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Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)**

NIH Community Roundtable on Disability Research: Clinicians and Professional Associations

**November 6, 2024
Virtual Meeting**

Meeting Summary

Disclaimer: The opinions and perspectives expressed in this document are those of the panel members and do not reflect the view of the National Institutes of Health, the Department of Health and Human Services, or the United States government.

Panel Members

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Ms. Rachel Miller, American Physical Therapy Association
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Dr. Maggie Nygren, American Association on Intellectual and Developmental Disabilities
Dr. Peter Poulos, Stanford Medicine
Dr. Monica Sampson, American Speech-Language-Hearing Association
Ms. Rebeccah Wolfkiel, National Association of State Head Injury Administrators

Welcome and Introduction

Ms. Vicki Gottlich, Senior Advisor, DPCPSI, NIH, welcomed the participants to the meeting. She explained that this discussion will inform the development of the NIH Strategic Plan for Disability Research.

Dr. Tara A. Schwetz, NIH Deputy Director for Program Coordination, Planning, and Strategic Initiatives, provided opening remarks. She noted that more than one in four adults in the United States has a disability, representing a range of conditions that affect health and well-being. Many barriers, including discrimination and inaccessible environments, can impede their access to timely and comprehensive health care, leading to poor health outcomes. Dr. Schwetz stated that NIH is committed to improving the health and well-being of people with disabilities and acknowledged that more work is needed in this space.

The National Institute on Minority Health and Health Disparities recently designated people with disabilities as a health disparity population. NIH issued a notice of funding opportunity calling for research on novel and innovative approaches to address the intersecting effects of disability, race, ethnicity, and socioeconomic status in the context of access to care and health outcomes. Additionally, NIH recently announced a new program to understand how ableism contributes to health disparities and how to counter the associated negative health effects.

The development of the NIH Strategic Plan for Disability Research is being led by the recently formed NIH Disability Research Coordinating Committee (Committee). Dr. Schwetz explained that this meeting is the second a series of six virtual community roundtables, followed by a virtual public town hall, that

will inform the Committee's strategic planning efforts. Each roundtable includes a panel of disability researchers, clinical care providers, and representatives from advocacy organizations and professional associations. Dr. Schwetz expressed appreciation to the panel members for their contributions to the meeting's discussions.

Ms. Gottlich briefly outlined the timeline for the strategic planning process. She explained that the Committee is developing a draft framework that will be presented during the town hall meeting. The full strategic plan is scheduled for public release in 2025, and updates will be provided throughout the process.

Roundtable Discussion

Ms. Gottlich invited the panel members to respond to three questions. She noted that panelists and attendees also are encouraged to provide additional written comments to NIH after the meeting.

What are the primary scientific opportunities and challenges in disability research that should be addressed by NIH? How can the NIH mission statement most accurately reflect NIH's disability research priorities?

Several panelists suggested that NIH's mission statement—to reduce illness and disability—communicates to people with disabilities that they themselves are part of a problem that needs to be reduced. Disability is a natural, expected part of the life course. NIH's mission should directly recognize disability as a vital aspect of an individual's identity. Rather than focusing on the reduction of disability, NIH could focus on solutions that improve quality of life and support individuals with disabilities in meeting the demands of their environment. Panelists noted the importance of using inclusive language regarding the disability community in NIH's mission and practice.

A significant opportunity for NIH could be to support studies that address disparities faced by people with disabilities. A panelist highlighted the impact of socioeconomic and environmental factors on health care access for individuals with disabilities, particularly as current federal policies limit the availability of necessary resources and services for people with disabilities. For example, physical therapists play a critical role in supporting individuals with disabilities throughout their life span, but access to rehabilitative care is limited.

Panelists highlighted that diversity and intersectionality within the disability community could be reflected in research initiatives. People with disabilities could have full and meaningful representation across all NIH staff, including in leadership roles. In addition, continuous engagement between researchers and the disability community throughout all stages of the research processes could achieve inclusivity in disability research and care. For example, individuals with communication disorders are often excluded from research studies and are reported to have worse health outcomes than individuals without communication disorders. A panelist suggested that disability identification could be treated as a demographic variable in federal and health care surveys, similar to how other demographic information is collected.

Additional research could focus on long-term care and health outcomes for individuals with disabilities. One panelist noted that disability is defined as the gap between the capacity of the individual and the demands of the environment, and research initiatives could seek to understand and support the everyday experiences of people with disabilities, including how they adapt to and navigate everyday society. Innovations in current technologies and machine learning features could be utilized to improve quality of life throughout the life span of people with disabilities.

A panelist stated that NIH could develop a research advisory committee comprising an interdisciplinary team of individuals with disabilities, professional associations, researchers, and advocacy groups to help guide the development of disability research initiatives. Members of the research advisory committee could be compensated for their time and contributions. This type of interdisciplinary collaboration could help identify gaps in disability research. Implementation science research could be prioritized to improve outcomes within the disability community. The panelist highlighted the importance of disseminating these research findings and suggested that professional associations can be valuable partners for the dissemination of research and development of implementation strategies.

How can NIH encourage new investigators to enter the field of disability research, support existing researchers, and promote disability inclusion in the scientific workforce?

Several panelists suggested that NIH designate a centralized repository for training programs, funding initiatives, and resources for investigators in the field of disability research. The centralized repository could help researchers trying to navigate the research process because disability research topics span multiple NIH institutions.

