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

August 2023

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Contents

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Acknowledgements

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.

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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.

Introduction

The lack of African American stakeholder, researcher, and research participant representation has consequences for the relevance and generalizability of autism 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. The underrepresentation of African American autism researchers, autistic individuals and their families exacerbates gaps in access to knowledge, evidence-based therapies, and the inclusion of more racially diverse autistic voices. This contributes to an urgent need to center the lived experiences of African American autistic individuals and their families to create a research agenda that is truly inclusive and ensures equity in future access and outcomes.

The project described in this paper, Building Capacity in the African American Autism Community for Patient-Centered Outcomes Research, builds on the longstanding work of Family Voices, a national grassroots network of family-led organizations and families of children and youth with special health care needs (CYSHCN) including those with autism, that promotes partnerships with families to improve health care services and policies. The project built a research community of African American self-advocates, family stakeholders, and researchers by developing culturally appropriate training materials for self-advocates and families and by conducting training sessions for self-advocates, families and researchers. These activities resulted in the development of a community of diverse stakeholders ready to engage in research; trained African American self-advocates and families who were previously not involved in research; and articulated the research questions and interventions that would be most valued by the African American autism community. The scaffolding of Family Voices, its national network of families, professional partners and other key stakeholders provided a platform to sustain these activities in the service of improved outcomes for autistic African American children, youth, adults, and their families.

The Problems

A Brief Description of the Problems

African American autistic individuals and their families are underrepresented in autism research (Steinbrenner et al., 2022). While there is some evidence that more research networks and researchers focused on autism have reached out to self-advocates and family stakeholders in their work, an enormous demand for more meaningful stakeholder engagement remains, especially with people of color.

Of particular importance is the need to engage African American self-advocates and families with lived experience of autism. The urgency for such outreach is clear in light of the growing ratio of children and youth with an autism diagnosis. Autism is a lifelong developmental disability, impacting 1 in 36 of all children and 1 in 34 Black children in the United States, affecting children's ability to learn and interact with others in areas of behavior, communication, and socialization (Maenner et al., 2023).

There are large disparities in the timing of diagnosis, access to care, referral frequency, and unmet needs for African American children and youth with autism (Constantino et al., 2020; Kuhlthau et al., 2001; Liptak et al., 2008; Maenner et al., 2020; Travers et al., 2014). Along with these disparities, African American populations are often under-represented as both research participants and researchers in the autism space (Hilton et al., 2010; West et al., 2016).

Family Engagement in Research

Studies have found that African Americans are less engaged in autism research for two primary reasons: 1) lack of trust in researchers and research methods and 2) limited understanding of the research process and materials (Boulware et al., 2003; Hooper et al., 2019; Shaia et al., 2020). The historical catalog of unethical research practices performed on African Americans—including the Tuskegee syphilis study and the consent and privacy concerns highlighted by the story of Henrietta Lacks, among many others—has engendered a deep, shared legacy of mistrust of health research within the African American community (Boulware et al., 2003; Hooper et al., 2019). This mistrust extends into the autism research community as well (Shaia et al., 2020). Additionally, the underrepresentation of African American researchers contributes to the lack of trust and understanding of the research process (Taani et al., 2020). In a study completed by Shaia and colleagues (2020), a caregiver indicated that, "when you're sitting in a room with [people] who don't look like you, you feel that [they] can't sympathize with what I'm going through."

Burkett et al. (2015) found that African American families are highly motivated to increase knowledge and awareness of autism as a way of helping their own children. In fact, African American ASD families feel that it is important to hear about research from other African American families (Shaia et al., 2020). Failure to engage African American researchers and stakeholders in autism research can lead to both the development of materials that are not culturally or linguistically appropriate, and a lack of understanding of the research process and materials. This, in turn, drastically impacts the participation and retention of African American families in autism studies (Shaia et al., 2020; van Beusekom et al, 2016).

> I hope to learn how to become more empowered to help give back what I have learned in my community.

Diversity of the Research Community

The literature indicates that having research teams that are representative of the community being studied can increase trust in the research process, and thus increase participation and retention of African American individuals and families in research studies (Sankare et al., 2015; Taani et al., 2020). Involving African American families with lived experience with autism as part of the research team can help to assuage the mistrust in research that exists in the African American autism community. Several families participating in the study by Shaia and colleagues (2020) stated that "it was important that the interviewer identified herself as a Black mother of a child with autism," as the presence of researchers who are themselves representative of the study population increases trusting relationships between the research team and identified participants.

About Our Project

An underlying principle of this work is that culturally responsive engagement of families will lead to more relevant research questions, more inclusive and appropriate research methods, interventions with greater community acceptance, a higher likelihood of successful outcomes, and thus improved health and well-being of the target population, autistic African American children, youth, and adults.

The work undertaken in this project sought to fill a critical gap in autism research. Through promoting the work of, and increasing the engagement of, African American autism stakeholders in autism PCOR (patient-centered outcomes research), we can more effectively respond to the disparities in healthcare outcomes for autistic African American children, youth and adults.

The project aims were to:

- Create a portfolio of engagement research training materials specifically tailored to African American autism stakeholders.
- Train African American autism community members to serve as stakeholders in research projects.
- Train researchers on partnering with African American autism community members.
- Create a research agenda that addresses the specific needs of the African American autism community.

Reality

This is a unique time in history. The Black Lives Matter movement increased the visibility of longstanding issues of systemic racism and initiated conversations about how to move forward. At the same time, the COVID-19 pandemic disproportionately disrupted the lives of underserved individuals, African American autistic children, youth and adults, and their families, among them.

> “Autism has to come second to his blackness. The burnout and trauma from that is real. It can be life and death.”

As our country and our world move forward, there will hopefully be increased opportunities to develop research, services, and systems that are culturally appropriate and that lead to equitable outcomes for marginalized populations who are too often excluded from authentic roles in research.

Vision

To address the unique needs of the African American autism community, researchers must intentionally implement culturally responsive strategies to ensure their research is relevant to the African American community, ensure equal opportunity for African Americans to participate, and consider how research results will be shared back with the community in ways that are accessible and actionable. Altogether, these actions will strengthen the African American community’s engagement with the research process and engender confidence and trust in the researchers who are conducting it. Consequently, establishing a stakeholder collaborative that brings together African American families, African American self-advocates, community organizers serving the African American autism community, and African American autism researchers as key members of a research team is critical to the progression of an African American autism research agenda that builds toward equity.

Our Methodology

Methodology

Over the course of the project, Family Voices engaged 34 African American parents/family caregivers, 19 African American self-advocates, 156 researchers, three health care clinicians, one government official, and one funder across numerous project activities. The breakdown of how participants engaged is below.

We engaged the following groups in this work:

- Stakeholder Collaborative
- Community Autism Research Ambassador Program participants
- Key-Informant Interviews
- Self-Advocate Roundtable
- Autism Researcher Equity Training participants

Stakeholder Collaborative

Family Voices successfully recruited 11 Stakeholder Collaborative members to guide this project. The Stakeholder Collaborative consists of three African American autistic self-advocates (two males, one of whom is non-speaking, and one female), three African American parents of children with autism, two autism practitioners, two autism researchers, and one funder. The Stakeholder Collaborative was an integral part of this project. They established strong partnerships among stakeholders, cultivated culturally responsive training materials about autism, developed an interview guide for the key informant interviews, and created metrics for evaluating the training materials.

Community Autism Research Ambassador Program

Families were recruited to participate in the Community Autism Research Ambassador Program (ARAP), a program designed by members of the African American autism community to engage families in autism research and provide culturally relevant education about patient-centered outcomes research.

