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“I Know How to Get Around Your ‘No:’” A Follow-Up of the FACES Psychoeducational Intervention --Manuscript Draft--

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Abstract

Black children and their families encounter systemic disadvantages in their journey to and through an autism diagnosis. Black families often experience social and systemic barriers to service use. Providing family-centered, psychoeducational interventions can reduce barriers to service access and utilization for Black families raising autistic children. Fostering Advocacy, Communication, Empowerment, and Support (FACES) has demonstrated preliminary efficacy in strengthening outcomes among Black families, yet little is known about the long-term impact of the intervention. The purpose of this qualitative interview study was to understand the experiences of FACES graduates 16 months after the intervention. Four major themes emerged: (a) strengthened advocacy, (b) strengthened empowerment, (c) systemic barriers, and (d) home and community barriers. We provide implications for research and practice.

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Black children and their families encounter systemic disadvantages in their journey to and through an autism diagnosis. While statistical prevalence of autism now appears comparable

for White and Black children (Maenner et al., 2021), Black autistic¹ children typically receive their diagnosis years later than White children (Constantino et al., 2020; Dattaro, 2020; Jenco, 2020). Delayed diagnoses result in delayed service access and utilization for many Black families (e.g., Pearson, 2015; Pearson & Meadan, 2018; Mandell et al., 2007; Taylor & Henninger, 2015). Even after families have access to services, Black families often experience additional social and systemic barriers to service use, such as: (a) unfamiliarity with service options, (b) racial macro- and microaggressions from autism professionals; and (c) stigma from friends and family about autism and disability (Blanchett et al., 2009; Dababnah et al., 2018; LaClair et al., 2019; Pearson & Meadan, 2018; Pearson et al., 2021).

While barriers are abundant, solutions are scarce. Black autistics face empirical neglect as autism research typically involves primarily-White samples (Malone et al., 2022). Studies exploring interventions for autistic children or youth often do not report the ethnicity or race of participants, prohibiting readers from determining if the intervention is culturally representative, let alone culturally appropriate (Canella-Malone et al., 2021; Steinbrenner et al., 2022). Most of the extant research involving Black autistic children, youth, and adults focused on quantifying disparities (e.g., Maenner et al., 2021; Cuccaro et al., 2007; LaClair et al., 2019; Mandell et al., 2009); few studies investigated reducing disparities through interventions (Pearson et al., 2021).

FACES: A Parent Intervention

One way to **mitigate** barriers to service access and utilization for Black families is to intervene at the family level (Pearson & Meadan, 2021). Education, training, support, and advocacy skills may help Black parents combat the barriers they face in accessing and using

¹ To honor the voices of self-advocates, we use identity-first language throughout this manuscript by referring to individuals identified with autism as “autistic” Many autistic self-advocates and advocacy groups prefer identity-first language (e.g., autistic child), and have also expressed preferences for the term “autism” rather than autism spectrum disorder.

services (Meadan et al., 2010; Mueller & Carranza, 2011; Pearson, 2015; Pearson & Meadan, 2018; Pearson, Trificante et al., 2020). **While advocacy does not remove structural barriers, family empowerment and advocacy skills can help overcome systemic challenges (Koren et al., 1992).** Parent advocacy is associated with improved academic and functional outcomes for children and youth with profound autism (Bruder, 2010; Carter et al., 2012; Irvin et al., 2012; Meadan et al., 2016). Because cultural perspectives play a role in service use, parent advocacy programs for Black families may be most effective when built around affinity shared among parents and educators (Warren-Grice, 2021).

To address this need, we designed a community-based parent advocacy and empowerment intervention program specifically for Black families raising autistic children that paired evidence-based, parent-implemented interventions (e.g., i-PiCS; Meadan et al., 2016) with adult learning practices (e.g., Trivette et al., 2009). This curriculum, entitled *Fostering Advocacy, Communication, Empowerment, and Support (FACES)*, was intended to improve social, behavioral, and academic outcomes for Black autistic children by strengthening parents' advocacy capacity and knowledge of autism (Pearson & Meadan, 2021). Participants in the FACES pilot study demonstrated positive immediate outcomes, including: (a) increased knowledge, (b) strengthened perceptions of empowerment and advocacy skills; and (d) established peer support networks (Pearson & Meadan, 2021). However, we wanted to explore if and to what extent the FACES program led to positive long-term outcomes. Therefore, the purpose of this study was to understand the experiences of Black families raising autistic children 16 months after the conclusion of the FACES intervention. Two research questions (RQ) guided us: (1) What are the advocacy, empowerment, and community experiences of Black

families raising autistic children 16 months following participation in the FACES intervention? and (2) What barriers and areas of need continue to persist among FACES graduates?

