Research Brief: Convening to Identify Patient-Centered CER Priorities of Black and Hispanic Parents of Children with Disabilities

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Acknowledgements

This Research Brief was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-38503). The views, statements, and opinions presented in this Research Brief are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors, or Methodology Committee.

Introduction and Rationale

Black and Hispanic families of children with Down syndrome (DS) often face systemic barriers in healthcare access, representation, and culturally competent care. Despite these inequities, their voices remain underrepresented in disability research and policy formation. Prior studies document racial disparities in prenatal diagnosis delivery, lack of culturally responsive resources, and disproportionate assumptions around decision-making, particularly concerning abortion and care planning.

This project centers on identifying patient-centered comparative effectiveness research (CER) priorities that authentically reflect the lived experiences, values, and concerns of Black and Hispanic parents of children with disabilities. Understanding these priorities is essential for designing equitable, inclusive healthcare interventions and shaping future research agendas focused on diagnosis, support, and outcomes for children of color with disabilities.

A key aspect that emerged through community engagement is how families decide whether to participate in research. Factors influencing participation include whether the research will "benefit them" rather than "use them," clear information surrounding transparent study goals, assurances about confidentiality, and whether participants will receive results and meaningful support. Families emphasized the importance of trust, transparency, and mutual benefit, underscoring the need for research to provide tangible, culturally relevant outcomes, and compensation for participation. This requires acknowledging current and historical injustices and engaging in restorative justice by validating past harms and building empathy.

Method

To ground our recommendations in authentic community input, we employed a two-pronged engagement strategy:

1. *Online Community Conversations:*
   For full details, see the Research Priority Report.
2. *In-Person Breakout Session at the National Down Syndrome Congress (NDSC) Conference, Dallas, TX:*
   Table hosts included three researchers, one medical provider, two Black parents, and two Hispanic parents who were facilitating for breakout discussions with 49 attendees (12 Hispanic parents of children with DS, 10 Black parents of children with DS, 11 researchers, 11 medical professionals, one Hispanic person with DS, and 4 Black individuals with DS). Notably, about 59% of the medical professionals and researchers also identified as Black or Hispanic.

We conducted three rounds of community conversations using the World Café model (https://theworldcafe.com/key-concepts-resources/world-cafe-method/) focusing on the following three questions to ascertain what motivates Black and Hispanic parents of children with DS to participate in research, what research topics are most compelling to them, and how researchers can better engage participants:

1. *In what ways can Black and Hispanic people with DS and their parents be involved in research studies?*
2. *What factors do you think are most important in determining whether or not Black and Hispanic people with DS and their parents want to be involved in research?*
3. *Which priorities already identified in the Research Priority Report would you be most interested in and why?*

We set up eight tables with 5-8 participants each led by table hosts who represented either the parent, research, or medical communities. To recruit participants in the meeting, Dr. Meredith actively participated in the NDSC DIR committee for 6 months prior to the event and coordinated with conference coordinator to advertise the session, and four table hosts were from selected from the NDSC DIR leadership. Specifically, we sent a recruitment email to conference participants who signed up for events geared toward Black and Hispanic families as well as participants in previous conversations. The recruitment email included a pre-registration form, and 50 people pre-registered for the event.

Given that the event was in-person with competing activities, about 15 participants (30%) who pre-registered did not show up, so we used snowball sampling to recruit more participants on site through the participants and table hosts, including the President of the Black Down Syndrome Association. We further provided a full complimentary lunch buffet as compensation for participants and to help with on-site recruitment. Table hosts were compensated for their time during the session and also travel reimbursement for the conference.

To be inclusive of Spanish-speaking participants, we utilized a professional translation company to facilitate translation for two tables during the session for 13 participants.

