

**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**

**November 7, 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. Beth Carter, AARP Public Policy Institute  
Ms. Sabrina Epstein, Disability Rights California  
Ms. Lisa McCorkell, Patient-Led Research Collaborative  
Ms. Kim Musheno, Autism Society of America  
Ms. Dana Sciallo, National Down Syndrome Society  
Ms. Claire Stanley, American Council of The Blind  
Dr. Dan Stewart, National Disability Rights Network  
Ms. Sara Struwe, Spina Bifida Association  
Ms. Tauna Szymanski, Communication FIRST

**Welcome and Introduction**

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 (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.

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 third 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.

Ms. Vicki Gottlich, Senior Advisor, DPCPSI, NIH, 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 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 mission and research agenda. They suggested that NIH integrate the social model of disability into its perspective and address how societal barriers affect the health of people with disabilities. Many panelists highlighted ableist language in the NIH mission statement about seeking to reduce disability. Social determinants of health could be incorporated into NIH's mission. One panelist suggested the establishment of an NIH-wide office for disability research to promote advancements in disability research, encourage collaboration with advocacy groups and professional associations, and enhance training pipelines that support people with disabilities.

Panelists suggested a holistic approach to disability research to consider the overlap between disabilities and mental health, age, race, ethnicity, class, geography, sexual and gender expression and identity, the criminal and legal systems, and other areas of intersectionality. The strategic plan could consider that people with disabilities are not just patients; they are researchers, activists, caregivers, and organizers who work in and across the spectrum of disability research and care. It was suggested that no one involved in disability research assumes that people with developmental or intellectual disabilities cannot or will not participate in the research process. One panelist said that the strategic plan could acknowledge the autonomy of people with disabilities, as well as their right to informed choice and dignity of risk.

Panelists suggested increased community engagement, including input on NIH research priorities and NIH-funded research from experts outside of academia and people with disabilities who exist across all identities, especially those who are marginalized. NIH could ensure that medical interventions and other progress in the field become available and accessible to those who need them most.

A panelist highlighted the needs of students with disabilities, who experience negative outcomes because of school absenteeism, restraint and seclusion, and psychiatric and law enforcement removals. The panelists also emphasized the vocational effects of disability, especially the adaptive effects of acquired brain injuries and *in utero* effects of drugs and alcohol on fetal development.

Another panelist discussed communication tools. People with disabilities who lack access to these tools are more likely to remain institutionalized or segregated and at high risk for abuse. NIH could include in its strategic plan provisions that will ensure that people who need and use communication tools are involved in setting NIH funding priorities and grant reviews of relevant research and that NIH-funded researchers meaningfully collaborate with people who need and use these tools in their studies.

***Several panelists commented on the timeliness of the roundtable. One panelist noted the importance of addressing disability-related inequities as a public health priority, especially as COVID-19 infections and long COVID increase the prevalence of disabilities worldwide. 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 be represented in research. Systemic ableism and barriers to people with disabilities that are currently present in higher education and training pipelines in all fields related to disability research should be eliminated, with support and reasonable accommodations (e.g., Flex time, remote work, breaks) made more available to trainees with disabilities. When researchers do not have to focus on advocating for their own rights or the inclusion of people with disabilities in research, they can incorporate their lived experience and perform more in-depth research. Funding support could ensure that these investigators can establish their research programs and hire trainees. Furthermore, the presence of more researchers and clinicians with disabilities helps ensure the presence of mentors for young trainees with disabilities.

The panelists suggested new programs, funding mechanisms, and systemic changes to promote disability inclusion in the biomedical research workforce. Training programs on effectively including people with disabilities in research settings and clinical studies could be developed, as well as financial incentives to promote disability inclusion in the scientific workforce provided for all health professions. Federal and state governments could explore funding and loan forgiveness programs to encourage students to enter the field of disability research. Graduate, medical, and nursing school recruitment and curricula could place more emphasis on the unique needs of patients with disabilities. Research careers could be evaluated based on how they affect populations with disabilities rather than on publication numbers. NIH could support this change with updated grantee requirements.

One panelist remarked that increased dissemination of NIH research would be beneficial. Awareness of ethical and well-designed studies that benefit people with disabilities could encourage more people with disabilities to become interested in joining NIH-funded research efforts.

***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 re-iterated their call for the inclusion of people with disabilities at all stages of research. NIH could support increased community engagement and partnerships with advocacy groups and professional organizations to connect with people with disabilities who have lived experience, including accessibility and accommodations at NIH meetings and workshops. Advisory councils could be established to receive input from populations with disabilities. Help by organizations with recruitment and dissemination efforts could build trust and ensure sustained engagement.

Eligibility criteria for study populations could be more inclusive and not automatically exclude people with disabilities; inclusion of people with disabilities in study populations could be required. For example, U.S. adults with disabilities are less likely to own smartphones and computers than people without disabilities. Research with a technology component could include accommodations for people with disabilities. Similar accommodations related to the amount of time and travel required by

participants with disabilities could be provided. One panelist noted ethical standards for including individuals with disabilities in all aspects and phases of research, including at the clinical review stage, could be developed. Multiple panelists commented that public health data could include people with disabilities as a core demographic data element and consider the intersectional identities of people with disabilities.

The panelists suggested specific changes to NIH funding priorities and processes, for example, not conflating lack of speech (e.g., a motor function impairment) with intellectual disability (e.g., a cognitive impairment). Another panelist requested that paywalls be removed from NIH-funded research. One panelist remarked that NIH funding could be made more accessible to patient organizations, which perform the most critical research in rare diseases and chronic conditions and have a much more difficult time acquiring NIH funding than academic institutions. Another panelist suggested that NIH NOFOs have requirements for community engagement and including representatives from populations with disabilities and advocacy groups. The panelists agreed that NIH could provide funding to compensate community members for their engagement efforts.

Panelists discussed populations that could be included in NIH studies. One panelist shared that slightly more than 30 million U.S. residents aged 50 and older live with a disability, comprising more than half the population living with disabilities. Many populations with disabilities are living longer and experiencing the effects of aging. Older adults could be recruited for clinical trials, countering the assumption that disability is a natural part of aging. Another panelist noted that studies could focus on populations with complex medical and behavioral support needs and include medical and nonmedical interventions, with accommodations made to include people with more complex needs in research efforts.

## **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?***

Several participants noted that income and asset limits tied to eligibility for health care and medical insurance coverage via Medicaid, Supplemental Security Income, and Social Security disability benefits often force people with disabilities to choose between working at levels that allow them to maintain benefits and losing access to care when employed at higher levels. Panelists raised concerns about how reimbursement for participation in research might affect eligibility for these and other public benefits.

Many participants suggested that NIH directly sponsor disabled academic professionals conducting disability health research and enable their research (e.g., through support networks and strategies to enhance their retention), including by establishing 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. Another panelist suggested NIH work with 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.

The panelists discussed remove ableist language from the NIH mission statement and reframing it from the medical model to a civil rights perspective to address concerns expressed by the disability community.

Panelists emphasized that people from the disability community could be included in every step of the research process, including formulating important research questions, setting priorities, obtaining funding, designing methodologies, interpreting findings, and disseminating information. One panelist highlighted transportation as a major barrier to participation. People with disabilities need help with access to

transportation across the spectrum of research (e.g., training, conducting research, participating in research).

### **Closing**

Ms. Gottlich 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.