The ARAP recruitment flyer was shared online and within the national network of Family-to-Family Health Information Centers to inform prospective participants about the purpose of the project, the stipend for participating, and the scope of work. Prospective participants were invited to submit an application via Survey Monkey with their contact information, connection to the African American autism community, and reason for wanting to participate in the program.

The dissemination of the recruitment flyer by autistic individuals and their family members via online communities engaged trusted community partners and was key to the success of the recruitment efforts. In total, 134 people applied to ARAP, which consisted of 18 African American autistic self-advocates and 116 parents/family caregivers, service providers, and organizations. Applicants resided in 30 states and Washington, DC.

Selecting Participants for ARAP

Family Voices used extensive selection criteria to ensure that we included the voices of the most marginalized individuals within the African American community. The leadership team excluded applicants who were from outside the United States, did not identify as African American, and did not identify as a parent/family caregiver or self-advocate. Next, the leadership team sought to have representation from as many states as possible. Therefore, we identified the states form which we had only one applicant and included them in the participant selection. To further promote diversity, the leadership team then selected underrepresented groups within autism research, including fathers, individuals that identify as gender non-conforming, self-advocates, and female family caregivers. We prioritized female family caregivers of autistic female children due to the underrepresentation of females in autism research.

Family Voices asked applicants to select their preferred convening days out of four potential dates that occurred between June and August 2022. Family Voices invited 20 applicants to participate in the June convening, representing 17 states and the District of Columbia. The invited June participant group consisted of four self-advocates and 16 parents/family caregivers (including one grandparent). Additionally, three participants identified as male, three as gender non-conforming, and 14 as female. Only one of the 20 invited applicants did not attend the June convening.

Family Voices invited 21 applicants to participate in the August convening, representing 18 states and the District of Columbia. The invited August participant group consisted of seven self-advocates and 14 parents/family caregivers (including one grandparent). Additionally, two participants identified as male, two as gender non-conforming, and 18 as female. Of the 21 invited applicants, 17 attended the August convening. In all, 36 individuals participated in the ARAP convening, which included eight self-advocates, 27 parents/family caregivers (including two grandparents), and one autism clinician.

> “Looking at nontraditional ways of doing research, reaching out to more of the community, and educating key members of that community could increase research engagement.”

Culturally Responsive Materials

Recruitment for the Community Autism Research Ambassador Program was culturally responsive in that the recruitment materials were designed by members of the African American autism community and included plain language and graphics and images that were reflective exclusively of the community being recruited.

FAMILY VOICES®

COMMUNITY
Autism Research Ambassador
PROGRAM

Help change the face of autism research.

This virtual program empowers African American families and self-advocates to be more involved in autism research. Help develop autism services and information that meet the needs of our community.

APPLY today!

Apply today if you:

- Are the parent or grandparent of someone with autism OR
- Are an autistic self-advocate AND
- Identify as African American

If you are selected for the **Community Autism Research Ambassador Program**, you will receive a stipend of **$250** for your time.

Choose either the June OR August sessions:

June 21 and 22 12:00 - 4:30 ET
August 2 and 4 3:00 - 7:30 ET

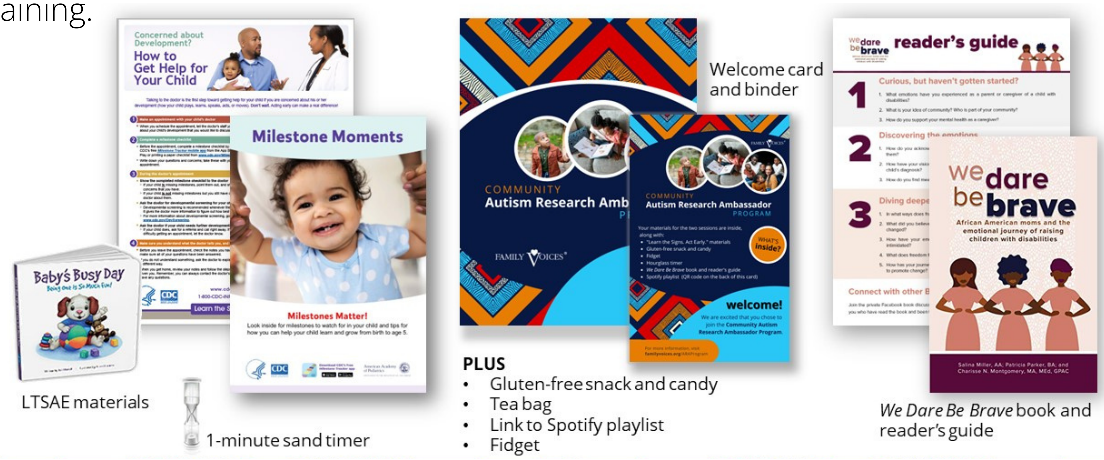
For more information, visit
familyvoices.org/ARAProgram

ARAP Recruitment Flyer

One week prior to the June and August convenings of the Community Autism Research Ambassador Program, program materials were shipped to all confirmed participants. The "welcome box" included a binder with printouts of the slides for each training module, aligned with best practices for engaging neurodivergent individuals. The slides included a culturally responsive design and inspirational quotes from African American celebrities, autistic individuals and scholars. The binder also contained caregiver resources.

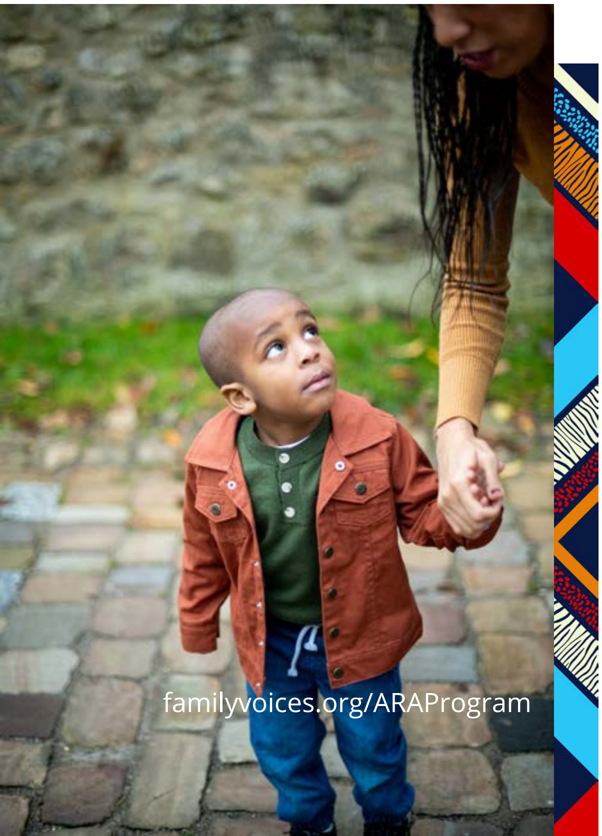
Also included in the "welcome box" was a postcard that welcomed participants to the program, the link to a culturally relevant Spotify playlist, a set of the CDC's "Learn the Signs. Act Early!" materials, a book written by African American parents of autistic children, a sand timer and fidgets, and snacks and candies. The sand timer was included to encourage consideration of timed responses from participants, to allow ample time for those with communication difficulties to participate in discussions. The fidgets were included to engage neurodivergent participants, and snacks were included because the four-hour session length might not allow participants to take a lunch or dinner break during the course of the sessions. The candies were culturally relevant to African American participants and were mentioned by multiple participants as indicators of the cultural connection with the hosts of the program. A web landing page was also developed to provide a project overview and house additional resources to support ARAP participants after the training.

