Prenatal Disability Education Summit

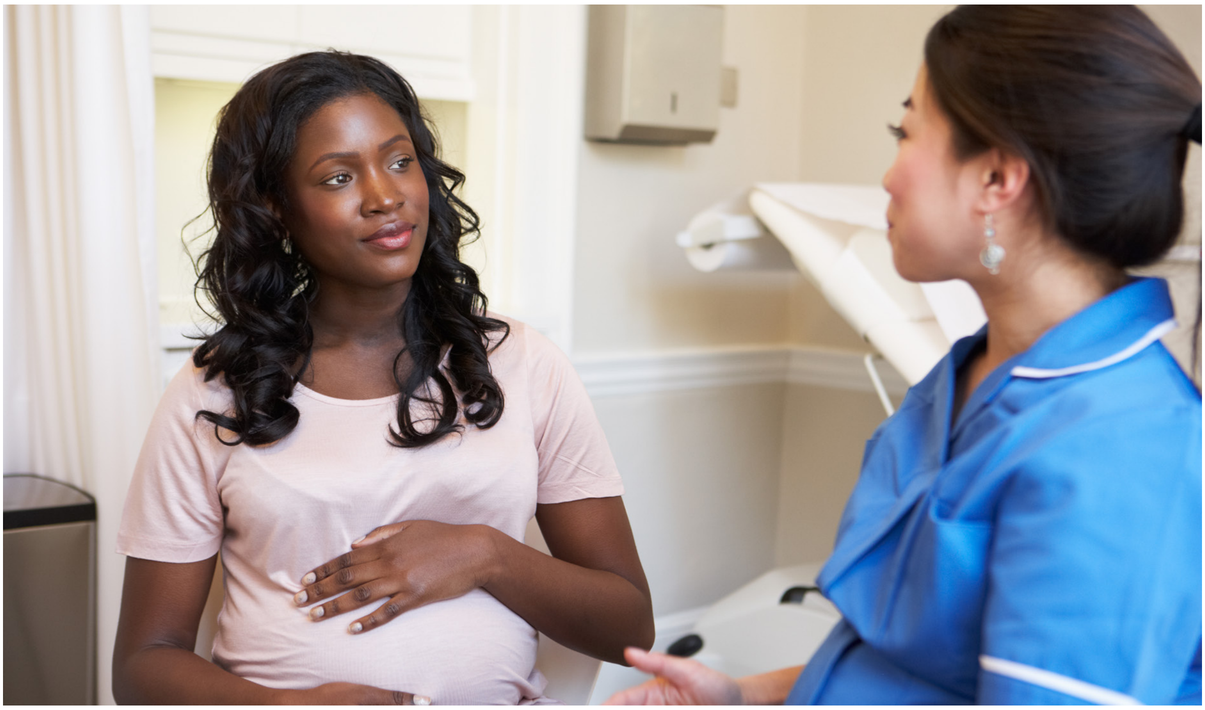
Sponsored by the Joseph P. Kennedy, Jr. Foundation

Johns Hopkins Medical Campus:
Baltimore, MD

May 13, 2022

Table of Contents

Prenatal Summit: Executive Summary



A historic meeting bringing together medical, advocacy, and public policy leaders to discuss equity in prenatal disability education.

Description: The Prenatal Disability Education Summit (the "Prenatal Summit"), sponsored by the Joseph P. Kennedy, Jr. Foundation, was held from 8am-4:30pm on May 13, 2022, at the Johns Hopkins Medical Campus in Baltimore. This event hosted about 50 invited stakeholders, representing the medical, advocacy, and public policy communities, to discuss the future of prenatal education about disabilities.

Executive Summary

Participants

National organizations represented included:

- Administration on Disabilities at Administration for Community Living
- American Academy of Pediatrics
- American College of Medical Genetics and Genomics
- American College of Obstetricians and Gynecologists
- Association of Maternal & Child Health Programs
- Center for Dignity in Healthcare for People with Disabilities
- Down Syndrome Diagnosis Network
- Genetic Support Foundation
- Illumina
- International Society for Prenatal Diagnosis
- Joseph P. Kennedy, Jr. Foundation
- Kennedy Krieger Institute
- MDSC National First Call Center
- National Center for Prenatal and Postnatal Resources
- National Council on Disability
- National Down Syndrome Congress
- National Down Syndrome Society
- National Institute of Child Health and Human Development
- National Institute of Health
- National Society of Genetic Counselors
- Redefining Spina Bifida
- Society of Maternal Fetal Medicine
- Spina Bifida Association of America
- Trisomy 18 Foundation
- U.S. Department of Health and Human Services
- 11q Resource and Research Group

Objectives

The overall objectives of the Prenatal Summit were the following:

Assess the current state of education about disabilities for expectant parents receiving a prenatal diagnosis.

1. Review collaborative accomplishments since the last Down Syndrome Consensus Meeting in 2008.
2. Establish collaborative goals in the areas of public policy, organizational policies/ guidelines, research, and ethical practices for the next decade to ensure that families receive accurate and up-to-date information, resources, healthcare, and support they need following a diagnosis or screening results and to help families and clinicians better understand the current outcomes for people living with disabilities.
3. Discuss best practices for both maintaining and creating relationships between the advocacy and medical communities. Additionally, discuss strategies for the education and training of medical and genetics professionals to better understand current life outcomes for people with disabilities and incorporate that understanding into clinical practice.
4. Produce a directory of stakeholders who will continue to work collaboratively on disability education in the prenatal setting.

Common Themes

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1. Meaningfully include representation from leaders in the disability community as stakeholders in initiatives that impact them, as is best practice with other historically marginalized populations.
2. Conduct more research on clinical care when discussing prenatal testing and a potential diagnosis, patient needs and experiences, and health professional perceptions about people with disabilities.
3. Incorporate education about disabilities and social justice perspectives about disability in broader education initiatives, including public awareness initiatives, K-12 and post-secondary curriculum, medical and genetics education curriculum, and continuing professional education. Curriculum and certification in disability equity should be mandated for the medical workforce and include national consensus on disability competencies and disability bias training, particularly for those presenting a diagnosis.
4. Ensure patients and providers have access to accurate and up-to-date information about genetic conditions and prenatal screening/testing. Information about conditions should include medical information and also social aspects and supports and services.
5. Develop effective strategies to increase dissemination of existing recommendations for for obstetric and genetic health professionals regarding the delivery of diagnosis and screening results.
6. Address inequities in funding that contribute to inequities in the administration of prenatal testing and education about disabilities.

