AAMC

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March 12, 2025

NIH Disability Health Research Coordination Team
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892

Re: Request for Information (RFI) Inviting Feedback on the Framework for the NIH Strategic Plan for Disability Health Research FY26-FY30 (NOT-OD-25-038)

Submitted by email to: disabilityhealthresearch@nih.gov

The Association of American Medical Colleges (AAMC) appreciates the opportunity to provide feedback to the National Institutes of Health (NIH) on the agency's draft framework for the Strategic Plan for Disability Health Research FY26-FY30.

The AAMC (Association of American Medical Colleges) is a nonprofit association dedicated to improving the health of people everywhere through medical education, health care, biomedical research, and community collaborations. Its members are all 160 U.S. medical schools accredited by the Liaison Committee on Medical Education; 12 accredited Canadian medical schools; nearly 500 academic health systems and teaching hospitals, including Department of Veterans Affairs medical centers; and more than 70 academic societies. Through these institutions and organizations, the AAMC leads and serves America's medical schools, academic health systems and teaching hospitals, and the millions of individuals across academic medicine, including more than 210,000 full-time faculty members, 99,000 medical students, 162,000 resident physicians, and 60,000 graduate students and postdoctoral researchers in the biomedical sciences. Through the Alliance of Academic Health Centers International, AAMC membership reaches more than 60 international academic health centers throughout five regional offices across the globe.

The AAMC's perspective is informed by the goal of the AAMC's Center for Health Justice (Center), founded in 2021, for all communities to have an equal opportunity to thrive — a goal that reaches well beyond medical care. Achieving health equity means addressing the common roots of health, social, and economic injustices and implementing community- and data-driven policies and practices that are explicitly oriented toward equal opportunity. The Center partners with public health and community-based organizations, government and health care entities, the private sector, community leaders, and community members to build a case for health justice through research, analysis, and expertise.

The AAMC strongly supports the NIH's efforts to advance disability health research and improve disability inclusion in the biomedical workforce and research environment. We believe that it is critically important to engage the disability community in the development and implementation of these efforts. The AAMC appreciates the effort and community expertise which informed the recommendations made in 2022 by the NIH Advisory Committee to the Director (ACD), Subgroup with Individuals with Disabilities.[1] We strongly urge the NIH to prioritize the recommendations in the report to maximize its impact on supporting people with disabilities in the scientific workforce and research enterprise, an effort that will diversify and strengthen research in the United States. The comments in this letter were informed by individuals who represent the AAMC's constituents and the broad community, through a series of listening sessions convened by the AAMC.

We are pleased to provide input on the proposed framework for the strategic plan and four 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.

The AAMC agrees that significant knowledge gaps exist regarding the health and well-being of people with disabilities, and that further research is needed to understand and address the health needs of people with disabilities across their lifespans. While the proposed framework references health and health care delivery, we believe it must include health care access, which is critical for improving health outcomes. NIH may also consider adding research that investigates the prevention of disabilities, such as prevention of perinatal infections or reducing drug toxicities.

We recommend adding explicit consideration and inclusion of people with multiple disabilities and people with intersectional identities (e.g., disability, race, and sex). We encourage NIH to collect and disaggregate disability data, particularly among ethnic groups historically excluded from research, such as Black, Indigenous, and Latino disabled individuals. In response to the Office of Management and Budget's (OMB) proposed revisions to its data collection standards, the AAMC supported the OMB's proposal to require federal agencies to collect detailed information, including the collection of demographic data for groups that are not currently represented in the statistical standards.[2] We recommend that the NIH ensure that disability data collection methods reflect updates to the OMB's collection standards, which will enable a more nuanced understanding of people with multiple disabilities across various demographic groups. There are key insights to be gained from incorporating these individuals and communities that may be lost with a 'disability-only' lens.

Current mechanisms for collecting and identifying disability data in clinical settings remain inadequate. More work is needed to develop standardized, precise, and inclusive measures to accurately capture disability status and experiences. Such information should be captured within an electronic health record and tracked over time, with the ideal being self-reported data that is collected in a way that allows for longitudinal tracking and meaningful analysis. Additionally, the NIH should prioritize investments in health informatics and data infrastructure to facilitate comprehensive disability data collection to inform research, policy, and care delivery. Furthermore, we emphasize

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[1] National Institutes of Health Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities REPORT December 1, 2022.
https://acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf

[2] AAMC Comments on Initial Proposals for Updating OMB's Race and Ethnicity Statistical Standards, Docket No. OMB – 2023 – 0001, https://www.aamc.org/media/66246/download?attachment, April 17, 2023.

the need for health surveillance systems that track the prevalence of disability and examine individual and community-level factors that shape health outcomes for these populations.

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 meaningful partnerships. Effective collaborations should involve individuals with disabilities as co-creators of research and ensure that disability health research is informed by and benefits the communities it seeks to serve. We appreciate NIH's interest in building external partnerships and would like to bring to NIH's attention a resource that the AAMC Center for Health Justice[3] co-created with community members—the *Principles of Trustworthiness*. [4] This resource provides guidance on how to build authentic, long-term community partnerships. Incorporating the Center's Principles and corresponding toolkit will equip sponsors with guidance and practical tools on how to strengthen and build new partnerships with individuals, communities, and community-based organizations. We believe that partnerships should extend beyond NIH Institutes, Centers, and Offices (ICOs) to include disability-led organizations, researchers with disabilities, and cross-sector governmental and community collaborations.

