FEDERAL EVIDENCE AGENDA ON DISABILITY

A Report by the

DISABILITY DATA INTERAGENCY WORKING GROUP

of the

NATIONAL SCIENCE AND TECHNOLOGY COUNCIL

January 2025

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About this Document

The Federal Evidence Agenda on Disability provides a roadmap for opportunities for the federal government to continue to build evidence and leverage data to improve outcomes for people with disabilities. This report will help agencies approach evidence building more effectively and strategically with a clear focus on positively impacting the lives of people with disabilities across the country.

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Abbreviations and Acronyms

AAC	Augmentative and Alternative Communication
ABLE	Achieving a Better Life Experience Act
ADA	Americans with Disabilities Act
APS	Adult Protective Services
CDC	Centers for Disease Control and Prevention
DDIWG	Disability Data Interagency Working Group
ECE	Early Childhood Education
FAIR	Findable, Accessible, Interoperable, and Reusable
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
IDEA	Individuals with Disabilities Education Act
ICDR	Interagency Committee on Disability Research
LTSS	Long-Term Services and Supports
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NSTC	National Science and Technology Council
OMB	Office of Management and Budget
OSTP	Office of Science and Technology Policy
PII	Personally Identifiable Information
RFI	Request for Information
SME	Subject Matter Expert
SNAP	Supplemental Nutrition Assistance Program
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income

Introduction

In order to improve outcomes for people with disabilities,[1] the federal government must gather the data needed to understand people with disabilities and their communities, identify the barriers they face, and evaluate the effectiveness of policies and programs designed to address those barriers. The Disability Data Interagency Working Group (DDIWG) took on this charge with the creation of a Federal Evidence Agenda on Disability ("Evidence Agenda"). Like all Americans, people with disabilities deserve fair, just, and impartial treatment. This Evidence Agenda strives to further this goal by advancing the federal government's ability to make data-informed decisions that improve outcomes for people with disabilities.

Purpose

The purpose of this Evidence Agenda is to provide a roadmap for how the federal government can build additional evidence to make data-informed decisions that improve outcomes for people with disabilities.

The objectives of the Evidence Agenda are to:

    i.   Describe disparities faced by people with disabilities that could be better understood through federal statistics and data collection;

    ii.   Identify opportunities where improved collection and use of federal disability data may advance the federal government's ability to measure disparities facing people with disabilities; and

    iii.   Identify practices for all agencies engaging in disability data collection to follow in order to safeguard privacy, security, and civil rights.

People and Process

This Evidence Agenda was developed by the DDIWG, which is led by staff from the White House Office of Science and Technology Policy (OSTP) and the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). The DDIWG includes over 70 subject matter experts (SMEs) from more than 30 departments and agencies across the federal government, including many individuals who identify as people with disabilities and bring lived experience that complements their subject matter expertise.

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[1] The term "people with disabilities" is considered "person-first language" and is used throughout this report in order to be consistent with other federal reports. Though many individuals in disability communities use person-first language, the DDIWG recognizes that other individuals prefer "identify-first language" (e.g., "disabled people").

To develop the Evidence Agenda, robust and meaningful community engagement was essential. The DDIWG conducted three types of community engagement activities in order to elicit input and feedback regarding disparities faced by people with disabilities, opportunities for improving the collection and use of disability data, and considerations for protecting the privacy, security, and civil rights of people with disabilities:

- First, the DDIWG held a series of listening sessions with more than 75 individuals and organizations representing a range of subject matter expertise and lived experience. This included advocacy groups, professional associations, researchers, direct service providers (e.g., clinicians and support staff), businesses, philanthropic organizations, and state, local, Tribal, and territorial government data officials.

- Second, the DDIWG held interviews with over 30 SMEs in disability data, policy, and research internal and external to the federal government.

- Finally, OSTP issued a Request for Information (RFI) on May 30, 2024[2] to obtain broad input from the public. Nearly 200 RFI responses were received, representing over 400 individuals and organizations.

The DDIWG utilized the knowledge, expertise, and lived experience of its members and the many individuals and organizations who provided input and feedback via the community engagement activities to develop the Evidence Agenda.

About this Evidence Agenda

This Evidence Agenda consists of three chapters:

1. **An Overview of Disability and Disability Data** – This chapter provides a brief overview of disability, including conceptual models and definitions, and describes how disability data can be categorized and understood.

2. **Learning Agenda to Improve Disability Outcomes** – This chapter utilizes the Learning Agenda[3] framework to address the critical question: "What additional evidence does the federal government need to improve outcomes for people with disabilities?" Using this central focus, the Learning Agenda identifies a series of overarching and illustrative

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2 Office of Science and Technology Policy. (2024). *Notice of Availability and Request for Information; Federal Evidence Agenda on Disability Equity* (FR Doc. 2024-11838). Executive Office of the President. https://www.federalregister.gov/documents/2024/05/30/2024-11838/notice-of-availability-and-request-for-information-federal-evidence-agenda-on-disability-equity

3 Learning agendas are "systematic plans for identifying and addressing priority questions relevant to the programs, policies, and regulations of the agency" (OMB Memorandum M-19-23). Learning agendas are required by the Foundations for Evidence-Based Policymaking Act of 2018.

questions that will guide the federal government's efforts to understand, support, and positively impact people with disabilities and their families.

3. **Guidelines for Collecting and Using Disability Data** – This chapter identifies important guidelines for collecting and using federal disability data. Following these guidelines will enable federal agencies to improve and expand their efforts to collect disability data, use disability data to make evidence-based policy decisions that improve outcomes for people with disabilities, and safeguard disability data in order to protect the privacy, security, and civil rights of people with disabilities.

The Evidence Agenda lays out a roadmap to systematically and strategically further the evidence needed to inform policies and programs to improve the lives of people with disabilities and their families. By identifying those questions that, when answered, will help our government better serve this population, the Evidence Agenda serves as a call to action for federal agencies and the broader external community. Moreover, it provides guidelines for federal agencies as they approach this work to ensure that they are doing so in an effective and responsible way that includes people with disabilities.

Chapter 1: An Overview of Disability and Disability Data

More than one in four Americans have a disability.[4] Disability is a part of the human experience and will be experienced by nearly everyone at some point in their life. Disabilities may be present at birth or acquired later in life. They may be visible (e.g., a wheelchair user navigating an inaccessible office) or invisible (e.g., a person with generalized anxiety disorder experiencing intrusive thoughts). People may have more than one disability and the impact of their disabilities may change over time.

Disability is a complex, multidimensional concept that cannot be reduced to a single definition. It is a dynamic and context-dependent experience shaped by the interaction of an individual's health condition(s) with societal attitudes, cultural contexts, and environmental barriers. This complexity presents challenges not only for measuring disability, but also because data on barriers are needed to inform the context in which disability occurs.

Conceptual Models and Definitions of Disability

Models of Disability

One of the early models for understanding disability is the **charity model**, which views disability as a tragedy, problem, or misfortune that requires sympathy, care, and charitable intervention. In this model, people with disabilities are often viewed with pity and are assumed to be dependent on others for support and assistance. The charity model focuses on fundraising and providing financial or material aid, often through organizations or community groups. Though this approach has been crucial in delivering essential services to people with disabilities, it has also been critiqued as disempowering those it aims to help. By framing individuals with disabilities as passive recipients of care, the charity model reinforces a view of disabled people as dependent and may overlook opportunities to encourage autonomy or full participation in society. Critics of this model argue that it places the responsibility on individuals or charitable entities to address disability, rather than challenging societal structures or policies that create barriers.

The **medical model** is another well-known model, defining disability primarily as an individual's health condition or impairment that requires treatment, cure, or management. In this model, non-disability is the norm and is viewed as superior to disability. Disability is framed as a problem within the individual— something to be fixed or mitigated. For instance, someone with a visual impairment may be considered "disabled" because of their inability to see clearly, with the solution focused on medical interventions such as surgery. The medical model has been criticized for narrowing the focus to the individual's limitations, overlooking the role of societal and environmental factors that can exacerbate or reduce the impact of disability. By focusing on "fixing" the individual, it tends to neglect the broader systemic changes needed to create an inclusive society.

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[4] National Center on Birth Defects and Developmental Disabilities. (2024). *Disability Impacts All of Us Infographic*. U.S. Centers for Disease Control and Prevention. https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html

The **social model** of disability significantly contrasts with both the charity and medical models, shifting the focus from impairments in the individual to the barriers that prevent people with disabilities from fully participating in society. According to this model, disability is not caused by a person's impairments but by the physical, social, and attitudinal barriers present in the environment. For example, a person using a wheelchair is not disabled because of their condition, but because of a lack of accessible infrastructure, like ramps or elevators. The social model advocates for removing these barriers and creating an inclusive society that enables individuals with disabilities to engage as equals in all aspects of life. It emphasizes that the problem lies not in the individual, but in how society is often structured in a way that excludes people with disabilities.

The **biopsychosocial model** integrates elements of both the medical and social models, offering a more holistic understanding of disability. It recognizes that disability results from the interaction of biological, psychological, and social factors. While this model acknowledges that an individual's health condition or impairment may contribute to disability, it also considers individual strengths and how psychological factors (such as coping strategies) and social factors (such as societal attitudes, stigma, and access to resources) influence the experience of disability. For instance, someone with chronic pain may face disability not only due to the physical limitations of their condition, but also due to the mental health consequences such as depression and anxiety, and negative social attitudes or the lack of accommodations in the workplace. This model encourages a comprehensive approach to disability that incorporates medical care, social support, and societal change to address the full spectrum of challenges that individuals with disabilities face.