Agenda:

- 11:30am – 11:40am: Lunch Buffet
- 11:40am - 12:05pm: PCORI Research Fundamentals Training
- 12:05pm - 12:15pm: Explain World Café Community Conversation Model
- 12:15pm - 12:35pm: Question #1
- 12:35pm - 12:55pm: Question #2
- 12:55pm - 1:10pm: Question #3
- 1:10pm - 1:30: - Share results

Throughout these efforts, we prioritized inclusivity, cultural sensitivity, and meaningful dialogue. The engagement was structured to allow participants to express their concerns about research participation. Participants brought up fears of exploitation, burdens of involvement, and language accessibility. We also challenged them to articulate what would encourage trust and sustained involvement. These conversations were critical in shaping CER priorities grounded in real community needs and preferences.

Results

Online Community Conversation Findings

- Racial Disparities in Diagnosis and Care
  - Many Black and Hispanic parents reported being pressured toward abortion following a suspected DS diagnosis.
  - Clinicians often delivered diagnoses in rushed, insensitive ways lacking cultural context and compassionate support.
  - Parents shared experiences of disbelief and dismissal, both prenatally and at birth, magnifying trauma and mistrust.
  - The manner of communication during diagnosis deeply affects parental trust, stress, and decision-making.
- Lack of Representation and Support
  - Families noted a striking absence of racial and cultural representation among medical professionals, DS materials, and support organizations.
  - They rarely saw children of color in pamphlets, websites, or advocacy literature, leading to feelings of exclusion.
  - Many parents created informal support networks due to feeling marginalized by traditional spaces.
  - Representation in recruitment and educational materials is critical to overcoming perceptions of “tokenism” and fostering inclusion.
- Emotional and Psychological Impact
  - Systemic bias and inadequate support led to significant emotional trauma, isolation, and mental health strain.
  - Lack of culturally competent counseling left many feeling unprepared and unsupported.
  - Parents emphasized the importance of providers who demonstrate empathy, validate their experiences, and engage with cultural humility.
- Factors Influencing Research Participation
  - They want to know that research is conducted for them, not on them, with clear information on objectives, procedures, and potential benefits.
  - Participants expect to receive study results and ongoing communication in accessible language tailored to diverse literacy levels and dialects.
  - Research must offer tangible support, compensation, and care resources. Families expressed concern over the burden of participation and sought flexible scheduling and minimized disruption to existing care.
  - Trust requires recognizing past abuses and demonstrating restorative justice through honest dialogue and empathy.
  - Families desire providers and researchers who reflect their communities racially and culturally and who respect their values and belief systems without judgment or coercion.
  - Especially for Hispanic families, assurances that participation will not affect immigration status.

Drawing from these insights, we identified priority research questions that address the intersection of culture, healthcare experience, and outcomes for Black and Hispanic families:

- How does provider training in culturally competent care affect the mental health and trust of Black and Hispanic parents receiving a DS diagnosis?
- What impact do post-diagnosis support systems tailored for families of color have on long-term health and developmental outcomes for children with DS?
- What are the comparative effects of different diagnosis delivery models (e.g., in-person with counseling vs. phone-based, rushed delivery) on parental stress, decision-making, and trust?
- What are the long-term outcomes for children of color with DS based on access to early intervention and culturally tailored support systems?

NDSC Community Conversation Results

The following section presents the results of our community engagement efforts, highlighting key themes and insights gathered from both the online conversations and the in-person breakout session. These findings reflect the lived experiences, priorities, and perspectives of Black and Hispanic families of individuals with Down syndrome, as well as input from researchers, providers, and advocates, and serve as the foundation for our final recommendations.

Involving Black and Hispanic People with DS and Their Families in Research

The most fundamental component of involving Black and Hispanic people with DS and their families in research is to build relationships of genuine trust between medical providers/researchers and potential research participants. In plain language, people with DS and their families need to know that medical providers and researchers care about them as human beings and not just as a project. Moreover, they need to see representation of people who share their identities in every part of the research process so that the agenda, the recruitment, the methods, and the findings are influenced by them. During our conversations, families identified themes to increase participation in research through research education communication about research, outreach/connection, representation in research, accessibility, and listening to patients. Specifically, one table pointed out that most families do not know about the Institutional Review Board protections that now exist and did not exist in those historical incidences they reference, like the Tuskeegee Syphilis study and Henrietta Lacks. They concluded that there needs to be more education for families about these processes that are in place and that they should ask questions about the approval process for the study.

