



Response to Request for Information (RFI) issued by the White House Office of Science and Technology Policy Seeking Input on the Federal Evidence Agenda on Disability Equity

[Federal Register Notice](#) (published May 30, 2024)

Transmitted via Regulations.gov on July 9, 2024

The Federation of American Societies for Experimental Biology (FASEB), a coalition of 22 scientific societies representing over 110,000 researchers in the biological and biomedical sciences, appreciates the opportunity to provide comments that will inform the development of the Federal Evidence Agenda on Disability Equity. FASEB has a long-standing history of utilizing existing public data collections to better understand the STEM workforce. Through these efforts, we have identified key gaps in existing data collections that limit our understanding of persons with disabilities working in STEM fields and support the overarching goals of the Federal Evidence Agenda on Disability Equity to foster and enhance data-driven policymaking.

Per the guidance within the RFI, our response focused on only those questions for which FASEB could offer a clear perspective or experience.

Section 1: Describing Disparities

1. What disparities faced by individuals with disabilities are not well-understood through existing Federal statistics and data collection?

Inconsistent data definitions and data collections by existing federal surveys pose key challenges to understanding disparities faced by individuals with disabilities. Similarly, survey questions focus on the extent to which a particular disability limits an individual's ability to work rather than understanding the extent to which the physical workplace or professional culture serves as a barrier for individuals requiring accommodations. This latter point is particularly important to STEM fields, in which many laboratory spaces are not designed with accessibility in mind.

Another factor limiting our understanding is the stigma associated with disability disclosure. While surveys such as those directed by the U.S. Census Bureau ([American Community Survey](#), [Current Population Survey](#), and the [Survey of Income and Program Participation](#)), the National Center for Science and Engineering Statistics (NCSES) ([Women, Minorities and Persons with Disabilities Report](#) and [Survey of Doctoral Recipients](#)), include questions regarding an individual's disability status, many respondents may be wary to self-disclose. The result is an underreporting of individuals with disabilities, one consequence of which is inadequate resource allocation to address inequities.

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?

As noted in our response to Question 1, while several surveys collect information about an individual's status, there is minimal information that examines intersectionality of disability with other identities. Similarly, data collections emphasize the effects of disability on workforce contributions versus physical

and/or cultural accessibility of workspaces to individuals with disabilities. As a federation of 22 scientific societies in the biological and biomedical sciences, FASEB is interested in understanding more about the current population of STEM researchers (undergraduate and doctoral students, postdoctoral scholars, and independent investigators) with one or more disabilities to improve accessibility of research environments. Data from existing surveys, including NCSES, U.S. Census Bureau, and the Centers for Disease Control and Prevention, were used by FASEB to assemble factsheets on the [Intersection of Disability, Other Identities, Age, and Employment Sector for PhDs in 2021](#) and [PhDs with a Disability in 2021](#). As noted at the bottom of the latter, areas requiring additional evidence include 1) an understanding of changes necessary to create accessible research environments; 2) the ability of institutional resources, such as the student disability office, to meet the needs of STEM graduate students and postdoctoral scholars; 3) instruments to obtain data to better understand additional challenges faced by individuals with one or more disability with multiple intersecting historically excluded identities.

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?

In addition to aligning existing survey instruments, FASEB recommends approaching policy discussions on disability from the perspective of physical and/or cultural barriers limiting the accessibility of community spaces. Similarly, any actions taken by the DDIWG must aim to reduce stigma associated with responding to questions pertaining to disability status. This can be partially achieved through clear articulation of intended use of collected data and privacy assurances.

Section 2: 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?

Inconsistent data definitions and data collections by existing federal surveys pose key challenges to understanding disparities faced by individuals with disabilities. Alignment of terms and definitions across federal surveys would provide critical interoperability of existing instruments. Similarly, survey questions focus on the extent to which a particular disability limits an individual's ability to work rather than understanding the extent to the physical workplace or professional culture serves as a barrier for individuals requiring accommodations.

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

Multiple factors contribute to survey response rate, including community awareness and outreach regarding the survey collection and intended uses of resulting data. Another factor to be considered when

collecting data about disability is accessibility, such as offering the survey in machine readable formats for those with visual impairments and posing questions in non-technical language to ensure comprehension by those with cognitive impairments.

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

As noted in our response to Question 4, survey accessibility can pose a significant barrier to survey participation by individuals with disabilities. Therefore, we recommend that DDIWG work with the disability community to ensure surveys are compatible with accessibility tools, such as machine reading and/or voice activated response software.

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?

In the FASEB factsheet, [PhDs with a Disability in 2021](#), several areas requiring additional evidence were identified. These include 1) an understanding of changes necessary to create accessible research environments; 2) the ability of institutional resources, such as the student disability office, to meet the needs of STEM graduate students and postdoctoral scholars; 3) instruments to obtain data to better understand additional challenges faced by individuals with one or more disability with multiple intersecting historically excluded identities.

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?

Similar to our response for Question 4 regarding strategies to increase response rates to questions about disability, public awareness of sources of disability data is dependent upon a robust communications plan that is accessible to a broad range of recipients and highlights key components of the data (e.g., total population, timeframe for collection and recurrence, and key limitations). Partnering with key stakeholders in the disability community will aid agencies in managing expectations related to data collected and limitations. Engaging with stakeholders contributing key data also helps to reinforce the important contributions survey respondents and give them a voice in how data are used in subsequent analyses.

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?

As noted in our response to Question 2 in the section on Describing Disabilities, FASEB uses data from federal surveys and data collections to gain understanding about the current population of STEM researchers (undergraduate and doctoral students, postdoctoral scholars, and independent investigators) with one or more disabilities to improve accessibility of research environments. In addition to informing policy statements, cross-cutting data are used to develop factsheets and infographics highlighting key trends and potential policy gaps.

Data from existing surveys, including NCSES, U.S. Census Bureau, and the Centers for Disease Control and Prevention, were used by FASEB to assemble factsheets on the [Intersection of Disability, Other Identities, Age, and Employment Sector for PhDs in 2021](#) and [PhDs with a Disability in 2021](#). While assembled using these independently rich data sources, there were still some gaps. In some cases, data were not published due to report limitations, but there is the option to work with the agency to produce special tabulations. While this option is technically available, requesting special tabulations can be a slow and potentially cumbersome process, with many data points concealed due to limited sample size. While recognizing data limitations will occur, FASEB strongly recommends agencies implement a uniform, mostly automated process for requesting custom or previously unpublished data tabulations.