Finally, the **human rights model** emphasizes that all people, regardless of ability, are entitled to live in the community and setting of their choice and enjoy equal rights and opportunities. Rooted in the principles of equality, dignity, and non-discrimination, this model positions disability as a societal issue requiring systemic change. Rather than focusing on "fixing" the individual or seeing disability as a misfortune to be pitied, the human rights model calls for the recognition of people with disabilities as equals with the same rights as everyone else. This approach stresses the importance of laws, policies, and practices that ensure people with disabilities can access education, employment, health care, and public services on an equal basis with others. The human rights model has also given rise to the emergence of the disability pride and self-advocacy movements that have united people with disabilities around their shared lived experiences and efforts toward disability justice. This model has also led to recognition of disability as a valuable form of human diversity to be appreciated and protected. The United Nations Convention on the Rights of Persons with Disabilities, a key international human rights instrument, has been instrumental in promoting this model, advocating for accessibility and equality in all aspects of life. The human rights model challenges traditional perceptions of disability, urging a shift toward autonomy and respect for the dignity of all individuals.

Definitions of Disability

This concept of disability is complex, leading to multiple definitions of disability that vary depending on context and purpose. For example, definitions used in the medical field may focus on diagnosing

and treating impairments, while definitions in legal contexts may focus on eligibility for benefits or protections, and definitions in social contexts may prioritize participation.

In the United States, there are dozens of definitions of disability in federal statute,[5] each tailored to specific policy areas such as employment, education, or health care. For instance, the Americans with Disabilities Act (ADA) defines disability as a physical or mental impairment that substantially limits one or more major life activities.[6] The ADA's broad definition is intended to include individuals with a wide range of conditions, from mobility impairments to mental health conditions, as long as the condition substantially limits major life activities such as walking, seeing, hearing, or working. The ADA also includes provisions for reasonable accommodations in the workplace and public services, ensuring that people with disabilities are not excluded from employment, education, or public life.

Disability definitions used to determine eligibility for federal government programs and benefits are often more stringent compared to the ADA. For example, the Social Security Administration (SSA) determines eligibility for disability benefits under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs by defining disability as a condition that prevents an individual from engaging in substantial gainful activity and is expected to last at least 12 months or result in death.[7] In this context, the SSA applies a stricter standard compared to the ADA, often requiring medical evidence that the disability is severe enough to prevent the individual from working and earning a living.

These varying definitions have significant implications for people with disabilities. In practice, the differences in how disability is defined across these laws can lead to disparities in access to services and protections. For example, someone who qualifies as a person with a disability under the ADA may not necessarily meet the SSA's criteria for disability benefits, even if their condition substantially impacts their daily life.

Understanding Disability Data

Disability data are essential for understanding the experiences of people with disabilities, identifying systemic barriers, and guiding policy decisions that improve outcomes. However, disability data are not monolithic and can be categorized in several ways, including by the purpose for which the data are collected and, as mentioned above, the definition being operationalized. The methods used to collect information on disability, and how that information is utilized, also vary. Understanding the important nature of disability data, and the ways in which it can be categorized by collection and use, help to

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[5] New Editions Consulting, Inc. (2024). *Federal Statutory Definitions of* Disability. Prepared for the Interagency Committee on Disability Research.
https://pfs2.acl.gov/strapib/assets/Federal_Statutory_Definitions_of_Disability_508_3ba4b711de.pdf

[6] U.S. Department of Justice Civil Rights Division. (n.d.) *Introduction to the Americans with Disabilities Act.*
https://www.ada.gov/topics/intro-to-ada/

[7] Social Security Administration (n.d.) *How Do We Define Disability.*
https://www.ssa.gov/redbook/eng/definedisability.htm

provide a more nuanced understanding of disability and ensure that the data collected is meaningful, relevant, and actionable.

Disability as a Demographic

Demographic characteristics are essential human characteristics about which population data are collected for statistical purposes. They are the qualities or attributes widely accepted as essential for categorizing people into subgroups. Often, these attributes are so widely accepted, they become essential to our understanding of the experiences of people in the subgroup. Like age, sex, race, ethnicity, and education, disability is also a fundamental characteristic. Recognition of disability as a demographic aims to achieve, among other things, two basic outcomes:

1. First, broad endorsement of disability as an important characteristic about which we should collect information.
2. Second, it follows that this acknowledgement should naturally lead to disability being included as a standard data element in all data collections. Inclusion of disability items should be routinized, and when at all possible, harmonized.

Approaches to operationalizing and collecting demographic information vary across characteristics and evolve over time. While there is no single measurement approach for collecting demographic data, using the resulting data allows for the comparison of groups. When disability data are collected and used as a key demographic, it ensures that we can identify people with and without disabilities and use this information to measure access and well-being.

Methods of Collecting Disability Data: Surveys and Administrative Forms

Disability data can be obtained from different types of data collections. Surveys are widely used to gather self-reported data on the experiences of people with disabilities. These surveys can be conducted at the national, state, or local level. Depending on the purpose of the survey, the disability data collected may be limited to only that which is needed to determine disability status. Or, the data collection may be more expansive, such as health surveys that include collecting information about health conditions and health care access and utilization. The U.S. Census Bureau's American Community Survey (ACS) includes respondent questions about six disability types (e.g., difficulty hearing), for instance. Other surveys collect information on the experience of challenges related to accessibility in employment, education, transportation, and other areas of social participation.

In addition to surveys, administrative forms are also commonly used by government agencies, health care providers, and other organizations to collect data on disability status. These forms are often required for accessing services or benefits or accommodations in education and employment. Administrative data can include detailed records on the types of services provided to people with disabilities, eligibility for specific programs, and usage of health care resources. While administrative data are valuable for tracking service provision and resource utilization, it may not always capture the full range of disability experiences or the reasons why certain individuals do not seek services.

Uses of Disability Data: Prevalence, Disparities, and Effectiveness

Finally, disability data can also be categorized by how they are used. Disability data serve a range of critical purposes, including estimating prevalence, identifying disparities, and evaluating the effectiveness of policies and programs.

Accurate estimates of how many people have disabilities within a population are essential for understanding the scope of the issue and ensuring that adequate resources and services are available. For instance, the Centers for Disease Control and Prevention's (CDC's) Disability and Health Data System[8] provides data on the prevalence of disability overall and by functional disability type (i.e., mobility, cognitive, hearing, vision, self-care, and independent living). This information is vital for planning health care services, educational and community accommodations, and disability support programs.

Another important use of disability data is to identify disparities in access to services and opportunities, and ultimately outcomes. For example, demographic data on race, ethnicity, and socioeconomic status, when combined with disability status, can reveal disparities in health care access, employment opportunities, or educational attainment. Disability data can show, for instance, that non-Hispanic Black and Hispanic people with disabilities experience higher rates of unemployment or have less access to health care compared to their white counterparts. Identifying such disparities is a critical first step in addressing systemic barriers faced by people with disabilities.

Finally, disability data are invaluable for evaluating the effectiveness of policies and programs. For example, data collected through administrative forms or surveys can be used to assess whether certain laws, such as the ADA, are achieving their intended goals of improving accessibility and reducing discrimination. Evaluations may assess how policies affect outcomes such as employment rates, educational attainment, or participation in community activities. By tracking data before and after the implementation of policies or programs, policymakers and advocacy groups can determine whether their efforts are making a measurable difference in the lives of people with disabilities.

Summary

Disability is a multifaceted experience, shaped not only by an individual's health condition but also by the societal, environmental, and cultural contexts in which they live. The various models of disability—ranging from the charity and medical models to the social, biopsychosocial, and human rights frameworks—highlight the shifting perspectives from individual "deficits" to societal responsibilities. Disability data play a pivotal role in identifying systemic barriers, measuring disparities, and evaluating the effectiveness of policies aimed at improving outcomes for people with disabilities. By collecting and analyzing these data, we can better understand the varied experiences of people with disabilities and implement policies that ensure equal rights, opportunities, and access

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[8] U.S. Centers for Disease Control and Prevention. (2024). *Disability and Health Data System (DHDS) Overview.* https://www.cdc.gov/dhds/about/overview.html

for all. Ultimately, a comprehensive understanding of disability and a commitment to effective data practices are key to improving outcomes for people with disabilities.

Chapter 2: Learning Agenda to Improve Disability Outcomes

Introduction

A learning agenda is a systematic plan for identifying and addressing priority questions relevant to the programs, policies, and regulations of an agency.[9] As a strategic evidence-building plan, a learning agenda broadly identifies big problems, issues, or questions and provides a roadmap for developing the evidence needed to solve them. A learning agenda enables us to ask: what is it that we need to do, what do we need to know to do it best, and what do we wish we knew? While generally focused on agencies' work, learning agendas can also tackle government-wide topics where additional evidence is needed.

This government-wide Federal Evidence Agenda for Disability leverages the learning agenda framework to address the question: "What additional evidence does the federal government need to improve outcomes for people with disabilities?" Using this primary question as its central focus, this learning agenda includes a series of additional overarching questions, each with a set of detailed illustrative questions that will assist the federal government to understand, support, and positively impact the lives of people with disabilities as they are answered.

Central to the development of any learning agenda is community engagement.[10] The DDIWG undertook a process rooted in meaningful engagement with internal and external parties with an emphasis on engaging a range of perspectives from individuals with lived experience. This Learning Agenda reflects those activities.

Caveats and Considerations

It is important to recognize and discuss some specific caveats and considerations that are important to this Learning Agenda. First, this Learning Agenda uses the term "people with disabilities" to capture the large and heterogenous group of people that make up this population. Where appropriate, learning agenda questions address specific subpopulations, and in answering these questions, agencies are encouraged to consider relevant sub-populations.

At the same time, people with disabilities are members of other demographic groups that face additional barriers for program participation and successful outcomes. As agencies continue to build the evidence needed to improve outcomes of people with disabilities, it is critical that they do so with the unique experiences of people with different demographic characteristics in mind.

