



FASEB

Federation of American Societies
for Experimental Biology

Representing Over 115,000 Researchers

6120 Executive Blvd., Suite 230, Rockville, MD 20852 | faseb.org

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Advisory Committee to the Director
National Institutes of Health
c/o Cyndi Burrus-Shaw
One Center Drive, Building 1, Room 126
Bethesda, MD 20892

Submitted electronically via email: shawcy@od.nih.gov

Dear Committee members,

Federation of American Societies for Experimental Biology (FASEB) is appreciative of the thoughtful [report](#) from the Working Group on Diversity, Subgroup on Individuals with Disabilities [presented](#) during the December 2022 National Institutes of Health (NIH) Advisory Committee to the Director meeting. Representing over 115,000 individual biological and biomedical scientists and 28 member societies, FASEB is committed to improving the culture of science to be more welcoming and inclusive. While NIH has made meaningful strides in eliminating harassment and promoting anti-racism, there has been a lack of focus on disability inclusion. FASEB supports a vast majority of the Subgroup's recommendations, with priority areas emphasized below.

Office of Disability Research and Disability Equity and Access Coordinating Committee

Addressing structural ableism and promoting disability inclusion are necessary to foster a welcoming scientific environment. To achieve this, significant expertise in universal design and understanding the lived experience of disability is required. Creating an Office of Disability Research (ODR) will elevate efforts to enhance disability representation in the workforce and research on health disparities and health equity that affect populations with disabilities. This central office will also facilitate improved coordination of policies, programs, and research activities across NIH Institutes and Centers, Office of Equity, Diversity, and Inclusion (EDI), and Chief Officer for Scientific Workforce Diversity (COSWD). The Disability Equity and Access Coordinating Committee will be an important resource for the ODR by coalescing representatives from different disability communities. Input from a wide array of stakeholders on NIH activities, trainings, and data collection efforts is essential for well-informed initiatives.

COSWD and EDI are critical components in the system to address ableism. Charged with cultivating all aspects of diversity and inclusion—notably overall workforce diversity, promoting anti-racism in science, and eliminating harassment in scientific environments—it is understandable that existing staff may lack proficiency in anti-ableism practices. For instance, COSWD's [draft strategic plan](#) included ableist language of “differently abled individuals,” which was thankfully revised to “individuals with disabilities” in the [final strategic plan](#). Appointing a deeply knowledgeable Director of the ODR and regularly engaging the Disability Equity and Access Coordinating Committee will help empower all of NIH to advance its anti-ableism practices.

Full members: American Physiological Society • American Society for Biochemistry and Molecular Biology • American Society for Pharmacology and Experimental Therapeutics • American Society for Investigative Pathology • The American Association of Immunologists • American Association for Anatomy • Society for Developmental Biology • Association of Biomolecular Resource Facilities • The American Society for Bone and Mineral Research • The American Society for Clinical Investigation • Society for the Study of Reproduction • Endocrine Society • American College of Sports Medicine • Genetics Society of America • The Histochemical Society • Society for Glycobiology • Association for Molecular Pathology • Society for Redox Biology and Medicine • Society For Experimental Biology and Medicine • American Aging Association • Society for Leukocyte Biology • American Federation for Medical Research • Environmental Mutagenesis and Genomics Society • Shock Society • **Associate members:** American Society of Human Genetics • Society for Birth Defects Research & Prevention • American Society for Nutrition

Data Collection, Dissemination, and Stakeholder Engagement

Echoing the Subgroup's sentiments, current efforts to collect disability data on the NIH-funded workforce are inadequate, and very little literature focused on individuals with disabilities in the biomedical and behavioral sciences exists. The Subgroup reportedly had limited time and resources to systematically collect personal stories of lived experiences of disabled scientists, which is an area that FASEB has [previously recommended](#) NIH undertake through a Request for Information (RFI). Listening sessions, akin to the [public events held by UNITE](#), may also prove effective. Furthermore, FASEB supports additional data collection recommended by the Subgroup, including: a focus on intersectionality; expanding disability data beyond physical and cognitive disabilities; collection that allows for granularity of results by types of disabilities, roles, salaries, and career levels; and gathering data on disability wherever demographic information is collected.

EDI is [conducting an analysis](#) on barriers for individuals with disabilities with respect to employment policies, procedures, practices, and conditions. While results will focus on the NIH workforce and its policies, broad dissemination of the findings may encourage extramural institutions undertake this type of assessment. Dissemination of these data will be crucial for the community at large to initiate corrective actions. FASEB looks forward to robust data collection to enable evidence-based strategies for improving mentorship, training, access, and other resources to support disabled scientists.

Accessibility Resources

As the primary funder of biological and biomedical sciences, NIH is well-suited to influence positive cultural change through leading by example. FASEB is excited to see EDI creating a webpage to serve as a [portal for accessibility resources](#) at NIH. However, as [previously described](#), FASEB urges NIH to create a central hub of accessibility resources useful in research environments relevant for all scientists—intramural and extramural alike. Trainees not categorized as staff may not have access to their university's ergonomics office, and university disability offices are often understaffed and focus on coursework accommodations. Items like low force forceps, ergonomic pipettes, forearm rests for microscopy, and similar, may vastly improve one's daily research experience. As the largest federal funder of biological and biomedical research in the U.S., NIH has the opportunity to empower disabled scientists to more effectively self-advocate for their needs by providing a list of tools that improve accessibility in laboratory settings.

Centering Anti-Ableism and the Spirit of Inclusion

FASEB supports the overarching theme in the Subgroup report of making anti-ableism part of all NIH DEIA programs, initiatives, policies, and funding opportunities. A first step FASEB would applaud is revising the NIH [mission statement](#) to remove “reduce disability.” Further actions that would change the ethos of how NIH views and treats disability include adopting the social model of disability, and therefore expanding the definition of disability beyond [targeted disabilities](#). FASEB looks forward to NIH's future actions that go above and beyond legal obligations for compliance and instead center the spirit of fostering an inclusive culture for all scientists, including people with disabilities.

Sincerely,



Kevin C. Kregel, PhD
FASEB President

Cc: Marie A. Bernard, MD, and Roberta Diaz Brinton, PhD, Co-Chairs of the Working Group on Diversity; Steven Barnett, MD, Lisa I. Iezzoni, MD, MSc, and Bonnielin Swenor PhD, MPH, Co-Chairs of the Subgroup on Individuals with Disabilities; Lawrence A. Tabak, PhD, DDS, Performing the Duties of the NIH Director; Tara A. Schwetz, PhD; Acting Principal Deputy Director; Jon R. Lorsch, PhD, NIGMS Director; Ericka M. Boone, PhD, Director of the Division of Biomedical Research Workforce.