

Essential Science Conversations

Barriers for Individuals with Disabilities in the Scientific Workforce

September 12, 2023



Essential Science Conversations presents Barriers for Individuals with Disabilities in the Scientific Workforce

We will begin shortly.

- **Submit a question or comment to the panelists any time: Type it into the “Q&A” tool on the webinar control panel**
- **If you have issues viewing or hearing the webinar, log out and dial in using the information in your confirmation email.**

AMERICAN PSYCHOLOGICAL ASSOCIATION

September 12, 2023



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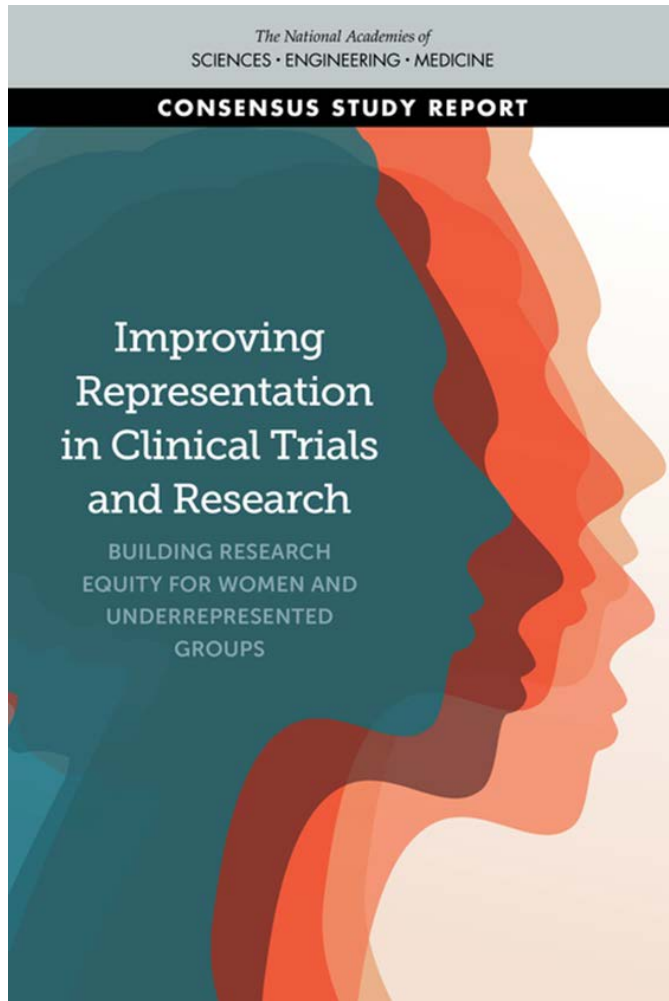
Let's have an
essential science
conversation!



NIH Diversity, Equity, Inclusion, and Accessibility

Optimizing Inclusion of People with Disabilities in Federal Research Activities

Alison Cernich, Ph.D., ABPP-Cn



While we all bear the cost of excluding women, racial and ethnic minority groups, LGBTQIA+ populations, people with disabilities, older adults, and pregnant and lactating individuals from clinical trials, the populations left out of research bear the greatest cost, as they may lose out on benefiting from the United States' substantial investment in scientific advancement and may be deprived of access to novel treatments - Victor J. Dzau, President, NASEM

- Less than 7% of NIH funding addresses disability that is not within the context of disease-based research
- There is no data on the active inclusion of PWD in NIH funded research; NIH does not collect this data
- Executive and Legislative Mandates set standards for data collection and prohibit discrimination based on disability (Rehabilitation Act, 1973; ADA, 1990; Affordable Care Act, Section 4302, 2010)



Why Inclusion Matters for Disabled People

- NIH's obligation is to support research that is representative of the US population
- Healthcare costs for People With Disabilities (PWD) are 4.8 times higher than non-disabled
- Public health resources are tied to evidence of health needs, disparities, and inequities
- For specific interventions, therapeutics, devices, and protocols we do not understand the safety, efficacy, effectiveness, or efficacy for PWD
- We cannot improve what we do not measure



Why Are Disabled People Underrepresented in Research Participation?



- **Ableism:** Assumption that PWD are inferior or inadequate leading to discrimination and social prejudice; assumptions about quality of life, need for protection for all PWD
- **Medical Model:** Presumptive model for medical research which focuses on illness/disease
- **Cost and Complexity:** Assumption that the accommodations needed to include PWD will impact the feasibility because of proxy consent or needed accommodations
- **Data Assumptions:** People with disability introduce heterogenous characteristics that make data "messy"

