity of the intervention (RQ3).

Pre-FACES focus group. Six parents (five mothers and one father) participated in the pre-FACES focus group interview. Prior to beginning the interview, I explained the purpose and gave participants an opportunity to ask questions. I also informed participants that what they shared during the focus group would be confidential and would not be shared outside of the group in any way that would reveal their identity. I conducted the focus group with support from a graduate student assistant. The graduate student assistant was responsible for collecting consent forms, recording field notes, and audio recording the interview. The pre-FACES focus group lasted 67 minutes, and was recorded using a Sony® digital audio-recorder.

The pre-FACES focus group interview protocol (Appendix F) was employed to address research question one. I developed the interview protocol based on a review of literature around parent advocacy training and experiences and needs of African American families of children with ASD (e.g., Burke et al., 2016; Trainor, 2010; Whitley et al., 2011). The main areas of inquiry that were included in the pre-FACES focus group interview protocol were: (a) African American parents' experiences advocating for services, (b) the types of services parents have advocated for, and (c) parent perceptions of advocacy. The pre-FACES focus group interview protocol included six open-ended questions and a series of probes. The pre-FACES focus group

interview protocol was pilot tested with three mothers of children with ASD in a small Midwestern urban community prior to conducting the pre-FACES focus group. Participants provided suggestions such as clarifying the definition of advocacy and clarifying probing questions; protocol revisions were made accordingly.

Pre-FACES questionnaire. Participants who were not able to attend the pre-FACES focus group (e.g., signed up for FACES after the focus group was conducted) were asked to complete a four-item Google Form questionnaire (Appendix G) that was adapted from the pre-FACES interview protocol. Three participants (two mothers and one father) completed the pre-FACES questionnaire.

Post-FACES focus group. Three parents (two mothers and one father) participated in the first post-FACES focus group interview and six parents (four mothers and two fathers) participated in the second focus group. Both focus groups were conducted on the same day in the same location. To strengthen the probability of objective responses from participants regarding the social validity of FACES, the post-FACES focus group interviews were co-facilitated by two graduate student assistants in Special Education. The secondary graduate student assistant was responsible for recording field notes and audio-recording the interview. Prior to beginning the interview, the graduate student assistant explained the purpose and gave participants an opportunity to ask questions. The researchers also informed participants that what they shared during the post-focus group would be confidential and would not be shared outside of the group in any way that would reveal their identity. One post-FACES focus group interview lasted 39 minutes, and the other post-FACES focus group interview lasted 61 minutes. Both post-FACES focus group interviews were recorded using a Sony digital audio-recorder.

The post-FACES focus group interview protocol included six open-ended questions and a series of probes (Appendix H). Given the time restrictions during the post-FACES focus groups, participants were given hard copies of the interview questions (without the script and prompts) as a guide to help keep the groups on track (Appendix I). The main areas of inquiry that were explored during the post-FACES focus group interview protocol included: (a) overall views of the FACES training (i.e., importance of the goals, procedures, and outcomes), (b) perceived knowledge of ASD, and (c) parent perceptions of advocacy.

Post-FACES video testimonials. Ten parents (seven mothers and three fathers) participated in the post-FACES testimonials. During the testimonials, each participant was asked to reflect on (a) what he/she most got out of the FACES program and (b) how he/she hoped to apply his/her knowledge gained from FACES, in the future. The participant testimonials were recorded during the final FACES session (i.e., session six), and were facilitated by two graduate student assistants. Participant testimonials ranged in duration from 1-5 minutes. On average, each testimonial lasted 2 minutes, 21 seconds.

Data Analysis: Focus Group Interviews and Testimonials

Transcription. Prior to transcribing the focus group interviews, I met with the graduate student assistant transcriptionist to discuss the transcription procedures and review the transcription protocol. Following each focus group interview, the graduate student assistant transcribed the interviews verbatim and all names were replaced with pseudonyms to protect participant anonymity. The pre-FACES focus group transcript was 24 single-spaced pages; the first post-FACES focus group transcript was 10 single-spaced pages; the second post-FACES focus group transcript was 21 single-spaced pages. All communications were included in the

transcripts and a timestamp with a series of “x” in brackets was inserted in place of any text that was inaudible.

Testimonials. Following the participant testimonials, the graduate student assistant followed the same transcription procedures that were employed for the focus group transcriptions. Each testimonial transcription was one single-spaced page or less. Once transcribed, I listened to the focus group interviews and testimonials and compared the transcripts to the audio recordings for verification. Discrepancies were found to be minimal and were corrected before data analysis.

Coding. After the focus group transcripts were verified, I completed the data analysis with Dr. Meadan, using a constant comparative method (Corbin & Strauss, 2015). In the first level of analysis, we independently read each transcript and organized the data into broad categories. During the second level of analysis, we reread the transcripts to reach a consensus on initial categories and to develop a structured coding scheme. During the third level of analysis, we revised the codes as needed and identified emerging themes across the data.

Testimonials. After the testimonial transcripts were verified, I read each transcript and coded them independently. Because the participant testimonials also addressed the social validity of the FACES program (RQ 3; within an individual context), I used the codes that were developed during the focus group data analysis to code the testimonials (i.e., a priori coding).

Member checks. At the end of the pre-FACES focus group I conducted initial member checking by reviewing the main themes that emerged from the pre-FACES focus group (i.e., types of supports they were seeking from FACES) with the participants. Then, I asked participants to validate, add to, or change any of the areas of needed support that I highlighted.

Following the post-FACES focus group data analysis, I conducted level two member checks to ensure the accuracy of the interpretation (Brantlinger et al., 2005). To complete the member checks, I developed two brief summaries (one for each focus group interview) by utilizing the data from the transcripts, and consulting the memos. Then, I sent the summaries of overarching themes and findings to a graduate student assistant who read each summary to check for clarity, accuracy, and sensitivity. After the graduate student assistant provided feedback, I made revisions to the summaries as needed, and then sent the appropriate summary to each group of participants (via email) and asked them to determine whether our interpretation of their responses were valid and representative (see Appendix J for example summary). The participants were asked to reply as soon as possible if (a) they had any concerns or suggestions for the interpretations or (b) they agreed with the interpretation.

Seven participants from the post FACES focus groups participated in the member checks (87.5%). Feedback from all seven participants confirmed the validity of our interpretation of the focus group responses and they had no additional comments to add. Participant feedback included comments such as, “Thank you for providing the updated summary. No changes needed,” “I think that the summary accurately reflects what we discussed during our focus group. No changes needed,” and “Yes, that covers my experience.”

Credibility and trustworthiness. There are a number of quality indicators used in qualitative research in Special Education to ensure that focus group data meet high standards (Brantlinger et al., 2005). To ensure that this study met high-quality standards, I recruited an appropriate sample, worked collaboratively with a team, provided thick, detailed descriptions of the data, triangulated the data, and conducted member checks.

To select appropriate participants (i.e., African American parents of children with ASD), I recruited participants from a number of community agencies, social networks in and around a large, Midwestern urban area. I screened each participant to verify that they met criteria for the study, and I employed a selective snowball sampling technique such that several parents who agreed to participate received recruitment flyers and were asked to share them with other families they knew who met criteria. Each of these measures was taken to ensure that the sample was purposely identified, effectively recruited, adequate in number, and representative of the population of interest.

To ensure that the focus group interview questions were reasonable I (a) conducted a review of literature prior to the development of the questions, (b) revised and refined the questions based on feedback from my advisor and committee, and (c) piloted the interview questions prior to beginning the study. Moreover, I used adequate mechanisms to record and transcribe the interviews verbatim, and ensured that participants were represented sensitively and fairly in the summaries and final report. Finally, I ensured that participant confidentiality was maintained throughout the study (Brantlinger et al., 2005).

Additional measures were employed to strengthen the credibility during collection and analysis. First, I aimed for convergence of data sources through data triangulation (i.e., Family information questionnaire, pre-post FACES measures, focus group interviews, and participant testimonials) and investigator triangulation (e.g., myself and Dr. Meadan). Second, I worked collaboratively, with a culturally and ethnically diverse research team; I believe that the diversity and varying perspectives of the team helped to ensure that data analyses and interpretations were not idiosyncratic, but reliable and reflective of “situational realities” (Brantlinger et al., 2005). Third, I was forthright about my position and perspectives within the context of this research by

monitoring my possible biases through field notes, memos, and regular debriefings. Field notes were recorded by hand during each focus group interview. Field notes included both descriptive information (e.g., date, time, location, and a seating chart of the participants) and reflective information (e.g., our thoughts, questions, and ideas).

FACES Program

With support from Drs. Meadan and Burke, I adapted materials from existing programs and resources (e.g., i-PiCS modules, VAP PowerPoint presentations) to develop the FACES program.

Design. Following the pre-intervention focus group interviews, the FACES program was delivered during 18 hours of training over a 6-week period (i.e., once per week for 3 hours). The FACES program curriculum was delivered via mini lectures with PowerPoints, small group discussions, case study reviews and discussions, videos, application activities, and a parent advocacy panel discussion. All participants ($N = 10$) attended the training sessions together. I was the primary trainer for each session and one graduate student assistant was present during each session. Each training session was video recorded and made available on the FACES website to any participant who missed a session. The video recordings were also used for fidelity checks.

Before beginning the FACES training, I employed a number of steps to ensure the FACES program was feasible, well developed, and appropriate for the participants. First, I consulted with my dissertation committee (e.g., Drs. Meadan, Burke, Boyd, and Santos) to review the FACES curriculum. Second, I asked stakeholders (e.g., parent, content experts) to review the FACES program curriculum, and provide feedback prior to implementation (i.e., vetting). Finally, I used data from the pre-FACES focus group interview to ensure the program

material was well-developed and best tailored to meet the needs of this cohort of FACES participants, and inclusive of adult learning principles (Trivette et al., 2009).

FACES manual vetting. In August 2016, prior to beginning the FACES program, I developed a vetting manual that included a brief description of FACES, directions for how to vet the manual, and all of the FACES materials (e.g., curriculum overview, fidelity checklists, PowerPoint presentations, supplemental materials). I distributed the manual to five stakeholders: an African American mother of a child with ASD, a researcher with expertise in ASD and communication disorders, a researcher with expertise in advocacy interventions, a community ASD resource center director, and a researcher with expertise in professional development. The stakeholders were asked to review the vetting manual and provide any feedback and suggestions that they felt would strengthen the program (e.g., content, structure, activities). In late August and early September, I met with each of the stakeholders to discuss their feedback. Examples of stakeholder suggestions included restructuring the sequence of content delivery, embedding more interactive activities, and clarifying ASD diagnosis and definitions. Following the stakeholder meetings, I compiled the feedback and incorporated the suggested revisions into the FACES program curriculum.

Duration, scope, and sequence. The FACES program curriculum included three units that were delivered across six, three-hour training sessions for a total of 18 hours. While the VAP advocacy curriculum includes 40 hours of instruction and the LPLSP included 36 hours of training across nine sessions (Burke et al., 2016), the FACES program was reduced in duration for two reasons: (a) FACES was designed to provide foundational knowledge to parents, as opposed to training advocates to work with other families, and (b) FACES focused less on

special education law and procedures, and more specifically on the needs of African American parents of children with ASD (e.g., communicating with professionals and managing behavior).

The scope of the FACES program was based on (a) what we know about areas of needed support for individuals with ASD (e.g., Meadan et al., 2014; Tager-Flusberg & Kasari, 2013), (b) what we know about the need for advocacy among parents of children with ASD (Burke, 2013; Cohen, 2009; Mueller & Carranza, 2011), and (c) what we know about parent recommendations to feel better prepared to advocate for and address the needs of African American children with ASD and their families (Pearson & Meadan, in press).

The sequence of the FACES program was grounded in four key features: (a) a simple to complex sequencing approach (Schmidt, Loyens, Van Gog, & Paas, 2007), (b) the FACES theory of change (see Figure 1), (c) the characteristics of adult learning theory (Trivette et al., 2009), and (d) the principles of Sociocultural Theory (Baumgartner, 2001). That is, each session was designed to build on content from the previous session such that parents understood sequentially, (a) the needs of children with ASD, (b) strategies for addressing those needs (including knowledge of the law), and (c) how to communicate those needs to professionals. Therefore, unit one included (a) characteristics of ASD, strategies for promoting social communication skills and addressing challenging behavior (adapted from Meadan et al., 2016 and Meadan, Ayvazo, & Ostrosky, 2016), and (b) special education law and procedures. Unit two focused on (a) strategies for accessing services and (b) effective advocacy (adapted from the *Volunteer Advocacy Project (VAP)*; Burke & Goldman, in press; Goldman, Burke, Mason, & Hodapp, 2016). Unit three highlighted (a) ways to strengthen empowerment and (b) engaging in effective communication with professionals (see Appendix K for the FACES curriculum overview and Appendix L for detailed lesson plans/fidelity checklists for each session).

The goal in developing the FACES program was to embed both evidence-based, parent-implemented interventions *and* evidence-based adult learning practices in a curriculum that would be efficacious in strengthening parents' knowledge, advocacy, and empowerment related to ASD. Materials from the VAP and i-PiCS were purposely selected because of the demonstrated effectiveness of both interventions (e.g., Burke et al., 2016; Goldman et al., 2016; Meadan et al., 2014; Meadan et. al., 2016).

FACES Program

Social validity. Measures of social validity are critical in social science research because they include the values and opinions of individuals affected by our interventions. Judgments of social validity should address goals (i.e., do the goals of FACES actually meet the needs of African American parents of children with ASD?), procedures (i.e., do the participants view the FACES procedures as acceptable?), and effects (i.e., participant satisfaction with the results of the FACES program; Wolf, 1978). To measure the social validity of the FACES program, I (a) conducted post-FACES focus groups (facilitated by graduate student assistants), (b) recorded post-FACES participant testimonials, (c) measured participant satisfaction with the intervention via five-item formative evaluations at the end of sessions 1-5 (Appendix M), and (d) asked participants to complete a summative evaluation at the conclusion of the program (see Appendix N).

Feasibility and acceptability. The feasibility and acceptability of the FACES program were evaluated via attendance records and participants' reported satisfaction with the intervention (i.e., formative and summative evaluations).

Attendance and attrition. Because this was the first known parent advocacy training for African American parents of children with ASD, typical attrition rates were unknown. Based on

the low attrition rates during the LPLSP (Burke, Magaña, Garcia, & Mello, 2016) however, I expected that attrition rates for FACES would also be low (< 10%). To measure participant attendance, I divided the total number of sessions each participant (i.e., $N = 10$) attended by the total number of sessions held (i.e., six), and multiplied by 100. To measure attrition, I divided the number of participants who completed all FACES program requirements ($N = 10$) by the number of participants who began the program ($N = 13$).

Session videos. Each FACES session was video recorded and uploaded to a restricted website, available for participants to view sessions they were not able to attend in person. Participants who missed one session but reported that they viewed the session online were not counted absent for that session and were not included in participant attrition, providing they met all other study requirements. One participant (Chris) reported that he viewed the session he missed (i.e., session five) online. Data analytic tracking was not available to confirm this on the FACES site; therefore, viewer data were based on parent-report, alone.

Treatment fidelity. Consistent with the quality indicators for outcome measures in quantitative studies, I used two methods to measure treatment fidelity: intervention checklists and reliability checks (Gersten et al., 2005). For each session of the program, a graduate student assistant used a Google form session checklist (Appendix L) to conduct fidelity checks in person, during the training. The fidelity checklists were individualized for each training session. Examples of checklist items that were used to assess procedural fidelity of implementation during the training sessions include: mini lecture on the prevalence of ASD, disparities related to ASD diagnoses in the African American community, videos from the Philadelphia Autism Project, and small group activities to discuss experiences with family members. To measure fidelity, the graduate student assistant collected data on the steps that the trainer completed

during each training session and reported the percentage of steps completed. Fidelity to the curriculum was measured for 50% of the sessions and found to be 64.19%. Fidelity to the curriculum was impacted by shifts in the schedule for each FACES session.

Reliability of treatment fidelity. All sessions were videotaped and uploaded to the program website. Dr. Meadan viewed 50% of the FACES sessions ($n = 3$) and completed the fidelity checklist that corresponded with each session. Reliability for fidelity of implementation was measured by comparing the items the primary observer (i.e., graduate student assistant) selected to that of the secondary observer (i.e., Dr. Meadan). Then, point-by-point agreement was calculated by (a) summing the number of agreements and disagreements between observers, (b) dividing the sum agreements by the number of agreements *and* disagreements, and (c) multiplying that by 100. Inter-rater agreement was 85.42%.

FACES Measures: Data Collection

The Family Information Questionnaire and the Everyday Discrimination Scale were administered only once prior to the FACES program. The pre/post FACES measures included the FACES scale, Autism Knowledge scale, Family Empowerment scale, School Communication scale, Family-Professional Partnership scale, and the Special Education Advocacy scale. In addition to the pre/post FACES surveys, participants (a) completed formative evaluations at the end of sessions 1-5, (b) recorded testimonials following session six, and (c) completed summative evaluations upon completion of the six-week program.

Family Information Questionnaire. The Family Information Questionnaire (Appendix O) was developed by Dr. Meadan and myself and was administered to collect demographic information about the parents and the types of services that their children with ASD receive. The questionnaire includes 22 items and took 10-15 minutes to complete. The questionnaire includes

demographic questions such as parent’s age, gender, marital status, educational background, employment status, family income, and child information. The questionnaire also includes questions about the types and amount of services their child with ASD receives. This measure was completed prior to the intervention, only.

Everyday Discrimination Scale (EDS). The EDS (Appendix P) is a 9-item Likert scale questionnaire that was designed to assess discriminatory practices across domains (Lewis, Yang, Jacobs, & Fitchett, 2012). Each item is scored on a 5-point scale with responses ranging from “almost everyday” to “less than once per year.” Example questions include, “people act as if they are afraid of you” and “you are threatened or harassed.” If at least one response to items 1-9 is “a few times per year” or more frequently, participants are asked to complete a follow up question by selecting all reasons that apply (e.g., disability, race, weight; Williams, Jackson, & Anderson, 1997). The EDS has demonstrated strong internal consistency ($\alpha = .91$; Pérez, Fortuna, & Alegria, 2008), and has been used with individuals from diverse racial and ethnic backgrounds (Lewis et al., 2012). The EDS also demonstrated strong internal consistency for this study ($\alpha = .85$). Participants completed the EDS prior to the FACES program only; their scores are reflected in the participant demographic information table (see Table 2).

