

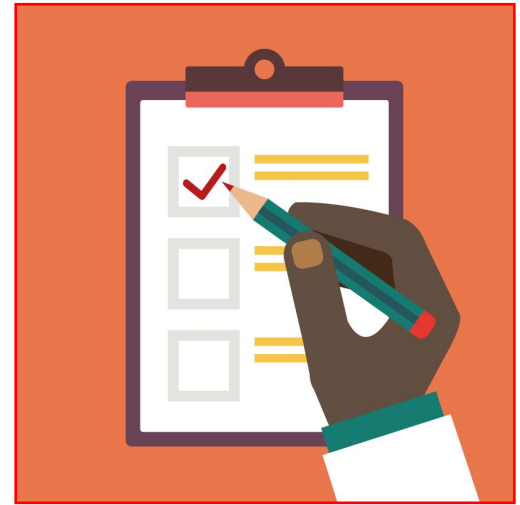
**NC STATE UNIVERSITY**

*Supporting the Needs of Black Autistic  
Youth and Their Families*

The Help Group Virtual Summit  
Dr. Jamie Pearson  
North Carolina State University  
October 16, 2021

# Agenda

- On autism and disparities
- About FACES
- Strategies and tips for you
- Questions/Discussion



**First...on language and neurodiversity**

# 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



**On autism and disparities...**

# Disparities in Autism Diagnoses



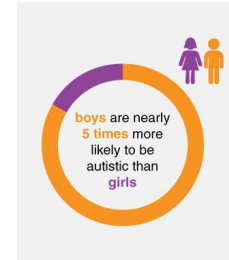
## Race/Ethnicity

According to the CDC, rates of autism are consistent across racial and ethnic groups. However, white children are 30% more likely to receive an ASD diagnosis than blacks, and 50% more likely than Hispanics.



## Geography

Despite similar rates of ASD in rural and urban areas, studies have found urban areas reported diagnosis rates more than 2.5 times greater than rural area and on average urban children received a diagnosis 0.4 years earlier than rural children.



## Gender--(i.e., SEX)

Males and females are diagnosed with ASD in a 4-to-1 ratio with females being diagnosed later than males and the average time between first signs and diagnosis being longer for females.

*Clear evidence now exists for the link between early diagnosis, access to early intervention services, and positive development outcomes. Despite these achievements, there is growing concern that many children with autism remain unidentified, and many of those who are diagnosed, may not be able to access specialized services.*

*(Murphy & Ruble, 2012)*



# Findings related to racial/ethnic disparities...

- Latinos and African Americans are significantly more likely to be **diagnosed with ASDs at a later age** if at all.
- **Limited knowledge of ASD** in minority communities. In focus groups parents of Latino children diagnosed with ASD often commented that they had never heard the word autism prior to their child being diagnosed.
- **Mental health stigma** among minorities and mistrust of the system due to years of institutionalized discrimination means that even “if parents have concerns, they may not raise the issue with health professionals based on fear of the potential consequences their child will suffer if he or she is perceived as disabled or having a mental health condition” (Krader, 2014).
- Despite the higher threshold minority parents have for expressing their concerns to pediatricians (Krader, 2014), **medical experts are more hesitant to respond to the concerns of minority parents and tend to instead “tend to see behavior problems rather than an impaired kid” (Arnold, 2016).**
- Language barriers contribute to disparities in screenings. A “survey of primary care providers in California...showed that only about 10% of the physicians offered Latino children ASD and general developmental screening in Spanish when it was needed” (Krader, 2014).
- **Socioeconomic status are often linked to race and ethnicity.** “It often takes multiple appointments to get a diagnosis, which is a problem in families where parents are paid hourly, only have a single car, and also have to arrange childcare for other siblings. Each additional step it takes for an assessment means that more people fall through the cracks” (Arnold, 2016).

