

FACES: An Advocacy Intervention for African American Parents of Children with Autism

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Abstract

Children with autism 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 to combat culturally insensitive service delivery and strained parent-professional partnerships. In this sequential mixed-methods study, we piloted a 6-week parent-training intervention (FACES) among African American parents of children with autism and evaluated participants' empowerment, advocacy, and partnerships pre- and postintervention. Results indicated that parents' advocacy, sense of empowerment, and community support were strengthened, following the FACES program. Participants also described the FACES intervention as socially valid. Implications for research and practice are discussed.

Keywords: autism, African American families, parent advocacy, parent-training intervention

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The prevalence of autism spectrum disorder (ASD) has recently increased in the United States to 1 in 59 children (Centers for Disease Control and Prevention [CDC], 2018). In their community report on ASD, the CDC purported that African American children are less likely to be identified with ASD than European American children (CDC, 2016), even though the risks of developing ASD are the same across racial/ethnic backgrounds. While the exact reasons for this disparity are unknown, findings suggest that lack of cultural responsiveness, stigma, lack of access to healthcare services, and poverty may be factors that influence ASD identification in African American children (e.g., Donohue et al., 2017; Pearson, 2016). Regarding socioeconomic status, however, findings have indicated that while the impact of socioeconomic status among European American children is starting to fade, this is not true among African American children. That is, there are extant disparities in diagnoses stemming from racial differences that are independent of socioeconomic status (Donohue et al., 2017; Wright, 2016). As such, the CDC has emphasized the 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).

Theoretical Context

Advocacy

Research related to autism awareness and advocacy programs among parents of children with disabilities exists, but is limited. In the autism literature, advocacy is described 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). Exploring predictors of parent advocacy, Ewles et al. purported that little is known about factors that (a)

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contribute to parent advocacy and (b) increase the likelihood of successful advocacy among parents of children with ASD. Efforts to address this need for parent training have been reflected in a few parent advocacy training programs 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 et al., 2016).

Empowerment

Empowerment has long been viewed as a central goal of the efforts to improve services for children with disabilities and their families (Koren et al., 1992). Regarding advocacy and empowerment among African American families, Whitley and colleagues (2011) suggested 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 et al., 2017) 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. 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 (see Donohue et al., 2017); and (b) resources to help parents advocate for the services and supports their children and families need (Azad & Mandell, 2015; Burkett et al., 2015; Pearson & Meadan, 2018; Zuckerman et al., 2013). Culturally responsive parent-advocacy training programs designed specifically for African American families have the potential to increase parents' knowledge of

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ASD, strengthen communication and partnerships with professionals, strengthen empowerment, and strengthen parents' advocacy efforts in the ASD community (Pearson & Meadan, 2018).

The purpose of this mixed methods pilot study was to measure the effectiveness and social validity (i.e., feasibility and acceptability) of a newly developed program entitled FACES (*Fostering Advocacy, Communication, Empowerment, and Support*), among African American parents of children with ASD.

Method

FACES

FACES is a six-session, 18-hour parent-training and advocacy program developed by the authors, and driven by a demonstrated need for: (a) community resources to increase knowledge of special education rights, especially among culturally and linguistically diverse families (Burke & Goldman, 2018); (b) advocacy programs among parents of children with ASD (Burke, 2013; Mueller & Carranza, 2011); and (c) advocacy specifically designed to address the needs of African American children with ASD (Pearson & Meadan, 2018).