Collaborative Action Plan Summary

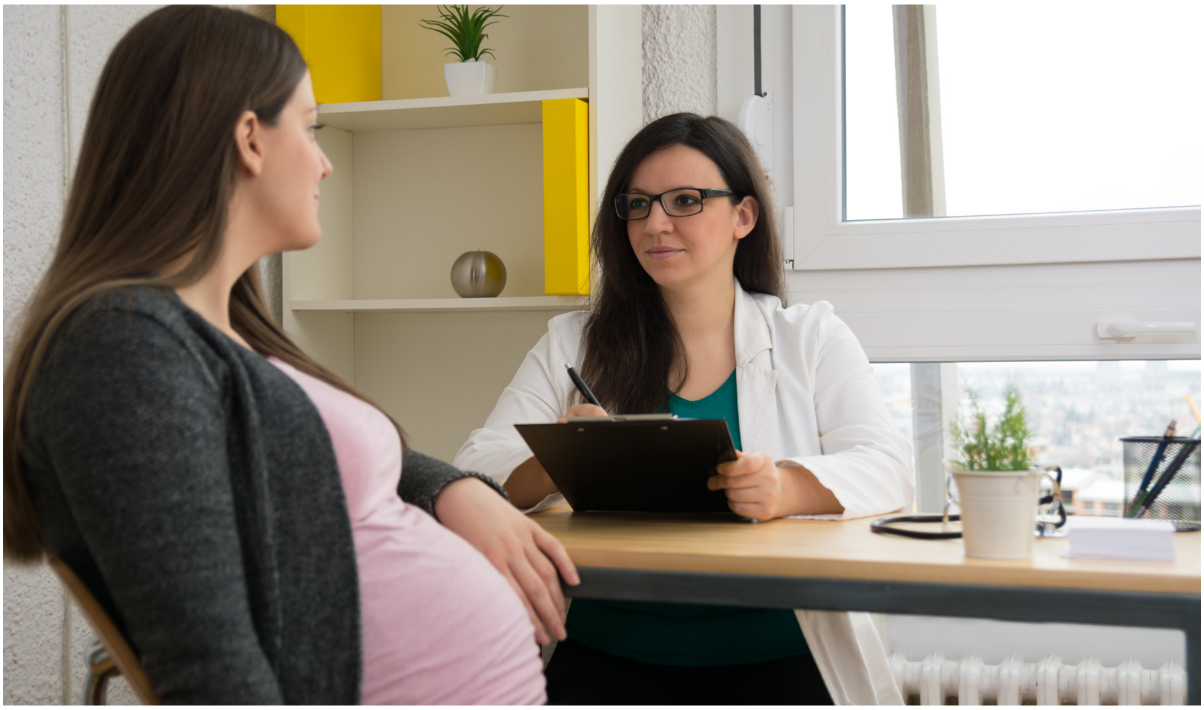
1. Convene a consensus development program and a stakeholder consensus group for the development of guidelines that impact people with disabilities as is done for other historically marginalized populations.
2. Develop an online database to connect medical organizations and patient advocacy groups with specific purposes outlined for this tool.
3. Advocate to mandate the inclusion of disability education and equity curriculum in education for the healthcare workforce with specific steps outlined to accomplish this task.
4. Create or identify an institutional home to be the clearinghouse/hub of valid information for providers and patients to go to for all conditions commonly screened, information about those conditions, and recommended support organizations.
5. Develop a collaborative policy group between the patient advocacy organizations and medical organizations to work together on policy and advocacy initiatives.
6. Improve tools to help clinicians when delivering a diagnosis with clear steps presented.
7. Work collaboratively to present at national conferences and present to member institutions on the topics.
8. Work on collaborative research projects on the following topics as well as other topics determined through interdisciplinary conversations about research priorities.
9. Create a collaborative document outlining steps to redefine organizational priorities and principles regarding data instrumentation for collecting and conveying data about disabilities.
10. Develop templates, initiatives, and campaigns to be used for public awareness and general education purposes.

See broader outline of details for Collaborative Action Plan in "Top Ten Action Items" on page 30.

Evaluation

Over 90% of respondents agreed that the Prenatal Summit increased their understanding of different perspectives about challenges regarding the provision of prenatal disability education, broadened their vision for different strategies to address the challenges regarding the provision of prenatal disability education, helped them identify new ideas to improve the way their organization approaches prenatal disability education, and made valuable connections with other leaders during the summit. All agreed that the community conversations were beneficial for sharing ideas in an accessible format.

Prenatal Summit: Full Report



An overview of the challenges identified and solutions proposed through community conversations with stakeholders.

Event Description

"The work of this interdisciplinary team is essential to ensuring all stakeholders are working together to meet the needs of vulnerable families."

The Joseph P. Kennedy, Jr. Foundation sponsored the Prenatal Disability Education Summit. The Prenatal Summit was held from 8am-4:30pm on May 13, 2022, at the Residence Inn adjacent to Kennedy Krieger Institute at the Johns Hopkins Medical Campus in Baltimore Maryland and included a welcome reception on Thursday, May 12 from 7-9pm. This event hosted about 50 invited stakeholders, representing the medical, advocacy, and public policy communities, to discuss the future of prenatal education about disabilities.

Stephanie Meredith, the event organizer and the Director of the National Center for Prenatal and Postnatal Resources, noted this event was the first of its kind to bring together such a diverse coalition of stakeholders to discuss strategies for making sure that patients undergoing prenatal screening get the support and information they need when learning about disabilities.

Meredith shares that, "Research shows that patients continue to struggle to get information about disabilities that meets their needs at that vulnerable moment when receiving prenatal screening results. They want to know about the medical issues and genetics, but they also want to know what life is like for people living with these conditions and their families. This is particularly vital because people with disabilities are part of a historically marginalized population. We must make sure discussions about disabilities are based on accurate and up-to-date information without being clouded by stereotypes or biases. The stakes are high because patients can experience lasting trauma when they don't receive the information and support that they need."

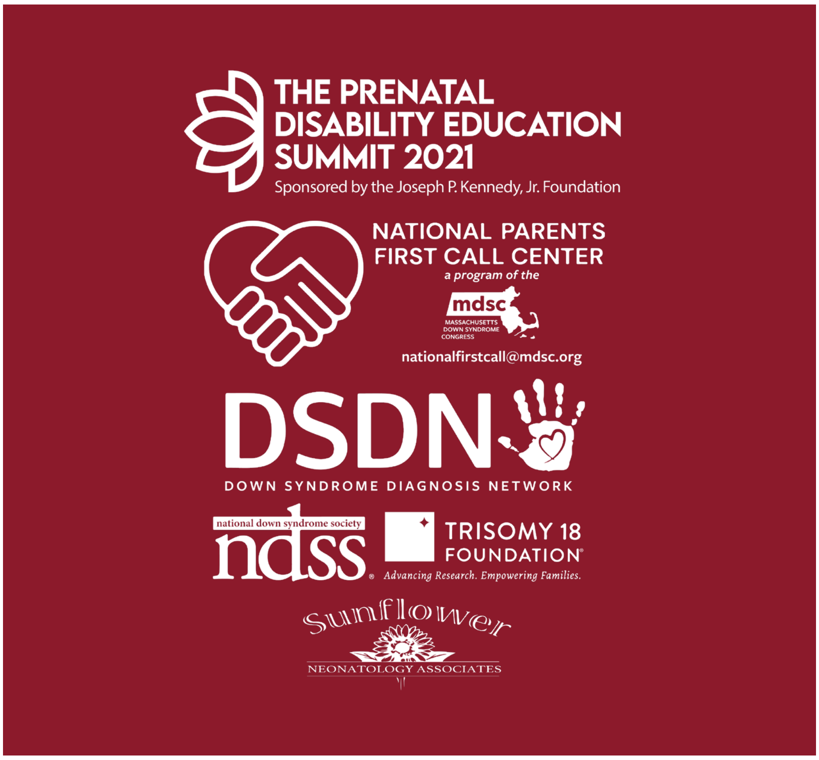
Meredith adds, "As prenatal screening efforts increase, we are heading into a looming public health crisis of genetic information without a sufficient infrastructure for patient education and support. The work of this interdisciplinary team is essential to ensuring all stakeholders are working together to meet the needs of vulnerable families and to provide clinicians accurate and up-to-date information and training about disabilities."

