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The Federation of American Societies for Experimental Biology (FASEB) appreciates the opportunity to provide feedback on the draft framework for the National Institutes of Health (NIH) strategic plan for disability health research FY2026 – FY2030 as published in the [NIH Guide](#) on December 12, 2024. We applaud the agency's commitment to pursue a strategy that explores both medical and environmental factors affecting the health and well-being of individuals with disabilities. Our comments are organized into the four requested areas for feedback within the RFI.

I. The appropriateness of the draft framework's cross-cutting themes and additional themes to consider

FASEB strongly supports the draft framework's emphasis on cross-cutting themes such as public participation, accessibility, and the complex dynamics of disability. The themes highlight the complexity of disability, providing greater opportunities to examine the intersectionality of disability, race, gender, and socioeconomic status in health research. Research from the [National Institute on Minority Health and Health Disparities \(NIMHD\)](#) has demonstrated that individuals with disabilities, particularly those from marginalized racial and ethnic backgrounds, face compounded barriers to healthcare access. Recognizing this intersectionality is crucial to ensure the experiences of all people with disabilities, especially those from historically excluded communities, are adequately represented in research.

An additional theme to consider would be the mental health and well-being of people with disabilities, which remains underrepresented in disability health research. In 2022, [The Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities](#) reported that people with disabilities experience higher rates of mental health disorders, yet they are often overlooked in mental health studies. Addressing mental health as an integral part of the disability health research agenda will ensure a more holistic approach to the health needs of individuals with disabilities.

II. The appropriateness of the draft framework's strategic goals and potential opportunities, including potential benefits, drawbacks, or challenges, and additional goals or opportunities to consider

To adequately produce impactful research that meaningfully engages members of the disability community, FASEB encourages inclusion of social determinants of health ([SDOH](#)) as an overarching

consideration within each goal. The impact of SDOH is particularly critical for individuals with disabilities, who experience greater and compounding barriers to accessing care. Incorporating an intersectional lens would provide a more comprehensive approach to address the health disparities faced by people with disabilities. Failure to address barriers posed by SDOH within each strategic goal will diminish NIH's capabilities to adequately support and increase the existing number of researchers with disabilities.

Creating an inclusive environment that enables full participation and recognition of individuals with disabilities as researchers, stakeholders, and community leaders requires a social and institutional examination of how ableism is reinforced in the various stages of healthcare and health research. Ableism in the healthcare system leads to disparities in access to care and treatment. Per the recent [report](#) issued by the National Advisory Council on Minority Health and Health Disparities Working Group on Persons Living with Disabilities, only 56.5 percent of physicians strongly agreed that they welcome patients with disabilities into their practice. By making ableism a focus within the strategic goals, NIH could help address these systemic challenges, ensuring that people with disabilities receive timely, accurate diagnoses and care.

III. Suggestions for indicators to measure progress on the draft strategic goals

To effectively track the success of the strategic goals, FASEB recommends the development of specific and measurable key performance indicators (KPIs). This can be achieved by including disability in all demographic surveys and data collection. One essential KPI would be the representation of people with disabilities in clinical research. For example, NIH's policy on the [inclusion of women and minorities in clinical research](#) serves as a good example of efforts to increase diversity in clinical trials and reports like [NIH Research, Condition, and Disease Categorization \(RCDC\) Statistics Report](#) can be expanded to include participants with disabilities to ensure their experiences and needs are addressed.

Another important indicator is the representation of individuals with disabilities in leadership roles in NIH-funded research. This representation should be reflected across the biological and biomedical ecosystem, from Principal Investigators to Senior Research Administrators. According to [NIH Workforce Demographics](#), while the NIH workforce has made progress in racial and gender diversity, leadership positions remain predominantly occupied by individuals without disabilities. Establishing goals for increasing the representation of people with disabilities in research leadership would demonstrate a commitment to ensuring diverse perspectives guide decision-making.

IV. Suggestions for ways NIH can share its strategic plan and communicate progress, success, and impact

FASEB encourages NIH to create an integrative, interactive, and accessible online portal to report progress made toward the goals outlined in the strategic plan. The portal should track progress on key indicators such as research inclusion, assistive technology development, and promotion of leadership diversity and community engagement. It should be designed with full accessibility in mind, in accordance with [Section 508](#), so that all stakeholders, including the disability community, can track NIH's progress. Transparency in reporting will foster trust and accountability.

To ensure broad reach, regular updates should be disseminated across multiple accessible platforms. NIH's [Community Engagement Guide](#) offers an excellent framework to ensure communication materials are both inclusive and effective, and explicitly reach members of the disability community and partner organizations interactive methods of community engagement, like town halls and community roundtables



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with various stakeholders, such those held by the Division of Program Coordination, Planning, and Strategic Initiatives to inform the development of the NIH Strategic Plan for Disability Health Research, should be a routine form of communication to ensure broad outreach to and engagement of all stakeholders throughout the strategic planning and implementation process.

Thank you for providing the research community with the opportunity to review and comment on the draft framework.

Sincerely,

Beth A. Garvy, PhD
FASEB President