Highlighting Efforts to Support Underrepresented Families of Children with Autism through a Community-Engaged Program

AAIDD Webinar
September 19, 2019
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North Carolina State University
A Quick Google IMAGE Search:

Keywords:

1. toddlers with autism
2. children with autism
3. adults with autism
4. women with autism
5. [insert your choice] with autism
A Quick **Google Image Search**: Results
Autism & African American children

- European American children are 30% more likely to be diagnosed with ASD than African American children (CDC, 2016).
- African American children with ASD are often misdiagnosed or go undiagnosed until years after the onset of symptoms (Mandell et al., 2009).
- Both parents and professionals play a role in the processes of obtaining diagnoses and gaining access to services for children with ASD (e.g., Bishop et al., 2007; Mandell et al., 2002; Zuckerman et al., 2013).
“Like many parents, Camille Proctor went to her first support group for parents of children with autism to feel less alone. Her son Hunter had just been diagnosed, and Proctor had lots of questions. All of the other parents at the various support groups she went on to visit were white; Proctor is African American. When she asked questions about how she should teach her son to interact with police, given that the wrong response by a black boy or man could be deadly, she just got blank stares.”

AUTISM’S RACE PROBLEM

PACIFIC STANDARD STAFF · MAY 25, 2016

For years, the medical community has studied and treated autism as a “white person’s” disease, and, today, research and therapy remain geared toward affluent, white people and families — leaving people of color in the lurch.

By Carrie Arnold
To address these disparities...
○ **Goals**
  ○ Address disparities in autism diagnoses among historically underrepresented populations
  ○ Increase equity in access to services for *all* families
FACES

- Intervention Group
- Waitlist control
- Evaluations
- Pre-FACES measures
- 4-6 week FACES training
- Post-FACES measures

FACES Lite

- AAAF Needs Assessment
- Meeting FACES

North Carolina
- Urban

Illinois
- Rural

RDU
- Urban
- 2-3 workshops
FACES
(Fostering Advocacy, Communication, Empowerment, and Support)

Full FACES program: 4-6 week training

Purpose: Designed to improve knowledge, advocacy, and empowerment among underrepresented parents of children with autism.

Participants receive:

- Training and resources on special education laws and procedures
- Strategies for managing behavior
- Coaching on how to increase autism knowledge and awareness among family and community members.
- Strategies to support effective communication
Meeting FACES
Program Goals

1. Connect ethnic minority families with professionals who provide services and support for individuals with autism living in central North Carolina.

2. Provide parents with an opportunity to learn more about available autism services and supports in their communities.

3. Conduct a needs assessment to learn more about minority families’ knowledge, use, and perceived helpfulness of existing services for children with autism in North Carolina.
The Workshops

• Raleigh
  • 50 total attendees
    • 40 participants
    • 10 speakers

• Durham
  • 31 total attendees
    • 23 participants: 5 educators, 18 parents/guardians/grandparents
    • 8 speakers: legal support, parent advocate/wellness coach, social worker, SLP, two clinical directors/BCBA’s, special education teacher

• Winston-Salem
  • 19 total attendees
    • 10 participants
    • 9 speakers
The Logistics

• A series of community-based workshops designed to connect families with providers in their communities.

• Held on Saturdays from 9am-12pm

• Breakfast/brunch provided

• Childcare/respite provided

• $10 gift card for completing the survey
Childcare
The FACES Cafe
# Participants

<table>
<thead>
<tr>
<th>Role of Respondent</th>
<th>Percent (%)</th>
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<tbody>
<tr>
<td>Parent/Caregiver</td>
<td>61.0</td>
</tr>
<tr>
<td>Teacher</td>
<td>10.2</td>
</tr>
<tr>
<td>Related service provider (e.g., SLP, OT, ABA therapist)</td>
<td>15.3</td>
</tr>
<tr>
<td>Healthcare provider</td>
<td>1.7</td>
</tr>
<tr>
<td>Community Agency Representative</td>
<td>8.5</td>
</tr>
<tr>
<td>Researcher</td>
<td>5.1</td>
</tr>
<tr>
<td>Other</td>
<td>6.8</td>
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**Gender of Respondent**

<table>
<thead>
<tr>
<th>Gender of Respondent</th>
<th>Percent (%)</th>
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<tbody>
<tr>
<td>Male</td>
<td>23.1</td>
</tr>
<tr>
<td>Female</td>
<td>78.9</td>
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**Gender of Child**

<table>
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<th>Gender of Child</th>
<th>Percent (%)</th>
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</thead>
<tbody>
<tr>
<td>Male</td>
<td>76.9</td>
</tr>
<tr>
<td>Female</td>
<td>23.1</td>
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**Race/Ethnicity of Respondent**

<table>
<thead>
<tr>
<th>Race/Ethnicity of Respondent</th>
<th>Percent (%)</th>
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<tbody>
<tr>
<td>Asian</td>
<td>3.4</td>
</tr>
<tr>
<td>Black/African American</td>
<td>67.8</td>
</tr>
<tr>
<td>Caucasian</td>
<td>22.0</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>5.1</td>
</tr>
<tr>
<td>Native American</td>
<td>3.4</td>
</tr>
<tr>
<td>Pacific Islander</td>
<td>1.7</td>
</tr>
<tr>
<td>Other</td>
<td>1.7</td>
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What did we learn?
Several existing services in the community offer at least some of the supports that families are looking for in “potential” services.
Implications

• These findings suggest that minority families of children with autism in central NC face barriers related to (a) knowledge/awareness of services, (b) access to services, and (c) satisfaction with services.

• The development of potential services was extremely important for participants in this study. On average, 68% of parents and 65% of providers rated the potential services (e.g., education or training for parents) as very important. These findings demonstrate a specific need for the development of services that are tailored to minority families’ needs to better support children with autism in NC.
Satisfaction with *Meeting FACES*

- 86.5% ($n = 32$) of parent participants indicated that they were *very likely* to recommend the Meeting FACES workshop to someone else.

- 13.5% ($n = 5$) of parent participants indicated that they were *somewhat likely* to recommend Meeting FACES to someone else.

- 100% ($n = 27$) of professionals were *very likely* to recommend the Meeting FACES workshop to a patient or colleague.
Satisfaction with Meeting FACES

The speakers.
Hearing from parents.
The wealth of knowledge.
Sharing experiences and resources.
To connect, laugh, cry, and understand.
Community feeling.
The Voices of FACES Families
Our Next Steps...

1. Meeting FACES: Across NC
   Hold Meeting FACES events in all 100 NC counties.

2. Develop Resource Repository
   Provide online access to navigation of services.

3. Partner with service providers to address areas of concern.
   Disseminate findings to local providers.
Next Steps in *Your* Communities...
References


Contact Us!

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https://sites.google.com/ncsu.edu/facesprogram/home