The sequence of the FACES program was grounded in three key features: (a) a simple-to-complex sequencing approach (Schmidt et al., 2007); (b) the FACES theory of change (i.e., parent knowledge, parent perceptions, and parent and child outcomes); and (c) the characteristics of adult learning theory (Trivette et al., 2009). 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). Each FACES session is built on content from the previous session such that parents understand 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. Unit

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Unit 1 content includes (a) characteristics of ASD, strategies for promoting social communication skills and addressing challenging behavior (adapted from Meadan, Snodgrass, et al., 2016; Meadan, Ayvazo, et al., 2016), and (b) special education law and procedures (e.g., six principles of IDEA). Unit 2 focuses on (a) strategies for accessing services and (b) effective advocacy (adapted from Burke & Goldman, 2017; Goldman et al., 2017). Unit 3 highlights (a) strategies for strengthening empowerment and (b) engaging in effective communication with professionals. This study was guided by the following research questions: (a) Does the FACES program strengthen empowerment, advocacy, and parent professional partnerships in African American parents of children with ASD? and (b) Do African American parents of children with ASD perceive the FACES program as socially valid?

Participants

Following approval from the Institutional Review Board, participants were recruited through community agencies and organizations (e.g., parent support groups) in a large, Midwestern city. The criteria for selecting participants were as follows: (a) a parent or guardian who had a child (aged 3-14 years) with a primary diagnosis of ASD (verified by the Social Communication Questionnaire (SCQ); Berument et al., 1999); (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 6-week FACES program and participate in and complete pre-/postintervention focus group sessions and questionnaires. During the informed consent process, participants were assured 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. The study included 10 parents and/or caregivers of African American children with ASD. Seven participants were mothers, two participants were fathers, and one

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participant was a grandmother. Participant ages ranged from 36 to 63 years (mean age = 46.6 years). Three of the 13 participants who began the FACES training did not complete it (attrition rate = 23%) and were not responsive to follow-up email messages to inquire about why they were unable to complete the training. However, the remaining participants ($n = 10$) attended 80% or more of the training sessions. See Table 1 for additional demographic information.

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 across three library branches (all within a 7-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).

Research Design

This study 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). The purposes for mixing methods in this study included: development, complementarity/initiation, and triangulation. Data were mixed for development of the training program and during the analysis and interpretation stage. The 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) generating deeper understandings of the experiences of African American parents of children with autism; and (c) advancing the dialogue between parents with similar experiences, parents and professionals, and researchers in the field (Greene, 2007).

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Data Collection and Measures

Data collection included a demographic questionnaire (i.e., Family Information Questionnaire), formative and summative evaluations, pre- and postFACES surveys, pre- and postintervention focus groups, and participant testimonials. The pre- and postFACES surveys were a compilation of the following: *FACES scale*, *Family Empowerment Scale*, *School Communication Scale*, *Family-Professional Partnership Scale*, and *Special Education Advocacy Scale*.

Prior to the first FACES session, each participant provided informed consent, completed the demographic questionnaire, and the preFACES survey. At the end of each session, participants completed a formative evaluation, and on the last day of the FACES program, participants completed the postFACES survey, the summative evaluation, and recorded video testimonials (i.e., individual interview). All FACES sessions were facilitated by the first author.

Focus Groups and Testimonials

One preFACES and two postFACES focus groups were conducted. Additionally, participants recorded testimonials, following the program.

PreFACES Focus Group. Six parents (five mothers and one father) participated in the preFACES focus group interview. The lead author facilitated the focus group with a graduate assistant and informed participants of their participant rights. The main areas of inquiry in the preFACES 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 preFACES focus group lasted 67 minutes, and was recorded using a Sony® digital audio-recorder.

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PostFACES Focus Group. Three parents (two mothers and one father) participated in the first postFACES 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 postFACES focus group interviews were co-facilitated by two graduate student assistants in Special Education. 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. The first postFACES focus group interview lasted 39 minutes, and the second postFACES focus group interview lasted 61 minutes. Both postFACES focus group interviews were recorded using a Sony digital audio-recorder.

PostFACES Video Testimonials. Ten parents (seven mothers and three fathers) participated in the postFACES testimonials. During the testimonials, each participant was asked to reflect on (a) what they most got out of the FACES program and (b) how they hoped to apply their 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.

Family Information Questionnaire

The tool was developed by the authors and administered to collect demographic information (e.g., income and marital status) and the types of services that their children with

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ASD received (school-based therapies and home and community therapies). The questionnaire included 22 items and took 10-15 min to complete.