Sponsors

The primary sponsor of the event was the Joseph P. Kennedy, Jr. Foundation.

Other vital sponsors included:

- **The National Parents First Call Center, a program of the Massachusetts Down Syndrome Congress**
- **Down Syndrome Diagnosis Network**
- **The National Down Syndrome Society**
- **The Trisomy 18 Foundation**
- **Sunflower Neonatology Associates**
- **Case Western Department of Bioethics**
- **Genetic Support Foundation**
- With support from the **Kennedy Krieger Institute at the Johns Hopkins Medical Campus** and the **Center for Dignity in Healthcare for People with Disabilities**.
- Snacks donated by the **Down Syndrome Association of Maryland**



Sponsor Message

Alexandra Pender

Trustee, The Joseph P. Kennedy Jr. Foundation

“This summit is an important step forward to advance the way in which women and families are given a medical diagnosis at the early stages of pregnancy and will be pivotal in how doctors care for the women and children these practices will impact most.”

Welcome to Baltimore for the first ever Prenatal Disability Education Summit. My name is Alexandra Pender, and I am the 4th generation of the Kennedy Family to serve as a trustee of the Joseph P. Kennedy, Jr. Foundation (JPKF), created by my great grandparents to honor their son, my great uncle, who died in World War II, and inspired by my great aunt Rosemary who had what is now termed an intellectual disability. For more than 75 years, JPKF has pushed for progress, inclusion, and respect for people with intellectual disabilities. To this day, the foundation has maintained a laser-like focus on policies, programs and research that seeks to improve the lives of people with intellectual disabilities.

We are so proud to sponsor today’s event and support the work of the Lettercase National Center for Prenatal and Postnatal Resources at the University of Kentucky’s Human Development Institute and their tireless efforts to provide parents, researchers and practitioners scientifically accurate information concerning pre-natal and post-natal diagnosis of conditions that cause intellectual disability.

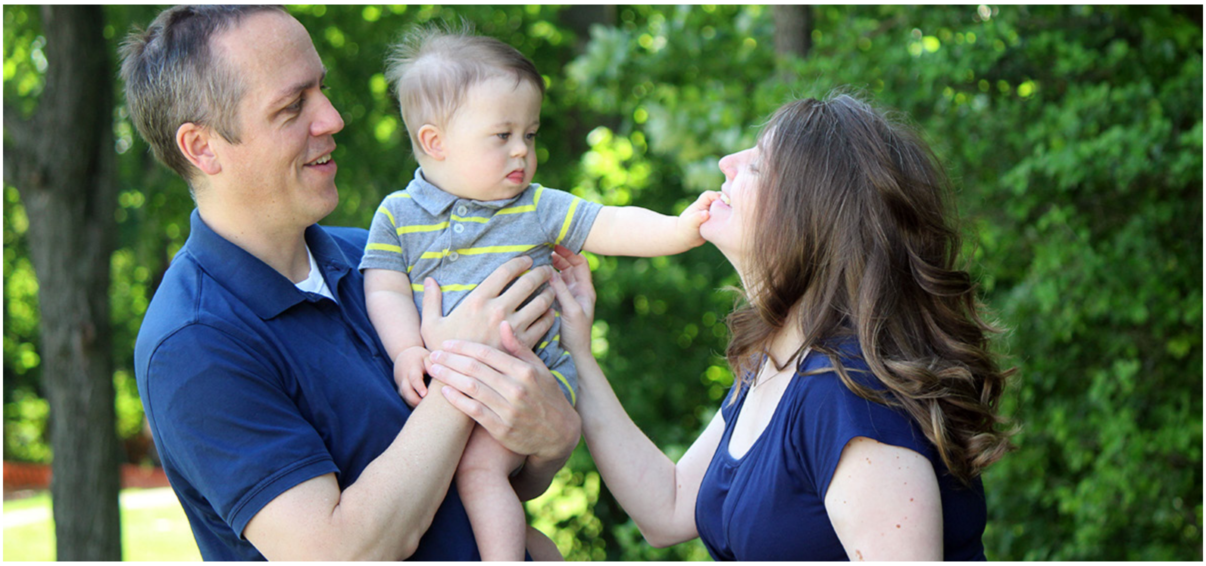
In 2008, Senator Kennedy and Senator Brownback co-sponsored the Prenatally and Postnatally Diagnosed Condition Awareness Act which was signed into law. It was the work of two U.S. Senators who came together with different vantage points to address the concerns of parents, researchers, and scholars from a variety of disciplines. The law initially focused on Down Syndrome and Congress authorized funds, but to-date no funds have been appropriated. The lack of support spurred the development of the Lettercase National Center for Prenatal and Postnatal Resources at the University of Kentucky's Human Development Institute and the longtime support by the Joseph P. Kennedy, Jr. Foundation.

On a personal note, I am first and foremost a mother to two beautiful little ones, a 3-year-old, and our newest 2-month-old. I know the feeling the moment you find out you are expecting. It is one of excitement and joy but also a lot of unknowns – the unknown of what is to come, what to expect, and how to handle it all. I am fortunate to have been supported by family, close friends, and an incredible team of doctors who helped me through every step of the way. I learned there is tremendous power in finding and providing parents with a community of resources to support them and shine light on some of the unknowns. Prenatal diagnoses are important tools to support parents and help them answer large and at times difficult questions. They provide scientifically accurate and readable information and will remain an important part of the support community to help parents feel less alone.

We hope that the work done here today will carry on the collective efforts of advocates, scholars, researchers, practitioners, and others concerned about this important issue. This summit is an important step forward to advance the way in which women and families are given a medical diagnosis at the early stages of pregnancy and will be pivotal in how doctors care for the women and children these practices will impact most.

Thank you for your commitment to this important work and community. All of us at the Joseph P. Kennedy Jr. Foundation are excited to see how the findings from today's summit will impact generations to come.

Alexandra Pender



Summit Attendees

Broad representation between different disability advocacy groups, medical and genetics organizations, bioethicists, policy leaders, and academics.

The majority of the Prenatal Summit participants have impressive academic credentials and are nationally recognized leaders in their respective fields. To promote equity between professional and community leaders during the Prenatal Summit conversations, we chose to use first and last names during the Prenatal Summit.

