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# A Patient-Centered Autism Research Agenda to Engage the African American Community

A guide to change the landscape of autism research and create the conditions for true engagement and equitable outcomes for the African American autism community

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## Executive Summary

Read the full Research Agenda at familyvoices.org/ARAProgram.

## A Patient-Centered Autism Research Agenda to Engage the African American Community

African Americans are underrepresented in autism research. While there is some evidence that more research networks and projects focused on autism spectrum disorder (ASD) have reached out to self-advocates and stakeholders in their work, an enormous demand for more meaningful stakeholder engagement remains. The lack of African American stakeholder, researcher, and research participant representation has consequences for the relevance and generalizability of research findings for African American communities and thus has potentially negative consequences for the health and well-being of African American children, youth, adults, and families affected by this developmental disability. This underrepresentation exacerbates gaps in access to knowledge, evidence-based therapies, and the inclusion of more racially diverse autistic voices and contributes to an urgent need to create a research agenda that is truly inclusive and ensures equity in future access and outcomes.

Recognizing this need, Family Voices developed an African American autism research agenda with funding from the Patient-Centered Outcomes Research Institute. The Research Agenda was co-created by more than 200 partners, including autistic self-advocates, parent/family caregivers, researchers, providers, and funders. It outlines three key strategies for researchers to ensure their research is culturally responsive and relevant to the African American community, provides equal opportunity for African Americans to participate, and considers how research results will be shared back with the community in ways that are accessible and actionable.

**The Research Agenda can help:**

- Guide the development of research studies and initiatives that are focused on, and led by, members of the African American autism community.
- Inform researchers on how best to engage African American self-advocates and family caregivers as valuable research partners and avoid the pitfalls of tokenizing and exploiting the African American autism community.
- Acknowledge the value of including self-diagnosed African American autistic individuals in autism research.

**The Research Agenda outlines three key strategies to address the needs of this underserved community, using a patient-centered approach:**

1. Establish authentic partnerships with African American autistic self-advocates and families, including self-diagnosed self-advocates.
2. Address research questions and research topics developed by the African American autism community.
3. Develop policies and practices that facilitate increased engagement of the African American autism community.

Adopting and implementing these recommendations when designing and conducting future autism research studies will enhance evidence-based practices and interventions and work toward equity by addressing the needs of African American autistic children, youth, and adults, as well as their families.

> “Researchers need to understand the complexity of being Black and its impact on accessing autism services.”

## Recommendation 1

Establish authentic partnerships with African American autistic self-advocates and families, including self-diagnosed self-advocates.

**To address the unique needs of the African American ASD community, researchers must intentionally implement culturally responsive strategies to strengthen the community's engagement in the research process and to engender confidence and trust in the researchers who are conducting it. Using the Family Voices Family Engagement in Systems Assessment Tools Framework's four domains (commitment, transparency, representation, impact), the project team engaged stakeholders from the African American autism community in the project to explore and add further insight on what this community defines as meaningful engagement.**

### Commitment

- It is vital that self-advocates and family leaders are involved in all aspects and phases of a research study and that this engagement should move from inclusion to leadership.
- Researchers demonstrate commitment by listening and hearing their concerns, being humble and respectful (cultural humility), and following through on agreements.
- Researchers must be intentional in identifying and removing barriers to participation, including time and travel barriers.
- Consideration and respect of cultural dynamics are essential to engaging the African American autism community.
- Researchers must invest in long-term support for African American autistic individuals, their family caregivers, and the institutions that serve them.
- Changes in research practices and policies must include the continued diversification of the research workforce and a shift from favoring research aptitude over lived experience.
- Researchers need to establish and nurture long-term relationships with those who have not built power through coalitions.

**Transparency**

- Researchers need to be open, honest, unbiased, and available to self-advocates and families.
- Researchers need to be open to examination and willing to acknowledge mistakes and grow.
- Researchers should focus on problems faced by those with lived experience rather than exploiting autistic African American people for what can be learned from autistic individuals.
- Researchers need to share their priorities, how the research will impact participants’ lives, and how their data will be shared and stored, prior to engaging them in research.
- Researchers need to share how a research problem is defined, and it should come from the community, not researchers.
- Researchers need to create literacy-friendly materials so that self-advocates and families can understand the scope of the research study.

