Research Priority Report

Stephanie Meredith, MA University of Kentucky Human Development Institute
Nicholas L. Wright, PhD University of Kentucky Human Development Institute
Terria Brown

Acknowledgements

This Research Priority Report was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASCS-38503-IC). 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 assistant for helping with the white papers and learning modules, Sonia Chavez (currently pursuing a Masters in Social Work).

Introduction

Research shows significant health disparities between Black and Hispanic children with Down syndrome (DS) when compared to White children with DS.[1] Indeed, recent research funded by PCORI found that nearly one-third of Latino/a caregivers perceive that Latino/a patients with DS receive lower quality medical care due to their ethnicity, particularly if they do not speak English [2]. Correspondingly, over half of Black caregivers felt that patients with DS receive lower quality medical care due to race or ability to speak English [3]. Moreover, nearly one-third of Hispanic caregivers and over half of Black caregivers reported feeling frustrated with finding health information about DS.[2,3]

Black and Hispanic caregivers encounter additional barriers to addressing social determinants of health (SDOH) such as finances, transportation, technology access, and social supports, which subsequently impact long-term health outcomes for their children [2,3]. The research found that 59% of Hispanic caregivers and 53% of Black caregivers of children with DS reported that they worried about taking time off work for medical appointments, and 46% of Hispanic caregivers worried about out-of-pocket expenses.[2,3] In addition, racially diverse parents of children with DS are often referred to advocacy organizations later than White parents,[4] and Hispanic parents further report that their stress is "exacerbated by social isolation."[2] Montoya-Williams et al. explain that health disparities cannot be reduced and health equity cannot be achieved unless we address social determinants of health, particularly given the inequities and structural racism faced by individuals and caregivers with multiple marginalized identities.[5]

These disparities were validated by the participants in our recent PCORI project, which focused on dissemination strategies for Black and Hispanic new and expectant parents of children with DS, who wanted more research into the potential impacts of social supports and services that would be most beneficial for their children's health.[6] Specifically, they discussed wanting information to be disseminated about 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; the outcomes and potential benefits of peer mentors with DS (such as medical checklists) and available supports at the moment of diagnosis with a specific focus on racial and ethnic concordance; the impact of different early intervention strategies on meeting developmental milestones and long-term outcomes; the benefits and drawbacks of raising a child with DS to be bilingual; the impact of prenatal care and insurance coverage options on miscarriage and stillbirth rates; and the impact of early connection to parent support and advocacy groups on all members of the family (including mother, father, siblings).[6]

Research by Kennedy & Wood confirms that people with disabilities generally experience significant disparities in terms of economic stability, education, neighborhood and built environment, social and community context, transportation, and healthcare.[7] Moreover, the data indicate that these disparities are further exacerbated when individuals have additional minority identities.[7] When these disparities in social determinants of health are addressed through targeted intervention, the recent ASPE report on "Addressing Social Determinants of Health: Examples of Successful Evidence-Based Strategies and Current Federal Efforts" indicates that interventions in the provision of financial support, such as cash payments to people with disabilities, have been shown through multiple randomized trials to be associated with positive health outcomes.

Research about how to address social determinants of health is particularly critical for new and expectant parents because the information provided at the first point on the life-course establishes a trajectory for understanding the condition and accessing services and supports which are essential to addressing health disparities for people with disabilities.[7] A life course framework recognizes that health trajectories are particularly affected at certain times in life where psychosocial stress is heightened, such as the moment of diagnosis.[5,8] Therefore, it is essential that all new and expectant parents of children with DS receive accessible, understandable patient-centered outcomes research (PCOR) to address social determinants of health as soon as possible.

Indeed, comparative effectiveness research has demonstrated the value of addressing social determinants health at the first point on the life course to improve long term health outcomes. For example, in the area of nutrition, breastfeeding has long been known to reduce morbidity in infants when compared to formula feeding, but this CER has yet to specifically compare the impact of these interventions for people with Down syndrome, particularly among Black and Hispanic populations who experience higher rates of infant and maternal morbidity.[9] In addition, in the area of education, early intervention has been shown to improve cognitive, language, motor, and social emotional development when compared to children who receive less or no early intervention.[10] Research has further uncovered significant racial disparities in access to early intervention,[11] but CER has yet to specifically assess how the introduction of early intervention can impact health and life outcomes for these intersectional populations.

