



# NIH Disability Research Strategic Plan

Advisory Committee to the Director Meeting  
December 12, 2024

# Background

# Activities and Charge

## Key Activities

- ACD Subgroup on Individuals with Disabilities
- DEIA Strategic Plan
- NIH Mission Statement RFI
- NIMHD Health Disparities designation

## DPCPSI's Charge

- Coordinate NIH disability-related research and activities in partnership with NIH Institutes, Centers, and Offices

# Initial Activities

## Established Disability Research Coordination Team

- Disability research and policy experts with lived experience

## OPA developing Disability Research portfolio analysis

- Coordinating with RCDC and other ICs completing analyses

## Created [DPCPSI Disability Research webpage](#)

## Established NIH Disability Research Coordinating Committee

# Charge and Timeline

# Coordinating Committee Charge

The NIH Disability Research Coordinating Committee (DRCC) provides an NIH-wide forum for discussing the diverse health issues facing disability communities and how NIH research can help address those needs. It serves as a catalyst for developing research, research training, and career development initiatives focused on people with disabilities.

# Charge

## Specific DRCC responsibilities include:

- Participating in the development, implementation, and ongoing evaluation of the NIH Strategic Plan for Disability Research;
- Facilitating and coordinating collaborations and other activities related to disability research across the NIH Institutes, Centers, and Offices (ICOs), as well as with other federal agencies; and
- Developing potential research and research training activities for NIH and ICO leadership to consider.

# DRCC Leadership and Members

## Co-Chairs

- Larissa Avilés-Santa, NIMHD
- Theresa Cruz, NICHD/NCMRR
- Adam Politis, OD/DPCPSI

## Executive Secretary

- Cheryl Jacobs, OD/DPCPSI

## Members

- 69 members
- 24 ICs and 18 Offices and Programs represented



# DRCC Writing Team

**Larissa Avilés-Santa (NIMHD)**

Coretté Byrd (OAR)

Rachelle Brick (NCI)

**Theresa Cruz (NICHD)**

Lauren Fordyce (OBSSR)

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Lynne Padgett (NIMHD)

**Adam Politis (DPCPSI DO)**

Joy Postell (NIDCR)

Nancy Praskievicz (OER)

Valerie Robinson (ODP)

# Community Engagement Events

# Goals

- Build trust, support, and open dialogue between disability communities and NIH
- Identify and understand disability communities' health and research concerns and unique needs and preferences
- Raise awareness of and promote community participation in the strategic planning process
- Obtain diverse input from a wide range of individuals and organizations to use in development of the draft strategic plan framework

# Community Roundtable Discussions

## Researchers

October 30<sup>th</sup> and November 12<sup>th</sup>

## Clinicians and Professional Associations

November 6<sup>th</sup> and 14<sup>th</sup>

## People with Lived Experience and Advocacy Organizations

November 7<sup>th</sup> and 20<sup>th</sup>

# Roundtable Discussion Questions

- 1. 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?
- 2. How can NIH encourage new investigators** to enter the field of disability research, support existing researchers, and promote disability inclusion in the scientific workforce?
- 3. 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 Town Hall on Disability Research

**Date:** December 3, 2024

## **Agenda:**

- Welcome and Introduction (Dr. Tara Schwetz)
- Opening Remarks (Dr. Monica Bertagnolli)
- NIH Institute Perspective - NIMHD (Dr. Eliseo Pérez-Stable)
- NIH Institute Perspective - NICHD (Dr. Alison Cernich)
- Overview of the Strategic Plan Development Process (Mr. Adam Politis)
- Public Q & A

**Event recording and summary:**

<https://dpcpsi.nih.gov/disabilityresearch/events>

# Strategic Plan Development

**Sept 2024**

Establish NIH Disability Research Coordinating Committee

**Dec 2024**

Host Town Hall  
Publish RFI on Draft Strategic Plan Framework

**Summer 2025**

Release Strategic Plan



**Oct-Nov 2024**

Host Community Roundtables  
Create Draft Strategic Plan Framework

**Jan-May 2025**

Hold Additional Community Engagement Activities  
Analyze RFI Responses  
Draft Strategic Plan



# Draft Strategic Plan Framework



# Strategic Plan Framework Content

Cross-Cutting Themes

Strategic Goals

Potential Opportunities

# Cross-Cutting Themes

Public Participation and Community Engagement

Accessibility

Complexity and Heterogeneity

Dynamics of Disability

# Strategic Goals

**Goal #1: Support high-quality, innovative, and impactful research** to improve the health and well-being of people with disabilities of all ages.

**Goal #2: Build and sustain meaningful internal and external partnerships** to promote disability health research.

**Goal #3: Promote engagement and inclusion of people with disabilities** in the biomedical and behavioral research ecosystem.

**Goal #4: Develop a highly skilled scientific workforce** that includes researchers with disabilities and researchers trained in disability health research.

