July 15, 2024

Office of Science and Technology Policy
Eisenhower Executive Office Building
1650 Pennsylvania Ave. NW
Washington, D.C. 20504

RE: Federal Evidence Agenda on Disability Equity
The American Society for Biochemistry and Molecular Biology is an international nonprofit scientific and educational organization that represents more than 12,000 students, researchers, educators and industry professionals. The ASBMB strongly advocates for strengthening the science, technology, engineering and mathematics (STEM) workforce; supporting sustainable funding for the American research enterprise; ensuring diversity, equity, accessibility and inclusion (DEAI) in STEM; and addressing emerging issues in the scientific enterprise.

The ASBMB appreciates the opportunity to respond to the Office of Science and Technology Policy’s Federal Evidence Agenda on Disability Equity. Individuals with disabilities are the largest minority group in the nation. Ensuring that federal agencies have a framework for more comprehensive data collection practices will be valuable in achieving equity for all populations in the scientific enterprise. The ASBMB has formulated responses to questions under the “Describing Disparities” and Information Data Collections and Public Access” sections of the call for information.

Describing Disparities

2. What types of community-based or non-Federal statistics or data collections could help inform the creation of the Federal Evidence Agenda on Disability Equity?

Professional and scientific societies can provide statistics and information on their disabled constituents. Delving into the data collections by these organizations and other community-based organizations that serve individuals with disabilities will give OSTP a better insight into formulating its agenda. To ensure the privacy of the data collected, OSTP should only collect unidentified data.

3. Community-based research has indicated that individuals with disabilities experience disparities in a broad range of areas. What factors or criteria should the DDIWG consider when considering policy research priorities?

The Disability Data Interagency Working Group (DDIWG) should consider how intersectional identities affect disparities. Understanding intersectional identities will help the working group develop polices to serve populations that may be more vulnerable. For instance, a person with disabilities from a low socioeconomic background may face more difficulties than a person with disabilities from a high socioeconomic background and need more accommodations. The working group should also consider all forms of disabilities including non-visible disabilities and work with the disability community to determine the necessary accommodations needed to support these disabilities.
Informing Data Collections and Public Access

2. In some instances, there are multiple surveys or data collection tools that could be used to collect data about a particular disparity faced by the disability community. In addition to factors like sample size, timeliness of the data, and geographic specificity of related data products, what other factors should be considered when determining which survey or data collection tool would best generate the relevant data? Which surveys or data collection tools would be uniquely valuable in improving the Federal Government’s ability to make data-informed decisions that advance equity for the disability community, and why?

The National Science Foundation Survey of Earned Doctorates is widely used by science policy professionals and advocates. However, the survey needs to better capture data from individuals with intersectional identities and from those from foreign countries.

4. How can Federal agencies increase public response rates to questions about disability in order to improve sample sizes and population coverage?

Federal agencies should collaborate with disability stakeholders, advocacy groups, and work with the disability community to determine the tools needed to respond to surveys. When creating surveys, federal agencies should use the information collected to determine if technologies such as machine-reading technologies, such as voice-activated response software are the best tool to increase public response rates.

5. What barriers may individuals with disabilities face when participating in surveys or filling out administrative forms?

Barriers that individuals with disabilities face may be due to inaccessibility issues and these barriers vary person to person. As stated above, working with the disability community to identify and make available the tools to accommodate these individuals should be a priority.

6. Disaggregated data—data about groups separated out by disability, race/ethnicity, gender identity, sexual orientation, geography, income level, veteran status, rural/urban location, and other factors—are essential for identifying and remediating disparities in how the government serves American communities. Which data disaggregated by disability that are currently collected by Federal agencies are useful? Which data disaggregated by disability are not currently collected by Federal agencies and would be useful, and why?

Data from the National Center for Science and Engineering Statistics (NCSES) Women, Minorities and Persons with Disabilities Report and the Survey of Doctorate Recipients are not disaggregated. Disaggregating the data from these surveys will better equip federal science agencies and the scientific community to better serve individuals with disabilities within the scientific enterprise. As stated above, understanding intersectional identities are important to creating policies to serve those who are most vulnerable. By disaggregating data from these surveys, it will allow researchers to better understand from multiple facets of an individual’s identity that are critical in serving underrepresented groups in STEM.
7. How can Federal agencies best raise public awareness about the existence of sources of disability data? How can Federal agencies best communicate with the public about methodological constraints to collecting data or publishing disability statistics?

Federal agencies can increase public awareness by collaborating with disability stakeholders and advocacy groups, such as the Association on Higher Education and Disability, and with professional and scientific societies to host public events.

8. How do individuals and organizations external to the Federal Government utilize data from Federal surveys and administrative data collections? Which practices employed by Federal agencies facilitate access to and use of these data? Are there additional practices that would be beneficial?

Organizations such as scientific societies use data from federal surveys to inform programming and creation of resources to better serve specific populations. Also, scientific and professional societies often use federal data in their advocacy pursuits. Many organizations use the data as evidence in fact sheets, policy memos, position statements and other documents.