**Representation**

- It is important to ensure that representation in research studies includes not only race, but also differences in income, location, school setting, etc.
- It is important to include those who are unable to advocate for themselves due to limited language ability.
- Researchers should include those who are undiagnosed and/or underdiagnosed due to the pervasive delays in diagnosis and misdiagnosis of African American children and youth.
- Researchers should recruit different family structures and home environments to ensure representation.
- The research team should include African American researchers conducting research specifically for and about the African American community.
- There is a need for people with lived experience from different backgrounds to co-lead research efforts.
- Cultural matches between the researcher and the participants are an important facilitator of engagement.
- Cultural liaisons, people *from* and *within* the community being recruited, are critical to promoting engagement in research in the African American autism community.

**Impact**

- The Framework defines impact as how an organization or researcher uses self-advocates' and family leaders' ideas to improve policies and programs. Stakeholders stated that they viewed impact as the thoughtful consideration of not just collecting information but also creating a plan to use it to support the community.
- One self-advocate stated that impact "means that my voice is not only heard but shared for the purpose of improving policies and programs."
- Program participants also indicated that they should know the positive and negative impact of research so that areas of weakness can be identified and improved.
- Self-advocates and families need to be able to provide input into the research progress, rather than blindly impacted by decisions made without them.
- Effective information informing stakeholders about the impact of their participation is a key to engaging the community.

**Ensuring that commitment, transparency, representation, and impact are present in research studies focused on the African American autism community will facilitate the engagement of African American autistic self-advocates and their families.**

**Without these four domains being met, families will continue to feel a lack of trust in research and researchers.**

## Recommendation 2

Address research questions and research topics developed by the African American autism community.

**Over 80% of the funded autism projects focus on screening and diagnosis, services, and risk factors. While these are important areas of research for the African American autism community, these areas are not in alignment with many of areas identified by the stakeholders engaged in this work.**

The following questions were identified to enable comparative research to be conducted for the African American autism community:

# Research Questions

### Identification and Diagnosis

- What information can educate extended family members about the autism diagnosis?
- How do late diagnosis and self-diagnosis affect quality of life and wellbeing?
- What factors contribute to the overidentification of intellectual disability in Black children?
- What are the experiences of individuals who receive a late diagnosis or self-diagnosis?

### Family Support and Training

- Is parent education for African American parents more effective when delivered by African American self-advocates, as compared to parent education delivered by parents or professionals?
- What are the facilitators to families discovering, navigating, and accessing autism services?
- What strengths and assets do African American families possess that facilitate access to, and utilization of, autism services?

# Research Questions

## Intersectionality

- What are the disparities experienced by African American autistic individuals?
- How can interventions and treatments be more relevant to the African American community?
- What are the factors that contribute to late diagnosis for African American girls with autism?
- What are the unique presentations of African American autistic girls and women, in contrast to African American autistic boys and men?
- How does the intersectionality of gender identity, race, and disability affect quality of life and wellbeing for African American autistic individuals?
- How does the intersectionality of sexual orientation, race, and disability affect quality of life and wellbeing for African American autistic individuals?
- How is autistic masking different from masking as an African American for autistic individuals?
- Does racial concordance between the family and their navigator impact outcomes for African American autistic individuals?
- Does [autistic] identity concordance between the family and their navigator impact outcomes for African American autistic individuals?
- How does the intersectionality of race, disability, and low-income status impact outcomes for African American autistic individuals?

## Family Systems

- How can African American family caregivers feel supported in their advocacy in systems?
- How does autism affect siblings and other family members for African American families?
- What are the most effective strategies for engaging African American fathers of autistic individuals?
- What are the unique parenting needs and experiences of African American autistic individuals?

## Awareness and Acceptance of Autism

- What are the public/community perceptions of language used to describe autism, such as profound autism, Aspergers, low functioning, and high functioning?
- How does stigma impact the acceptance of autism in the African American community?
- What does autism mean to African American autistic individuals and families in comparison to white autistic individuals and families?

# Research Questions

## Autism across the Lifespan

- What supports are effective for African American autistic individuals in adulthood?
- How does the risk for caregiver burnout evolve for African American family caregivers across the lifespan?
- What strategies are effective for helping African American autistic individuals and their families navigate adult services and systems?
- What factors contribute to the level of independence, self-efficacy, and quality of life for African American autistic adults?
- How does income level effect the outcomes of African American autistic individuals and their families across the lifespan?
- What services and support are necessary for pregnant African American autistic individuals in comparison to pregnant non-autistic individuals?

## Community Inclusion

- How are outcomes different for African American autistic individuals attending public and private schools?
- What are the differences in supports and services for African American autistic individuals attending public and private schools?
- What educational accommodations and supports are most effective in increasing quality of life for African American autistic individuals?
- What strategies are effective in fostering and improving engagement between law enforcement and African American autistic individuals and their families?
- How do African American autistic individuals navigate social and sexual relationships?
- What supports and education are effective in helping African American autistic individuals navigate social and sexual relationships?
- How do the interests and hobbies of African American autistic individuals differ from those of neurotypical individuals?