Welcome Box Contents



Key-Informant Interviews

The Family Voices leadership team conducted nine key informant interviews to inform the development of research questions and a research agenda based on the needs of the African American autism community. Key informant interview participants were recruited from across the US through recommendations from members of the stakeholder collaborative group and other stakeholders who had been previously engaged in the work of this project. Invitations were sent via email and those who accepted were scheduled to participate in the individual one-hour, Zoom-based conversations. Participants of the key informant interviews included four parents/ family caregivers (one parent, two grandparents, and one sibling), two researchers, two clinicians, and one local government official.



Self-Advocate Roundtable

In December 2022, the project team convened a group of eight African American autistic self-advocates to learn more about their experiences and needs for engaging in autism research. Key informant interview participants were recruited from across the US through recommendations from members of the stakeholder collaborative group and other stakeholders who had been previously engaged in the work of this project.

Self-advocates were also recruited from the pool of previous participants in the ARAP training. Invitations were sent via email and those who accepted were scheduled to participate in the one-hour, Zoom-based group discussion. Their insights provided information about engaging the African American autistic self-advocate community to develop and drive research to improve healthcare outcomes. Gyasi Burks-Abott, a member of the Stakeholder Collaborative and an autistic self-advocate, moderated the discussion. He was integral to the success of this activity. He supported the development of the roundtable by providing input on the structure of the discussion and the discussion questions and provided recommendations on additional self-advocates to invite to participate in this discussion.

Project Objectives

To meet the aims and goals of this project, five key objectives guided the activities:

1. Create a research community that is dedicated to the needs of the African American community through the engagement of African American families of children with autism, African American self-advocates, and autism researchers and practitioners from the Autism Care Network (ACNet). This objective helped to lay the foundation for changing the culture of the autism research space by establishing a stakeholder collaborative and building a partnership between families, self-advocates, and researchers with a keen interest in the needs of the African American autism community.

2. Create culturally responsive training materials about conducting autism research and partnerships for African American autistic self-advocates, families of children with autism, and autism researchers and practitioners. These materials supported building the knowledge and capacity of African American families and self-advocates to authentically and willingly engage in PCOR projects.

3. Use the training materials to conduct two two-day virtual trainings and skill-building leadership development opportunities for African American self-advocates and families. Conducted with families recruited from across the country by the Family Voices network, these trainings furthered capacity-building efforts of African American self-advocates and families to partner in PCOR at all levels of the research process. Furthermore, by working with the F2Fs to recruit self-advocates and families, we created a sustainable model of recruiting, training, partnering, and supporting African American families and self-advocates to partner in the autism research space.

4. Build the capacity of researchers to effectively partner with the African American autism community. Increasing researchers' understanding of effective strategies to authentically engage African Americans in all levels of autism research communities through training will allow us to sustain this model.

5. Develop research questions and a research agenda based on the needs of the African American autism community and disseminate the lessons learned. This final objective will create a sustainable plan for research to aid in addressing the disparities that exist for the African American autism community.

Project Activities and Outcomes

Objective 1 Activities

1. Establish a stakeholder collaborative
2. Conduct six virtual meetings with the Stakeholder Collaborative to establish trusting relationships, and work together to develop culturally appropriate training materials about autism research
3. Create an interview guide for the key informant interviews, based on gaps, barriers, and other concerns identified by the stakeholder collaborative.

Stakeholder Collaborative

The 11-member Stakeholder Collaborative met seven times over 13 months. The first Stakeholder Collaborative meeting introduced the members to the project, oriented them to the workplan and timeline, centered discussions on the engagement of stakeholders throughout the project, and answered members' questions and concerns.

Following the initial Stakeholder Collaborative meeting, members engaged in onboarding training to familiarize themselves with PCOR/CER and the Family Engagement in Systems Assessment Tool. Collaborative members completed three PCORI modules: The PCORI Approach to Patient-Centered Outcomes Research, Engaging in Stakeholder Driven Research, and Developing Research Questions. Furthermore, the Collaborative members reviewed a slide presentation about the Family Engagement in Systems Assessment Tool (FESAT). After the onboarding training, Collaborative members answered knowledge questions and provided feedback on the usefulness and effectiveness of the materials for the African American autism community.

Contributions of the Stakeholder Collaborative

Stakeholder Collaborative members provided input and feedback on training topics that would be most helpful for families and self-advocates. The topics include Partnering with African American Families, Centers for Disease Control and Prevention's (CDC) "Learn the Signs. Act Early." Program (LTSAE), The Family Engagement in Systems Assessment Tool (FESAT), and State of Research: Engagement of African Americans in autism PCOR. The Collaborative members agreed with the proposed slate of topics but recommended including information on service navigation and research on autistic individuals and self-advocates.

The project team added the Partnering with African American Families module, which covers the prevalence of autism in African American children, the barriers to the engagement of African Americans in autism research, facilitators to engage African Americans in autism research, consequences of limited engagement, and recommendations to improve engagement of the African American autism community.

> 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.

Collaborative members recommended the following for the self-advocate and family training:

Recruitment

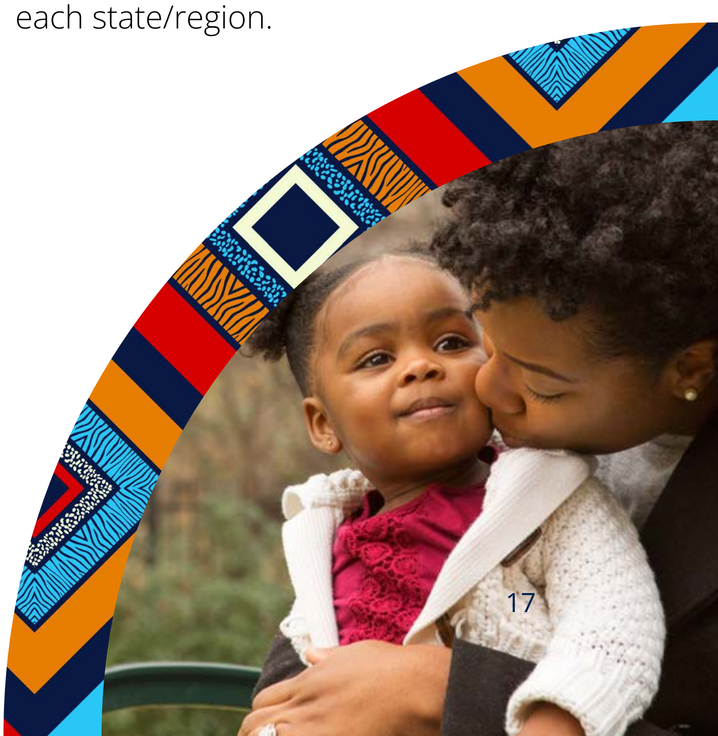
- Reaching out to Black sororities and fraternities

Format and Content

- Make the training more interactive.
- Adapt materials for plain language.
- Incorporate self-advocates into the training.

Additional impacts of inequities

- Add more information about the consequences of not engaging African American families in autism research.
- Share financial implications of late diagnosis for families.
- Include mental health consequences of being diagnosed for self-advocates and families.
- Provide information on resources in each state/region.



In January 2022, the Stakeholder Collaborative meeting focused on the new CDC prevalence report and an overview of the CDC's LTSAE Program. Drs. Matthew Maenner and Kelly Shaw shared the latest prevalence and early identification finding from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

The Stakeholder Collaborative shared that additional research or data collection is needed to look at disparities in co-occurring conditions, identification of Black children without an intellectual disability, the impact of over-representation of Black children in school emotional disturbance programs, and the need for further investigation into where Black children fall on the autism spectrum when they do not have an intellectual disability and receive late diagnoses. Drs. Maenner and Shaw stated that the questions were thought provoking and indicated the need for additional research into these important questions.

