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Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)
NIH Community Roundtable on Disability Research: Clinicians and Professional Associations

November 14, 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

Ms. Duffy Felmlee, University of Hartford
Dr. Nitin Gogtay, American Psychiatric Association
Dr. John Hall, University at Buffalo
Dr. Joy Hammel, University of Illinois Chicago
Dr. Amy Houtrow, University of Pittsburgh
Dr. Matthew P. Janicki, The University of Maine
Ms. Natalie Keller, Powers Pyles Sutter & Verville PC
Dr. Brad Kurowski, Brain Recovery after Injury Health and Wellness Center
Dr. Paul Mulhausen, Centene Corporation
Ms. Andrea Van Hook, Rehabilitation Engineering and Assistive Technology Society of North America
Ms. Aliya Siddiqui, American Medical Association

Welcome and Introduction

Mr. Adam Politis, Acting Senior Advisor for Disability Research, DPCPSI, NIH, welcomed the participants to the meeting. He 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 recently formed NIH Disability Research Coordinating Committee (Committee) are leading the development of the NIH Strategic Plan for Disability Research. Dr. Schwetz explained that this meeting is the fifth in a series of six virtual community roundtables. These will be 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.

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

Roundtable Discussion

Mr. Politis invited the panel members to respond to the three questions below. He 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 pointed out that NIH's mission could be revised to have more inclusive language and an anti-ableism lens. Rather than focusing on reducing disability, NIH could empower the disability community and recognize disability as a fundamental aspect of an individual's identity, with an emphasis of optimizing health and function. NIH should prioritize solutions that support individuals in navigating their environments and improving their quality of life. One panelist emphasized that quality of life is inappropriately equated to one's ability to function.

NIH could incorporate the diversity and intersectionality of disability into research initiatives. Rather than conceptualizing disability at the level of body function, disability research could be approached through a biopsychosocial model, focusing on environmental, social, and societal factors that influence emotional and physical health outcomes in the disability community. People with disabilities have overlapping identities, and racial, ethnic, and socioeconomic factors could be included in disability research. Panelists highlighted that NIH could actively incorporate the lived experience of people with disabilities to improve representation in disability research and understand their needs. This could be achieved through large-scale integration of community and health care systems and by integrating the perspectives of the disability community into research initiatives.

NIH could expand funding at the intersection of disability and neuroscience research. Several panelists highlighted aspects of neuroscience research (e.g., mental health, cognitive rehabilitation, biases toward intellectual disabilities). Mental health conditions often occur concurrently with physical and cognitive disabilities, offering a unique research opportunity. For example, understanding how mental health issues (e.g., anxiety, depression, post-traumatic stress disorder) affect individuals with physical disabilities could lead to more holistic treatment strategies. Additionally, advances in neuroscience with neurofeedback and cognitive rehabilitation could aid in both mental and physical recovery.

Panelists remarked that people with cognitive and intellectual health disabilities may be excluded from research topics and processes. The aging population, which is most affected by dementia, represents a major proportion of the disability community. A panelist suggested that NIH dedicate funding for research studies oriented toward cognitive impairment disabilities and engage with cognitive disability organizations to improve inclusivity for adults with a broad range of cognitive disabilities. Recognizing

the effect of discrimination on those with cognitive and intellectual disabilities could promote understanding and accurately representing the disability community.

Research efforts could consider the diverse nature of disabilities (e.g., age of onset, acquired vs. congenital). Panelists suggested research regarding long-term care and health outcomes for individuals with disabilities as people with disabilities often experience chronic comorbidities (e.g., obesity, diabetes, heart disease, complications from smoking) that evolve with increasing age. One panelist highlighted the need for collecting longitudinal data points in pediatric disability conditions, as the needs of children with disabilities may differ from the aging population.

Several panelists highlighted the importance of improving the quality of life for the disability community. NIH could prioritize research initiatives that focus on assistive technology and involve researchers that utilize these technologies in study designs. One panelist encouraged NIH to establish programs to educate the disability community on resources and research updates that could support them. Panelists agreed that interdisciplinary research is needed—especially involving engineers—to improve and promote assistive technology for the disability community.

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 establish a central office for disability research to streamline resources (e.g., educational material, training programs, funding initiatives, mentorship opportunities) for disability researchers at all career stages. They noted that disability research topics span multiple NIH institutions. NIH could support researchers with disabilities by ensuring accessibility and providing access to assistive technology and educational training to utilize these resources. One panelist suggested NIH improve salary support for investigators with disabilities, noting that salary caps can often discourage researchers from entering the field.

Panelists suggested that people with disabilities have full and meaningful representation across all NIH roles; representation in the workforce could help improve awareness of disability research. One panelist suggested that NIH fund awareness campaigns for researchers with disabilities, including highlighting publications from disability researchers. In addition, NIH could raise awareness of the advances in disability research by promoting workshops, funding announcements, conferences, and community events. Regarding funding announcements and recognition of disability researchers, one panelist suggested that NIH follow the structure of awareness campaigns led by the National Center for Medical Rehabilitation Research model of disability.