The parents in our 2022 PCORI project wanted these existing research data to better include racially and ethnically diverse people with DS and to provide more details about the impact of interventions specifically among historically marginalized subpopulations. Unfortunately, we found that the research data points they cared most about simply do not exist in existing CER, and we do not know which of the different concerns they discussed are most important to prioritize when moving forward with patient-centered comparative (CER) or how to best engage with communities to address those priorities given the lack of representation of those populations in past research.

Consequently, the purpose of this project is to convene stakeholders to determine what patient-centered comparative (CER) would be most highly prioritized by Black and Hispanic new and expectant parents of children with DS in accessing the supports and services that lead to the best outcomes. We would subsequently develop a Research Brief with a strategic plan for future patient-centered CER and patient engagement.

Methods

Aim 1: Identify research gaps of greatest interest to Black and Hispanic new and expectant parents of children with DS, including SDOH, by offering training about patient-centered comparative (CER) and gathering input from patient advocates.

Members of the Patient Advocacy Team received PCORI Research Fundamentals Training: Engaging in Stakeholder-Driven Research and Module 1: Developing Research Questions "as is" and utilize the Community Conversation model, which includes participants as decision-makers and implementers in research studies—a qualitative research method often referred to as a participatory action research (PAR).[17,18] Between each round of discussion, attendees switched sessions and continued the online conversation with the same combination of participants. Consistent with the PAR method, "the event culminates with a whole-group discussion in which attendees share the most promising and actionable strategies they heard throughout the conversation. During each round of conversation, detailed notes were taken to document every idea generated." [19(p362)]

Activities

During the first virtual meeting of the Patient Advocacy Team, we hosted a 1.5-hour training about what constitutes patient-centered comparative (CER) and how to identify gaps in research using the PCORI Research Fundamentals Training: Engaging in Stakeholder-Driven Research and Module 1: Developing Research Questions "as is".

The second virtual meeting lasted 2.5 hours and included community conversations to identify the CER topics that are of greatest importance for Black and Hispanic parents receiving a DS diagnosis. The Patient Advocacy Team participated in three distinct 30-minute rounds of small-group community conversations in Zoom breakout sessions. Each round addressed a single question that prompted attendees to identify the top three research priorities of Black and Hispanic parents of children with DS. Each group consisted of approximately 6 people amounting to four total groups with a session host for each group. This priority report represents the themes generated by project staff after synthesizing the notes and summarizing themes generated from the community conversation for common themes regarding research priorities. Group conversation leaders included Dr. Wright (Principal Investigator), Dr. Meredith (Co-Investigator), Terria Brown (Project Coordinator), and Sonia Chavez (Project Intern).

Project Participants/Consultants

We recruited the following participants to participate in the project:

- Patient Advocacy Team for the virtual meeting conducted over the University of Kentucky Zoom account (24 participants):
- 11 Black and 12 Hispanic female parents of children with DS. The parents had children with DS across a spectrum of ages, and they were recruited from the team formed during our recent PCORI project and via recommendations from the advocacy organization leaders (the local DS orgs who participated in our recent PCORI project, the Black Down Syndrome Association, and the National Down Syndrome Congress) based on individuals who are active in sub-groups or initiatives specifically dedicated to serving racially diverse members.
- 1 representative from the BDSA, 1 Hispanic representative from NDSC, and 1 Hispanic representative in a leadership position at a local DS organization who are also parents with lived experience.

Composition of Group Participants

Identifier	Race	Ethnicity	Preferred Language	State	Organization
Parent 1	Black	Not Hispanic	English	TX	Black Down Syndrome Association
Parent 2	Black	Not Hispanic	English	AZ	Down Syndrome Diagnosis Network
Parent 3	White	Hispanic	Spanish/English	TX	National Down Syndrome Congress
Parent 4	Black	Not Hispanic	English	MA	Project Staff
Parent 5	Black	Not Hispanic	English	GA	
Parent 6	Black	Not Hispanic	English	MN	
Parent 7	Black	Not Hispanic	English	MA	
Parent 8	Black	Not Hispanic	English	IL	
Parent 9	Black	Not Hispanic	English	MN	
Parent 10	Black	Not Hispanic	English	TX	
Parent 11	Black	Not Hispanic	English	TX	
Parent 12	Black	Not Hispanic	English	MA	
Parent 13	White	Hispanic	English	IL	
Parent 14	White	Hispanic	English	TX	
Parent 15	White	Hispanic	English	CA	
Parent 16	White	Hispanic	Spanish	CA	
Parent 17	White	Hispanic	English	CA	
Parent 18	White	Hispanic	English	GA	
Parent 19	White	Hispanic	Spanish	GA	
Parent 20	White	Hispanic	Spanish	GA	
Parent 21	White	Hispanic	Spanish	CA	
Parent 22	White	Hispanic	English	DE	
Parent 23	White	Hispanic	Spanish	TX	

Findings

PCORI Community Conversation
Notes from Thursday, April 17th, 2025
Descriptive & Thematic Coding

Discussion 1: What issues do you think are most critical to Black and Hispanic new and expectant mothers?

