



American Association on Health & Disability

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AAHD - Dedicated to better health for people with disabilities through health promotion and wellness



LAKESHORE

March 11, 2025

Re: RFI Response on Framework for NIH Strategic Plan for Disability Health Research FY26-FY30

Dear NIH Disability Health Research Coordination Team,

The American Association on Health and Disability and the Lakeshore Foundation thank the NIH and DPCPSI for sharing and soliciting input on the draft framework for the NIH Strategic Plan for Disability Health Research.

The American Association on Health & Disability (www.aahd.us) is a national cross-disability organization that conducts research, engages the community, and facilitates the development and implementation of programs to advance public health and healthcare policy for the health and wellness of people with disabilities. Through these actions, AAHD is committed to eliminating systemic barriers to healthcare and drive health equity for people across all disabilities, valuing the diverse and intersecting identities within the disability community. AAHD connects people with disabilities, disability advocates, health practitioners, researchers, and policy makers to accessible cross-disability health data and resources—creating a more inclusive society where data-driven healthcare leads to more equitable health outcomes.

The Lakeshore Foundation (www.lakeshore.org) mission is to enable people with physical disability and chronic health conditions to lead healthy, active, and independent lifestyles through physical activity, sport, recreation and research. Lakeshore is a U.S. Olympic and Paralympic Training Site; the UAB/Lakeshore Research Collaborative is a world-class research program in physical activity, health promotion and disability linking Lakeshore's programs with the University of Alabama, Birmingham's research expertise.

First, for two disability-led organizations, both of which have strong and robust disability research components, we appreciate the public engagement of the field to both provide input that led to the development and drafting of this framework and for the invitation to provide input at this stage. The value of this engagement with the disability community should not be overlooked, which is why we wanted to lead with our sincerest thank you for that. In the disability

community, there is a mantra: “nothing about us without us” and far too often, especially in the realm of research, the input from disabled individuals and/or disability led organizations is not prioritized. We are so grateful that it was throughout the process thus far.

Based on the specific questions asked in the RFI, we offer the following feedback:

We endorse the spirit of the strategic goals (SG1-SG4) of the draft framework for the Strategic Plan for Disability Health Research FY26-FY30.

For consideration based on the prompts provided in the RFI, we offer the following:

SG2: We hope the internal and external partnerships will also include across the federal government to OpDivs, centers, institutes and programs that are engaged in funding and/or conducting disability research that are outside of NIH such as the Interagency Committee for Disability Research, NIDILRR, ODEP, NSF and so forth.

SG3: We appreciate the acknowledgement of the need of involvement of people with disabilities across all stages of the scientific process, including review. We are concerned about how this will be implemented, particularly given the recent NIH news of centralizing peer review to the Center for Scientific Review (CSR) (<https://www.nih.gov/news-events/news-releases/nih-centralizes-peer-review-improve-efficiency-strengthen-integrity>). This is concerning because it is unclear whether CSR staff and study sections that are more generalized will have the specific disability knowledge and expertise to fairly review proposals. Some proposed disability health research does more harm than good for the community if it is focused on cure or eradicating disability, for example. Unfamiliarity with disability research proposals may result in deviations from standard protocols that are reasonable accommodations to allow for disabled individuals to participate in research, such as using alternative/augmentative communication devices to respond instead of spoken voice or relying on a supported decision-making process to provide consent. For these reasons, it will be imperative for reviewers to have not only disability research competencies but also disability cultural competencies to be able to provide a fair review of proposals. We hope this will be considered in implementation.

SG4: The importance of SG4 must not get lost based on the current climate. This specific strategic goal has direct alignment with recommendations from the previous Subcommittee on Disability Advisory Committee to the Director report that included the snapshot of what was known about the disability status of PIs with NIH funding. For far too long, there has been a lack of concerted effort to recruit, retain and promote investigators with disabilities, despite their qualifications to be investigators, making us largely underrepresented in biomedical research. We appreciate the focused attention of this important issue in this strategic goal.

Additions: Related, and not currently captured in any of the presented strategic goals, is the importance of disability data. AAHD and Lakeshore have been deeply engaged in efforts at NIH and across the federal government to improve the disability data infrastructure at the federal level. Accurate and reliable data is essential for measuring progress in all of the aforementioned strategic goals yet is also necessary in its own right to have a disability data infrastructure.

Therefore, we recommend **adding a strategic goal** encouraging the collection of systematic disability data and investigating innovative ideas for improving disability data collection throughout all of NIH.

Lastly, we strongly encourage the NIH to publish and implement this strategic plan by summer 2025 as planned. This strategic framework is a welcomed and robust step that is cross-cutting across all of NIH which follows the designation of people with disabilities as a health disparity population. Any delay in its publication would inadvertently signal to the disability research community and broader disability community that these important steps and commitment to disability research were not fully supported by NIH leadership and would further delay implementation.

Thank you for the opportunity to comment. If you have any questions please contact Dr. Anjali Forber-Pratt at aforberpratt@aahd.us

Sincerely,



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