Panelists noted that recruitment efforts and support for researchers with disabilities could target younger trainees as students. By gaining insights from these students, programs could be better tailored to support their career goals and address their needs. Many panelists suggested that NIH establish formal mentorship programs to guide researchers who are in the field of disability research at all career stages, including mid-level and advanced investigators.

NIH could create targeted research initiatives to address specific gaps in disability research and encourage interdisciplinary collaboration. Panelists touched on research opportunities at the intersection of mental health and disabilities, assistive technology, and chronic medical conditions that co-occur with disabilities. These research opportunities could exist as F-level grants for trainees and K- and R-level for new and late-stage investigators. NIH could lower barriers to entry by streamlining the application process and increasing funding paylines to incentivize trainees and researchers with disabilities to engage in disability research.

Panelists agreed that mechanisms to normalize disabilities could help accurately represent the disability population. One panelist remarked that the number of individuals with a disability may be higher than one in four because the fear of bias and stigma prevents individuals from reporting their disabilities. NIH could develop a structural and inclusive framework, such as with additional demographic information (e.g., race, gender), to encourage individuals with disabilities to report their disability status.

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?

NIH could ensure trust and transparency with the disability community by implementing inclusion plans for all NIH-funded projects. Specifically, panelists highlighted the need to improve inclusivity in research studies for individuals with intellectual and cognitive disabilities. Disability increases with age, and approximately 50% of people older than age 75 have a disability, including dementia; thus, the importance of including these populations in research studies. In addition to improving inclusionary criteria for research studies, a panelist suggested that NIH could mandate mixed and integrated research methodologies—shifting from traditional large-scale blinded trials toward rigorous smaller sample experimental designs.

Panelists discussed the importance of including people with disabilities and their caregivers throughout all stages of the research study to support people with disabilities in all aspects of their lives. The latter is particularly important for people who have profound intellectual disabilities and who might face difficulties in sharing their experiences directly. Additionally, inclusivity in disability research could be achieved through ongoing collaboration with the disability community, professional associations, and advocacy groups to improve inclusionary criteria for research studies. Several panelists stated that NIH could mandate scientific justification for any exclusion criteria involving individuals 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 help address the needs of the disability community. One panelist highlighted that the American Medical Association established the Center for Health Equity and a disability advisory committee to advise on policies and accessibility, models NIH might want to consider. NIH could ensure trust and transparency with the disability community by implementing inclusive language and clear communication in consent forms. Investigators with disabilities could provide their perspectives on clinical trial design to improve recruitment and inclusion of the disability community in research.

People in the disability community may be unaware of disability research updates and miss out on research studies, creating a disconnect between researchers and the community. NIH could disseminate findings and resources to the disability community in a clear and accessible way. This includes ensuring that all grant applications, products, papers, and presentations meet basic digital accessibility standards and developing training on this topic. Panelists suggested that NIH funding provide additional resources to ensure accessibility for individuals in the disability community to participate in clinical trials and community engagement events. This includes disseminating all findings and resources to the disability community in multiple formats to accommodate the different types of disabilities. One panelist highlighted that improvements in accessibility conferences and symposia are necessary (e.g., accessible conference programs and timelines).

Public Q&A

How can NIH support new researchers with disabilities entering the field of disability research?

A panelist noted that NIH could develop mentorship programs that connect new researchers with disabilities with established investigators to reduce the barrier of entry into the field. NIH could support the accessibility needs of the researchers with disabilities. This includes incorporating assistive technologies that are tailored to the needs of the respective researchers. The panelist encouraged new researchers with disabilities to actively involve physical medicine and rehabilitation (PMR) specialists who have experience with assistive technology in their repertoire of health care professionals.

Panelists noted NIH's mission to optimize health and functioning, prioritizing disability research initiatives that improve the quality of life for people with disabilities.

How can health and research information be clearly communicated to the disability community?

NIH could prioritize research initiatives that assess health literacy regarding accessibility in the disability community. The diverse nature of disabilities should be considered when disseminating information in various formats to accommodate each type of disability. Accessibility needs differ among sensory, physical, and cognitive disabilities. NIH could provide funding to disseminate information (e.g., research advances, recruitment for research studies, community partnerships) to the disability community in various accessibility formats, including plain language.

Panelists discussed how engaging people with disabilities throughout the research process helps improve health literacy and equitable care access and promotes consideration of people with disabilities through a biopsychosocial lens.

What do you consider the scope of disability research?

Several panelists noted that NIH could restructure the research approach beyond the level of the disability itself (e.g., at the body function level). The intersectionality of disability within marginalized populations is underrepresented. Improvements to reporting mechanisms could help accurately reflect the disability community. NIH could allocate funding to support chronic care for the disability community.

Efforts could be made to prioritize accessibility for the disability community with assistive technology. This could improve both mental and physical health outcomes in the disability community. NIH could focus on research initiatives that assess the feasibility of disability research (e.g., cost, time commitments, benefits).

Closing

Mr. Politis expressed appreciation to the panelists and attendees for their engagement during the meeting. He encouraged attendees to join the upcoming community roundtable that will feature the town hall and panelists with lived experience of disability. He adjourned the meeting.