Group 1
- Need culturally competent practitioner/providers
- Need for mentors to provide perspective
- Financial medical support for those in the middle class/early childhood intervention
- Delivery of down syndrome diagnosis

Group 2
- Challenges for services across the lifespan
- How diagnosis is delivered
- Navigating healthcare
- Limitations doctors put on children
- Early speech therapy
- Doctors language when navigating resources saying “waste of resources.”
- Medical providers not always educated holistically on other challenges.
- Navigating insurance
- Finding alternative solutions than major surgeries.
- Doctors push traditional way of care
- Medical providers dismissing parents and children without referrals.
- Parents feel dismissed
- Doctors not being flexible
- Speech
- Doctors do not share the whole answer

Group 3
- Not being taken seriously with concerns of delivery as mothers of other race would be
- Instantly being offered to terminate when Down syndrome is confirmed on ultra sound.
- Not enough information or resources given prior or during delivery
- Representation of people of color in media
- Being scheduled to terminate the pregnancy without being contacted
- Being judged by medical staff as single parent
- How the diagnosis is given
- Push for a termination of pregnancy

Group 4
- Being connected with a social worker to help understand medical terms
- More information about resources
- Receive resource/information at the time of diagnosis
- Reasoning behind treatments and why they are important
- Speech
- Language barrier
- Dialects from different Spanish speaking countries.
- Professionals should understand cultural differences
- Nutritional guidance at an early age

Discussion 2: Based on the issues identified, what research topics do you think are most critical for Black and Hispanic new and expectant parents of children with Down syndrome?

Group 1

- Doctors being empathetic
- Doctors understanding backgrounds of Black and Hispanic patients
- Advocating for oneself
- Hiring more culturally competent professionals

Group 2

- Having available resources all in one place for both medical providers and for parents
- Equipping parents with DS checklist
- Lack of resources for younger adults with DS
- Disconnected information

Group 3

- Medical providers need more training delivering diagnosis and resources to People of Color
- Life expectancy of children of color compared to others
- Why do medical providers push termination of pregnancy so much for children of color?
- What is the comparison between how often parents of color are pushed for termination compared to others.
- News being delivered with lack of compassion and care
- Educate medical providers on empathetic communication
- What closed the gap in life expectancy disparities
- Additional advocacy organizations
- Training and presentations
- Barriers to research for NIPOC families are hesitant to participate because of Henrietta Lacks
- Delivering cancer diagnosis is empathetic, what training can they share?
- Change the focus that Down syndrome is not negative.
- How to build relationships with advocacy organizations?
- Down syndrome clinics need to step up and step in with resources
- Bring more culturally competent professionals that understand health holistically
- Lack of representation
- Made own community and support system in DS group

Group 4

- Actually get to know the patients.
- Follow up on the patients at different states of their life
- Doctors knowing and offering a wide range of resources to offer parents
- Difficulties with bilingual specialist
- Explanation of early interventions
- Representation of children with Down syndrome at different stages of life in different areas of life
- Offer appropriate cultural resources
- Cultural competence
- Discrimination when seeking resources
- Language barriers

Discussion #3: How would you write these topics of concern as patient-centered CER questions?

Group 1 (Black parents)

- If we had competent providers/practitioners, would it impact the life expectancy of Black and Brown people? [1]
- If parents are enrolled in early childhood intervention before leaving the hospital, would that have an impact on development and life expectancy of Black and Brown people with Down syndrome? [7]
- How does offering automatic enrollment or opt-in pathways into Early Childhood Intervention (ECI) services for families receiving a pre-birth or birth diagnosis lead to improved developmental outcomes and longer life expectancy? [7]
- Does having a double board certified pediatrician and internal medicine doctor for life long continuous medical care improve health equities vs having a pediatrician when transitioning to an adult care physician? [7]
- What would be the long-term health outcomes for Black and Hispanic infants with Down syndrome and mental health outcomes for parents if we compared doctors who receive training on culturally competent care for people with disabilities vs. those with no training? [1]
- What would be the mental health outcomes for Black and Hispanic parents of children with Down syndrome and outcomes for babies if parents received advocacy training and medical providers with share racial identities? [5,6]
- Does having a genetic counselor give a DS diagnosis in a positive empathetic way improve the quality of life for Black and Hispanic families and have less traumatic experience vs being given a DS diagnosis in a negative way? [2]