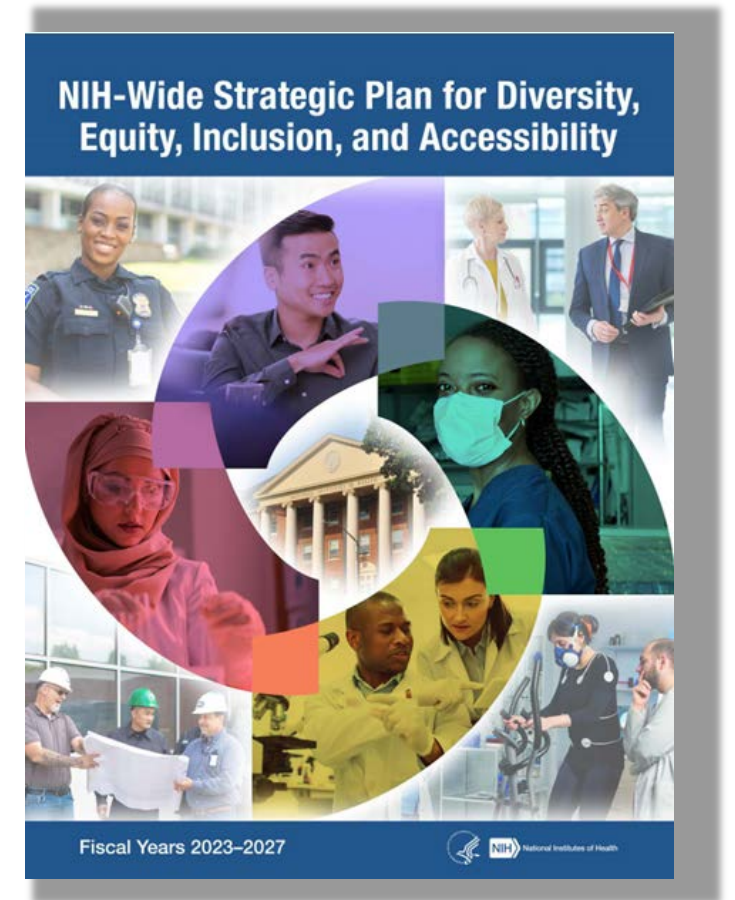




NIH Efforts on Disability Inclusion

NIH Advisory Committee to the Director

- The Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities provided a [road map](#) for NIH to address ableism and ensure inclusion of the disability inclusion (December 2022)
 - Update the NIH Mission Statement
 - Establish a NIH Disability Equity and Access Coordinating Committee
 - Develop NIH-wide Effort to Identify and Address Any Structural Ableism That May Exist and Promote Disability Inclusion
 - Ensure Disability Inclusion and Anti-Ableism Are Core Components of All NIH DEIA Efforts
 - Maintain Accountability for Disability Inclusion Efforts
- NIH-Wide [Strategic Plan for Diversity, Equity, Inclusion, and Accessibility](#)
 - Promote inclusion and address ableism in our training, communication, policies, and structures and to ensure anti-ableism is a core component of all of our DEIA efforts.



NIH Mission Statement: Opportunity for Input

- [NOT-OD-23-163](#)
- NIH's [current mission statement](#) is “to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.”
- Proposed revised mission statement:
 - “To seek fundamental knowledge about the nature and behavior of living systems and **to apply** that knowledge **to optimize health and prevent or reduce illness for all people.**”
- Responses are due by November 24, 2023 at the web address below:
 - <https://rfi.grants.nih.gov/?s=64caaa8bb1112e46ad0a1d52>





National Institute
on Minority Health
and Health Disparities

National Advisory Council on Minority Health and Health Disparities, September 2023

- Council Working Group Report – People Living with Disabilities and Health Disparities
 - Deliberate and advise on the benefits and risks of expanding the National Institutes of Health-designated health disparities populations to include PWD
 - Focus on the mission prioritization, process goals, and scientific activities of NIMHD
 - The Working Group recommended against the designation; decision from the Director and the AHRQ Director are pending
 - Queries or responses can be sent to NIMHD: NIMHDinfo@NIMHD.NIH.gov



Ableism in Medicine and Clinical Research Workshop

April 27-28, 2023 (NICHD/NCMRR)

- **Goal:** To raise awareness of ableism in both clinical care and the biomedical and behavioral research enterprise and to identify research opportunities to mitigate the effect of ableism.

Agenda

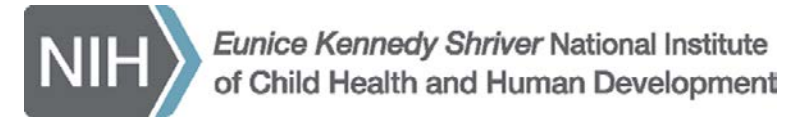
- Ableism as a barrier to clinical care and a contributor to health disparities experienced by people with disabilities
- Ableism in the biomedical and behavioral scientific workforce and graduate education system
- Accessibility in biomedical and behavioral research
- Research opportunities addressing structural and cultural barriers created by ableism

Workshop Takeaways

- Ableism is pervasive in research
- PWDs are often excluded from NIH funded studies with little scientific justification
- PWDs need to be part of research teams to broaden perspectives and ensure relevance of studies to the community
- Ableism must be addressed as a cause of health disparities, especially attitudinal barriers related to the dignity and value of disabled people



