NIH Community Roundtable on Disability Research: Researchers

October 30, 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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Dr. Juliann Anesi, University of California, Los Angeles
Dr. Amber Angell, University of Southern California
Dr. Kara Ayers, University of Cincinnati
Dr. Maryann Davis, University of Massachusetts Chan Medical School
Dr. Jean Hall, The University of Kansas
Dr. Wyatte Hall, University of Rochester Medical Center
Dr. Susan Havercamp, The Ohio State University Wexner Medical Center
Dr. Poorna Kushalnagar, Gallaudet University
Dr. Janice Light, The Pennsylvania State University
Dr. Monika Mitra, Brandeis University
Dr. Joel Michael Reynolds, Georgetown University
Dr. Margaret Turk, State University of New York Upstate Medical University
Dr. Rupa Valdez, University of Virginia

Welcome and Introduction

Mr. Adam Politis, Acting Senior Advisor for Disability Research, NIH Division of Program Coordination, Planning, and Strategic Initiatives, 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 (NOFO) 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 first 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 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 meeting. 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 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 could directly recognize disability as a vital aspect of human diversity and health research.

Panelists noted that NIH has viewed having a disability as a health outcome to be corrected—not a demographic group that experiences health disparities. NIH could develop better, more inclusive ways to identify disability as a demographic, rather than using indirect measures that are deficit based. Research has shown that these functional measures miss many people with disabilities, including those with psychiatric disabilities, intellectual disabilities, and disabilities due to chronic conditions including Long COVID. Panelists suggested that more work be done to broaden NIH's definition of health.

Several panelists remarked that a significant opportunity for NIH would be to challenge the traditional framework of disability as a condition to be cured and instead incorporate disability into diversity efforts (e.g., biopsychosocial model). Participants remarked that not considering disability through a social model lens or cultural model lens limits the way that researchers are able to integrate disability into the development of research questions. They suggested that research could move from identifying the deficits of people with disabilities toward acknowledging society's role in creating the challenges, using the tools of modern medicine to do so.

A panelist noted that expanding disabilities research offers unique insights into what it means to be human. For example, research on Deaf communities can improve understanding how language access shapes life processes. Rather than solely focusing on the reduction of disability, NIH could seek to understand and support the everyday experiences of people with disabilities, including how they adapt to and navigate everyday society. Innovations designed by and for people with disabilities have proven useful for all people (e.g., keyboards, electric toothbrushes, speech to text, voice recognition).

A panelist noted that people with mental health disabilities often are excluded from research topics and processes. Recognizing the effect of discrimination on those with mental health disabilities is key to understanding their access to services and functioning in society. Much of NIH's research has addressed the more straightforward issues relative to disability, and NIH could consider research to prioritize the most complex problems for individuals who need the most extensive support. NIH could support other groups and initiatives that are already performing work in this space through both long-term and short-term mechanisms.

Panelists suggested that NIH can play a transformative role in supporting disability research by funding studies that address the major health disparities faced by people with disabilities, identifying upstream factors causing these inequities, supporting intersectional research, and funding research on the development of evidence-based interventions that support people with disabilities. This can be achieved by designating people with disabilities as a priority population across all NOFOs and by developing NOFOs that specifically prioritize disability-focused research. The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development's research on pregnancy and disability could serve as a model for efforts in this space.

People with disabilities should be included in all research projects, not only those specifically focused on disabilities. NIH could consider how to promote the overall importance of disability to researchers throughout the agency. NIH could look to the research of advocacy organizations (e.g., Docs with Disabilities) that could apply to the research enterprise more broadly, identify tension points in the research training pipeline, proactively improve accessibility, and reconsider approaches to established processes (e.g., standardized testing). It was also suggested that NIH maximize accessibility to all NIH facilities, communications, publications, and events by integrating principles of universal design to help foster a culture of inclusion throughout NIH.

