

**U.S. Department of Health and Human Services (HHS)
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Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)**

NIH Town Hall on Disability Research

December 3, 2024

Virtual Meeting

Meeting Summary

Presenters

Dr. Monica M. Bertagnolli, Director, NIH

Dr. Alison Cernich, Deputy Director, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD)

Dr. Eliseo Pérez-Stable, Director, National Institute on Minority Health and Health Disparities (NIMHD)

Dr. Tara A. Schwetz, Director, DPCPSI, OD, NIH

Mr. Adam Politis, Senior Advisor for Disability Research, DPCPSI, OD, NIH

Welcome and Introduction: Purpose of the Town Hall

Dr. Tara A. Schwetz, Director, DPCPSI, welcomed the participants. She noted that DPCPSI is coordinating NIH disability-related research and other activities in partnership with the NIH Institutes, Centers, and Offices (ICOs). The DPCPSI team of disability research and policy experts, which includes people with lived experience of disability, has been meeting with leadership and staff across NIH, as well as engaging with individuals and organizations from disability communities. Dr. Schwetz indicated that the team, working in partnership with the ICOs, is leading the development of the NIH-wide Strategic Plan for Disability Health Research. This plan will identify crosscutting themes and develop goals and objectives to advance research activities that promote the health and well-being of people with disabilities. She further explained that from late October to November, NIH hosted six virtual Community Roundtable Discussions to inform the development of the framework for the strategic plan. The invited panelists for these roundtables represented a range of interested groups, including people with lived experience of disability, researchers, clinicians, professional associations, and advocacy organizations. Dr. Schwetz expressed gratitude to the panelists for sharing their perspectives and providing many important insights that have been incorporated into planning efforts. She concluded that the purpose of the Town Hall meeting is to share updates about disability research activities at NIH, provide a preview of the draft framework of the NIH Strategic Plan for Disability Health Research, and answer any questions attendees may have.

Opening Remarks

Dr. Monica Bertagnolli welcomed the Town Hall participants. She thanked the NIH ICOs for making disability research a priority, Dr. Schwetz and the DPCPSI research team for organizing the Town Hall and leading disability research coordination and planning, and the NIH Disability Research Coordinating Committee for helping develop the framework for the NIH Strategic Plan for Disability Research. She also acknowledged and thanked the researchers, clinicians, advocates, associations, and people with lived experience of disability for collaborating with NIH to provide input on research priorities and on strategies to improve accessibility and inclusion.

Dr. Bertagnolli noted that more than one in four people in the United States have a disability, which the Americans with Disabilities Act defines as having a physical or mental impairment that substantially limits one or more major life activities; having a history of such impairment, such as a cancer that is in remission; or being perceived by others as having such an impairment. She reminded participants that disabilities are a natural part of the human experience. People can be born with disabilities, can acquire them at any point across the lifespan, and may have more than one disability. Disabilities may be visible or invisible.

Dr. Bertagnolli contrasted the medical model of disability, which has historically been the dominant model in research and which strives to fix or cure people's impediments, with the social model of disability. The social model of disability is championed by the disability rights movement and emphasizes that disability is caused not by individual impairments but by environmental and social barriers that prevent people from fully participating in society. Although people with disabilities lead rich and full lives, they can experience medical conditions that can affect their health and well-being, and they may face such problems as discrimination and inaccessible facilities.

NIH is committed to understanding and addressing all the medical, environmental, and social factors that affect the health and well-being of all people, including people with disabilities. For example, inaccessible medical equipment may prevent people from getting the medical exams they need, and a person with a disability may not have access to new technologies that can help them.

Dr. Bertagnolli described NIH's long history of supporting research to improve the health and well-being of people with disabilities. Ongoing research programs include *All of Us*, a nationwide program to take a critical first step in understanding health and disease in ways that enable tailored approaches to care. *All of Us* partners with more than two dozen disability organizations. Other programs include the NIH Common Fund initiative on Transformative Research to Address Health Disparities and Advanced Health Equity; RECOVER: Researching COVID to Enhance Recovery, which addresses long COVID; and the INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) project to study the health and quality-of-life needs of people with Down syndrome.