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[9] Office of Management and Budget. (2019). *OMB M-19-23, Phase 1 Implementation of the Foundations for Evidence-Based Policymaking Act of 2018: Learning Agendas, Personnel, and Planning Guidance*. Executive Office of the President. https://www.whitehouse.gov/wp-content/uploads/2019/07/M-19-23.pdf

[10] Office of Management and Budget. (2021). *OMB M-21-27, Evidence-Based Policymaking: Learning Agendas and Annual Evaluation Plans*. Executive Office of the President. https://www.whitehouse.gov/wp-content/uploads/2021/06/M-21-27.pdf

In developing this Learning Agenda, addressing the social determinants of health was identified as critical to advancing health outcomes for people with disabilities, and many of these social determinants—economic stability, health care access, educational opportunities, safe neighborhoods, etc.—are reflected in the learning questions. However, fully addressing all of the learning questions related to the social determinants of health is beyond the scope of this document, and this Learning Agenda will not address the topic directly.

Disability is not static. An individual's experience with disability can change and evolve over the life course, and the age of onset and diagnosis of disability add other dynamics. Disability is also experienced by a large percentage of the population at some point in their lifetime, and there is a body of research that examines both aging with a disability and experiencing a disability with aging. The questions in the Learning Agenda are purposefully kept at a high-level and, as a result, may not fully address all the nuances of the evolving and dynamic nature of disability.

This Learning Agenda will help drive federal evidence-building and improved data collection around 10 topics:

1. Access to Accessible Technology
2. Education
3. Emergency Management
4. Employment
5. Financial Well-Being
6. Health and Access to Health Care
7. Housing and Housing Stability
8. Long-Term Services and Supports and Community Living
9. Safety, Security, and Justice
10. Transportation

The DDIWG prioritized these topics based on feedback received during community engagement and from federal staff about where additional evidence would help them better serve people with disabilities. Learning agendas are iterative, living documents. They can and should evolve over time as evidence is generated, new questions emerge, and priorities shift. As agencies undertake activities to answer the questions in this Learning Agenda, it should likewise evolve.

Structure

Across these 10 topics, the DDIWG identified 21 overarching questions. Each overarching question represents a broad theme that summarizes and prompts a set of more detailed illustrative questions. The illustrative questions are examples of questions that agencies can tailor to support evidence building based on their expertise and familiarity with their programs and policies. The background provided is not intended to be an exhaustive review of all available literature on a given topic but is instead intended to provide a high-level overview of the state of the evidence on a given topic to identify evidence gaps. Further, the overarching questions are not an exhaustive list of all topics that are

important to the federal government. Agencies should develop their own questions about their policies and programs as they relate to people with disabilities.

Cross-Cutting Evidence Gaps

The sections below highlight key evidence gaps in a range of domains. However, critical evidence gaps also cut across programmatic and policy areas.

1. What Does the Population of People with Disabilities in the United States Look Like?

Illustrative Questions

- To what extent do existing data collection activities capture the full diversity of people with disabilities in the United States? How does that compare to data collection on people with disabilities in peer countries?
- What are the characteristics of people with disabilities that may not be captured by current data collection efforts? What disabilities do they have? What are their demographic characteristics? To what extent do those differ from people with disabilities who are reflected in current data collections?
- What are the experiences of people with disabilities in the United States? How do those experiences differ by disability type, co-occurring disabilities, etc.? To what extent do these experiences change over time?
- What are the long-term outcomes of people with disabilities in key domains like health and well-being? To what extent do those outcomes vary by disability type and demographic characteristics?

2. How Can the Federal Government Better Define or Identify People with Disabilities?

Illustrative Questions

- To what extent are data on disability collected in administrative (i.e., non-survey data collected for program administration) contexts? What are opportunities to collect disability data on administrative forms?
- To what extent are data collection tools accessible to people with different types of disabilities?
- How can we better measure disability in both population-based surveys and administrative contexts?

3. How Can the Federal Government Promote Accessibility[11] and Access Across Services and Systems for People with Disabilities?

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[11] The term "accessibility" refers to the design, construction, development, and maintenance of facilities, information and communication technology, programs, and services so that all people, including people with disabilities, can fully and independently use them. Accessibility includes the provision of accommodations and modifications to ensure equal access to employment and participation in activities for people with

Illustrative Questions

- To what extent are federal programs, services, and supports accessible to people with disabilities, including all stages of the process (i.e., understanding what programs/services are available, applying for programs/services, and receiving services)? What barriers exist in making federal services and supports accessible for people with disabilities?
- To what extent do environmental factors, such as housing, transportation, and weather, affect accessibility to services for people with disabilities? What are those factors and what are their implications for full access?
- To what extent are federal services and programs designed to meet the needs of people with disabilities, particularly those intended to serve this population? What adaptations are needed to make these services more accessible for people with disabilities? What accommodations, including technology-based accommodations, would facilitate access for people with disabilities?

Programmatic Evidence Gaps

Access to Accessible Technology

Technology is essential to the lives of many people with disabilities. People with disabilities may rely on technology for mobility, speech, or breathing; to convey visual descriptions, the meaning of spoken words, or to describe ambient sounds; to facilitate understanding of complex information, manage stress or distractions; or to help them organize tasks. Technology can help make home environments operable; learning possible; workplace interactions more efficient;[12] health care available; gatherings with family and friends inclusive; movies and theatre understandable; public environments accessible; and telecommunications work for all.

Different factors can influence access to technology, such as age, geography (Tribal, territorial, rural, urban), language, and type of disability. For example, many people who could benefit from Augmentative and Alternative Communication (AAC) are never offered technology that could help them to communicate independently. Effective provision of AAC may require a skilled assessment by a local service provider, funding for the device, training of the individual and others (e.g., caregivers, family members), access to timely local repair, affordable internet connectivity, and transition of the technology from one setting to another. Some barriers to accessing technology are difficult to address, and insurmountable when combined. The resulting impact on individuals can range from an

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disabilities, the reduction or elimination of physical and attitudinal barriers to equal opportunities, a commitment to ensuring that people with disabilities can independently access every outward-facing and internal activity or electronic space, and the pursuit of best practices such as universal design. See: Executive Order 14035; Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce, 68 Fed. Reg. 34593 (February 16, 2023) (FR Doc. 2021-14127).

[12] Griffith, M., Wentz, B., and Lazar, J. (2022). Quantifying the Cost of Web Accessibility Barriers for Blind Users. *Interacting with Computers*, 34(6), 137-149. https://doi.org/10.1093/iwc/iwad004

inconvenience to life-threatening impact, yet there are little data on the impact of technology as a key accessibility support.

Different federal and state programs can help support access to different types of technologies in different settings. Terminology and program characteristics may vary across programs. The term "technology" is used broadly here. It can include auxiliary aids and services in educational settings; home modifications; reasonable accommodations in workplaces; accessible telehealth; hearing aids and other medical devices; assistive technologies, digital accessibility, and interoperability between all. While addressing barriers to technologies is beyond the scope of this Learning Agenda, increased data on access to technologies would illuminate opportunities to improve outcomes for people with disabilities.

4. How Can the Federal Government Improve Access to Technologies that People with Disabilities Need?

Illustrative Questions

- What is the impact on daily activities, health, and well-being of people with disabilities when they can or cannot access technologies?
- To what extent do people with disabilities have difficulty accessing technologies that are important for accessibility? What combinations of barriers might make it too difficult to acquire accessible technologies?
- To what extent does access to technology vary according to type of disability? Is it more difficult for people with some types of disabilities to access essential technologies?
- To what extent does access to technology vary by demographic characteristics other than disability? For instance, by age, geography (Tribal, territorial, urban, rural), race and ethnicity, income level, or veteran status?
- To what extent are technology accommodations available to employees with disabilities across sectors, including public and private?

5. How Can the Inventory of Federal Government Programs Improve Service Delivery for People with Disabilities Needing to Access Technologies?

Illustrative Questions

- What federal programs and services provide access to technologies that benefit people with different types of disabilities?
- What skilled federally resourced services and resources are available to assist with assessment, acquisition, training, repair, and replacement of accessible technologies as needed? What gaps in skills and knowledge do service providers and/or caregivers have related to additional training on technologies that support accessibility in different settings, or for specific disabilities?

Education

Education plays a critical role in the lives of all children. From early childhood to young adulthood, the education system provides children, including children with disabilities, foundational services and supports for their developmental, academic, social, and emotional growth and well-being. For children with disabilities, educational settings take on the added importance of playing a role in the screening for and ongoing assessment of their disability, as well as offer necessary intervention services. The Individuals with Disabilities Education Act (IDEA) ensures that eligible children with disabilities are provided a free appropriate public education in the least restrictive and most inclusive setting.[13]

Despite the IDEA's requirements, children with disabilities of all ages face disparities in their engagement with and outcomes from the education system. In early childhood, the availability and quality of early childhood education (ECE) is highly variable across the United States. Many families with children with disabilities struggle to find safe, affordable, quality, and accessible ECE, particularly as compared to families who do not have a child with a disability.[14,15] As a result, children with disabilities may enter care at a later age, attend fewer hours, and have reduced access to programs.[16] Parents of children with disabilities are more likely to have to take leave or experience job disruptions to care for their children.[17] Children with disabilities also face disparities in accessing inclusive preschool settings, and these disparities are worse for children of color, those who are low-income, non-native English speakers, or come from rural communities.[18] For children with disabilities who receive high-quality ECE, the evidence points to better outcomes. Children with disabilities placed in inclusive classrooms with their peers without disabilities experience gains in a range of outcomes – social-emotional, language, literacy, and math.[19, 20] Inclusive classrooms also have benefits for children without disabilities, including positive academic, social, attitudinal, and developmental outcomes from participating in these settings.[21]

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[13] Individuals with Disabilities Education Act, Pub. L. No. 101-476, 104 Stat. 1103 (1990).