Question 1: In what ways can Black and Hispanic people with DS and their parents be involved in research studies?

1. *Research Education*
   To meaningfully involve Black and Hispanic people with DS and their families in research, researchers need to be transparent about the objectives of the study, benefits and risks, why the outcomes are important and the potential impact for the individual and community, how they will protect confidentiality, and how it is a win-win for researchers and research participants. Further, they need to explain the research process possibly using a webinar or video and address common concerns for people with DS, like how the clinician will make a blood draw more comfortable for a participant with DS.
2. *Communication*
   To reach Black and Hispanic people with DS and their families, researchers need to make sure recruitment and educational materials are translated into the appropriate languages and dialects, including Spanish; they need to use culturally competent language, such as whether people identify as Latino or Hispanic and other differences within cultural identities; and they need to utilize the most effective methods of communication: digital/phone.

3. *Connection/Outreach*
   Researchers and doctors need to be relational and genuinely connect at social events, as volunteers, and at NDSC Black and Hispanic lunches/dinners. They can also get involved at DS clinics, advocacy organizations/NDSC, schools, churches, and community events. Moreover, Black and Hispanic parents of people with DS can get involved in parent-to-parent outreach themselves as trusted messengers about research opportunities. Participants also emphasized generational differences in perceptions about research and the value of reaching out to families while children are young and developing rapport and trust.
4. *Representation*
   Black and Hispanic people with DS and their families can be directly involved in research as participants, advisors, and advocates in the full scope of a research project, including research design at the beginning stages. Participants said they particularly valued when Black and Brown people were integral members of the research team and the Institutional Review Boards reviewing research, and they need to be featured in education videos about the research. They also discussed having support in place so that adults with DS can participate, including communication supports for those who have not yet developed verbal skills.
5. *Accessibility*
   Researchers can encourage research participation by making sure the project is accessible by focusing on flexibility, transportation, and time requirements. They also emphasized the importance of "Nothing About Us, Without Us" and the importance of making sure all materials are accessible for people with DS to participate in studies and understand what the research is about and what is being communicated about them.
6. *Inform/Listen*
   People with DS and families need to be properly informed about research. It is vital people with DS and families receive transparent information surrounding the intentions of the research and how the results may be used. Researchers also need to listen to the perspectives of people with DS and their families. Researchers must specifically listen for any medical trauma participants may have experienced.

Factors Determining Research Participation

The next question we explored was what factors determined whether or not Black and Hispanic people with DS and their families were willing and interested to participate in research. The following themes emerged during the discussions across the eight tables.

Question 2: What factors do you think are most important in determining whether or not Black and Hispanic people with DS and their parents want to be involved in research?