Group 2 (Hispanic parents)

- How does socioeconomic status give privilege or place barriers on the potential for children with Down syndrome to reach their full capabilities? [10]
- How can medical care and community support for children with Down syndrome and parents be streamlined? [9]
- How can resources be shared with people across diverse communities? [4]
- How to form the initial connections at the point of birth, and facilitate the connection throughout? [9]
- How can parents of children with Down syndrome better be prepared? [4]
- How does being connected with a parent mentor or advocate impact outcomes for parents of children with Down syndrome and the child's experience? [9]
- How can parents who have not been contacted before be connected? [9]

Group 3 (Black parents)

- What would be the long-term health outcomes for Black and Hispanic infants with Down syndrome and mental health outcomes for parents if we compared doctors who receive training on culturally competent care when delivering a diagnosis vs. doctors who receive no training on culturally competent care for people with disabilities? [1]
- What would be the mental health outcomes for Black and Hispanic parents of children with Down syndrome if hospitals hired more culturally appropriate people--merit and selection process? [5]
- What would be the mental health outcomes for Black and Hispanic parents of children with Down syndrome if they were not consistently encouraged to terminate the pregnancy? [3]
- What would be the mental health outcomes for Black and Hispanic parents of children with Down syndrome if they reported doctors to hospital ethics boards? [6]
- What would be the mental health outcomes for Black and Hispanic parents of children with Down syndrome if they advocated for themselves or had advocates? [6]

Group 4 (Hispanic parents-Spanish speaking)

- How does discrimination affect the growth of a child with Down syndrome throughout the medical, educational, and educational systems? [8]
- How can we better educate doctors, therapists, and parents to prepare more effectively to structure better ways of the development of a person with Down syndrome? [1]
- How would the quality of life for both the child with Down syndrome and the parent be different if they were connected with classes and resources before the baby was born? [4]
- How can medical providers have more humanity when communicating with parents of children with Down syndrome? [2]

Themes:
(1) Need for Cultural Competency Training
(2) Importance of Professional Empathetic Communication
(3) Push for Termination
(4) Need Parent Resources
(5) Representation Matters
(6) Need for Advocacy
(7) Early Intervention and Care Across the Lifespan
(8) Discrimination in Healthcare
(9) Connections with parent mentors and advocacy organizationss
(10) Social Determinants of Health

Top 3 Research Priorities Identified

After analyzing proposed research questions from four different stakeholder groups, we identified key overlapping themes and reframed them into the following top three Comparative Effectiveness Research (CER) questions. These questions were selected 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.

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?
Related Concerns Addressed:

- Connection with parent mentors and advocacy groups (Group 2)
- Need parent resources (Group 2 and 4)
- Need for Advocacy (Groups 1 and 3)

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?
Related Concerns Addressed:

- Importance of Professional Empathetic Communication (Groups 1 & 4)
- Cultural competency training at the point of diagnosis (Group 1, 3, 4). Cultural competence relates to training to avoid disability bias and racial/ethnic bias.
- Discrimination/Poor Treatment by Medical Staff (Group 4) and Push for Termination (Group 3)
- Representation of medical professionals with shared racial identities (Group 2, 3)

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?
Related Concerns Addressed:

- Socioeconomic status and access (Group 2)
- Connecting underserved families with early intervention and life span support (Group 1)
- Impact of provider continuity on long-term outcomes (Group 4)

Appendix

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. I 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.

Top 3 Research Priorities Identified

After analyzing proposed research questions from four different stakeholder groups, we identified key overlapping themes and reframed them into the following top three Comparative Effectiveness Research (CER) questions. These questions were selected 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.

