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Office of Science and Technology  
Executive Office of the President  
1650 Pennsylvania Avenue NW Washington, DC 20504  
Submitted via regulations.gov

RE: Request for Information; Federal Evidence Agenda on Disability Equity

The Amputee Coalition appreciates the opportunity to comment on the Federal Evidence Agenda on Disability Equity. We fully support the Office of Science and Technology Policy (OSTP)'s initiative to gather insights and develop a comprehensive agenda that improves the federal government's ability to make data-informed policy decisions that advance equity for individuals with disabilities.<sup>1</sup>

Established in 1986, the Amputee Coalition is dedicated to advocating for and supporting individuals who have limb loss and limb difference (LLLD). Our mission extends to providing comprehensive support both pre- and post-amputation, ensuring assistance during the recovery process. Amputations can result from various causes, including traumatic injuries and illnesses such as sepsis. Our organization offers these comments to improve the collection of demographic data on disability for the approximately 5.6 million+ people in the country who have limb loss or were born with limb difference.

## **Describing Disparities**

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

There are a number of areas in which there is a dearth of disability data collection across multiple policy issues, and this is by no means intended to be an exhaustive list. This lack of data can lead to policies that at best do not address the issues they were intended to solve, such as the failure of the Americans with Disabilities Act and other employment initiatives, to significantly improve employment rates and outcomes for people with

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<sup>1</sup> Office of Science and Technology Policy, *Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity* (May 30, 2024), <https://www.federalregister.gov/documents/2024/05/30/2024-11838/notice-of-availability-and-request-for-information-federal-evidence-agenda-on-disability-equity>.



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disabilities.<sup>2</sup> Other policies designed to protect people with disabilities and diminish suffering, such as guardianship and assisted suicide statutes, may in fact lead to the unnecessary loss of autonomy and life due to the fact that these policies are often based on erroneous assumptions about the ability of individuals living with disability to make their own decisions and misconceptions about their quality of life.

Currently, there is no reliable state or federal data on guardianship including the number of people currently under guardianship, whether less restrictive alternatives were considered, processes for determining capacity, and how, or if, due process was provided.<sup>3</sup>

The intent behind assisted suicide laws is to end the extreme pain and suffering experienced by some individuals with terminal diagnoses. Yet, the scant data available from states with assisted suicide statutes suggests that most patients requesting assisted suicide did not do so as the result of intolerable, untreatable pain, but as the result of loss of autonomy, decreased mobility, and increased interdependence on others for care.<sup>4</sup>

Another policy growing in popularity are police registries. In jurisdictions that have created registries, a person's disability status is provided to law enforcement, often without the consent of the individual, so they respond more effectively to situations involving individuals with disabilities when they receive service calls. However, there is no evidence to suggest that registries work as intended and keep those living with disabilities safe. Actually, anecdotal evidence indicates that registries may in fact put people at greater risk by invading their privacy and making them susceptible to data breaches and increasing the likelihood that a responding officer may overreact based on their own disability biases, making them more likely to respond with force.<sup>5</sup>

It is widely acknowledged that people living with disabilities face significant disparities in healthcare, yet there have been no material improvements in increasing health equity for this population. People with disabilities are more likely to use the healthcare system for disease management than disease prevention. A person living with a physical, intellectual,

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<sup>2</sup> **National Council on Disability.** (2020) *2020 Progress Report on National Disability Policy: Increasing Disability Employment*<sup>1</sup>. National Council on Disability<sup>2</sup>. Retrieved from [www.ncd.gov](http://www.ncd.gov).

<sup>3</sup> **National Council on Disability.** (2019)<sup>1</sup>. *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities*<sup>23</sup>. National Council on Disability.

<sup>4</sup> **National Council on Disability.** (2019). *The Danger of Assisted Suicide Laws: Part of the Bioethics and Disability Series*.<sup>1</sup> Washington, DC: National Council on Disability<sup>2</sup>. Retrieved from [www.ncd.gov](http://www.ncd.gov).