Table 2

Research Questions, Measures, and Analyses

	Research question	Measure	Analyses
1.	What experiences do African American parents of children with ASD have with advocating for services?	Pre-intervention focus group interview Pre-intervention questionnaire	Constant comparative method

(continues)

Table 2 (continued)

Research question	Measure	Analyses
2. Does the FACES program strengthen empowerment in African American parents of children with ASD?	Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992)	Descriptive statistics Wilcoxon Sign Rank Test
	Formative & summative evaluations	Descriptive statistics
	Post-intervention focus group interviews	Constant comparative method
	Participant testimonials	A priori coding
2a. Does the FACES program increase parents' knowledge of ASD?	Formative & summative evaluations	Descriptive statistics
	Post-intervention focus group interviews	Constant comparative method
	Participant testimonials	A priori coding
2b. Does the FACES program strengthen parents' understanding of and confidence in their ability to implement social communication strategies?	FACES Scale	Wilcoxon Sign Rank Test
	Formative & summative evaluations	Descriptive statistics
	Post-intervention focus group interviews	Constant comparative method
2c. Does the FACES program strengthen parents' understanding of and confidence in managing behavior?	Participant testimonials	A priori coding
	FACES Scale	Wilcoxon Sign Rank Test
	Formative & summative evaluations	Descriptive statistics
	Post-intervention focus group interviews	Constant comparative method
	Participant testimonials	A priori coding

(continues)

Table 2 (continued)

Research question	Measure	Analyses
2d. Does the FACES program increase parent-professional communication as reported by parents?	School Communication Scale (Burke, 2016)	Descriptive statistics
	Family-Professional Partnership Scale (Summers et al., 2005)	Wilcoxon Sign Rank Test
	Post-intervention focus group interviews	Constant comparative method
	Participant testimonials	A priori coding
2e. In what ways and to what extent does the FACES program strengthen parents' reported perceptions of their ability to advocate effectively for services for their children with ASD?	Special Education Advocacy Scale (Burke, 2016)	Wilcoxon Sign Rank Test
	Post-intervention focus group interviews	Constant comparative method
	Formative and summative evaluations	Descriptive statistics
	Participant testimonials	A priori coding
3. How do African American parents of children with ASD perceive the social validity of the goals, procedures, and outcomes of the FACES program?	Post-intervention focus group interviews	Constant comparative method
	Formative and summative evaluations	Descriptive statistics
	Participant testimonials	A priori coding

FACES pre/post measures. See Appendix Q for all pre/post measures.

FACES scale. The FACES scale is a seven-item, Likert scale questionnaire that was developed by Dr. Meadan and myself. Each item is scored on a 5-point scale from strongly agree to strongly disagree. The scale was designed to measure parents' confidence in their ability to advocate for and support their children's needs. Example items include, "I feel confident in my ability to communicate with my child's educators" and "I feel confident in my ability to manage my child's behavior" (see Appendix Q). For this study, both the pre-FACES and post FACES scales demonstrated high reliability ($\alpha = .93$ and $\alpha = .91$, respectively).

Family Empowerment Scale. The Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) was designed to measure empowerment among families of children with disabilities. The scale includes items that represent three distinct subscales, including family, service systems, and community/political. Example items include, “I feel confident in my ability to help my child grow and develop” and “I make sure I stay in regular contact with professionals who are providing services to my child.” The FES is a 34-item Likert-scale questionnaire with scores that range from 1 (*not true at all*) to 5 (*very true*). The Cronbach’s alpha for the FES subscales ranged from .87-.88 (Koren, DeChillo, & Friesen, 1992; Appendix Q). For this study, the pre FES scale demonstrated high reliability ($\alpha = .72$, $\alpha = .86$, $\alpha = .83$) for the family, service system, and community/political domains, respectively. The post FES scale demonstrated high to moderate reliability ($\alpha = .87$, $\alpha = .84$, $\alpha = .68$) for the family, service system, and community/political domains, respectively).

School Communication Scale. The School Communication Scale (Burke et al., 2016) measures parents’ communication with school-based professionals. This scale has seven items related to letter writing, communication, and school activities. Questions include: “How often have you written a letter to the school?”; “Called the school?”; and “Volunteered in the school?” Each question has a 5-point likert scale. The scale has been used with families of children with ASD before and has strong reliability ($\alpha = .87$; Appendix Q). For this study, the pre school communication scale demonstrated internal consistency of $\alpha = .78$ and the post school communication scale demonstrated internal consistency of $\alpha = .90$.

Family-Professional Partnership Scale. The Family-Professional Partnership Scale (Summers et al., 2005) can be used as a measure of parent satisfaction with programs, an outcome measure of pre and post effects on family-professional partnerships training, and as a

measure of variables that might affect other family outcomes. The scale includes 18 items related to child-focused relationships (e.g., “how satisfied are you that your child’s teacher has the skills to help your child succeed?”) and family-focused relationships (e.g., “how satisfied are you that your child’s teacher pays attention to what you have to say?”). Each item is rated on a 5-point Likert scale and the measure has strong reliability ($\alpha = .93$; Appendix Q). For this study, the pre Family-Professional Partnership Scale demonstrated internal consistency of $\alpha = .93$ and $\alpha = .89$ for the child and family subscales, respectively. The post Family-Professional Partnership Scale demonstrated internal consistency of $\alpha = .85$ and $\alpha = .88$ for the child and family subscales, respectively.

Special Education Advocacy Scale. The Special Education Advocacy Scale (SEAS; Burke, 2016) measures participants’ perceptions of their ability to advocate. This scale was developed by Burke for the Volunteer Advocacy Project and has been derived from other measures (e.g., Nachshen, Anderson & Jamieson, 2001). The scale includes 10 five-point Likert scale items with answers ranging from “not at all” to “excellent.” Two examples of items include, “How prepared do you feel to collaborate with the school at IEP meetings?” and “how well are you able to communicate effectively with the school?” The scale has been used with several cohorts of graduates from the VAP and has a Cronbach’s alpha equal to .87 (Appendix Q). For this study, the pre Special Education Advocacy scale demonstrated internal consistency of $\alpha = .94$ and the post scale demonstrated internal consistency of $\alpha = .76$.

Formative and Summative Evaluations. Both formative (Appendix M) and summative evaluations (Appendix N; adapted from the VAP; Burke, 2013) were used to adapt the program as needed, and to assess the usefulness of FACES. Following the completion of each session (e.g., 1-5), participants completed a five-item formative evaluation. Example items included,

“what improvements would you suggest?” and “to what extent do you feel the information covered during this session enhanced your knowledge?” Feedback from the formative evaluations was reviewed after each session and adjustments to the following sessions were made as needed.

Following completion of the FACES program (i.e., at the end of session six) participants completed a 30-item summative evaluation. The measure included questions specific to (a) the speakers, (b) content, (c) logistics, and (d) overall perceptions of the FACES program. Example items included, “are there any other topics you think the training should include?” and “what did you think about the relevance of each topic?” Scaled items on the summative evaluation data were analyzed via descriptive statistics and the open-ended items were analyzed using an open coding approach. See Table 2 for research questions, measures, and how the data were analyzed.

FACES Program: Data Analysis

Preliminary data analysis. Quantitative data analyses were computed and evaluated using SPSS software (version 24). During preliminary data analysis, I computed descriptive statistics for the formative and summative evaluation data. In addition, I addressed quality indicators for experimental research and ensured that each construct was reliable by computing Cronbach’s alphas for each scale (Gersten et al., 2005). I examined the pre and post measures for missing data and examined the missing data to determine whether it was missing at random or whether it constituted a pattern. Following the imputation guidelines of Harrell (2001), I employed the mean imputation method for less than 5% of the Family-Professional Partnership Scale for two participants.

Autism Knowledge Scale. With the exception of the Autism Knowledge Scale, all alpha levels were greater than .60; therefore, I treated the scales as unitary constructs. The reliability

for the Autism Knowledge Scale (AKS) was below .60 ($\alpha = .38$); given the poor internal consistency of the AKS, my small sample size, and subsequent lack of power, I decided to exclude the scale from primary data analysis.

Finally, I checked the distribution of the variables via graphic displays and skewness and kurtosis to determine whether the data were normally distributed. After (a) observing the skewness and kurtosis and (b) constructing and analyzing the bar graphs, it was evident that there was significant kurtosis and some skewness for most of the scales. Therefore, given the small sample size and the non-normal distributions, I proceeded with non-parametric statistics (i.e., Wilcoxon Sign Rank test; Tabachnick & Fidell, 2013).

Procedures for Mixing Methods

In this study, the goals were to (a) understand experiences with and needs related to advocacy and empowerment among African American parents of children with ASD, (b) embed those needs into the FACES program, and (c) assess the impact of the FACES program on addressing parent and family needs. As such, I employed a sequential mixed-methods design (Greene, 2007) that was achieved by mixing two different methodologies (e.g., focus groups and pre/post survey design). Focus group designs align with qualitative traditions, while survey designs align with quantitative traditions in social science. The purposes for mixing methods in this study include: *development*, *complementarity/initiation*, and *triangulation*. Data were mixed for development of the training program *and* during the analysis and interpretation stage (see Figure 6).

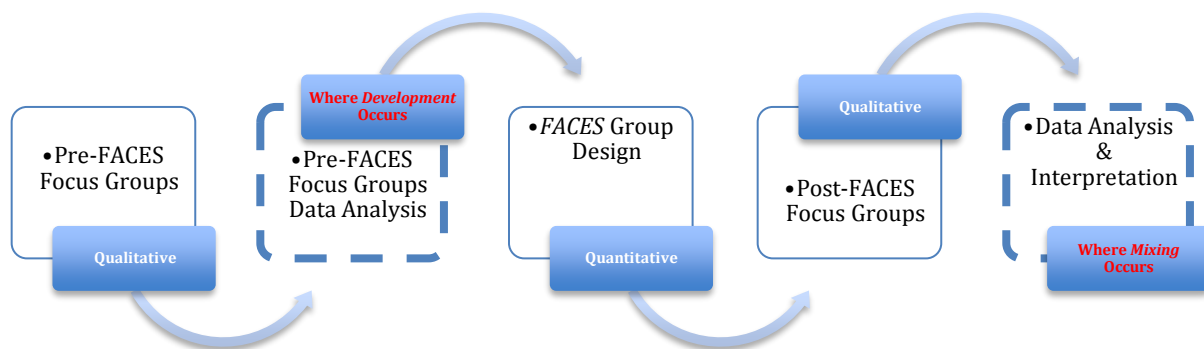


Figure 6. The mixing of methods.

Development. In mixed methods development studies, “the results of one method are used to inform the development of the other method (Greene, 2007, p. 102). In development mixed methods studies, the methods, by definition, have to be implemented sequentially; therefore, in the FACES study my aim was to further adapt and develop the program after analyzing pre-FACES focus group data and family information questionnaire data. Development for FACES included modifications to lesson plans and materials based on the following factors: (a) age range of participants’ children (i.e., 3-11), (b) communication needs of participants’ children, (c) existing perceptions and levels of engagement in advocacy approaches, and (d) expressed needs related to knowledge of ASD and empowerment in general. Employing the pre-intervention focus group data to better understand, qualitatively, African-American parents’ experiences with advocating for the needs of their children with ASD, was a critical component of this sequential, mixed methods design.

Pre-FACES focus group. During the Pre-FACES focus group, I asked participants to describe tools and/or resources they felt would help them feel like stronger advocates or support the needs of their families in general. Following the interview data collection and analysis, I

referred to the findings for further development of the FACES program and embedded participant recommendations into three of the sessions (i.e., mixed the data for development).

Complementarity/initiation. Second, the aim of mixing for complementarity/initiation in mixed methods research is to seek "broader, deeper, and more comprehensive social understandings by using methods that tap into different facets or dimensions of the same complex phenomenon" (Greene, 2007, p. 101). In other words, I expected that the results from the qualitative methods (i.e., FACES focus groups, formative/summative evaluations, participant testimonials) would complement the results from the quantitative methods (i.e., pre/post survey), to elaborate and deepen the overall inferences related to the experiences and perceptions of advocacy and empowerment in African American parents of children with ASD.

Triangulation. Finally, triangulation is used to obtain convergence, corroboration, or correspondence of results from multiple methods. The aim of triangulation is to increase the validity of inferences (Greene, 2007). Therefore, my hope was that multiple methods of data collection that were designed to measure the effectiveness of the FACES program would converge with each other, and further substantiate the findings. In this study, for example, the FES, focus group interviews, summative evaluations, and participant testimonials were all used to measure the same phenomenon (e.g., empowerment).

Given the overall broad purpose for mixing methods in social inquiry (i.e., developing a better understanding of particular phenomena; Greene, 2007), the FACES study lends itself to such discovery by employing multiple methods. My aim was to develop a better understanding within a mixed methods framework by (a) employing appropriate data collection and analysis strategies that would enhance both the validity and credibility of the findings, (b) generate deeper understandings of the experiences of African American parents of children with autism and

(c) advance the dialogue between parents with similar experiences, parents and professionals, and researchers in the field (Greene, 2007).

Chapter 4

Results

The purpose of this study was (a) to better understand experiences related to advocacy and empowerment among African American parents of children with autism, and (b) to develop and pilot the FACES (Fostering Advocacy, Communication, Empowerment, and Support) program. Findings from pre/post surveys, pre/post focus groups, formative and summative evaluations, and participant testimonials indicate that FACES program participants had stronger perceptions of advocacy and empowerment following the FACES, and overall, were satisfied with the program.

Organization of Results

In this chapter, I present the findings by research question. To emphasize the mixed methods nature of this study, and to highlight the integration of the data both during FACES development and during data analysis, I note the source of the data throughout.

RQ 1: What Experiences Do African American Parents of Children With ASD Have With Advocating for Services?

To gain a better understanding of African American parents' experiences advocating for services for children with ASD, I examined the pre FACES focus group and pre FACES questionnaire data. During the focus group interview (and on the questionnaire for the three participants who could not attend the pre-focus group), participants were asked to share their experiences with advocating on their child's behalf. Three emergent themes arose: advocacy strategies, perceptions of advocacy, and barriers to advocacy (see Figure 7 for themes and categories related to parents' experiences with advocacy prior to the FACES program).

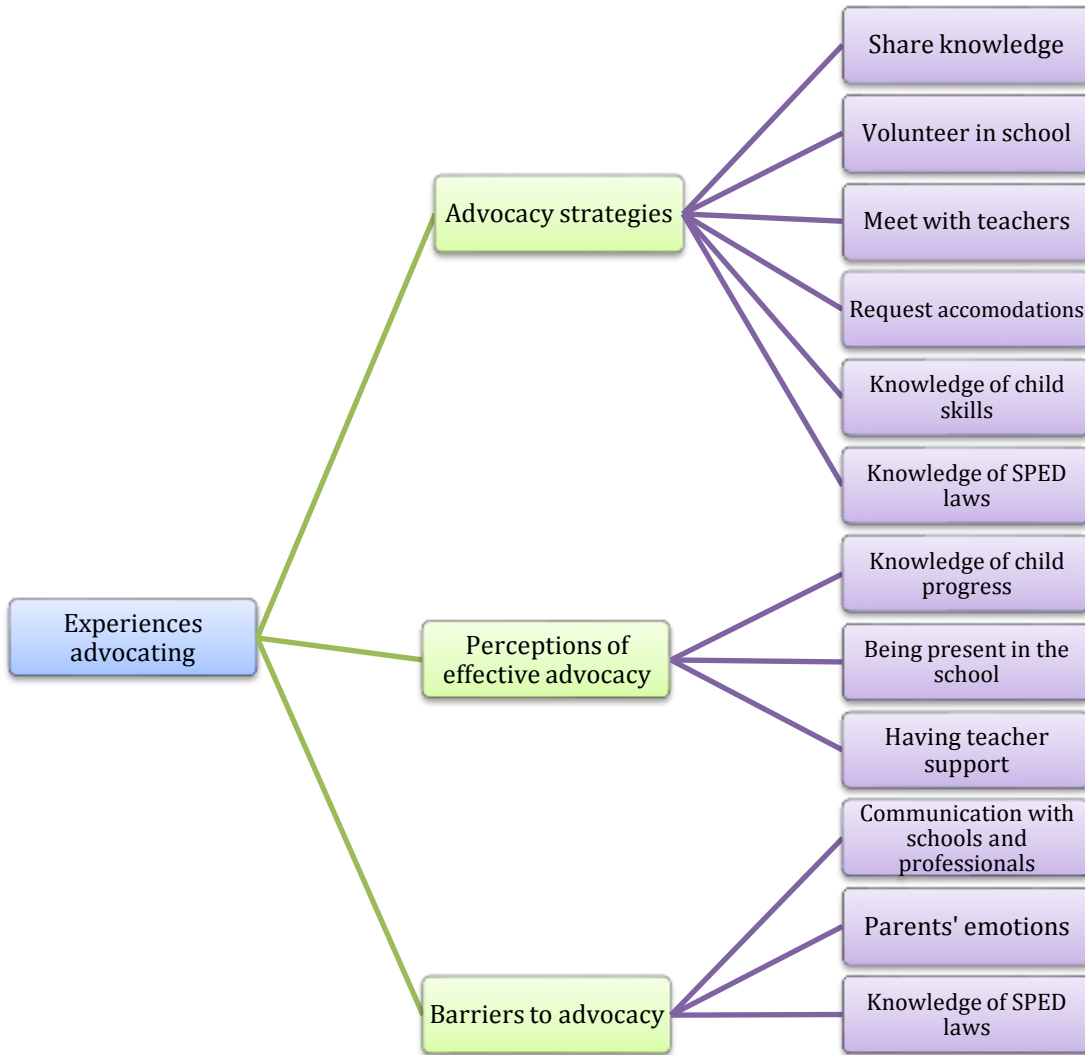


Figure 7. Pre FACES Focus group/questionnaire themes and categories.

Advocacy strategies. Parents indicated that they engaged in a variety of advocacy strategies to support the needs of their children with ASD. Some examples of strategies they identified were: sharing knowledge (e.g., helping other people understand their children’s needs), volunteering in their children’s classrooms, and scheduling meetings with their children’s teachers. While reflecting on how she engages with her son’s teachers, Tamryn, the mother of a 10-year-old son, shared the following about how she supported her son, “in the past, I sat in class with my son to make sure he was able to do what he was required to do” (pre-FACES

questionnaire). Another advocacy strategy that parents identified was meeting with teachers to ensure that their children (and other children) receive access to the services they need. Erika shared the following regarding her experience advocating for services after changes were made to her 8-year-old daughter's IEP:

Another layer is making sure the school doesn't change the IEP without your permission. And if they do (which just happened), making sure they change it back. One meeting a few years ago, she was supposed to have direct services for OT (occupational therapy), PT (physical therapy), and speech. Then the OT changed it to consultative services where she is in the classroom looking and telling the teacher what to do. I said, "no way, it says direct and I expect direct services. You do not have my permission. You need to change it back." (pre-FACES focus group, p. 9)

Similarly, Chris, the father of an 11-year-old son said, "I have supported students in need of services in school—I think my background [in social work] has really helped me push for the services my son needs" (pre-FACES questionnaire).

Participants also identified additional advocacy strategies they employed such as requesting accommodations, knowing their children's skills and abilities, and being familiar with special education rights and laws. Deborah, mother of an eight-year-old son, and also a teacher, noted the importance of being familiar with special education laws to advocate effectively: "Now I have to think really hard and know this IEP backwards and forwards, and know the law to keep them in line so that he gets exactly what he needs." (pre FACES focus group, p. 15).