*“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



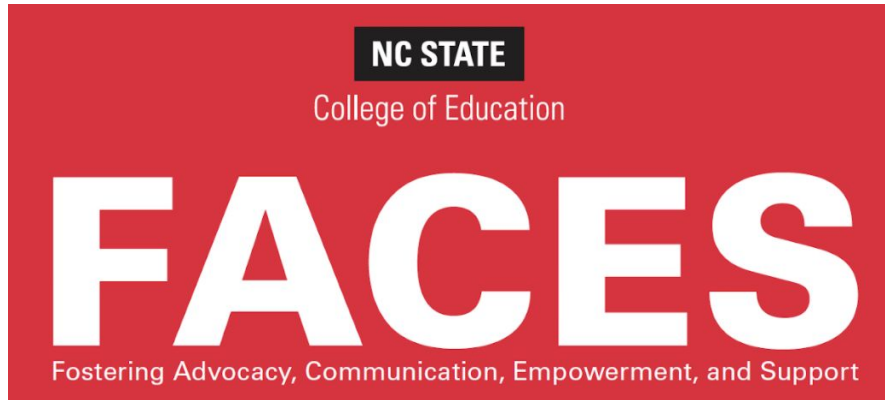
*For years, the medical community has studied and treated autism as a “white person’s” disease, and, today, research and therapy remain geared toward affluent, white people and families — leaving people of color in the lurch.*