Formative and Summative Evaluations

Both formative and summative evaluations (adapted from the VAP; Burke, 2013) were used to adapt the program as needed, and to assess the efficacy of FACES. Following the completion of each session, 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?” Written feedback from the formative evaluations was reviewed after each session and adjustments to the subsequent sessions were made as needed.

Following the final FACES session, 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?”

FACES Scale

The FACES scale is a seven-item, Likert scale questionnaire that was developed by the authors. The scale was designed to measure parents’ confidence in their ability to advocate for and support their children's needs. Each item was scored on a 5-point scale from *strongly agree* to *strongly disagree*. For this study, both the preFACES and postFACES scales demonstrated high reliability ($\alpha = .93$ and $\alpha = .91$, respectively).

Family Empowerment Scale (FES; Koren et al., 1992)

The FES measures empowerment among families of children with disabilities, and

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includes three distinct subscales: family, service systems, and community/political. 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 et al., 1992). For this study, the preFACES FES scale demonstrated high reliability ($\alpha = .72$, $\alpha = .86$, $\alpha = .83$) for the family, service system, and community/political domains, respectively. The postFACES 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 (SCS; Burke et al., 2016)

The SCS measures parents' communication with school-based professionals. Each question has a Likert scale. The scale has been used previously with families of children with ASD and has strong reliability ($\alpha = .87$). For this study, the preFACES SCS demonstrated internal consistency of $\alpha = .78$ and the postFACES SCS demonstrated internal consistency of $\alpha = .90$.

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

The FPPS includes 18 items related to child-focused relationships and family-focused relationships. Each item is rated on a Likert scale and the measure has strong reliability ($\alpha = .93$). For this study, the preFACES FPPS demonstrated internal consistency of $\alpha = .93$ and $\alpha = .89$ for the child and family subscales, respectively. The postFACES FPPS demonstrated internal consistency of $\alpha = .85$ and $\alpha = .88$ for the child and family subscales, respectively.

Special Education Advocacy Scale (SEAS; Burke, 2016)

The SEAS measures participants' perceptions of their ability to advocate. The scale includes 10 items on a Likert scale with answers ranging from *not at all* to *excellent*. The scale has been used with several cohorts of graduates from the VAP and has a Cronbach's alpha equal

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to .87. For this study, the preFACES SEAS demonstrated internal consistency of $\alpha = .94$ and the postFACES scale demonstrated internal consistency of $\alpha = .76$.

Social Validity

To measure the social validity of the FACES program, we (a) reviewed attendance records, (b) conducted postFACES focus group sessions (facilitated by graduate student assistants), (c) recorded postFACES participant testimonials (i.e., individual interviews), and (d) measured participant satisfaction via both formative and summative evaluations.

Data Analysis

Formative and Summative Evaluations

Scaled items on the formative and summative evaluations data were analyzed via descriptive statistics and the open-ended items were analyzed using an open-coding approach.

Pre-/PostFACES Survey

Pre- and postFACES measures were examined for missing data and to determine whether the data were missing at random or if this constituted a pattern. Following Harrell's (2001) imputation guidelines, we employed the mean imputation method for less than 5% of the FPPS for two participants. Finally, we 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, we proceeded with nonparametric statistics (i.e., Wilcoxon Signed-Ranks Test; Tabachnick & Fidell, 2013).

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Focus Groups and Testimonials

Following transcription and verification, we employed a constant comparative method for the focus group data analysis (Corbin & Strauss, 2015). In the first level of analysis, we independently read each transcript and organized the data into broad codes. During the second level of analysis, we reread the transcripts to reach a consensus on initial codes and to develop structured categories. During the third level of analysis, we revised the codes as needed and identified emerging themes throughout the data. Finally, we conducted member checks to ensure the accuracy of the interpretation (Brantlinger et al., 2005).