Perceptions of advocacy. A second emergent theme in response to parent's experiences with advocacy was related to the way parents perceive and define advocacy. When asked to define or describe advocacy, participants suggested that advocacy includes staying abreast of their child's progress and goals in school (e.g., making sure their children receive the services they need), being present in the school, and in theory, should include the work of teachers on their students' behalf. Janice shared her experience related to her son's academic progress in

school. When she learned that his grade had dropped significantly in one course, she immediately reached out to his teacher, and advocated on his behalf:

We just got the progress reports yesterday and my son had a D in one of his subjects. We were looking through the paperwork and we were like, “we have never seen any of this paperwork.” I am looking through it and my husband is like, “just put this away. We will talk to the teacher.” At that point [I was] internalizing like, “why hasn’t she called us? Why hasn’t she told us about this? What would give him the D?” You should have told us about this. (pre-FACES focus group, p. 10)

Luke shared his thoughts about the importance of having teacher support by advocating for his son who was 7 years old and was diagnosed with ASD at age 6:

I wanted his homeroom teacher to advocate for us because if you are already giving us a 25-page packet that you know my son very well may not be able to finish . . . you have to work with us to make sure that we can get this in even if we have to turn it in next week. (pre-FACES focus group, p. 13)

Erika noted how her relationship with and presence in her daughter’s school was one way that she engaged in advocacy efforts. She shared her experience related to open house:

I called the school that [my daughter] goes to because they did not publicize the open house. I did not know about the open house so I went to school and I asked the teacher, “how could you not post about the open house?” I only found out when I was dropping off the homework the other day. The school didn’t do a good job publicizing. (pre-FACES focus group, p. 14)

Janice also shared how she is present in her son’s schools as a form of advocacy: “I volunteered in a school for kids with disabilities so I spent a lot of time advocating for all the parents” (pre-FACES focus group, p. 9).

Barriers to advocacy. The theme that parents voiced the most during the pre-FACES focus group interview and questionnaire was barriers to advocacy. Parents identified communication with school as an obstacle that inhibited their ability to engage in effective advocacy. Phoebe, for example, shared her challenges and experiences with communicating with her son’s teachers to advocate for his needs:

I don't feel that the school offered him enough assistance with the social piece. And I don't know how to convey to let them know how I feel about that. I don't even know how do you go about it. But that is what I feel the strongest [about], so he has services in place for speech and social skills. (pre-FACES focus group p. 15)

Similarly, Deborah shared the challenges she faces with communicating with her son's teachers:

I just think that there is a lot going on as far as the school is concerned that should be better and could be better. I think that they need to be willing to listen a little bit more and understand that although my son looks completely normal, he is not. He has his challenges. (pre-FACES focus group, p. 13)

Other identified barriers included parents' emotions and limited knowledge of special education rights and laws. Participants explained that their emotions sometimes become a barrier to effective communication and advocacy. In response to how her emotions impede her ability to advocate effectively, Janice said, "I get angry. I want to fight. It's just like you know, me getting ready to fight for my child" (pre-FACES focus group, p. 10).

As it relates to knowledge of special education rights and laws, participants' perceptions of their (a) knowledge around special education rights, and (b) abilities to apply special education laws indicated that there was room to learn more. Phoebe, for example, shared the following:

When it comes down to advocating for him in the school, I think that we have obtained enough knowledge from resources that we have been receiving, but at the same time I feel like though there is something more that we should be able to do. (pre-FACES focus group, p. 11)

Overall, participants identified strategies, perceptions, and barriers as factors that have shaped their views and experiences related to advocating for the needs of their children with ASD. Participants expressed that they (a) value and understand the importance of advocacy, (b) identified barriers that have prohibited them from advocating effectively, and (c) expressed a need to learn more so they can advocate more effectively for their children.

RQ 2: Does the FACES Program Strengthen Empowerment in African American Parents of Children with ASD?

As a construct, empowerment is often associated with power and having the ability to influence the environments that affect peoples’ lives (Koren et al., 1992). To explore the degree to which FACES had an impact on parents’ perceptions of empowerment, I administered the Family Empowerment Scale (FES) before and after the intervention. Following the 6-week FACES program, findings indicated increased FES scores and positive perceptions of family empowerment.

The Wilcoxon Signed-Ranks Test indicated that post-FACES scores on the FES family subscale, service system subscale, and community/political subscale were statistically significantly higher than pre-FACES scores on the FES family subscale ($Z = -2.53, p = .01, ES = -.57$), FES service system subscale ($Z = -2.08, p = .04, ES = -.47$), and the FES community/political subscale ($Z = -2.45, p = .01, ES = -.55$) with moderate effect sizes (see Table 3).

Table 3

Findings for RQ2

Research question		Wilcoxon signed-rank analysis pre/post survey			<i>Z</i>	<i>p</i>	<i>r</i>	Categories and codes qualitative data
		Pre Mean (SD)	Post Mean (SD)					
Does the FACES program strengthen empowerment in African American parents of children with ASD?	FES (Family)	46.00 (5.03)	50.90 (5.76)	-2.53	.01	-.57	Empowerment • Dismantling stigma • Managing emotions • Addressing child needs	
	FES (Service)	49.40 (7.73)	54.20 (5.47)	-2.08	.04	-.47		
	FES (Com/Pol)	29.60 (7.49)	35.60 (4.72)	-2.45	.01	-.55		

Note. FES = Family Empowerment Scale.

The survey findings related to positive perceptions of empowerment following the FACES program were further substantiated by data from the post FACES focus group interviews and participant testimonials. Participants reflected on what they learned and how they benefited from the FACES program; their reflections revealed stronger perceptions of empowerment related to dismantling stigma, managing emotions (e.g., fewer feelings of embarrassment), and feeling more confident in their abilities to address their children's needs (i.e., self-efficacy). Antwon, a father of a 3-year-old son who attended FACES on occasion with his wife, Alicia, shared the challenges he faced with tackling stigma related to disability in his family and community before joining the FACES program. Antwon explained that he felt better prepared to tackle stigma following FACES:

Denial is a major thing too. You are a black family. Typically they are like, "he is alright." It is very frustrating to have to try to explain something to people who are not accepting. But FACES actually helps you develop a language. It gives you the application of the language. I think that is what is important. (post-FACES focus group 2, p. 10-11)

Mary, a mother of 6-year-old twins, one of whom has ASD, shared how FACES helped build her confidence in supporting her son's needs: "the support right here is huge because I just feel more confident about taking him places and just letting him be him. Before FACES, I didn't know how I was going to do it" (post-FACES focus group 2, p. 2).

When participants were asked to share how FACES has strengthened their feelings of empowerment, Alicia noted that FACES provided a space for her to think through the importance of balancing her emotions. She shared the following, "Checking your emotions at the door. We have learned to bring someone with us to meetings in case we need to step out, check our emotions, or bounce off of one another" (post-FACES focus group, p.15). Alicia shared more during her testimonial about controlling her emotions:

I have learned within FACES, the importance of controlling my emotions before going into a meeting. I know when it comes to [my child], whether it's doctors or social service providers, and now school, it's your kid. You have emotions invested. It's your baby and your defenses are up—I am like mother lion type. But what's most important is making sure the goals that we have set for [my son] and things that I know that he is interested in, that those things are happening. (Participant testimonial, 8)

While reflecting on the impact of historical practices related to raising individuals with disabilities, particularly within African American communities, Mary shared her thoughts:

We are first generation to bring our kids out in public. What I am learning and what I am finding out is that was true for a lot of autistic kids. I was doing it too. I wanted to keep them inside. But the more we force it, it forces people to actually see the diversity in autism. (post-FACES focus group 2, p. 10)

Antwon shared the following about how FACES has impacted and empowered him to feel more confident in his abilities to meet the needs of his family:

I just want to continue to advocate. I love my son. I love my wife. I love my family and I just feel like this right here, it re-educates me and it makes me know that there is no limitation to how great my son can be; he can still obtain some of the things that I had envisioned for being a man and having a son. FACES has definitely re-instilled and opened values of fatherhood to me again. (participant testimonial, 9)

Finally, Nanci shared how participating in FACES helped her feel more confident to seek and obtain the services and resources she needs for her son:

Prior to coming here, I didn't have that much information so I am grateful that I was able to gain this information that I have gotten by coming to FACES the last 6 weeks. With that, I feel more confident. (participant testimonial, 7)

While participants' perceptions of empowerment were reflected in a multiplicity of ways, each participant shared components of the FACES program that helped them feel more empowered to meet the needs of their children and their families. Overall, data from multiple sources supported stronger perceptions of empowerment among FACES participants following the intervention.

Perceived Empowerment

During the formative evaluations, when asked how relevant the FACES sessions were in helping the participants feel more empowered, 64.1% of the participants were “extremely satisfied,” 17.9% were “moderately satisfied,” 12.8% were “satisfied,” 2.6% were slightly, and 2.6% were “not at all satisfied” with the degree to which the sessions helped them feel more empowered (across all six training sessions). The 5.2% of the participants who indicated that they were “slightly satisfied” or “not at all satisfied” with the degree to which the FACES sessions helped them feel more empowered selected those responses following FACES session one ($n = 1$) and FACES session two ($n = 1$; formative evaluations, item four). The participant who selected “slightly satisfied” following session recommended two improvements: “more videos and small group discussions” (formative evaluation, item eight), and “more role-playing of communication strategies” (formative evaluation, item nine).

RQ 2a: Does the FACES Program Increase Parents’ Knowledge of ASD?

Following FACES, a number of themes emerged that were specific to participants’ knowledge and understanding of ASD (and disability, more generally). Post focus group interviews, testimonials, and summative evaluations indicated that participants benefitted from outcomes such as: increased knowledge of the prevalence and impact of ASD in the African American community, more knowledge around special education rights, laws, and procedures, and increased knowledge of resources for individuals with ASD (Figure 8).

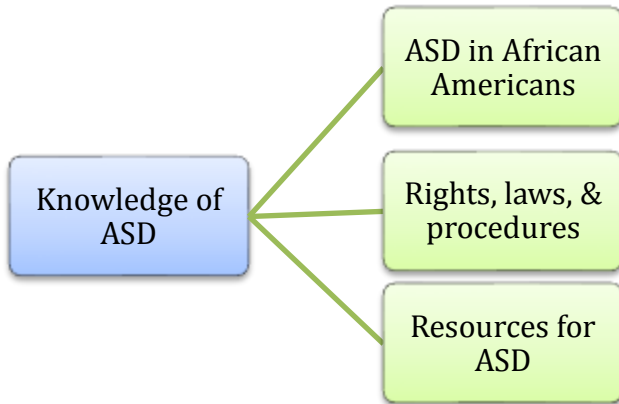


Figure 8. Findings for RQ 2a.

Luke shared the following about what he learned related to ASD among African American children, following FACES:

One thing that I did learn about the African American community is that our children are diagnosed with it later on. For one or two reasons: one, because they just don't have the medical resources to be able to go in for the early intervention and two, there is this bad stigma among the African American community. There is a lot of denial there. (Post focus group 1, p.4)

Alicia reflected on what she learned from FACES and how she has gained more knowledge about her rights for her son and has also learned more about resources that are available to her family in their community:

I think we have learned more about our rights. That was like the whole point of coming here--knowing more about our rights and guides and resources to exercise those rights. We just learned more resources that we may need to access for our child. This was a centralized, six-week boot camp. (post-FACES focus group, p. 15)

Alicia shared what she learned about the importance of documentation:

I have learned the importance of documentation. Even though I know the importance of documentation, it's kind of different when you are thinking about documenting your child's development and their interactions with other people. So, I am considering different methods of taking that on. In the future I plan to make sure everyone involved in [my child's] development has a journal, and I will be able to collect those journals and share those journals, have some sort of exchange, so we are working holistically for my baby, because it really does take a village. (participant testimonial 8)

Finally, Tamryn, a mother of a 10-year-old son shared how she had fears related to ASD prior to joining the FACES program, but now she feels like she has gained enough knowledge to be able to help other parents dispel myths and ease their anxieties related to ASD, “if I could help somebody, I would let them know that autism is not scary; I was scared at first—I thought it was like a disease or something, but it’s okay” (participant testimonial 5).

Overall, parents’ knowledge of ASD following FACES was related to disparities in the African American community (e.g., delayed diagnosis), rights, laws, and procedures, and, resources for children with ASD. Following FACES session two, which focused on ASD prevalence and disparities of ASD diagnoses in African American communities, participants were asked to share what they got the most out of. One participant shared, “this was my first time really talking with other African American families with children with autism” (formative evaluation, item six).

RQ 2b/2c: Does the FACES Program Strengthen Parent’s Understanding of and Confidence in Implementing Social Communication Strategies and Managing Behavior?

To explore parents’ perceptions of their understanding of and confidence in implementing social communication strategies and managing their children’s behavior, I administered the FACES scale before and after the intervention. Following the six-week FACES training, findings indicated that the program contributed to increased FACES scores and positive perceptions of skills related to social communication and behavior management strategies.

The Wilcoxon Signed-Ranks Test indicated that post-FACES scores on the FACES scale were statistically significantly higher than pre-FACES scores on the FACES scale ($Z = -2.46$, $p = .01$, $ES = -.55$) with a moderate effect size (see Table 4).

Table 4

Findings for RQs 2b/2c

Research question	Wilcoxon signed-rank analysis pre/post FACES Scale					Categories and codes qualitative data	
	FACES Scale	Pre Mean (SD)	Post Mean (SD)	Z	p		r
2b. Does the FACES program strengthen parents' understanding of and confidence in their ability to implement social communication strategies?	FACES Scale	24.60 (6.54)	30.30 (3.53)	-2.46	.01	-.55	Social Communication and behavior <ul style="list-style-type: none"> • Increased patience • Planned ignoring • Using visual supports, tools and strategies • School communication and carryover
2c. Does the FACES program strengthen parents' understanding of and confidence in managing behavior?							

Note. FACES Scale = seven-item scale developed for this study.

The FACES Scale survey findings related to parents' perceptions of their ability to manage behavior and implement social communication strategies following the FACES program were strengthened by data from the post FACES focus group interviews, formative evaluations, and parent testimonials. Participants highlighted strategies that they adopted following FACES, to increase social communication skills and manage behavior among their children. The social communication and behavior management parenting strategies included increased patience, planned ignoring, and using visuals supports, and school communication/carry-over (e.g., ensuring consistency in behavior management across settings). When asked to share what they got the most out of following the session on social communication, participant responses shared, "[I got the most out of] communication and modeling," and "[I got the most out of] the communication strategies presentation" (formative evaluations, session 3).

Janice shared how learning to practice more patience has helped her manage some of her son's challenging behaviors, and she notes that she has been motivated to implement strategies that require trial and error, and are not always effective:

We are learning a lot of patience. Even though we see ourselves as the seniors (parents of an older child who have been navigating services for several years), there is always so much to learn from other people and how they deal with their children. We are trying things that we heard in the group. They work, or they don't work. It depends on each child because each child is different. (post-FACES focus 2, group, p. 5)

Antwon also reflected on how having more patience and higher expectations with his three-year-old son is a critical practice for his family and more importantly, for his son's social-emotional development:

I have learned to have high expectations in this transition. Just to expect for him to grow and just basically have patience in the transitions of him growing. Instead of like forcing it on him or looking at his cousins and comparing him, just having patience in the process of him coming along. (post-FACES focus group 2, p. 9)

Likewise, in response to what he learned about increasing communication and managing behavior, Chris shared, "I have learned to be more patient" (post-FACES focus group 2, p. 8).

Erika, a single mother, had found herself completing activities of daily living for her daughter, even when she knew she was capable of completing many of those tasks independently. She shared the following about what she learned and adopted during FACES:

In the past, I would let her get away with stuff. The old me would have stopped what I was doing to find her shoes. "Noel are you going to find your shoes? We are going to be late; if you want to go to the library go and find your shoes." And I continued to get dressed. [She'd say] "I can't find my shoes." "Well yes you can. Check in front of the tv." She found them. I didn't stop what I was doing to get the shoes. I learned to expect more of her. (post-FACES focus group 2, p. 8)

During session four of the FACES program, participants created visual supports to use with their children. During the post focus group, Alicia reflected on how developing her own visuals supports has shaped how she uses them with her son:

Coming to these groups made me realize that all the visuals don't just have to be about academics. I know better as an adult but I didn't think that way for my child. I am a community organizer. The learning isn't just about academics. I had to think about his social and emotional development too. And I can use visuals for that too. And it is okay. (post-FACES focus group 2, p. 10)

Overall, post-FACES scores on the FACES scale, post focus group interview data, and participant testimonial data indicated that participants had strengthened perceptions of their ability to manage behavior and implement social communication strategies following the intervention.

RQ 2d: Does the FACES Program Increase Parent-Professional Communication and Partnership as Reported by Parents?

To explore the extent to which the FACES program strengthened parent-professional communication and partnerships, I administered the Family-Professional Partnership Scale (FPPS) and School Communication scales (SCS) before and after the intervention. Following the 6-week FACES program, findings indicated that there was no significant increase in parent-professional partnership as measured by the FPPS and the SCS (see table 5).

Table 5

Findings for RQ 2d

		Wilcoxon signed-rank analysis pre/post survey Quantitative data					Categories and codes qualitative data
Research question		Pre mean (SD)	Post mean (SD)	Z	p	r	
2d. Does the FACES program increase parent-professional communication as reported by parents?	SCS	25.80 (5.55)	26.70 (6.06)	-0.93	.35	-.21	Parent-Professional Partnerships - • Prepared to communicate with professionals -
	FPPS (Child)	36.00 (4.85)	37.00 (3.68)	-0.69	.49	-.15	
	FPPS (Family)	38.80 (3.62)	38.80 (3.62)	-0.12	.91	-.52	

Note. SCS = Social Communication Scale (Burke et al., 2016); FPPS = Family-Professional Partnership Scale (Summers et al., 2005).

The Wilcoxon Signed-Ranks Test indicated that post-FACES scores on the SCS were not statistically significantly higher than pre-FACES scores on the SCS ($Z = -0.93, p = .35, ES = -.21$). Moreover, the Wilcoxon Signed-Ranks Test indicated that post-FACES scores on the family-professionals child and family subscales were not statistically significantly higher than pre-FACES scores on the family-professionals child subscale ($Z = -0.69, p = .49, ES = -.15$) or the family-professionals family subscale ($Z = -0.12, p = .91, ES = -.52$).

Findings from post-focus group interviews and participant testimonials highlighted parents' perceptions of communication and collaboration with professionals. While participants did not share specific examples of how they had built strong parent-professional partnerships over the course of the FACES program, they did highlight ways that they felt better prepared to build more positive parent-professional partnerships in the future, following FACES.

Alicia shared how important it is for her to engage in effective communication with professionals to better meet the needs of her son,

In order to effectively get to those goals, I have to have solid communication and trust, which can only be built through that solid communication with the other people who are in his life. The teachers won't be replaced; the social workers won't be replaced, so communicating, setting my expectations, and understanding theirs, is what is most important for my son. (participant testimonial, 8)

Similarly, Catherine highlighted the importance of communicating with professionals:

What we shared with other parents is to stay in constant communication with the educational staff so that the IEP meeting and any other kind of meeting won't be so difficult. If you are on the same page all working toward the same goals, the IEP meeting shouldn't be such a distraction and you are able to keep your heart in place because you have already talked. Everybody already knows what is needed so it won't be so emotional. (post-FACES focus group 1, p.7)

Nanci shared how she feels better prepared to communicate with her son's providers, now that she has more knowledge of materials and resources following her participation in the FACES program:

My son has an ABA (applied behavior analysis) session coming up in December, for an actual assessment, so with me having this knowledge and the resources now, I can pre-research what I need to know prior going into this assessment with the provider, so now I don't feel so timid. I feel more confident going into this appointment in December. For that, I am grateful. (participant testimonial 7)

Across the participants, though not evidenced by the findings from the pre/post surveys, qualitative findings indicated that parents acquired skills and strategies that would enable them to develop effective parent-professional partnerships in the future.

