Students Enhancing FACES: Fostering Advocacy, Communication, Empowerment, and Supports for African American Families of Children with Autism

FACES Connects Families of Children with Autism to Resources

OIED 2017-2018 Diversity Mini-Grant Final Report

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Program Objectives and Impacts

Objective

The purpose of Students Enhancing FACES was to support the implementation of the FACES parent advocacy program at North Carolina State University by training underrepresented undergraduate and graduate students to engage in applied research in the social sciences. The purpose of the FACES program is to assess the effectiveness of a parent-advocacy program in shaping knowledge, advocacy, and empowerment among African American parents of children with autism spectrum disorder (ASD). As such, Students Enhancing FACES had an emphasis on the following target areas:

1. Enhancing the quality of teaching and learning about diversity in the social sciences
2. Enriching the diversity experiences of all students
3. Creating a welcoming and inclusive work and learning environment where differences are respected and valued, that offers opportunity for and supports the success of all students, staff and faculty
4. Improving recruitment, retention and graduation of students from historically underrepresented groups in social science research

Impact

Along with PI, Dr. Jamie Pearson, two graduate research assistants (school psychology) and one post-baccalaureate student (registered behavior technician) worked on the FACES project during the funding period. The FACES team conducted two critical, preliminary research projects that will facilitate the implementation of the full FACES intervention during the fall of 2018. First, the team hosted community events, called Meeting FACES, that promote knowledge of autism and aim to build connections between parents, educators, and service providers in the community. Second, the team conducted an Autism and African American Families (AAAF) Needs Assessment Interview Study to explore the experiences and needs of African American families of children with autism in and around the Triangle.

Meeting FACES. The research team held two Meeting FACES events in March, 2018. The first event was held at the College of Education’s off-campus location on Cox avenue, Raleigh, NC. During our first Meeting FACES event, 41 parents and/or caregivers/family members and 16 service providers were in attendance (i.e., signed the attendance sheet). The second Meeting FACES event was held at the Cooperative
Extension Office in Durham. At the second event, 18 parents and/or caregivers/family members and 13 service providers attended the event (i.e., signed the attendance sheet). During the Meeting FACES events, graduate research assistants along with additional volunteers provided childcare for families who needed it. Childcare was provided for six children at the Raleigh event and four children at the Durham event. Each of the Meeting FACES events lasted approximately three hours and included introductions, meet and greets, and an informational session during which educators, services providers, and representatives from various community agencies (e.g., TEACCH, Mariposa Autism School, NCSU Psychoeducational Clinic) shared information about the resources and services they provide. Following the informational session, participants had an opportunity to engage in question and answer sessions and build connections with service providers of need/interest to them. Overall, the research team received very positive feedback about the Meeting FACES events from families and service providers.

AAAFF Study. As an extension of promoting autism and community resource awareness in the community, the FACES team conducted the AAAF Interview Study to assess the needs of families in the community. Information gathered included family demographics, past experiences advocating for children with ASD, areas that families felt they were lacking in resources, and recommendations they had for other families and service providers to make them better prepared to advocate for their families. Thus far, 30 parents have been interviewed.
**Student Impact.** Commensurate with the initiatives of the FACES project, Students Enhancing FACES has accomplished the following through the Meeting FACES events and the AAAF Interview Study:

1. Provided graduate students in the Psychology Department with the opportunity to contribute to an interdisciplinary research team,
2. Provided graduate students with an opportunity to engage in applied research experiences related to (a) the development and implementation of parent-training interventions, (b) culturally responsive research methods, and (c) both quantitative and qualitative data collection and analysis (i.e., mixed methods research),
3. Provided training to graduate students to conduct assessments and provide services for the widely diverse population of children and families they will serve as professionals in the field, and
4. Fostered a community of interdisciplinary autism researchers, clinicians, and students at NCSU that (a) addresses the underrepresentation of minority graduate students in applied research, (b) builds the platform and capacity to procure external funding that will support ongoing autism research and scholarship, and (c) contributes to the enhancement of the overall research and scholarship enterprise at NCSU.