[14] The Center for American Progress. (2020). *The Child Care Crisis Disproportionately Affects Children With Disabilities.*
https://www.americanprogress.org/article/child-care-crisis-disproportionately-affects-children-disabilities/

[15] The U.S. Departments of Education and Health and Human Services. (2023). *Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs.*
https://www.acf.hhs.gov/sites/default/files/documents/ecd/policy-statement-on-inclusion.pdf

[16] Ibid.

[17] The Center for American Progress, 2020.

[18] The U.S. Departments of Education and Health and Human Services, 2023.

[19] Office of Planning, Research, and Evaluation, Administration for Children and Families. (2023). *Children's Learning and Development Benefits from High-Quality Early Care and Education: A Summary of the Evidence. OPRE Report #2023-226.* U.S. Department of Health and Human Services.
https://www.acf.hhs.gov/opre/report/childrens-learning-and-development-benefits-high-quality-early-care-and-education

[20] Office of Planning, Research, and Evaluation, Administration for Children and Families. (2010). *Head Start Impact Study: Final Report.* U.S. Department of Health and Human Services.
https://www.acf.hhs.gov/sites/default/files/documents/opre/hs_impact_study_final.pdf

[21] The U.S. Departments of Education and Health and Human Services, 2023.

Despite the large number of students in the United States receiving early intervention or special education services, academic and career outcomes for learners with disabilities have persistently lagged behind their same-age peers without disabilities for decades. These gaps are smaller for some disability categories (e.g., speech and language) and much larger for others (e.g., intellectual and developmental disabilities). Further, these gaps are evident early in students' education and persist over grade levels, and they have increased in the wake of the COVID-19 pandemic. For example, while both students with and without disabilities are performing worse in reading compared to before the COVID-19 pandemic, significantly more students with disabilities are performing poorly. On the 2022 National Assessment of Educational Progress for Grade 4 Reading, 70% of students with disabilities scored below the basic level compared to 32% of students without disabilities, with similar patterns in Grade 4 mathematics.[22] Within schools, the nation's special education has been plagued by persistent shortages in the teacher, paraeducator, and related service provider workforce. Further, there is limited evidence describing the service delivery models schools use to deliver special education services and the outcomes associated with these models. Across all levels of education, questions remain about the extent to which staff – teachers, administrators, and support staff – have sufficient training to meet the needs of children with disabilities.

6. How Can Federal Government Programs Support Access to and Success in High-Quality Early Childhood Programs for Young Children with Disabilities?

Illustrative Questions

- What is the geographic distribution of children with disabilities who receive ECE? To what extent do these settings vary by type of disability or delay, demographic, or geographic (e.g., rural/urban) characteristics?
- What barriers exist to accessing high-quality ECE programs for children with disabilities? What barriers prevent or limit programs' ability to include children with disabilities?
- What early intervention services do children with disabilities receive in ECE settings? What gaps in services do they experience?
- To what extent does participating in high-quality ECE improve outcomes for children with disabilities?
- What training and supports do ECE service providers need to effectively serve children with disabilities? To what extent does the current ECE workforce have access to those opportunities?

7. How Can the Federal Government Effectively Address the Needs of Children and Youth with Disabilities in the Public Education System?

Illustrative Questions

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[22] National Center for Education Statistics. (n.d.). *National Assessment of Educational Progress (NAEP) Reading Achievement: Grade 4 (2022). The Nation's Report Card.* U.S. Department of Education. https://www.nationsreportcard.gov/reading/nation/achievement/?grade=4

- How many children in the United States are identified for early intervention services? How many children in the United States are identified for special education? To what extent has this changed over time?
- How does receipt of early intervention services vary by demographic and other characteristics, such as race and ethnicity, gender, age, type of disability, state/locality, etc.?
- What specific special education and related services do students with disabilities receive in the United States? To what extent do the services received vary by demographic and other characteristics?
- To what extent do students with disabilities have access to necessary services and in settings that meet their needs, such as assistive technologies and communication supports, least restrictive environments, and mental health and behavioral health services?
- In the United States, how much federal funding goes toward educating students with disabilities? To what extent does spending vary by demographic, geographic, and other characteristics?
- What training and expertise gaps exist in the special education workforce (special education teachers, paraeducators, and related service providers)?
- What percent of individuals with disabilities pursue postsecondary education? To what extent do these patterns vary by demographic, geographic, and other characteristics, including type of disability?

Emergency Management

The moments before, during, and after a disaster are challenging for all people. Decisions about whether and when to evacuate, for example, are often difficult. When a disaster strikes, people with disabilities require accessible emergency communication and may need additional lead time or extra assistance. As with many topics, the interplay of poverty and disability is an added barrier for people with disabilities as they may lack the resources to adequately prepare through mitigation efforts such as elevating their home, for example.

Historically, people with disabilities were more likely to be abandoned or die in disasters than most other survivor groups and are more likely to be placed in congregate settings following disasters.[23] Some estimates suggest that the fatality rate for people with disabilities may be as much as four times that of other survivors.[24] Though pre-disaster inequities, such as lack of inclusion in local government disaster planning and structural inaccessibility, can be major contributors to higher mortality when disasters hit, more research is needed to understand the contribution of other contextual factors. People with disabilities also face barriers to recovery following a disaster, and the disasters themselves may increase the number of people with disabilities. Disasters also limit access to needed services and

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[23] National Council on Disability. (2019). *Preserving Our Freedom: Ending Institutionalization of People with Disabilities During and After Disasters.* https://www.ncd.gov/report/preserving-our-freedom-ending-institutionalization-of-people-with-disabilities-during-and-after-disasters/

[24] Economic and Social Commission for Asia and the Pacific. (2015). *Disability-Inclusive Risk Reduction.* https://www.unescap.org/sites/default/files/pre-ods/E_CDR(4)_INF4.pdf

supports, such as medication, independent living assistance, or accessible living arrangements. Taken together, these factors contribute to disasters disproportionately impacting people with disabilities.

<u>8. How Can the Federal Government More Effectively Meet the Needs of People with Disabilities Before, During, and After Disasters or Other Emergency Situations?</u>

Illustrative Questions

- How can disaster planning and emergency communications more effectively meet the needs of people with disabilities and reduce disaster-related disparities experienced by people with disabilities?
- What are the participation rates for people with different types of disabilities and federal disaster response, recovery, and mitigation programs, by demographic, geographic, and other characteristics?
- What factors drive decision-making (e.g., decisions about to evacuate) for people with disabilities and their caregivers during a disaster?
- To what extent do pre-disaster barriers influence people with disabilities' decision to evacuate?
- In federally-funded disaster preparedness activities, to what extent are people with disabilities included in all preparedness and response efforts, including evacuation drills and other preparedness planning and policies?

Employment

Employment is important for both individuals and society. It promotes financial security, personal fulfillment, and social inclusion, while also contributing to economic growth and community well-being. However, people with disabilities face large and persistent employment gaps compared to those without disabilities, beginning with youth transitioning into the workforce. People without disabilities are nearly three times as likely to be employed compared to people with disabilities.[25] Workers with disabilities face higher unemployment rates, are more likely to work part-time, generally earn lower wages, and have less job security compared to workers without disabilities.[26,27] Many individuals face

[25] U.S. Bureau of Labor Statistics. (2024). *Persons with a Disability: Labor Force Characteristics – 2023.* U.S. Department of Labor. https://www.bls.gov/news.release/pdf/disabl.pdf

[26] Yin, M., Shaewitz, D. & Megra, M. (2014). *An Uneven Playing Field: The Lack of Equal Pay for People with Disabilities*. Washington, DC: American Institutes for Research. https://www.air.org/sites/default/files/Lack%20of%20Equal%20Pay%20for%20People%20with%20Disabilities_Dec%2014.pdf

[27] Center for Research on Disability. (2024). *Annual Disability Statistics Compendium.* https://www.researchondisability.org/sites/default/files/media/2024-07/2024-compendium-final.pdf

barriers such as discrimination,[28,29,30] inadequate education or training, the need for workplace accommodations, and limited access to accessible transportation.[31] Millions of workers each year acquire disabilities that limit their ability to work and the associated lower employment rates and earnings losses that can persist for years.[32,33] Additionally, SSDI and SSI beneficiaries face disincentives to work, as those who earn over a certain income threshold may be at risk of eventually losing their benefits.[34] Improving the employment of people with disabilities, both in the number and quality of job opportunities, is a key policy goal.

One of the goals of Section 501 of the Rehabilitation Act of 1973[35] is to increase the representation of people with disabilities in the federal workforce. Regulations implementing Section 501 state that the federal government serves as a model employer of individuals with disabilities and that federal agencies take affirmative action to hire, retain, and advance qualified individuals with disabilities. To this end, agencies must adopt and implement an Affirmative Action Plan that provides sufficient assurances, procedures, and commitments to provide adequate recruitment, hiring, and advancement opportunities for individuals with disabilities at all levels of federal employment. Schedule A is an Excepted Service Appointing Authority for federal agencies to tap into a diverse talent pool of people with disabilities without going through the traditional hiring process. Schedule A is a critical tool for agencies to increase the recruitment, hiring, and advancement of people with disabilities. However, there is limited information on the effectiveness of this hiring authority.