NIH has implemented policies to promote the inclusion of people with disabilities in research and to advance health-related health disparities research. In December 2022, the NIH Advisory Committee to the Director Working Group on Diversity convened a subgroup on individuals with disabilities that provided recommendations for making the scientific workforce and the research environment more inclusive. NIH established an Internal Disabilities Subcommittee to coordinate the response to several of the subgroup's important recommendations. Last year, NIH sought input on proposed revisions to the NIH mission statement, which included a recommendation from one working group that NIH remove the words "reduce disability" from the mission statement. The summary report for the request for information on this issue has been released, and NIH will follow up to better understand the concerns raised by the wide range of people who responded.

Dr. Bertagnolli concluded by saying that NIH knows that words matter and that how the agency presents itself to communities like the disability community is very important. More work needs to be done to understand health care disparities affecting people with disabilities by investing in research, training, and career development resources and infrastructure. NIH is committed to advancing health equity for people with disabilities and being more inclusive of people with disabilities who engage in research, whether by participating in clinical trials or by running the trials as a research team member. Dr. Bertagnolli emphasized that success requires coordination and input from a wide range of people and organizations, which is why NIH is holding the Town Hall meeting.

IC Perspective: NIMHD

Dr. Eliseo Pérez-Stable, Director, NIMHD, provided an overview of NIMHD and its efforts related to disability research. He highlighted the importance of addressing health disparities among individuals with disabilities, a focus since NIMHD's establishment in 2000. In September 2023, NIMHD designated people with disabilities as a population that experiences health disparities. This designation acknowledges the unique challenges faced by the disability community and highlights the need for comprehensive, multilevel interventions to address intersectional systemic barriers. Dr. Pérez-Stable highlighted funding opportunities, including collaborations with other NIH institutes, to advance research and develop strategies to improve health outcomes and quality of life for individuals with disabilities, with a focus on the whole individual and other factors that might lead to health disparities.

Many barriers, including discrimination and inaccessible environments, can impede access to timely and comprehensive health care for people with disabilities, leading to poor health outcomes. Dr. Pérez-Stable highlighted the diversity within the disability community, which includes multiple subpopulations with a wide range of experiences and subcultures. For example, individuals with disabilities who are also socioeconomically disadvantaged are more likely to experience limited opportunities for effective independent living, driven by factors like unemployment, adverse living conditions, food insecurity, transportation limitations, social isolation, low-quality health care, and ableism from society and health care systems. An intersectional lens is needed to understand how a person's experience of disability will vary based on their gender, ethnic origin, sexual orientation, and other identities.

NIMHD and six other institutes issued a notice of funding opportunity calling for research on novel and innovative approaches that could address the intersecting effects of disability, race, ethnicity, and socioeconomic status on access to care and health outcomes. Dr. Pérez-Stable noted that the funding opportunity is open for 3 years and that the next submission date is February 5, 2025. He described other examples of projects funded by NIMHD, including a church-based intervention in Chicago's West Side to improve physical function in African Americans, a project to mitigate ethnic disparities in access and engagement in spine pain rehabilitation, and a project to address urban and rural disparities in health care quality for children with complex or disabling conditions.

IC Perspective: NICHD

Dr. Alison Cernich, Deputy Director, NICHD, works to support the institute's mission to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all. She highlighted the critical role of disability research in NICHD's mission. While intellectual disabilities are foundational to its work, NICHD also addresses other disabilities, including congenital anomalies, physical impairments, and research in assistive technologies. The NICHD Strategic Plan 2025 includes a number of research opportunities that focused on those areas, specifically around congenital anomalies and developmental processes, examining the underlying causes of some of the structural birth conditions that people can experience. NICHD also studies traumatic injury—especially in pediatric populations, where such injuries are understudied—and considers how to better serve people who acquire a disability as result of a trauma early in their life.

The National Center for Medical Rehabilitation Research (NCMRR) within NICHD works to advance interventions for both pediatric and adult conditions, such as cerebral palsy. NCMRR aims to develop scientific knowledge that will enhance the health, productivity, independence, and quality of life of people with physical disabilities across the life span. NCMRR pioneered some of the rehabilitative interventions that are offered to people with acquired disability, developmental disability, or lifelong disabilities, including populations that do not get much attention. It worked with the U.S. Department of

Defense to launch the Limb Loss and Preservation Registry to understand outcomes for people with limb loss who are undergoing preservation surgery or surgical care and rehabilitation.