Method

In the FACES pilot study, 10 Black parents raising autistic children participated in six, 3-hr training sessions. During the first three sessions, participants received training in: (a) characteristics and diagnostic criteria of autism; (b) strategies for promoting social communication skills; and (c) special education law and terminology. During the final three sessions, facilitators provided: (a) approaches to accessing services; (b) procedures for advocating for their child(ren); and (c) strategies for effective communication with professionals. Session leaders used a researcher-generated curriculum that featured principles of explicit instruction (e.g., vocabulary, instruction, modeling) and included opportunities for group discussion throughout each session. Refer to Pearson & Meadan (2021) for a complete description of the FACES intervention and results. We conducted the follow-up study 16 months after the final FACES session. In the current exploratory phenomenological study, we sought to capture experiences of participants (Moustakas, 1994) and use these data to refine the FACES training. We aligned our study method with quality indicators of special education research (Brantlinger et al., 2005).

After receiving Institutional Review Board approval, we used the FACES registration list to recruit participants. We initially contacted the 10 FACES graduates via email. After one week, we followed up via phone, with any participants who had not responded. Six parents agreed to participate in interviews. Two participants did not respond to our request, and two participants expressed interest in being interviewed, but were unable to schedule a meeting within our data collection timeline.

Positionality

Our team included four researchers with diverse cultural and professional identities. This ensured data analyses and interpretations were not idiosyncratic (Brantlinger et al., 2005). The first author was the principal investigator (PI) and facilitator of the FACES training from which the participants graduated. This, along with her identity as a Black woman, allowed her to be perceived as an insider (Merton, 1972) and ally of the interview participants. As a former family service professional, she was aware of families' typical support needs. The first author developed the interview protocol, and assisted with data analysis. The second author, an experienced special education teacher, has collaborated with families of children with autism to support their education. As an Asian American scholar, she identifies with culturally responsive interventions to meet the needs of diverse families of children with exceptionalities. She assisted with data cleaning and analysis. The third author, a white man, applied training and experience in program evaluation and implementation research to assist the first and second authors with generating themes and organizing findings. The fourth author, a Black woman, assisted with manuscript development. As an experienced K-12 special education teacher and previous psychology associate, she has supported diverse families raising autistic children across the lifespan. She has also been a foster mother to autistic children. All four authors held professional expertise in special education and shared a commitment to equity, antiracism, and providing culturally responsive interventions for autistic individuals and their families.

Participants

Six FACES graduates (Pearson & Meadan, 2021) participated in the follow-up study. We report participant demographics and pseudonyms in Table 1. Five participants were mothers and one participant was a grandmother. Participants varied in age (range 35–63 years; $M = 46.6$

years) and annual household income (range \$47,000–165,000; $M = \$87,875$). Five participants had autistic sons and one participant was raising an autistic daughter.

(Insert Table 1 here)

Data Collection

We conducted the interviews in a public library ($n = 4$), a café ($n = 1$), and a community resource center ($n = 1$). Each location provided free parking and was located within one block of public transit systems. One of two research assistants facilitated each interview with the participants using a semi-structured interview protocol (See Table 2; Kvale & Brinkmann, 2015). Interviews ranged from 41 to 56 minutes ($M = 50$ min). Interviews were recorded, transcribed, and verified by two graduate research assistants.

Data Analysis

The research team analyzed data using deductive constant comparative coding (Corbin & Strauss, 2015; Saldaña, 2021). First, the first and second authors met to organize and define structural codes according to our research questions. The researchers established two structural codes: (a) experiences and (b) barriers. Next, we created seven subcodes nested within each of the codes. We report structural codes and subcodes in Figure 1. After creating the codebook, the pair independently coded each transcript according to the structural coding scheme, recorded suggested revisions to the structural and subcodes as needed. Then, the pair met to form dialogic consensus on initial structural codes and subcodes (Lawless & Chen, 2019). Next, the pair re-read all transcripts and ensured units were accurately coded. After this round of analysis, the pair triangulated findings with the third author. Last, the first three authors reviewed final structural codes and subcodes and worked together to group emerging themes. We conducted member checks to confirm the accuracy of the transcript summaries with participants by emailing all

participants a summary of their interviews and requesting they confirm or amend the summary. Five participants replied and confirmed the interview summary; one participant did not respond.