<sup>5</sup> **National Center on Criminal Justice & Disability**<sup>®</sup>. (n.d.). *Policy Brief: Law Enforcement Registries for Individuals with Disabilities*.



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or developmental disability has a lower life expectancy than someone without a disability. They are more than three times as likely to have arthritis, diabetes, and to have experienced a heart attack. They are five times more likely to report having had a stroke, Chronic Obstructive Pulmonary Disease, and depression. They are more likely to be obese and significantly more likely to have unmet medical, dental, and prescription needs.<sup>6</sup>

Women with disabilities are more likely to receive poorer maternity care and less likely to have received a Pap smear test or mammogram. A pregnant person living with a disability is at much higher risk for severe pregnancy and birth-related complications and has eleven times the risk of maternal death.<sup>7</sup>

These health disparities are exacerbated for people with disabilities who are multiply marginalized.<sup>8</sup> More intersectional data can help identify and address the systematic root causes of disparate impact in order to mitigate inequitable outcomes. More robust intersectional data collection can also help address the health needs of individuals with a range of conditions, including those living with limb loss or limb difference, who are likely to experience co-concurrent conditions.

As the federal government continues to look at issues such as bodily autonomy, mental capacity, and healthcare disparities faced by people with disabilities the consideration of intersectional and co-concurrent conditions is imperative. This includes the inclusion of youth in any longitudinal data collection initiative.

## **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?**

While federal data sources are among the most important collections related to people with disabilities, a number of non-federal health data sources contribute to our understanding of health equity for people with disabilities. One such source is the Limb Loss and Preservation Registry (LLPR).<sup>9</sup> The LLPR is a national program to improve the

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<sup>6</sup> [National Council on Disability. \(2023\). Policy Framework to End Health Disparities of People with Disabilities.](#)<sup>1</sup> Retrieved from [National Council on Disability website](#).

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> The LLPR was developed and launched under a sole source government contract through a partnership of the Mayo Clinic and the Thought Leadership & Innovation Foundation (TLI). Funded by the National Institutes of Health and the Department of Defense (Contract No. HHSN275201800005I). During this 5-year contract, the LLPR was designed, developed, accredited for data security and privacy and launched as a live system



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quality, safety, effectiveness and cost of limb loss treatment and limb loss preservation. The LLPR is a centralized data warehouse designed to collect relevant patient data and perform analysis to improve the quality of care and patient outcomes.

Being able to measure the care patients receive in a hospital and at an O&P clinic allows for better understanding regarding the level of care patients are receiving across the country. Measuring care provided paves the way to standardizing higher levels of care for patients in all regions across the country which leads to improved patient outcomes for a better quality of life.

The Registry is a multi-stakeholder model. This means that it includes a broad group of participants such as patients, care providers (OT, PT, physicians, prosthetists etc.), care sites (hospitals, clinics wound centers), insurance payors, device manufacturers, suppliers, and regulatory agencies.

While the registry's primary value is to enhance treatment and care for limb preservation and patients with limb loss, the multi-stakeholder model highlights secondary value streams from the LLPR data to:<sup>10</sup>

- Create a unified voice for all stakeholders, uniting for a common purpose
- Identify and support this underserved population
- Drive enhanced reimbursements
- Validate design concepts, evaluate new devices, and accelerate time to market for new devices
- Offer a timely and direct feedback channel about how products are performing
- Provide key data needs: billing data, component device, and most importantly objective non-biased measures of patient outcomes
- Provide a tool for patient education and self-advocacy

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collecting data in February 2022. The 5-year contract with the National Institutes of Health (NIH) and the funding for the LLPR ended on March 23, 2024. To ensure long-term sustainability, NIH transferred ownership of the LLPR to a nonprofit entity, Thought Leadership & Innovation Foundation (TLI) and operated in partnership with the Amputee Coalition of America (ACA).

<sup>10</sup> Limb Loss and Preservation Registry (LLPR)<sup>1</sup>. Retrieved from <https://www.llpr.org/>.