Disabilities are multifaceted, and approaching disability research strategies with both an interdisciplinary lens and consideration of the needs of the disability community could help address research gaps. NIH could establish research initiatives to address specific gaps in disability research—for example, limb loss or limb difference rehabilitation -building on existing programs for disability researchers.

Panelists agreed that targeted funding and training opportunities could encourage new investigators to enter the field of disability research. NIH could fund training programs to equip new investigators with the skills and resources needed to engage in meaningful disability research, including language guidelines and workshops to improve grant proposals. NIH also could lower entry barriers for new investigators by streamlining the application process and incentivizing proposal submissions with pilot data. Mentorship networks and career development programs could help recruit and retain investigators and trainees in disability-centered research.

Researchers with disabilities could be recognized as underrepresented and over excluded in research, with more work to address the barriers that these researchers face. A panelist suggested that NIH fund awareness campaigns and create recognition programs for accomplished researchers with disabilities to reduce the stigma and redefine cultural perceptions of disability. Several panelists remarked that the inclusion of people with disabilities in research—both as researchers and participants—leads to greater scientific impact. Research has shown that personal experience with disability strengthens external validity and facilitates more relevant problem identification and framing. Another panelist suggested creating support networks specifically for researchers with disabilities, stating that individuals with a disability often feel alone in their disability. NIH could create incentives and opportunities to support researchers with disabilities through funding opportunities and training programs

Mechanisms for implementing accessibility could be continuously assessed and systematically updated. Panelists agreed that ongoing feedback from researchers with disabilities could promote accessibility in research facilities. NIH could hold institutions accountable for supporting disability inclusion in the workforce by conducting accessibility audits. All NIH initiatives could be framed with an anti-ableist and intersectional lens to reduce and eliminate bias.

How can NIH improve the inclusion of individuals with disabilities in research and clinical trials, including the development of research topics, and foster collaboration with advocacy groups and professional associations?

Panelists noted that minimal training is available on including individuals with disabilities in research protocols. Inclusion criteria or inaccessible procedures may exclude individuals with disabilities. A panelist remarked that individuals with intellectual and developmental disabilities are often excluded from disability research studies due to the misconception that they are unable to consent. Another panelist highlighted a case study where researchers at Gallaudet University pointed out communication barriers that excluded deaf and hard of hearing participants from clinical studies. Investigators with disabilities could provide their perspectives and influence disability community representation in research. A panelist suggested creating a universal database with detailed disability information to assist researchers in designing more inclusive studies for people with disabilities.

Several panelists suggested that researchers focus on including people with disabilities in the entire process of their research and listen to what is important to various disability communities. Integrating the perspectives of the disability community into policies and implementation strategies could increase inclusivity in disability research initiatives. A panelist suggested that NIH could ensure trust and transparency with the disability community by implementing inclusive language and clear communication in consent forms. Additionally, NIH should mandate scientific justification for any exclusion criteria involving individuals with disabilities.

Researchers could have a plan to incorporate people with disabilities in their projects, including actively recruiting researchers with disabilities, considering the needs and goals of relevant disabled populations for research outputs, and incorporating feedback longitudinally from disability organizations and other experts in an advisory capacity. Panelists discussed that supplemental funding could be included in research studies to cover costs associated with meeting the accessibility needs of participants with disabilities. Patient-centered outcomes research could provide insights into best practices for inclusion in clinical trials.

Public Q&A

How can NIH meaningfully engage with the disability community such that the needs of these individuals are addressed?

A panelist suggested that continuous interdisciplinary engagement helps research studies reflect the needs of the disability community. Members of the disability community could share their lived experiences and provide feedback through public meetings and participation in research studies.

Another panelist noted that NIH could encourage academic centers to recruit and retain students with disabilities. By gaining insights from these students, programs could be tailored to support students' career goals and address their needs. Community engagement could be a priority in disability initiatives.

A panelist highlighted that individuals often do not disclose their disabilities due to fear of stigma and bias. Addressing this issue helps foster an environment where individuals with disabilities feel comfortable requesting necessary accommodations.

Panelists noted that definitions of disability and identity vary greatly depending on the individual and suggested that NIH incorporate this diversity in the mission statement.

Panelists shared resources for the disability community (e.g., Docs with Disabilities, Disability in Medicine Mutual Mentorship Program, Disability Equity Collaborative, National Roadmap for Disability-Inclusive Healthcare).

How can NIH improve accessibility and inclusion for the disability community?

A panelist suggested that NIH go beyond the minimal legal requirements for accessibility and assess the needs of individuals with disabilities.

Another panelist discussed the importance of collaborating with NIH to enhance support for disability-related services across the life span. Advocating research-driven coverage for treatments, particularly physical therapy, is critical to addressing health care coverage accessibility for individuals with disabilities.

Closing

Ms. Gottlich expressed appreciation to the panelists and attendees for their engagement. She noted that the team will follow up with individuals who submitted questions that were not addressed during the meeting. Ms. Gottlich also encouraged attendees to submit additional questions; instructions for submitting questions will be provided via email after the meeting. She reminded the attendees of additional roundtable discussions to be held in the coming weeks and encouraged them to attend. Ms. Gottlich adjourned the meeting.