

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

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Acknowledgement

This White Paper was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EADI-24186). The views, statements, and opinions presented in this White Paper 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.

Many thanks to the parents and professionals who contributed their time and expertise for this project, and thanks to our project assistants for helping with the white papers and learning modules, Cameron Elder (currently pursuing a Doctorate in Physical Therapy) and Hannah Keene, MS (currently pursuing a Doctorate in Early Childhood, Special Education, and Counselor Education).

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.¹⁻³ 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.⁴ 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.⁴ 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:⁵

- 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?*⁶
2. *What are the benefits and drawbacks of different treatments for common medical issues experienced by people with DS (such as heart defects, gastrointestinal defects, etc.)?*⁶
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?***⁷
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.*⁸
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?***^{1,9}
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?*³
8. *What are the best treatment options for psychological support and counseling for parents following a DS diagnosis?*⁹

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

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

Recommendations for Medical Professionals

The ability to share research findings with any parent of a child with DS—particularly parents from diverse racial backgrounds who have faced additional discrimination—is to develop relationships of trust from the moment of diagnosis. This is particularly vital given these populations' increased health and social needs. Consequently, the recommendations are essential for establishing those relationships of trust and providing research-based information on the spectrum of social and health outcomes from the first point on the life course. The tone set in that first conversation often impacts whether parents are willing to listen to providers in the future on other essential topics related to their child's health.

1. **Provide clinical training on how to sensitively deliver a diagnosis and avoid racial/disability bias.** Both Black and Hispanic parents emphasized that medical providers, geneticists, hospital social workers, nurses, and ultrasound technicians need training on how to discuss DS sensitively (not saying “I’m sorry” and not pressuring pregnancy decisions), what information and PCOR results to share, and other resources that can be helpful. The medical team emphasized that the first visit after a diagnosis needs to include discussions about goal and value setting to guide patient conversations. Additionally, clinicians need ongoing education on racial and disability bias—especially on ableism, identity vs. disease, and the social vs. medical models of disability—and current research-based outcomes for conditions given the significant change for people with DS over the past 40 years.

Medical professionals and health equity experts recommended that the training be available for students in residency programs as well as practicing providers through continuing education. They further recommended that the trainings be created with input from the disability community and include case study vignettes with video modeling; sample scripts for navigating difficult conversations and providing PCOR findings; testimonial videos featuring provider and patient perspectives, and communication tools to help providers sensitively provide the PCOR findings most important to patients. Moreover, the clinicians emphasized that each situation is unique with different perspectives about abortion, different time constraints with reproductive decision-making, where applicable, and different health concerns.

Participants indicated that social workers could be an important source of support in maternal fetal medicine practices where they can offer emotional support, connect families to emotional and financial support systems, and provide resources in multiple languages.

Implementation strategies:

- Provide tools and training about how to educate and inform families at the base level in residency training and offer mandatory ongoing education through professional certification and workshops on how to sensitively deliver the news and discuss research-based outcomes at events like national American Academy of Pediatrics (AAP) and American College of Obstetricians and Gynecologists (ACOG) meetings for practicing clinicians. Clinicians indicated that anti-ableist training should be a required part of curricula, certification, professional recertification and licensure, including implicit bias training at the state level to

avoid discrimination against people with disabilities. Certification organizations like the American Board of Genetic Counseling can be important allies. Moreover, organizations need to collect evidence and data to assess the impact of the training.

- Medical schools, nursing programs, and genetic counseling programs could partner with advocacy organizations to share the patient/disability perspective.
- Offer online training provided for clinicians with certification incentives like CEUs/CMEs for continuing education. This online training could be available to provide a consistent foundation of knowledge where organizations/medical systems can follow up with face-to-face training and address remaining questions. **This training should be a required part of professional maintenance in certification modules.**
- Include disabilities as part of existing diversity, equity, and inclusion training initiatives in medical systems and professional curricula—and address the specific informational needs of people with disabilities and other intersectional identities. The inclusion of disability in DEI training should be universal across different disciplines and different hospital requirements.
- Provide clinicians with guidance from genetic counselors and national medical and genetics organizations, who are trained and informed by the disability community, to develop research-based care plans in the diagnosis of DS.
- Professional organizations should disseminate resources and tools for delivering a diagnosis. These materials should be broadly available and created in partnership with advocacy organizations.