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

Panelists remarked that NIH can play a role in dismantling the barriers faced by trainees with disabilities. More work is needed to recruit trainees with disabilities who can take a lead in disability research, establish mandatory training for all NIH-funded researchers on working with trainees with disabilities, and create written policies and procedures for ensuring accessible environments. A participant suggested that those training programs be led by individuals with disabilities. Another participant suggested developing innovative approaches for mentors with lived experience to engage with trainees on how to navigate challenges in this space.

Mechanisms are needed to support researchers with disabilities, similar to those that support investigators from underrepresented racial and ethnic populations. Mechanisms could also be established to support co-researchers who do not have an academic background. 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. The panelists also noted that spaces of solidarity are needed to bring together disabled researchers from multiple disciplines.

Researchers with disabilities could be recognized as underrepresented and over excluded in research, and with more work done to address the barriers that these researchers face. Panelists suggested that people with disabilities have full and meaningful representation across all NIH staff, including in leadership roles, and that NIH recognize atypical career paths for researchers with disabilities. NIH could fund training programs to provide new and established investigators with the skills and resources needed to engage in meaningful participatory research. Grant programs could prioritize this type of research and

establish participation groups that work with researchers to co-develop research questions and co-lead the conduct of research.

Panelists discussed misconceptions about researchers with disabilities in the grant review process. The process could require grant proposals to explicitly include team leadership from the communities they affect, ensuring that research priorities are shaped by those with lived experience. Additionally, the peer review community could include members of the disability community. Increasing the presence and influence of researchers with disabilities is crucial for providing relevant, ethical, and impactful studies. NIH could create funding mechanisms that support the process of engagement between researchers, advocacy groups, and people with disabilities that will lead to the identification of high-priority research questions. NIH could require and allocate points for having project staff with disabilities.

Panelists suggested more research to address systemic ableism and to develop technologies and research approaches to dismantle those barriers; with people with disabilities engaged in these efforts. People with disabilities also could be involved in developing NOFOs, and NIH could require researchers to allocate spaces for people with disabilities on their research teams. Models from other entities, such as mechanisms supported by the U.S. National Science Foundation, could provide a guide for efforts in this area. Administrative supplements could be provided for making existing research opportunities fully accessible to people with disabilities.

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 about including individuals with disabilities in research protocols. Inclusion criteria or inaccessible procedures may result in excluding individuals with disabilities. A panelist suggested that applicants for NIH funding provide a letter of support saying that they have the appropriate resources and budget to provide accommodation to any potential participants Disability and inclusion enrollment reports for clinical trials could emphasize the importance of planning and intentionally recruiting individuals with disabilities into clinical trials.

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. This type of research requires additional time and resources. People with disabilities should also receive fair compensation for participating in research. Patient-centered outcomes research could provide insights into best practices for inclusion.

Researchers could ask questions that matter to the disability community, including research on the mechanisms that contribute to health disparities and the recognition that many people with disabilities have other marginalized identities. NIH could engage members of the disability community in a way that encompasses the diversity of that community.

Panelists suggested work to ensure that data collection methodologies (e.g., surveys) are inclusive of people with disabilities. People with disabilities could be incorporated into research 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. Supplemental funding could be used to cover costs related to accessibility for funded projects.

The panelists suggested that NIH could support mechanisms for community members and researchers to share their insights on supporting more inclusive research and methodologies, which can be accelerated to

become standard expectations for all research. For example, NIH could fund networks to foster the sharing of resources and knowledge regarding research that includes people with disabilities.

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?

A panelist underscored the importance of including people from the community in every step of the research process (e.g., formulating important research questions, setting priorities, obtaining funding, designing methodologies, interpreting findings, disseminating information).

Another panelist noted that NIH could establish mechanisms to foster direct engagement between program officers and community members via regular meetings; the NIH Common Fund's Transformative Research to Address Health Disparities and Advance Health Equity initiative was highlighted as a model for future efforts.

A panelist also noted that NIH could turn to other organizations (e.g., National Institute on Disability, Independent Living, and Rehabilitation Research) for models that establish community-partnered researchers as a core principle for funding.

Closing

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