

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

AAIDD Webinar

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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

124
SHARES

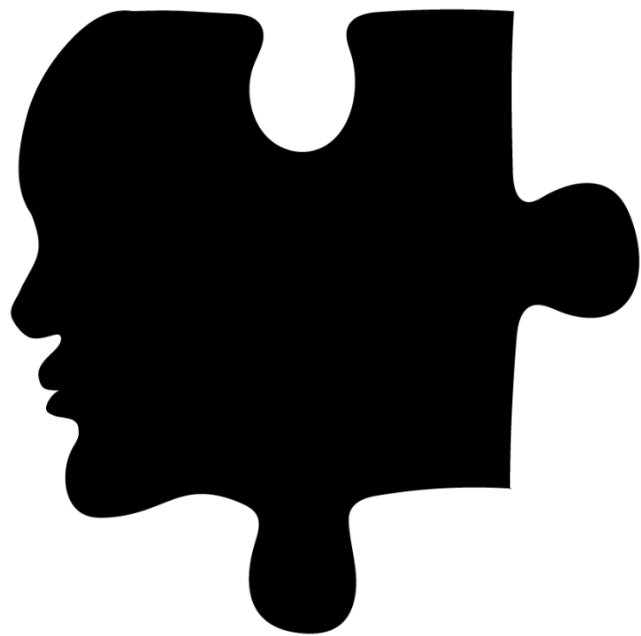


For years, the medical community has studied and treated autism as a “white person’s” disease, and, today, research and therapy remain geared toward affluent, white people and families — leaving people of color in the lurch.

By Carrie Arnold



To address these disparities...



FACES

Fostering Advocacy, Communication, Empowerment,
and Support for African American Families
of Children with Autism

- Goals
 - Address disparities in autism diagnoses among historically underrepresented populations
 - Increase equity in access to services for *all* families

FACES

FACES

FACES Lite

Intervention Group

Waitlist control

AAAF Needs Assessment

Meeting FACES

Evaluations

North Carolina

Illinois

RDU

Pre-FACES measures

4-6 week FACES training

Urban

Rural

Urban

2-3 workshops

Post-FACES measures

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

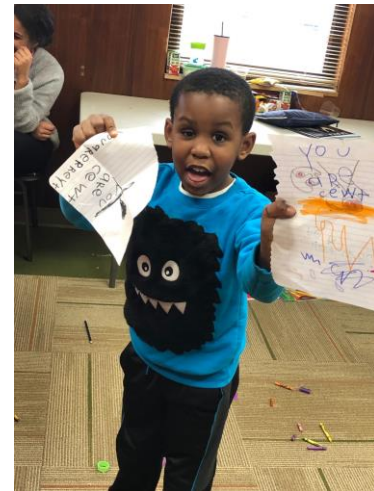
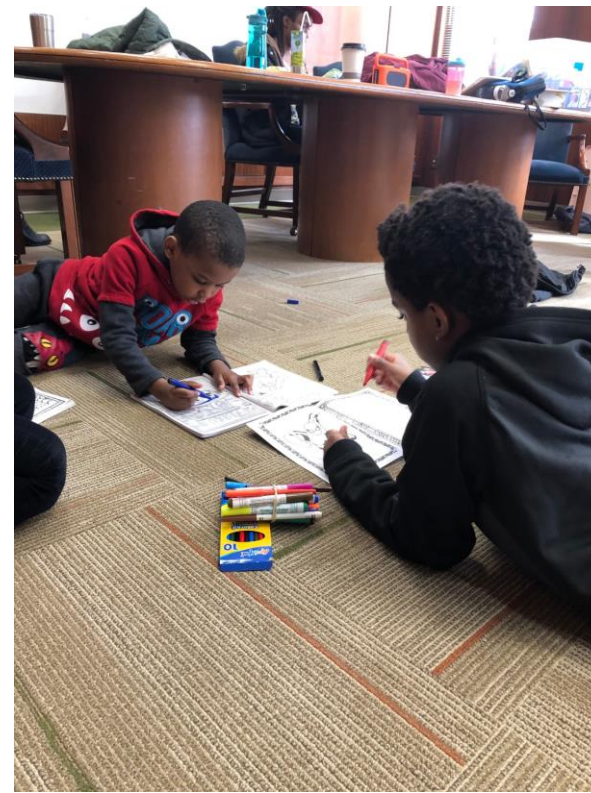


The Logistics

- 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/respice provided
- \$10 gift card for completing the survey



Childcare



The FACES Cafe



Participants

<u>Role of Respondent</u>	Percent (%)
Parent/Caregiver	61.0
Teacher	10.2
Related service provider (e.g., SLP, OT, ABA therapist)	15.3
Healthcare provider	1.7
Community Agency Representative	8.5
Researcher	5.1
Other	6.8
<u>Gender of Respondent</u>	
Male	23.1
Female	78.9
<u>Gender of Child</u>	
Male	76.9
Female	23.1
<u>Race/Ethnicity of Respondent</u>	
Asian	3.4
Black/African American	67.8
Caucasian	22.0
Hispanic or Latino	5.1
Native American	3.4
Pacific Islander	1.7
Other	1.7

What did we learn?