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- Generate real-time outcomes – the ‘lived experience’
  - Provide data points for evidence-based medicine and aftercare:
    - Validate providers’ belief in how to care for patients and how to inform patient expectations
    - Risk factor modeling
    - Forecast clinical trajectory
    - Optimize resources – helping understand who needs what device
    - Inform standards of care –i.e., validate surgeon expertise, compile objective data on provider performance/outcomes
- 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?**

It is critical that the Federal government take a broad look at disability and consider all types of disabilities, and the various types of disparities experienced by people with disabilities, in its surveys and other research.

The disability community is not monolithic, and instead includes people with all types of physical, mental, and intellectual disabilities. It also ranges from people with less serious functional limitations to those with serious limitations that impact all aspects of life. The impact of disability varies widely among individuals, even for those with the same diagnosis. Factors such as the severity of the condition, availability of support systems, cultural beliefs and attitudes, and personal coping strategies can influence how a disability affects a person's daily life. For example, the experiences of and needed support for someone with a below the knee amputation are going to be vastly different than that of someone who has had a quadruple amputation.

Therefore, assessments must be individualized to capture the unique experiences and needs of each person and ensure that the Federal government is capturing the full spectrum of experiences for people with disabilities. Standardized tools should be flexible enough to allow for customization based on individual circumstances. This may involve using open-ended questions, incorporating person-reported outcomes, and allowing respondents to provide additional context about their disabilities. Such open-ended



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questions must be developed with the input of, and piloted with, individuals from diverse racial/ethnic/cultural/language backgrounds to ensure that they will generate accurate responses across these differences.

Existing Federal statistics often overlook the nuanced disparities faced by individuals with disabilities and the differences between different types of disabilities, particularly in areas such as access to technology, transportation, and specialized health care services. Disparities faced by individuals with disabilities in pain management and mental health services are not well-understood. People who have limb loss can experience pain for years after an amputation. Those who rely on opioids for pain management face skepticism and bias, resulting in under-treatment and unnecessary suffering. There is also significant room for improvement in gathering long-term outcome data on employment and education for individuals with disabilities, which can provide deeper insights into their ongoing challenges and successes in these critical social determinants of health.

It is particularly important that the Federal government look at the full life cycle of people with disabilities, including the key junctions where people with disabilities face barriers to joining the “mainstream” of American life, and how these experiences are different for people with different types of disabilities. For example, what barriers do people with mental health disorders face in education, employment, marriage, retirement, or access to health care? How are these barriers different across different stages of life or different races/ethnicities? How are these barriers different for people with physical disabilities, such as limb loss or limb difference? How might these barriers differ for those who exist at the intersections of these various communities? Studying these issues needs to be a focus of policy research moving forward, so that people with all types of disabilities and at all stages of life are fully able to participate in their community and society. By undertaking these studies, the Federal government can help ensure accessibility for all.

### **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?**

The 2023 Compendium of Disability Data Collection Methods compiled by Mathematica for the Administration for Community Living’s National Institute on Disability, Independent



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Living, and Rehabilitation Research (NIDILRR) cites over 600 articles related to measuring disability. Written primarily over the last decade, the range of articles explicitly or implicitly include the following different conceptual frameworks for understanding disability:

- Disability as medical diagnosis;
- Disability as a demographic characteristic that demonstrably accompanies or affects individual outcomes;
- Disability as a demographic characteristic that impacts outcomes both in isolation, and in combination with other demographic characteristics such as race, gender, age, and LGBTQIA+ status;
- Disability itself as a social, health, or other outcome;
- Disability as a pre-condition to eligibility for government benefits;
- Disability as a protected characteristic under civil rights law;
- Disability as a factor that triggers a legal requirement to provide reasonable accommodations and/or policy modifications for equally effective communication, employment, healthcare, and participation in government programs and activities, and the services offered by public accommodations, including equal participation in complaint mechanisms and quality surveys;
- Disability as a specific health condition that requires physical, mental, and/or social support interventions that must be evaluated for evidence of effectiveness, efficiency, and value; and
- Disability as social, cultural and/or political identity, or as a component of such.