1. Amanda Kern: President, Redefining Spina Bifida
2. Amy Allison: Executive Director, The Farmers House
3. Angela Trepanier: Past President, National Society of Genetic Counselors
4. Beth Pletcher: Representative, American Academy of Pediatrics
5. Bob Dinerstein: Director of the Disability Rights Law Clinic, American University Washington College of Law
6. Bradley Schlaggar: President, Kennedy Krieger Institute
7. Brian Skotko: Director, Massachusetts General Down Syndrome Program and Associate Professor, Harvard Medical School
8. Britton Rink: Representative and Past Chair of Genetics, American College of Obstetricians and Gynecologists and Obstetric and Maternal Fetal Medicine Specialist, Nationwide Children's Hospital
9. Catherine Zinck: Board Member, Trisomy 18 Foundation
10. Cedrik Ngongang: Diversity, Equity, and Inclusion Committee, American College of Medical Genetics and Genomics and National Human Genome Research Institute [NHGRI] /National Institutes of Health
11. Christina Wurster (virtual): Chief Executive Officer, Society of Maternal Fetal Medicine
12. Colleen Hatcher: Senior Manager of Community Relations, National Down Syndrome Society

13. Colleen Payne: Program Coordinator, Spina Bifida Association of Kentucky
14. Deanna Darnes: Genetic Counselor and Parent Volunteer, Down Syndrome Diagnosis Network
15. Diana Bianchi (Virtual): Director, National Institute of Child Health and Human Development
16. Erin Huggins: Genetic Counselor, Duke Department of Pediatrics
17. Hannah Pascucci: Director of Medical Outreach, Down Syndrome Diagnosis Network
18. Hilarie Rosselot: Executive Director, National Fragile X Foundation
19. Igna Van Der Veyer: Past President, International Society for Prenatal Diagnosis
20. Jenny DiBennedetto: Board Member, Down Syndrome Diagnosis Network
21. Judy Thibadeau: Director of Research and Services, Spina Bifida Association of America
22. Julia Castro: Genetic Counselor, Johns Hopkins Bloomberg School of Public Health
23. Kara Ayers: Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities; Assistant Professor, University of Cincinnati Department of Pediatrics; Director, Center for Dignity in Healthcare for People with Disabilities
24. Katherine Cargill-Willis: Program Specialist, the Administration on Disabilities at Administration for Community Living, The U.S. Department of Health and Human Services
25. Katie Stoll: Executive Director, Genetic Support Foundation
26. Leah Smith: Project Coordinator, Center for Dignity in Healthcare for People with Disabilities
27. Leila Jamal: Genetic Counselor, National Institute of Health, and Associate Director for Cancer Genomics in the Johns Hopkins/NIH Genetic Counseling master's degree program
28. Linzee Carroll: President, 11q Resource and Research
29. Madeleine Will (Virtual): Former Assistant US Secretary of Education for Special Education and Rehabilitation
30. Marc Williams: President, American College of Medical Genetics and Genomics
31. Margot Rhondeau: Senior Director of Health & Wellness, National Down Syndrome Society
32. Mark Leach: Attorney, Mark W Leach Law Firm, Lettercase Review Committee, Bioethics Specialist at the National Center for Prenatal & Postnatal Resources
33. Marsha Michie: Assistant Professor, Department of Bioethics at Case Western Reserve University
34. Maureen Van Stone: Director, Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute
35. Mirian Ofonedu: Director of Training, Maryland Center for Developmental Disability
36. Mitchell Levitz: Board Member, Lettercase Review Committee
37. Nancy Iannone: Staff, Lettercase National Center for Prenatal and Postnatal Resources
38. Paige Bussanich Falion: Senior Program Manager, Children and Youth with Special Health Care Needs at The Association of Maternal & Child Health Programs

39. Patricia Winters: Medical Affairs Manager and Genetic Counselor, Illumina
40. Rick Rader: National Council on Disability
41. Rosemarie Garland: Bioethicist and Professor Emerita, Emory University
42. Roxanne Hoke-Chandler: Representative, MDSC National First Call Center
43. Sarah Cullen: Director, MDSC National First Call Center
44. Sara Struwe: President and CEO, Spina Bifida Association of America
45. Scotti Brackett: Representative, Down Syndrome Diagnosis Network
46. Sierra Weiss: Staff, Lettercase National Center for Prenatal and Postnatal Resources
47. Sonja Rasmussen: Professor, Departments of Pediatrics and Epidemiology at the University of Florida
48. Stephanie Meredith: Director, Lettercase National Center for Prenatal and Postnatal Resources
49. Steve Eidelman: Executive Director, Joseph P. Kennedy, Jr. Foundation
50. Tamara Pursley: Programs & Partnerships Director, National Down Syndrome Congress
51. Vardit Ravitsky: Professor, University of Montreal/ International Society for Prenatal Diagnosis

Many thanks to the Prenatal Summit Planning Committee:

Amy Allison

Harold Kleinert

Kara Ayers

Mark Leach

Marsha Michie

Stephanie Meredith

Event Format

Schedule

- **8-8:30am:** Continental Breakfast and Welcome
- **8:30-9am:** Welcome and Message by Alex Pender, Joseph P. Kennedy, Jr. Foundation Trustee, and Mitchell Levitz
- **9-10:45am**: Presentations by speakers
- **10:45-11am**: Break
- **11-11:45am**: Discussion Topic Table #1
- **11:45-12:30am**: Discussion Topic Table #2
- **12:30-2:00pm**: Working lunch while table leaders debriefed the entire group on the outcomes of the discussions and then entire group voted to identify the top two most critical priorities to solve in each area.
- **1:45-2pm**: Update about Pegasus Project by Dr. Vardit Ravitsky
- **2-3pm**: Divided into 8 tables again. Returned to Topic Table #1. Identified at least 3 solutions, strategies, and action steps to solve challenges.
- **3-4:00pm**: Reported out the solution ideas for each group and documented the results. Led by Dr. Marsha Michie.

Speakers on Discussion Topics

- Prenatal treatments and the NIH-supported INCLUDE project: **Dr. Diana Bianchi**
- Overview of the current state of education about disabilities for expectant parents and review collaborative accomplishments between the medical and advocacy communities:: **Stephanie Meredith, MA**
- Application of the health equity lens to prenatal diagnosis conversations: **Roxanne Hoke-Chandler, MS**
- Review of laws and regulations pertaining to the provision of information following prenatal screening: **Mark Leach, MS, JD**
- Review of the medical organization guidelines regarding prenatal education about genetic conditions: **Dr. Brian Skotko and Katie Stoll, MS, CGC**
- Review of education initiatives for medical providers delivering a diagnosis: **Angela Trepanier, MS, CGC**
- Review of federal reports/grants pertaining to prenatal education about genetic conditions and the different models of disability and ableism: **Dr. Kara Ayers**
- Internation update about the Pegasus Project: **Dr. Vardit Ravitsky**

Community Conversation Format

This meeting utilized the community conversation model, which includes “participants as decision-makers and implementers” to improve systems and practices.[1,2] The community conversations covered the following topics, which were assigned as tables at the Prenatal Summit:

1. Public policy and legislation such as Down Syndrome/Genetic Condition Information Acts, Wrongful Birth and Wrongful Life
2. Evaluating disability representation and education in organizational policies/guidelines
3. Researching to improve the diagnosis experience and provision of information about conditions
4. Assessing ethical practices/disability studies perspective regarding prenatal screening and disability
5. Addressing ableism, stigma, and the needs of populations with multiple vulnerabilities: socioeconomic, racial, etc. when administering prenatal testing
6. Training for healthcare professionals and students about genetic conditions and disability equity

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[1] Carter, E. W., & Bumble, J. L. (2018). The promise and possibilities of community conversations: Expanding opportunities for people with disabilities. Journal of Disability Policy Studies, 28(4), 195-202.

[2] Trainor, A. A. (2018). Community conversation as a method of gathering and analyzing qualitative data. Journal of Disability Policy Studies, 29(1), 2-6.

7. Developing and disseminating patient education tools about conditions
8. Ensuring best practices for delivering a diagnosis.

