

**U.S. Department of Health and Human Services (HHS)
National Institutes of Health (NIH)
Office of the Director (OD)
Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)
NIH Community Roundtable on Disability Research: People with Lived Experience and Advocacy
Organizations Session**

**November 20, 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. Zainab Alkebsi, Deaf Equality
Mr. Michael Brogioli, TASH
Mr. Karl Cooper, American Association on Health and Disability
Ms. Marissa Ditkowsky, American University Washington College of Law, National Disabled Legal Professionals Association, and National Partnership for Women & Families at the Disability Economic Justice Counsel
Dr. Rebecca Edelmayer, Alzheimer’s Association
Dr. Jacqueline Rodriguez, National Center for Learning Disabilities
Dr. Arielle Silverman, American Foundation for the Blind
Dr. Vijay Vasudevan, Autism Speaks
Ms. Ashlie White, Amputee Coalition
Ms. Silvia Yee, Disability Rights Education and Defense Fund

Welcome and Introduction

Mr. Adam Politis, Acting Senior Advisor for Disability Research, DPCPSI, NIH, welcomed the participants. He explained that this meeting is the last of six virtual community roundtables, which will be followed by a virtual public town hall. Each roundtable includes a panel of disability researchers, clinical care providers, advocacy organizations, and professional associations.

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 highlighted the diversity within the disability community, which includes multiple subpopulations with a wide range of experiences and subcultures. 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.

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.

DPCPSI is currently leading the development of an NIH-wide Disability Research Strategic Plan. This plan will identify scientific themes and develop 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 NIH Disability Research Coordinating Committee (Committee). DPCPSI is seeking input from all NIH Institutes, Centers, and Offices, as well as external interested parties. Dr. Schwetz explained that this meeting is the last in 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.

Mr. Politis 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 meeting. The full strategic plan is scheduled for public release in 2025, and updates will be provided throughout the process.

Roundtable Discussion

Mr. Politis provided instructions for the roundtable discussion and invited the panel members to respond to the three questions below.

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 noted that the medical model of disability—which focuses on the causes of disability and views disability as an impairment that needs to be healed—is woven into NIH's mindset, mission, and research agenda. One panelist remarked that NIH's mission statement could recognize the equal worth of people with disabilities and the need for scientific research that maximizes their quality of life. The mission statement could better reflect NIH's disability research priorities by including a clear statement about accessibility, health equity, and research on health disparities in the disability community. Ableist language in the NIH mission statement about seeking to reduce disability could be removed. NIH could continue efforts to integrate the social model of disability into its perspective and address how societal barriers affect the health of people with disabilities. People with lived experience could shape priorities in these areas.

The panelists provided suggestions related to collecting population-level data about people with disabilities. One panelist stated that designating people with disabilities as a health disparities population was an important step toward more accurate and inclusive research. With the new designation, NIH could conduct a Committee on National Statistics (CNSTAT) study on more accurate and inclusive disability data collection and research practices. Federal organizations and agencies could collaborate with experts and people with lived experience to establish consistent definitions and standards for measuring disabilities. Health disparities data could be collected on different subpopulations within the disability community (e.g., autism, developmental disabilities, learning disabilities, limb differences, and sensory disabilities). Current measurements could be revised because they do not accurately capture certain disabilities (e.g., learning disabilities), and surveys could avoid subjective questions to avoid underrepresentation of certain disabilities. A panelist stated that measurements could enable comparisons of data from different sources and across different areas of life. Another panelist suggested that NIH-funded research address the measurement of disabilities within different contexts (e.g., school systems, workforce, health care systems).

The panelists discussed certain forms of research and research areas. Research on genetic screening and diagnosis could be conducted in a way that considers how people with disabilities and their families will be affected. Training material for artificial intelligence (AI) models could be screened for negative stereotypes about disability and people with disabilities so that these models do not perpetuate ableism. This is especially important when AI is being used as a decision-making tool or when a model is self-learning and self-correcting.

Panelists suggested comprehensive and intersectional approaches to disability research. Research could be conducted on certain conditions (e.g., autism, Down syndrome, sensory and mobility disabilities) and their connections to Alzheimer's disease and other forms of dementia. The research could determine whether aging adults with these conditions have unique needs. They suggested increased awareness of the intersectionality of deafness, communication access, and health outcomes is needed. Research could explore aspects of health and health care—especially regarding mental health—that affect the deaf and hard-of-hearing community. Communication barriers and barriers to health literacy that prevent access to health information in this community also could be studied. They also suggested research to help support families in assisting family members with neurodevelopmental disorders. Studies could focus on people with the most significant disabilities who are underrepresented, even within the disability community, and NIH could allow studies with small sample sizes to accommodate this research.