Yetta Myrick, the CDC's Act Early Ambassador to the District of Columbia, provided an overview of the presentation on the CDC's LTSAE Program to the Stakeholder Collaborative. Collaborative members felt the information was critical for families and recommended adding resources to the self-advocate/family training to help families navigate resources. Additionally, a collaborative member thought it would be helpful to include examples of visuals showing pages of books, etc. Another Collaborative member is a member of Zeta Phi Beta Sorority, which has an autism initiative and training for families. She recommended that we consider adding the sorority's training to our work on this project.

The February 2022 Stakeholder Collaborative meeting covered the state of research and the FESAT tool. Karen Kuhlthau, PhD provided an overview of the state of autism research. The Stakeholder Collaborative provided extensive feedback that highlighted the need to think about questions that matter to the African American autism community. They indicated that certain questions and studies are privileged over others.

The Stakeholder Collaborative indicated that the following additions would be beneficial for the self-advocate/family training:

- The kinds of questions self-advocates and families want to answer through research
- Gaps in research on autism
- What is known about the outcomes for African American autistic people
- Research initiatives beyond PCORI that exist
- Samples of research questions
- Information on how to retain African American autism researcher
- Information about the impact of autism on families
- Information about how participation in research benefits autistic individuals and their families

Shaping the Self-Advocate/Family Training

The Stakeholder Collaborative felt strongly that the self-advocate/family training should be framed in a way that empowers families instead of leaving them feeling hopeless. The project team used these recommendations to augment the self-advocate/family training and developed the concept of the Community Autism Research Ambassador Program (ARAP). The Stakeholder Collaborative provided extensive feedback on the design and cultural relevance of the training materials, the training schedule, language accessibility, and gaps in the materials.

The ARAP sessions were hosted in June and August of 2022. Following the two cohorts of the ARAP training, Family Voices shared the results of the ARAP training with the Stakeholder Collaborative. The Stakeholder Collaborative members expressed excitement for the findings from the training and the need to expand this work. The Stakeholder Collaborative members expressed the importance of engaging with trusted individuals in the African American community to understand how to better support families.

Stakeholder Collaborative members provided insight on who should be recruited for indicated the need for key informant interviews and future conversations, including:

- Members of the African American community, in general
- Faith community leaders
- Early interventionists
- Teachers
- Counselors (school and mental health)
- Black fraternities and sororities
- Clinicians
- Early childhood and daycare providers

Stakeholder Collaborative members provided extensive feedback on the Family Engagement in Systems Assessment Tool (FESAT), a tool developed by Family Voices and used in healthcare improvement initiatives nationwide. While the tool was developed with the input of families, the project team wanted to understand the relevance of this tool for engaging African American self-advocates and families specifically. Members of the Stakeholder Collaborative and participants from the ARAP training completed a survey about the FESAT and the relevance of each domain of the tool. The survey revealed a need among African American respondents to add components about transparency. Ensuring that self-advocates and families know the purpose of a study and what will happen with their information were key components of this domain. Additionally, expanding the definition of representation to include the race and ethnicity of the researcher was important to those who completed the survey.

The recommendations of the Stakeholder Collaborative and participants in the ARAP training were used to develop the Autism Researcher Equity Training, which was held in February and March of 2023. Based on findings from the key informant interviews and the self-advocate roundtable discussion, the Stakeholder Collaborative also discussed the need to educate the faith community about autism so that they can be a better support and resource to African American families and self-advocates.

> There needs to be a real education happening in faith communities and other groups where people come together and say it is okay to get help. Just because you have acknowledged that your child has a challenge doesn't mean you don't have faith.

Throughout the project, the Stakeholder Collaborative provided valuable insight on how to approach training and engaging African American self-advocates and families of children with autism. Additionally, they advocated for plain and accessible language that was culturally relevant for the intended audience. The Stakeholder Collaborative also reinforced the need to take a community-based approach to recruitment and training that takes into account the collectivist values and beliefs of the African American community. The Stakeholder Collaborative encouraged Family Voices to tap into the faith community, African American fraternities and sororities, and other community-based organizations that have well-established relationships within the African American community.

The Stakeholder Collaborative emphasized the importance of using accessible and family-friendly language with stakeholders. The Stakeholder Collaborative indicated that the ARAP materials were accessible and family-friendly, overall. They indicated that when terms were used that may be difficult to understand, they were appropriately defined.

> I will not participate in any research that requires bodily fluids because of the historical traumas that the African American community has experienced. There needs to be a better explanation and understanding in the African American community that there are different types of research where you don't have to give your epithelia. Not one eyelash.

Objective 2 Activity

Create culturally responsive training materials for African American autistic self-advocates, families of autistic children and youth, and autism researchers and practitioners about conducting autism research and partnering with African American self-advocates and families. These materials support building the knowledge and motivation for African American families and self-advocates to engage in PCOR projects authentically and enthusiastically.

Utilizing the PCOR Research Fundamentals: Preparing You to Successfully Contribute to Research training modules, CDC's LTSAE materials, and information from the Stakeholder Collaborative on the state of autism patient-centered outcome research, Family Voices developed a culturally responsive two-day virtual training curriculum for African American self-advocates with ASD and families whose children are autistic.

To ensure that the materials covered critical information necessary for the stakeholders to engage in this work, Family Voices asked the Stakeholder Collaborative to identify gaps in the materials for the ARAP Training. Members indicated the importance of discussing neurodiversity and identity vs. person-first language in the Autism 101 presentation. Furthermore, members felt that examples of current research and advocacy in the African American autism community were important to share with the ARAP participants. The Stakeholder Collaborative also recommended that the FESAT information be removed from the ARAP training. Finally, members recommended including brief case studies or video testimonials from an African American parent or self-advocate who had experience participating in research.

The design and cultural relevance of the materials to be shared with the stakeholders were a key focus of the Stakeholder Collaborative's feedback. The contents of the "welcome box" received positive feedback; however, there was a recommendation to include images of African American people in a barbershop or with an elderly person. The Stakeholder Collaborative provided input on the schedule for the convening, including the order of presentations and information over the two days of the training. While the Collaborative felt there was a lot of information in the ARAP training, they thought it was important to have a panel or speakers with lived experience over the two-day convening. They encouraged having self-advocates and family members as panelists or speakers to understand both perspectives. Additionally, they indicated the importance of centering both days on the voices of those with lived experience by having speakers on both days of the convening.

Objective 3 Activities

- In partnership with the Stakeholder Collaborative, develop and conduct the Autism Research Ambassador Program Training, a two-day convening for African American autistic self-advocates and family members to understand their experiences navigating life with autism.
- Work with participants to provide information and feedback to develop research questions and a research agenda for the African American autism community.

Hosting the Autism Research Ambassador Program (ARAP)

The two-day convening consisted of presentations, breakout sessions, and interactive discussions. On day one, participants shared information about themselves and why they applied for the program. Many participants indicated the desire to help other people in their community and understand how to help their child or themselves. Participants went into Zoom breakout rooms to share their broader story and identify where they saw commonality.

The common themes included:
- Ambiguity in diagnosis
- The need to trust yourself and what you know throughout the diagnostic journey
- Seeking community as an alternative due to lack of engagement with, and mistrust of, the health care system. Initial help came from outside the medical community.
- The need for tenacity and perseverance – “We have to be fighters.”