Each table was provided a community conversation guide, a pre-assigned table leader, and a notetaker. The table leader stayed with their table for all conversation rounds. Participants were divided into tables with interdisciplinary representation at each table. Prior to the conference, each participant was given the opportunity to rank their topic preferences in an online Prenatal Summit survey, and they were given the opportunity to discuss two of their top topic preferences.

A total of three community conversations were held at each table throughout the day where participants were instructed to do the following:

- **Community Conversation 1**: First group identified the top 3 most critical problems to solve for the discussion topic.
- **Community Conversation 2**: Second group identified the top 3 most critical problems to solve for the discussion topic.
- During the working lunch, the table leaders reported out to the whole group the list of critical challenges identified in the first two community conversations. The challenges were also added to a PollEverywhere on-line poll so that summit participants could vote electronically on what they perceived as the top two most critical challenges.
- **Community Conversation 3**: First group reconvened to identify at least 3 solutions, strategies and action steps to solve the collectively identified top challenges.

Top Challenges

Identify the top 2 most critical problems to solve for each discussion topic. Voted upon by all attendees after presented with outcomes from two community conversations.

Evaluating disability representation & education in organizational policies/guidelines

1. We need increased disability representation that is really meaningful and effective. Inclusion must be real – not tokenism. Effective representation at the outset of the process will lead to better questions and solutions. **37%***
2. Difficulty of collaboration among organizations. Need to increase communication among professional organization and patient advocacy groups in guideline development to ensure guidelines are developed to meet needs of community being served – not just certain interests such as the laboratories offering the testing. **29%**

Assessing ethical practices/disability studies perspective regarding prenatal screening and disability

1. Disability perspective consideration in medical education initiatives and broader public cultural awareness in curriculum. **36%**
2. Why test and what can we learn? Assumptions about disability and quality of life need to be clarified. **20%**

*Percentrage of attendees who indicated that the challenge identified was most important to address.

Training for healthcare professionals and students about genetic conditions and disability equity

1. Limited training in most healthcare professional programs about disabilities. Education needs to include experiences with families, focus on medical and social aspects, needs to continue beyond training in programs to post-graduation. **40%**
2. Curriculum needs to be mandated not suggested. **23%**

Ensuring best practices for delivering a diagnosis

1. Insufficient or outdated information/resources are given to parents/patients at time of diagnosis (families go home and self-seek information that may be unreliable or a worst-case scenario). **27%**
2. Time constraints of health care provider – lack of establishing the purpose of the visit so the provider can answer the most important questions at that time for that patient/family and lack of establishing a follow up plan. **22%**

Researching to improve the diagnosis experience and provision of information about conditions

1. Evidence based studies (both quantitative and qualitative) on how best to provide a prenatal diagnosis for more disabilities beyond Down syndrome. **25%**
2. Better educational tools and way to inform all patients about the tests, the risks and benefits, what a positive test means and doesn't mean (utilize tools we've developed and learned during COVID-19). **24%**

Developing and disseminating patient education tools about conditions

1. Developing the materials: use of appropriate tone (without political/religious/cultural/personal bias/etc.) and terminology that is accessible and understandable by a wide audience. **34%**
2. Follow up with patients after they receive the materials to answer questions, clarify content, check in, etc. whether this be through interaction with the health care provider, other families, advocacy groups, etc. **25%**

Addressing ableism, stigma, and the needs of populations with multiple vulnerabilities: socioeconomic, racial, etc. when administering prenatal testing

1. Lack of awareness of implicit ableism resulting in negative bias when discussing prenatal testing, test results and access to counseling. **41%**
2. Tool kit of questions to help HCPs to ask the right questions rather than making assumptions about what the patient thinks (“this is not the diagnosis we were hoping for”). **20%**
3. Lack of awareness and preconceived notions of family response at the diagnosis moment affecting the information and resources offered to families. **20%**

Public policy and legislation

1. Systematic challenges posed by the politicized nature of prenatal genetic testing and imbalance of lobbying ability between disability stakeholders and laboratories. **31%**
2. Implementation of public policy: stakeholder buy-in and funding required for successful implementation. **21%**

Solutions

Evaluating disability representation and education in organizational policies/guidelines

1. Solutions to Problem #1: Difficulty of collaboration among organizations. Need to increase communication among professional organizations and patient groups in guideline development to ensure guidelines are developed to meet needs of the community being served – not just the constituents' interests of individual organizations.
   a. We need to convene a consensus development program similar to former NIH hosted program.
      - Exploration - Identify a trusted entity to convene a stakeholder consensus group
      - Federal entity? NGO organization?
      - Federal entities are more politicized and underfunded with COVID-19. But can't have all states doing everything differently. Wastes precious resources.
      - Define the stakeholders that would be participating.
2. Solutions to Problem #2: We need increased representation of people with disabilities - also representation that is meaningful and effective - Inclusion must be real – not tokenism. Effective representation at the outset of the process will lead to more likely questions that will lead to better representation that is more inclusive.
   a. Consider developing an online connection database that organizations could share information about guidelines that are planned or in the works; disability groups could register interest to be involved, or to nominate a topic.
      - Developing a charter
      - Identify host/moderator for connector database
      - Highlight/model successes of collaboration
   b. Involve disability/patient advocacy groups in defining the questions that a guideline aims to answer at the outset, when a guideline is first conceptualized.
   c. More research on patient needs and experiences.

Assessing ethical practices/disability studies perspective regarding prenatal screening and disability

1. Incorporate disability justice studies in public education curriculum, in medical education school, and continuing education for providers.
    a. Create a speakers' bureau of people with disabilities and experts to speak at Grand Rounds, national conferences
        - Compassion in Art of Medicine
        - Speakers network model: Diversity of culture and disability
        - University Center for Excellence in Developmental Disabilities (UCEDD) dissemination: speaker and media training including parents, siblings, and self-advocates
        - Speaking and media: best practices for engaging
        - Make sure every event is accessible with a set of best access practices
        - Make sure to reflect intersectional diversity: other languages, experiences, races.
    b. All institutions need Diversity, Equity, and Inclusion (DEI) priorities that include people with disabilities.
    c. Provide information about disability civil rights earlier in high school, teacher education, Parent Teacher Organization, Community Assistance Programs (CAPS) (employment training).
2. Need broader media campaigns about disability because medical providers are reflections of broader societal bias about disabilities
    a. Engaging PR campaigns about lived experience of people with disabilities. Examples: Josh Blue (Last Comic Standing) and X-box ad—Different Hands
        - Tik-Tok
        - Social media campaigns targeted to different ages.
3. Need to improve instrumentation about collecting and conveying data on subjective quality of life
    a. Define what quality of life is with interdisciplinary stakeholders
    b. Health and wellness, diversity, psychosocial research and data
    c. Raise general awareness about redefining Quality of Life
    d. How does diversity impact access to supports and services and models?
    e. IRB: Representation of disability, diversity, and race in IRB.
    f. There could be an opportunity to work with NIH to develop Patient-Reported Outcome Measures specific to disabilities that could be validated then included as tool in the PROMIS measures that are required to be used in NIH-funded research involving patient reported outcomes. https://www.healthmeasures.net/explore-measurement-systems/promis/measure-development-

Training for healthcare professionals and students about genetic conditions and disability equity