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?
Related Concerns Addressed:

- Connection with parent mentors and advocacy groups (Group 2)
- Need parent resources (Group 2 and 4)
- Need for Advocacy (Groups 1 and 3)

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?
Related Concerns Addressed:

- Importance of Professional Empathetic Communication (Groups 1 & 4)
- Cultural competency training at the point of diagnosis (Group 1, 3, 4). Cultural competence relates to training to avoid disability bias and racial/ethnic bias.
- Discrimination/Poor Treatment by Medical Staff (Group 4) and Push for Termination (Group 3)
- Representation of medical professionals with shared racial identities (Group 2, 3)

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?
Related Concerns Addressed:

- Socioeconomic status and access (Group 2)
- Connecting underserved families with early intervention and life span support (Group 1)
- Impact of provider continuity on long-term outcomes (Group 4)

Tres Principales Prioridades de Investigación

Después de analizar las preguntas de investigación propuestas por cuatro grupos de partes interesadas diferentes, identificamos temas clave que se repetían y los reformulamos en las siguientes tres principales preguntas de Investigación Comparativa de Efectividad (CER, por sus siglas en inglés). Estas preguntas fueron seleccionadas en función de su frecuencia, relevancia en múltiples áreas (médica, educativa, social, racial) y su potencial para generar resultados medibles. Los participantes mencionaron con frecuencia al impacto de la experiencia del diagnóstico en la salud mental y la capacidad de acceder a servicios y apoyos para el cuidado y bienestar a largo plazo.

Tema: Impacto del Apoyo Temprano (Mentores, Apoyo , Educación, Recursos)
¿Cuál es la efectividad comparativa de las intervenciones de apoyo dirigidas a padres que sean culturalmente competentes —como mentores que también sean padres que comparten la misma identidad racial/étnica; información/recursos sobre el síndrome de Down en el idioma nativo con representación diversa; capacitación para que los padres puedan abogar por sus hijos en su idioma nativo; y acceso a grupos de apoyo con personas de su misma raza o cultura — en comparación con la atención estándar, en relación con la salud mental de los padres y los impactos en la salud y desarrollo de los niños negros e hispanos con síndrome de Down y sus familias?
Preocupaciones relacionadas abordadas:

- Conexión con mentores parentales y grupos de defensa (Grupo 2)
- Necesidad de recursos para padres (Grupos 2 y 4)
- Necesidad de apoyo para abogar por sus hijos (Grupos 1 y 3)

Tema: Papel de la Atención Médica Culturalmente Competente, Empática, Relacional y Continua
¿Cómo afectan los diferentes modelos de capacitación que reciben los profesionales de salud (por ejemplo, en competencia cultural, competencia en discapacidad, ambos o ninguno); el acceso a distintos tipos de profesionales de salud (como consejeros genéticos); y la diversidad racial y étnica diversa del personal de salud en las experiencias que viven los padres al momento del diagnósticos (incluida la forma en que se presentan las opciones para tomar decisiones reproductivas), en la salud mental de los padres y la confianza que tiene el paciente en los profesionales de salud, así como en la calidad de vida, salud y esperanza de vida a largo plazo de niños negros e hispanos con síndrome de Down?
Preocupaciones relacionadas abordadas:

- Importancia de la comunicación profesional empática (Grupos 1 y 4)
- Capacitación en competencia cultural en el momento del diagnóstico (Grupos 1, 3 y 4). La competencia cultural se refiere a la formación para evitar sesgos por discapacidad y sesgos raciales/étnicos.
- Discriminación/maltrato por parte del personal médico (Grupo 4) y presión para la terminación del embarazo (Grupo 3)
- Representación de profesionales médicos con identidades raciales mixtas (Grupos 2 y 3)

Tema: Abordar las Barreras Socioeconómicas y Estructurales a la Equidad
¿Cómo se comparan las intervenciones que ayudan a conectar familias negras e hispanas con servicios que abordan los determinantes sociales de la salud para personas con síndrome de Down (por ejemplo, la divulgación de información sobre apoyos económicos y opciones de servicios disponibles y opciones de seguros médicos, incluyendo exenciones de Medicaid y el Ingreso Suplementario del Seguro Social; referencias automáticas a programas de Intervención Temprana en la Infancia; atención médica continua; y navegación del sistema de servicios) con los sistemas estándar para mejorar el acceso a la atención y los resultados del desarrollo de los niños con síndrome de Down en todos los grupos raciales y niveles de ingreso?
Preocupaciones relacionadas abordadas:

- Estado socioeconómico y acceso (Grupo 2)
- Conexión de familias desatendidas con la intervención temprana y el apoyo a lo largo de la vida (Grupo 1)
- Impacto de la continuidad del proveedor en los resultados a largo plazo (Grupo 4)