ARAP participants learned from several modules: Autism 101, Building Advocacy Skills, CDC’s LTSAE Program, Patient-Centered Research Outcomes for African American Autistic Individuals and their Families, and Effective Strategies for Partnering with African American ASD Self-Advocates and Families.

> “I would like for researchers to speak a language that African American people would understand and have a peer on the research team.”

ARAP Day 1

A module called Autism 101 helped to ensure common understanding, including factual, evidence-based information about autism, its prevalence, and its presentation. The Autism 101 module proved to be highly beneficial, as many of the participants discussed having held myths about autism.

Yetta Myrick, BA, the CDC's Act Early Ambassador to the District of Columbia, provided information on LTSAE Program, including information on resources she developed specifically for African American families. Many of the participants indicated that they were not aware of the materials presented and did not understand developmental monitoring.

Nikki Montgomery, MA, MEd, GPAC, conducted a module on developing advocacy skills and increasing engagement. The focus of this module was to help participants understand the process of moving from engaging in research and activities for their own needs to engaging in systems level efforts for the greater good of the community.

Karen Kuhlthau, PhD, provided a module on the state of patient-centered outcomes research in the African American community to participants. Dr. Kuhlthau's module demonstrated the limited number of autism studies that include African American individuals, either as participants or as researchers. Additionally, the module provided information on where funding dollars are spent in addressing the needs of people with autism.

ARAP Day 1

Allysa Ware, PhD, MSW, provided a module on the strategies to effectively partner with the African American community. This presentation was followed by a discussion on what it would take for participants to engage in research. Participants indicated that they needed to understand how the information would be used before they participated. Furthermore, participants felt that they should own their information and have access to findings.

One participant indicated that she was not aware that research existed that did not require her to give DNA. She went on to say that she "would not provide any DNA for research, not even an eyelash." Other participants in the group echoed her sentiment.

> "The word **research** can be intimidating, but this presents it in a way that make you want to get engaged."

Participants indicated the following needs that should be considered to engage African Americans in autism research:

- Inclusion of those who are self-diagnosed in research, especially in light of the disparities in obtaining a timely diagnosis.
- Share what researchers will do with the information.
- Member checking/feedback loop is critical.
- Show how the data will be applied to practice.
- Share who is overseeing the compliance.

ARAP Day 2

Day two of the ARAP training began with reflections on day one. Participants indicated that they felt empowered after day one. Additionally, they felt a sense of community and connection to other participants in the group. Several participants indicated that they had never sat in a space that was specifically for them regarding autism, highlighting the cultural responsiveness of the training.

The rest of day two consisted of storytelling and mapping the path to partner in research. Following the reflections, a panel discussion with Gyasi Burks-Abbott (self-advocate), Lari Warren-Jeanpierre (parent), and Lauren Ware (self-advocate) focused on their lived experience with autism and the importance of engaging in research to broaden the knowledge about the needs of the African American community. The second half of day two was dedicated to mapping the path to partnering in research. Participants developed care maps to understand all the domains that were relevant in their lives.

Participants self-selected topic-based breakout groups, which included diagnosis, treatment and interventions, and community supports. Surprisingly, participants had little interest in the discussion on diagnosis. They indicated a priority for knowing how to support their child, or themselves, in the broader community, which includes effective treatments and interventions. ARAP participants completed evaluations of the program.

97%

Ninety-seven percent of ARAP participants who agreed that:

- Attending this training will help me feel more equipped to partner with researchers.
- As a result of this training, I am more likely to engage in research studies.
- As a result of the training, I feel better prepared to share resources on how to monitor a child's developmental progress
- I feel prepared to share this information with other individuals in my community to help increase knowledge about autism and autism research.
- I am likely to recommend the Community Autism Research Ambassador Program to others.

Priorities Identified by ARAP Participants

Identification and Diagnosis

Access to information in the doctor's office that provides information on milestones and what to do if your child is not meeting those milestones

Public Awareness and Acceptance of Autism

Family Support and Training

- Bring awareness to the services that are available.
- Resource navigation is desperately needed in the community.
- Greater efforts by the health care community to connect to the Black community

Autism across the Lifespan

- Providers and researchers who are African American reduce the need to explain "Blackness."
- Additional research on transition age treatments and interventions, including ABA, education, life skills training, financial responsibility
- What are the needs of those diagnosed later in life?
- Treatments to address challenges with elopement and interaction with law enforcement

Family Systems

- The importance of extended family in the treatment and intervention process
- Increased understanding that caregiving is a full-time job
- Research on respite models that take into account the cultural needs of African American families

Access to Care and Services

- Greater integration between the medical systems and other systems (education, mental health, community, etc.)
- Researchers need to understand the complexity of being Black and its impact on accessing services.
- Access to resources and supports for adults that are "high functioning"
- The financial cost of seeking medical care

Community Inclusion

- What it means to be autistic and its impact
- College disability accommodations (families are dismissed)
- Training community members to provide interventions

Research Questions from ARAP Participants

- How do families discover and navigate services?
- Will these interventions work for my child?
- What information can we share with extended family to get them educated and on board?
- How can we compare outcomes and supports between public school and private school (this needs to be longitudinal)?
- What is the effectiveness of education of parents by self-advocates?
- What supports are effective in adulthood?
- What accommodations and education are most effective to make society more accessible?
- How do we support family caregivers so that they can continue to advocate?
- How does autism impact siblings and other family members in the African American community?
- What is the impact of caregiver burnout?
- What are the equitable resources available across the country and the barriers to implementing these resources?
- How are autistic people similar to non-autistic people?
- How much do African American self-advocates and families understand how to use resources and services?
- How do they make speech assessment more customized to children with autism?
- What are the key disparities and how do they affect African American children with autism?

Objective 4 Activity

Based on what was learned from the ARAP training, the stakeholder roundtable, and the key informant interviews, develop a training program for autism researchers.

Hosting the Autism Research Equity Training (ARET)

The Autism Research Equity Training focused on helping researchers learn how to engage the African American autism community effectively and authentically. The sessions were conducted in February and March of 2023. Two cohorts of trainees were recruited to engage in the three-hour training, which was divided into two 90-minute sessions over the course of two days.

Recruitment for the Autism Research Equity Training (ARET) included a flyer that was similar in design to the one developed for the Community Autism Research Ambassador Program. The flyer included a program description, the stipend amount for participating, and the dates of the program, along with a link to apply. The recruitment materials were disseminated through the Autism Care Network (ACNet) and other established research networks. Through extensive recruitment efforts, 257 researchers applied for the training. Through Survey Monkey, applicants submitted their contact information, reason for wanting to participate, and curriculum vitae to help the selection committee select participants from across the US and in various stages of their careers. Of the 257 researchers who applied, 152 were invited for the live sessions. Applicants who were not slotted for the live sessions were provided the training materials and recordings afterward.

Autism Research Equity Training Schedule

Day 1

- Welcome and Overview of Project
- Findings from the Community Autism Research Ambassador Program...so far
- Engaging African Americans in Patient-Centered Outcomes Research
- Research Partnerships with African American Families

Day 2

- Day 1 Recap
- Panel Discussion – The lived experiences of self-advocates and family caregivers
- Call to Action – Tools and strategies to effectively engage the African American autism community

CALLING ALL
Autism Researchers

Help change **equity** in autism research.

This virtual program helps autism researchers reach and engage African American families and self-advocates in research. Learn to develop processes and practices that improve equity.

