

**U.S. Department of Health and Human Services (HHS)
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Office of the Director (OD)
Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI)
NIH Community Roundtable on Disability Research: Researchers**

**November 12, 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

Dr. Erin Bouldin, The University of Utah
Dr. Luis Columna, University of Wisconsin–Madison
Dr. Robert Dembo, The University of Chicago
Dr. Anjali Forber-Pratt, American Association on Health and Disability
Dr. Gilbert Gimm, George Mason University
Dr. Jae Kennedy, Washington State University
Dr. Scott Landes, Syracuse University
Dr. Gina Livermore, Mathematica
Dr. Michelle Meade, University of Michigan
Dr. Corey Moore, Langston University
Dr. Megan Morris, University of Colorado Anschutz Medical Campus
Dr. Bonnielin Swenor, Johns Hopkins University

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 (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 help in understanding how ableism contributes to health disparities and how to counter the associated negative health effects.

The recently formed NIH Disability Research Coordinating Committee (Committee) is leading the development of the NIH Strategic Plan for Disability Research. Dr. Schwetz explained that this meeting is the fourth 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 agreed on the importance of designating people with disabilities as a health disparity population. NIH could lead the way in embracing disability as a demographic rather than a health outcome or status, as well as driving the research agenda across all Institutes and Centers (ICs). The panelists suggested that NIH's mission be revised. One panelist thought that NIH could acknowledge and integrate definitions used by various federal laws and regulations; the definition of disability has changed over time, and NIH's language could reflect these changes. Another panelist highlighted the importance of open communication regarding the implications of changes to the NIH mission statement.

Panelists suggested looking to work in the fields of racial and ethnic disparities to help describe disability disparities and to develop interventions. Additionally, disability identity could be considered separately from functional impairments. NIH could consider disability through a biopsychosocial model. Disability affects all people, and understanding the social consequences of disability status is critical to developing interventions. A panelist emphasized that disability could be considered an independent variable in research. Disability research has the potential to improve the reach of NIH research more broadly (e.g., accessible diagnostic testing, reduced bias, understanding aging) and to close research gaps.

Disability research represents an interdisciplinary field. More data are needed to identify mechanisms, pathways, and determinants that contribute to health disparities. Methodologies from other fields could be applied to address this topic and implement interventions and policies to promote health equity for people with disabilities. Additionally, prior research on other types of disparities could offer insights into understanding disability-related disparities. A panelist also remarked that innovations in assistive technology and artificial intelligence can enhance the health and independence of people with disabilities. It was noted that these efforts could foster both primary and secondary research on this topic, leading to a better understanding of various health conditions that co-occur with disabilities. In particular, the intersection of disability and aging (e.g., Alzheimer's disease and related dementias) offers an opportunity for future research.

Disability is complex, and research efforts could focus on a variety of factors (e.g., acquired vs. congenital, age of onset, level of functional impairment). Specific measures and common data elements also are needed. People with disabilities often have multiple identities, including multiple disabilities,

making it challenging to study an individual's disability identity comprehensively. Disability research also could be expanded to include racial, ethnic, and socioeconomic backgrounds. Limited representation remains a challenge in this space. Research often reflects the majority population, leaving gaps in understanding diverse communities. The diverse lived experiences of people with disabilities could be reflected in these efforts. Meaningful community engagements and partnerships could help enhance trust in science research. Open communication will be essential for progress in this area.

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

A panelist pointed out that many researchers are passionate about this topic, but limited funding remains a challenge. Several panelists discussed the need for dedicated, sustained funding for disability research more broadly; it was noted that most NIH research is focused on specific diseases and body systems. An NIH-wide disability research office could serve as a critical hub for advancing disability research, coordinating disability-related research and activities across NIH, and ensuring meaningful community input in NIH programs and policies. NIH could also ensure that funding opportunities reach the appropriate researchers.

Several panelists talked about dedicated funding for capacity building (e.g., mentorship). A T32 postdoctoral fellowship program, for example, could help bridge gaps in this space. They also discussed appropriate compensation for both mentors and researchers, particularly because ableism contributes to additional labor-related needs in this space. Offering fellowships for disability research could attract scholars with lived experience, even if having lived experience is not a requirement. Structures supported by NIH ICs (e.g., National Institute of Mental Health, National Institute on Aging [NIA]) could serve as models for such mechanisms. NIH could identify barriers that have historically prevented people with disabilities from participating in research to inform new strategies that would enable greater participation in the future.

Panelists suggested that NIH recognize investigators with disabilities as being underrepresented in biomedical research. Efforts could include hiring people with disabilities, especially those from diverse backgrounds. It was noted that partnerships with key communities—particularly marginalized communities—would be essential for this effort. NIH could ensure that all relevant voices are represented in this space and could encourage investigators and peer reviewers to report disability demographics. Training for study section reviewers would also help researchers recognize the importance of research in this space.

Several participants suggested that an NIH-wide office could help inform funded priorities encouraging investigators with disabilities to enter the field of disability research, support existing investigators, and promote inclusion. This office could be led by people with lived experience and could play a key role in pushing the field forward; this could include developing tools to promote inclusion of people with disabilities in research. The office also could coordinate efforts with other federal agencies. Panelists said that funding for this office would help its success.

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?