1. Limited training in most healthcare professional programs in disability. Education needs to include experiences with families, focus on medical and social aspects, needs to continue beyond training in programs to post-graduation (residency, practice). Challenge is no defined curriculum, curriculum varies by profession in terms of what to cover, when to cover, and how much so hard to standardize.
    a. Rationale for this Objective
        - Need to be able to identify patients with rare conditions to prevent further healthcare disparities where only some get access to such diagnoses and concomitant treatment
        - Good training will avoid diagnostic overshadowing/diagnostic odyssey (healthcare costs)
        - Inclusive health-85% of all the practicing providers should be able to manage 85% of patients- but instead of 15% going to specialists, 40% are.
    b. There are some national curricula so do not need to recreate it- but need to mandate inclusion:
        - National curriculum in intellectual and developmental medicine (CDC) (NCIDM)
        - AAHD-American Association of Health and Disability AAHD.us
        - Havercamp et al., (2021). What should we teach about disability? National consensus on disability competencies for health care education. Disability and Health Journal, https://doi.org/10.1016/j.dhjo.2020.100989
        - Highlighting best practices at national conferences and publications to encourage adoption by other institutions
        - National Board of Medical Examiners, National Board of Medical Specialties
    c. Incorporating families- Project Doc, Alliance for Disability in Healthcare Education
    d. Engaging societies for instructors-STFF (Society of Teachers of Family Medicine), Association of Genetic Counseling Program Directors, other like organizations
    e. Finding opportunities for healthcare professionals to engage with people who have disabilities outside of medical care –
        - Special Olympics Healthy Athletes Program
        - NADD (National Association of Dual Diagnoses)
        - DDNA (Developmental Disabilities Nurses Association)
        - American Academy of Developmental Medicine and Dentistry
2. Curriculum needs to be mandated not suggested (should versus may).
    a. Engage and influence the decision makers
        - AAMC (Association of American Medical Colleges and affiliate organizations)
        - CMS (Centers for Medicare & Medicaid Services)

    - LCME (Liaison Committee on Medical Education)
    - Joint Commission
    - National Council on Disability- Health Equity Framework
    - Congressional support- through caucuses, committees.

  b. What would make these groups recognize the importance of this initiative? If you have a well-trained medical workforce that understands this population you can avoid trips to the ER rehospitalization (back after short period of time), plays into ability to be employed and part of the community. “Health care is the vehicle to allow other aspirational things.”

  c. Pre-existing pieces of legislation have called for this- maybe ADA-but not mandated. (Check).

  d. Continuing education mandates- state licensure laws that require training in disability.

  e. HMO/Health Plans- mandates for providers to do training in certain topics or if not mandates get recognition.

  f. One of the measures of being a top provider is to have training in disability.

  g. Include training in disabilities for certification of hospitalists.

  h. Other groups: Internal Medicine (is hard nut to crack), Family Practice, Behavioral Pediatricians, Developmental Pediatricians, sometimes Medical Pediatricians are good targets.

Ensuring best practices for delivering a diagnosis

1. Single clearinghouse/hub of information for providers and patients to go to with all conditions commonly screened, info about conditions, recommended organizations
   a. Save time for providers: have simple checklists for commonly diagnosed/screened conditions
   b. Variety/series of resources - for doctors delivering diagnosis (e.g., best practices, a “bot” to practice with), for doctors’ deeper understanding, for families pre- and post-decision (e.g., videos of families living real life)
   c. Stable leadership/governance structure: coalition of organizations an integral part of governance, but an institutional home like Kennedy-Krieger, National Center for Prenatal and Postnatal Resources at the Human Development Institute, or similar
   d. Government funding, e.g., Kennedy-Brownback.
2. Certification/title for both institutions and individual health care providers in Disability Equity
   a. Through Association of University Centers on Disability (AUCD), National Center for Prenatal/Postnatal Resources, Center for Dignity, or similar organization
   b. National conferences and talks at member institutions by experts.

Researching to improve the diagnosis experience and provision of information about conditions

1. Evidence based studies (both quantitative and qualitative) on how best to provide a prenatal diagnosis for more disabilities beyond Down syndrome
    a. Requires money, there isn't NIH money to do this. Most money has been on prenatal diagnosis and non-invasive screening, so money to do studies like this. Need funding mechanism to fund national research.
    b. Advocacy groups need to combine to advocate.
    c. Utilize the successes of Down syndrome research to validate the need for further studies for studies for additional conditions.
2. Better educational tools and way to inform all patients about the tests, the risks and benefits, what a positive test means and doesn't mean (utilize tools developed and learned during COVID-19):
    a. Research on accurate pretest counseling, developing videos and written materials that parents can consume to better understand what the purpose of screening test are and how they should inform their decisions
    b. Ensure a diverse population in the research conducted in trying to understand the knowledge gaps and receptiveness to different educational materials
        - Ensure the recruitment is broad and includes diverse populations and includes incentives so people can participate
        - Intentional partnerships with organizations and partnerships as a tangible way to ensure diverse contribution to research outcomes
        - Use researchers and health care providers that reflect the populations participating in the studies
        - Invest in the people who are going to be using the tools into the development of the research.

Developing and disseminating patient education tools about conditions:

1. Develop materials with a variety of stakeholders: individuals with the condition when possible and their family members/caregivers/community, medical professionals and researchers/experts in the field, and experts in communication (such as professional writers, genetic counselors, illustrators, etc.) Consider forming a network of these individuals that is accessible when an individual or group wants to develop materials and can request volunteers to help form these.
2. Lobby for genetic testing laboratories to be required to provide funding for material development that is provided to HCPs at the same time as the test kits or test information is distributed.

3. Integrate an easy-to-remember method for providers when providing a diagnosis: CARES that is displayed in the EMR, on the test report, or otherwise in the physician's office so it is visible to the provider
    a. Compassion in meeting the patient where they are regarding the diagnosis
    b. Answer questions about the condition
    c. Resources – provide physical/online information
    d. Ensure follow up (schedule a phone call or return visit)
    e. Support – provide information for support or advocacy groups at a local or national level.

Addressing ableism, stigma, and the needs of populations with multiple vulnerabilities: socioeconomic, racial, etc., when administering prenatal testing:

1. Increase research on what existing training is regarding disability and bias
2. Increase research regarding who and how the diagnosis is being delivered with regards to conditions outside of Down syndrome
3. Advocate for increased reimbursement for genetic counseling
4. Advocate for access to telehealth for genetic counseling for those who don't have local access
5. Advocate for reimbursement for telehealth to deliver screening and diagnosis results
6. Give access to implicit bias training as part of education
7. Increase dissemination of existing recommendations regarding delivery of diagnosis and screening results.

Public policy and legislation such as Down syndrome/genetic condition Information acts, wrongful birth and wrongful life

1. Politicization: Maryland model of stakeholders coming together where there is a public/private funding for stakeholder discussion of polarizing issues.
2. PCORI grant for dissemination of pro-information marketing campaign and then dissemination of patient support information.
3. Tying dissemination/required training to accepting federal dollars for medical schools to share information about various laws.

Consolidated Themes

Themes identified across topics during community conversations.

Representation

Meaningfully include representation from leaders in the disability community as stakeholders in initiatives that impact them, as would be done with other historically marginalized populations. "Nothing about us without us" and avoid tokenism. Initiatives that should be considered for collaboration between patient advocacy groups and professional medical and genetics organizations include the following: professional guideline development, collaborative research initiatives, patient education materials, and data collection instrumentation, particularly regarding quality-of-life measures.