1. *Potential Impact of Research*
   All groups indicated that the potential benefits and outcomes of research need to be clearly communicated to research participants. They also need to be specifically informed about why the participation of Black and Hispanic families is valued and needed. The need to know the how the research could possibly help the individual, the family, and the community. Specifically, they want to know that the research is mutually beneficial and not just using them.
2. *Communication About Research*
   Communication about research needs to be clear, accessible, and in the preferred language and dialect of the participant (Spanish). Any flyers or recruitment materials also need to include genuine representation of communities of color (not just tokenism), and participants recommended having members of each community lead grassroots, small group discussions about research and the benefits of participating in research. Moreover, once research activity is completed, researchers need to inform participants about the results and facilitate communication for the participants to provide feedback.
3. *Authenticity, Identity, and Empathy of the Research Team*
   Research teams need to genuinely care about the research participants and build relationships of trust with them. This also means developing cultural competence by being vulnerable and getting involved in the communities. Representation of people with the same racial and ethnic identity on the team is also critical. Furthermore, research teams need to convey empathy by acknowledging past wrongs in research among people of color, including the Tuskegee Syphilis Project and Henrietta Lacks. By acknowledging the individual and collective research and medical trauma experienced by communities of color and people with DS, researchers can validate and then address their fears and anxiety about participation
4. *Recognition of People with DS*
   Researchers need to also demonstrate that they recognize the distinct needs of people with DS, including addressing generational differences between parents and individuals with DS, making materials available in plain language, being patient and genuine, speaking directly to the person with DS as well as caregivers, and adapting to the difficulty of blood draws for many people with DS.
5. *Education about Research*
   Researchers need to provide potential research participants with education about the research to enable truly informed consent, including webinars about the research process, information about risks and benefits, and information about the objective of the research and why it's important. There also need to be a recognition of the different education levels of different participants and adapting to their needs.
6. *Level of Invasiveness*
   Research teams must share the time commitment required to fulfill the needs of the study, the amount of testing/type also mattered to them. Participants need to understand the driving distance to participate in the study and the overall cost of participating.
7. *Value Participants*
   Finally, research teams need to demonstrate they value the participants by providing equitable compensation for their valuable time that incentivizes but doesn't take advantage; vigilantly protecting confidentiality and anonymity, particularly for families who may be concerned about immigration status; and providing reasonable timeframes for participation. Researchers should also provide ongoing support, services, and resources and make participation easier for participants—such as consolidating blood draws. Finally, researchers need to understand the religious and cultural sensitivities of the participants and respect their values and where they are coming from. "Our children are not experiments; they are our babies."

Engagement in Research Priorities

During our online conversations in March, parents identified the following top three Comparative Effectiveness Research (CER) questions based on frequency, relevance across multiple domains (medical, educational, social, racial), and potential for measurable outcomes. Participants frequently referred to the impact of the diagnosis experience on mental health and the ability access services and supports for long-term care and well-being. We presented these questions during the live session at NDSC to determine which priorities they found most compelling and how they would prefer to engage.

Theme: Impact of Early Support (Mentors, Advocacy, Education, Resources)

What is the comparative effectiveness of culturally competent parent support interventions—such as parent mentors who share the same racial/ethnic identity; parent information/resources about Down syndrome in native language with diverse representation; parent advocacy training in a native language; and access to advocacy groups with racial/ethnic affinity groups —versus standard care on the mental health of parents and health and developmental outcomes for Black and Hispanic children with Down syndrome and their families?

Theme: Role of Culturally Competent, Empathetic, Relational, and Continuity-Based Healthcare