Several panelists noted that NIH could ensure that people with disabilities are included in all stages of research, highlighting the importance of ensuring optimal representation of people with disabilities—for both researchers and participants—across the biomedical and behavioral research ecosystem. They suggested focused efforts to advance policies that address this topic as a way to help better understand the

barriers and challenges facing people with disabilities that prevent them from participating in research studies and clinical trials.

A panelist remarked that NIH is uniquely poised to address systemic inequities and ableism in the research process by leveraging its intramural research program and educating extramural Institutional Review Boards. Inclusion plans could be required for all NIH-funded projects, similar to NIH's requirements for inclusion of minority groups and genders. Including people with disabilities on research teams could help foster progress in this area; this could be considered when assessing organizational capacity in grant reviews. Medical education training would also help health professionals better understand the experiences of people with disabilities.

Research topics could be developed in collaboration with advocacy groups and professional associations. Community-based listening sessions were suggested. People with disabilities could be included in institute advisory councils that set research priorities. It was noted that these partnerships would help set best practices within the field. Several panelists also suggested including family members and caregivers in research to provide inclusive support, particularly for people who have profound intellectual disabilities and would face difficulties in sharing their experiences directly. Furthermore, a panelist remarked that 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.

It was noted that guidance on developing more inclusive recruitment strategies for research would be useful, with a focus on ensuring that exclusion criteria do not disadvantage people with disabilities. It would be beneficial to help investigators understand how to make the processes of data collection and study involvement more inclusive. Efforts could be made to increase representation on project evaluation panels and study sections; NIH also could increase requirements and prioritize partnerships with disability organizations. Additionally, researchers could be required in grant proposals to explain how their work will contribute to optimizing health and reducing disparities affecting people with disabilities.

Panelists suggested a more structured effort (e.g., demographic-based research centers) to help promote progress in disability research, and NIH ICs (e.g., NIA, National Institute on Minority Health and Health Disparities) could serve as models for such a mechanism. Additionally, collaborations with other federal agencies (e.g., National Institute on Disability, Independent Living, and Rehabilitation Research [NIDILRR]), organizations (e.g., advocacy groups), and research institutions could help inform strategies for promoting inclusive research. Such linkages would enable longitudinal studies that consider social determinants of health and support public policy research.

Public Q&A

How will NIH include the perspectives of individuals with disabilities and caregivers in grants?

A panelist noted that other agencies (e.g., U.S. Department of Defense, NIDILRR) have established advisory committees for research grants. The applicant for the grant could propose such a committee to move their science forward. Working with such advisory committees requires ongoing training and coordination (e.g., through a participatory action model).

Efforts could be made to ensure that this participation is meaningful and that the participants are compensated appropriately for their time to recognize the participants' expertise. Another panelist commented that individuals with disabilities could be considered as equal members of the research team. A reciprocal knowledge translation process would be crucial for these efforts, and NIH could focus on developing trust and relationships with communities over time.

Is there a way to support caregivers of people with disabilities to conduct and participate in disability research?

A panelist responded that investigators could engage with caregivers about potential strategies for involving caregivers in research. Programs and interventions also could be considered to meet caregivers' needs, and NIH could dedicate funding for such efforts. Previously established structures for caregivers of patients with dementia, developed through NIA, could be applied in this context. Another panelist added that Family Voices is facilitating collaborations between researchers and parents of children with disabilities.

It was also noted that research on parenting stress has focused exclusively on parents of children under 18. Parents' roles as caregivers can be considered from a life course perspective, particularly for adults with intellectual disabilities. Another panelist pointed out concerns about NIH's language regarding caregiving (e.g., informal vs. formal caregivers). NIH also could consider revising its language on caregiving to more fully address caregivers' roles and needs.

How would you describe ableism, and how does ableism contribute to challenges within research?

Panelists remarked that ableism is pervasive within society, and it has a detrimental effect that is independent of the etiology of disability. Ableism is a form of imposed social disadvantage that restricts opportunities for learning, working, and living independently. Changing the conceptualization of disability is necessary for societal change regarding ableism. An NIH-wide office focused on disability research could help centralize discussions related to ableism and lead to meaningful change.

A panelist noted that investigators may inadvertently miss the needs of certain populations when collecting data and performing research. A panelist pointed out that ableism represents a larger issue across biomedical research and society more broadly. Ableism exists across established research methods; for example, screening criteria and methods may exclude individuals who otherwise would have been capable of participating in a study. Additionally, misconceptions regarding disability persist among researchers, clinicians, and society more broadly; training in this space would be critical.

Several panelists acknowledged that ableism has become embedded within the research community, including the exclusion of and failure to promote researchers with disabilities. They also noted that these dynamics are changing. A panelist highlighted the need to challenge assumptions about research and noted that NIH could play a role in fostering these discussions and advancing meaningful change.

Is there any movement in translating research into plain language to make it more accessible?

A panelist remarked that research is underway on how Artificial Intelligence (AI) can be used as a tool for simplifying language (e.g., legislative documents) related to disability; however, concerns (e.g., privacy) regarding the use of this tool should be considered. Overall, the panelist said that generative AI tools could help enhance communication accessibility for people with disabilities.

Another panelist noted that AI might not simplify language sufficiently for people with some cognitive disabilities; these tools would need to be improved. It was suggested that investigators should receive training on how to communicate their research with the public in an accessible way, and more focused attention in this space will be essential.

Closing

Mr. Politis expressed appreciation to the panelists and attendees for their engagement. 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.