



## Disseminating Patient-Centered Outcomes Research Results about Disabilities to Black and Hispanic New and Expectant Parents

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# Introduction

Research shows significant health disparities exist when comparing Black and Hispanic children with Down Syndrome (DS) to White children with DS and more limited access to services and support.<sup>1-3</sup> One problem is the extent to which families of color learning about a diagnosis receive the latest accessible and research-based information about DS from their medical providers. The moment of diagnosis is the first point on the life course, often described as a flashbulb memory that is remembered with vivid clarity for decades.<sup>4</sup> That moment frames the whole experience and establishes a trajectory for understanding the condition and accessing services and healthcare. Research shows that families of children with DS are able to cope better when they receive information about the condition in that moment; however, new and expectant parents often experience trauma when they receive limited or no additional resources or support systems during that vulnerable time.<sup>4</sup> Parents also experience trauma when the information is exclusively negative, so they also need positive information to be included. Therefore, it is essential that all new and expectant parents of children with DS receive accessible, understandable patient-centered outcomes research (PCOR) to make informed decisions about healthcare and to access supports and services.

# Methods

To develop recommendations for disseminating PCOR findings to new and expectant parents learning about DS, we facilitated online community conversations between 2022-2024 with the following interdisciplinary team of parents, health equity experts, and medical professionals:<sup>5</sup>

- **Parent/Advocacy Leader Team meeting (26 participants):** 10 Black and 10 Hispanic parents of children with DS and 6 local advocacy organization leaders from seven local urban DS organizations with racial affinity groups in Atlanta, GA; Minneapolis, MN; Boston, MA; McAllen, TX; Pasadena, CA; Baltimore, MD; and Chicago, IL. Parents represented a range of socioeconomic backgrounds, diverse types of insurance coverage, and two were exclusively Spanish-speaking while two others were English-Spanish bilingual.
- **Health Equity Team meeting (5 participants):** 5 public health equity experts with a range of professional and lived experience, including Persons of Color and with disabilities.
- **Medical Professional Team meeting (5 participants):** 5 medical professionals who

work as leaders from various disciplines, including pediatrics, genetic counseling, genetics, and obstetrics. Medical professionals have diverse racial and gender identities, and three have lived experience as family members of people with disabilities.

During the 8-hour online Parent/Advocacy Team meeting, participants provided input about their preferences for receiving information about PCOR during small group breakout sessions focused on eight discussion topics. Next, health equity experts developed recommendations based on the feedback from the parents in the context of common social justice issues encountered by people with disabilities and Black and Hispanic families. Finally, the medical team reviewed and discussed the feedback from the other teams to identify how those themes and recommendations could be braided into strategies, platforms, and formats available in their fields to improve the dissemination of the latest health and psychosocial research PCOR/CER to new and expectant Black and Hispanic parents of children with DS.

## Top PCOR Research Questions Valued by Black and Hispanic Families

Because there are many overlaps between the research questions valued by Black and Hispanic participants in the current project and information valued by respondents in previous studies, we have bolded the research questions that are more specific to these populations in the list below. We also cited the studies where there is overlap, and these overlaps suggest that these needs are universal for all parents of children with DS. Another question is whether Black and Hispanic parents might be even more impacted given historic inequities in breastfeeding for Black women and insurance coverage for Hispanic immigrants, for example.

1. *What are the benefits and drawbacks of different prenatal testing/screening options?<sup>6</sup>*

*people with DS (such as heart defects, gastrointestinal defects, etc.)?<sup>6</sup>*

2. *What are the benefits and drawbacks of different treatments for common medical issues experienced by*

3. *What is the impact of prenatal care and insurance coverage options on miscarriage and stillbirth rate?*

4. What are the benefits and drawbacks of different feeding strategies, like breastfeeding, pumping, formula-feeding, and supplementing, and methods to optimize feeding and weight gain in children with DS?<sup>7</sup>

5. What are the impacts of different social determinants of health (such as health insurance options, marital status, financial support) on short and long-term outcomes for people with DS?<sup>8</sup>

6. What is the impact of early connection to parent support and advocacy groups on all members of the family (including mother, father, siblings) and long-term impact of racially and ethnically concordant sub-groups within local DS organization?<sup>9</sup>

7. What are the outcomes and potential benefits of peer mentors and DS (such as medical checklists) and available supports at the moment of diagnosis with a specific focus on racial and ethnic concordancy?<sup>3</sup>

8. What are the best treatment options for psychological support and counseling for parents following a DS diagnosis?<sup>9</sup>

9. What are the impacts of different early intervention strategies on meeting developmental milestones and long-term outcomes?<sup>6</sup>

10. What are the benefits and drawbacks of raising a child with DS to be bilingual, including sign language?<sup>8</sup>

## Recommendations for Advocacy Organizations

A core theme from the meeting was to make Black and Hispanic families a priority by intentionally seeking them, recognizing them, talking to them about their specific needs and priorities, determining how organizations and programs might need to be modified to be inclusive, and providing space for fellowship and leadership. All groups expressed the importance of local and national advocacy groups offering training and outreach to medical professionals, the community, and parents. Further, the Black parents talked about the importance of making this training consistent across all Down Syndrome organizations. Additionally, health equity experts emphasized that these efforts require funding and resources for cash-strapped advocacy organizations; therefore, funding and grantmaking agencies need to be aware of these needs.