RQ 2e: In What Ways and to What Extent Does the FACES Program Strengthen Parents' Perceptions of Their Ability to Advocate Effectively for Services for Their Children With ASD?

Advocacy in special education differs from empowerment, in that it focuses specifically on the actions and activities that parents engage in on behalf of their children (Burke & Hodapp, 2016). Advocacy is an active exercise of empowerment that contributes to problem-solving and developing solutions (Munro, 1991). Therefore, to explore the extent to which the FACES program strengthened parents' abilities to problem-solve and develop solutions to meet the needs of their children, I administered the Special Education Advocacy Scale before and after the intervention. Following the six-week FACES program, data analysis indicated that the FACES program contributed to increased scores on the Special Education Advocacy Scale and positive perceptions of advocacy strengths and abilities (see Table 6).

Table 6

Findings for RQ 2e

Research question		Wilcoxon signed-rank analysis pre/post advocacy scale					Categories and codes qualitative data
		Pre mean (SD)	Post mean (SD)	Z	p	r	
2e. In what ways and to what extent does the FACES program strengthen parents' reported perceptions of their ability to advocate effectively for services for their children with ASD?	SEAS	34.60 (8.07)	41.20 (4.13)	-2.32	.02	-.52	Advocacy <ul style="list-style-type: none"> • Sharing knowledge with others • Knowledge and Understanding of ASD • Skills for stronger advocacy • Knowledge of SPED laws

Note. SEAS= Special Education Advocacy Scale.

The Wilcoxon Signed-Ranks Test indicated that post-FACES scores on the Special Education Advocacy scale were statistically significantly higher than pre-FACES scores on the Special Education Advocacy scale ($Z = -2.32, p = .02, ES = -.52$).

Parents' perceptions of their advocacy strengths and abilities were also reflected in the post-FACES focus group interviews and participant testimonials. When participants were asked to discuss their perceptions of advocacy following FACES, one of the most common themes was parents' increased confidence in their ability to share knowledge with others about autism. Participants indicated that participating in FACES enabled them to develop more knowledge about autism in African American communities, and then to share that knowledge, by dismantling stigmas and myths in their communities. Catherine, for example, shared the following:

The training in FACES has prepared the parents that are here to go out and spread the good word to other parents of color because sometimes that information was not available to them and then sometimes because of the stigma of a disability they don't always go towards the information. (post-FACES focus group one, p. 3)

Other participants reflected on how FACES provided them with information that enabled them to be stronger advocates. Luke, for example, shared the following with regard to how FACES has prepared him to be a stronger advocate, “It gave us information that we didn’t have before. Information we didn’t even know existed. So in that regard it kind of built our arsenal for what we can use to be able to advocate” (post-FACES focus group 1, p. 7). Luke went on to express how his participation in FACES not only encouraged him to advocate on his son’s behalf, but also on behalf of other families of children with ASD:

In the future I see myself not just being an advocate for my own son, but an advocate for others. As the old saying goes, “when you know better, you do better.” So now that I know so much more it makes me want to reach out and advocate for others, especially those that are being misunderstood . . . if I can help some other parent who may not have any idea of what they are dealing with and lead them somewhere so they can find help, be able to help their child, that to me would be very, very rewarding. That’s what I would like to do with this knowledge going into the future. (participant testimonial 3)

Luke’s wife Phoebe, also shared how she plans to use her knowledge for advocacy in the future:

I received a lot of knowledge regarding the IEP. You can never receive enough knowledge and information. I desire to be able to apply it even more, being an advocate for my son. Not only just my son, I desire to be an advocate for other children. Even since we have been in the program, I have shared knowledge to others, to family members as well as individuals from church. (participant testimonial 3)

Catherine shared how having more knowledge of special education laws helped her feel stronger about her ability to advocate effectively:

FACES gave you the resources as far as special education law and special education facts to back up what you as a parent can say. So not only can I say that I feel my child needs this but my child should receive this. Now I have a background, I have facts. It’s like I have a law book running through my head saying this is what we are going to do. (Post focus group 1, p. 6)

She went on to share the following:

I have the right that if I don’t agree that I can appeal and if I still feel that it doesn’t work that way I know that I can go through legislation to make a change. I am not making a change just for my child but making a change for children that are present and the

children that are coming after him. So [FACES] made my foundation stronger to ask, to demand, and to expect good things in return for him. (post-FACES focus group 1, p. 6-7)

Moreover, Janice shared the following about what she gained from FACES in terms of advocacy:

What I got out of FACES was a lot of the advocacy part. Making sure that you stand up for your child because nobody else is going to do it. The communication amongst others about autism and what they can expect, what you know, how to communicate with other people about your child because like we've always said, nobody else is going to be an advocate for your child like you are. (participant testimonial 1)

Chris shared similar views, "The information I received, it gives me more confidence when I go into the school, and the doctor's office, to advocate more" (participant testimonial 2).

Other parents discussed their plans for advocating in the future. Erika, for example, shared the following:

I am going to try to advocate for after school groups that all parents can access and participate in, regardless of income. It's at the school, so that the kids are there, they are already in a safe place. It really equalize the afterschool needs of kids on the spectrum versus kids who are neuro-typical, because they need that time to really be with their friends, they need time to really practice socializing, and in schools, during the day you are supposed to be quiet and focused, do your work, be quiet, and as adults we don't do that. I hope to use my newly learned advocating skills to try to advocate for things that are not always talked about. We talk a lot about services. We talk a lot about ABA therapy. And that's all well and good, but we need to talk about helping the whole family have a high quality of life. (participant testimonial 6)

Finally, Nanci reflected on how she, too, felt better prepared to advocate on behalf of her son, "I feel that with this information I can continue to advocate for [my son] in his schools, with service providers, and down the line" (participant testimonial, 7).

During the post FACES focus groups, all FACES participants indicated that they felt better equipped to advocate in both formal and informal ways. Following the FACES program, findings indicated that participants had more knowledge, information, and access to resources that prepared them to engage in constructive activities that can contribute to solutions that meet

the needs of their children (Burke & Hodapp, 2016; Munro, 1991). When asked if they felt the FACES training prepared them to advocate for their children with ASD, all of the participants reported, “yes.” (summative evaluations, item one, overall). When asked to rate the relevance of the FACES topics in developing their roles as advocates, seven participants (87.5%) rated the FACES topics as “extremely relevant” or “moderately relevant” to their role as advocates.

Preparation for Advocacy

During the summative evaluations, when asked how relevant the FACES session was to becoming an advocate, 67.5% of the participants indicated that they were “extremely satisfied,” 15% reported that they were “moderately satisfied,” and 17.5% of the participants reported that they were satisfied with the degree to which the sessions were relevant to becoming an advocate. Overall, 50% of the participants indicated that the FACES program included topics that were “extremely relevant” to developing their role as advocates, while 37.5% of the participants indicated that the FACES program included topics that were “moderately relevant” to developing their role as advocates, and 12.5% indicated that the FACES program included topics that were “relevant” to developing their role as advocates (summative evaluation, item two). When asked if the FACES program should devote any additional time to a specific topic, one participant suggested, “finances and advocacy” (summative evaluation, item six).

RQ 3: How do African American Parents of Children With ASD Perceive the Social Validity of the Goals, Procedures, and Outcomes of the FACES Program?

Social validity. The post-*FACES* focus group interviews, formative evaluations, summative evaluations, and participant testimonials were analyzed to assess the degree to which the FACES program met the needs of African American parents of children with ASD (i.e.,

participants' overall views of the FACES training, importance of the goals, procedures, and outcomes).

Participant attendance and attrition. Overall, 53.84% of the FACES participants attended all six sessions and 76.92% ($n = 10$) of the FACES participants attended (or viewed videos) at least five out of six sessions. In addition, at least one guest (i.e., non-participant who accompanied a family member/participant) was present during each FACES session.

Of the participants who were not included in data analysis ($n = 3$), Alicia attended four of the training sessions, stayed in contact with the research team following her absences, and completed all other study components (other than the attendance requirement). Alicia reported that she missed one session because she and her family were moving into a new apartment; she missed a second session due to extenuating circumstances in her community (i.e., a murder near her apartment). The remaining two participants (Deborah and Marva) attended three sessions and one session, respectively. Deborah and Marva did not complete the post-FACES surveys, did not attend post-FACES focus groups, and they did not respond to contact emails regarding their absences. These three participants constituted the attrition rate at 21.08% ($n = 3$).

Sense of community. When asked to share their views about the FACES program, all 10 FACES participants identified sense of community as one of the greatest benefits of the program. Participants indicated that FACES created a space where they could (a) network, (b) learn from shared experiences, (c) discuss stigma and disability in African American communities, and (d) develop a support system (see Figure 9).

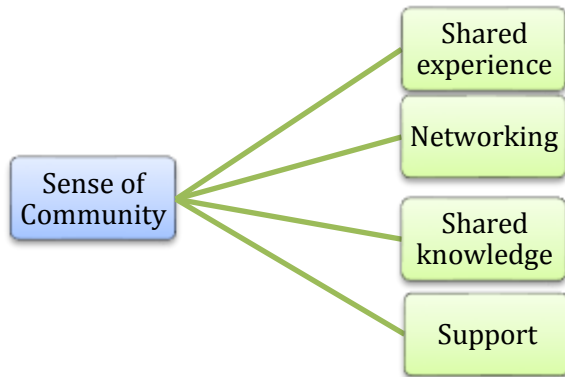


Figure 9. Post-FACES social validity: sense of community.

Luke shared the following about how FACES created a sense of community for him and his family:

To find out first that FACES even existed was a breath of fresh air for me and my family. Our son was officially diagnosed with autism last year some time in October. I think what is typical with parents whose child has been diagnosed is that you can feel a little alone because you may not know anyone directly around you who has experienced the same things. So you don't know who you can talk to. You don't know who you can share this with. You do not know who will understand. And then all of a sudden you run into something like FACES and then you realize that there is this entire community of people who share the exact same experience. (post-FACES focus group 1, p. 1)

Similarly, while reflecting about how FACES became a source of support for her, Mary shared the following:

I think the worst part is when you are handling challenges privately. You know that when you are sick because of your secrets. And as I slowly started to talk about it with more friends and family and then the support here has just made me feel so much better. (post-FACES focus group 2, p. 2)

During her reflection on FACES outcomes, Janice spoke to the importance of the networking experiences, "We didn't always stick to what was on the sheet or what was in the weekly plan but we always had insightful passionate emotional conversations that I think we all gained a lot from" (post-FACES focus group 2, p. 1). "We got to network with people and listen to other people's ideas and thoughts about their kids" (participant testimonial 1).

Antwon shared his thoughts about how the FACES program created a supportive community and safe space that was therapeutic for him.

FACES is therapeutic. It's therapeutic. Just hearing a lot of your stories, being here, and being in one space and sharing that energy. Just knowing and understanding as a man and just seeing a man. And to be able to be like you know act like, he is struggling too. It's rejuvenation. Come on Saturday and be prepared for Monday. (post-FACES focus group 2, p. 15-16)

Mary also shared her thoughts about how being around other FACES families has supported her by helping her stay on track with tasks that she wanted to accomplish for her son and their family:

I look forward to Saturday because I have a huge folder and FACES keeps me on task; just being around you guys and to be able to voice that. You guys give me more information. It keeps me on task to say I have to work on that, and keep up with that, and do that. (post-FACES focus group 2, p. 16)

Chris noted how FACES created a family feeling that included a space to express shared experiences:

I think what I received from this program, this training, is good parents, good information, and more resources. I am not the only parent out here—I know that other parents are reporting the same struggles that we go through. We have an opportunity to share some of our different experience with our kids at school, at home, and out in society. I am looking forward to keeping a lot of the parents' information so we can build that relationship so we can move forward as our kids kind of grow together. So it's like having a family. (participant testimonial 2)

Finally, as reflected in her direct communication to another FACES participant, Phoebe indicated that participating in FACES provided her with an opportunity to learn more about being patient with her son:

I was observing you because I am admiring how you are displaying more patience. I wish I could be patient. I tend to feel like I may over react you know because he appears so normal. But your knowledge is blessing me. (pre-FACES focus group, p. 20)

Participant satisfaction. Formative evaluations, summative evaluations, focus group interview data, and participant testimonials indicated that participants were highly satisfied with

the FACES program. On average, eight participants completed the formative evaluations each week; therefore, the formative evaluation data represents $n = 40$ and the summative evaluation data represents $n = 8$. See Figure 10 for participant satisfaction across all six FACES sessions based on formative evaluation data, and Figure 11 for participant satisfaction based on summative evaluation data.

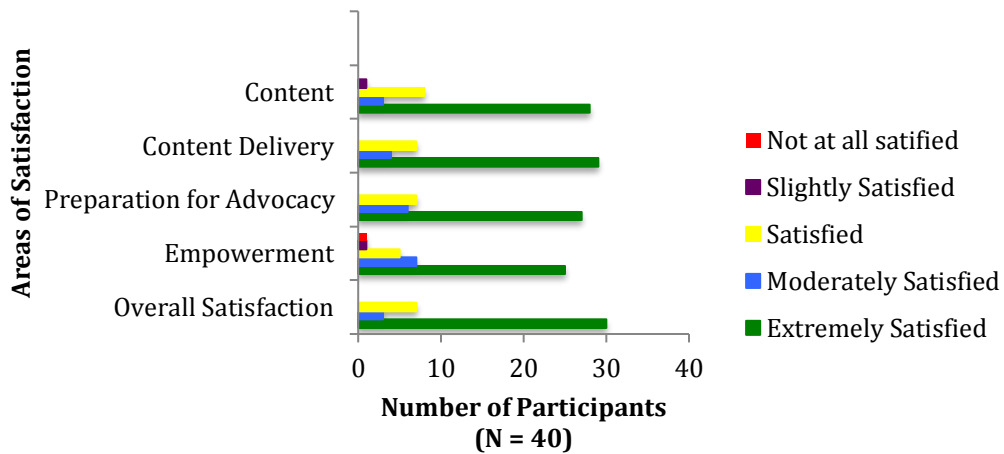


Figure 10. Post-FACES social validity: participants' satisfaction across FACES sessions.

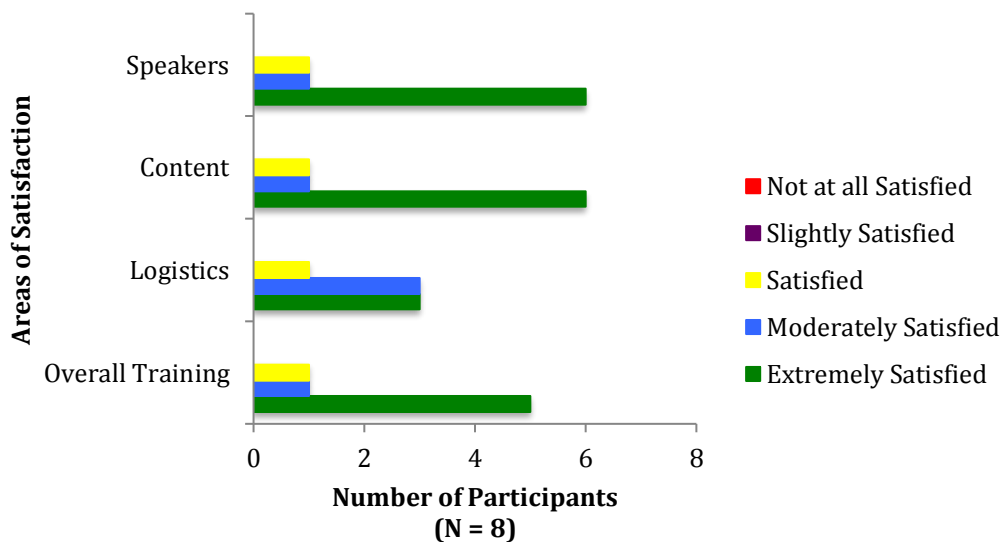


Figure 11. Post-FACES social validity: participants' overall satisfaction following the FACES program.

Content. Across all six FACES sessions, 70% of the participants reported being “extremely satisfied” with the information that was covered during the sessions, 7.5% were “moderately satisfied” (sessions two; [$n = 2$] and session three; [$n = 1$]), 20% were “satisfied” (session one; [$n = 1$]; session two; [$n = 2$]; session three; [$n = 3$]; session four; [$n = 1$]; session five; [$n = 1$]), and 2.5% were “slightly satisfied” (session two; [$n = 1$]; formative evaluations, item one). The participant who indicated that she was “slightly satisfied,” with the content of FACES session two reported, “I think everything is going good.” when asked to provide suggestions for future sessions (formative evaluation, item eight).

In addition, 75% of the participants indicated that the FACES topics were “extremely relevant,” 12.5% of the participants indicated that the FACES topics were “moderately relevant,” and 12.5% of the participants indicated that the topics were “relevant” (summative evaluations, item one). One participant suggested that the content of the FACES training as delivered, was good. He/she shared the following, “you covered great topics” (summative evaluation, item three).

Content delivery. With regard to the way the information was delivered, 82.5% of the participants were “extremely satisfied” or “moderately satisfied,” while the remaining 17.5% of the participants reported being “satisfied” with the way the information was delivered (formative evaluations, item two). Moreover, 75% of the participants indicated that they were “extremely satisfied” with the speakers’ knowledge, while 12.5% indicated that they were “moderately satisfied,” and 12.5% were “satisfied” with the speakers’ knowledge (summative evaluation, item one).

Overall satisfaction. When asked to indicate their *overall* satisfaction with the FACES sessions, 75% of the participants indicated that they were “extremely satisfied,” 7.5% indicated

that they were “moderately satisfied,” and 17.5% of the participants indicated that they were “satisfied” with the program (formative evaluations, item five). During the post focus group, Janice said,

I thought it was a wonderful training. I thought it was a great networking opportunity; I learned so much. I felt that we gained so much as parents. Knowing more about autism. Some of the slides that Jamie had were like, “Wow! I didn’t know that.” So I thought that overall I would recommend it. Overall, I would come back if I could. (Post focus group, p. 1)

Phoebe shared her thoughts about FACES, “I appreciate the program that we participated in. I enjoyed the coordination of how everything went and the providers—everything was put together beautifully” (participant testimonial 3).

On the summative evaluations, participants indicated that overall, they were satisfied with the FACES program (see Figure 9). When asked if the FACES training met participant expectations and to explain why or why not, participants shared the following:

“Yes, FACES empowered me.”

“Yes. I have more knowledge and access to resources.”

“Yes, it has exposed me to a complete new world of resources regarding my son.”