*By Carrie Arnold*



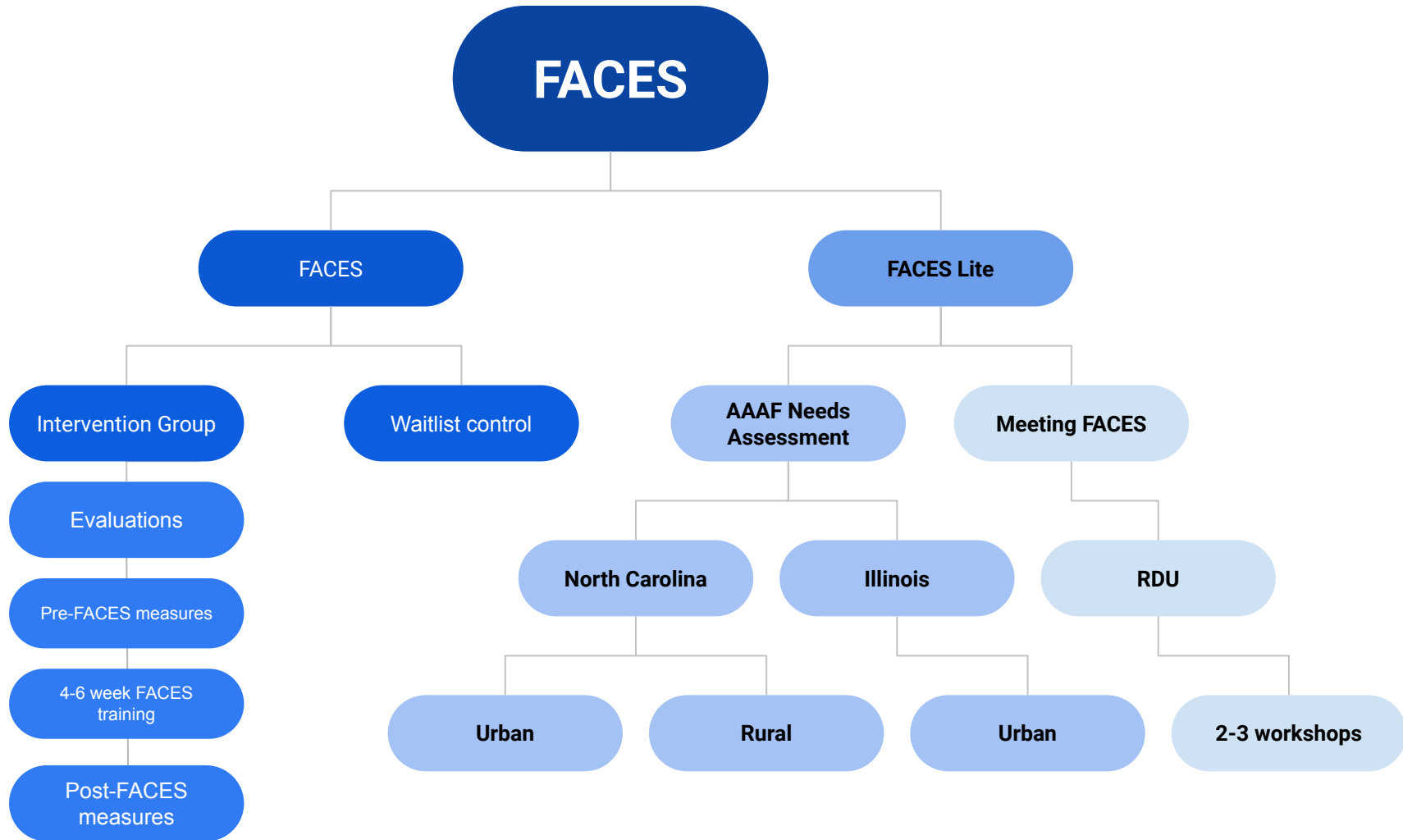
**So, what should we do?!**

**Through research...**



- **Goals**
  - Address disparities in autism diagnoses among historically underrepresented populations
  - Increase equity in access to services for ethnic minority families
  - Increase service utilization for ethnic minority families

# FACES




# 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

**Let's hear from previous FACES  
families...**

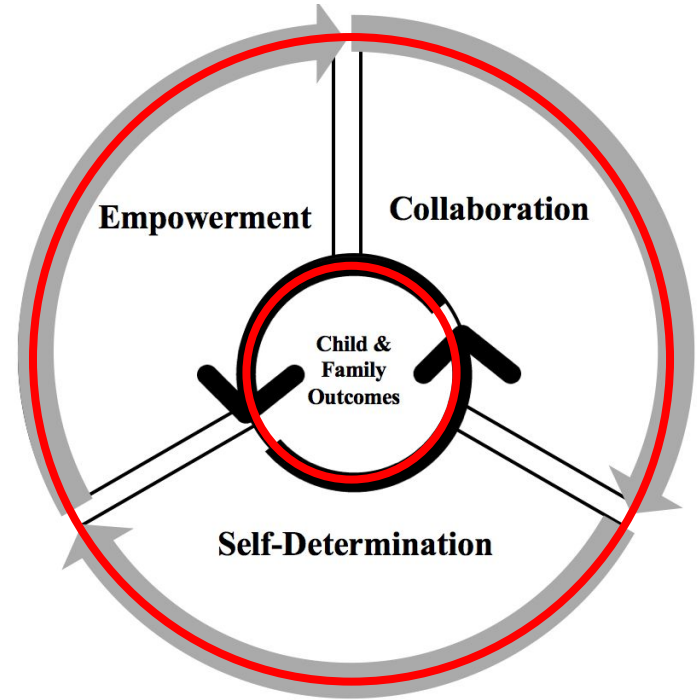


(insert video here)