Workplace accommodations, such as help with transportation, flexible work schedules, and assistive technologies, play an important role in improving employment.[36,37] But, while the ADA increased

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[28] Ameri, M., Schur, L., Adya, M., Bentley, S., McKay, P., & Kruse, D. (2015). *The Disability Employment Puzzle: A Field Experiment on Employer Hiring Behavior (Working Paper No. 21560)*. National Bureau of Economic Research. https://doi.org/10.3386/w21560

[29] Baldwin, M.L. & Choe, C. (2014). Wage Discrimination Against Workers with Sensory Disabilities. *Industrial Relations*, *53*, 101-124. https://doi.org/10.1111/irel.12048

[30] Cichy, K. E., Li, J., McMahon, B. T., & Rumrill, P. D. (2015). The Workplace Discrimination Experiences of Older Workers with Disabilities: Results from the National EEOC ADA Research Project. *Journal of Vocational Rehabilitation, 43*(2), 137–148. https://doi.org/10.3233/JVR-150763

[31] U.S. Bureau of Labor Statistics. (2022, March 3). *The Employment Situation – February 2022* [Press release]. U.S. Department of Labor. https://www.bls.gov/news.release/archives/dissup_03302022.htm

[32] Mudrazija, S. & Smalligan, J. (2019). *How Work-Limiting Health Shocks Affect Employment and Income*. Washington, DC: Urban Institute. https://www.urban.org/sites/default/files/publication/100748/how_work-limiting_health_shocks_affect_employment_and_income_2.pdf

[33] Meyer, B., and Mok, W. (2013). Disability, Earnings, Income, and Consumption. *Journal Of Public Economics, 171*, 51-69. https://www.sciencedirect.com/science/article/abs/pii/S0047272718301245

[34] Government Accountability Office. (2024). *SSA Disability Programs: Work Incentive and Modernization Challenges Remain*. https://www.gao.gov/products/gao-24-107614

[35] Rehabilitation Act of 1973, 29 U.S.C. § 701 et seq. (1973).

[36] Anand, P. & Sevak, P. (2017). The Role of Workplace Accommodations in the Employment of People with Disabilities. *IZA Journal of Labor Policy, 6*(12). https://link.springer.com/content/pdf/10.1186/s40173-017-0090-4.pdf

[37] Maestas, N., & Mullen, K. J. (2019). Unmet Need for Workplace Accommodation. *Journal of Policy Analysis and Management, 38*(4), 1004–1027. https://doi.org/10.1002/pam.22148

accommodation for all workers,[38] evidence suggests that workplace accommodations are not provided widely and provision varies based on employer and worker characteristics.[39,40] One third of nonworking people with disabilities reported employment barriers that could be addressed by workplace accommodations.[41] Further, employers may perceive that the cost of accommodations is an issue when hiring people with disabilities.[42]

There is mixed evidence on the effectiveness of various disability employment interventions, such as employment transition programs, vocational rehabilitation, supported employment, and mental health and behavioral supports.[43] Research shows that individual placement and support, a supported employment model, improves competitive integrated employment outcomes for people with mental health conditions. There is promising, but limited, evidence on the effectiveness of early intervention stay-at-work/return-to-work services in improving employment outcomes for people with newly acquired disabilities.[44,45,46] A recent literature review emphasizes the need for more high-quality, longitudinal research to investigate outcomes by disability type and determine which service combinations best improve employment outcomes and wages.[47]

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[38] Burkhauser, R., Schmeiser, M, & Weathers, R. (2012). The Importance of Anti-Discrimination and Workers' Compensation Laws on the Provision of Workplace Accommodations Following the Onset of a Disability. *Industrial and Labor Relations Review, 65*, 161-180. https://doi.org/10.1177/001979391206500109

[39] Bronchetti, E. T., & McInerney, M. P. (2015). What Determines Employer Accommodation of Injured Workers? The Influence of Workers' Compensation Costs, State Policies, and Case Characteristics. *ILR Review, 68*(3), 558-583. https://doi.org/10.1177/0019793915570874

[40] Hill, M. J., Maestas, N., & Mullen, K. J. (2016). Employer Accommodation and Labor Supply of Disabled Workers. *Labour Economics*, *41*, 291–303. https://doi.org/10.1016/j.labeco.2016.05.013

[41] Anand, P. & Sevak, P., 2017.

[42] Houtenville, A. & Kalargyrou, V. (2014). Employers' Perspectives about Employing People with Disabilities: A Comparative Study across Industries. *Cornell Hospitality Quarterly*, *56*(2), 168-179. https://doi.org/10.1177/1938965514551633

[43] Clearinghouse for Labor Evaluation and Research. (2024). *What Do We Know about the Effectiveness of Disability Employment Interventions?* (Research Synthesis). U.S. Department of Labor. https://clear.dol.gov/synthesis-report/research-synthesis-disability-employment-policy

[44] Smalligan, J. & Boyens, C. (2019). *Supporting Employment for Newly Ill and Injured Workers: Evidence on Early Intervention*. Washington, DC: The Urban Institute. https://www.urban.org/sites/default/files/publication/99660/supporting_employment_for_newly_ill_and_injured_workers_0.pdf

[45] Abt Associates. (2020). *Synthesis of Evidence about Stay-to-Work/Return-to-Work and Related Programs. Prepared for the Chief Evaluation Office and Disability Employment Policy*. U.S. Department of Labor. https://www.dol.gov/sites/dolgov/files/OASP/evaluation/pdf/SAW-RTW_Deliverable-2-2_SynthesisofEvidence_508c.pdf

[46] Ben-Shalom, Y, S. Bruns, K. Contreary, & D. Stapleton. (2017). *Stay-at-Work/Return-to-Work: Key Facts, Critical Information Gaps, and Current Practices and Proposals*. Washington, DC: Mathematica Policy Research. https://www.mathematica.org/publications/stay-at-work-return-to-work-key-facts-critical-information-gaps-and-current-practices-and-proposals

[47] Clearinghouse for Labor Evaluation and Research, 2024.

While poorer employment outcomes among people with disabilities are widely recognized, significant gaps remain in the evidence needed to address employment disparities for people with disabilities.[48] In addition to addressing supply-side factors affecting workers with disabilities, there is also a need to focus on the demand side of disability employment by developing effective strategies to help employers improve their capacity to support workers with disabilities.

9. How Can the Federal Government Increase Quality Employment for People with Disabilities?

Illustrative Questions

- What are the most common employment challenges faced by people with disabilities? What are common challenges faced by people with disabilities in securing, retaining, and progressing in employment? How do those vary by disability type and demographic characteristics?
- What are the services, supports, and accommodations needed to ensure people with disabilities can succeed in the workplace? How do these vary by disability type, disability onset, nature of accommodation, employer traits, and other characteristics?
- Which federal workforce training services have the greatest impact on youth and adult disability employment outcomes? How does access to and impact of workforce training services for people with disabilities vary by demographic, geographic, and other characteristics? How have outcomes changed over time?
- What are effective strategies for addressing work disincentives in federal disability programs, such as SSDI and SSI?
- What policies may increase the hiring and retention of people with disabilities in the federal government? How effective are Schedule A[49] and other authorities in hiring and retaining people with disabilities within the workforce?
- To what extent are federal policies effectively reducing the incidence of employment-related discrimination experienced by people with disabilities?

Financial Well-Being

Poverty is inextricably linked to educational attainment, employment, housing, and many other areas, all of which have implications for people with disabilities. Addressing the social determinants of health is outside the scope of this Learning Agenda. Nevertheless, any effort to build evidence to improve outcomes for people with disabilities must necessarily describe some of the key evidence gaps on financial well-being—including income, earnings, assets, etc.—and the role and contributions of public assistance programs.[50]

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[48] Sundar, V., O'Neill, J., Houtenville, A., Phillips, K., Keirns, T., Smith, A., & Katz, E. (2018). Striving to Work: The Experiences of People with Severe Functional Limitations. *Journal of Vocational Rehabilitation*, *48*, 93-109. https://braceworks.ca/wp-content/uploads/2018/05/Striving-to-Work-JVR-2017.pdf

[49] For more information on Schedule A and other hiring authorities, please see: https://www.opm.gov/policy-data-oversight/disability-employment/hiring.

[50] Three data resources to consider when researching this topic are the American Community Survey, the Survey of Income and Program Participation (SIPP) and the Current Population Survey (CPS).

People with disabilities have lower incomes than the general U.S. population and are more likely to have "extremely low" incomes.[51] The poverty rate for adults with disabilities is more than double the rate for adults who do not have a disability. Incomes are, on average, lowest for people with disabilities of color, particularly African Americans (as compared to other groups).[52] People with disabilities have lower levels of overall wealth, are more likely to use alternative (and often predatory) financial services like payday loans, have lower credit scores, and are more likely to be un- or under-banked relative to people without disabilities.[53]

At the same time, people with disabilities often require a higher income to maintain a comparable standard of living to their peers.[54] Costs include forgone earnings due to disability or caring for a family member with a disability, as well as the added expenses of personal assistance services, modifications to homes, etc. Some estimates suggest that people with disabilities pay nearly 30% more to achieve the same standard of living as people without disabilities.[55] People with disabilities also face higher health care costs. While many are covered by Medicaid or Medicare, they are more likely to have trouble paying their medical bills and incur medical debt.[56] Finally, food security is lower for people with disabilities.[57]

Social safety net programs like SSI, SSDI, Medicaid, and the Supplemental Nutrition Assistance Program (SNAP) provide critical support to people with disabilities. They may, however, also perpetuate poverty and create other restrictions. Despite being eligible for SNAP, many SSI households do not receive SNAP benefits, and SNAP uses a narrow definition of disability aligned to SSI and SSDI.[58] Many of these programs are income-based and have asset limits, some of which have been set at the same limit for decades (i.e., $2,000 for SSI). This contributes to low levels of income, and pushes people with disabilities towards benefit cliffs (i.e., a decrease in benefits due to a small increase in income), forcing them to choose between earning more income and holding assets or keeping critical benefits.[59] The Achieving a Better Life Experience (ABLE) Act created tax-advantaged ABLE accounts that generally do

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[51] Popkin, S., Hermans, A. Oneto, A., Farrell, L., Connery, M., & Cannington, A. (2022). *People with Disabilities Living in the US Face Urgent Barriers to Housing* (Fact Sheet). The Urban Institute and the Kelsey. https://www.urban.org/research/publication/people-disabilities-living-us-face-urgent-barriers-housing

[52] Goodman, N., Morris, M., & Boston, K. (2019). *Financial Inequality: Disability, Race and Poverty in America*. Washington, DC: National Disability Institute. https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf

[53] Ibid.