Results

This qualitative follow-up study with FACES graduates revealed insights into parents' experiences, reflections, and outcomes 16 months after they completed the FACES intervention. **We list the frequency of each code in Table 3.** Four major themes emerged from our deductive analysis, organized by each research question.

RQ 1: What are the experiences of FACES graduates 16 months following completion of the program, with respect to advocacy, empowerment, and community?

“The advocacy piece is...tools I got from FACES”

Participants described how they have begun or continued to advocate for their child using knowledge gained from the FACES training. For example, when the classroom setting was not challenging her daughter academically, Eliza decided to advocate for a different classroom setting for her daughter. Eliza shared, “I’m not sending her to be in a Gen[eral] Ed[ucation] classroom, but it’s not going to be the same classroom [she’s currently in].” Maria described how she facilitated a powerful network of communication among **school and agency** service providers:

I realized, I was like...“I got this great team, now it’s for me to make sure that we are all in sync and we’re working together... [so] when it’s time for the parent-teacher conference, I contact the ABA [service provider] and the BCBA [Board Certified Behavior Analyst]. We all are on the same email; we coordinate a time that all of us can meet up.

Renée felt she effectively advocated for her son to receive additional behavioral intervention. “I advocate for the hours that he needs. He gets maybe three and a half, sometimes five [hours per day].” When her son’s speech therapist expected her to purchase a highchair to confine him during agency speech services, Angelica advocated for her son's behavioral needs. “My son, he's also hyperactive... confining him he would just throw a fit, so I’m like, ‘I’m not doing that to my son so your job is easier.’” Angelica reflected, “the advocacy piece is naturally from tools I got from FACES.” To ensure her son received needed medical services, Jasmine discussed how she advocated with the insurance company. “So, we had to fight with the insurance company, because they felt that he didn’t need it... [I’m] making sure that he’s covered.” Angelica discussed her plan to enroll her son in karate lessons to help him develop self-determination, “You also have to make sure he knows how to defend his self, communicate effectively, and advocate for himself.” Renée drew upon her insider knowledge from working in insurance when searching for the best services for her son. She shared,

I did take off a day of work to seek out ABA [Applied Behavior Analysis] services for him, which I was able to find through my insurance company. It's helpful because I'm working in the insurance sector, so I'm familiar with the carve outs and the H plans that may work with the insurance plan that we have in place for him.

Jasmine summarized her “big takeaway” from FACES:

It was just making sure that you continue to advocate, and making sure you’re advocating correctly. And, making sure that you’re talking to the right people, and not to be afraid of going over their head, that you don’t have to go in order. Because sometimes, that don’t work, and you just have to skip everybody else, and do what you have to do.

“I want people to know I’m empowered”

While some parents described activities related to advocacy, others described a stronger sense of empowerment. For instance, Angelica revealed her son is now able to access more services due to her ability to utilize standard English. Her experiences taught her the role race and language play in accessing services:

If I want access to the colonizer's tools, I'm going to have to communicate like them.

They are not going to listen to me and my vernacular... I got to role switch.

Angelica acknowledged that code switching was a critical tool she and her husband used to ensure her son received all of the support services he needed **from schools and agencies**. Renée highlighted the significance of her confidence in advocating and communicating for her child during school IEP (Individualized Education Program) meetings:

So I had all my notes, who I need to ask, I was ready to go. I'm not trying to intimidate people, but I want people to know that I'm empowered, and I feel confident now in his IEP [Individualized Education Program] meetings. But at the first IEP meeting, I didn't know what I was doing. Now, after FACES, and me just continuing doing research, I'm ready. Don't tell me no, cause I know how to get around your "no." Is it not carved in your budget? What's going on?

Some parents attributed this lasting sense of empowerment to affinity with fellow participants. For example, Maria expressed, "Being able to be around other parents that were experiencing similar situations that I can bounce off questions and [get] a little possible peek-a-boo of what this is gonna look like in a few years or later on down the road was priceless." Angelica shared that the most influential aspect of FACES was "...hearing from the other parents about the experiences they have with their children and the techniques that worked – and didn't work – that they tried." Having a community of other parents was critical in learning from other families'

experiences in raising and advocating for their children. Parents also expressed how the emotional support they received from the FACES families was instrumental. Similarly, Renée stated:

Coming together with other parents, grandparents, and everyone else in the room... that helped me so much. Because I was lost and I think it is very important to connect with other people that are having the same challenge or barriers.