Many of the above frameworks are embedded in U.S. law and practice. For example, Section 504 of the Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, and the Individuals with Disabilities Education Act recognize disability as a protected characteristic because individuals with disabilities experience systemic, harmful stereotypes, denials of equal participation, and discriminatory treatment. The Social Security Act and the Medicaid Act, as well as individual state benefit programs, define disability for the purposes of service eligibility.

Some agencies draw upon the World Health Organization's International Classification of Functioning, Disability and Health (ICF) Framework that attempts to consider disability within a broader social context and wellness perspective. The ICF emphasizes the complex



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interaction of individual health, contextual, and personal factors that can affect life participation and functioning. This framework accords well with a “social model of disability” that refuses to place disability as purely a medical condition that exists within an individual. This social model necessarily requires broader and more inclusive and collaborative methods of data collection, research and policymaking because individual and population health depends on understanding the relationship between diverse factors, including a person’s own identification as an individual with disabilities and what that means, rather than simply relying on external diagnoses.

Federal agencies must keep in mind across all the conceptual frameworks, the means by which disability is counted cannot be just a secondary consideration of “survey design” after a conceptual framework is adopted. Any tool used to measure disability must be fully accessible to people with a range of different disabilities across the full gamut of cultural, social, and economic characteristics. It is all too easy to entirely miss sub-populations and their experiences of disability by using measures that present physical, communication, social, economic, or other barriers to participation.

We must always be clear about our goals for measuring disability, ensure that we match our conceptual framework of measurement to our goal, guard against the sloppy use of disability statistics and data, and always ensure that people with disabilities and disability advocates are included in goal setting and the ongoing evaluation of whether those goals are being achieved.

- 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?**

Other critical factors include an inclusive survey design that addresses health literacy, accessibility of data collection methods, and cultural competence of data collectors. It is also important to ensure that data collection tools are capable of capturing the full range of benefits and challenges experienced by individuals with disabilities, beyond traditional health outcomes.





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**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?**

Surveys that do not include accessibility accommodations should not be used to collect data on disability. While we do not have recommendations on specific survey tools not to use, we note that tool design should pay special attention to who answers the survey tool, as it is very common that someone else – a parent or guardian or case manager, will fill out survey forms on behalf of an individual with a disability with whom they work or live.<sup>11</sup> If a survey form does not specify who filled out the answers, the data drawn from the survey can mislead.

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

Federal agencies can improve response rates by ensuring surveys and forms are accessible in multiple formats (e.g., Braille, large print, electronic formats), conducting outreach through trusted community organizations, and providing assurances of confidentiality. Additionally, simplifying the process of responding to surveys and providing support during the process can help increase participation. Additionally, highlighting the benefits of participation – such as contributing to better services and policies for individuals with disabilities – can motivate respondents. Emphasizing the positive impact that their input can have on advancing disability equity and improving community resources can encourage individuals to better engage with the survey process.

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

Individuals with disabilities may face a range of barriers when participating in surveys or completing administrative forms. Physical accessibility issues, such as the inability to reach or use survey kiosks, can prevent participation. Cognitive load can also be a

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<sup>11</sup> Kristen Miller, J. Brent Vickers & Paul Scanlon, Collaborating Ctr. for Questionnaire Design and Evaluation Research (CCQDER), National Ctr. for Health Statistics, *Comparison of American Community Survey and Washington Group Disability Questions* (Oct., 2022), [https://wwwn.cdc.gov/qbank/report/Miller\\_2020\\_NCHS\\_ACS.pdf](https://wwwn.cdc.gov/qbank/report/Miller_2020_NCHS_ACS.pdf).



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significant barrier, as complex or lengthy forms may be overwhelming and difficult to navigate. Additionally, a lack of assistive technologies, such as screen readers or speech-to-text software, can hinder the ability of some individuals to complete forms independently.