[54] National Council on Disability. (2023). *2023 Progress Report: Toward Economic Security: The Impact of Income and Asset Limits on People with Disabilities*. https://www.ncd.gov/report/2023-progress-report-toward-economic-security-the-impact-of-income-and-asset-limits-on-people-with-disabilities/

[55] Morris, Z., McGarity, S., Goodman, N. & Zaidi, A. (2020). *The Extra Costs of Living with a Disability in the United States* (Working Paper). Washington, DC: National Disability Institute. https://www.nationaldisabilityinstitute.org/wp-content/uploads/2020/10/extra-costs-working-paper.pdf

[56] Rakshit, S., Rae, M., Claxton, G., Amin, K., & Cox, C. (2024). *The Burden of Medical Debt in the United States* (Issue Brief). Washington, DC; Kaiser Family Foundation. https://www.kff.org/health-costs/issue-brief/the-burden-of-medical-debt-in-the-united-states/

[57] Goodman, N., Morris, M., & Boston, K., 2019.

[58] Swenor, B., Cahill, R., & L. Samuel. (2021). Food Insecurity in the Disability Community: Disparities in SNAP Access. *Health Affairs Blog*. https://www.healthaffairs.org/do/10.1377/forefront.20210513.420153/full/

[59] National Council on Disability, 2023.

not affect SSI or Medicaid eligibility (unless the total in the account exceeds $100,000) for people whose disability began before age 26.[60] Despite their availability, very few eligible SSI recipients have them, and overall asset holdings in them are relatively low.[61]

10. How Can the Federal Government Promote Economic Well-Being and Income Security for People with Disabilities?

Illustrative Questions

- What is the overall picture of financial well-being – income, earnings, assets, debt, etc. – for people with disabilities? To what extent does this vary over the life course, by demographic characteristics, other factors, and types of disabilities?
- What are the effects of asset and income limits in programs like SSI and Medicaid on the overall financial well-being of people with disabilities?
- What are effective strategies to promote economic well-being for people with disabilities?

11. How Can the Federal Government Promote Access to and Participation in Federal Programs, Benefits, and Funding Opportunities for People with Disabilities?

Illustrative Questions

- What are the rates of participation for people with disabilities in federal benefits programs, and how do these rates compare to the general population? Do these participation rates differ by geographic units such as states, regions, or the urban/rural divide? Do these rates differ by other demographic characteristics, including type of disability?
- To what extent are federal programs and benefits accessible for people with disabilities, such as application forms or service receipt locations? What barriers exist? What are effective approaches to increase accessibility to benefits for people with disabilities?
- To what extent do award rates differ for applicants with disabilities to federal funding opportunities, such as research grants or federal contracts?
- To what extent do people with disabilities experience discrimination or mistreatment when accessing government benefits? How do rates of reported discrimination or mistreatment experienced by people with disabilities when accessing federal programs differ from rates experienced by people who do not have a disability?

Health and Access to Health Care

It is well documented that people with disabilities experience worse health outcomes compared to people without disabilities due to multiple factors. The U.S. Department of Health and Human Services (HHS) is working to better understand and address the overall health needs and outcomes for people with disabilities, both related and unrelated to the person's disability or disabilities. This section of the

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[60] Achieving a Better Life Experience Act of 2014, Pub. L. No. 113-295, 128 Stat. 3077 (2014).

[61] Weathers, R.; Kelly, P.; & Hemmeter, J. (2024). ABLE Account Use among Supplemental Security Income recipients. *Journal of Vocational Rehabilitation*, 60 (1), 99-119. https://doi.org/10.3233/JVR-230059

Learning Agenda will focus on health disparities and barriers to access to care for people with disabilities.

Health disparities refer to adverse health differences affecting marginalized groups, arising from systemic factors that lead to social disadvantage.[62] People with disabilities experience a range of documented health disparities, such as higher rates of depression,[63] chronic obstructive pulmonary disease,[64] heart disease,[65] diabetes,[66] asthma,[67] and smoking compared to people without disabilities. Additionally, people with disabilities have lower rates of cancer screening (potentially resulting in delayed diagnosis and less favorable treatment options), vaccinations, and poorer maternal health and pregnancy outcomes compared to people without disabilities. People with disabilities are more likely to forgo seeing a doctor due to cost than people without a disability.[68] They often face barriers to care in effective communication accommodations, inaccessible medical equipment, and architectural barriers. People with disabilities also have difficulty finding health care providers with adequate knowledge regarding how to care for their particular health care needs, who can provide adequate time for medical exams, and who are knowledgeable about and comply with their obligations under the ADA. In addition, due to a shortage of direct care workers[69] that allow people with disabilities to receive home and community-based services required by law, people with disabilities can be institutionalized, which contributes to poor health outcomes (such as those observed during the COVID-19 pandemic).

More evidence is needed to understand and remediate health disparities experienced by people with disabilities. Improved data collection can help reduce disparities by identifying barriers to care. As

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[62] Kilbourne, A.M., Switzer, G., Hyman, K., Crowley-Matoka, M., & Fine, M.J. (2006). Advancing Health Disparities Research within the Health Care System: A Conceptual Framework. *American Journal of Public Health*, 96(12), 2113-2121. https://doi.org/10.2105/AJPH.2005.077628

[63] National Center on Birth Defects and Developmental Disabilities. (Accessed September 27, 2024). *Category: Chronic Conditions, Indicator: Ever Had Depression, 2021*. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[64] National Center on Birth Defects and Developmental Disabilities. (Accessed September 27, 2024). *Category: Mental & Emotional Health, Indicator: Ever Had Chronic Obstructive Pulmonary Disease (COPD), 2022*. Centers for Disease Control and Prevention https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[65] Reichard, A., Stolzle, H., & Fox, M. H. (2011). Health Disparities Among Adults with Physical Disabilities or Cognitive Limitations Compared to Individuals with No Disabilities in the United States. *Disability and Health Journal*, 4(2), 59–67. https://doi.org/10.1016/j.dhjo.2010.05.003

[66] National Center on Birth Defects and Developmental Disabilities. (Accessed September 27, 2024). *Category: Chronic Conditions, Indicator: Ever Had Diabetes, 2022.* Centers for Disease Control and Prevention. (https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[67] Havercamp, S. M., & Scott, H. M. (2015). National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with no Disabilities. *Disability and Health Journal*, 8(2), 165–172. https://doi.org/10.1016/j.dhjo.2014.11.002

[68] National Center on Birth Defects and Developmental Disabilities. (Accessed September 27, 2024). *Category: Barriers & Cost of Health Care, Indicator: Could Not See a Doctor Due to Costs in the Past 12 Months, 2021.* Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html

[69] Lyons, B. & Watts, M. (2024). Addressing the Shortage of Direct Care Workers: Insights from Seven States. The Commonwealth Fund: New York, NY. https://www.commonwealthfund.org/publications/issue-briefs/2024/mar/addressing-shortage-direct-care-workers-insights-seven-states

noted by a recent Agency for Healthcare Research and Quality systematic evidence review, there is a lack of evidence on what facilitates preventive care for people with disabilities.[70]

12. To What Extent Can the Federal Government Safeguard and Improve Health Conditions and Outcomes for People with Disabilities?

Illustrative Questions

- To what extent do federal policies, programs, and communication enhance promotion of healthy behaviors and wellness among people with disabilities to reduce occurrence of and disparities in co-occurring chronic physical and mental health conditions, preventable injury, illness, and death?
- What barriers do youth with disabilities face in transitioning from pediatric to adult health care providers? To what extent do health outcomes for people with disabilities vary by demographic, geographic, and other characteristics, including, but not limited to, race, ethnicity, age, veteran status, and rural/urban?
- To what extent do people with disabilities experience co-occurring physical and mental health conditions and to what extent do those conditions contribute to poorer health outcomes?
- To what extent are improvements to federal capabilities needed to predict, prepare for, respond to, and recover from public health emergencies and threats to the health of people with disabilities in the United States and across the globe?
- To what extent are federal programs and policies aimed at protecting people with disabilities from infectious disease and preventing non-communicable disease through development and delivery of effective, innovative, and readily available treatments, therapeutics, medical devices, and vaccines effective?
- What improvements would strengthen public health surveillance, epidemiology, and laboratory capacity to understand and more effectively address diseases and conditions that impact people with disabilities?

13. To What Extent Can the Federal Government Help Protect and Strengthen Access to High-Quality and Affordable Health Care for People with Disabilities Across the Lifespan?

Illustrative Questions

- To what extent do federal policies and programs affect choice, affordability, and enrollment among people with disabilities and their families in high-quality health care coverage? To what extent does this vary by type of disability?

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[70] Buckley, DI., Nygren, P., Blackie, K., Dana, T., Hsu, F., Holmes, R., Horner-Johnson, W., Nicolaidis, C., & Chou, R. (September 2024). *Healthcare Delivery of Clinical Preventive Services for People With Disabilities. Comparative Effectiveness Review No. 275.* (Prepared by the Pacific Northwest Evidence-based Practice Center under Contract No. 75Q80120D00006.) AHRQ Publication No. 24-EHC032. Rockville, MD: Agency for Healthcare Research and Quality. https://effectivehealthcare.ahrq.gov/sites/default/files/related_files/cer-275-people-with-disabilities.pdf

- To what extent do federal programs and policies improve quality of health care services for people with disabilities?
- To what extent do federal policies encourage or dissuade providers to provide health care services for people with disabilities?
- What are the disparities and/or unmet needs among subgroups of individuals with disabilities (e.g., low-income, individuals living in rural or geographically isolated areas, food insecure, etc.) with respect to promoting improved health outcomes?
- To what extent do federal programs and policies support and promote access to complex rehabilitation technology, including repair and maintenance?
- To what extent do federal programs and policies strengthen and expand access to mental and behavioral health services, primary care, and preventive services for people with disabilities?
- What role do local, state, and federal laws play in restricting or enhancing access to quality and affordable health care for people with disabilities?
- To what extent do people with disabilities face disproportionate denials of health insurance claims? To what extent do these denials impact health outcomes for this population?
- To what extent do federal policies on electronic health records allow for identification of people with disabilities, longitudinal tracking of disability status and reasonable accommodation requirements in the medical and health care settings?
- To what extent do federal policies impede linkage of health data to other benefits systems?
- What training do medical providers receive in cultural competency and health care for people with disabilities including legal obligations under the ADA? To what extent does this training affect care and health outcomes for people with disabilities?