Credibility and Trustworthiness. To ensure that the qualitative data analysis met high-quality standards, we recruited an appropriate sample, worked collaboratively as a team, provided thick, detailed descriptions of the data, triangulated the data, and conducted member checks (Brantlinger et al., 2005). Moreover, the first author was forthright about their position and perspectives within the context of this research by monitoring possible biases through field notes, memos, and regular debriefings.

Findings

Findings from pre- and postintervention surveys, focus groups, formative and summative evaluations, and participant testimonials indicate that FACES program participants increased their positive perceptions of empowerment and advocacy following FACES, and perceived the program as socially valid. All participant names in the following sections are pseudonyms.

Parent Empowerment

Following the 6-week FACES program, findings indicated increased FES scores and positive perceptions of family empowerment. The Wilcoxon Signed-Ranks Test indicated that postFACES scores on the FES family subscale, service system subscale, and community/

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political subscale were significantly higher than preFACES 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 2).

The survey findings related to positive perceptions of empowerment following the FACES program were further substantiated by data from the postFACES 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, father of a 3-year-old son who attended FACES 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, [Black families] 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.

Mary, mother of 6-year-old twins, one of whom had ASD, shared how FACES increased her sense of empowerment to support 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."

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Knowledge of ASD

Following FACES, a number of themes emerged that were specific to participants' knowledge and understanding of ASD (and more generally, disability). PostFACES focus group interviews, testimonials, and summative evaluations indicated that participants benefited 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. Luke, father of a 7-year-old boy, 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.

Alicia reflected on what she learned from FACES and how she had gained more knowledge about her rights for her son and had also learned more about resources that were 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, 6-week boot camp.

Finally, Tamryn, mother of a 10-year-old son shared how she had fears related to ASD prior to joining the FACES program, but now she felt like she had gained enough knowledge to able to help other parents dispel myths and ease their anxieties related to ASD: "If I could help

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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.”

Communication and Behavior Strategies

Following the 6-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 postFACES scores on the FACES scale were significantly higher than pre-FACES scores on the FACES scale ($Z = -2.46$, $p = .01$, $ES = -.55$) with a moderate effect size (see Table 2).

The FACES scale 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 postFACES focus group interviews, formative evaluations, and parent testimonials. Participants highlighted strategies that they adopted following FACES, to increase social communication skills and manage their children’s behavior. The social communication and behavior management parenting strategies included increased patience, planned ignoring, using visual supports, and school communication/carryover (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.”

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

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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.

Advocacy

Data analysis indicated that the 6-week FACES program contributed to increased scores on the SEAS and positive perceptions of advocacy strengths and abilities (see Table 2). The Wilcoxon Signed-Ranks Test indicated that postFACES scores on the SEAS were significantly higher than pre-FACES scores on the SEAS ($Z = -2.32, p = .02, ES = -.52$).

Parents' perceptions of their advocacy strengths and abilities were also reflected in the postFACES 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.

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

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FACES 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’s kind of built our arsenal for what we can use to be able to advocate.” Luke went on to express how his participation in FACES encouraged him to advocate not only 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.

During the postFACES focus group interviews, all FACES participants indicated that they felt better equipped to advocate in both formal and informal ways. Findings indicated that participants had more knowledge, information, and access to resources that prepared them to engage in constructive activities that could 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.” 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.

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Partnership

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

Findings from postFACES 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 in which they felt better prepared to build more positive parent-professional partnerships in the future, following FACES. Alicia shared how important it was 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.

Similarly, Catherine highlighted the importance of communicating with professionals:

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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.

Nanci shared how she felt better prepared to communicate with her son's providers, now that she had 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 to 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.

Social Validity

Participant attendance, postFACES focus group interview data, formative evaluations, summative evaluations, and participant testimonials were analyzed to assess the degree to which the FACES program met the needs of these African American parents of children with ASD (i.e., participants' overall views of the FACES training, and importance of the goals, procedures, and outcomes of the intervention).