“The information I received has been more than I expected” (summative evaluations, overall, item four).

Logistics. In regards to the length of the sessions, 81.3% of the participants indicated that the FACES session length (i.e., three hours) was “just right” while 18.8% of the participants suggested that the FACES sessions were “too short” (formative evaluations, item seven). When asked about the convenience of the day on which the sessions were held (i.e., Saturday), 62.5% of the participants indicated that Saturdays were “very convenient,” 25% of the participants indicated that Saturdays were “convenient,” and 12.5% of the participants indicated that

Saturdays were “somewhat convenient.” All ten participants agreed that the training should *not* be changed from Saturdays (summative evaluation, logistics, item 10). Moreover, 50% of the participants indicated that the time of the training (i.e., 9:30 am-12:30 pm) was “very convenient” and 50% of the participants indicated that the time of the training was “convenient” (summative evaluation, logistics, item one). In terms of parking, 42.9% of the participants indicated that the parking was “very convenient,” 28.6% indicated that the parking was “convenient,” and 28.6% of the participants indicated that the parking was “somewhat convenient” (summative evaluations, logistics, item three). All ten participants indicated that they were very comfortable (87.5%) or comfortable (12.5%) in the rooms provided for the FACES training (summative evaluations, logistics, item four), and 100% of the participants agreed that the same location would be appropriate for future trainings in their area (summative evaluations, logistics, item seven).

Recommendations for future FACES trainings. When asked if there were any other topics they felt the FACES training should have covered, participants indicated that they wanted to know more about (a) special needs trusts, (b) acceptance, (c) the importance of father involvement, (d) sibling behavior, and (e) financial resources and support. Erika, for example, shared the following:

I also need to learn how to advocate for more money. I don't think we covered that enough (the expense for raising children on the spectrum). I looked at my healthcare bill the other day and my insurance company has spent over almost \$275,000 on autism treatments. I had to sit down. I mean, and that's not out of my pocket, but I have had to pay for the insurance that would pay that, and what if I didn't have that insurance? What if I didn't have that job? And even with that insurance, and even with that job, I still can't pay my other bills all of the time. I am still waking up worrying what bills aren't going to get paid this month, because I have to make sure the insurance is paid.
(participant testimonial six)

When asked if there were any topics included in the FACES training that should be left out in future trainings, 100% of the participants responded, “no” (Summative evaluation, logistics, item ten). When asked if we should change the meeting time for each session, 25% of the participants recommended starting the sessions later in the morning (i.e., 10am; Summative evaluation, logistics, item six). When asked if we should change the number of sessions included in the program, 50% of the participants recommended that we keep the number of sessions the same (i.e., six) and 50% of the participants indicated that they would like to have more sessions (e.g., 8-10; summative evaluations, logistics, item nine). Finally, all participants agreed that they would like to be added to an email list serve to stay in touch with the researchers and fellow participants of the FACES program (post-FACES focus groups, summative evaluation overall, item five). Catherine shared the following:

When you don't have a village to help you sometimes you have to reach out. I think these parents here are reachable you know. I would like to stay in contact because sometimes it is a lonely road when you think your kid is the only one but you know I think that if these kids kind of get together, they will be fine. (post-FACES focus group)

Chapter 5

Discussion

The purpose of this study was to understand African American parents' experiences with advocacy on behalf of their children with ASD, and, to develop and pilot the FACES program. To answer each of the research questions, I (a) conducted a pre-FACES focus group, (b) administered a pre-FACES survey, (c) developed and implemented a six-week parent advocacy-training program, (d) administered a post-FACES survey, (e) conducted post-FACES focus groups, and (f) recorded participant testimonials. Following a sequential mixed methods approach, I collected data from multiple sources (i.e., pre/post surveys, focus group interviews, formative evaluations, summative evaluations, and participant testimonials). During data collection, I mixed data for the purpose of development, and following data collection I mixed the data to answer the research questions.

Revisiting the Theory of Change

Based on the theory of change, I expected that following FACES, proximal outcomes for participants (i.e., parents) would include: increased knowledge of ASD, increased understanding and confidence in implementing social communication strategies, and increased understanding and confidence in managing behavior. I expected that outcomes for participants would include: strengthened positive perceptions of parent-professional partnerships, strengthened perceptions of empowerment, and strengthened perceptions of advocacy skills. Findings indicated that (a) parent knowledge and understanding of ASD and (b) parent perceptions of advocacy and empowerment resulted in bidirectional relations where knowledge not only provided a foundation for advocacy and empowerment, but perceptions of advocacy and empowerment also impact parent knowledge.

Overall findings. With the exception of participants' perceptions of parent-professional partnerships, the overall findings were consistent with the expected outcomes noted in the FACES theory of change. Regarding participants' experiences with advocacy prior to FACES, findings indicated that (a) parents employed several types of strategies to advocate on behalf of their children, (b) held specific ideas of what advocacy should look like, and (c) identified barriers that were prohibitive of engaging in advocacy efforts on behalf of their children. Following the FACES program, participants demonstrated (a) stronger perceptions of advocacy skills, (b) stronger feelings of empowerment, (c) greater knowledge of ASD, (d) greater confidence in implementing social communication strategies, and (e) greater confidence in managing problem behavior. Overall, participants were satisfied (i.e., social validity) with the FACES program and offered specific recommendations to further improve future FACES trainings.

Revisiting the conceptual model. Following the FACES program, findings indicated that participants learned from shared knowledge and experiences with other participants who came from a similar cultural background, and they valued the strong sense of community that they developed during the program. This sense of *community* enhanced the outcomes related to participants' perceptions of advocacy, empowerment, and partnership following FACES program. Given the importance of the sense of community that participants developed, the FACES conceptual model was revised to reflect how participants' feelings of community connectedness has the potential to (a) enhance advocacy, empowerment, and partnership, and (b) strengthen child outcomes and family quality of life. The aim of the revised FACES conceptual model, then, is to represent through an ecological systems lens, the complexity of identity, ability, advocacy, empowerment, parenting practices *and community* that ultimately shape child

outcomes for African American children with ASD and their families (see the revised conceptual model in Figure 12).



Figure 12. Revised FACES conceptual model.

Empowerment

Following FACES, parent's scores on the FES increased and parents reported positive perceptions of family empowerment. Parents' strengthened perceptions of empowerment were related to dismantling stigma in their communities, having fewer feelings of embarrassment (about parenting a child with ASD), and increased sense of self-efficacy. While FACES is the first known advocacy and empowerment training adapted to meet needs specific to African American parents of children with ASD, the findings are corroborated by the work of Burke et al (2016). Following the LPLSP, a parent advocacy program for Latino families, Burke and colleagues found the advocacy training to be both feasible and effective in increasing parents' feelings of empowerment and knowledge of advocacy skills among Latino families. In their qualitative work, Burkett et al. (2015) found that African American families of children with

ASD believed a stigma of disability existed in their communities, and indicated that they wanted to change their communities' knowledge and perception of ASD through education and awareness initiatives. These sentiments are echoed in the FACES participants' desires and determination to increase awareness and decrease stigma in their communities. Therefore, the FACES program is one example of an approach to provide African American parents of children with ASD with the knowledge, tools, and feelings of empowerment to shift perceptions and dismantle the stigma related to ASD (and other disabilities) in their communities.

Advocacy

Before FACES, parents engaged in advocacy strategies such as sharing knowledge, volunteering in their children's schools, meeting with teachers, requesting accommodations, building knowledge about their children's skills and abilities, and working to build their knowledge of special education rights and laws. The ways that parents engaged in advocacy efforts prior to FACES were consistent with the literature on parent advocacy among European American and Latino families. That is, for some parents, advocacy is specific to their child (i.e., the "intuitive advocate"; Trainor, 2010), and for other parents, advocacy is political. Still for other parents, advocacy includes improved public awareness and community education (Wright & Taylor, 2014). Similarly, Burke and colleagues (under review) identified advocacy strategies that parents (though not all African American) use on behalf of their children with social-communication needs. They identified strategies that were consistent with the findings from the current study: communicating with the school and acquiring and sharing knowledge.

Following the FACES program, parents demonstrated increased scores on the Special Education Advocacy Scale and positive perceptions of advocacy strengths and abilities. These findings were consistent with the findings from the VAP study, which also resulted in

improvements in advocacy skills (Burke et al., 2016). In the current study, positive perceptions of advocacy were reflected in parents' confidence in their ability to (a) research and develop more knowledge about ASD in African American communities and (b) share their knowledge of ASD with others. Specifically, participants indicated that FACES enabled them to develop and then to share that knowledge by dismantling stigmas and myths related to ASD and disability, in their communities.

Knowledge of ASD. Researchers have noted the positive impact that knowledge of ASD can have on families of children with ASD. Findings have indicated, for example, that increased parent knowledge and awareness of ASD among minority families has the potential to help families address barriers related to the accessibility of services (CDC, 2016). Moreover, among Latino families, maternal knowledge of ASD can improve access to services and help to reduce the disparities in access among families of color (Magaña et al., 2013). Given the impact of knowledge of ASD, and the need to reliably measure knowledge of ASD as an outcome, the literature has called for ASD knowledge measures that (a) include cross-cultural utility, and (b) specifically include measures of stigma and misconceptions that vary across cultures, and have a negative impact on families (Harrison, Slane, Hoang, & Campbell, 2016).

To my knowledge, no intervention studies have measured African American parent knowledge of ASD pre and post intervention. Following FACES, qualitative findings reflected parents' (a) increased knowledge and understanding of the prevalence and impact of ASD in the African American community, (b) increased knowledge and understanding of special education rights and laws, and (c) increased knowledge of resources for individuals with ASD. A core component of this knowledge outcome following FACES, was parents' ability to subsequently dismantle stigma related to ASD in their communities. Existing quantitative measures of ASD

knowledge (e.g., AKS; Stone 1987; Gillespie-Lynch, 2015) have included few, if any, cultural adaptations to the AKS. As such, the findings related to stigma in this study align with the literature that has called for the development of cross-cultural measures of ASD knowledge that embed constructs into scales that reflect the diversity of all children and families in the ASD community (Harrison et al., 2016).

Social communication and behavior. Even among children with ASD and an IQ above 70, African American children with ASD have demonstrated poorer language and communication skills than European American children, possibly due to delayed diagnoses and inaccessibility to early and effective behavioral treatments (Wright, 2016). Parents, however, have the unique ability to influence their child over many years, and are, therefore, integral in facilitating the development of their children's communication skills (Shire et al., 2015).

Findings from the current study indicate that the FACES program contributed to positive perceptions of social communication and behavior management strategies among African American parents of children with ASD. Following FACES, parents reported that their use of social communication and behavior management skills and strategies included increased patience, planned ignoring, use of visuals supports, and school communication/carry-over (e.g., ensuring consistency in behavior management across settings). These findings support the existing research in this domain (i.e., the potential to influence child development), and produce promising implications for the impact of parent-implemented social communication strategies in African American families of children with ASD. Previous work has also pointed to the importance of developing interventions that include a combined focus on changing children's behavior *and* parents' well being (Meadan et al., 2010). Therefore, by embedding behavior

management strategies that parents can implement with their children, the FACES program extends the existent literature.

Partnership

Following the FACES program, findings indicated that there was little to no increase in parent-professional partnership as measured by the FPPS and the SCS. Qualitative data however, indicated that participants felt better prepared to build more positive parent-professional partnerships with their children's' educators following the program. In previous studies, African American mothers have suggested that partnership and open communication were key ingredients in special education advocacy and gaining access to services (Pearson & Meadan, in press; Stanley, 2015), which aligns with participant views on partnership in the current study. The findings from the current study highlight parent's strategies and skills for developing stronger partnerships with educators and healthcare professionals. As such, those findings are corroborated by earlier research that suggests that advocacy, particularly among African American mothers of children with disabilities, includes locating and utilizing community resources, ongoing communication within schools, and being visible in their children's' schools and communities (Stanley, 2015). Stanley also found that African American mothers who participated in her study utilized their community resources, and noted how important it was to develop relationships in the community to ensure that their children were able to receive appropriate educational services.

Community

Revisiting the theoretical frameworks. In developing the FACES program, I drew from the Adult Learning Theory and the Sociocultural Theory to inform the scope, structure, sequence, and rationale of the intervention. During the FACES program, I embedded the six

characteristics of adult learning (i.e., introduce, illustrate, practice, evaluate, reflect, master) to support positive learner outcomes. Moreover, in drawing from the Sociocultural Theory, the FACES program (a) engaged learners as active participants, and provided space for observation, collaboration, and questioning, and (b) embedded multiple opportunities for participants to reflect and discuss their experiences throughout the program (Baumgartner, 2001). In addition to supporting participants in building knowledge, advocacy, and empowerment via the FACES curriculum, one of the most critical components of the FACES program was to provide a communal space for participants to (a) engage with each other, (b) share knowledge of resources and experiences, and (c) help brainstorm, and troubleshoot challenges related to their experiences as African American parents of children with ASD (Baumgartner, 2001).

For some participants, FACES was the first opportunity that participants had to meet other African American families of children with ASD. For other participants, FACES was the first opportunity they had to learn about resources that were available in their communities for children with disabilities. Still, for others, FACES was their first opportunity to meet parents who were willing to schedule play dates for their children. These are the types of experiences that reflect one of the primary outcomes from this study--participants developed a sense of community that they felt, was one of the greatest benefits of the FACES program. Participants indicated that FACES created a space where they could (a) network, (b) learn from shared experiences, (c) discuss stigma and disability in African American communities, and (d) develop a support system. These findings speak to the importance of learning within a cultural-historical context, and through their reflections, participants highlighted a major strength of the FACES program—that it was grounded in the Sociocultural Theory, where their shared experiences can be understood within the context of their everyday lives (John-Steiner & Mahn, 1996).

In their work, Burke and Goldman (under review) noted that for culturally and linguistically diverse (CLD) advocates working with CLD families, having shared cultural experience, shared disability experience, and shared understanding of family were facilitators for more effective advocacy.

Limitations

While the findings of the current pilot study produce strong potential for the feasibility and effectiveness of the FACES program, there are some limitations that should be noted here. In this section, I delineate six limitations of this study with regard to methodology, generalization, and feasibility.

First, recruiting participants was difficult, and, as such, the sample size for this study was small ($N = 10$). Despite the small sample size and subsequent lack of power, however, the quantitative findings were triangulated with multiple sources. Therefore, together, the findings produced pilot data that are promising in terms of the effectiveness of FACES, and also critical for refining the intervention.

Second, this was a single group, pre-post design. Given the nature of this design (no control group) and the composition of the sample (i.e., participant demographics), threats to internal validity cannot be ruled out.

A third limitation was the presence of two mother-father dyads. While this study focused on individual parent outcomes, their partner having also attended the FACES program could have influenced participants' experiences and perspectives. Despite this however, having mother-father dyads participate in the FACES program also highlights how parents' experiences diverge, even when parenting the same child(ren).

The fourth limitation to be noted is the impact of the researcher as the trainer. As the researcher and also the facilitator for each of the FACES sessions, it was sometimes challenging to collect rigorous field notes and record observational data. The video-recordings however, were available and useful for adding depth and breadth to the field notes as needed.

The fifth limitation was the length of the training. The FACES training was delivered during 18 hours of instruction across six weeks. While all of the intended topics were covered, some activities and discussions were limited due to time constraints (e.g., participants were engaged in discussions about community resources, school districts, etc.). Following the program, participants suggested increasing the duration of the FACES program (e.g., four hours per week across eight weeks). This is an important recommendation to consider for future iterations of the FACES program to address this limitation. Future FACES sessions should build in additional time for participants to build their community and share experiences, which has been highlighted as a major benefit throughout the FACES program.

Finally, the findings from this study are specific to African American families of children with ASD in a large, urban, Midwestern area. More than half of the participants in this study held bachelor's degrees or higher. Based on the U.S. Census Bureau income and poverty guidelines, of those participants who reported their income, no one was living in poverty. Therefore, the experiences of African American families (a) living in rural communities, (b) living in poverty, and/or (c) having less education, might be vastly different. As such, findings from this study cannot necessarily be generalized to those twice, or three times underserved communities.

Notwithstanding the aforementioned limitations, this study contributes to our understanding of (a) the development of a culturally responsive parent advocacy training

intervention, (b) African American parents' experiences with advocacy on behalf of their children with ASD, (c) the impact of a parent-advocacy and empowerment intervention on families of children with ASD, and (d) the resources, strategies and skills that would better suit the needs of this population in future iterations of the training.

Implications

This is the first known parent-advocacy and empowerment intervention study designed for African American parents of children with ASD. Researchers have noted the need for qualitative and mixed methods research aimed at understanding and addressing minority parents' reluctance to participate in ASD intervention research (West et al., 2016). As such, this study extends the research, through a mixed methods lens, on what we know about the impact of parent advocacy and empowerment interventions for African American families of children with ASD.

Implications for research. Research findings around racial and ethnic disparities in ASD research indicate that there are barriers such as poverty and cultural and linguistic differences that limit minority families' participation in research (e.g., Hilton et al., 2010; West et al., 2016; Wright, 2016; Yee, 2016). The findings from this study contribute to our knowledge of advocacy and empowerment among African American parents of children with autism—an area of research that has been persistently lacking in the literature (e.g., Pearson & Meadan, in press). The mixed methods findings from this study indicate that (a) the FACES program was effective in strengthening parents' perceptions of advocacy and empowerment, and (b) overall, parents were very satisfied with the program. Given these positive pilot data, future research in this domain should: (a) embed parent recommendations and existing FACES testimonials into the program, (b) include a larger, powered sample of participants, and (c) deliver the intervention via a randomized, waitlist-control trial. Moreover, future randomized control trials should

compare the FACES program (i.e., training plus community building) to community-building only (i.e., support group without training) to evaluate the extent to which changes are related to the FACES program alone. Data analysis in this domain should aim to explore additional variables that might contribute to the efficacy of the FACES program. Example variables might include duration and content of group discussions, participant communication outside of the program, and availability of childcare.

Future research should also include measurements of maintenance and sustainability to assess (a) the degree to which participants are employing skills and strategies they learned during the FACES program, and (b) the extent to which they still find them to be beneficial. Future research should also include child outcome measures to explore the extent to which the FACES program has a direct and long-lasting impact on the behavior, socialization, and communication of African American children with ASD.

Finally, as a field, much work is needed to carefully adapt the Autism Knowledge Scale (or develop a new ASD knowledge scale) so that it (a) includes culturally responsive measures of autism knowledge that are appropriate for diverse respondents (e.g., parents, health care providers, educators), (b) demonstrates strong psychometric properties, and (c) can be used to examine the efficacy of interventions (such as FACES) in increasing parent knowledge of ASD (Harrison et al., 2016).