Apply by 2/15/23 if:
- ✓ You are a researcher focused on autism AND
- ✓ You are seeking to improve equity in your work

If you are selected for the **Autism Research Equity Training**, you will receive a stipend of **$125** for your time.

Choose either the first OR second training:
Training 1: 2/28/23 and 3/7/23 12:00 - 1:30p ET
Training 2: 3/2/23 and 3/9/23 3:00 - 4:30p ET

ARET Recruitment Flyer

Priorities Identified by ARET Participants

The researchers who participated in the ARET training discussed challenges that prevent them from engaging with the African American autism community.

Systemic Challenges

- Limited funding for early career professionals
- Few researchers and research team members who identify as African American or people of color
- Policies/red tape that make research inaccessible
- Research information that is not clear and transparent
- Historical medical racism in genetics research
- Culture within academic institutions that does not support researchers who are Black, Indigenous and People of Color (BIPOC) or BIPOC-focused research

Logistical and Relational Challenges

- How to build trust with families and advocates
- Fostering and maintaining long-term relationships with the African American community
- Knowing where to connect with communities in their state
- Lack of motivation by families and advocates to participate
- Communicating research opportunities via social media while protecting stakeholders from trolls
- Identifying community partners
- BIPOC stakeholders not trusting BIPOC researchers who are based in predominantly white institutions (concerns about “selling out”)

The participants in the ARET training identified resources needed to effectively engage with the African American autism community. Additional time and funding to engage and foster relationships with the African American autism community were a top priority for participants.

Additionally, participants expressed a need for tools to ensure materials are accessible and transparent. Sample scripts and welcoming spaces were also an identified need. The researchers indicated a need for diverse researchers and staff as well as increased collaboration among African American researchers. Finally, the researchers indicated a need for information on groups that are open to collaboration with researchers.

Objective 5 Activity

Develop research questions and a research agenda based on the needs of the African American autism community and disseminating the lessons learned. To meet this objective, Family Voices conducted key informant interviews, a self-advocate roundtable, and a final convening of the Stakeholder Collaborative.

Key Informant Interviews

The Family Voices project team conducted nine key informant interviews to inform the development of research questions and a research agenda based on the needs of the African American autism community. The questions for the interviews were developed with input from the Stakeholder Collaborative (Objective 2).

The interviews were conducted by two African American mothers of autistic individuals: Project Lead, Allysa Ware, PhD, and Subject Matter Expert, Yetta Myrick, BA. Participants in the key informant interviews included four parents/family caregivers (one parent, two grandparents, and one sibling), two researchers, two clinicians, and one local government official. The individual interviews were conducted between November 2022 and February 2023. Below are the lists of questions asked of parents/family caregivers and researchers/clinicians.

Questions for Parents/ Family Caregivers

- What have been the most effective methods for reaching out to the African American autism community?
- How can outreach be improved to include African American families with lived experience?
- How have you been engaged through research?
- What topics do you think are important to research with the African American autism community?
- What is one question you would like researchers to answer with the African American autism community?

Questions for Researchers/Clinicians

- What have been the most effective methods for reaching out to the African American autism community?
- How can outreach be improved to include African American self-advocates and families with lived experience?
- How have you engaged African American self-advocates and families with lived experience through research?
- How are you addressing racism and bias to be culturally responsive in your research?
- What topics do you think are important to research with the African American autism community?
- What is one question you would like to answer as a researcher?

Recruitment Methods Identified in Key Informant Interviews

The researchers and parents/family caregivers who participated in the key informant interviews identified effective methods for reaching the African American autism community:

- Reflecting on how information is packaged and delivered to ensure it is culturally sensitive
- Word of mouth
- Having researchers who are people of color
- Connections/relationships and support
- Utilizing parent-to-parent organizations
- Partnering with churches, barbershops, and beauty salons

When asked about the best way to improve outreach to include African American autistic self-advocates and families, participants felt that it was important for researchers to be honest about the continuous, harmful actions research has perpetuated for African Americans and people with disabilities. Families felt that researchers needed to partner with people from the African American community, including families, schools, hospitals, and churches. Families highlighted the importance of having conversations and forums to build trust with the African American community. All participants talked about the potential role of the faith community and other groups where people come together.

Key informants highlighted research projects that have successfully engaged African American self-advocates and families. These projects included a study on advocacy that developed Black mothers to be systems navigators. Another study worked with a group at Yale called the Cultural Ambassadors. Families also indicated getting engaged in research through scientific advisory boards and partnerships with their local churches and afterschool programs.

Researchers were asked about strategies for addressing racism and bias in their research. They indicated the importance of ensuring that the research questions are important to the people they are trying to impact. Additionally, they indicated the need to ensure that families feel comfortable when they are participating. One researcher discussed the need to train staff on microaggressions and biases. Another researcher shared the importance of providing a lot of supervision to junior faculty and trainees.

Research Topics and Questions Identified in Key Informant Interviews

We asked all key informant interview participants to identify potential research topics and questions.

Research Topics Identified from Key Informant Interviews

- How the system has impacted the Black autistic person and their families
- Thinking about how at various phases of development a person is impacted and how those things build upon one another
- What are some of the factors that influence a black autistic child from getting that diagnosis or not?
- What are some of the factors that influence their family's awareness of how to be able to get that diagnosis or not?
- Training families and cross systems of care
- Parent burden and stress on how to navigate the systems
- Emotional regulation skills
- African American fathers and autism
- Early diagnosis and the barriers that families have to overcome both within their community and without their communities
- African American girls with learning differences
- Relationship between people with law enforcement

Research Questions Identified from Key Informant Interviews

- How is ASD determined and why are African American children being diagnosed at higher rates with ASD?
- What are key aspects of advocacy for Black mothers and advocacy development for mothers who have children with autism?
- How do researchers recruit and maintain more African American clinicians?
- What are you doing to enhance and empower my son’s future?
- Why can’t we earmark some of the penal resources into prevention?
- How does race show up in issues/experiences of people with autism?

Self-Advocate Roundtable

We conducted a self-advocate roundtable in December 2022 to understand the experiences and needs of African American autistic self-advocates and to develop and drive research to improve healthcare outcomes. The roundtable was led by Gyasi Burks-Abbott, an African American autistic self-advocate. Eight African American autistic self-advocates participated in the roundtable. Participants answered six questions (see Table 4) based on their lived experience.

Self-Advocate Roundtable Questions

1. What have been the most effective methods for reaching out to the African American autistic self-advocates, especially those who are self-diagnosed?
2. How can outreach be improved to include African American self-advocates?
3. How have you been engaged through research?
4. What topics do you think are important to research with the African American autistic self-advocate community, especially those who are self-diagnosed?
5. What ways can autistic self-advocates and parents of autistic children partner to advance the research agenda for the African American autism community?
6. What is one question you would like researchers to answer with the African American autism community?

In response to question one, participants shared a list of places where self-advocates can be reached, including social media groups and platforms.

For question two, participants identified several ways that outreach can be improved to include African American autistic self-advocates. Participants indicated that it is critical for researchers to listen to and respect the words of African American autistic people.

Additionally, the self-advocates said researchers should seek to connect similar families and individuals and adult self-advocates with children. The self-advocates expressed the desire to have mentors and participate in recurring groups of African American autistic self-advocates.

When asked about their previous experiences with research, many participants were unaware of autism research and were unaware of the self-advocate terminology. However, they indicated that it is important to have research centered on African Americans. Additionally, they wanted to see “Black-only” spaces due to the unique cultural norms of the African American community.