Research

Conduct more research on the following topics regarding clinical care, patient needs and experiences, and health professional attitudes about disability: evidence-based studies (both quantitative and qualitative) on how best to provide a prenatal diagnosis for more disabilities beyond Down syndrome; pre-test counseling strategies; research on what existing training is regarding disability and bias; research regarding who and how the diagnosis is being delivered with regards to conditions outside of Down syndrome. Research should be inclusive of broadly diverse populations (as participants and research designers) and organizational partnerships to reach different populations.

Education

Incorporate education about disabilities and social justice perspectives about disability in broader education initiatives, including public awareness initiatives, K-12 and post-secondary curriculum, medical and genetics education curriculum, and continuing professional education. Content should include lived experiences of families and individuals with disabilities, medical and social aspects, the history of disability rights, and available supports and services. Curriculum and certification in disability equity should be mandated for the medical workforce and include national consensus on disability competencies and disability bias training.

Resources

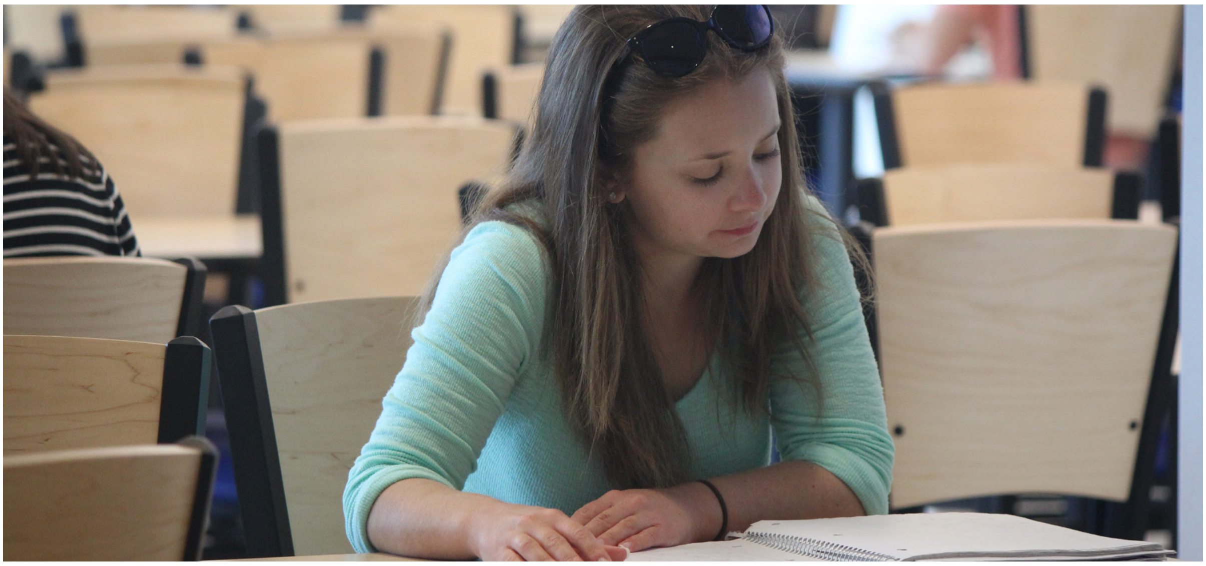
Ensure patients and providers have access to accurate, up-to-date, and balanced information about genetic conditions and prenatal screening/testing. The development of materials should include representation from individuals with the condition when possible and their family members/caregivers/community, medical professionals and researchers/experts in the field, and experts in communication (such as professional writers, genetic counselors, illustrators, etc.). Advocate for the better utilization and dissemination of existing educational tools and a central clearinghouse for distribution.

Clinical Care

Develop and monitor effective and concise strategies to increase dissemination of existing recommendations regarding delivery of diagnosis and screening results, including checklists and an easy-to-remember method for providers to remember when providing a diagnosis (CARES).

Funding

Address inequities in funding that contribute to inequities in the administration of prenatal testing and education about disabilities: reimbursement for genetic counseling, reimbursement for telehealth to access genetic counseling services and deliver screening and diagnosis results, and dissemination of resources about disability and prenatal screening/testing. Sources of funding could include government funding as outlined in the Prenatally and Postnatally Diagnosed Awareness Act, NIH funding, labs to provide funding to disseminate resources about genetic conditions at the moment of diagnosis, or a PCORI-type institution and funding model.



Top Ten Action Items

1. **Convene a consensus development program and a stakeholder consensus group that includes leaders in the disability community in the development of medical guidelines that impact people with disabilities and other historically marginalized populations.**
2. **Develop an online database to connect medical organizations and patient advocacy groups for the following purposes:**
    a. Collaboration on guideline development.
    b. Speaker's Bureau to be accessed for medical schools, Grand Rounds, and national conference. Racial, cultural, and disability diversity will be an important component.
    c. Organizations share guidelines and best practices.
    d. Share collaborative research opportunities between researchers and organizations to share with members.
    e. A network of individuals who are accessible when an individual or group wants to develop materials and can request volunteers to help form these.
    f. Steps for development:
        i. Developing a charter
        ii. Identify host/moderator for connector database
        iii. Highlight/model successes of collaboration.
3. **Advocate to mandate the inclusion of disability education and equity curriculum in education for the healthcare workforce by taking the following steps:**
    a. Identify the curriculum to include (National curriculum in intellectual and developmental medicine—CDC, NCIDM; AAHD-American Association of Health and Disability AAHD.us; Havercamp et al., (2021). What should we teach about disability? National consensus on disability competencies for health care education (Disability and Health Journal).
    b. Highlight best practices at healthcare education conferences and publications to encourage adoption (National Board of Medical Examiners, National Board of Medical Specialties).
    c. Incorporating families- Project Doc, Alliance for Disability in healthcare education.
    d. Identify opportunities for healthcare professionals to engage with people who have disabilities outside of medical care. Special Olympics Healthy Athletes Program, NADD (National Association of Dual Diagnoses), DDNA (Developmental Disabilities

    Nurses Association).

    e. Engage and influence decision-makers who develop medical curriculums (AAMC (and affiliate organizations); Centers for Medicare & Medicaid Services (CMS); Liaison Committee on Medical Education (LCME); Joint Commission; National Council on Disability- Health Equity Framework; Congressional support- through caucuses, committees.
    f. Engaging societies for instructors-STFM (Society of Teachers of Family Medicine), Association of Genetic Counseling Program Directors, other like organizations.
    g. Certification of individuals and healthcare providers in Disability Equity through AUCD, National Center for Prenatal/Postnatal Resources, Center for Dignity, or similar organization.
    h. Give access to implicit bias training about disability as part of education.

4. **Create or identify an institutional home to be the clearinghouse/hub of information for providers and patients to go to with all conditions commonly screened, information about conditions, recommended organizations:**
    a. Stable leadership/governance structure: coalition of organizations an integral part of governance, but an institutional home like Kennedy-Krieger National Center for Prenatal and Postnatal Resources at the Human Development Institute, or similar.
    b. Government funding, e.g., Kennedy-Brownback.
    c. Develop materials with a variety of stakeholders: individuals with the condition when possible and their family members/caregivers/community, medical professionals and researchers/experts in the field, and experts in communication (such as professional writers, genetic counselors, illustrators, etc.) for the range of conditions that can be prenatally diagnosed.
5. **Develop a collaborative policy group between patient advocacy organizations and medical organizations to work together on policy and advocacy initiatives such as:**
    a. Research funding, funding for clearinghouse/hub.
    b. Funding of Prenatally and Postnatally DIagnosed Conditions Awareness Act.
    c. Increased reimbursement for genetic counseling.
    d. Access to telehealth for genetic counseling for those who don’t have local access.
    e. Reimbursement for telehealth to deliver screening and diagnosis results.
    f. Public/private funding for stakeholder discussion of polarizing issues.
    g. Tying dissemination/required training to accepting federal dollars for medical schools to share information about various laws.

   h. PCORI type funding model for dissemination of pro-information marketing campaign and then dissemination of patient support information.