Implications for practice. In this study, participants identified knowledge of child progress, being present in the school, and having teacher support as three core components of advocacy. Although participants identified the aforementioned partnership components as critical, they also indicated that communication with schools and lack of resources in schools were two primary barriers to effective advocacy. Given the diverse needs of African American

children with ASD, and the challenges that their families often face in accessing services, building strong parent-professional partnerships in school settings has the potential to help parents feel more empowered, and better prepared to advocate for their children. Together, advocacy, empowerment, and partnerships reflect an important combination of practices that educators and health care providers should adapt to (a) be more responsive to the needs of diverse families and (b) influence positive change for *all* families (e.g., child outcomes and family quality of life). In other words, practitioners should encourage and respect parent advocacy, help support families in fostering stronger feelings of family empowerment, and contribute to positive family-professional collaboration (i.e., partnerships) in their service delivery to provide high quality, family-centered care for African American families of children with ASD.

Within the community context, there is a need to (a) develop and maintain support groups that are available and accessible for African American families of children with ASD (particularly for African American fathers), (b) develop and disseminate literature about autism (and disability, more generally) that dispels myths and tackles stigma, and (c) provide opportunities for community engagement with health care providers, service providers, and educators that will aide parents in reducing cultural clash and developing stronger partnerships, that ultimately, can facilitate better access to services for children with ASD.

Conclusion

Given the disparities in diagnoses and access to services for African American children with ASD and their families (e.g., CDC, 2016; Gourdine et al., 2011; Sansosti et al., 2012) and the dearth of literature around the experiences of African American families, there is a clear need to develop and sustain programs that will help African American parents overcome barriers and

gain more timely and adequate access to services for their children with ASD (e.g., Boyd & Correa, 2005). Trainor (2010) has noted the intricacies of conducting research among populations whose everyday experiences are entrenched in sociocultural issues. That is, in some cases, parents of color may be less likely to engage in advocacy approaches due to their history and experiences in education, healthcare, and other settings driven by systemic inequality. Previous research findings have suggested that overcoming these barriers might be achieved through increased parent education about ASD, parent advocacy training, and providing parents with assistance to navigate the service system (Kipke & Kubicek, 2014; Pearson and Meadan, in press). The FACES program was the first step toward helping parents overcome these barriers, by providing parents with a six-week advocacy and empowerment training, designed specifically for African American families. The FACES program serves as a form of community education that not only aims to build advocacy, empowerment, and partnerships, but the program takes into account the historical marginalization of African American people, and the intersectionality of each participant. Participants learned more about prevalence, stigma, and challenges related to ASD in the African American community, and they had an opportunity to engage in discourse with other parents who had shared experiences. The ultimate goal was to help African American parents learn more about effective advocacy for their children with ASD and to feel empowered to be sure that their voices are heard (see Figure 13).

I believe that by drawing upon a mixed methods way of thinking—that is, to intentionally invite into the same inquiry space multiple ways of seeing and engaging in order to understand particular phenomena (J. Greene, personal communication, October 28, 2015), I was able to (a) provide implications for effectively developing and implementing a parent advocacy training program to support parents of children with ASD and (b) highlight the *experiences* of African

American parents of children with ASD—parents whose voices often go unheard. Let’s listen when they speak.



Figure 13. Participant quotes embedded in FACES logo.

References

- Akella, D., & Jordan, M. (2011). Impact of social and cultural factors on teen pregnancy. *Journal of Health Disparities Research and Practice*, 8, 41-62.
- Artiles, A. J. (2011). Toward an interdisciplinary understanding of educational equity and difference: The case of the racialization of ability. *Educational Researcher*, 40, 431-445.
- Azad, G., & Mandell, D. S. (2015). Concerns of parents and teachers of children with autism in elementary school. *Autism*, 1362361315588199.
- Baumgartner, L. M. (2001). Four adult development theories and their implications for practice. *Focus on Basics*, 5, 29-33.
- Berry, T. R., Jay, M., & Lynn, M. (2010). Introduction: Thoughts and ideas on the intersectionality of identity. *The Journal of Educational Foundations*, 24, 3.
- Berument, S.K., Rutter, Lord, C., Pickles, A., & Bailey, A. (1999). Autism screening questionnaire: Diagnostic validity. *British Journal of Psychiatry*, 175, 444-451.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional children*, 70, 167-184.
- Boyd, B. A., & Correa, V. I. (2005). Developing a framework for reducing the cultural clash between African American parents and the special education system. *Multicultural Perspectives*, 7, 3-11.
- Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention*, 32, 75-98.

- Brantlinger, E., Jimenez, R., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*, 195-207.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development: Research perspectives. *Developmental psychology, 226*, 723-742.
- Bronfenbrenner, U. (1994). Ecological models of human development. *Readings on the development of children, 2*, 37-43.
- Bruder, M. B. (2010). Early childhood intervention: A promise to children and families for their future. *Exceptional Children, 76*, 339-355.
- Burke, M. M. (2013). Improving parental involvement: Training special education advocates. *Journal of Disability Policy Studies, 23*, 225-234.
- Burke, M.M., Goldman S. E., (under review). Special education advocacy among culturally and linguistically diverse families.
- Burke, M. M., Goldman, S. E., Hart, M. S., & Hodapp, R. M. (2016). Evaluating the efficacy of a special education advocacy training program. *Journal of Policy and Practice in Intellectual Disabilities, 13*, 269-276.
- Burke, M. M., Magaña, S., Garcia, M., & Mello, M. P. (2016). Brief Report: The feasibility and effectiveness of an advocacy program for Latino families of children with autism spectrum disorder. *Journal of autism and developmental disorders, 1-7*.
- Burke, M. B., Meadan, H., Patton, K., Pearson, J., Cummings, K., & Lee, C. (under review). *Parent Advocacy for Children with Social-Communication Needs: Perspectives from Parents and School Professionals*.

- Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., & Shambley-Ebron, D. (2015). African American families on autism diagnosis and treatment: The influence of culture. *Journal of autism and developmental disorders, 45*, 3244-3254.
- Centers for Disease Control and Prevention. (2016). Prevalence of autism spectrum disorders among children aged 8 years — Autism and developmental disabilities monitoring network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report, 65*, 1-23.
- Chandler, S., Charman, T., Baird, G., Simonoff, E., Loucas, T., Meldrum, D., Scott, M., & Pickles, A. (2007). Validation of the Social Communication Questionnaire in a population cohort of children with autism spectrum disorders. *Journal of the American Academy of Child and Adolescent Psychiatry, 46*, 1324-1332.
- Cooper, J. O., Heron, T. E., & Heward, W. L. (2007). *Applied behaviour analysis* (2nd ed.). Upper Saddle River, NJ: Pearson.
- Corbin, J., & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage Publications.
- Council of Parent Attorneys and Advocates (2016). Special Education Advocate Training. Retrieved from <https://copaa.site-ym.com/?page=SEATHistory>
- Crone, D. A., & Horner, R. H. (2003). *Building positive behavior supports systems in schools: Functional behavior assessment*. New York, NY: Guilford.
- Dei, G. J. S. (2005). Social differences and the politics of schooling in Africa: A Ghanaian case study. *Compare: A Journal of Comparative Education, 35*, 227-245.
- Delgado, R., & Stefancic, J. (2012). *Critical race theory: An introduction*. NYU Press.
- Durand, V. M., & Carr, E. G. (1989). *Operant learning methods with chronic schizophrenia and autism: Aberrant behavior*.

- Efird, J. (2010). Blocked randomization with randomly selected block sizes. *International Journal of Environmental Research and Public Health*, 8, 15-20.
- Gersten, R., Fuchs, L. S., Compton, D., Coyne, M., Greenwood, C., & Innocenti, M. S. (2005). Quality indicators for group experimental and quasi-experimental research in special education. *Exceptional Children*, 71, 149-164.
- Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., ... & Smith, D. S. (2015). Changing college students' conceptions of autism: An online training to increase knowledge and decrease stigma. *Journal of Autism and Developmental Disorders*, 45, 2553-2566.
- Gourdine, R., Baffour, T., & Teasley, M. (2011). Autism and the African American community. *Social Work in Public Health*, 26, 454-470.
- Greene, J. C. (2007). *Mixed Methods in Social Inquiry*. San Francisco, CA: Jossey-Bass.
- Harrell, F. E. (2001). *Regression modeling strategies*. New York: Springer.
- Harrison, A. J., Slane, M. M., Hoang, L., & Campbell, J. M. (2016). An international review of autism knowledge assessment measures. *Autism*, doi: 1362361316638786.
- Harry, B. (1992). *Cultural diversity, families, and the special education system: Communication and empowerment*. Teachers College Press.
- Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism*, 9, 377-391.
- Heidgerken, A. D., Geffken, G., Modi, A., & Frakey, L. (2005). A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders*, 35, 323-330.

- Hilton, C. L., Fitzgerald, R. T., Jackson, K. M., Maxim, R. A., Bosworth, C. C., Shattuck, P. T., Geschwind, D. H., . . . Constatino, J. N. (2010). Brief report: Underrepresentation of African Americans in autism genetic research: A rationale for inclusion of subjects representing diverse family structures. *Journal of Autism and Developmental Disorders*, 40, 633-639.
- Hoare, C. H. (2006). *Handbook of Adult Development and Learning* (pp. 68-102). New York: Oxford University Press.
- Individuals With Disabilities Education Act, 20 U.S.C. § 1400 (2004).
- Harry, B. (2002). Trends and issues in serving culturally diverse families of children with disabilities. *The Journal of Special Education*, 36, 132-140.
- Harry, B., Allen, N., & McLaughlin, M. (1995). Communication versus compliance: African-American parents' involvement in special education. *Exceptional Children*, 61, 364-377.
- Irvin, D. W., McBee, M., Boyd, B. A., Hume, K., & Odom, S. L. (2012). Child and family factors associated with the use of services for preschoolers with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 6, 565-572.
- John-Steiner, V., & Mahn, H. (1996). Sociocultural approaches to learning and development: A Vygotskian framework. *Educational Psychologist*, 31, 191-206.
- Kipke M., & Kubicek, K. (2014). Addressing Racial Disparities in Autism Care. Retrieved from http://www.autismspeaks.org/science/science-news/addressing-racial-disparities-autism-care?utm_source=email&utm_medium=text-link&utm_campaign=sciencedigest
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., ... & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, 124, 1395-1403.

- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: a brief questionnaire. *Rehabilitation Psychology, 37*, 305.
- Krathwohl, D. R. (2009). *Methods of educational and social science research: The logic of Methods*. Long Grove, IL: Waveland Press.
- Lewis, T. T., Yang, F. M., Jacobs, E. A., & Fitchett, G. (2012). Racial/ethnic differences in responses to the everyday discrimination scale: A differential item functioning analysis. *American Journal of Epidemiology, 175*, 391-401.
- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of autism and developmental disorders, 24*, 659-685.
- Luyster, R., & Lord, C. (2009). Word learning in children with autism spectrum disorders. *Developmental Psychology, 45*, 1774–1786.
- Magaña, S., Lopez, K., Aguinaga, A., & Morton, H. (2013). Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities, 51*, 141-153.
- Magaña, S., Parish, S. L., & Son, E. (2015). Have Racial and Ethnic Disparities in the Quality of Health Care Relationships Changed for Children With Developmental Disabilities and ASD? *American Journal on Intellectual and Developmental Disabilities, 120*, 504-513.
- Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of Autism and Developmental Disorders, 37*, 1795-1802.

- Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*, 41, 1447–1453.
- Mandell, D. S., & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*, 11, 110-115.
- Mandell, D. S., Novak, M., & Zubritsky, C. (2005). Factors associated with the age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116, 1480–1486
- Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism*, 111-122.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuseppi, C., Durkin, M. S., ... & Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*, 99, 493.
- Maskey, M., Warnell, F., Parr, J. R., Le Couteur, A., & McConachie, H. (2013). Emotional and behavioural problems in children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 851–859.
- McKay, C. L. (2010). Community education and critical race praxis: The power of voice. *The Journal of Educational Foundations*, 24, 25.
- Meadan, H., Ayvazo, S., Ostrosky, M. M. (2016). Challenging behavior: The ABC and beyond for parents and educators. *Young Exceptional Children*, 19, 3-15.
- Meadan, H., Halle, J. W., & Ebata, T. A. (2010). Families of children who have autism spectrum disorder: Stress and support. *Exceptional Children*, 77, 7-36.

- Meadan, H., Snodgrass, M. R., Meyer, L. E., Fisher, K. W., Chung, M. Y., & Halle, J. W. (2016). Internet-based parent-implemented intervention for young children with autism: A pilot study. *Journal of Early Intervention, 38*, 3-23.
- Mueller, T. G., & Carranza, F. (2011). An examination of special education due process hearings. *Journal of Disability Policy Studies, 22*, 131-139.
- Munro, J. D. (1991). Training families in the “Step Approach Model” for effective advocacy. *Canada’s Mental Health, 39*, 1–6.
- Nachsen, J., Anderson, L., & Jamieson, J. (2001). The parent advocacy scale: Measuring advocacy in parents of children with special needs. *Journal on Developmental Disabilities, 8*, 93–105.
- Pearson, J. (2015). Disparities in diagnoses and access to services for African American children with Autism Spectrum Disorder. *DADD Online Journal, 2*, 52-65
- Pearson, J., & Meadan, H. (in press). African American Mothers’ Perceptions of Diagnoses and Services for Children with Autism. *Education and Training in Autism and Developmental Disabilities*.
- Pérez, D. J., Fortuna, L., & Alegria, M. (2008). Prevalence and correlates of everyday discrimination among US Latinos. *Journal of Community Psychology, 36*, 421-433.
- Raudenbush, S. W., & Liu, X. (2000). Statistical power and optimal design for multisite randomized trials. *Psychological Methods, 5*, 199-212.
- Rosenthal, R., & Rosnow, R. L. (2012). *Essentials of behavioral research: Methods and Data Analysis*. New York, NY: McGraw-Hill Humanities Social.
- Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities, 27*, 81-92.

- Schmidt, H. G., Loyens, S. M., Van Gog, T., & Paas, F. (2007). Problem-based learning is compatible with human cognitive architecture: Commentary on Kirschner, Sweller, and Clark (2006). *Educational Psychologist, 42*, 91-97.
- Shire, S. Y., Goods, K., Shih, W., Distefano, C., Kaiser, A., Wright, C., ... & Kasari, C. (2015). Parents' adoption of social communication intervention strategies: Families including children with autism spectrum disorder who are minimally verbal. *Journal of Autism and Developmental Disorders, 45*, 1712-1724.
- Stanley, S. L. G. (2015). The Advocacy Efforts of African American Mothers of Children with Disabilities in Rural Special Education: Considerations for School Professionals. *Rural Special Education Quarterly, 34*, 3-17.
- Summers, J. A., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. L. (2005). Measuring the Quality of Family—Professional Partnerships in Special Education Services. *Exceptional Children, 72*, 65-81
- Tabachnick, B. G. & Fidell, L. S., & Osterlind, S. J. (2013). *Using multivariate statistics*. Pearson Education.
- Tager-Flusberg, H., & Kasari, C. (2013). Minimally verbal school-age children with autism: The neglected end of the spectrum. *Autism Research, 6*, 468–478.
- Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorders, 37*, 1902-1912.
- Tipton, L. A., & Blacher, J. (2014). Brief report: Autism awareness: Views from a campus community. *Journal of autism and developmental disorders, 44*, 477-483.

- Trainor, A. A. (2010). Diverse Approaches to Parent Advocacy During Special Education Home—School Interactions Identification and Use of Cultural and Social Capital. *Remedial and Special education, 31*, 34-47.
- Trotter, Y. D. (2006). Adult learning theories: Impacting professional development programs. *Delta Kappa Gamma Bulletin, 72*, 8-13.
- United States Census Bureau. (2013). *State & County Quick Facts*. Retrieved from <http://quickfacts.census.gov/qfd/states/00000.html>
- West, E. A., Travers, J. C., Kemper, T. D., Liberty, L. M., Cote, D. L., McCollow, M. M., & Stansberry Brusnahan, L. L. (2016). Racial and ethnic diversity of participants in research supporting evidence-based practices for learners with autism spectrum disorder. *The Journal of Special Education, 50*, 151-163.
- Wheeler, B., & Marshall, D. (2008, March). Special education advocacy training (SEAT). Paper presented at the Council of Parent Attorneys and Advocates Conference, Anaheim, CA.
- Whitley, D. M., Kelley, S.J. & Campos, P.E. (2011). Perceptions of family empowerment in African American custodial grandmothers raising grandchildren: Thoughts for research and practice. *Families in Society, 92*, 110–119.
- Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health socio-economic status, stress and discrimination. *Journal of health psychology, 2*, 335-351.
- Wolf, M. M. (1978). Social validity: The case for subjective measurement or how behavior analysis found its heart. *Journal of Applied Behavior Analysis, 11*, 203-214.
- Wolfensberger, W. (1977). A balanced multi-component advocacy/ protection schema. Toronto: Canadian Association for the Mentally Retarded.

Wright, J. (2016). Disparities in diagnoses might harm minority groups. Retrieved from:

<https://spectrumnews.org/news/disparities-in-autism-diagnosis-may-harm-minority-groups/>

Yee, A. (2016). Autism's full spectrum. Retrieved from:

<https://spectrumnews.org/features/deep-dive/autisms-full-spectrum/>

Zuckerman, K. E., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, C. (2013).

Pediatrician identification of Latino children at risk for autism spectrum disorder.

Pediatrics, 132, 445-453.

Appendix A

IRB Approval

UNIVERSITY OF ILLINOIS
AT URBANA-CHAMPAIGN

Office of the Vice Chancellor for Research

Office for the Protection of Research Subjects
328 East Green Street
Suite 203
Champaign, IL 61820



October 5, 2016

Hedda Meadan-Kaplansky
Special Education
288 Education Bldg
1310 South Sixth Street
Champaign, IL 61820

RE: *FACES: Fostering Advocacy Communication Empowerment and Supports for African American Families of Children with Autism*
IRB Protocol Number: 16877

Dear Dr. Meadan-Kaplansky:

Thank you very much for forwarding the modifications to the University of Illinois at Urbana-Champaign Institutional Review Board (IRB) office for your project entitled *FACES: Fostering Advocacy Communication Empowerment and Supports for African American Families of Children with Autism*. I will officially note for the record that these minor modifications to the original project, as noted in your correspondence received 10/3/2016, adding everyday discrimination scale; changing to pre and post-test design; reducing number of participants; adding video-recordings and still photos, have been approved. The expiration date for this protocol, IRB number 16877, is 06/07/2017. The risk designation applied to your project is *no more than minimal risk*.

As your modifications involved changes to consent form(s), I am attaching the revised form(s) with date-stamp approval. Please note that copies of date-stamped consent forms must be used in obtaining informed consent. If modification of the consent form(s) is needed, please submit the revised consent form(s) for IRB review and approval. Upon approval, a date-stamped copy will be returned to you for your use.

Please note that additional modifications to your project need to be submitted to the IRB for review and approval before the modifications are initiated. To submit modifications to your protocol, please complete the IRB Research Amendment Form (see <https://www.oprs.research.illinois.edu/forms-templates/forms/protocol-amendment-form>). Unless modifications are made to this project, no further submittals are required to the IRB.

We appreciate your conscientious adherence to the requirements of human subjects research. If you have any questions about the IRB process, or if you need assistance at any time, please feel free to contact me at the OPRS office, or visit our website at <https://www.oprs.research.illinois.edu>.

Sincerely,

A handwritten signature in black ink that reads "LeaAnn Carson".