Sense of Community

When asked to share their views about the FACES program, all 10 FACES participants identified a sense of community as one of the greatest benefits of the program. Participants

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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. Luke shared the following about how FACES created a sense of community for 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 sometime 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.

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.

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. We got to network with people and listen to other people's ideas and thoughts about their kids.

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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.

Mary also shared her thoughts about how being around other FACES families 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.

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.

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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 overreact you know because he appears so normal. But your knowledge is blessing me.

Participant Satisfaction

Formative evaluations, summative evaluations, focus group interview data, and participant testimonials indicated that participants were highly satisfied with the FACES program. 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. When asked if the FACES training met the participants' 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;" and "The information I received has been more than I expected." During the postFACES focus group interview, 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 [facilitator] 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.

Discussion

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) who found the LPLSP to be both feasible and effective in increasing parents' feelings of empowerment and knowledge of advocacy skills among Latino families. Following FACES, participants demonstrated strengthened perceptions of empowerment, advocacy, partnerships, and most notably, community. See Figure 1.

Empowerment

In the field, family empowerment has emerged as a construct rooted in consumer, professional practice, and research communities. Within the consumer movement, empowerment is 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). This study's findings not only highlight participants' perceptions of empowerment, but they highlight participants' empowerment as demonstrated by: (a) their knowledge of ASD (and dissemination of said knowledge) and (b) their knowledge and use of communication and behavior management strategies following FACES.

Knowledge of ASD

To our knowledge, no intervention studies have measured African American parents' knowledge of ASD pre- and postintervention. 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

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rights and laws, and (c) increased knowledge of resources for individuals with ASD. A core component of parent knowledge following FACES was their ability to subsequently dismantle stigma related to ASD in their communities. Existing quantitative measures of ASD knowledge (e.g., Gillespie-Lynch, 2015) have included few, if any, cultural adaptations to measures of knowledge such as the Autism Knowledge Scale (AKS; Stone, 1987). 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).

Communication and Behavior

Even among children with ASD and IQs 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 children 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 visual supports, and school communication/carryover (e.g., ensuring consistency in behavior management across settings). While the FACES program focused less specifically on parent-mediated interventions, these preliminary findings support the extant research in this domain (e.g., Ingersoll & Berger, 2015). Moreover, the findings yield

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promising implications for the impact of parent-implemented social communication strategies in African American families of children with ASD, a community who is consistently underrepresented in parent-mediated intervention research for children with autism (e.g., Ingersoll & Berger, 2015; Weatherby et al., 2014).

Advocacy

Advocacy has been described as an active exercise of empowerment that contributes to problem-solving and developing solutions (Munro, 1991). Following the FACES program, parents demonstrated their ability to exercise their empowerment via advocacy. Increased scores on the SEAS and positive perceptions of advocacy strengths and abilities were reflected in both quantitative and qualitative data. These findings were consistent with the findings from Burke et al.'s (2016) VAP study which also resulted in improvements in advocacy skills. 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 addressing stigmas and debunking myths related to ASD and disability, in their communities.

Partnership

Although the current study failed to achieve statistical significance related to parent-professional partnerships, the qualitative findings 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

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community resources, ongoing communication within schools, and being visible in their children's schools and communities (Stanley, 2015).

Community

For some participants, FACES was the first opportunity they 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 of 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—where their shared experiences could be understood within the context of their everyday lives (John-Steiner & Mahn, 1996). Similarly, Burke and Goldman (2017) 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.

Implications

For Research

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

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persistently lacking in the literature (e.g., Pearson & Meadan, 2018). Given the positive pilot data from this study, 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 randomized control trial.

For Practice

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. Previous work has pointed to the need for advocacy and empowerment supports among CLD families of children with disabilities (Burke & Goldman, 2018), and more recent work has started to address the gap between parents and providers through community-based programs such as Meeting FACES (Pearson, et al., 2020). Future work should continue to embed advocacy, empowerment, and partnership-building as 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).