Research Topics and Questions Identified in the Self-Advocate Roundtable

Research Topics Identified from the Self-Advocate Roundtable

- Independence, self-maintenance, and quality of life
- Life expectancy after high school
- Suicide rate
- Mental health
- Effects of late diagnosis or self-diagnosis on long-term health outcomes, employment, educational attainment, and relationships
- Exploring our gender, disability, sexuality, and sexual identity
- Getting academic accommodations
- Overidentification of intellectual disabilities
- Social relationship navigation
- Parenting while Black and autistic
- Navigating SSI with invisible disability

Research Questions Identified from the Self-Advocate Roundtable

- How is autistic masking different from masking as a Black person?
- What is the best possible way to share information about ASD diagnosis to communities?
- What are the interests and hobbies of autistic individuals?

Stakeholder Collaborative Convening

Family Voices organized and hosted a two-day virtual convening of the Stakeholder Collaborative to review the work accomplished over the course of the project, solidify a research agenda, and determine next steps to carry out the research agenda through patient-centered outcomes research in partnership with ACNet, as well as to establish the framework for this paper.

On day one, the project team focused on an overview of the project, findings from the many stakeholders who participated across the project, and making meaning of the findings. The Stakeholder Collaborative noticed that many of the findings were consistent across the groups we engaged. Additionally, they expressed the importance of researching topics such as public awareness of autism, caregiver strengths, vocational supports, family planning, sexuality, the impact of social media on mental health, and navigating the adult service system. They also expressed the importance of staying away from using functional labels when discussing autism, as it only increases stigma and separation within the African American autism community.

On the second day of the convening, the Stakeholder Collaborative reviewed possible research questions, discussed dissemination strategies, and determined next steps. Members discussed the eight topic areas identified across the many stakeholders engaged in this project.

Topic Areas for Autism Research Identified through the Work of This Project

- Identification and diagnosis
- Intersectionality
- Family support and training
- Family systems
- Autism across the lifespan
- Access to care and services
- Community inclusion
- Public awareness and acceptance of autism

Stakeholder Collaborative members expressed the importance of using an asset-based framework in the presentation of the research agenda, as they perceived that much of the research and information on the African American autism community is focused on deficits, challenges, and weaknesses. Collaborative members saw an opportunity to change the narrative and focus on the strengths that exist within the African American family. Additionally, Collaborative members reiterated the importance of couching the findings of this work in theories that value the strengths of the African American family.

The Stakeholder Collaborative identified dissemination strategies to share the project paper and research agenda with a wide audience. They recommended developing a lay version of the materials, podcasts, submissions to academic journals, presenting at the UC Davis Mind Institute Summer Conference, and family-facing materials.

Project Impact

Impact of Outreach and Engagement Strategies

The recruitment and engagement strategies used in this project helped to connect African American families and autistic self-advocates from across the country. Individuals from the African American autism community led the efforts and helped with reaching networks and groups that are often not engaged. Recruitment through the Family Voices network, social media groups, and community networks reached almost 200 families and self-advocates. Most of these families and self-advocates had very little to no engagement with research efforts prior to this project. Connecting these families and self-advocates not only helped to fulfill the goal of our project but also aided in developing a community of families and self-advocates interested in addressing the needs of the African American autism community. We heard from participants across this project that this is critical work; they indicated that they had never been in spaces with other people that looked like them talking about autism research and the needs of autistic individuals.

The recruitment strategies reached a subgroup of African American autistic individuals who are often excluded from research: self-diagnosed autistic people. The delays in diagnosis and misdiagnosis of African Americans contribute to self-diagnosis in adulthood. We heard from several adult self-advocates about the many challenges of getting a diagnosis, including being turned away by professionals or misdiagnosed, as well as the cost of obtaining a formal diagnosis. Consequently, many of the self-diagnosed autistic people involved in this project did their own research, joined groups of other autistic people, and determined their own identity. These individuals are generally excluded from research studies and initiatives, which omits critical voices from the conversation.

In addition to the recruitment strategies employed, the engagement strategies are just as critical for a community that has a history of mistrust in research. Developing “welcome boxes” with culturally relevant content was impactful to how engaged the families and self-advocates felt in the ARAP training. One participant indicated that she was skeptical when she signed up but when she received the box, which included candy and treats that were reminiscent of home, she felt that the training was created for her. The music, slide presentations and materials were all developed by members of the African American autism community. This approach helped the participants feel connected throughout the two-day training, which allowed for deeper conversations and trust across the cohorts and richer findings.

Lessons Learned

The goal of this PCOR project was 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. This approach is intended, in the long term, to reduce disparities in diagnosis and treatment and improve care and culturally relevant treatment models for the African American community impacted by autism.

1. Building trust among African American self-advocates, families, researchers and practitioners is of primary importance, as without trust, families are reluctant to participate in research for reasons both historical and current. Moreover, engagement of African American self-advocates and families in co-creating research questions, study design, and protocols will result in more relevant research questions and methods and a faster pathway from findings to implementation.

2. The two ARAP cohorts of autistic self-advocates and families of children with autism provided insight about the needs of the African American autism community. Transparency, accountability, trust, cultural competence, and community building were key takeaways from the ARAP training. Furthermore, the two cohorts identified the imperative to understand the needs of self-diagnosed self-advocates.

   Often self-diagnosed autistic individuals are self-diagnosed because of known barriers: misdiagnosis, lack of access to diagnosticians, the cost of pursuing a diagnosis, and dismissal of their concerns by medical providers, not to mention bias and disparities in care and engagement that are well-documented for African American patients. Consequently, African Americans who are seeking an autism diagnosis are left to seek information through community-based channels such as social media groups. Considering the ongoing disparities in access to timely diagnosis for African American children, this finding needs to be considered when conducting autism research with the African American community.

> “Stop telling people to have a spa day when I can’t get ABA.”

3

Hearing from autistic self-advocates that they often feel like tokens and as if they are not heard in the research or engagement process helped us refocus how we engaged self-advocates in this work. Family Voices has historically focused on the needs of families with children with autism and other special health care needs and disabilities. We ensure the inclusion of family voices in all aspects of our work; however, we have not always effectively included the voices of self-advocates in the work that we do. This is clear in our proposal and our initial approach to the project. After much reflection, we understood the need to put the voices of self-advocates at the center of our work. Consequently, we included an additional module featuring self-advocates who led the conversations; we shifted by understanding their perspectives and letting them drive the work. Additionally, we added the self-advocate roundtable discussion, which was led by a self-advocate. The families were extremely receptive to this and discussed the desire to have self-advocates mentor parents on meeting the needs of their autistic children.

4

Another lesson learned from this project is the importance of budgeting for deep engagement. Creating printed materials and sending “welcome boxes” was tremendously impactful to our project. While these efforts did not come at a small cost, they had a large return on investment. Ensuring that money is allocated to develop materials that connect with participants is critical for this community, and sending materials in advance of the training added an element of accessibility to the training.

5

The final lesson learned from this project is the importance of having studies and initiatives focused exclusively on the African American community and led by members of the community. Many of the participants in this project indicated that seeing a project that was strictly focused on their community meant a lot to them and encouraged them to remain engaged. Furthermore, participants expressed that they are bothered when they are asked to be in research studies or initiatives where they are the only, or one of a few, African Americans included in the effort, leaving them feeling tokenized and exploited.

Recommendations for Future Research and Funding

Through engagement with stakeholders from the African American autism community, this paper promotes a Research Agenda consisting of three key strategies to address the needs of this underserved community, utilizing 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 the evidence-based practices and interventions and work toward equity by addressing the needs of African American autistic children and youth, and their families.

