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NIH Disability Health Research Coordination Team
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director
National Institutes of Health
Sent via email: disabilityhealthresearch@nih.gov

To whom it may concern:

On behalf of the organizations we represent, the [Population Association of America](#) and [Association of Population Centers](#), we are pleased to submit comments regarding the draft framework of the FY 2026-2030 National Institutes of Health (NIH) Strategic Plan for Disability Health Research.

As you may know, PAA and APC are two affiliated organizations that receive federal funding and conduct research on the causes and consequences of population change. Our members, which include demographers, economists, sociologists, and epidemiologists, conduct scientific and applied research, analyze changing demographic, health, and socio-economic trends, and train undergraduate and graduate students. Their research expertise covers a wide range of issues, including fertility, infant and adolescent health and development, maternal health, health disparities, mortality, family dynamics, and disability. Our comments reflect input that we received from expert population scientists who conduct disability research across the lifespan.

Cross-cutting themes

Overall, we agree with the aims of the plan's four cross-cutting themes. Our comments offer suggestions regarding these themes and propose a fifth one for your consideration.

The first theme, *Public Participation and Community Engagement*, contends that research should 'involve' disabled people and build 'two-way relationships with disability communities.' Our concern is that this can be done without achieving equity. There are many studies that 'involve' disabled people as participants in research. While this is better than not involving disabled people at all, we think it would be better to aim to collaborate with disabled people. Collaboration implies a greater degree of reciprocity with disabled people in research allowing greater room for building the 'trust-based, long-term, and two-way relationships' that are mentioned. In addition, this theme does not specify the nature of the two-way relationships that are desired. Again, without clearly

defining a desire for reciprocity in the relationship, it is possible that researchers will think that simply interacting with disabled communities, or providing disabled communities information regarding research activities, constitutes a two-way relationship. Thus, our recommendation is that this theme be revised to: “The biomedical and behavioral social science research communities should *collaborate with* people with disabilities in identifying disability health research priorities and build trust-based, long-term, and *reciprocal* relationships with disability communities.”

The second theme, *Accessibility*, contends that all research and healthcare facilities, equipment, technology, and information must be accessible. As the reporting of research in peer-reviewed journals and policy briefs is typically not accessible to many disabled people, we think it necessary to better specify research products in this theme. We recommend revising this theme to: “Research and healthcare facilities, equipment, technology, information, and *research products* must be accessible so all people, including people with disabilities, can fully and independently use them.”

The third theme, *Complexity and Heterogeneity*, contends that these characteristics of the disability experience must be acknowledged by researchers to conduct meaningful research and community engagement. It is our experience that acknowledgement is not enough as it is possible, and common, for researchers to acknowledge the complexity and heterogeneity of disability and view this as a problematic characteristic of this population and/or ignore this complexity and heterogeneity. In order to dissuade this tendency among researchers, we suggest this theme be revised to: “This complexity and heterogeneity must be *respected and accounted for in the research process* in order to conduct meaningful research and community engagement.”

The fourth theme, *Dynamics of Disability*, claims that disability involves interaction with medical conditions. While true for some disabled people, other disabled people do not have medical conditions associated with their disability. To better reflect this heterogeneity in the disability community, we suggest this theme be revised to: “Disability is a dynamic process that *may, at times, involve medical conditions*, and may fluctuate over time with variable behavioral, sociocultural, and environmental factors.”

In addition to these four cross-cutting themes, we suggest a fifth theme on disability data. A lack of sufficient and/or accurate disability data severely impedes the ability of researchers to examine and understand health outcomes for the disabled population. In addition, the available data on disability rarely meets minimum accessibility standards; moreover, current disability measures used in US data are based on a deficits-based model of disability that fails to account for the rich heterogeneity and complexity of this experience articulated in the fourth theme. We propose a fifth theme: “Research data on disability status must be accessible to disabled people and accurately reflect the complexity and heterogeneity of the disability experience.”

Strategic Goals

Our feedback on the strategic goals closely aligns with our suggestions regarding the plan's cross-cutting themes.

1. **Goal #1: “Support high-quality, innovative, and impactful research to improve the health and well-being of people with disabilities of all ages,”** is well stated. We want to underscore however that understanding disability trends and dynamics with aging is imperative to supporting older adults to maintain health, longevity and independence in their daily lives. A crucial piece of this understanding evolves from including persons with disabilities, including older adults, in social and behavioral and biomedical research to understand barriers and access to care, accommodations, and societal engagement.
2. **Goal #2: “Build and sustain meaningful internal and external partnerships to promote disability health research,”** addresses the need for NIH to build partnerships. To achieve this goal, we suggest NIH consider appointing a disabled researcher with ties to the disability community as the central point of contact for disability health research. Doing so would improve the chances of ensuring that NIH research achieves collaboration and reciprocity with the disability community.
3. **Goal #3: “Promote engagement and inclusion of people with disabilities in the biomedical and behavioral research ecosystem.”** Once again, we encourage NIH to specify an aim of collaboration in its strategic plan as opposed to using less specified terms such as “engagement,” “participation,” and “include.” As described in our comments on the cross-cutting themes, all of these can be met without actually collaborating with disabled people in the research process.
4. **Goal #4: “Develop a highly skilled scientific workforce that includes researchers with disabilities and researchers trained in disability health research.”** It is important to specify that the representation of disabled people in “all aspects of the research enterprise” is inclusive of leadership of research projects. 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.

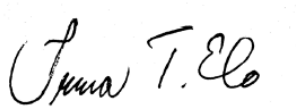
Measuring and sharing progress

The RFI also requests feedback on how NIH can measure and share progress on these goals and their impact. We think the best way to do this is by establishing a scientific advisory

committee with majority representation among people across the complexity and heterogeneity of the disability experience, as well as research roles – researchers and community members. The committee could be tasked with creating appropriate indicators and strategies for sharing results. We believe establishing this committee would facilitate more collaboration and reciprocity in NIH funded research on disability.

Thank you for considering our comments as you finalize the Fiscal Year 2026-2030 NIH Strategic Plan for Disability Health Research.

Sincerely,

A handwritten signature in black ink, reading "Irma T. Elo". The signature is fluid and cursive, with the first name "Irma" being more prominent.

Dr. Irma T. Elo
2025 PAA President

A handwritten signature in black ink, reading "Sarah Burgard". The signature is fluid and cursive, with the first name "Sarah" being more prominent.

Dr. Sarah Burgard
2025-2026 APC President