Privacy concerns is another critical issue. Many individuals may worry that their personal information could be misused or not kept confidential, which deters participation in surveys. This fear is particularly concerning when surveys are not accessible, and individuals with disabilities must rely on family members or acquaintances for assistance. Requiring individuals to disclose personal information to others can increase the risk of compromised confidentiality and skew survey results if respondents are uncomfortable sharing sensitive information. Providing strong assurances of confidentiality and robust data protection measures can help alleviate these concerns and encourage participation.

Ensuring that health literacy is addressed is also crucial. Recognizing different learning capabilities and providing information in plain language are essential for helping individuals understand what is being asked in surveys and on administrative forms. This can include using clear and straightforward instructions, avoiding technical jargon, and incorporating visual aids to make the content more accessible.

To overcome these barriers, it is essential to provide tools that facilitate objective, individualized assessment methods. This includes offering assistance tailored to various learning needs and ensuring that forms are available in multiple formats (e.g., Braille, large print, electronic formats) to accommodate different disabilities. Ensuring effective, empathetic communication by engaging people with disabilities to help codevelop surveys and training staff to interact respectfully and supportively with individuals with disabilities can also make a significant difference.

- 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?**



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Useful data currently collected include those related to health care access, educational attainment, and employment status. However, there is a need for more detailed data on the intersectionality of disability with other factors such as race, socioeconomic status, and geographic location to fully understand and address disparities.

**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?**

While this RFI is an important step towards raising awareness of disability data, it is crucial that the federal government continually engages with people with disabilities to ensure comprehensive and accurate data collection. The federal government should establish a committee of external experts, including individuals with disabilities, to evaluate best practices in data collection and to test and implement effective statistical methods. This committee should actively seek input from organizations like the Amputee Coalition and other groups representing people with disabilities. Engaging with these stakeholders will help raise awareness about the importance of collecting better disability data and ensure that the process is inclusive and representative.

A key principle of the disability movement is that decisions and policies affecting people with disabilities should be made with their direct involvement and input. Federal agencies should recognize the invaluable insights that individuals with disabilities can provide on these issues. Public service announcements and social media campaigns can play a significant role in raising public awareness about the need to collect disability data. However, it is essential that these communication methods are fully accessible to all people with disabilities.

To effectively communicate methodological constraints, federal agencies should prioritize transparent reporting, public forums, and educational materials that clearly explain the limitations and ongoing efforts to improve data collection methods. These strategies will help build trust and ensure that the public is well-informed about the challenges and advancements in disability data collection.

**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?**



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Individuals and organizations external to the Federal Government utilize data from federal surveys and administrative data collections for a variety of purposes, including research, advocacy, and program development. Academic institutions and research organizations, for example, use this data to study health disparities, access to services, and the social determinants of health. By analyzing these datasets, researchers can identify patterns and trends that inform public health interventions and policy decisions. Patient organizations leverage federal data to support policy changes, highlighting the specific needs of their constituents to policymakers and the public. This data-driven advocacy is crucial for securing funding, improving services, and enacting legislative changes that benefit individuals with disabilities.

Enhanced collaboration with external organizations is another beneficial practice employed by federal agencies. By establishing partnerships to co-create data collection tools and methodologies, agencies can ensure that the data collected meets the needs of all stakeholders. This collaborative approach not only improves the relevance and usability of the data but also fosters trust and cooperation between the government and external entities. Overall, these practices enable individuals and organizations to effectively utilize federal data, driving advancements in research, advocacy, and program development that support individuals with disabilities.

## **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?**

Privacy and confidentiality are paramount when collecting disability data for administrative purposes. The DDIWG should ensure that individuals provide informed consent, fully understanding how their data will be used. Clear communication about data usage and the steps taken to protect personal information can help build trust and encourage participation.

Data minimization practices should be employed, collecting only the data necessary for the specific purpose. This reduces the risk of privacy breaches and ensures that sensitive information is not unnecessarily exposed. Robust anonymization and encryption



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techniques should be implemented to protect personal data from unauthorized access or disclosure.