Later, Renee described how her advocacy capacity has allowed her to translate knowledge with other families:

I'm so proud of myself, because I hit the ground running and continued being [involved] with other parent support groups to have that knowledge, to be able to help other people when they have their children. I was like, "Oh I know what you can do," and "look at this," and, "go to [AGENCY]." I was just like a hub of trying to help as much as I can. My mother in law actually reached out to me a couple months back, because she knew someone whose child was diagnosed with autism and wanted any help I could give her. I was like, "How old is the child? Are they in early intervention? This is what they need to do to start this. Do they have an IEP in school?" And so I was just going, [and] she was like, "Slow down. Just put it all in the email." Step one, do this. Get the assessment done, look up these people, go here. There's a support group I have that meets once a month and she's interested, so I was just going just from step by step, and she was just like, "Okay just slow down, put it in an email, and I'll make sure she gets the information."

Moreover, Maria focused on celebrating the small victories: "Yeah the steps always feel like baby steps but steps are still happening." While we intended to include disconfirming evidence, no participants conveyed that their advocacy skills or sense of empowerment had diminished in

the months following training. Parents shared continued experiences of engaging in advocacy and feeling empowered after participating in FACES.

RQ 2: What barriers and areas of need continue to persist among FACES graduates?

In addition to positive lasting outcomes following their FACES participation, parents also described ongoing systemic barriers they encountered parenting autistic children. These barriers included factors related specifically to advocacy and empowerment, as well as factors related to child outcomes and family quality of life, systemic oppression, and partnerships.

“Let me put on my armor”

While some FACES graduates felt a heightened sense of empowerment following the training, several participants faced ongoing challenges that impacted their feelings of empowerment. Participants discussed how, even with their newfound advocacy skills, they encountered negative attitudes from service providers in efforts to support their child. For instance, Angelica shared that after the training, she advocated for her child to receive services from a prominent university in the area. The first step was an observation:

So you go through, like, another diagnosis at the [UNIVERSITY] where they specialize in this. And I'm like, “okay it's like, a six hour interview where they just watch your child for six hours.” Oh my god it was forever. And before I went to the thing, I wanted to know who would be in the room. And their names. And when I would call the coordinator, I guess it is, she was surprised that I wanted to know who would be in the room. And so I was like “okay, how many people [will] be in the room with my son? What are they names? And what are their titles?” And so, she was like, “Well, why do you need to know all of that?” I said, “so I can do my research on them to see what their specialty is [laughs]. So I know where they got they credentials from [laughs]. And

because I'm his mama, what you mean? So I was a little taken aback that someone would ask me [why] would I want to know who's in that room. So what? I was like, “[We’re] back to the institution of navigation. Here we go, let me put on my armor.”

Similarly, Eliza detailed how she felt ignored by her daughter’s speech-language pathologist:

I kind of got upset with two of her therapists, 'cause when they all walked in, I said hello, cause *you* walked in where *I* was, but when I would go to therapy, they'd say, “Hi, [Daughter], and I'm ignored. I'm like I'm the one who drove her. I'm the one paying [for] her.

Eliza was frustrated by **agency** providers who would not acknowledge her, yet she continued to utilize their services, because she was afraid of the alternative – no services.

Angelica criticized how inaccessible the system of service providers is for working families: “It was really hard scheduling the therapist for early intervention because I’m not a stay at home mom... so the only people who can truly benefit from this is some middle class mom who wouldn’t qualify for the program [anyway]”.

Renée shared her experience with healthcare providers who were uneducated about autism. She made an appointment for Applied Behavior Analysis screening and assessment months in advance with an agency in town.

They sent me to a behavioral health office, like maybe [providing support] for ADHD [attention deficit hyperactivity disorder] or depression. So I waited three months for this appointment to arrive to see that I'm at the wrong place, because no one nowhere called [about] the reason for my visit. So I get to the front desk, and I ask the girl, “Is it in the computer, in your electronic health records, or your scheduling matrix, or management system, whatever you want to call it, does it show in the note that when I called, that I'm