Ableism – Understanding and Mitigating Health Disparities Experienced by People with Disabilities



- **Funding Opportunity [RFA-HD-24-007](#):**
 - Encourage research to understand how ableism contributes to health disparities for PWD and/or to develop systems level interventions to combat the negative health impacts of ableism*
 - **Observational studies:** (1) examine the impact of ableism on health, and/or (2) evaluate the impact that existing efforts to address ableism (e.g., laws, policies, programs, organizational practices and procedures) have on the health of individuals, families, and communities
 - **Systems level intervention studies:** Interventions may focus primarily on addressing ableism to improve health outcomes, or ableism may be included as one of several determinants of health addressed to improve health outcomes. For both types of intervention approaches, interventions must directly address the cause or mechanism of action of the ableism, not just help individuals or populations with disability to cope with ableism.
- **Co-sponsors:** National Eye Institute and National Institute of Biomedical Imaging and Bioengineering

*Requires “plan to include lived experience”



Implementation of Accessibility Recommendations



- All recommendations have been tracked and accountable entities assigned
- A subcommittee of the Steering Committee DEIA WG was recently launched to address those recommendations that do not have a discrete owner. Will address:
 - Culture
 - Ableism
 - Research policies and systems



Co-Leads of the Disabilities Subgroup of the Steering Committee DEIA Working Group



Alison Cernich, PhD
Deputy Director, *Eunice Kennedy Shriver*
National Institute of Child Health and
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Executive Officer
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Research Institute

Kevin D Williams, Esq
Director, Office of Equity,
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Transforming Definitions, Data and Stigma



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- Encouraging adoption of the biopsychosocial-ecological model rather than the medical model to reset NIH culture
- Resolving the definitions used for disability in specific programs and initiatives
- Addressing the stigma associated with reporting disability for our extramural community, intramural scientists, and employees
- Combatting discrimination based on disability at research organizations



Increasing Options and Career Paths for Disabled People in Biomedical and Biobehavioral Science

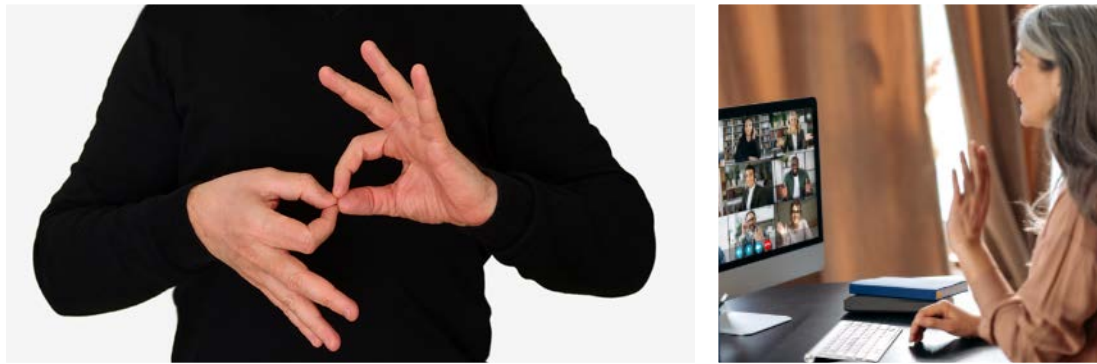
- Approximately 1.2% of our funded investigators and 3% of diversity supplement recipients report a disability in our official system
- Work with the stakeholder community, internally and externally, to understand the barriers across training, education, and funding that impede the careers of disabled people in the sciences
- Determine within our policies and programs how we include funding of accommodations and/or supports for disabled people as they write grants and seek support for their science.



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Enable Universal Design and Accessibility



- Examine facilities, promote inclusive design, and address accessibility barriers
- Ensure materials are compliant, consumable, and easy to access internally and externally
- Provide low barrier opportunities to participate in scientific meetings, scientific review, and advisory council engagements; ensure staff meetings and gatherings are accessible in hybrid formats



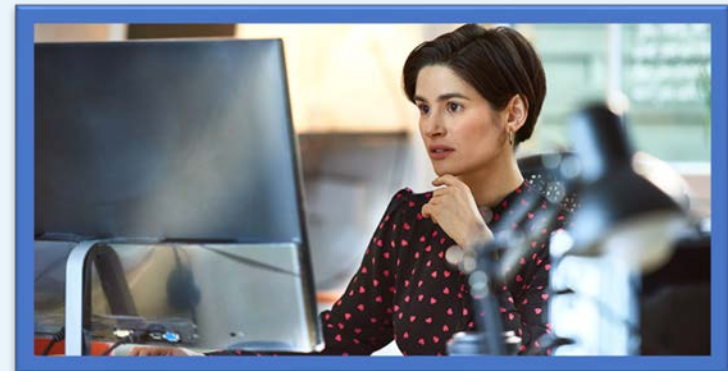
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