6. **Improve tools to help clinicians when delivering a diagnosis:**
   a. Increase dissemination of existing recommendations regarding delivery of diagnosis and screening results. Simple checklists for commonly diagnosed/screened conditions.
   b. Variety/series of resources - for doctors delivering diagnosis (e.g., best practices, a “bot” to practice with), for doctors’ deeper understanding, for families pre- and post-decision (e.g. videos of families living real life).
   c. Develop **CARES** to be implemented in Electronic Health Records.
   d. National conferences and talks at member institutions by experts about best practices for delivering a diagnosis.
7. **Work collaboratively to present at national conferences and present to member institutions on the following topics:**
   a. Including people with disabilities in Diversity, Equity, and Inclusion initiatives.
   b. Highlight best practices for delivering a diagnosis and discussing disability.
8. **Work on collaborative research projects on the following topics as well as other topics determined through interdisciplinary conversations about research priorities:**
   a. Patient needs and experiences
   b. Evidence-based studies (both quantitative and qualitative) on how best to provide a prenatal diagnosis for more disabilities beyond Down syndrome
   c. Pre-test counseling strategies: research on what existing training is regarding disability and bias
   d. Research regarding who and how the diagnosis is being delivered with regards to conditions outside of Down syndrome
   e. Developing videos and written materials that parents can consume to better un-

derstand what the purpose of screening test are and how they should inform their decisions

9. **Create a collaborative document outlining steps to redefine organizational priorities and principles regarding data instrumentation for collecting and conveying data about disabilities.**
   a. Research should be inclusive of broadly diverse populations (as participants and research designers) and organizational partnerships to intentionally reach different populations.
   b. Define what quality of life is with interdisciplinary stakeholders.
   c. Health and wellness, diversity, psychosocial research and data.
   d. Raise general awareness about redefining Quality of Life.
   e. How does diversity impact access to supports and services and models?
   f. IRB: Representation of disability, diversity, and race in IRB.
10. **Develop templates, initiatives, and campaigns to be used for public awareness and general education purposes.**
    a. Provide information about disability civil rights earlier in high school, teacher education, PTO Parent education, CAPS program (employment training).
    b. Engaging PR campaigns about lived experience of people with disabilities—Josh Blue (Last Comic Standing), X-box ad—different hands, Tik-Tok, Social media campaigns targeted to different ages.

Evaluation

Over 90% of respondents agreed that the Prenatal Summit helped them identify new strategies to improve the administration of prenatal screening.

Please rate the following regarding the summit Objectives:

1. Overall, the summit increased my understanding of different perspectives about challenges regarding the provision of prenatal disability education.
    - 92% Agree or Strongly Agree
    - 8% Disagree
2. Overall, the summit increased my vision for different strategies to address the challenges regarding the provision of prenatal disability education.
    - 92% Agree or Strongly Agree
    - 8% Disagree

Please rate the following regarding the summit Content and Connections:

3. I identified new ideas to improve the way my organization approaches prenatal disability education.
    - 92% Agree or Strongly Agree (42% Strongly Agreed)
    - 8% Disagree
4. I identified new strategies to improve the prenatal screening/diagnosis experiences for patients.
    - 92% Agree or Strongly Agree (46% Strongly Agreed)
    - 8% Disagree

5. I identified new strategies that organizations can use to evaluate the representation of people with disabilities in their policies and resources.
    - 92% Agree or Strongly Agree (42% Strongly Agreed)
    - 8% Disagree
6. I made valuable connections with other leaders during the summit.
    - 92% Agree or Strongly Agree (85% Strongly Agreed—Highest response)
    - 8% Disagree

Please rate the following regarding the summit Program Format:

7. The presentations helped me better understand the discussion topics
    - 100% Agreed or Strongly Agreed (39% Strongly Agreed)
8. I liked the community conversation format for sharing ideas.
    - 100% Agreed or Strongly Agreed (77% Strongly Agreed)
9. The community conversation model helped everyone share ideas equitably.
    - 100% Agreed or Strongly Agreed (62% Strongly Agreed)
10. The composition of my community conversation group was interdisciplinary and balanced.
    - 100% Agreed or Strongly Agreed (54% Strongly Agreed)
11. "PollEverywhere" was a useful tool for identifying priorities.
    - 100% Agreed or Strongly Agreed (42% Strongly Agreed)
12. The solutions identified for an action plan represented sufficient interdisciplinary collaboration.
    - 92% Agreed or Strongly Agreed (69% Strongly Agreed)
    - 8% Disagree

How often should a summit like this be held?

- **38%** Every Year
- **46%** Every Three Years
- **8%** Frequency should be matched to the action items and the opportunity to effect change
- **8%** Every 2 years

Top takeaways from the event from survey respondents

- It is critical for the disabilities community members to be at the table when decisions are being made about education surrounding prenatal diagnosis and shared decision-making.
- There is a wide gap in education for providers and trainees about genetic diagnoses and how best to relay this to families so they can make informed decisions.
- Need to have health care provider buy-in for regulatory/statutory requirements.
- It is contrary to testing laboratories financial interests to improve informed consent for their tests because it will result in fewer people having their tests and therefore revenue will decline.
- Canada has a Down syndrome educational resource that could improve the administration in that country and show how it can be improved here.
- That we're all better together; we have done a lot but there's so much more to do; we are making an impact.
- How our organization talks about termination with changes in abortion laws, the need for interdisciplinary and interagency coordination, and that medical materials need more psychosocial and real life info.
- Collaboration among multiple specialties/backgrounds is critical to developing a comprehensive response to challenges we face.
- There is an entire legal side of this issue that I had not known much about before.
- There is a lack of disabled voices and representation among much of the medical training/education and other tools that providers use to deliver diagnoses.
- It was great to re-connect with some colleagues who are dedicated to the same content area.
- It was clear that the grass-roots advocacy efforts--while important--are not sufficient to address the urgent unmet needs for expectant families.
- The lack of participation from leaders in the national Down syndrome organizations and representative from the for-profit NIPS companies was telling. [The respondent clarified that even though representatives from organizations and companies were present, top tier decision-makers from those organizations also need to attend to change systems.]
- The imperative to include the patient voice more prominently. Update on relevant legislation for disability rights. Identification of prominent voices for the community.
- Prenatal counseling may be adversely impacted by a number of issues including: implicit biases, ableism, negative messaging and inequitable access to appropriate counseling services.

- More research is needed to better define best practices for providing this information to expectant parents and identifying point of care resources.
- First line providers need access to educational materials and training to best counsel patients as they make collaborative, informed pregnancy decisions.
- Other people to work with on these issues; hearing different perspectives and experiences; ideas for next steps to help expectant parents.

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