NICHD is active in the Interagency Committee on Disability Research. Dr. Cernich indicated that the institute also is an active partner and collaborator on the INCLUDE initiative and has an institutional commitment to other research in intellectual and developmental disabilities, including the Intellectual and Developmental Disabilities Research Centers.

In collaboration with the HHS Administration for Community Living's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), NICHD has launched a Community Champions for Disability Health Challenge to support effective, sustainable, and community-led solutions to reduce disparities and promote health equity for people with disabilities. The initiative specifically empowers people with disabilities to take an active role in their health and the health of future generations and answer research questions important to the community. NICHD and NIDILRR are hoping to announce the final winners of the challenge in February 2026.

Dr. Cernich reaffirmed NICHD's commitment to advancing disability research through ongoing collaboration across government agencies. For example, she highlighted that NICHD recently sponsored a request for applications with the National Eye Institute and the NIH Office of Behavioral and Social Sciences Research to understand and mitigate health disparities that people with disabilities experience because of ableism. NICHD also recently announced the funding of 10 projects focused on discrimination and barriers faced by people with intellectual or physical disabilities and visual impairments in health care settings, with a particular focus on maternal health care.

Overview of the Strategic Plan Development Process

Mr. Adam Politis, Senior Advisor for Disability Research, DPCPSI, NIH, discussed the framework for the NIH Strategic Plan for Disability Health Research. He outlined the timeline for the strategic planning process and explained that the NIH Disability Research Coordinating Committee (Committee) is developing a draft framework that will be presented during the Town Hall meeting.

DPCPSI is currently leading the development of an NIH-wide Strategic Plan for Disability Health Research that will identify scientific themes and present goals and objectives to advance research activities that promote the health and well-being of people with disabilities. The plan's development is being led by the recently formed Committee, which includes interdisciplinary expertise across various aspects of disability research. The Committee officially commenced in September 2024. DPCPSI is seeking input from all NIH ICOs, as well as interested external parties. Mr. Politis noted that the full strategic plan is scheduled for public release in 2025 and that updates will be provided throughout the process.

Mr. Politis expressed appreciation to the panel members for their contributions to the meeting discussions. He reviewed the feedback from the six community engagement roundtables, emphasizing disability as a natural aspect of life and highlighting the need to address disability as part of individual identity and rights, to recognize the diversity and multifaceted experiences of people with disabilities, and to include people with disabilities throughout all stages of the research process. Mr. Politis noted the need for research that supports individuals' needs and autonomy. Key themes included prioritizing meaningful participation by people with disabilities across the research process—from setting priorities to sharing results—and fostering and encouraging the role of researchers with disabilities.

The draft Strategic Plan for Disability Health Research is organized into three parts. The first part focuses on crosscutting themes like public participation and community engagement; accessibility; and the

complexity, heterogeneity, and dynamics of disability. The second focuses on the strategic goals, which will span a 5-year period starting in fiscal year 2026. The final part focuses on prioritizing opportunities for improvement, as well as specific actions to address these goals. The strategic plan represents the insights and perspectives shared by disability researchers, advocates, clinicians, and individuals with lived experiences to ensure research and health care facilities are accessible to all. The plan also considers the dynamic and multifaceted nature of disabilities by incorporating sociocultural and environmental factors.

The draft framework outlines four strategic goals:

1. Support high-quality, innovative, and impactful research to improve the health and well-being of people with disabilities of all ages.
2. Build and sustain meaningful internal and external partnerships to promote disability health research.
3. Promote engagement and inclusion of people with disabilities in the biomedical and behavioral research ecosystem.
4. Develop a highly skilled scientific workforce that includes researchers with disabilities and researchers trained in disability health research.

NIH will issue an RFI on December 12, 2024, inviting public feedback on the framework for a period of 90 days. Additionally, DPCPSI will continue to host community engagement events in 2025. Feedback will be solicited from a broad range of stakeholders, including individuals with disabilities, researchers, and advocacy organizations. The draft framework emphasizes interdisciplinary research and improving research environments to support inclusivity and improve quality of life in the disability community. NIH will share RFI details through social media, email, and its Disability Research website.

Public Q&A

How can community-based organizations partner with and contribute to NIH's research efforts to improve the health and well-being of individuals with disabilities?