here for Applied Behavior Analysis?" And again, the lady goes "Yes." I'm like, "And do you all prep[are] your charts, or know what the reason [is] why the people come in, so I wouldn't have wasted my time?" You all didn't know this before I came? We waited three months for this, I took a day off from work." I just explained it all. Everything. I even told her to give my copayment back. I thought it was dumb. But my thing was, I was always thinking about somebody else in my shoes, that probably went through this ... right, I'm like, "This is not gonna happen again." I told her that, I was saying, I was nice, "Have a good day. It's not your fault, sweetie, but I will make sure this will not happen again." I was just that upset to know that you all don't provide those type of assessments and/or screenings here, then you could have canceled my appointment months ago and redirected me accordingly. So the person that ended up taking me into the room, I believe she was a psychiatrist, she thought I was there for behavioral health, mental health challenges for my child. [She] gave me [HOSPITAL] hospital resources. And that's how I start my path too, to try to find ABA. But still, it was a process because I don't have time throughout the day to go over this list to see who's contracted. I already knew it was [AGENCY]. This is why I'm going through the way I was going. So, I actually filed a grievance with the [AGENCY] for the insurance company to let them know, I know I'm not the only parent that went through this. I was trying to make a statement and/or a point. It's the principle behind it.

While several participants described barriers in agencies, others expressed difficulties in ensuring appropriate school-based services for their children. Although school-based related services listed within a student's IEP are legally binding, many schools continued to refuse or were incapable of fulfilling these services. For instance, one preschool contacted Maria, a mother

of twins, and informed her that they would be unable to support her autistic child anymore, but could continue to serve her other twin son. Maria shared how she has to determine how to explain to her son why his twin brother cannot go to school with him because “he wants to know when his brother is going to be able to go back to school with him.” Also, schools with minimal resources and funding were unable to provide the entirety of students’ needed related services. Jasmine noted the school’s lack of funding for speech therapy support, “They even cut it from the school funding in [state]... where the speech therapist was in the classroom five days a week all day, now she’s in there part-time.” Peggy faced difficulties when the school refused to honor the services in her grandson’s IEP. When she reminded the principal about her grandson’s accommodation of having a personal bus aide, the principal responded, “[It] wasn’t going to happen.” In reflecting on her efforts to initiate communication to support her grandson’s education, Peggy declared, “I know the principal was not listening to my voice.” In addition to being a legal compliance issue in not fulfilling a child’s IEP, decreased funding, resources, and personnel for school-based services was also a significant barrier in home-school partnerships.

Some parents acknowledged how their Black identities impacted their ability to access services. For example, Alica noted challenges to finding a school that would provide adequate resources for her son due to unequal funding amongst nearby schools: “You have the community-based schools that’s like [where] 90% of the students live under the poverty line, and I’m like, ‘no, my son can’t go to these schools because the services gonna be wack.’ Just by institutional design, it’s not my people’s fault that the Black school is gonna have the least services.” Moreover, as families work to prepare their autistic children for adulthood and independence, they are teaching them to survive and advocate for themselves as Black individuals. For example, Eliza expressed challenges with teaching privacy and sexuality

development with her autistic daughter as she entered puberty. “I’m looking for ways to communicate, talk to her about sexuality.” Angelica taught her autistic son to not stare others down because she wants him to understand that people could shoot him for that by assuming his behavior as defiance:

He’s a Black man, so that male privilege don’t mean [expletive] compared to race, and class, and his autism...like, no. In this world, somebody [is] gonna pop you for that...

Sometimes, systemic barriers affected how parents viewed themselves. For example, Peggy described several setbacks in trying to seek care for her son, who has profound autism.

This led to a reflective and emotional exchange with the interviewer:

INTERVIEWER: So you're just taking things one day at a time right now? Is that fair?

Peggy: Yes. Yeah, that's fair. Yes.

INTERVIEWER: You have a lot on your plate, Ms. Peggy, and I really admire how hard you work and how much you advocate for yourself and for [grandson] and for your community.

Peggy: But I don't feel like I advocate. I should have did more. [audible crying] I'm sorry.

INTERVIEWER: No, you're okay.

Peggy: I should have did more than what was done...sometimes I get emotional.

Multiple parents experienced similar systemic barriers when trying to build relationships and understanding with clinical providers, which forced them to advocate more ardently for their child. Systemic barriers required parents to put on their “armor,” but sometimes limited their capacity to advocate, whether in perception or actuality.