**1. Engage in medical outreach and training.** Both Black and Hispanic parents emphasized the importance of advocacy organizations forging strong partnerships with universities and medical centers so that parents of children with DS are the teachers and giving medical centers training on how to deliver a diagnosis and how to engage with patients with Down syndrome. They specifically mentioned the value of outreach to specialized medical offices like mental health therapy centers and OB/GYNs, as well as hospital social workers who can inform OBs about patient education/advocacy.

### Implementation Strategies:

- Provide training for all disciplines as much as possible, including obstetric and genetic professionals, technicians, nurses, and hospital social workers. This training can be done online and in person, and you can access resources, including a slide deck for presentations here:
- <https://www.lettercase.org/education/advocacy-organizations/>
- Create a partnership model between organizations and medical centers/universities. The medical team indicated that newer generations of trainees have significant interest in health equity and the potential application of those principles for the disability community, as well as community-engaged research and implementation.
- Another idea was to partner with medical schools to pair medical students with parent mentors of children with a medical condition, where the medical students visit the families at home and help them organize medical information. The medical team stressed the value of including family participants from different races and ethnicities to share their experiences with providers. To do this, the medical experts recommended creating a master list of medical/nursing/genetic counseling schools where they can establish parent partnership programs.

- They also recommended that advocacy organizations share information with medical professionals through their social media platforms and medical outreach pages on their websites. The team mentioned the value of offering physicians incentives to engage with social media.
- The medical team also expressed the value of advocacy organizations hosting interprofessional communication between the different professionals who might serve new and expectant parents ranging from mental health professionals to developmental pediatricians to genetic counselors and obstetric care providers.
- The medical team further discussed the value of facilitating partnerships outside the clinical setting such as invitations to events and project/research collaborations.
- Moreover, the medical team shared the value of advocacy organizations establishing relationships with people, such as genetic counselors and social workers, who can build bridges between physicians and advocacy groups to provide the information and research parents are seeking.

**2. Engage in community outreach and training.** Both sets of parents shared that advocacy organizations need to engage in more community outreach to extend to broader and more diverse populations. They expressed that this type of outreach would train more people to give correct information about research findings.

*Implementation Ideas:*

- Participate in community outreach activities such as cultural events and festivals like Juneteenth celebrations and Down syndrome awareness presentations in classrooms. Both groups mentioned the value of church outreach, and Hispanic parents specifically recommended community outreach to schools and the La Leche to provide more information specific to babies with Down syndrome.
- Other community outreach ideas presented by the health equity team were to reach out to women's groups with pastor connections; distribute information at churches and schools; and hold events, including health fair events and conferences in locations that are accessible to communities of color. The medical professionals reiterated the value of community outreach at events, festivals,

recreation centers, health fairs, and community centers. These strategies would be helpful for education purposes and to establish community connections.

- Create a slide deck to be used for community presentations.
- Engage in outreach to health departments and early intervention programs with guidance on the standard of care communication about a new diagnosis. Be sure to account for variations between states and newborn screening.

**3. Offer parent outreach and training.** Both groups shared the value of parent education so that families are empowered with information and can advocate for themselves.

*Implementation Strategies:*

- DS organization could offer education classes, zoom calls, and webinars for new and expectant parents to share vital information about research and resources.
- Health equity experts emphasized the value of organizations sharing research findings and information via social media platforms like TikTok (highly valued by younger parents), WhatsApp (highly valued by Hispanic parents), moderated Facebook groups, and Instagram.

**4. Offer new and expectant parent support.** Both groups also discussed the importance of parent support through parent mentors, and Black parents particularly emphasized the value of parent mentors who share the same racial identity.

*Implementation Strategies:*

- Consider providing a hotline with parent mentor volunteers that reflects the different identities and has information about the research findings most important to Black and Hispanic new and expectant parents, particularly regarding social determinants of health regarding financial supports, psychological support, and health insurance options and associated health outcomes.
- Offer support from another mom with a child a few years older to connect with, someone to sit down with and learn from, a "sister model" to hold their hand along the way (a peer mentor), or a family to provide a glimpse into the future and show what is possible. They indicated that immediate connection

at the time of diagnosis was vital before being ready to absorb information, and they said that the connection was critical in empowering them to advocate for themselves and their child.

- Be understanding about some of the historical discrimination faced by Persons of Color including the discrimination Black women have faced with breastfeeding; higher infant and maternal mortality rates in the Black population; and language barriers faced by Hispanic immigrants and immigrants from other locations.
- Follow the model offered by the National Parents First Call Center.

**5. Provide family members with education and support.** Parents indicated that the whole family needed support and education, including dads and siblings. Sometimes men's emotional needs are overlooked, and they also need to be a priority.