Recommendation 1

African Americans are under-represented as both research participants and researchers in the autism space (Hilton et al., 2010; West et al., 2016). This 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 health equity and the health and well-being of African American children, youth, and families affected by this developmental disability. Studies have found that African Americans are less engaged in autism research for two primary reasons: lack of trust in researchers and research methods and limited understanding of the research process and materials (Boulware et al., 2003; Hooper et al., 2019; Shaia et al., 2020).

Further review of the literature for this project also indicates that African Americans are underrepresented in autism research. Steinbrenner and colleagues (2022) conducted a meta-analysis of interventions for autistic children in inclusive settings. This meta-analysis identified 30 studies focused on interventions for autistic children. Of these 30 studies, half of the studies did not report race. Furthermore, of the 15 studies that reported race, only 8% (n=20) of participants were Black. Specifically for PCORI-funded studies, there were 32 studies listed as being related to autism. Of the 32 studies, only four reported engaging Black children and youth with autism.

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.

The literature indicates that having research teams representative of the community being studied can increase trust in the research process, and thus increase participation and retention of African American individuals and families in autism research studies (Sankare et al., 2015; Taani et al., 2020). We heard from the stakeholders in this project that they wanted not only to focus on training researchers on how to engage with the African American autism community, but also wanted to extend the training to autism practitioners. Family Voices is exploring this recommendation to determine how best to move forward.

Framework for Engaging the African American Autistic Community

Family Voices developed the Family Voices Family Engagement Framework and Family Engagement in Systems Assessment Tools (FESAT). The Framework identifies four domains (commitment, transparency, representation, impact) and 20 items that ensure authentic self-advocate, family, and professional engagement for planning, assessing, and improving family engagement in systems-level initiatives such as stakeholder engagement in research. The items address the importance of compensating all family members and professional partners for their time (commitment); ensuring self-advocates, families, and other partners have a clear understanding of their roles (i.e., a job description) and are provided a mentor (transparency); that the participants are representative of the population to be served (representation); and that the contributions that self-advocates and families make to the research are identified (impact). These tools developed by Family Voices provide a rich compendium of strategies and resources that organizations frequently use to ensure meaningful family engagement in systems change and research. Each domain of the FESAT was explored by stakeholders from the African American autism community in the project, to add to our understanding of what this community defines as meaningful engagement.

Commitment

The Framework for Assessing Family Engagement in Systems Change defines commitment as “families [being] included in all system-level initiatives that impact the organization’s policies, programs, services, and practices” (Hoover et al., 2018). The stakeholders involved in this project agreed that commitment is critical for them to engage in research initiatives. However, they added that the definition needed to indicate the importance of self-advocates and family leaders being involved in all aspects and phases of a research study and that this engagement should move from inclusion to leadership.

Families and self-advocates indicated that researchers need to demonstrate commitment by listening and hearing their concerns, being humble and respectful (cultural humility), and following through on agreements. Furthermore, researchers must be intentional in identifying and removing barriers to participation, including time and travel barriers. Considering and respecting cultural dynamics is also essential to engaging the African American autism community.

To achieve commitment, researchers must invest in long-term support for African American autistic individuals, their family caregivers, and the institutions that serve them. Additionally, research practices and policies must include the continued diversification of the research workforce and a shift from favoring research aptitude over lived experience. Finally, stakeholders indicated that it is essential for researchers to establish and nurture long-term relationships with those who have not built power through coalitions.

Transparency

Transparency, in the Framework, is defined as “showing and telling how we look for problems faced by children, youth, self-advocates, and families and giving them support and information to participate in solving the problems” (Hoover et al., 2018). Stakeholders indicated that transparency was necessary in order to engage African Americans in research effectively. However, they thought that the definition of transparency needed to be augmented for this community. Researchers need to be open, honest, unbiased and available to self-advocates and families. Additionally, stakeholders felt that it was important for researchers 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.

Due to the lack of trust and history of exploitation in research, stakeholders indicated that prior to engaging them in research, researchers need to share their priorities, how the research will impact participants’ lives, and how their data will be shared and stored. Doing so will help to build trust and foster accountability. Self-advocates and families also wanted to see how a given research problem was defined, as it should come from the community, not researchers. Finally, self-advocates and families indicated the need for literacy-friendly materials so that they could understand the scope of the research study.

Representation

Representation is defined in the Framework as the condition when the self-advocates and family members engaged in the work are as diverse as the community that the organization or researchers serve. For the stakeholders we engaged from the African American autism community, representation took on a much broader definition. Stakeholders indicated that it is important to ensure representation includes not only race, but also differences in income, location, and private or public school settings. Specific to autism, stakeholders felt that it was important to include those who are unable to advocate for themselves due to limited language ability. Additionally, 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. It is also important for researchers to recruit different family structures and home environments to ensure representation.

In addition to being attentive to the socio-demographic representation of study participants, stakeholders indicated the importance of representation for the research team. They wanted to see African American researchers conducting research specifically for the African American community. Additionally, they indicated the need for people with lived experience from different backgrounds to co-lead research efforts. Stakeholders identified cultural matches between the researcher and the participants as an important facilitator of engagement. Cultural liaisons, people from and within the community being recruited, were also identified as a critical component to promoting engagement in research in the African American 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.

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 felt that they are often blindly impacted by decisions made without their input in the process. Stakeholders indicated that a lack of effective information about the impact of their participation was a major barrier to their engagement.

Recommendation 2

As indicated above, most of the research on the autism community fails to effectively involve and engage the African American autism community. According to the 2018 *Autism Spectrum Disorder Research Portfolio Analysis Report* by the IACC, only 6% of all funded autism projects were focused on addressing autism disparities. As shown in the graph below, 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 section highlights research questions that were identified as important by the various stakeholders who helped develop this Research Agenda. The Research Agenda recommends that future research with the African American autism community consistently focus on one or more of these questions to enable comparative research to be conducted for this community. This will allow evidence-based interventions and programs to be developed that are effective for the African American autism community. The Stakeholder Collaborative met to review all the findings from the project to develop research questions that address the needs identified by the stakeholders.

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?

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

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

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.

Stakeholders indicated that researchers require support from their institutions for research focused on African American autism community. At the heart of these recommendations are concerns about policies that inhibit engagement with African American families. This includes belief systems and policies that deter researchers from conducting research exclusively for the African American community instead of all racial and ethnic groups. Therefore, it is recommended that 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.

It is also critical for institutions to address inequities in workforce hiring and development in order to promote the engagement of African Americans in autism research. Institutions should 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. Additionally, institutions should create opportunities for these researchers to collaborate with other African American autism researchers. Institutions should invest resources to support the development of accessible information and materials to help facilitate engagement with minoritized communities.

In addition to policy and practice changes at the institutional level, funders also need to take intentional steps to promote the engagement of African Americans in autism research. Funders should seek to provide funding opportunities that build in time and money to cultivate relationships with the African American autism community. Additionally, funders should 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. All stakeholders expressed a need for the development of culturally relevant materials for developmental monitoring. These materials should be shared by cultural liaisons and trusted members of the African American community. It is important for self-advocates and family leaders to be trained as cultural liaisons and research partners to help facilitate trust and engagement with this community. Furthermore, materials and other educational efforts need to be shared with the community using a multigenerational approach, due to the collectivist nature of the African American community.

In short, the development and execution of an autism Research Agenda that engages the African American community is a systems-level endeavor that requires inputs from funders, researchers, institutions, community liaisons, self-advocates and families. All of these partners must 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.

> “There's concern about what happens to the information and data that's collected, how transparent that process is. Will it be used in a negative way? There is a lot of fear, not just with the history, but with those who are willing now.”