



July 15, 2024

To: Stacy Murphy, Deputy Chief Operations Officer/Security Officer
White House Office of Science and Technology Policy
Executive Office of the President
1650 Pennsylvania Avenue NW
Washington, DC 20504

Re: Federal Evidence Agenda on Disability Equity RFI, Docket Number 2024-11838

I. INTRODUCTION

The Center for Democracy & Technology (CDT) submits these comments to the White House Office of Science and Technology Policy (OSTP) on the development of the Federal Evidence Agenda on Disability Equity. CDT is a nonprofit, nonpartisan 501(c)(3) organization that advocates for civil rights and civil liberties in the digital age. CDT's Disability Rights program specifically focuses on centering disability rights in issues of technology policy. One of the goals of the Disability Rights program is to advocate for policies that mitigate the impacts of algorithmic bias on people with disabilities.

Algorithmic systems are trained on datasets, where the system learns patterns reflected in the dataset and then uses those patterns to create new outputs, whether those be a credit score, a risk score, or novel text. When datasets that are used to build and train algorithmic models are underinclusive or noninclusive of people with disabilities, those outputs may be biased to the detriment of people with disabilities, as well as other marginalized groups. To minimize these effects, it is important to train algorithms on datasets that are representative of people with disabilities. The existence of a federal evidence agenda on disability equity will be a helpful tool in ensuring that data is gathered in ways that mitigate discrimination in many contexts, including technology-facilitated disability discrimination. CDT commends the OSTP for engaging in this vital work. Below, we respond to questions asked by OSTP regarding describing disparities, informing data collection and public access, and privacy, security and civil rights.

II. DESCRIBING DISPARITIES

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

As the Request For Information mentions, people with disabilities face disparities in healthcare, education, employment, and more. Technology, and algorithmic systems in particular, can amplify these disparities when integrated into healthcare, education, employment, and other systems, thus multiplying discriminatory impacts on disabled people. For example, in the employment context, many employers use automated employment decision systems throughout the hiring process – a series of tools, most of which use algorithms, that can include anything from resume screeners to tools that measure physiological reactions during interviews like eye contact or vocal cadence.¹ People with disabilities may be unfairly screened out of jobs due to these tools – for example, individuals who have experienced strokes may have atypical vocal cadences, and those who are blind or low-vision may have atypical visual patterns that are flagged by algorithmic systems.² While existing Federal statistics may reflect those disparities, it is important to consider that algorithmic systems can enhance disparities in systems where disabled people already face inequity.

(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 the impact of technology on people with disabilities, the Disability Data Interagency Working Group (DDIWG) should consider whether and how disability data can offer insights regarding disparities in certain critical areas. For instance, if agencies use disability data to inform how access to resources and information is provided, this can help agencies better ensure those resources and information reach a wider audience. Disability data related to decisions to grant or deny access to employment and housing can inform new agency guidance on preventing disability discrimination in such decisions. Examining the use of disability data in the administration of government services (including education and state or federally sponsored benefits) can alert agencies to risks of disability discrimination or due process violations arising from government service delivery.³

¹ Center for Democracy & Technology, *Algorithm-Driven Hiring Tools: Innovative Recruitment or Expedited Disability Discrimination* (2020), <https://cdt.org/insights/report-algorithm-driven-hiring-tools-innovative-recruitment-or-expedited-disability-discrimination/>.

² *Id.*

³ For a discussion of these risks, see Lydia X.Z. Brown et al, Center for Democracy & Technology, *Challenging the Use of Algorithm-Driven Decision-Making in Benefits Determinations Affecting People with Disabilities* (2020), <https://cdt.org/insights/report-challenging-the-use-of-algorithm-driven-decision-making-in-benefits-determinations-affecting-people-with-disabilities/>.

In determining policy research priorities, the DDIWG should also consider how disability data is sourced, including the formats of surveys or other tools through which responses are solicited, as well as the sufficiency and accessibility of the guidance and instructions on how to use those formats. This will make it more likely that responses are accurate and representative of those across the disability community.

III. INFORMING DATA COLLECTIONS AND PUBLIC ACCESS

(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?

- When considering how disability is measured and defined, the DDIWG should consider that there are at least four different models of defining disability: legal, medical, social, and identity/demographic.
- The legal model refers to the various ways that statutes – including the Americans with Disabilities Act – define disability.⁴
- The medical model of disability most often views disability as defined by a diagnosis – under the medical model, disability can be temporally limited, and an individual can cease to be disabled if an underlying condition is “cured.”
- The social model of disability argues that individuals with differences experience hardship not as an inevitable result of their differences, but rather as a result of discriminatory and/or inaccessible physical spaces and social, political, and economic systems that people with disabilities interact with.
- Finally, the identity-based model recognizes that, for many individuals with disabilities, their disability is an aspect of their personal and cultural identity⁵ – under this model, disability would be considered a demographic, as opposed to something that can be temporally or even environmentally mitigated.