Housing and Housing Stability

For people with disabilities living in the community, having safe, stable, and affordable housing is foundational to well-being. The costs and consequences of homelessness and housing instability are high. Many people with disabilities are priced out of any housing, as estimates show that the average monthly income for someone receiving SSI is far less than the average cost of a one-bedroom apartment.[71] While housing assistance may be available, the vast majority of eligible people with disabilities do not receive it.[72] People with disabilities further struggle to find affordable and accessible housing that meets their needs. Nearly 40% of households that include a person with accessibility needs do not currently have the accessibility features like ramps or lifts they need.[73] Across the United States, there is a dearth of accessible and/or modifiable housing stock.[74] Even when housing can be modified, estimates of the number of households that plan to make the needed modifications, such as

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[71] Technical Assistance Collaborative. (2024). Priced Out: The Affordable Housing Crisis for People with Disabilities in 2024. https://www.tacinc.org/blog/priced-out-the-affordable-housing-crisis-for-people-with-disabilities-in-2024/

[72] Popkin, S., Hermans, A. Oneto, A., Farrell, L., Connery, M., & Cannington, A., 2022.

[73] Office of Policy Development and Research, U.S. Department of Housing and Urban Development. (2019). Accessibility in Housing: Findings from the 2019 American Housing Survey. https://www.huduser.gov/portal/sites/default/files/pdf/Accessibility-in-Housing-Report.pdf

[74] Ibid.

adding a first-floor bathroom or bedroom, are quite low.[75] When people with disabilities are able to find accessible housing, they pay a higher share of their total income on that housing.[76] They are also more likely to live in housing that does not meet basic standards and reside in neighborhoods with higher rates of crime and higher susceptibility to natural disasters.[77]

People with disabilities continue to face discrimination from landlords.[78,79] Although fair housing laws enable renters to make requests for reasonable accommodations, they must negotiate modifications with their landlord and are often responsible for paying the costs for these changes. This puts necessary modifications out of scope for many people with disabilities. Particularly for older Americans, but for many people with disabilities, the result of housing instability may be institutionalization, which has additional implications for their well-being and outcomes.[80]

At the same time, people with disabilities are at higher risk of experiencing homelessness. Estimates vary, but among the homeless population—both sheltered and unhoused—the percentage of people with a disability is higher than among the general population.[81,82] This lack of housing stability contributes to and has implications for the health outcomes for people with disabilities. Evidence suggests that supportive housing models can help people with disabilities exit homelessness and improve their health, and do so at a lower cost relative to the costs associated with their chronic homelessness.[83]

14. How Can the Federal Government Increase Housing Accessibility, Stability and Security for People with Disabilities and their Families?

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[75] Ibid.

[76] National Low Income Housing Coalition. (2017). *People with Disabilities Face Significant Affordability Challenges in Rental Market. National Low Income Housing Coalition*. https://nlihc.org/resource/people-disabilities-face-significant-affordability-challenges-rental-market

[77] Trivedi, K., Meschede, T., & Gardiner, F. (2020). *Unaffordable, Inadequate, and Dangerous: Housing Disparities for People with Disabilities in the U.S. Community Living Policy Center*. Brandeis University, Waltham, MA.

[78] National Fair Housing Alliance. (2024). *2024 Fair Housing Trends Report*. nationalfairhousing.org/wp-content/uploads/2023/04/2024-Fair-Housing-Trends-Report-FINAL_07.2024.pdf

[79] Freddie Mac. (2023). *Renters and Homeowners with Disabilities Struggle with Financial Security and Housing Accessibility*. https://www.freddiemac.com/research/consumer-research/20230313-renters-and-homeowners-disabilities-struggle-financial

[80] Zelaya, E. (2023). *How to Meet the Housing Needs of Older Adults Aging in Place*. Washington, DC: The Urban Institute. https://housingmatters.urban.org/articles/how-meet-housing-needs-older-adults-aging-place

[81] Brown M. and McCann E. (2021). Homelessness and People with Intellectual Disabilities: A Systematic Review of the International Research Evidence. *Journal of Applied Research in Intellectual Disabilities.* 34(2), 390-401. https://doi.org/10.1111/jar.12815

[82] Office of Community Planning and Development, U.S. Department of Housing and Urban Development. (2023). *The 2023 Annual Homelessness Assessment Report (AHAR) to Congress*. https://www.huduser.gov/portal/sites/default/files/pdf/2023-AHAR-Part-1.pdf

[83] U.S. Interagency Council on Homelessness. (2019). The Importance of Housing Affordability and Stability for Preventing and Ending Homelessness. https://www.usich.gov/sites/default/files/document/Housing-Affordability-and-Stablility-Brief.pdf

Illustrative Questions

- What barriers do people with disabilities and their families face in accessing services to support housing stability, including federal services related to shelter access and housing affordability? To what extent do those barriers vary among people with different types of disabilities?
- What is the prevalence of homelessness among people with disabilities and what is the prevalence of disability within the homeless population? To what extent do these prevalence rates vary by demographic, geographic, and other characteristics?
- Which approaches and/or strategies are effective in reducing homelessness and/or increasing access to safe, stable, and accessible housing for people with disabilities?
- What is the rate of home ownership among people with disabilities? How does this compare to the general population? How does this vary by demographic and other characteristics?
- To what extent do home modifications allow people with disabilities to stay in their homes? What home modifications are needed based on different disability types? What are the associated outcomes for people with disabilities who can/cannot stay in their homes?
- To what extent do people with disabilities experience discrimination when renting or buying a home? Does any potential discrimination vary by type of disability and demographic and other characteristics?

Long-Term Services and Supports and Community Living

Over the past half-century, there has been a tremendous shift in the number of individuals with disabilities living in and accessing the community in more meaningful ways. This trend toward community living has been supported by federal and state policy, as well as the Supreme Court's 1999 Olmstead decision. [84] There is no formal definition of community living for people with disabilities in statute or by general consensus.[85] For many people with disabilities, community living can be anything from living where and with whom one chooses, to participate in meaningful community activities, to carrying out responsibilities of citizenship like voting.[86] People with disabilities use a variety of formal and informal services and supports based on their individualized needs to live and participate in their communities, ranging from simple supports like a ramp to highly complex nursing services.

Long-term services and supports (LTSS) generally refers to services that assist people with disabilities with their everyday needs, such as assistance with activities of daily living, and can range from community-based care provided in private homes to services provided in residential care facilities or institutional settings. Few financing options exist for LTSS. Health insurance, including employer

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[84] The Americans with Disabilities Act, Civil Rights Division, U.S. Department of Justice. (2022). *Olmstead: Community Integration for Everyone*. https://archive.ada.gov/olmstead/index.html

[85] Community Living Policy Center, The Heller School for Social Policy and Management, Brandeis University. (Accessed September 27, 2024). Community Living Equity Center. https://heller.brandeis.edu/community-living-policy/clec/index.html

[86] Association on Intellectual and Developmental Disabilities. (2016). *Community Living and Participation for People with Intellectual and Developmental Disabilities.* https://www.aaidd.org/news-policy/policy/position-statements/community-living-and-participation

sponsored or Medicare, generally does not cover these services,[87] and private insurance for services and supports is limited in its availability, coverage, and is often prohibitively expensive.[88]

Medicaid can cover the costs of services and supports, but only for individuals who meet income and other eligibility requirements. While states must cover institutional LTSS care, similar services in the community–home and community-based services (HCBS)–are optional. However, increasingly, state Medicaid programs are paying for HCBS rather than LTSS in institutional settings.[89] As of 2021, 86% of Medicaid LTSS users received HCBS.[90] The demand for HCBS currently outstrips availability, exacerbated by a limited supply of HCBS workers, which can, in addition to other factors, lead to waiting lists for services.[91,92]

15. How Can the Federal Government Support People with Disabilities, Across the Lifespan, to Live Well and Independently within their Communities?

Illustrative Questions

- To what extent do people with disabilities use federal programs and services, such as disability and aging programs, to support independent living? What are the characteristics of people with disabilities who do, and do not, access these services and supports?
- To what extent do the services that people with disabilities access enable them to live independently? To what extent does this vary for individuals who are aging with an existing disability compared to those who will acquire a disability as they age?
- To what extent do people with disabilities participate in local arts, athletics, recreation activities? What are the characteristics of those who do, and do not, participate? Does participation vary by type of disability? What are the barriers to participation?

16. How Can the Federal Government Understand LTSS Needs and Improve the Receipt of LTSS in Settings of Choice?

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[87] Office of Behavioral Health, Disability, and Aging Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. (2022). *Long-Term Services and Supports for Older Americans: Risks and Financing, 2022.* https://aspe.hhs.gov/sites/default/files/documents/08b8b7825f7bc12d2c79261fd7641c88/ltss-risks-financing-2022.pdf

[88] Iezzoni L. I. et al. (2022). Have Almost Fifty Years Of Disability Civil Rights Laws Achieved Equitable Care? *Health Affairs. 41*(10), 1371-1378. https://pmc.ncbi.nlm.nih.gov/articles/PMC10359967/

[89] Ibid.