# Goal #1

**Support high-quality, innovative, and impactful research** to improve the health and well-being of people with disabilities of all ages.

*Knowledge gaps exist regarding the health and well-being of people with disabilities. Research is needed to further understand and address the health needs of people with disabilities across the lifespan. In addition, research resources and infrastructure to support the study of disability health are also needed.*

# Goal #1 – Potential Opportunities

- **Develop measures of disability** relevant to health and health care delivery that can be easily collected with other demographic data.
- Establish resources to **track longitudinal health outcomes** of people with disabilities in the context of sociodemographic backgrounds, coexisting health needs, and social determinants of health across the lifespan.
- Encourage research to **develop interventions** to address the health needs of people with disabilities, including addressing the role of ableism and diagnostic overshadowing.
- **Identify and address barriers and facilitators to health care** experienced by people with disabilities.
- **Develop novel technologies and leverage existing technologies** to improve the health and functioning of people with disabilities.

# Goal #2

**Build and sustain meaningful internal and external partnerships** to promote disability health research.

*Advancing research on the health and well-being of people with disabilities requires genuine partnerships among NIH Institutes, Centers, and Offices (ICOs) and between NIH and the extramural community, including people with lived experience and community organizations. NIH-supported research can be enhanced and communicated more effectively by utilizing the skills, expertise, and experience of partners in the community and in other federally supported research programs working to promote the health of people with disabilities.*

# Goal #2 - Potential Opportunities

- **Facilitate engagement opportunities** with the public by designating a central point of contact for disability health research at NIH.
- **Partner with NIH ICOs and community organizations** to develop and host disability health research events, solicit input and feedback on research topics, and communicate and disseminate research findings.
- **Expand collaborations between federal agencies** with expertise and portfolios in disability health research.
- **Increase awareness of disability-relevant research initiatives** at the NIH to increase the number of applications.

# Goal #3

**Promote engagement and inclusion of people with disabilities** in the biomedical and behavioral research ecosystem.

*Meaningful participation of people with disabilities in the research process is needed. This includes engagement at all stages of the scientific process from identifying priorities to designing, reviewing, conducting, and communicating results of studies. People with disabilities may be unnecessarily excluded as participants in clinical research studies, either explicitly or implicitly. Participation and appropriate representation of people with disabilities in research will strengthen the significance and generalizability of study findings. Advancing research on the health and well-being of people with disabilities requires rigorous collection of disability data in NIH-funded research. This must be done in a safe, secure, and non-stigmatizing manner to minimize potential negative consequences of disability disclosure.*



# Goal #3 – Potential Opportunities

- **Include people with lived experience of disability** in the design, review, conduct, and dissemination of research.
- **Encourage data collection about disability representation** in all NIH-supported research.
- **Develop and evaluate accessibility toolkits** to assist in the inclusion of people with disabilities as participants in clinical research.
- Generate evidence to **support the development, adaptation, and/or implementation of guidelines** for prevention, diagnosis, and treatment of health conditions that may manifest differently in disabled populations.

# Goal #4

**Develop a highly skilled scientific workforce** that includes researchers with disabilities and researchers trained in disability health research.

*Researchers with disabilities are an overlooked resource in the biomedical and behavioral research ecosystem and have unique and valuable perspectives to contribute. Supports and accommodations should be provided to attract and retain researchers with disabilities in their chosen research disciplines. Furthermore, building interdisciplinary careers in disability health research will accelerate improved health care for disability populations.*

# Goal #4 - Potential Opportunities

- **Support researchers with disabilities** across all biomedical and behavioral research disciplines throughout their careers.
- **Support individual and institutional training efforts** in disability health research.
- **Increase cultural competency in disability** at NIH, including more representation of people with disabilities in all aspects of the research enterprise.
- Support staff, employers, and supervisors to **implement inclusive design practices and ensure accessibility** of events and workplaces.

# Request for Information

# Request for Information (RFI)

**Issue Date:** December 12, 2024

## **Feedback Requested:**

- The draft framework's cross-cutting themes
- The draft framework's strategic goals and potential opportunities
- Suggestions for indicators to measure progress on the draft strategic goals
- Suggestions for ways NIH can share its strategic plan and communicate progress, success, and impact

Available at: <https://dpcpsi.nih.gov/disabilityresearch/rfi>

# NIH Council of Councils Disability Research Working Group

# Working Group Charge

**Provide input to the Council on activities of the Division of Program Coordination, Planning, and Strategic Initiatives that relate to disability health research**

- Identification of areas of opportunity and priorities for promising areas of disability health research
- Strategies for increasing the number of investigators with disabilities and the number of investigators conducting disability health research
- Approaches for optimizing outreach to disability communities
- Opportunities for interdisciplinary collaborations

# Questions?



# Thank You!



**Have Questions, Ideas, Feedback?**

Email us at: [disabilityresearch@nih.gov](mailto:disabilityresearch@nih.gov)