“A gilded cage”

While some parents had to put on their “armor” when communicating with autism service professionals, others described the same phenomena with family members and close friends. For example, Maria described the ongoing shame she feels from her family:

When I say my “family,” my mother and I had a lot of back and forth issues but my whole family... kinda [said], “Nothing's wrong with [my son].” [It was] kind of a thing that I had to go through. And I think now that he's a little older and they see that he's talking in this “broken” way or whatever, that they're probably a little more...they realize that it must be some kind of challenge of some sort. I don't know if they are willing to call it autism, but you know what I'm saying? I think when [the child is] three or four [years old], you go, “all kids have issues, you're just making a big deal out of it.” And now that he's [seven years old], I think that they realize he does [have autism]. That kinda thing, my thing is being able...like I had to deal with my own shame with it. And that ... I still struggle with that if I was to be honest with you. When I go into new environments with him and he starts...because he's 7 years old and he likes stuffed animals and most 7-year-olds don't walk around with stuffed animals.

This stigma from family members plays a role in how much Maria shares with family members:

My mother had a little get together at her house and it wasn't just the core family. It was more of her friends and I wondered, I was like should I tell them that he's autistic? Or should I just let them look at him and wonder why he's doing that? I decided not to, I didn't. One of the reasons is because one of her friends, she's a doctor and she lives next door and I'm like I'm pretty sure she's probably told her. Now the other neighbor that lives a few houses down, I don't know if she did.

Eliza moved in with her mother after her daughter was diagnosed with autism. While she appreciated having her mother's help, she shared that her mother wanted to make educational decisions for her daughter:

It's been a gilded cage and I've always felt that way. I think I cried the day I had to move back on the block and I had to move back in that house...My hope and prayer is that next year, I'm in my own house off the block. I mean that sincerely, I'll be close enough to come visit once a week and whatever but...I know that sounds like I'm anti-grandma, and I don't mean to be an anti-grandma. But that's 'cause you got to... I'm her mother, you gotta let me handle this. The other day I said, "I don't really care for her teacher very much, I don't like the way that she communicates or doesn't communicate." [My mother said,] "Well I don't see a problem." I didn't ask you, I said I didn't like her. This is not a debate, you don't need to convince me, I don't like the way she fails to communicate. I'm not pleased with it. I want her to have another teacher next year.

Similarly, Angelica described how stigma from her family may be connected to the stigma they experience as Black people:

My folks are dealing with the denial. I can't do nothing about no services cause you aint even accepting this diagnosis, or that this might be an issue, and to get above the curve. Because we have all this negative stigma attached to it and you just don't want that because there are so many aspects of our life that already has a negative stigma. Where you live and how you pronounce your name? (laughs) It's all this other negative stigma so that parent that's of color, that's disenfranchised, that is going to experience language barrier whether it's just ... the level of literacy right like ... I don't know they, it's hard to think of living and your child living when you're just trying to survive.

While several parents described “gilded cage dynamics,” others described how their family members had eventually come to accept their autistic child. For example, Angelica shared,

Taking care of my son, it's me, my husband, and my mom. Now we have brought my aunt on board, and she picks [NAME] up from his school bus and takes him to my mom's house. So she does that three, sometimes four times a week.

Though family members sometimes “came around,” families often found themselves in disagreements with extended family members who didn’t understand that autism is lifelong. Parents and caregivers found themselves having to explain that autism can’t be “treated” or outgrown as the child ages. While having a network of support from extended families is appealing, it also became a major source of stigma for families when the extended family members were not in agreement with or supporting the decisions of the child’s primary caregiver.

Through discussions, Black parents described the perceived lasting effects of the FACES intervention, which included new intrapersonal knowledge and interpersonal connections. Participating in FACES spurred and sustained their advocacy efforts. Simultaneously, parents described encountering ongoing systemic barriers and stigma from their family, which sometimes impeded or complicated their advocacy efforts.

Discussion

FACES is still one of very few culturally responsive, family-centered interventions designed to strengthen advocacy and empowerment in Black families raising autistic children. Although psychoeducational interventions such as *Parents Taking Action* have been adapted for Black families raising autistic children (Dababnah et al., 2022), this is the first known follow-up study that provides novel insight into the successes and ongoing challenges that Black

participants experience after completing a psychoeducational intervention (i.e., FACES). Nearly 1.5 years following FACES, parents reported still feeling empowered and, thus, better prepared to advocate for the needs of their autistic children and families. **Our participants attributed some of this empowerment to the FACES intervention.** They also noted acquiring improved communication skills and using these skills with family, school personnel, and service providers. However, despite these perceived impacts, systemic barriers persisted for most participants. From our findings, we note two significant implications.