Although we were unable to recruit traditionally underrepresented research assistants for this project, we are committed to recruiting and retaining underrepresented students to support future iterations of the project.

Figure 3. FACES Research Team
Project Evaluation

Preliminary Findings

Currently, the research team is wrapping up data collection on the AAAF project and will begin comprehensive data analyses for both projects in the fall. Preliminary findings for both projects are outlined below:

Meeting FACES. Following the two Meeting FACES events, participants were asked to complete a brief survey to indicate their satisfaction with the program and to gain more information about the types of autism services and supports families would benefit from. Example survey questions included:

- Below is a list of potential services that may currently be limited, non-existent, or not customized for children and young adults with autism and their families. We would like to know how important these potential services might be for you, your family, or the families you serve (educators/providers).
- Overall, how satisfied were you with the Meeting FACES event today?
- How likely is it that you will recommend the Meeting FACES program to others? (e.g., family members, friends, parents, patients).

Following the events, 59 participant surveys were submitted. A snapshot of the descriptive, preliminary findings from three of the survey questions are reflected below:

![Figure 4. Snapshot of Meeting FACES Survey](image-url)
Figure 5. Snapshot of responses from three Meeting FACES survey items

<table>
<thead>
<tr>
<th>What did you like most about Meeting FACES?</th>
<th>Overall, how satisfied were you with the Meeting FACES event today?</th>
<th>How likely is it that you will recommend the Meeting FACES program to others? (e.g., family members, friends, parents, patients).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presenters</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The presenters were very informative.</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>N/A</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The variety of information and the number of resources available</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Hearing about resources</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The amount of new useable information</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Exposure to services</td>
<td>Satisfied</td>
<td>Likely</td>
</tr>
<tr>
<td>Ample time provided for parents to ask questions</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Community feeling</td>
<td>Unsure</td>
<td>Likely</td>
</tr>
<tr>
<td>Variety of presenters</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Learning!</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Other professionals</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The Q&amp;A</td>
<td>Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>Needed support</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>available service offerings</td>
<td>Satisfied</td>
<td>Likely</td>
</tr>
<tr>
<td>Everything I love it I learned a lot</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>It was great to listen and understand disabilities in many different ways.</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The wealth of knowledge</td>
<td>Very Satisfied</td>
<td>Very likely</td>
</tr>
<tr>
<td>The presenters</td>
<td>Unsure</td>
<td>Likely</td>
</tr>
</tbody>
</table>
**AAAF Interview Study.** The AAAF interview study is a semi-structured interview that is designed to glean more insight on the experiences, challenges, facilitators, and needs of African American families of children with autism living in the Triangle. Example interview questions include:

- Please tell me about your experiences with advocating on your child’s behalf.
- How you think educators, healthcare providers, and service providers perceive your advocacy efforts?
- What resources, information, or supports do you think would help you better support your child with autism and your family?
- What recommendations do you have for educators to better serve the needs of African American children with ASD?

Thus far, 30 parents, caregivers, and/or services providers have participated in the AAAF interview study. While data collection and analysis are ongoing, we can note anecdotally, two primary themes that have emerged from the interviews. First, participants have consistently identified a need for someone/something who/that can help them navigate accessing services for their children with autism. Second, participants have consistently identified their experiences with pediatricians as a barrier to early and effective diagnoses (i.e., dismissive of parent concerns). Below are two interview excerpts that reflect participant responses related to (a) recommendations for educators (e.g., effective communication) and (b) the impact of training programs to support families of children with autism (e.g., knowing how to navigate the device system).

**Excerpt 1**

Interviewer: So, we were talking about preparing pre-service teachers. If you could go into a class as a guest speaker, what would be some of the recommendations you might give them, knowing that they are about to go into the schools and potentially teach children with autism and other disabilities?