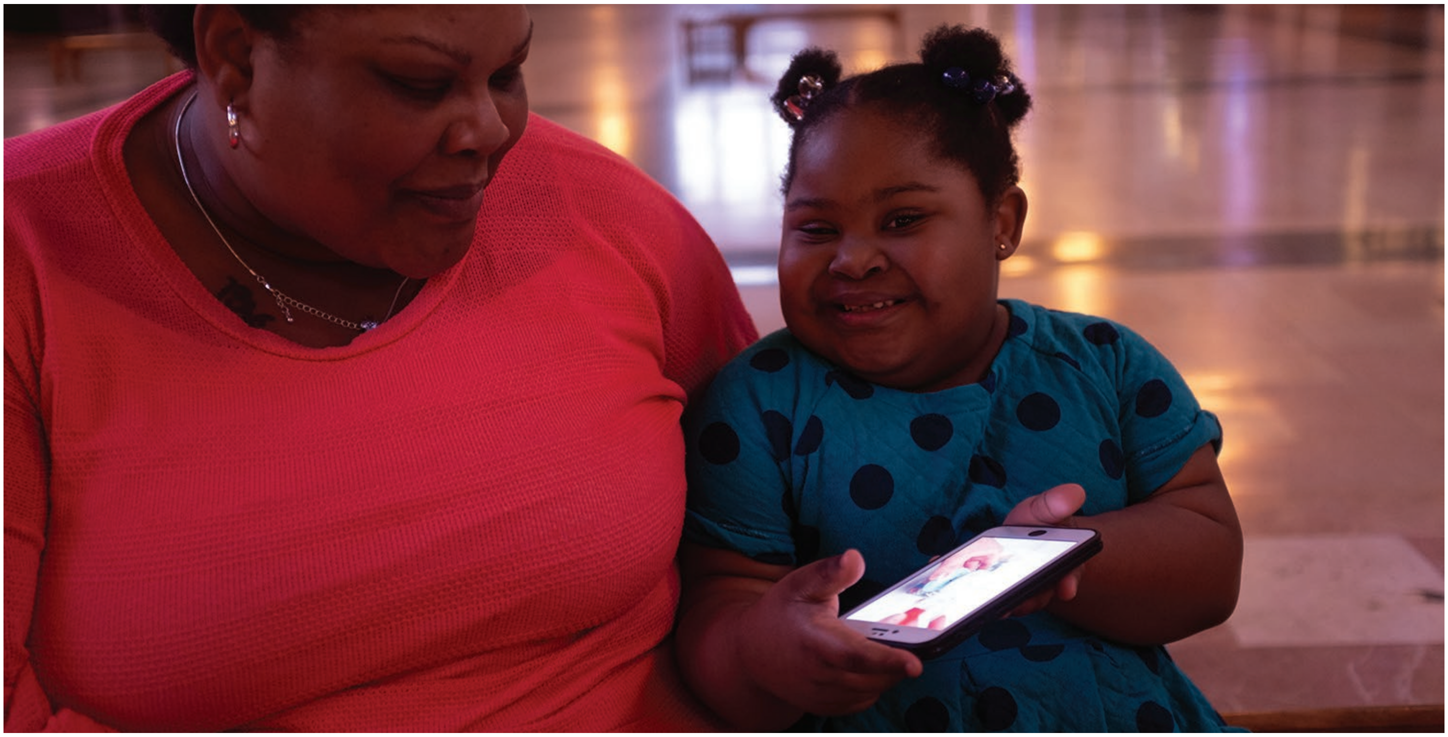
How do different models of healthcare provider training (e.g., cultural competency, disability competency, both, or none); access to different types of providers (such as genetic counselors); and diverse racial and ethnic representation in the healthcare workforce affect parent diagnosis experiences (including the presentation of reproductive decision-making options), parent mental health, and patient-provider trust, as well as quality of life and long-term health and life expectancy outcomes for Black and Hispanic children with Down syndrome?

Theme: Addressing Socioeconomic and Structural Barriers to Equity
How do interventions that connect Black and Hispanic families to services that address social determinants of health for people with Down syndrome (e.g., targeted outreach about financial supports and services and health insurance options, including Medicaid waivers and Supplemental Security Income; automatic referrals to Early Childhood Intervention (ECI); continuity of care; and systemic support navigation) compare to standard systems in improving access to care and developmental outcomes for children with Down syndrome across racial and income groups?

To determine which research questions were most valued by our participants and which ones would motivate them to participate in research projects that they found mutually beneficial, we asked the following question.

Question 3: Which priorities already identified in the Research Priority Report would you be most interested in and why?

1. Participants expressed interest in addressing socioeconomic and structural barriers to assess how interventions might change treatment and outcomes over time for Black and Hispanic people with DS.
2. Participants discussed the importance of addressing racial and disability discrimination and poor treatment by medical staff and the potential impact of training medical providers to be culturally competent on long-term health outcomes for Black and Hispanic people with DS.
3. Participants emphasized the value of expanding the workforce of medical professionals to include Black and Hispanic professionals and the potential impact on long-term health outcomes for Black and Hispanic people with DS and their families as they are treated by those who share the same racial identity.
4. Participants expressed the importance of the diagnosis story and how a diagnosis is communicated, including assessing how assumptions about race might be impacting diagnosis stories, and then determining how interventions such as training clinicians to more sensitively deliver a diagnosis impact long-term health and emotions outcomes.
5. Participants also wanted to assess the impact of early support when a baby is born, such as early intervention, parent mentors, and connection to culturally competent and empathic resources and support organizations, on long-term life and health outcomes and how we continue the flow of information as the baby grows.
6. One group felt the questions were not attainable or realistic at this time, so they felt more work needed to be done to dismantle barriers and to build relationships and infrastructure.