Limitations

While the findings of the current pilot study demonstrate strong social validity following the FACES program, three primary limitations should be noted. First, the sample size for this study was small ($N = 10$). Despite the small sample size and subsequent lack of power, the quantitative findings were triangulated with multiple sources. Second, this was a single group, pre-post design. Given the nature of this design (i.e., no control group) and the composition of the sample (i.e., participant demographics), threats to internal validity cannot be ruled out. A third limitation is the presence of two mother-father dyads. While this study focused on individual parent outcomes, their partner's having also attended the FACES program could have

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influenced participants' experiences and perspectives. 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 families were experiencing 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 be generalized or transferred to those twice-, or three times-underserved communities. Notwithstanding the aforementioned limitations, this study contributes to our understanding of (a) the effectiveness of the FACES intervention, and (b) the social validity of the intervention in meeting the needs of African American families of children with autism.

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 inequity.

Previous research findings have suggested that overcoming these barriers might be achieved through increased parent education about ASD, parent advocacy training, and

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providing parents with assistance to navigate the service system (Kipke & Kubicek, 2014; Pearson & Meadan, 2018). The FACES program is the first step toward helping parents overcome these barriers, by providing parents with a 6-week advocacy and empowerment training program 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 considers 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 similar 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.

Finally, the findings from this study produce critical implications about the social validity of such studies for African American families of children with autism. The FACES program may be one intervention that can strengthen advocacy, empowerment, and partnerships, among African American families of children with ASD—a first step in the right direction toward addressing disparities in autism diagnoses and increasing autism service-utilization in African American communities.

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Figure 1. FACES Conceptual Model



Table 1

FACES Participants

Participant Pseudonym	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
Phoebe ¹	Mother	43	Married	A.A.	At home mom	\$34,500	1	No	Male	7	6	45
Luke ¹	Father	36	Married	B.A.	Computer Technician	\$34,500	1	No	Male	7	6	41
Janice ²	Mother	46	Married	B.A.	Accountant	\$100,000	2	No	Male	11	9	44
Chris ²	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**	Mother	35	Married	B.A.	Community Organizer	\$48,000	1	No	Male	3	3	
Deborah***	Mother	48	Divorced	M.A.	Teacher	\$85,000	2	Yes	Male	8	4	
Marva***	Mother	36	Married	Some College	Safe Passage Supervisor	\$30,000	2	No	Male	8	3	--

Note. ¹Parent dyad. ²Parent dyad. *Everyday Discrimination Scale; Range 9-45, where lower scores reflect higher perceptions of everyday discrimination. **Missed two FACES sessions; completed all other study requirements. Not included in survey data analysis; ***Missed three or more FACES sessions; did not complete post FACES survey. Not included in survey data analysis.

Table 2
Pre/post survey findings

Pre/post Measures	Wilcoxon Signed-Rank Analysis					Emergent Themes
	Pre	Post	Z	p	r	
Empowerment (Family)	46.00 (5.03)	50.90 (5.76)	-2.53	.01	-.57	Dismantling stigma, managing emotions, addressing needs
Empowerment (Service)	49.40 (7.73)	54.20 (5.47)	-2.08	.04	-.47	
Empowerment (Com/Pol)	29.60 (7.49)	35.60 (4.72)	-2.45	.01	-.55	
Communication/Behavior (FACES Scale)	24.60 (6.54)	30.30 (3.53)	-2.46	.01	-.55	Increased patience, planned ignoring, home/school carryover
Partnerships (SCS)	25.80 (5.55)	26.70 (6.06)	-0.93	.35	-.21	Prepared to communicate with professionals
Partnerships (FPPS-Child)	36.00 (4.85)	37.00 (3.68)	-0.69	.49	-.15	
Partnerships (FPPS-Family)	38.80 (3.62)	38.80 (3.62)	-0.12	.91	-.52	
Advocacy	34.60 (8.07)	41.20 (4.13)	-2.32	.02	-.52	Sharing knowledge, understanding ASD, advocacy skills