First, acquiring knowledge through training is perceived as beneficial but insufficient to remove all barriers Black parents raising autistic children experience to service access and use. Consistent with other studies (e.g., Dababnah et al., 2021; Pearson & Meadan, 2018; Pearson, Meadan et al., 2020; Pearson & Meadan, 2021; Rivera-Figuera et al., 2022; Stahmer et al., 2019), Black parents of autistic children continued to encounter challenges with educators, related service providers, and healthcare providers who were not responsive to their needs. Throughout the study, participants shared examples where they felt school personnel, service providers, and healthcare providers ignored their voices or acted as though they were inept in understanding the needs of their child. Even though these Black families **believed they** were using the tools they acquired through FACES, the professional community did not respond in a helpful manner. By their account, family members were forced to increase the frequency or intensity of their advocacy efforts to ensure their child received equitable services. Black families (and Black women in particular) often feel as though they bear sole responsibility for improving their familial quality of life (e.g., Avent Harris, 2019). While parents may benefit from improved advocacy capacity following FACES, societal barriers must also be dismantled to ease cultural inequities.

Second, findings echo previous studies (e.g., Dababnah et al. 2021; Kinnear et al., 2016; Mak & Kwok, 2010) in suggesting that in addition to systemic barriers, ideational barriers such as stigma, isolation, and self-image can inhibit parents' advocacy. Parents described how family members' misgivings about autism or reluctance to support their child eroded their confidence in advocating. Further, even when family members were supportive, Black parents expressed doubt in their advocacy abilities or the feeling that their advocacy activities were not "enough," such as Peggy's heartfelt exchange with the interviewer. This perception is thematically similar to the feelings of shame and powerlessness many Black people experience daily due to historic minoritization and oppression (Avent Harris et al. 2020; DeFreitas et al. 2018; Fripp & Carlson, 2017; Ward & Besson, 2012). These findings serve as evidence to the importance of building advocacy capacity in Black parents raising autistic children through tenets of empowerment, such as promoting self-efficacy and reducing self-blame (Gutiérrez, 1990).

Despite still-present barriers, parents conveyed that FACES had lasting impacts on their family more than a year after the intervention. They viewed the knowledge, empowerment, and affinity developed through the training as beneficial.

Implications for Research and Practice

Black families in the current study reported barriers to care and treatment for their autistic children. These barriers included feelings of being ignored, disregarded, and dehumanized. Their experiences alluded to systemic racism, which can present as devaluation, dehumanization, bigotry, and unequal access to quality care and resources (Golash-Boza, 2016). Though racism was not the only barrier to service access and use, the frequency in which racism is experienced by Black families from providers is concerning. Therefore, further research is needed to examine ways to improve responsiveness of practitioners to the needs of Black autistic children and their

families. Accurate and timely responsiveness can lead to prompt access to service, increased service utilization, appropriate treatment (Oswald et al., 2017; Telesford, 2021), and, in turn, significant short- and long-term benefits for Black autistic children (Straiton & Sridhar, 2021).

Despite the positive advocacy and empowerment outcomes uncovered in this FACES follow-up study, participants are still having to navigate around systemic “nos.” Researchers and practitioners should seek to evaluate and implement practices that specifically address and improve professionals’ responsiveness to Black families raising autistic children. Educators, healthcare providers, and support service personnel should work diligently to eliminate personal biases, assumptions, and discriminations they may have toward minoritized families (Shorter-Gooden, 2004). Educators and providers could benefit from learning more about cultural differences, biases, and stereotypes faced by Black families with autistic children. Furthermore, the dismantling of systemic issues requires providers as a collective to intentionally challenge racism and its practices. It is critical for providers to make meaningful efforts to better understand the identity and culture of individual clients, particularly Black autistic children and their families. Providers should be cognizant that one narrative does not fit all, and adopting an individualistic, compassionate approach to care could help alleviate disparities in practice, and promote equity in care for Black autistic children and their families (Blanchett et al., 2009; Pearson et al., 2018).

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Figure 1.