Discussion

The findings underscore persistent disparities in the experiences of Black and Hispanic families navigating the Down syndrome (DS) diagnosis, care, and engagement with research. Parents conveyed deep frustration with discriminatory treatment in clinical settings, citing a lack of racial and cultural representation among healthcare providers and an absence of culturally responsive care. These disparities significantly shaped how families interacted with the healthcare system and influenced their attitudes toward participating in research.

A recurring theme was mistrust, which was rooted in both historical injustices and contemporary experiences of bias. This left many families hesitant to engage with researchers or institutional initiatives. Families expressed concerns about being tokenized or treated as subjects rather than partners, echoing a powerful "Nothing about us without us" sentiment. Despite this, many also conveyed a willingness to participate in research when addressing issues of critical importance identified by them and when approached with authenticity, transparency, and a genuine commitment to equity.

Families outlined clear pathways toward trust and engagement. They called for respectful communication that honors lived experiences, transparency about research goals and potential outcomes, and community centered approaches that meet families where they are. They emphasized the importance of culturally grounded partnerships, where research is not only for the community, but with the community. Tangible benefits and feedback loops made participation meaningful.

Education also emerged as a critical need. Families requested clear, accessible information about what our research entails and how it can directly benefit their children and communities. Many noted that this knowledge gap is not due to community disinterest, but to a lack of outreach and inclusive educational efforts that affirm cultural values and address historical harms.

Representation was another central concern. Families stressed the need for more Black and Hispanic professionals, not only among research participants, but within research teams and the broader medical field. They explained that having researchers and providers who "look like us" and share similar lived experiences fosters trust, empathy, and more effective communication. Participants noted that even recruitment materials should reflect the communities they aim to reach. Material should feature diverse faces, stories, and languages that resonates.

In reflecting on research priorities, families did not unanimously identify a single dominant research question. Instead, their responses affirmed that the multiple proposed priorities were all deeply relevant and interconnected. However, in both the online and in-person community conversations, participants echoed findings from previous studies across the general population of parents of children with DS when emphasizing the importance of interventions to improve diagnosis experiences PCORand the impact of supports and services on improving social determinants of health and long-term health and social outcomes. Yet, they emphasized concerns about exponential discrimination when people with DS and their caregivers are Black or Hispanic.

Importantly, one group voiced skepticism, not about the research questions themselves, but about the readiness of the system to pursue them. Their concern centered on the need to first build the infrastructure and trust necessary for equitable research engagement. While this perspective may not align with all stakeholders, it underscores a vital point, that research cannot be separated from the context in which it occurs. Without addressing systemic barriers and building sustainable pathways for inclusive research, even the most well-intentioned efforts risk not being successful.

Ultimately, what families asked for was not charity or symbolic inclusion but genuine respect, accountability, and a seat at the table. Their insights challenge researchers and institutions to go beyond performative gestures and toward meaningful, community-driven collaboration rooted in mutual benefit and authentic care. By engaging in research in this way, it truly was a collaborative experience that amplified marginalized voices.

Limitations

The session would have benefited from additional time, as well as more thorough preparation for table participants. Training through a brief video or meeting in advance, rather than relying solely on written instructions, would have provided greater clarity. Participants and table hosts indicated that the PCORI Research Fundamentals training video itself felt somewhat dry and that incorporating direct outreach to participants prior to the event could have helped clarify both the session goals and event structure. Table hosts also expressed that assigning seats ahead of time may also be valuable, though this can be difficult in a busy conference setting; therefor, table hosts should be prepared for this responsibility and given clear explanations about distinctions between paid roles and participants receiving lunch. Allowing more time for introductions would strengthen engagement and set the tone for discussion. Finally, there was some confusion at one table regarding whether a Spanish-language video needed to be played or if the translation was already being managed through headsets.