**...in practice**

# Supporting Black Families: Cultural Reciprocity

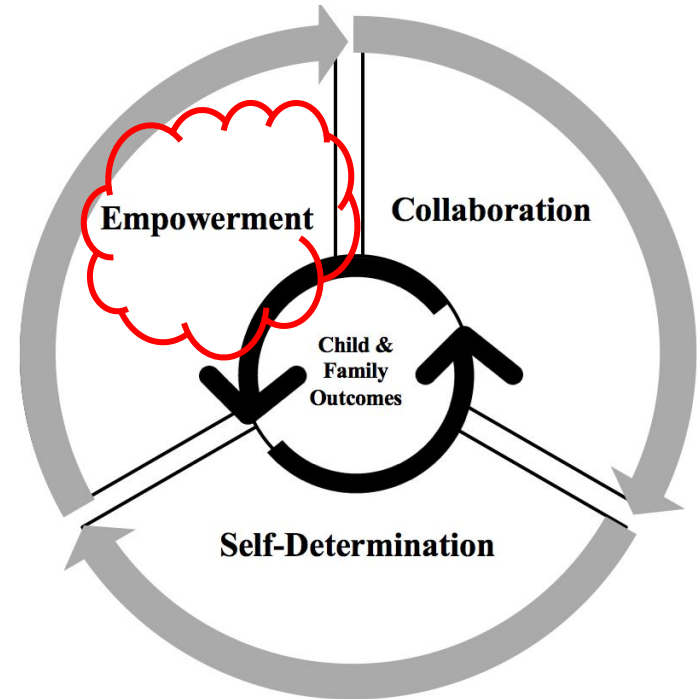
- **Identify your own perceptions** (i.e., biases), values, and beliefs
- Get to know your families' values and beliefs
- Assess the similarities and differences in these beliefs
- Discuss these with your families
- **Be responsive to families' differences!**



Pearson, Hamilton & Meadan (2018)

# Supporting Black Families: Empowerment

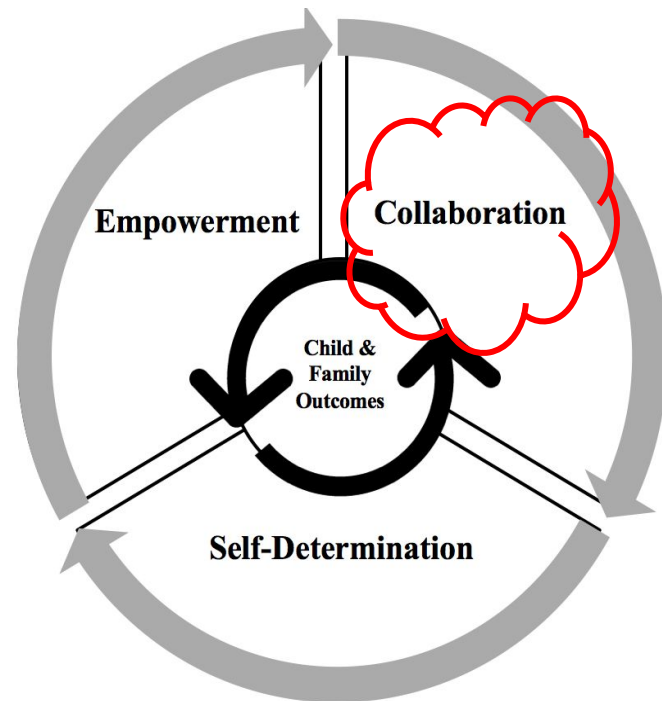
- AA families susceptible to vulnerability (Whitley et al., 2011)
- A way to support marginalized families gain a sense of control
- Empowerment → advocacy
- **Ways to support empowerment**
  - Dispel assumptions (what is important to *them*?!)
  - Acknowledge cultural beliefs (schedules/routines)
  - Demonstrate culturally responsive strategies (communicative goals)
  - Build rapport
  - Be responsive (e.g., preferred mode of communication)
  - Be flexible! (e.g., parent engagement)



Pearson, Hamilton & Meadan (2018)