2. **Communicate with sensitivity, discuss prenatal testing and reproductive options, and provide balanced information about DS.** Both Black and Hispanic parents expressed the importance of dialogue and cultural humility when communicating with families. For example, they recommended starting the conversation with, “tell me what you understand about DS” and “how do you want information to be given to you?” The health equity team emphasized that this recommendation should be standard ethical practice as a manifestation of patient autonomy in healthcare. Specifically, they indicated that clinicians should avoid saying “I’m sorry” or assuming the diagnosis is bad news. They emphasized reframing in that screening results should be delivered in a value neutral way as unexpected news—not good or bad. Parent recommendations to improve communication included:

- Deliver PCOR findings about health issues in basic terminology using visuals.
- Share research-based factual information—without bias or judgment—and ensure that all information provided to families is the most recent and relevant. Avoid bias in language and bedside manner/body language.
- Show compassion and empathy when delivering the diagnosis. Be aware of the impact of language in establishing trust between patient and provider.
- Hispanic parents recommended starting conversations with person-centered positive news and information, and Black parents shared the value of discussing realistic and research-based long and short-term outcomes for people with DS, including research about the possibilities beyond the textbook medical information, and data specific to each racial demographic.
- Black parents also discussed the importance of sharing PCOR about all available prenatal testing options and sensitively discussing reproductive options with no pressure about what decision to make. They specifically said not to mention abortion until supplying

accurate and balanced information about the condition. Health equity experts said adoption should also be mentioned as an option if patients do not want to parent the child.

Implementation Strategies:

- Provide clinical training as described above.
 - Clinicians need a centralized set of guidelines developed by their national organizations in collaboration with advocacy groups for how to discuss disabilities and what PCOR findings to provide.
 - Genetic counselors may serve a valuable role in helping people make informed decisions about prenatal testing and reproductive options.
 - Develop and utilize videos to help patients understand prenatal testing and conditions and decision trees to help parents make decisions like whether to have diagnostic testing after positive NIPT.
3. **Make referrals, coordinate care, and offer different clinic models to address the informational and support needs of new and expectant parents.** Both parent groups emphasized the importance of referrals to trained specialists, occupational therapists, physical therapists, audiologists, genetic counselors and geneticists, lactation specialists, social workers, psychologists, and developmental pediatricians who are familiar with the information needs of parents regarding research on social determinants of health and early intervention options. Specifically, they discussed the importance of psychologists and social workers to provide support for coping with stress.

Participants discussed the value of different clinic models such as DSC2U and telehealth, DS clinics in-person across the county, wholistic practitioners, and a multi-specialty group including social workers, genetic counselors, and medical providers to address concerns expressed. DSC2U is an online tool that provides customized information for people with Down syndrome from age 1 through adulthood/senior years based on the latest research and recommendations. These options allow clinicians to deliver the diagnosis and start the conversation and then other professionals can provide follow up support and information. Moreover, the health equity team noted the systemic problem of overbooked clinicians with little time per patient and the challenge of accessing genetic counseling services given that insurance does not universally cover that service, including Medicaid, and some areas might not have genetic counselors. While some parents might have better physical proximity to genetic counseling services in urban areas, health insurance coverage can still pose a significant challenge, particularly when genetic counselors have the most training to provide information about psychosocial outcomes and support based on PCOR findings. The provision of care can also be more difficult in rural communities.

Implementation strategies:

- Clinics/hospitals can develop and utilize a list of available specialists who can provide the full spectrum of support for patients learning about a diagnosis of DS.
- Contact referrals in clinic while the patient is present to avoid delay.
- Facilitate collaboration and coordination between specialists.
- Select clinic models that employ interdisciplinary strategies and have “care plans” in place for a team to address concerns and connect parents with the needed specialists/information. Multidisciplinary clinics with a social worker, OT, and PT are particularly helpful.