Structural Codes and Subcodes

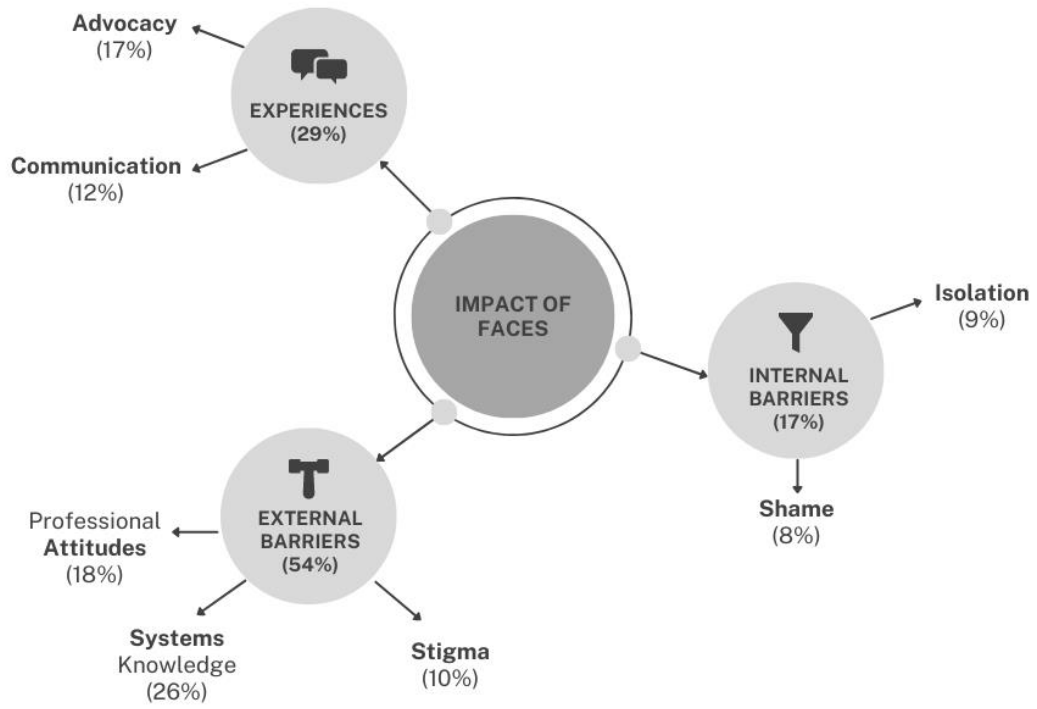


Table 1
Participants

Name	Relationship to Child	Age	Marital Status	Education	Employment	Family Income	# of children	Child Age	Age at Diagnosis
Peggy	Grandmother	63	Widowed	Some College	Retired	–	2	9	–
Eliza	Mother	47	Married	B.A.	Supervisor	\$67,500	1	8	6
Jasmine	Mother	47	Married	B.A.	Healthcare	\$47,000	3	11	9
Renée	Mother	39	Married	Some College	Service Rep	–	1	3	3
Maria	Mother	46	Married	Some College	At home mom	\$165,000	2	6	4
Angelica	Mother	35	Married	B.A.	Community Organizer	\$48,000	1	3	3

Note. B.A. = Bachelor of Arts degree; All data derived from participant self-report during interviews. All names are pseudonyms.

Table 2*Individual Interview Protocol*

Interview Questions

1. Please tell me about your family and your autistic child.
 2. Please tell me about their abilities and areas of need.
 3. 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?
 4. What have you advocated for?
 - a. Time or place for services?
 - b. Additional services?
 - c. One-on-one services?
 - d. Specific strategies?
 5. 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?
 6. 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?
 - c. What tools or resources do you feel would help you to be a stronger advocate?
 7. Please discuss your advocacy efforts as they relate to gaining access to the following services:
 - a. Schools of choice
 - b. Funding/healthcare
 - c. Transportation
-

- d. Waivers
- e. Waiting lists

8. Have you ever participated in advocacy or empowerment trainings in the past?
 - a. If yes, which program?
 - b. Would you say that program has had an impact on your current advocacy efforts?
 1. If so, how?
 - c. Would you say that program has had an impact on your current access to services?
 1. If so, how?
 - d. What else did you find beneficial about this program?
 - e. Would you participate in this type of program again?
 9. What resources, information, or supports do you think would help you better support your child with autism and your family?
 - a. Do you know how to access those supports?
 - b. If not, what do you think is creating a barrier?
 10. What recommendations do you have for other Black parents of children with autism who are working to navigate access to services?
 11. What recommendations do you have for educators to better serve the needs of Black autistic children?
 12. What recommendations do you have for service providers to better serve the needs of Black autistic children?
 13. What recommendations do you have for healthcare providers to better serve the needs of Black autistic children?
 14. Is there anything else you would like to add?
-

Table 3*Code Frequencies*

Code	<i>n</i> (%)
Isolation	41 (9.5%)
Shame	33 (7.6%)
Attitudes	79 (18.2%)
Systems	111 (25.6%)
Stigma	45 (10.4%)
Communication	52 (12.0%)
Advocacy	72 (16.6%)