⁴ The Americans with Disabilities Act defines individuals with disabilities as those with any physical or mental impairment that impacts one or more major life activities (including, but not limited to, walking, sleeping, and eating). The ADA also includes within its definition of disability individuals with a “history or record” of such impairment, as well as individuals who would be “perceived by others as having such impairment.” See Americans with Disabilities Act, 42 U.S.C. § 12101.

⁵ Steven E. Brown, *Disability Culture and the ADA*, Disability Studies Quarterly (2015), <https://dsq-sds.org/index.php/dsq/article/view/4936/4062>.

These models can all impact how, as well as if, people identify as having a disability – for example, under a medical model, one may choose to identify as disabled only if they receive an official medical diagnosis, whereas a social or identity-based model may also include individuals who self-diagnose. These differences can, of course, influence the outcomes of data gathering or collection processes, and it is therefore important to recognize that they all do exist, and that different respondents may be keeping different definitions of disability in mind when answering surveys. The identity-based model would be the most inclusive model, and therefore the one least likely to lead to underinclusive datasets – however, depending on the context of the survey, different definitions may be more appropriate.

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

To improve response rates and increase dataset sample sizes, Federal agencies should do the following:

- Ensure that their survey(s) define disability. The method of defining disability that will likely be most all-encompassing would be one based on the identity/demographic model; however, there may be times wherein a legal or other definition is better suited to the individual agency. Regardless of how the agency in question chooses to define disability, they should provide respondents with a definition so that those individuals can respond accordingly.
- Explain to respondents how their responses (their data) will be used, as well as any data protection measures (including deletion) that have been put into place to minimize the chance that potential respondents do not answer due to concerns about privacy.
- Explain to respondents how their answers to these survey questions may impact them. For example, if a lack of response could lead to an undercounting of individuals with disabilities such that allocation of resources for benefits would then be impacted, ensuring that potential respondents are aware of this could influence their decision on whether or not to participate.⁶
- Ensure that survey(s) are accessible to people with disabilities, including either being written in plain language or providing plain-language versions.

⁶ See National Disability Rights Network, *Count Everyone, Include Everyone – The Need for Disability Inclusion and Representation in Federal Data* (2021), https://www.ndrn.org/wp-content/uploads/2021/10/NDRN_Count_Everyone_Include_Everyone_2021.pdf.

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

In addition to accessibility concerns and questions as to whether they “count” as disabled for the purposes of any particular survey (discussed above), people with disabilities may face additional challenges when participating in surveys. For example, disabled people are disproportionately incarcerated,⁷ and many people with disabilities live in institutions,⁸ both of which can make it difficult for surveyors or data collectors to reach them. In addition, many individuals with disabilities may feel that their disability is stigmatized by various cultural and social factors, which then could impact their ability and/or desire to identify as disabled on a survey. Agencies should be aware that these barriers exist, and engage in thoughtful and preemptive measures to account for them.

IV. PRIVACY, SECURITY AND CIVIL RIGHTS

(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?

To best safeguard respondent privacy, and in recognition of the special sensitivity of disability-related data, data collectors should adhere to the following best practices when gathering this data for administrative purposes:⁹

- Agencies should provide plain language and easy-to-read disclosures including descriptions of:
 - What data is collected;

⁷ Prison Policy Initiative, *Disability* (last updated Jul. 1, 2024), <https://www.prisonpolicy.org/research/disability/#:~:text=People%20with%20disabilities%20are%20overrepresented,state%20prisons%20have%20a%20disability>.

⁸ Michael Roppolo, *16,000 People with Disabilities are In State-Operated Institutions. This is How Experts Say Health Care Should Change*, CBS News (Apr. 30, 2024) <https://www.cbsnews.com/news/16000-people-disabilities-institutions-no-place-like-home-cbs-reports/#>.

⁹ Miranda Bogen, Center for Democracy & Technology, *Navigating Demographic Measurement for Fairness and Equity*, <https://cdt.org/insights/report-navigating-demographic-measurement-for-fairness-and-equity/>; Hannah Quay-de la Vallee, Center for Democracy & Technology, *Sharing the Health Guidance for Schools When Procuring Mental Health Technologies* (2023), <https://cdt.org/wp-content/uploads/2023/06/2023-06-28-Civic-Tech-Guidance-for-Schools-When-Procuring-Mental-Health-Technologies-report.pdf>.