Participant: I would say don't generalize. They'll automatically generalize or pigeonhole the kid. I would meet with the parent. We met with [child’s] teacher from the beginning and told her, "This is how she is. This is what to look out for." Then constant communication with the parent. Her teacher now, we talk all the time. She doesn't have the time. The teachers are so overworked. She knows that being prepared will help her. If [child] had a bad day the night before, I will tell her and she'll be better prepared. Instead of [child] coming in and blowing up on people and she's like, "Where's this coming from?" I think constant communication with the
parents. That's if there's the time to be informed. I don't know. So many kids. I think most parents of children on the spectrum are kind of in the loop. But it's hard when there's no communication.

**Excerpt 2**

Interviewer: Have you ever participated in any advocacy or empowerment program training in the past?

Participant: Like how so? I'm trying to think.

Interviewer: Maybe like the Faces event or events that you might go to where people are filling you in with information or giving you resources, tools, networking.

Participant: Yeah. I've gone to programs on how do you set up your book for your IEP, your folder. I've done those. I've done programs at the Hill Center. They've had free programs in the past where you listen to a seminar, a therapist speaks. What else? I've gone to so many things. What else have I gone to? It'll come to me later, but I have.

Interviewer: How have those trainings affected your current advocacy efforts or current access to services?

Participant: I guess just knowing that there are places that you can go to get assistance. My go-to was always ... The first call was to the Autism Society. That was my first go-to. Usually when I'm calling, I was in crisis mode. Knowing that they were ... Being able to know where to go. You just start looking through your paperwork. Well, what can I do? Now I more so know the signs of when something is going on with him. Okay, this is happening. Okay, this is happening. He's doing this, he's doing that.
**Sustainability**

Moving forward, the FACES team plans to host one additional *Meeting FACES* event towards the end of the summer of 2018 and continue with data analysis on both the Meeting FACES and the AAAF Interview Study. The findings from the data analysis on both projects will be incorporated into the full FACES program to be run as a randomized control trial in the Fall of 2018 (funded by the NCSU Faculty Research and Professional Development Fund).

The full FACES program is a face-to-face parent training and advocacy program that will be delivered across four 3-hour training sessions for a total of 12 hours of training and instruction. The scope of the FACES program is based on (a) what is known about areas of needed support for individuals with ASD (e.g., Meadan *et al.*, 2014; Tager-Flusberg and Kasari, 2013), (b) what is known about the need for advocacy among parents of children with ASD (Burke 2013; Cohen, 2009; Mueller & Carranza, 2011), and (c) recommendations about how parents can be better prepared to advocate for and address the needs of African American children with ASD (Pearson and Meadan, 2018). Through Meeting FACES and the AAAF interview study, the FACES team can adapt the FACES program to meet the needs of local families. The randomized control trial will include participants from the AAAF interview study and participants from the Meeting FACES events.

Overall, Students Enhancing FACES is intended to be a long-standing community resource for underserved families of children with autism across the state of North Carolina. This project has the potential to be embedded in collaborative initiatives with the Autism Society of North Carolina, the Psychoeducational Clinic in the Department of Psychology at NCSU, and the Center for Family and Community Engagement in the College of Humanities and Social Sciences at NCSU. As such, this program creates a unique opportunity for NCSU to become a pillar in the autism community, particularly among families who are otherwise underserved. The NCSU Diversity Mini-Grant funding has supported our development and implementation of the aforementioned programs and has provided us, we believe, with leverage to gain external funding that increases our potential to scale up and reach a larger number of underserved families of children with autism across the state of North Carolina. Our full FACES intervention is scheduled to begin in September, 2018 and it is with every intention that this program be sustained beyond the University Diversity Mini-Grant period.
Publications, Presentations, and Press Releases

- Press Releases/Media
  - 3 College of Education Projects Receive Diversity Mini-Grants from OIED
  - FACES Connects Families of Children with Autism to Resources
  - Duke Center for Autism and Brain Development Announces Meeting FACES Event
  - Dr. Pearson Goes Live with the Exceptional Children’s Assistance Center of NC to discuss the FACES program

- Articles in preparation

- Conference Proposals under review