The framework proposes that engagement opportunities with the public could be improved by designating a central point of contact for disability health research at NIH. While this is a laudable goal, we suggest that, to be more effective and strategic, the designated NIH contact should be a member of a broad advisory group at NIH comprised of representatives from each ICO. This approach will ensure better coordination across the agency and ensure that disability health research is considered across research fields. Collaboration with other agencies within Health and Human Services and across the federal government would also strengthen the NIH's ability to improve disability health research. Finally, we recommend frequent engagement of these groups with the public through disability health research events, town halls, and other opportunities for feedback or input into research priorities and process. The NIH could also support outreach efforts to researchers who have not worked with disability populations or colleagues by providing training, strategies, tools and resources.

To strengthen disability health research, NIH should prioritize the expertise of organizations with deep experience in disability health equity, such as the Disability Equity Collaborative, Association of University Centers on Disabilities, and the Disability Health Equity Research Network. Additionally, academic medical institutions with established community partnerships should serve as models for ethical, comprehensive, and community-led disability research.

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

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[3] AAMC Center for Health Justice, https://www.aamc.org/healthjustice.

[4] AAMC Principles of Trustworthiness, https://www.aamc.org/trustworthiness, Principles of Trustworthiness Toolkit, https://www.aamc.org/trustworthiness#toolkit.

The AAMC agrees with the need for community-engaged and meaningful participation of people with disabilities in all stages of the research process, from identifying priorities to designing, reviewing, conducting, and communicating the results of studies. As with the other goals in this framework, additional data is needed on disability representation within the context of NIH-supported research.

Despite NIH's steps to improve broad involvement in clinical trials, persistent structural barriers continue to limit participation of individuals with disabilities in clinical trials and NIH-supported research. These barriers include exclusionary eligibility criteria, inaccessible trial protocols, insufficient trial accommodations, and insufficient outreach and engagement efforts tailored to disability communities. We encourage NIH to seek mechanisms to remove these barriers to participation in research.

Adapting research methodologies is essential to achieve the goal of ensuring that people with disabilities can participate in clinical trials. For example, as clinical research increasingly moves outside of traditional healthcare settings, it is important to give greater attention to how people with disabilities could engage with research in decentralized sites such as mobile vans, community based clinics, and participants' homes, settings which may require customized accommodations. Additionally, the presence of a dedicated disability research advocate— an individual trained to address questions or concerns or to advocate for participants' needs and bridge communication issues—should be standardized as part of the clinical trial design.

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

Adherence to federal mandates prohibiting discrimination on the basis of disability—including Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990—set the legal requirement for both NIH and grantee institutions to provide reasonable accommodations for scientists and research staff with disabilities. We acknowledge existing efforts and evidence-based recommendations to meet these goals and promote accessibility in research.

A research environment that encourages and facilitates involving highly skilled researchers with disabilities would integrate universal design principles into basic science labs, clinical research facilities, and fieldwork settings. We note the heterogeneity of the disability community, which includes people with disabilities that may not be readily apparent to others, and the many different ways in which scientists with disabilities should be accommodated in research settings. Incorporating considerations of these members of the research workforce (both for current and future researchers) would reduce the burden on research trainees and scientists to self-disclose disabilities and request individual accommodations, a process that can be challenging, time-consuming, and may lead to discrimination in the workplace. The default use of assistive technologies, captioning, and other accommodations may improve learning and working conditions for scientists of all abilities. We recommend that the NIH promote the use of maximally inclusive technical standards and essential job functions in research, supporting accessible infrastructure by:

- Developing and disseminating standards and best practices for accessible research environments;

- Expanding the use of research facilities and infrastructure improvement grants to address accessibility issues; and
- Providing supplemental funding for ADA-compliant renovations, ensuring that scientists with disabilities have equitable access to research facilities.

We emphasize the critical role of community, mentorship, and sustained support for fostering the success of individuals with disabilities in the scientific workforce. This begins with early exposure to and support of STEM (science, technology, engineering and mathematics) education, access to degree programs, and robust support systems for academic and professional advancement within the scientific workforce. Ensuring that a research ecosystem has a place for all skilled researchers, including people with disabilities, requires intentional investments in mentorship to ensure that these individuals enter the field, thrive, and lead within it. As part of this effort, we encourage NIH to host seminars and community forums that highlight available resources for researchers with disabilities. These events would support individuals with disabilities and benefit principal investigators, mentors, and institutional leaders by providing tools that would create more accessible research environments.

We share NIH's long-standing and continued commitment to advancing disability health research and strengthening disability inclusion within the research workforce. The AAMC looks forward to continued engagement with NIH as this strategic plan develops. Please feel free to contact me or my colleagues Anurupa Dev, PhD, Director of Science Policy and Strategy (adev@aamc.org) and Daria Grayer, MA, JD, Director of Policy and Regulations and Director of Policy for the Center for Health Justice (dgrayer@aamc.org), with any questions about these comments.

Sincerely,

Elena Fuentes-Afflick, MD, MPH

Elena Fuentes-Afflick, MD, MPH
Chief Scientific Officer

cc: David J. Skorton, MD, AAMC President and Chief Executive Officer