Transparency in the investigation process is critical. Individuals should be informed about how their data will be stored, used, and protected. Providing support during the complaint process and ensuring that individuals have recourse if their data is misused can further enhance trust and participation.

Implementing strict access controls is another key consideration. Ensuring that only authorized personnel can view or use the data helps safeguard privacy. Regular audits and compliance checks can ensure that these controls are adhered to, and that data is handled responsibly.

**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.**

Collecting disability data can lead to stigmatization and discrimination if not handled properly, as individuals may fear that disclosing their disability status could result in negative consequences, such as being denied services or facing bias in employment or health care settings. Ensuring that data collection is voluntary and providing strong privacy protections can help mitigate these risks. However, strong privacy protections must be complemented by robust cybersecurity measures to prevent data breaches, as the exposure of sensitive disability data can lead to identity theft, discrimination, and other harms. Federal agencies must protect the data and respond quickly to any breaches that do occur.

Misidentification due to inadequate data collection methods is another risk. Inaccurate data can lead to improper allocation of resources and ineffective policies. Ensuring that data collection methods are accurate, inclusive, and regularly updated can help prevent misidentification and ensure that the data reflects the true needs of individuals with disabilities. Additionally, providing clear information about the purpose of data collection and how the data will be used can help address concerns about misuse. Individuals should know that their data will be used to improve services and support for people with disabilities, not to penalize or stigmatize them.



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Engaging people with disabilities in the development of survey questions can further ensure that the questions are understandable and free from stigmatization. This collaborative approach helps create a more inclusive data collection process that more accurately reflects the experiences and needs of individuals with disabilities.

**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.**

Federal agencies should establish clear data retention policies that define how long data will be kept and when it will be securely destroyed. Retaining data only as long as necessary for the specific purpose reduces the risk of unauthorized access or misuse. Ensuring that data is securely destroyed when no longer needed is a critical aspect of data management.

Implementing strict access controls can help protect data during its retention period. Only authorized personnel should have access to sensitive disability data, and robust authentication methods should be used to verify their identities. Regular audits and compliance checks can ensure that these controls are maintained, and that data is handled responsibly.

Privacy and confidentiality protections, such as anonymization and encryption, can help mitigate concerns about data retention. By anonymizing data, agencies can reduce the risk of identifying individuals if the data is accessed without authorization. Encryption ensures that even if data is intercepted, it cannot be easily read or misused.

Transparency about data retention practices can also help build trust. Providing clear information about how long data will be kept, the measures in place to protect it, and the processes for securely destroying it can reassure individuals that their information is being handled responsibly. This transparency can encourage more individuals to participate in data collection efforts.

**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?**



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Ensuring equitable data use is crucial. Data collected for civil rights enforcement should be used to protect and support individuals with disabilities, not to harm or discriminate against them. Limiting the use of data to the specific purposes for which it was collected can help prevent misuse and ensure that it is used ethically.

Purpose limitation is another important consideration. Data should only be used for the purposes explicitly stated at the time of collection. This helps prevent data from being repurposed in ways that could negatively impact individuals with disabilities. Clear guidelines and policies on data use can help enforce this principle.

Maintaining transparency and accountability is essential. Individuals should be informed about how their data is used and have recourse if it is misused. Establishing accountability mechanisms, such as regular audits and oversight by independent bodies, can help ensure that data is used responsibly and that any misuse is promptly addressed.

Protecting individuals' privacy and confidentiality is also critical. Strong data protection measures, including anonymization and encryption, can help safeguard personal information. Ensuring that data is stored and transferred securely can prevent unauthorized access and misuse. Providing clear information about these protections can help build trust and encourage more individuals to participate in data collection efforts.

### **Conclusion**

The Amputee Coalition appreciates the opportunity to provide input on improving data collection and reporting disability data across the federal government. We look forward to continuing our collaboration with the OSTP.

Sincerely,

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Director of Advocacy & Government Relations  
Amputee Coalition