Future Directions

Moving forward, research must deepen engagement with underrepresented communities to remain responsive to their unique needs. Research must focus on building long-term, trusting partnerships with families, advocacy groups, and community organizations to co-develop research questions and study designs. It is also important to create linguistically and culturally appropriate materials that respect diversity within racial and ethnic identities and avoid tokenism. Incorporating flexible, low-burden participation options that align with families' logistical realities and values would be beneficial. It is also crucial to ensure transparency about the research process, confidentiality, and how findings will impact the community. Another emphasis is on providing fair compensation and tangible benefits, acknowledging the time and expertise families contribute. Lastly, focus must be on training providers and researchers in cultural humility and empathy, ensuring respectful and inclusive communication at every step.

Future CER efforts should prioritize the areas identified by community stakeholders, including improved diagnosis experiences and provision of supports and services, better access to care, more culturally responsive healthcare, and stronger support across the lifespan for individuals with DS. Interdisciplinary collaboration bridging medical, educational, and social systems will be crucial to addressing systemic disparities. By centering the voices of historically excluded communities and treating participants with empathy, respect, and partnership, research can improve not only health outcomes for individuals with DS but also foster broader equity in healthcare and research environments.

Evaluation Results

16 participants responded and provided feedback about the event (amounting to 33% of the participants), including 11 parents, one DS group leader, five health professionals, and four researchers. Four participants overlapped identities. Five respondents identified as Black, one as Asian, seven as White/Hispanic, and three as White/Not Hispanic. Two identified as having a disability.

100% of participants agreed or strongly agreed that:

- This community conversation accomplished the goal of identifying better strategies for engaging Black and Hispanic people with Down syndrome and their caregivers in patient-centered comparative effectiveness research.
- The event produced strategies and recommendations that will help to improve research involving Black and Hispanic individuals with DS if implemented.
- I felt my input was valued at the community conversation meeting.
- This conversation was a valuable investment of my time.
- I would invite someone I know to attend another event like this if one is held in the future.

Comments:

- Please continue these conversations.
- The convening was highly valuable, bringing together diverse perspectives and lived experiences from all parties. The discussions were rich and meaningful, though additional time would have allowed for deeper exploration and continuation of these important conversations.
- Excellent experience.

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Appendices

Appendix 1: Viviana and Cameron's Story

When my son Cameron was born in 2001, I had no idea he had Down syndrome. I was under 35, and all the tests available at the time showed no signs of anything unusual. Nothing could have prepared me for what happened next.

I didn't even get to hold him. The moment he was born, a nurse rushed him over to a warmer. He wasn't crying. I was still in the delivery position when, from across the room, the nurse suddenly shouted, "Did you know your son might have Down syndrome?" Her words cut through the air like a knife. I was stunned—completely in shock.

Cameron was rushed to the NICU and placed on oxygen. Hours went by without anyone telling me anything. I finally had to beg for information. A nurse handed me a Polaroid picture of him lying in the NICU, tiny and hooked up to machines. Later, a doctor and a geneticist came to talk to me. They said they suspected Down syndrome based on his physical features but would need to run more tests to confirm it.

I fell into one of the darkest depressions of my life. I remember telling my sister that if I didn't feel better in a few days, I needed her to take me to a hospital. I was drowning.

And then, something changed. One day, while I was changing Cameron's diaper, he locked eyes with me. His gaze was so deep, so pure—it was like he was reaching straight into my heart. In that moment, I finally felt the bond that so many mothers describe when they first hold their baby.

Cameron stayed on oxygen for several weeks. When it was time to leave the hospital, I went home a terrified first-time mom with a car full of oxygen tanks and a stack of pamphlets from a social worker. No psychologist. No explanations about therapies. Just a flood of information and a thousand unanswered questions.

What research is being done about how diagnoses are delivered at birth? Are mothers seen as whole people in those moments—culturally, emotionally, and psychologically? Is there coordinated support that includes mental health professionals, parent mentors, and interpreters when needed?

