



OFFICE OF SCIENCE AND TECHNOLOGY POLICY

Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity

AGENCY: Office of Science and Technology Policy (OSTP).

ACTION: Request for information (RFI).

SUMMARY: Through this Request for information (RFI), the White House Office of Science and Technology Policy (OSTP) seeks input from the public to help inform the development of the Federal Evidence Agenda on Disability Equity. Executive Order 14091 on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (February 16, 2023) directed the OSTP National Science and Technology Council Subcommittee on Equitable Data (SED) to coordinate implementation of recommendations of the Equitable Data Working Group. To address the recommendations relevant to disability, the SED established the Disability Data Interagency Working Group (DDIWG). The DDIWG is tasked with the development and release of a Federal Evidence Agenda on Disability Equity, in order to improve the Federal government's ability to make data-informed policy decisions that advance equity for the disability community.

DATES:

Interested persons and organizations are invited to submit comments on or before [INSERT DATE 45 DAYS AFTER DATE OF PUBLICATION IN THE **FEDERAL REGISTER**].

ADDRESSES:

Interested individuals and organizations should submit comments electronically via the Federal eRulemaking Portal at <https://www.regulations.gov/>. Information on how to use regulations.gov, including instructions for accessing agency documents, submitting

comments, and viewing the docket, is available on the site under “FAQ”

(<https://www.regulations.gov/faq>).

Instructions for Submission: OSTP has provided some key questions on which public insights would be most valuable (see Supplementary Information, Part II). You may respond to some or all of these questions, and additional feedback beyond these questions is also welcome. Any links you provide to online materials or presentations must be publicly accessible. Please feel free to share this RFI with colleagues or others for feedback.

Privacy Act Statement:

Response to this RFI is voluntary. Please note that all submissions received in response to this notice may be posted on <https://www.regulations.gov/> or otherwise released in their entirety.

Do not include in your submissions any copyrighted material; information of a confidential nature, such as personal or proprietary information; or any information you would not like to be made publicly available.

Individuals and organizations who respond to this RFI may be contacted for additional clarification.

OSTP will not respond to individual submissions. A response to this RFI will not be viewed as a binding commitment to develop or pursue the project or ideas discussed. This RFI is not accepting applications for financial assistance or financial incentives.

Responses containing references, studies, research, and other empirical data that are not widely published should include copies of or electronic links to the referenced materials. Responses from minors, or responses containing profanity, vulgarity, threats, or other inappropriate language or content will not be considered.

Comments submitted in response to this notice are subject to the Freedom of Information Act (FOIA). Please note that the United States Government will not pay for response preparation, or for the use of any information contained in a response.

FOR FURTHER INFORMATION CONTACT: Please email

disabilitydata@ostp.eop.gov with “Federal Evidence Agenda on Disability Equity RFI” in the subject line, or contact Adam Politis, Senior Policy for Disability and Equity, at 202-881-8448. Individuals who use telecommunication devices for the deaf and hard of hearing (TDD) may call the Federal Relay Service (FRS) at 1-800-877-8339, 24 hours a day, every day of the year, including holidays.

SUPPLEMENTARY INFORMATION:

I. Background

Executive Order (E.O.) 13985 on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (January 20, 2021) established the Equitable Data Working Group (EDWG) to study existing Federal data collection policies, programs, and capabilities and provide recommendations for increasing data available for measuring equity and representing the diversity of the American people. Subsequently, E.O. 14091 on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (February 16, 2023) directed the White House Office of Science and Technology Policy (OSTP) National Science and Technology Council Subcommittee on Equitable Data (SED) to coordinate implementation of the recommendations of the EDWG.

To address the recommendations relevant to disability, the SED established the Disability Data Interagency Working Group (DDIWG). The DDIWG is tasked with the development and release of a Federal Evidence Agenda on Disability Equity, in order to improve the Federal Government’s ability to make data-informed policy decisions that advance equity for the disability community.

The Federal Evidence Agenda on Disability Equity will:

- i. Describe disparities faced by individuals with disabilities that could be better understood through Federal statistics and data collection, such as disparities in health, employment, educational, and other outcomes, or in Federal program participation.
- ii. Identify, in coordination with agency staff, Federal data collections where improved disability data collection may be important for advancing the Federal Government's ability to measure disparities facing individuals with disabilities; and
- iii. Identify practices for all Federal agencies engaging in disability data collection to follow in order to safeguard privacy, security, and civil rights, including with regard to appropriate and robust practices of consent for the collection of this data and restrictions on its use or transfer.

We invite members of the public to share perspectives on how the DDIWG should address these requirements in the Federal Evidence Agenda on Disability Equity. OSTP seeks responses to one, some, or all of the questions that follow.

II. Topics and Key Questions

Describing Disparities

In its March 2023 progress report, the Subcommittee on Equitable Data states, “At its core, the principle of equitable data is about disaggregating and analyzing data to identify disparities in federal policies and programs, using levers of the federal government to address those disparities, and then enabling members of the public to hold government accountable.” With this in mind, OSTP seeks response to the following questions:

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

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?
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?

Informing Data Collections and Public Access

Ultimately, individual agencies decide what data to collect and publish through their surveys and forms, taking into account considerations like informed consent, privacy risk, statistical rigor, intended use of the data, budget, burden to respondents, and more. With that in mind, OSTP seeks response to the following questions:

1. Disability can be defined and measured in multiple ways. Federal surveys and administrative data collections use different definitions of disability and measure it in different ways depending upon the goal(s) of data collection. What frameworks for defining and measuring disability or specific considerations should the DDIWG be aware of?
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?
3. Are there any Federal surveys or administrative data collection tools for which you would recommend the Federal Government *should not* explore collecting disability data due to privacy risk, the creation of barriers to participation in

Federal programs, or other reasons? Which collections or type of collections are they, and why would you make this recommendation?

4. How can Federal agencies increase public response rates to questions about disability in order to improve sample sizes and population coverage?
5. What barriers may individuals with disabilities face when participating in surveys or filling out administrative forms?
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?
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?
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?

Privacy, security, and civil rights

The EDWG recommended that “...as the federal government expands its use of disaggregated demographic data, it must be intentional about when data are collected and shared, as well as how data are protected so as not to exacerbate the vulnerability of members of underserved communities, many of whom face the heightened risk of harm if

their privacy is not protected.” Though previous work by the SED has identified how privacy, confidentiality, and civil rights practices apply to other marginalized groups, OSTP seeks input on privacy, confidentiality, and civil rights considerations that are unique to the disability community and/or are experienced differently by individuals with disabilities. Accordingly, OSTP seeks response to the following questions:

1. What specific privacy and confidentiality considerations should the DDIWG keep in mind when determining promising practices for the Federal collection of data for administrative purposes, such as applications for programs or benefits, compliance forms, and human resources and restrictions on their use or transfer?
2. Unique risks may exist when collecting disability data in the context of both surveys and administrative forms. Please tell us about specific risks Federal agencies should think about when considering whether to collect these data in surveys or administrative contexts.
3. Once disability data have been collected for administrative or statistical purposes, what considerations should Federal agencies be aware of concerning retention of these data? Please tell us how privacy or confidentiality protections could mitigate or change these concerns.
4. Where administrative data are used to enforce civil rights protections, such as in employment, credit applications, healthcare settings, or education settings, what considerations should the DDIWG keep in mind when determining promising practices for the collection of these data and restrictions on its use or transfer?

Dated: May 24, 2024.

Stacy Murphy,

Deputy Chief Operations Officer/Security Officer.