> “We desire respect and transparency when it comes to access to resources and cultural competency. We want to be heard and [we want] equal partnership.”

# Research Questions

## Access to Care and Services

- What are the perceptions of African American autistic individuals and families on how to use resources and services?
- What therapies and supports help improve the quality of life of African American autistic individuals?
- What supports are effective for African American autistic individuals in adulthood?
- How does the risk for caregiver burnout evolve for African American family caregivers across the lifespan?
- What strategies are effective for helping African American autistic individuals and their families navigate adult services and systems?
- What factors contribute to the level of independence, self-efficacy, and quality of life for African American autistic adults?
- How does income level effect the outcomes of African American autistic individuals and their families across the lifespan?
- What services and support are necessary for pregnant African American autistic individuals in comparison to pregnant non-autistic individuals?
- What are the mental health needs of African American autistic individuals and their families?
- What supports and strategies are effective in addressing suicidal ideation in African American autistic individuals?
- What are the lived experiences of African American autistic individuals in navigating the SSI system?
- What supports and strategies are effective in facilitating the successful navigation of the SSI system?
- What is the impact of social media on the mental health of African American autistic individuals?

# Recommendation 3

## Develop policies and practices that facilitate increased engagement of the African American autism community.

**Stakeholders continuously expressed concerns about the policies, practices, and beliefs that create barriers to engaging the African American autism community. The feedback from stakeholders landed in two primary areas: support for research focused on the African American autism community and support within the African American community. The Research Agenda outlines action steps academic institutions and funders to develop policies and practices.**

### Action Steps for Academic Institutions

- Develop policies that intentionally promote the development of research projects for the African American community to address longstanding disparities and inequities for this community.
- Address inequities in workforce hiring and development to promote the engagement of African Americans in autism research and take a targeted approach to hire and support African American researchers, including early researchers whose research is focused on addressing the needs of the African American autism community.
- Create opportunities for these researchers to collaborate with other African American autism researchers.
- Invest resources to support the development of accessible information and materials to help facilitate engagement with minoritized communities.

### Action Steps for Funders

- Take intentional steps to promote the engagement of African Americans in autism research.
- Seek to provide funding opportunities that build in time and money to cultivate relationships with the African American autism community.
- Provide specific funding opportunities to diverse early career professionals to advance research agendas focused on, and guided by, minoritized communities.

**Stakeholders engaged in this project reported the need for additional support within the African American autism community to facilitate increased engagement in research.**

- Development of culturally relevant materials for developmental monitoring.
- Culturally relevant materials should be shared by cultural liaisons and trusted members of the African American community.
- Train self-advocates and family leaders as cultural liaisons and research partners to help facilitate trust and engagement with this community.
- Due to the collectivist nature of the African American community, materials and other educational efforts need to be shared with the community using a multigenerational approach.

## Next Steps: Implementing the Research Agenda

**These research priorities provide a roadmap for funders, researchers, institutions, community liaisons, self-advocates and families to work together in a multifaceted way that changes the landscape of autism research and creates the conditions that allow for true engagement and equitable outcomes.**

1. Use recommendations to inform new research studies for the African American Autism community. Design research using the recommended research questions.
2. Pursue research with the African American autism community. Autism self-advocates and family members need to be engaged through the research process.
3. Engage self-diagnosed autistic individuals in your work. This is an untapped group that needs to be engaged in research to address barriers in access to timely diagnosis.
4. Develop an African American Autism research network. This network can provide an opportunity for stakeholders to work together in a coordinated way to design, analyze, and learn from each other's efforts.
5. Invest in African American researchers. Academic Institutions, funders, policymakers, and organizational leaders can prioritize investing in the workforce development and support of African American researchers.

# About the African American Autism Research Agenda

The American African Autism Research Agenda provides a blueprint to change the culture of the autism research space by building a community of African American self-advocates, family stakeholders, and researchers who will work to improve trust and ensure equitable representation of the African American community in autism research. It was developed by Family Voices and a team of committed partners through support of the Patient-Centered Outcomes Research Institute. The recommendations reflect the expertise and lived experience of a diverse community of autistic self-advocates, parent/family caregivers, researchers, providers, and funders, who are working to reduce disparities in diagnosis and treatment and improve care and culturally relevant treatment models for the African American autism community. To learn more, visit familyvoices.org/ARAProgram.

## About FAMILY VOICES®

Family Voices transforms systems of care to better work for all children and youth, especially those with special health care needs and disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes. For more information, visit www.familyvoices.org.

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