Implications

Several existing services in the community offer at least some of the supports that families are looking for in “potential” services.

Table 4

Importance of Potential Services

Service	Very Unimportant		Somewhat Unimportant		Neutral		Somewhat Important		Very Important	
	Parents	Professionals	Parents	Professionals	Parents	Professionals	Parents	Professionals	Parents	Professionals
Telephone Referral Service (57)	--	--	--	--	--	5.0% (1)	5.4% (2)	10.0% (2)	94.6% (35)	85.0% (17)
Place to go for Information about Autism and Services (54)	--	--	--	--	2.7% (1)	5.0% (1)	5.4% (2)	25.0% (5)	83.8% (31)	70.0% (14)
Library of Information about Autism (51)	--	--	2.7% (1)	--	2.7% (1)	10.0% (2)	16.2% (6)	30.0% (6)	78.4% (29)	60.0% (12)
Case Management or Coordination of Services (51)	--	--	--	5.0% (1)	--	--	18.9% (7)	25.0% (5)	78.4% (29)	70.0% (14)
Parent Mentors (57)	--	--	2.7% (1)	--	5.4% (2)	--	5.4% (2)	25.0% (5)	86.5% (32)	75.0% (15)
Support Group for Siblings of Children with Autism (50)	--	--	2.7% (1)	--	5.4% (2)	5.0% (1)	16.2% (6)	30.0% (6)	73.0% (27)	65.0% (13)
Family Therapy (55)	--	--	8.1% (3)	--	2.7% (1)	5.0% (1)	13.5% (5)	5.0% (1)	75.7% (28)	80.0% (16)
Marital Therapy (56)	5.4% (2)	--	10.8% (4)	--	5.4% (2)	10.0% (2)	8.1% (3)	30.0% (6)	67.6% (25)	60.0% (12)
Social Skills Training for Children/Young Adults with Autism (57)	--	--	--	--	--	--	5.4% (2)	15.0% (3)	94.6% (35)	85.0% (17)
In-Home Consultation or Training for Parents (56)	--	--	5.4% (2)	--	5.4% (2)	--	18.9% (7)	15.0% (3)	67.6% (25)	85.0% (17)
In-Home Therapy (57)	--	--	2.7% (1)	--	5.4% (2)	5.0% (1)	18.9% (7)	15.0% (3)	73.0% (27)	80.0% (16)
Summer Programs or Camps (56)	--	--	2.7% (1)	--	2.7% (1)	--	5.4% (2)	5.0% (1)	86.5% (32)	95.0% (19)
Education or Training for Parents (56)	--	--	--	--	2.7% (1)	--	2.7% (1)	20.0% (4)	91.9% (34)	80.0% (16)
Training for Healthcare Providers (56)	--	--	--	--	10.8% (4)	--	5.4% (2)	10.0% (2)	81.1% (30)	90.0% (18)
Training for Professionals (56)	--	--	--	--	5.4% (2)	--	2.7% (1)	10.0% (2)	91.9% (34)	85.0% (17)

Table 2.

Knowledge and Use of Services

Service	Did not know about the service	
	Parents	Professionals
A Small Miracle	67.6% (25)	20.0% (4)
Access Family Services	59.5% (22)	30.0% (6)
Alliance Behavioral Healthcare	24.3% (9)	10.0% (2)
Alpha Management Services	56.8% (21)	45.0% (9)
Autism Society of North Carolina	10.8% (4)	5.0% (1)
Embrace	67.6% (25)	35.0% (7)
ECAC	54.1% (20)	20.0% (4)
Going Full Circle	56.8% (21)	40.0% (8)
Gupta	67.6% (25)	55.0% (11)
Mariposa School	51.4% (19)	25.0% (5)
NCCU Speech Services	59.5% (22)	35.0% (7)
NCSU Psychoeducational Clinic	62.2% (23)	45.0% (9)
ABA Therapy	35.1% (13)	10.0% (2)
Rescare	56.8% (21)	25.0% (5)
Residential Services, Inc	51.4% (19)	20.0% (4)
TEACCH	21.6% (8)	10.0% (2)
ARC of NC	40.5% (15)	10.0% (2)
UNC Speech Clinic	48.6% (18)	30.0% (6)
Overall Average	49.6% (18.3)	26.1% (5.2)

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 a 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...

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Thank You

Contact Us!

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



Q&A