*Implementation Strategies:*

- Offer support specifically for siblings and dads. Black dads often value support from other Black dads. Parents also recommended matching according to sibling ages
- Offer information about National Dads and sibling groups.

**6. Disseminate resources and research about Down syndrome.** Advocacy organizations can be a vital source of resources that contain PCOR findings important to new and expectant parents such as treatments for health issues, impacts of social determinants of health (transportation, marital status, financial status, and housing), and impacts of intervention (therapies and early intervention strategies). Parents emphasized that this is one of the most important roles advocacy organizations can play. They also advised pointing out to clinicians why resources and research are important in terms of social determinants of health.

*Implementation Strategies:*

- Disseminate accurate, balanced, and up-to-date resources about Down Syndrome and other prenatally diagnosed conditions when discussing prenatal screening results. The materials should cover research outcomes about treatments for medical issues and the impact of support and services on life outcomes.

- Make sure resources reflect diverse racial identities, include multiple translations, and use accessible plain language.

**7. Utilize Technology.** Parents emphasized the value of advocacy organizations sharing information about research findings with families and an area on the organization's website for research topics/studies.

*Implementation Strategies:*

- Utilize social media platforms like Facebook, TikTok, X/Twitter, YouTube, Instagram, and private FB/WhatsApp groups.
- Make sure the social media messages are in English, Spanish, and other regional languages and dialects.

**8. Prioritize representation in resources and support.** Both groups discussed the value of representation in making sure that resources feature People of Color and representation in the organization membership, including the representation of fathers and the whole family. Black parents conveyed the importance of representation in advocacy groups to intentionally encourage more Black families to get involved and get support, and they encouraged advocacy organizations not to give up if participation is low at first.

*Implementation Strategies:*

- For local groups
  - Offer both inclusive and racial affinity support groups.
  - Share research findings in discussions about guided topics during events like food events, holiday events, and Zoom meetings.
  - Provide online resources like 21 Shades and Black Down Syndrome Association.
  - Recruit, train, and hire racially and ethnically diverse employees.
- For national groups
  - Include talks about the Black community of people with DS.
  - Include reports on research for families of color.
  - Be involved with research initiatives and include race as part of data collection.
  - Brochures and postcards should include photos of People of Color to depict their inclusion in the Down Syndrome community.
  - Host national quarterly calls with racially

concordant groups.

- Utilize patient education resources that feature racial and ethnic diversity.
- Recruit, train, and hire racially and ethnically diverse employees.

## 9. Prioritize inclusive language.

*Implementation Strategies:*

- Hispanic parents discussed the importance of having resources and support available in multiple languages, including Spanish.
- Black parents further recommended a task force to help advocacy leaders navigate the most sensitive and correct terminology for advocacy organizations to use when discussing race and disability. They said there was a need to recognize differences in preferences for terminology and needs between different geographic regions and cultures.

**10. Advocate for equity.** Participants commented on the importance of determining whether Black and

Hispanic parents of children with DS are more likely to experience issues with social determinants of health than White parents of children with DS. For example, participants indicated that published data demonstrate that Hispanic and Black patients are about 3 times less likely to be offered genetic counseling or screening, and data show profound disparities in prenatal care and maternal and infant mortality. Consequently, more research needs to be done to address existing disparities for all parents of children with disabilities and how those disparities may disproportionately impact Black and Hispanic parents.

*Implementation Strategies:*

- Advocate for better genetic counselor access, better health insurance coverage, better access to healthcare and prenatal screening options, improved access to social determinants of health (like housing and financial support), and more research on health disparities experienced by people with disabilities from different racial identities.

# Conclusion

This project has several implications for practice that fit into the existing body of knowledge and contribute substantially to the areas of information delivery and training, cultural concerns in communication, lack of representation, effective use of social media, community outreach, viewing the whole picture, and positive life outcomes. These findings present a more nuanced approach and understanding when discussing the populations of new and expectant Black and Hispanic mothers of children with DS.

*Professional and Parent Note:*

*The first researcher conducted this project as a program director, researcher, educator, and White mother of a person with Down Syndrome. Her identity as a parent gave her particular access and understanding of the family experience after learning about a diagnosis. The second researcher is a multiracial man who serves as Director of DEI and has a traumatic brain injury. Neither of these researchers having a positionality that aligned with participants caused them to worry about leading this work viewing the experiences of Black and Hispanic mothers of children with DS. We were so grateful that as we started the conversations with the 20 parents who participated in this project, they were generous in sharing their thoughts and insights about what types of research were important to them and how to improve the systems. In fact, when we asked the first question about their research priorities, they were so eager to talk about their thoughts on the diagnosis experience that we had to repeat the question to gather all their important insights. At the risk of being vulnerable and emotional, their willingness to share felt sacred and they correspondingly expressed that they appreciated the opportunity to offer those insights. We were also grateful to our health equity and medical professional teams for sharing their unique insights and for being wonderful professionals who are committed to helping families.*

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