- The purpose for each category of data collected;
 - Sources of each category of data;
 - Which, if any, third parties will or could have access to each category of data, and for what purpose;
 - The method by which a person can opt in to the use of their data for secondary purposes and how they can also withdraw that consent;
 - The data retention periods for all categories of data, and how appropriate retention and deletion will be ensured for all parties; and
 - Whether the agency infers disability or health status from other data.
- Disability data should not be transferred for purposes other than that for which it was provided, unless the person to whom the data belongs opts in to its use for those purposes. To the extent the Privacy Act of 1974 applies to such disability data, an agency must inform the person about the “routine uses” (i.e. purposes which are compatible with the purpose for which the data was collected) which may be made of the data¹⁰ – and to comply with this requirement, agencies should ensure such notice is provided in an accessible format, including in plain language, so disabled people are meaningfully informed about how their data will be used prior to collection.
 - Agencies should use encryption to protect personal data that needs to remain linked to a person’s identifiers or is otherwise reasonably linkable to an individual; they should use de-identification for personal data that does not need to be linked to a person’s identifiers but does need to be linked to other data about the person to be useful for the purpose for which the data is collected.
 - Agencies should use aggregation and other methods (such as secure multi-party computation or differential privacy) that would allow dataset(s) to be analyzed without identifying individual people or needing to share raw data.
 - Access to the data should be limited to the government staff responsible for carrying out the purposes for which the data was provided, and they should be trained on permitted uses and data security protocols.
 - When government contractors are handling the data, agencies must maintain control over how the data is used and safeguarded and ensure contractors do not repurpose the data.
 - Agencies should regularly audit their own and their contractors’ processes for handling disability data, and should solicit disabled people’s input regarding appropriate handling of their data, which uses and transfers of their data that would benefit them, and which uses and transfers would harm them.

¹⁰ 5 U.S.C. §552a(e)(3)-(4).

(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.

As discussed above, disability-related data can be particularly sensitive, in part due to a potential overlap with sensitive health data and the aforementioned stigma (and corresponding social or cultural consequences) that many people with disabilities may face when identifying or being identified as disabled. As a result, it is vital that Federal agencies consider the following possibilities:¹¹

- Disability data could be repurposed for uses beyond that for which the data was collected (and/or purposes that have not been disclosed to or understood by the person whose data is being used). Implementing the practices described in question (1) of this section could mitigate some of those harms.
- Poor security practices – whether due to an agency’s inadequate internal infrastructure, procedures, or training for data security or its over-reliance on private contractors to manage data security – can lead to data breaches or to sensitive disability data being misused by data brokers and other private actors. Agencies should employ technical, administrative, and physical security measures, have in place security breach incident response procedures, and provide remedies for breaches.
- It is possible, and perhaps likely, that there will be inconsistencies in the type of data collected to determine a person’s disability, which could also lead to inconsistencies or even inaccuracies in datasets. For example, there will be differences in the amount of data used and how accurately it reflects a person’s disability depending on:
 - Whether the person simply stated their disability status, or more data (including proxy data) was gathered to “verify” that the person is disabled or draw conclusions about how their disability affects them.
 - Whether the disability data is reported by the person, is based on an agency’s observation of the person, or is obtained from sources other than the person (the latter two may not be consensual or in line with the person’s expectations about what data is collected about them and how).

¹¹ Bogen, *supra* note 9.

(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.

Regarding data retention, agencies should engage in the following practices:¹²

- Data collected should be retained only for as long as necessary, and it should be deleted once the purpose for which it was provided has been fulfilled, or once no longer needed for monitoring.
 - Retention for monitoring should be subject to a person's consent.
 - Retention should be limited, as a general rule, because the longer an agency fails to dispose of disability data responsibly once it is no longer needed, the longer the risk remains that the data could be exposed in a data breach and misused.
- Agencies should provide disclosures regarding their data retention practices and any changes to those practices (including any third parties that store data), and they should perform periodic assessments of their retention policies and processes.
- Agencies should also ensure that they employ appropriate and secure practices for deleting and disposing of data once it no longer needs to be retained.

(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?

When determining best practices for the collection of administrative data used to enforce civil rights protections, particularly those affecting people with disabilities, the DDIWG should consider the following:¹³

- Collection and use of disability data should be scoped so that it is sufficient to determine when a regulated entity is using proxies for disability or other data that tends to disproportionately subject disabled people to adverse outcomes. This task should be informed by consultation with disabled people about the types of relevant data and potential uses that can result in civil rights violations.

¹² *Id.*

¹³ See *id.*; see also Elizabeth Laird & Hannah Quay-de la Vallee, Center for Democracy & Technology, *Data Sharing & Privacy Demands in Education: How to Protect Students While Satisfying Policy & Legal Requirements* (2019), <https://cdt.org/wp-content/uploads/2019/11/2019-11-13-CDT-Data-Integration-Issue-Brief-Final.pdf>.



- Data sharing between agencies may strengthen the government’s ability to address civil rights violations and reduce the burden on people to repeatedly provide data. However, to the extent the Privacy Act of 1974 applies, agencies should be limiting inappropriate uses of the data (ensuring that all uses are compatible with the purpose for which the data was collected) and preventing it from being leaked.¹⁴ These sorts of protocols can allow both agencies and people with disabilities to benefit from data sharing practices, while being insulated from potential risks.

V. CONCLUSION

The development of a Federal Evidence Agenda on Disability has a significant impact potential to enhance equity for people with disabilities, including in the context of technology. We are looking forward to continuing to collaborate on this effort.

Respectfully submitted,

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¹⁴ 5 U.S.C. §552a.