When Cameron was two, he started private Montessori preschool. He flourished. He was fully included. A speech therapist once told me to only speak English to him so he wouldn't get confused. But my mother spoke to him only in Spanish. Today, Cameron understands Spanish, responds in English, and even uses some Spanish and sign language. Communication was the goal—not the language. I also explored alternative therapies. When he was four and still using single words, I took him to a few hyperbaric oxygen chamber sessions. Within days, he started speaking in full sentences. At a recent national conference, a leading researcher from Global talked about how one of their most recent studies showed that people with DS lack oxygen at times. He said, "but I would not say everyone has to go running to a hyperbaric chamber with their child with DS." I waited until the Q&A session, and I told him I told him our story about the hyperbaric chamber, and he said I should be included in future studies.

Why are bilingual homes still discouraged by some therapists? What is being done to study alternative therapies like hyperbaric oxygen? How do we create better resources to help parents understand the importance about practicing with our child what we learn by observing in therapy sessions, especially those who don't speak English or have access to specialists?

When Cameron was ready for first grade, I wanted him to have an IEP and enrolled him in public school. Without an evaluation, they tried to assign him to a different school and a special education bus. I refused. After a year and a half—and having to hire an advocate, an attorney, and thousands withdrawn from my 401(k) to pay them—the school finally created their first co-taught class. Cameron was fully included until the end of elementary school. It was a Title I school. He was the first student with Down syndrome to graduate from there.

Why aren't children with disabilities being educated in their neighborhood schools? How do language barriers, lack of knowledge of the law, or inability to afford legal help impact education for kids with disabilities, especially in underserved communities? How do zip codes and “titles” impact inclusion?

Middle school was another battle. The school again wanted to assign him elsewhere. I moved to a wealthier county where he was fully included. But in high school, even there, they wanted to place him in self-contained classes. II moved again—this time to a charter school focused on the arts where Cameron thrived.

Why is full inclusion not the default? Why do Hispanic families often not know about postsecondary programs for students with intellectual disabilities? What cultural misconceptions need to be addressed, and how can resources be made more accessible and centralized in multiple languages?

Now, Cameron is about to graduate from an inclusive college program at Georgia State University. He’s had mentors, peer support, and inclusive education. It’s been transformative. Yet earlier access to this model might have made every stage of his schooling more successful.

On the medical side, we are fortunate now to live in a county where he can access a clinic specializing in adult care for people with disabilities. Comprehensive care matters. Otherwise, doctors miss checkups, misinterpret symptoms, or overlook his needs. Mental health is another huge concern—especially as Cameron processes grief or social exclusion. Too often, issues are dismissed as ″just Down syndrome.″

Where are the specialists trained in both intellectual disability and mental health? What happens when parents don’t speak English or can’t advocate effectively? Who ensures that these young adults receive proper care?

Cameron’s journey has been filled with joy and incredible milestones, but each one came after an advocacy fight. My hope is that sharing our story will inspire research that leads to better systems—ones that see the whole child, the whole family, and the future they all deserve.

Within Our Own Community: Inclusion Means Everyone

Over the years, I’ve also seen how even some local Down syndrome associations struggle with inclusion—within our own community. I’ve witnessed firsthand how the existence of culturally specific groups—like Hispanic or Black families coming together for mutual support—is sometimes questioned or even discouraged. I’ve heard debates about whether these subgroups should exist at all. Often, these decisions are made without input from the people most impacted.

I’ve seen associations shut down initiatives that supported culturally diverse families—not because they weren’t working, but because they weren’t prioritized, didn’t align with a white-centered view of inclusion, or simply cost money. Sometimes, it’s about appeasing the discomfort of majority-white members who don’t see the value of supporting something they don’t personally need.

But we need to ask ourselves some hard questions as a community:

- If we’re an organization that advocates for inclusion, why are we making decisions for other cultural groups without including them in the process?
- Why are we trying to shape their needs through a white lens, rather than building a shared set of inclusive values that reflect the richness of all cultures in this country?
- Are we truly practicing the inclusion we preach, or only when it feels safe and familiar?

Inclusion isn’t just about disability—it’s about race, language, religion, class, and culture too. We can’t create an inclusive future for our children if we’re not willing to face uncomfortable truths about how we operate today.