- Utilize telehealth in rural areas where access to specialists might be limited.
4. **Provide patient resources/education at the moment of diagnosis.** Both groups said parental education and information resources were essential. They want some information immediately after diagnosis and in follow-up meetings with layers of support. They said some families want research findings right away while others might need more minimal information at first before they receive more details, so they said to ask families what type of information they want and when. Black parents also emphasized that they want health information specific to their child such as heart defects and research findings on the best treatment for applicable conditions. Further, Hispanic parents said resources should be available in multiple formats, including print and web resources, as well as contact information for local support groups (phone numbers, addresses, and websites).

Implementation Strategies:

- Providers need access to up-to-date, balanced, and accurate resources with PCOR findings to be provided at diagnosis and in follow-up conversations.
 - All national and local resources should include diverse racial representation, multiple translations, and accessible health literacy levels in all languages. Support systems should also be available for families who cannot read or write.
 - Credible and valuable resources with PCOR findings could be made available in clinics for low cost through patient portals with resource recommendations or QR codes leading to websites with resources.
 - The health equity team also recommended a toolkit for medical professionals to provide information to clinicians and resources embedded in training/guidelines.
 - One solution could be using technology to create an online module with a patient-centered algorithm to provide diverse videos featuring families, physicians, and genetic counselors sharing research findings. The technology could provide a “go to” source that is online, patient-driven, and asynchronous for learning the information they need as determined by questions about how they learn and what information they want. This could be funded from investments by key stakeholders like clinical diagnostic laboratory.
5. **Make connections to local and national parent support organizations.** Both groups said they wanted their physicians to initiate contact with local and national advocacy organizations as well as peer supports. Medical/advocacy partnerships can help new and expectant parents access the information, support, and research findings that interest them, as well as provide follow-up support and information as needed. These organizations can also help address the needs of the whole family. However, clinicians indicated that families leaning in the direction of termination might be reluctant to interface with an advocacy group, so they also need other options for parent support or anonymity. Hospital and clinic social workers can be another valuable resource.

Implementation strategies:

- Clinicians should be aware of local Down Syndrome support groups and community leaders to share with expectant parents the value and benefits of parent advocacy groups. Persons of Color specifically indicated that racial affinity groups were a priority in receiving support. These organizations can provide welcome baskets and make connections with other parents/mentors who can speak multiple languages. Some local organizations even have consent forms that patients can sign for clinicians to connect their patients with local support groups.

- Timing matters. Provide families with information about support groups right away.
 - Clinicians should also be aware of national organizations supporting parents at the intersection of race and disability like the Black Down Syndrome Association.
 - Clinicians should also be aware of local social workers and the National Parents First Call Center which can provide anonymous support for families considering termination by parent volunteers trained by a genetic counselor.
6. **Make racial and ethnic representation a priority.** Both groups discussed the value of representation in making sure that resources feature People of Color and representation in the medical workforce to establish relationships of trust and recognition. Interpreters should also be readily available in the medical setting.

Implementation strategies:

- Utilize patient education resources that feature racial and ethnic diversity.
 - Recruit, train, and hire racially and ethnically diverse health workers.
7. **Follow up with patients after the diagnosis.** Both groups also expressed that clinicians need to follow up with families after the diagnosis and before leaving the hospital or the next appointment about any research-based information they might need, and clinicians also need to follow up in the days/weeks following discharge from the medical facility.

Implementation Strategies:

- Quickly set up a follow-up visit. Clinicians can also call right away from the office to set up referral appointments.
 - Utilize different technologies to reach families including social media, an office communication manager, and technology access training for patients.
 - Use technology tools used for professional communication—patient portal—but be aware of access issues.
 - Check in and supplement as needed, and do not assume another clinician has followed up with the patient.
 - Strategies for follow up could include connecting patients to a care coordinator, resource RN, social worker, and/or genetic counselor.
8. **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 significantly less likely to be offered genetic counseling or screening, and data show profound disparities in prenatal care and maternal and infant mortality.¹⁰⁻¹² 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.
- Advocate for a federally funded call center to provide support in multiple languages.

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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