LeaAnn Carson, MS
OPRS Specialist

Attachment(s) c: Jamie Pearson

U of Illinois at Urbana-Champaign • IORG0000014 • FWA #00008584
telephone (217) 333-2670 • fax (217) 333-0905 • email IRB@illinois.edu

Appendix B

Recruitment Flyer

African American Parents of Children with Autism Spectrum Disorder (ASD) Needed for Parent-Training Research Study



Hello! My name is Jamie Pearson and I am a doctoral student in Special Education at The University of Illinois at Urbana-Champaign. My advisor is Dr. Hedda Meadan. We are looking for participants for an exciting research project that will help African American parents learn more about advocating for services for their children with ASD. We have described the study below and hope that you will contact us if you would like to participate in this project or if you have any questions.

Title of the Project: FACES: Fostering Advocacy, Communication, Empowerment, and Support for African American Families of Children with Autism

About the Project: As a participant, you will be asked to complete a 30-minute pre-program set of surveys, participate in a one-hour pre-program focus group, complete a six-week parent-training program (FACES), to be held once per week for three hours, complete a 30-minute post-program set of surveys, and participate in a one-hour post-program focus group. This will help us to understand the experiences African American parents of children with ASD have advocating for their children and the effectiveness of the FACES program. We believe that your participation will help to inform the practices in schools and homes, and also increase advocacy efforts in this community.

Potential Participants: Please consider participating in this study if:

- (a) You are an African American parent or caregiver of an African American child who has a primary diagnosis of autism spectrum disorder **AND**
- (b) Your child is ages **3-14** at the time of the study

In appreciation for your time, **you will receive a \$75 gift card** for participating in this study. **For more information please contact:** Jamie Pearson, jnpears2@illinois.edu, 217-333-0260 or Hedda Meadan, meadan@illinois.edu, 217-333-0260.

Thank you for considering participating in our project!!!

Appendix C

Screening Script

Researcher: Hello! My name is Jamie Pearson and I am a doctoral student in Special Education at The University of Illinois at Urbana-Champaign. My advisor is Dr. Hedda Meadan. We are recruiting participants for our exciting FACES program that, we hope, will help African American parents learn more about advocating for services for their children with ASD.

I understand that you are interested in participating in the project. Is now a good time to talk?

Participant: (response)

Researcher: (*if no*) [schedule a different date/time for screening, Confirm]. Thank you so much for your time. I look forward to speaking with you on [scheduled date and time].

Researcher: (*if yes*) Wonderful! First, I would like to review the participant criteria with you to make sure this will be a good fit:

1. Do you identify as African American?
2. Does your son or daughter's father (or mother) also identify as African American?
3. Do you identify your son or daughter as African American?
4. Does your son or daughter have a primary diagnosis of autism spectrum disorder?
5. Is your son or daughter between the ages of 3 and 14 years old?
6. Are you able to provide medical documentation or school documentation (like an IEP) that confirms his or her diagnosis?

Researcher: (*if NO to ANY*) Thank you so much for your interest, but it sounds like some of the criteria are not met for this study (explain criteria that are not met). Thank you so much for your interest and your time. We will keep you in mind in the future!

Researcher: (*if yes to ALL*) Great! I'd like to explain a little more about the study and if you're still on board, we'll move forward with the consent process.

The FACES Program is a six-week intervention designed to help African American parents feel more empowered and prepared to advocate for their children with autism. The program will be conducted once per week (likely on Saturdays) for six weeks, in downtown Chicago. Each session will last for 3 hours. Although we are recruiting 50 participants for this study, we can only have 20 participants in the training at a time. Therefore, you will be randomly assigned to the first group who will go through the FACES program this fall. Alternatively, you could be assigned to the second group who will go through the FACES program later in the winter.

Before we begin the program, we will ask you to complete a set of surveys and also participate in a focus group, which is a group-style interview. After the six-week program, we will ask you to complete the same surveys, and participate in a focus group interview as well.

Finally, in appreciation for your time and participation, at the end of the project, you will receive a \$75 stipend, *no matter whether you are in the first program group, or the second group.* If you are in the second training group, we will contact you in the winter to schedule the winter FACES training sessions. Participants in the second group will complete the surveys a total of three times.

Researcher: Do you think you would be willing to go through with all of these components of the study? Do you have any questions about the study?

Participant: (response)

Researcher: (answer questions, if any) Are you still okay with moving forward with the study?

Participant: (response)

Researcher: (*if no*) Okay. We thank you for your time and interest!

Researcher: (*if yes*) Okay! The next step is to have you complete a Social Communication Questionnaire. This will help us learn more about your child's communication. We will also use this to confirm ASD diagnosis. I will be mailing you the SCQ via USPS. Could you please give me your address?

Participant: (response)

Researcher: [Confirm mailing address or email address]. You should be receiving the questionnaire in the next few days. As soon as we receive this back from you, we'll be in touch. If your child meets criteria, we will get your consent to participate in the study. Once we receive your signed consent, we will also send you a set of surveys to complete before we begin. In addition, we will notify you regarding your assignment to the fall FACES group or the winter FACES group. Do you have any questions?

(*if no*) Thank you so much for your time. We're excited to have you participate in our FACES program and we look forward to meeting you soon. If you need to reach me you can call me (Jamie) at 217-333-0260 or email me at jnpears2@illinois.edu. Thanks again!

Appendix D

Consent Form

Dear Parent,

My name is Jamie Pearson and I am a doctoral student in the department of Special Education at the University of Illinois, Urbana-Champaign. My advisor and responsible Principal Investigator for this project is Dr. Hedda Meadan. We are conducting a research study to understand African American parents' experiences with advocating for their children with autism. As an African American parent or caregiver of a child with autism, providing valuable information from your own experiences can shape future development of FACES as well as future practices for other families like yours. The potential benefits include: increased knowledge and awareness of advocacy skills, social communication skills, and challenging behavior management strategies for parents of children with autism. Joining this study is completely voluntary. During this study you will be involved in the following procedures:

(a) *Surveys*: First, we would like for you to provide some background information about you and your family, and complete a set of surveys. Participants will be asked to complete the pre and post surveys before and after the training program. The surveys will take about 30 minutes to complete, and will need to be completed 2-3 times throughout the project. The surveys will include topics such as family empowerment, knowledge of autism, and school communication.

(b) *FACES Program*: During this program, you will participate in a three-hour training session once per week, for six weeks. Topics covered during the training will include information about autism, ways to increase social communication in children with autism, ways to communicate effectively with professional, and how to feel more empowered.

(c) *Focus group interviews*: You will be interviewed two times in a group setting with other participants for approximately one hour, at a time and location that is most convenient for you. These interviews will be audio-recorded.

All information you provide during the FACES program and the focus groups will be kept confidential by the researchers. We cannot guarantee however, that other participants will do the same. Notes, tapes, and transcriptions collected during this study will be retained for five years after results are disseminated, in a secure location, and then destroyed. Your name and any other identifying information will not appear in the study report. The researchers who are involved in this study are the only people who will have access to the original data. When this research is discussed or published, no one will know that you were in the study. However, laws and university rules might require us to give information about you. For example, if required by law or University Policy, study information that identifies you and the consent form that you signed may be seen or copied by people or groups at the university such as university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for Protection of Research Subjects; University and state auditors, and Departments of the university responsible for oversight of research; Federal government regulatory agencies such as the Office of Human Research Protections in the Department of Health and Human

Services; and the financial sponsor of the research, the U.S. Department of Education. Finally, if you disclose actual or suspected abuse, neglect, or exploitation of a child or a disabled or elderly adult, the researcher or members of the study staff will report the information to Child Protective Services, Adult Protective Services, and/or a law enforcement agency.

We expect that your involvement in the study will involve minimal risks such as time required to complete forms, and risk of loss of confidentiality. You can withdraw from this study at any time. You will receive a \$75 gift card for participating in this study upon completion of all project activities.

If you have questions or concerns about this study, please contact Jamie Pearson (217-333-0260; jnpears2@illinois.edu) or Dr. Hedda Meadan (217- 333-0260; meadan@illinois.edu). We will be happy to answer any of your questions. If you feel you were not treated according to the descriptions in this form, or if you have any questions about your rights as research subjects, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu. Please keep the attached copy of this letter for your records.

If you are willing to participate in this study, please sign this consent form and return it to Jamie Pearson. Attached is a copy of this consent form for your records. Thank you for considering participating in this important study.

Sincerely,

Jamie Pearson, M.A.
Hedda Meadan, Ph.D., BCBA-D
Department of Special Education
College of Education
University of Illinois at Urbana-Champaign

By signing below, you are certifying that you are 18 years of age or older, that you understand the information above, and that you voluntarily consent to participate in this research study.

Name (please print): _____

Signature: _____

Date: _____

Contact information (email/phone): _____

Appendix E

Data Collection Timeline

Complete Data Collection Timeline

Date	Activity
09/7/16-10/08/16	Participant screenings & Social Communication Questionnaires
10/08/16	Demographic questionnaire and pre survey
10/08/16	Pre FACES Focus Group
10/08/16	Pre FACES Focus Group Member Check
10/15/16	FACES Session 1
10/22/16	FACES Session 2
10/29/16	FACES Session 3
11/05/16	FACES Session 4
11/12/16	FACES Session 5
11/19/16	FACES Session 6
11/19/16	Participant Testimonials
11/19/16	Post FACES Survey
12/03/16	Post FACES Focus Group 1
12/03/16	Post FACES Focus Group 2
02/14/17	Post FACES Focus Group Member Check

Appendix F

Pre-FACES Focus Group Interview Guide

PRE-FACES FOCUS GROUP INTERVIEW GUIDE

Thank you for participating in this study. I will ask you some questions about your child with autism and your family experiences with advocacy. For the purposes of our discussion today, I want to define advocacy as “any action taken by a parent on behalf of their child or other children with ASD to ensure adequate support, proper level of care, and basic human rights.”

There are a few ground rules that will help the group run smoothly.

1. We want you to do the talking, and we would like everyone to participate.
2. There are no right or wrong answers. Every person's experiences and opinions are important. Speak up whether you agree or disagree. We want to hear a wide range of opinions!
3. What is said in this space stays here. We want everyone to feel comfortable sharing. The researchers will inform participants that what they share during the focus group will be confidential and will not be shared outside of the group.
4. We will be audio recording the focus group. We want to capture everything you have to say. I will not identify anyone by name in the report. Researchers will keep all comments confidential, but complete confidentiality cannot be guaranteed because that is the nature of group interviews.

If everyone agrees to these ground rules, we will begin.

1. Please tell me about your experiences with advocating on your child's behalf.
 - a. How would you describe your “advocacy style?”
 - b. How has your knowledge of autism impacted your ability to advocate?
 - c. How has your knowledge of special education laws impacted your ability to advocate?
2. What have you advocated for?
 - a. Time or place for services?
 - b. Additional services?
 - c. One-on-one services?
 - d. Specific strategies?
3. Do you feel like your advocacy efforts have been effective?
 - a. Has your child benefited after you advocated?
 - b. Has your family benefited after you advocated?
4. How do you think educators, healthcare providers, and service providers perceive your advocacy efforts?
 - a. Do you think your race plays a role?
 - b. Do you think your communication style plays a role?
5. What tools or resources do you feel would help you to be a stronger advocate?
6. Is there anything else you would like to add?

Appendix G

Pre-FACES Questionnaire

Pre-FACES Interview Questions

****If you were not able to come to our Focus Group on October 8th, please answer these questions before our next session on November 12th!!****

1. 1. Please tell me about the experiences you have had with advocating on your child's behalf. This can be formal advocacy in schools, or more informal advocacy in community and family settings.

2. 2. What sorts of services and supports have you advocated for in the past?

3. 3. Do you feel like your advocacy efforts have been effective? (For example, have you seen positive changes in services and instruction after you advocated for change?)

4. 4. How do you think educators, healthcare providers, and service providers perceive your advocacy efforts? (For example, do you think your race or communication style plays a role?)

Appendix H

Post-FACES Focus Group Interview Guide

POST-FACES FOCUS GROUP INTERVIEW GUIDE

Thank you for participating in the FACES training! During this interview I am going to ask you some questions about your experiences during FACES.

There are a few ground rules that will help the group run smoothly.

1. We want you to do the talking, and we would like everyone to participate.
2. There are no right or wrong answers. Every person's experiences and opinions are important. Speak up whether you agree or disagree. We want to hear a wide range of opinions!
3. What is said in this space stays here. We want everyone to feel comfortable sharing.
4. We will be audio recording the focus group. We want to capture everything you have to say. I will not identify anyone by name in the report. Researchers will keep all comments confidential, but complete confidentiality cannot be guaranteed because that is the nature of group interviews

If everyone agrees to these ground rules, we will begin.

1. Please share your overall views on the FACES training program.
 - a. Were the goals well suited for you and your family's needs?
 - b. Were the content and procedures logical and useful?
 - c. How do you feel you and your family have benefited from FACES?
2. How has the FACES training helped you learn more about autism, especially within the African American community? Please explain.
3. How has the FACES training prepared you to increase communication and manage behavior with your children?
 - a. Have you used any of the social communication strategies you learned about during FACES?
 - b. Have you used the visual supports we created during FACES?
 - c. Have you used any of the behavioral strategies you learned about during FACES?
4. Has the FACES training prepared you to advocate for your child(ren) with ASD? If so, how?
5. After completing the FACES training, do you feel more empowered to advocate for, and make decisions for your child and family? How so?
6. How do you plan to stay in touch with other parents you met during FACES?
7. Is there anything else you would like to add?

Appendix I

Post-FACES Focus Group Participant Interview Guide

POST-FACES FOCUS GROUP PARTICIPANT INTERVIEW GUIDE

1. Please share your overall views on the FACES training program.
 - a. Were the goals well suited for you and your family's needs?
 - b. Were the content and procedures logical and useful?
 - c. How do you feel you and your family have benefited from FACES?
2. How has the FACES training helped you learn more about autism, especially within the African American community? Please explain.
3. How has the FACES training prepared you to increase communication and manage behavior with your children?
 - a. Have you used any of the social communication strategies you learned about during FACES?
 - b. Have you used the visual supports we created during FACES?
 - c. Have you used any of the behavioral strategies you learned about during FACES?
4. Has the FACES training prepared you to advocate for your child(ren) with ASD? If so, how?
5. After completing the FACES training, do you feel more empowered to advocate for, and make decisions for your child and family? How so?
6. How do you plan to stay in touch with other parents you met during FACES?
7. Is there anything else you would like to add?

Appendix J

Example Member Check Summary

Post FACES FG 2
Transcript Summary

Following the six-week training, six participants attended the first post FACES focus group.

Participants indicated that overall, the FACES program was informative. The participants learned information about autism, the stigma of autism in the African American community, and parenting strategies. Participants enjoyed building relationships with other parents in the training.

Participants indicated that the resources they received from the FACES training benefitted themselves, their families, and their friends. The FACES participants indicated that the training created a safe space for them to share common experiences and learn from other parents.

Participants discussed the need for Health Care Professionals (HCP) to receive more training on autism. The participants felt that HCP's should provide more information to parents during the autism diagnosis process.

Participants discussed fathers in the African American autism community. The father participants indicated the challenges they face with parenting a child with a disability, the shift in expectations they had for their child with autism, and the need they see for more father participation in the community.

Primary themes from this interview include:

- Sense of Community
 - Shared experiences
 - A space to come together
- Specific learning outcomes
 - Knowledge of resources
 - Managing behavior
- Perceptions of Advocacy
- Perceptions of Fatherhood

Appendix K

FACES Curriculum Overview

	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
Topics Covered	1. Brief introductions 2. Purpose, goals, logistics 3. Prevalence of ASD 4. ASD in the African American community	1. Special Education Law 2. Role of Families 3. Impact of communication delays in children with ASD 4. Naturalistic teaching strategies	1. Social Communication 2. Function of behavior 3. Challenging behavior & stigma in the AA community 4. Managing challenging behavior	1. Overview of advocacy 2. Importance of advocacy 3. What advocacy looks like in action 4. What can be achieved through advocacy	1. Advocacy continued 2. Communicating with educators, healthcare providers, and service providers 3. Effective communication 4. Empowerment Panel	1. Strengthening empowerment 2. (Catch-up on missed material) 3. Review of FACES 4. Post-FACES surveys

Appendix L

Training Protocol and Fidelity Checklists

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

Sign-in

- Participants will sign in and pick up any handouts for the session

Introductions (1 hour)

- Participant Introductions (30 minutes)
- Introduction to FACES (30 minutes)
Introduce trainer and graduate student assistant; present PowerPoint about purpose, goals, and logistics for FACES, answer questions

Overview of ASD (30 minutes)

- Show intro video clip: Engaging African Americans affected by ASD
- Present PowerPoint about ASD prevalence, characteristics, areas of needed support

Break (15 minutes)

ASD in the African American Community (1 hour)

- Watch video clip: Wondering & Worrying (15 minutes)
- Participant activity (15 minutes)
After watching the video, participants will work together in small groups to discuss highlights from the video that resonate with their own personal experiences as African American parents of children with ASD. After 10 minutes, the groups will come together to share as a large group.
- Present PowerPoint about prevalence, perceptions, and experiences related to ASD in the African American families of children with ASD. (30 minutes)

Questions and Concerns (15 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Provide information and reminders for the next session.
- Complete formative evaluations

Training Protocol and Fidelity Checklist for *FACES* Session 2

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

The activities do not have to occur in the order listed. Please check the activity off as long as it occurs at some point during the training.

Sign-in

- Participants will sign in and pick up any handouts for the session

Special Education Law (30 minutes)

- Mini-lecture: IDEA, LRE, FAPE, Parents as partners
- Practice: IDEA scenarios
- Check for understanding

Role of Families (45 minutes)

- Mini-lecture: roles of families, stigma and disability in the African American community, how to engage family members, how to communicate effectively to address needs
- Video: Families & Feelings (12 minutes)
- Discussion: Think-Pair-Share (“What challenges do you face with your family members’ thoughts, perceptions, and reactions to your child with ASD?”)

Break

- (15 minutes)

Communication and ASD (1 hour)

- Mini-lecture: impact of communication delays in children with ASD, importance of social communication, functions of communication, naturalistic teaching strategies
- Practice: practice naturalistic teaching strategies with a partner
- Check for understanding

Questions and Concerns (15 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Provide information and reminders for the next session
- Complete formative evaluations

Training Protocol and Fidelity Checklist for *FACES* Session 3

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

The activities do not have to occur in the order listed. Please check the activity off as long as it occurs at some point during the training.

Sign-in

- Participants will sign in and pick up any handouts for the session

Social Communication (45 minutes)

- Mini lecture: brief review of social communication
- Practice: Video-Identifying modes of social communication with Marcus
- Reflect & Discuss: Think-Pair-Share: “How does your child communicate with you?”