Drs. Schwetz and Cernich emphasized the importance of partnering with community organizations that focus on the lived experience of people with disabilities rather than academic centers. Dr. Cernich mentioned that NICHD, along with other NIH institutes and centers, has prioritized the lived experiences of people with disabilities in its initiatives. As part of this effort, NICHD launched a challenge that has received significant engagement, with 20 community-based organizations submitting entries. Dr. Cernich noted that NCMRR Director Dr. Theresa Cruz has been instrumental in leading this effort. Dr. Cernich noted that not all participants could be included due to funding limitations, but the robust involvement of disability communities and related organizations has been encouraging.

What actions is NIH taking to ensure that recipients of NIH funding are following requirements and best practices regarding accessibility for disabled researchers?

Dr. Cernich explained that NIH is actively addressing accessibility through three primary lenses: physical and scientific facilities, policies and procedures, and external collaborations. Efforts include making clinical centers and conference facilities more inclusive for individuals with disabilities by accommodating various impairments and ensuring that facilities are welcoming. She noted that policies are being revised to meet accessibility standards—including Section 508 compliance—for processes like grant applications and reviews. NIH also is collaborating with partners to improve accessibility in research publications and processes. The goal is to better support individuals with disabilities and ensure accessibility across NIH's workforce and research community and the broader public engaging with NIH resources.

What is the status of the proposed changes to NIH’s mission statement regarding disabilities?

Dr. Bertagnolli explained that community feedback is not uniform regarding the proposed language changes around reducing disability. She stated that NIH is considering options for obtaining additional feedback on revisions to the mission statement.

How is NIH addressing the health and well-being needs of people with disabilities who are part of other marginalized populations or part of other health disparity populations?

Dr. Pérez-Stable highlighted the concept of intersectionality, emphasizing its relevance to health equity. He explained that this concept has broader implications for both national and global health initiatives. Intersectionality serves as a guiding theme for current funding opportunities aiming to address health disparities linked to intersecting identities. Dr. Pérez-Stable underscored the importance of receiving grant applications that address these issues, reflecting a commitment to advancing inclusive health research and interventions.

Will NIH establish an Office of Disability Research?

Dr. Bertagnolli emphasized avoiding a one-size-fits-all approach, acknowledging the diversity of disabilities. Instead, she suggested leveraging the diversity of disabilities and ensuring that all NIH Institute incorporate various patient experiences into their research. To support this, Dr. Schwetz advocated for a coordinated research team across NIH to provide data and insights for informed decision-making. Dr. Bertagnolli also underscored the importance of proportional representation in disability research and suggested that the number of researchers studying disabilities should reflect the size of the disability population.

Does NIH plan to require collection of disability status of study participants in research studies?

Dr. Schwetz stated that this has been a recurring theme throughout the six roundtable discussions regarding the data being collected. She stated that NIH will take disability reporting into consideration and acknowledged the process is extensive and will require time to appropriately execute. Dr. Pérez-Stable discussed the need for data, including data about people with disabilities from other marginalized populations that experience health disparities. Dr. Cernich stressed the sensitive nature of this effort, noting that participants and researchers with disabilities often face stigma and may not feel comfortable disclosing their disability status. Respect for individuals’ privacy and autonomy was emphasized as essential to fostering trust and inclusiveness in research.

What information will be available about NIH programs?

Drs. Cernich and Pérez-Stable provided the following links:

- [Community Champions for Disability Health Challenge](#)
- Understanding and Mitigating Health Disparities experienced by People with Disabilities caused by Ableism (R01 Clinical Trial Optional) ([RFA-HD-24-007](#))
- [Health and Health Care Disparities Among Persons Living with Disabilities \(R01 Clinical Trials Optional\)](#). This open funding opportunity for research focuses on novel and innovative approaches and interventions to address the intersections of disability, race, ethnicity, and socioeconomic status on health care access and health outcomes. The next submission date is February 2, 2025.

Closing Remarks

Dr. Schwetz expressed appreciation to the presenters and attendees for their engagement during the meeting. She noted that the team will follow up with individuals who submitted questions that were not addressed during the meeting. She added that NIH will issue an RFI on December 12, 2024, and encouraged the attendees to submit a response and share the RFI with others to provide feedback. The recording of the Town Hall will be publicly available, and information on future community engagements will be posted on the DPCPSI disability health research website.