# Supporting Black Families: Collaboration/Partnerships

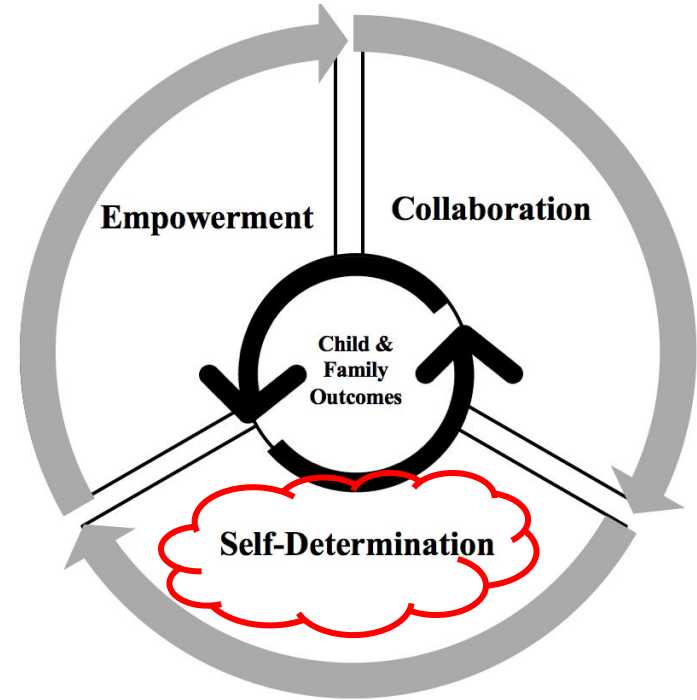
- In many cases, African American autistic (AAA) children are not identified until school age or later
- SLPs play a critical role in this identification and **collaborating** with parents and educators to establish supports
  - Be present in the classroom (or appropriate space)
  - Modify curriculum/strategies to include culturally appropriate materials
  - Partner with teachers. Be creative!



Pearson, Hamilton & Meadan (2018)

# Supporting Black Families: **Self-Determination**

- Self-determination (self-advocacy)
  - Perseverance in the face of obstacles (Wehmeyer et al., 2010)
  - Choice-making, decision-making, problem-solving
- Strengthened by partnerships
- Clinical applications for teaching SD
  - Respect family values (e.g., choices/freedom)
  - Utilize familiar environments (appropriate generalization)
  - Use culturally relevant materials (social stories that reflect experiences)



Pearson, Hamilton & Meadan (2018)

# The Take Home!

- How can you apply these strategies to your practice?
- How can you achieve the 3 Cs?
  - **C**ommunity empowerment
  - **C**ollaboration
  - **S**ocial **C**hange

**C**

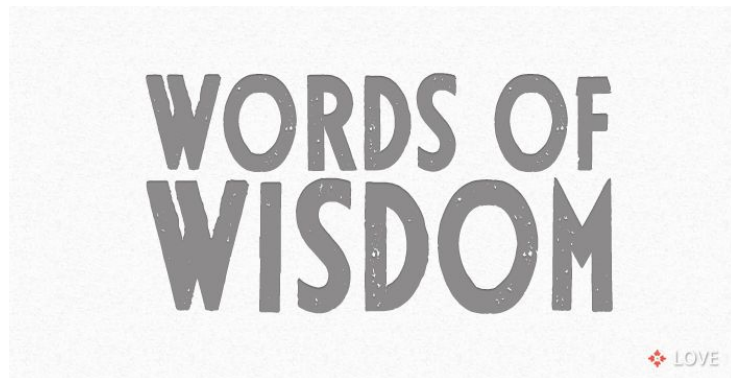
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**C**



# Words of Wisdom

- Be reflective
  - Cultural reciprocity
  - Academic privilege
- Be responsive
  - What are the needs of this community/population?
- Be passionate
  - Let your work reflect your passion
- Be flexible
  - Learn to wear different hats
  - Have a plan B
- Remember *why* you are *where* you are
  - Be guided by humility





# Recommended Reading



On race and ethnicity

- [Autism's Race Problem](#)

On gender

- [The Invisible Women With Autism](#)

On geography

- [The Challenges of Autism in Small-Town America](#)

# Recommended **viewing**



On race and ethnicity

- [Young, Gifted & Black With Autism](#)

On gender

- [Women and Autism. Towards a Better Understanding](#)

On geography

- [Ruralities of Autism](#)

Q&A

The image features three large, 3D-rendered characters: a red 'Q', a green '&', and a blue 'A'. Each character is thick and has a slight shadow cast to its right. They are positioned on a white, reflective surface, which creates a clear, slightly blurred reflection of each character directly beneath it. The lighting is bright and even, highlighting the smooth, matte texture of the characters. The overall composition is clean and minimalist, focusing entirely on the three characters.

# Thank You

## Contact Info

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



# References

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