Behavior (45 minutes)

- Mini lecture: What is behavior? What are the functions of behavior? Why is it important to understand the functions of behavior?
- Practice: Case study response
- Check for understanding

Break

- (15 minutes)

Managing Challenging Behavior (1 hour)

- Mini lecture: Functions of behavior ABCs of behavior, collecting data, strategies for managing challenging behavior
- Practice: conduct a functional behavior assessment (Brooke video)
- Check for understanding
- Practice: Revisiting Jeremiah

Wrap Up (15 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Provide information and reminders for the next session
- Complete formative evaluations

Training Protocol and Fidelity Checklist for *FACES* Session 4

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

The activities do not have to occur in the order listed. Please check the activity off as long as it occurs at some point during the training.

Sign-in

- Participants will sign in and pick up any handouts for the session

Overview of Advocacy (15 minutes)

- Mini lecture: What is advocacy?
- Demonstrate: Tommi Lee's Story (3 minutes)
<https://www.youtube.com/watch?v=3ZySVPHNLi8>
- Reflect & Discuss: *Why* do we advocate?
- Check for understanding

Formal and Informal Advocacy (30 minutes)

- Mini lecture: What are formal and informal advocacy?
- Large group discussion: what are some of your examples of formal and informal advocacy?
- Check for understanding

Break

- (15 minutes)

Advocacy in action (45 minutes)

- Mini lecture: advocacy in action: common ways to advocate in special education, appropriate documentation, challenges of advocacy, types of support
- Practice: Each small group will read a scenario and practice engaging in advocacy through role-play

Formal Advocacy in Action (1 hour)

- Watch video clip: (advocacy reflections)
- Mini lecture: formal advocacy in action: collaboration, mediation, formal dispute resolution, outcomes of advocacy
- Check for understanding: develop advocacy plan

Wrap Up (15 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Provide information and reminders for the next session
- Complete formative evaluations

Training Protocol and Fidelity Checklist for *FACES* Session 5

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

Sign-in

- Participants will sign in and pick up any handouts for the session

Advocacy Continued: Effective Advocacy (20 minutes)

- Mini lecture: non-adversarial ways to advocate (Adapted from Burke)
- Group Reflections: What are your experiences related to communicating with professionals about your child’s needs?

Partnering and Communication (25 minutes)

- Mini lecture: developing partnerships, & multi-modal communication

Break (15 minutes)

Parent Panel (1.5 hours)

- Led by parent advocate Mallory Robertson, the parent panel guests will share their experiences with advocacy, navigating the service system, and ways to feel more empowered. Panelists will engage in an open dialogue with the participants.

Wrap Up (15 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Provide information and reminders for the next session
- Complete formative evaluations

Training Protocol and Fidelity Checklist for *FACES* Session 6

Date:	
Starting Time: (3 hour training)	Ending Time:
Location:	Number of Participants:

The activities do not have to occur in the order listed. Please check the activity off as long as it occurs at some point during the training.

Sign-in

- Participants will sign in and pick up any handouts for the session

Strengthening Empowerment (30 minutes)

- Mini lecture: strengthened and sustained empowerment
- Modeling: Video clip:

***Flexible topic for catch up/ to address participant needs (30 minutes)**

- Video clip:
- Mini lecture:
- Participant discussion/activity:

Break (15 minutes)

Review of FACES (30 minutes)

- Briefly review and discuss how parents can engage with educators, service providers, and healthcare providers to address the needs of their children.
Re: SPED laws, role of families, managing behavior, advocating effectively, activating empowerment
- Brief Group Reflections: Example questions: “How will you advocate differently this year?”

Post-Intervention Measures and Summative evaluation (45 minutes)

- Participants should complete all pre/post measures
- Complete Summative evaluation

Wrap Up (30 minutes)

- Share resources relevant to session topic
- Give participants opportunity to ask questions
- Schedule post-FACES focus groups
- Distribute Stipends

Appendix M

FACES Formative Evaluation

Please select one answer for each of the following questions.

1. To what extent were you satisfied with the information covered during this session?

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

2. How satisfied were you with the way the information was delivered?

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

3. How relevant was this session to becoming an advocate?

Not at all relevant _____
Slightly relevant _____
Relevant _____
Moderately relevant _____
Extremely relevant _____

4. How relevant was this session in helping you feel more empowered?

Not at all relevant _____
Slightly relevant _____
Relevant _____
Moderately relevant _____
Extremely relevant _____

5. Please indicate your overall satisfaction with today's session:

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

6. I got the most out of _____

7. The session was: Too short _____ Just right _____ Too long _____

8. What improvements would you suggest? _____

9. Is there anything you wish this training had covered? _____

Appendix N

FACES Summative Evaluation

(Adapted from Burke, 2012)

Please select one answer for each of the following questions.

1. Speakers (*Jamie Pearson, Parent Panel*)

Overall, how would you rate your satisfaction with the knowledge of the speakers?

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

Overall, how would you rate your satisfaction with the speakers' presentations as it relates to developing your role as an advocate?

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

Please indicate your overall satisfaction with the speakers:

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

2. Content (*Introduction to the training; Special Education Law, Prevalence of Autism, Role of Families, Social Communication, Functional Behavior, Advocacy Skills; Your Role as an Advocate*).

What did you think about the relevance of each of the topics?

Not at all relevant _____
Slightly relevant _____
Relevant _____
Moderately relevant _____
Extremely relevant _____

Overall, how would you rate the relevance of the topics in developing your role as an advocate?

Not at all relevant _____
Slightly relevant _____
Relevant _____
Moderately relevant _____
Extremely relevant _____

Are there any other topics that you think the training should cover?

Are there any topics you think the training should leave out?

Is there anything you would change about the order of the topics in the training? If so, what?

Would you devote any more time to a specific topic?

Would you devote less time to a certain topic?

Please indicate your overall satisfaction with the content:

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

3. Logistics

Was the time of the training convenient?

Not at all convenient _____
Not convenient _____
Somewhat convenient _____
Convenient _____
Very Convenient _____

Were the days of the week (Saturday) convenient for the training?

Not at all convenient _____
Not convenient _____
Somewhat convenient _____
Convenient _____
Very Convenient _____

Was the parking convenient?

Not at all convenient _____
Not convenient _____
Somewhat convenient _____
Convenient _____
Very Convenient _____

Was the room comfortable?

Not at all comfortable _____
Not comfortable _____
Somewhat comfortable _____
Comfortable _____
Very comfortable _____

What did you think about the length of each session?

Too short _____
Just right _____
Too long _____

If you feel we should change the length of the training, how long should it be?

Should we keep the same room for the training? If not, do you have any suggestions for a different location for the training?

Should we change the time of the training? If so, what times do you suggest and why?

Should we change the number of sessions in the training (which is presently 6 sessions)? If so, what should the number of sessions be?

Should we change the day of the training? If so, what day should the training be and why?

Please indicate your overall satisfaction with the logistics:

Not at all satisfied _____
Slightly satisfied _____
Satisfied _____
Moderately satisfied _____
Extremely satisfied _____

4. Overall

Do you think the training prepared you to advocate for your child(ren) with ASD?

What would have helped you to better advocate?

Please indicate your overall satisfaction with the training:

Not at all satisfied _____

Slightly satisfied _____

Satisfied _____

Moderately satisfied _____

Extremely satisfied _____

Do you think the training was appropriate given the age your child?

Yes ____

No ____

If no, when would you have liked to have this training?

Did the training meet your expectations? Why or why not?

What kind of ongoing support would better enable you to advocate for your child(ren)?

Is there anything else you would like to say?

Appendix O

Family Information Questionnaire

FAMILY INFORMATION QUESTIONNAIRE

Please tell us about yourself and your family. You may skip any questions that you prefer not to answer.

PARENT

1. Participant # _____
2. Male _____ Female _____ Other _____ (select one)
3. What is your age? _____
4. What is your marital status? _____
5. What is your highest grade level or degree received? _____
6. What is your current occupation? _____
7. What is your *total* family income? _____
8. Including yourself, how many adults live in your house? _____
9. Including your focus child, how many children live in your house? _____
10. Do any of your other children have disabilities? _____

FOCUS CHILD (child who has ASD)

11. Name _____
12. Male _____ Female _____ Other _____ (select one)
13. What is your child's date of birth? _____
14. At what age was your child diagnosed with autism? _____
15. Does your child have any other diagnoses? Please describe.

16. By whom was your child diagnosed? _____

17. How would you describe your child's communication skills? (verbal/non-verbal)

18. What are your child's strengths and areas of need?

19. Does your focus child receive any of the following therapies/services *outside of school*? (please check all that apply.)

- Speech Therapy ____
- Occupational Therapy ____
- Physical Therapy ____
- Applied Behavior Analysis ____
- Social Skills Group ____
- Medicaid Funded Services ____
- Other ____ (_____)

20. How many hours per week does your focus child receive services *outside of school*? _____

21. Does your focus child receive any of the following services/therapies *in school*? (please check all that apply.)

- 1:1 Aide ____
- Speech Therapy ____
- Occupational Therapy ____
- Physical Therapy ____
- Applied Behavior Analysis
- TEACCH ____
- Social Skills Group ____

22. How many minutes/ hours per week does your focus child receive services *in school*? _____

FOCUS CHILD #2 (for parents who have more than one child with ASD)

11. Name _____

12. Male ____ Female ____ Other ____ (select one)

13. What is your child's date of birth? _____

14. At what age was your child diagnosed with autism? _____

15. Does your child have any other diagnoses? Please describe.

16. By whom was your child diagnosed? _____

17. How would you describe your child's communication skills? (verbal/non-verbal)

18. What are your child's strengths and areas of need?

19. Does your second child receive any of the following therapies/services *outside of school*? (please check all that apply.)

Speech Therapy ____

Occupational Therapy ____

Physical Therapy ____

Applied Behavior Analysis ____

Social Skills Group ____

Medicaid Funded Services ____

Other _____ *Please specify* (_____)

20. How many hours per week does your second child receive services *outside of school*?

21. Does your second child receive any of the following services/therapies *in school*? (please check all that apply.)

1:1 Aide ____

Speech Therapy ____

Occupational Therapy ____

Physical Therapy ____

Applied Behavior Analysis

TEACCH ____

Social Skills Group ____

22. How many minutes/ hours per week does your second child receive services *in school*?

Appendix P

The Everyday Discrimination Scale

In your day-to-day life, how often do any of the following things happen to you?

	Almost everyday	At least once a week	A few times a month	A few times a year	Less than once a year
1. You are treated with less courtesy than other people are.	1	2	3	4	5
2. You are treated with less respect than other people are.	1	2	3	4	5
3. You receive poorer service than other people at restaurants or stores.	1	2	3	4	5
4. People act as if they think you are not smart.	1	2	3	4	5
5. People act as if they are afraid of you.	1	2	3	4	5
6. People act as if they think you are dishonest.	1	2	3	4	5
7. People act as if they're better than you are.	1	2	3	4	5
8. You are called names or insulted.	1	2	3	4	5
9. You are threatened or harassed.	1	2	3	4	5

Follow-up Question (Asked only of those answering "A few times a year" or more frequently to at least one question.): What do you think is the main reason for these experiences? (CHECK MORE THAN ONE).

- Your Ancestry or National Origins
- Your Gender
- Your Race
- Your Age
- Your Religion
- Your Height
- Your Weight
- Some other Aspect of Your Physical Appearance
- Your Sexual Orientation
- Your Education or Income Level
- A physical disability
- Your shade of skin color
- Your tribe (SASH)
- Other (SPECIFY) _____

Williams, D.R., Yu, Y., Jackson, J.S., and Anderson, N.B. (1997)

Appendix Q

FACES Pre/Post Measures

FACES Scale

Please rate the degree to which you agree with the following statements:

	Strongly Disagree	Disagree	Neither agree nor Disagree	Agree	Strongly Agree
1. I feel confident about my knowledge of Special Education Laws.	1	2	3	4	5
2. I feel confident in my ability to communicate with my child's' educators.	1	2	3	4	5
3. I feel confident in my ability to communicate with my child's' health care providers.	1	2	3	4	5
4. I feel confident in my ability to help my child communicate with others.	1	2	3	4	5
5. I feel confident in my ability to practice social communication strategies with my child.	1	2	3	4	5
6. I feel confident in my ability to manage my child's behavior.	1	2	3	4	5
7. I feel confident in my ability to advocate for my child's needs.	1	2	3	4	5

Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992)

This survey is about how empowered you feel related to family, services, and community. We will use what we learn from this survey to help participants feel more empowered to advocate, and to compare empowerment levels before and after FACES.

FAMILY EMPOWERMENT SCALE SCORING SHEET

(Rev. 8/19/03)

Child ID: _____ Date Assessed: ___/___/___ Service Start Date: ___/___/___
 Case Number: _____ Medicaid #: _____ DOB: ___/___/___ Gender: ___M___F
 Child's Residence County: _____ BDS Region ___I___II___III
 Rater Name: _____ Agency/Program Name: _____
 Rater ID#: _____

(Check appropriate items in the following categories)

FES Administration	Services Program	School-Age	Birth-5
___ Baseline ___ Entry into Service	MH Case Mgmt	___	___
___ Annual ___ Exit ___ Other _____	MR Case Mgmt.	___	___
	Habilitation Svcs. (Sec.24)	___	
	Beh. Health Svcs. (Sec.65H)	___	

Disability Group ___MH___MR___MH/MR___Autism
 ___MR/Developmental Disabilities___Developmental Delays

Relationship of Person Completing FES ___Parent___Guardian___Foster Parent___Other

FES Statements	Not True at all	Mostly not True	Somewhat True	Mostly True	Very True
1. I feel that I have a right to approve all services my child receives	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
6. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
7. I know what to do when problems arise with my child.	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
9. I feel my family life is under control	1	2	3	4	5
10. I understand how the service system for children is organized.	1	2	3	4	5
11. I am able to make good decisions about what services my child needs.	1	2	3	4	5
12. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
13. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
14. I have ideas about the ideal service system for children.	1	2	3	4	5
15. I help other families get the services they need.	1	2	3	4	5
16. I am able to get information to help me better understand my child.	1	2	3	4	5

Mail to: Dept. of Behavioral and Developmental Services
 Attention: Children's Quality Improvement Assessment Data
 40 SHS, Marquardt Bldg.
 Augusta, ME 04333

FAMILY EMPOWERMENT SCALE SCORING SHEET

(Rev. 8/19/03)

Child ID: _____ Date Assessed: ___/___/___ Service Start Date: ___/___/___
 Case Number: _____ Medicaid #: _____ DOB: ___/___/___ Gender: ___M___F
 Child's Residence County: _____ BDS Region ___I___II___III
 Rater Name: _____ Agency/Program Name: _____
 Rater ID#: _____

(Check appropriate items in the following categories)

FES Administration	Services Program	School-Age	Birth-5
___ Baseline ___ Entry into Service	MH Case Mgmt	___	___
___ Annual ___ Exit ___ Other _____	MR Case Mgmt.	___	___
	Habilitation Svcs. (Sec.24)	___	
	Beh. Health Svcs.(Sec.65H)	___	

Disability Group ___MH ___MR ___MH/MR ___Autism
 ___MR/Developmental Disabilities ___ Developmental Delays

Relationship of Person Completing FES ___Parent ___Guardian ___Foster Parent ___Other

Instructions: Below are 34 statements that describe how a parent or caregiver of a child with an emotional, behavioral and/or developmental challenges may feel about his or her situation. For each statement, please circle the response that best described how the statement applies to you.					
FES Statements	Not True at all	Mostly not True	Somewhat True	Mostly True	Very True
1. I feel that I have a right to approve all services my child receives	1	2	3	4	5
2. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
3. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
6. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
7. I know what to do when problems arise with my child.	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending.	1	2	3	4	5
9. I feel my family life is under control	1	2	3	4	5
10. I understand how the service system for children is organized.	1	2	3	4	5
11. I am able to make good decisions about what services my child needs.	1	2	3	4	5
12. I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5
13. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
14. I have ideas about the ideal service system for children.	1	2	3	4	5
15. I help other families get the services they need.	1	2	3	4	5
16. I am able to get information to help me better understand my child.	1	2	3	4	5

Mail to: Dept. of Behavioral and Developmental Services
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 Augusta, ME 04333

School Communication Scale

(Burke, 2016)

This survey is about your communication with your child's school professionals. We will use what we learn from this survey to teach parents more about effective communication, and to compare participant communication with schools, before and after FACES.

Items	Never	Occasionally	Sometimes	Often	Very Often
1. I call my child's school to talk about my child's progress.	1	2	3	4	5
2. I visit my child's school to talk about my child.	1	2	3	4	5
3. I talk to much child's school about the academic program in the classroom.	1	2	3	4	5
4. I make sure to tell my child's school when I think things are going well.	1	2	3	4	5
5. I feel free to contact my child's school.	1	2	3	4	5
6. I volunteer at my child's school.	1	2	3	4	5
7. I attend activities at my child's school.	1	2	3	4	5

Family-Professional Partnership Scale
(Summers et al., 2005)

This survey is about how you feel about your child’s IEP team. We will use what we learn from families to inform policy makers and service providers for children and families.

Thinking about your child ‘s IEP team over the **last six months**.

How **satisfied** are you that your child’s IEP team...

	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. Helps you gain skills or information to get what your child needs.	1	2	3	4	5
2. Has the skills to help your child succeed.	1	2	3	4	5
3. Provides services that meet the individual needs of your child.	1	2	3	4	5
4. Speaks up for your child’s best interests when working with other service providers.	1	2	3	4	5
5. Lets you know about the good things your child does.	1	2	3	4	5
6. Is available when you need them	1	2	3	4	5
7. Treats your child with dignity.	1	2	3	4	5
8. Builds on	1	2	3	4	5

your child's strengths.					
9. Values your opinion about your child's needs.	1	2	3	4	5
10. Is honest, even when there is bad news to give.	1	2	3	4	5
11. Keeps your child safe when your child is in his/her care.	1	2	3	4	5
12. Uses words that you understand.	1	2	3	4	5
13. Protects your family's privacy.	1	2	3	4	5
14. Shows respect for your family's values and beliefs.	1	2	3	4	5
15. Listens without judging your child or family.	1	2	3	4	5
16. Is a person you can depend on and trust.	1	2	3	4	5
17. Pays attention to what you have to say.	1	2	3	4	5
18. Is friendly.	1	2	3	4	5

Special Education Advocacy Scale (Burke, 2016)

This survey is about how you feel about your advocacy skills. We will use what we learn from this survey to teach participants more about advocating, and to compare your perceptions of your advocacy skills before and after FACES.

	Not at all	Below Average	Average	Good	Excellent
1. How knowledgeable do you think you are about your special education rights?	1	2	3	4	5
2. How able are you to apply your knowledge of the law in special education meetings?	1	2	3	4	5
3. How able are you to advocate for a child's educational needs at special education meetings?	1	2	3	4	5
4. How able are you to assert yourself at special education meetings?	1	2	3	4	5
5. How well are you able to communicate effectively with the school?	1	2	3	4	5
6. How well do you think	1	2	3	4	5

you stay calm and non-adversarial at school meetings?					
7. What is your self-confidence like in terms of working with the school?	1	2	3	4	5
8. What is your working relationship like with the school?	1	2	3	4	5
9. How able are you to effectively participate at IEP meetings?	1	2	3	4	5
10. How prepared do you feel to collaborate with the school at IEP meetings?	1	2	3	4	5