The panelists discussed other opportunities and challenges in disability research. A panelist commented that ableism in research and health care settings could be addressed, and NIH could fund research focused on interventions directed at reducing ableism. Other panelists pointed out that NIH could increase funding for disability research across the continuum of care and that support for systems-level research to identify barriers to service access could be expanded. For example, the National Institute of Mental Health currently has a committee on health services which could be replicated. One panelist hoped that research findings on how marginalization affects the health of disabled people could be translated into updated policy and legislature. Another noted that NIH could focus on areas of research in which private insurers and insurance programs require evidence-based clinical standards. This includes studies on substance use disorder and interventions to address unhoused populations.

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

The panelists suggested that people with disabilities need to be represented in research. Systemic ableism and barriers to people with disabilities could be eliminated from higher education and training pipelines in all fields related to disability research. The panelists discussed new programs, funding mechanisms, and systemic changes that would promote disability inclusion in the biomedical research workforce. Funding for disability research and disabled researchers could cover the career continuum, from graduate programs and early career pilot studies to larger R01 projects. NIH could provide guidance on how undergraduate and graduate schools can provide educational accommodations and policy modifications for students and faculty with disabilities. Data on students with disabilities could be collected from institutions that receive NIH funding. NIH could support disabled researchers through accessible outreach, technical assistance, and training opportunities. American Sign Language (ASL) and closed captioning could be available for NIH training and grant application information, and NIH could earmark a portion of grant funding for accessible communication. Training to promote inclusive mindsets could be developed for NIH staff and academic faculty. NIH could continue collecting data to ensure that the composition of its workforce reflects the wider population. Demographic information on positions, compensation, and supervisory responsibilities could be included.

One panelist highlighted several barriers that limit the number of deaf and hard-of-hearing researchers, including a lack of funding and inaccessible methodologies, which can be addressed. For example,

software commonly used by researchers could be made accessible, and barriers in the built environment could be removed. NIH could support deaf and hard-of-hearing investigators through targeted funding opportunities, mentorship programs, and partnerships with institutes that have expertise in deaf studies and research.

Another panelist focused on advancing research on neurodevelopmental disabilities. NIH could tailor fellowships and career development awards for neurodevelopmental disabilities researchers and establish preparation programs for people with neurodevelopmental disabilities to become teachers and researchers.

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 discussed increased community engagement. They noted that NIH funding could include a requirement for community-based participatory research when designing, funding, and disseminating science to ensure the research is relevant and appropriate. Study sections could include disabled reviewers, and study results could be disseminated in plain language. NIH could update Institutional Review Board (IRB) processes and protocols, including requirements for representation and input from the disability community and training for IRB members on issues relevant to the disability community. For example, certain members of the disability community require proxy consent, and training could help researchers include people who require proxy consent in their studies.

The panelists agreed that eligibility criteria for study populations could be more inclusive and not automatically exclude people with disabilities. Funding applications could require an explanation of why people with disabilities will or will not be included in a study. One panelist pointed out that drug side effects and changes in efficacy in disabled populations remain unknown when they are not included in studies. NIH could encourage diversity and representation in clinical trials through accessible clinical trial design. ASL and closed captioning could be available for study materials. Surveys could be translated into plain language and compatible with speech-to-text software and other assistive technologies to ensure that relevant data are generated.

Panelists highlighted populations that could be the focus of more inclusive studies. Clinical trials could include people with intellectual and sensory disabilities and people with Alzheimer's disease or other forms of dementia. NIH could prioritize trials focusing on the unique health experiences of deaf and hard-of-hearing people and require that people with neurodevelopmental disorders are included proportionately in population-based research and clinical trials.

Public Q&A

How can NIH meaningfully engage with the disability community such that individuals feel like there is relationship building, versus just checking off a box?

Panelists suggested how people from the disability community could be included in every step of the research process. Ample research demonstrates that people with lived experience have more informed perspectives on disability research than people without lived experience. Advocacy organizations and people with disabilities would like to be included in the early stages of research design and compensated fairly for their efforts. Funders could ensure that grants are sizeable enough for researchers to consult with one or more disability advocacy organizations in the early stages of their research. Research on caregiving required for people with disabilities—especially young people with disabilities—could include input from those receiving the care.

The panelists discussed ways to support students and trainees with disabilities. Exams for education and career advancement could accommodate people with disabilities. The costs associated with these tests are an additional barrier to people with disabilities entering the research workforce. Student disability organizations could be recognized and supported.

One panelist pointed out that not everyone with a developmental disability possesses an intellectual disability, and that differences in challenges and support needs exist, even within impairment groups.

Another panelist remarked that increases in extreme weather and natural disasters because of climate change disproportionately affect people with disabilities. They suggested that more data are needed on these effects and how to improve outcomes.

Closing

Ms. Vicki Gottlich, Senior Advisor, DPCPSI, NIH, expressed appreciation to the panelists 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. Attendees were encouraged to attend future roundtable discussions and submit additional questions and comments to NIH after the meeting.