[90] Medicaid, Centers for Medicare & Medicaid Services. (n.d.). *Home & Community Based Services*. https://www.medicaid.gov/medicaid/home-community-based-services/index.html

[91] Kaiser Family Foundation. (2023). *A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023*. https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023

[92] U.S. Department of Health and Human Services and U.S. Department of Labor. (2024). *Improving Data on the Workforce Delivering Home and Community-Based Services*. https://aspe.hhs.gov/reports/improving-data-hcbs-workforce

Illustrative Questions

- What is the prevalence of Americans with LTSS needs in the United States? To what extent does this vary by demographic, geographic, and other characteristics?
- What types of LTSS needs do people with disabilities have? To what extent do these needs vary by demographic, geographic, and other characteristics?
- To what extent do people have unmet needs for LTSS? What are the consequences of unmet LTSS needs?
- What is the landscape of care provided by caregivers, including the LTSS workforce? What care is provided, what are the characteristics of the providers, and to what extent are caregivers paid or unpaid?
- To what extent does the LTSS workforce meet the needs of people with disabilities?

Safety, Security, and Justice

All Americans deserve safety and security in their lives, including people with disabilities and their families. However, people with disabilities disproportionally face justice system involvement across all levels in the United States. This includes being targets of criminal action, such as maltreatment or violent crime, as well as civil litigation and interactions with the criminal justice system.

Living with a disability increases someone's risk of being a target of a crime. Despite accounting for only 12% of the population, people with disabilities were victims in 26% of all nonfatal violent crimes from 2017-2019.[93] In the same time period, the rate of violent victimization against people with disabilities (46.2 per 1,000 age 12 or older) was nearly four times the age-adjusted rate for persons without disabilities (12.3 per 1,000).[94] There are numerous reasons that place people with disabilities at increased risk, including living in an isolated or segregated environment, fear of reporting abuse and experiencing retaliation, and obstacles to reporting abuse, such as lack of knowledge or cognitive disabilities.[95] Another factor increasing vulnerability is the heightened risk of wandering or elopement in which individuals, particularly individuals with intellectual or developmental disabilities or dementia, leave a safe environment away from their caregivers. Wandering can place individuals in dangerous situations, including exposure to traffic, drowning, or becoming lost without the ability to communicate for help.

Abuse and neglect are serious concerns for both children and adults with disabilities, and there are systems in place to address the consequences. Evidence from the past 30 years suggests that children and youth with disabilities experience higher rates of abuse than their peers without disabilities,

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[93] Office of Justice Programs, Bureau of Justice Statistics. (2021). Crime Against Persons with Disabilities, 2009–2019 – Statistical Tables. U.S. Department of Justice. https://bjs.ojp.gov/content/pub/pdf/capd0919st.pdf
[94] Ibid.
[95] The Disability Justice Resource Center (n.d.). *Abuse and Exploitation of People with Developmental Disabilities.* https://disabilityjustice.org/justice-denied/abuse-and-exploitation/#cite-note-4

particularly child neglect.[96,97] Estimates vary, but some research suggests that roughly one-third of children in the child welfare system have a disability.[98] For children with a disability, their disability may make them more vulnerable to child abuse and neglect.[99,100] Once these children come into contact with the child welfare system, they experience worse outcomes compared to their peers. Children with disabilities are more likely to be removed from their homes, have a higher number of placements, are less likely to be placed with relatives or to be adopted, and are more likely to age out of foster care.[101,102] Youth with a disability that age out of foster care are at particularly high risk of poor outcomes.[103,104] Children with disabilities encounter a child welfare system with staff who may lack the training and resources necessary to fully meet their needs, or in some cases, diagnose their disability, as appropriate.[105] At a more basic level, they may not receive the health care needed to address their disability.[106]

Parents with disabilities are likewise overrepresented in the child welfare system.[107,108] Once involved with the child welfare system, these parents have disproportionately worse outcomes, including child removal and termination of parental rights.[109] Limited research has been conducted to understand the mechanisms by which parents with disabilities come into contact with the system and how that may

[96] Lightfoot E., Hill K., and LaLiberte T. (2011). *Prevalence of Children with Disabilities in the Child Welfare System and Out of Home Placement: An Examination of Administrative Records*. *Children and Youth Services Review*, *33*(11), 2069-2075. https://doi.org/10.1016/j.childyouth.2011.02.019

[97] Child Trends. (2020). *Children and Youth with Special Health Care Needs in Foster Care*. https://cms.childtrends.org/wp-content/uploads/2020/12/CYSHCN_ChildTrends_Dec20-2.pdf

[98] Slayter E. (2016). Youth with Disabilities in the United States Child Welfare System. *Children and Youth Services Review*, *64*, 155-165. https://doi.org/10.1016/j.childyouth.2016.03.012

[99] Vanderminden J. et al. (2023). Victimization and Abuse among Children with Disabilities: Age Adjusted Rates in a US National Sample. *Child Abuse & Neglect, 146*, 106495. https://doi.org/10.1016/j.chiabu.2023.106495

[100] Fang Z. et al. (2022). Global Estimates of Violence against Children with Disabilities: An Updated Systematic Review and Meta-analysis. The *Lancet Child and Adolescent Health*, *6*(5), 313-323. https://doi.org/10.1016/S2352-4642(22)00033-5

[101] Child Trends, 2020

[102] Slayter, 2016.

[103] Cheatham L. P., Randolph K. A., and Boltz L.D. (2020). Youth with Disabilities Transitioning from Foster Care: Examining Prevalence and Predicting Positive Outcomes. *Children and Youth Services Review*, 110, 110104777. https://doi.org/10.1016/j.childyouth.2020.104777

[104] McCauley E. (2021). Differential Risks: How Disability Shapes Risk in the Transition to Adulthood for Youth who Age Out of Foster Care. *Children and Youth Services Review*, *131*, 106293. https://pmc.ncbi.nlm.nih.gov/articles/PMC8657864/

[105] Child Trends, 2020

[106] Szilagyi M. A. et al. (2015). Health Care Issues for Children and Adolescents in Foster Care and Kinship Care. *Pediatrics*, *136*(4): e1142–e1166. https://doi.org/10.1542/peds.2015-2656

[107] Lightfoot E. and Slayter E. (2014). Disentangling Over-representation of Parents with Disabilities in the Child Welfare System: Exploring Child Maltreatment Risk Factors of Parents with Disabilities. *Children and Youth Services Review*, *47*(3); 283-290. https://doi.org/10.1016/j.childyouth.2014.10.001

[108] DeZelar S. and Lightfoot E. (2020). Who Refers Parents with Intellectual Disabilities to the Child Welfare System? An Analysis of Referral Sources and Substantiation. *Children and Youth Services Review*, *119*, 105639. https://doi.org/10.1016/j.childyouth.2020.105639

[109] National Council on Disability. (2012). *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*. https://www.ncd.gov/assets/uploads/reports/2012/ncd-rocking-the-cradle.pdf

affect their outcomes. However, parents with disabilities experience some risk factors like higher rates of poverty and lower educational attainment that are also risk factors for child welfare involvement.[110] Other research has documented the role that discrimination from child welfare professionals and attorneys plays with respect to parents with disabilities involved with the child welfare system.[111]

Adults with disabilities experience abuse at much higher rates than adults without disabilities. Estimates of rates of abuse range from 30% to over 50%.[112] Though not all older adults have a disability, elder abuse is one of the drivers of disproportionately high rates of abuse against adults with disabilities. Much of this abuse takes place in institutional settings, including long-term care facilities.[113] The adult protective services (APS) system provides services and supports for adults with disabilities who experience neglect, self-neglect, abuse, or financial exploitation. While all states have an APS system, little is known about their effectiveness and the overall outcomes for adults who engage with APS.

Not only are people with disabilities more likely to be targets of crimes, whether violent crime, abuse, or neglect, as discussed above, they are also more likely to face legal issues, and some of the most burdensome civil legal problems, like employment discrimination or access to health care, disproportionately affect those with disabilities.[114] Adults with disabilities are less likely to be able to bear legal costs, or afford legal representation and other justice system related costs, such as traveling to court.[115] Compounding these challenges are the many attitudinal, legal, communication, physical, and economic barriers across legal systems that people with disabilities face.

People with disabilities are overrepresented at all stages of the criminal justice system. Among a 2016 national sample of state and federal prisoners age 18 and older, 38% of respondents self-reported having at least one disability.[116] Nearly 4 in 10 state prisoners (40%) and 3 in 10 federal prisoners (29%) reported having a disability, and female prisoners were more likely than male prisoners to report a

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[110]Albert S.M. and Powell R.M. (2020). Supporting Disabled Parents and Their Families: Perspectives and Recommendations from Parents, Attorneys, and Child Welfare Professionals. *Journal of Public Child Welfare*, *15*(5), 529. https://pmc.ncbi.nlm.nih.gov/articles/PMC10202498/

[111]Ibid.

[112]National Center on Elder Abuse – Center of Excellence on Elder Abuse and Neglect, University of California, Irvine. (n.d.). *Research Brief: Abuse of Adults with a Disability.* https://centeronelderabuse.org/docs/ResearchBrief_Disabilities_508web.pdf

[113]Patel K. et al. (2021). Elder Abuse: A Comprehensive Overview and Physician-Associated Challenges. *Cureus, 8;13*(4), e14375. https://pmc.ncbi.nlm.nih.gov/articles/PMC8110289/https://pmc.ncbi.nlm.nih.gov/articles/PMC8110289/

[114]The Institute for the Advancement of the American Legal System, University of Denver and The Hague Institute for Innovation of Law. (2021). *Justice Needs and Satisfaction in the United States of America*. https://iaals.du.edu/sites/default/files/documents/publications/justice-needs-and-satisfaction-us.pdf

[115]U.S. Department of Justice. (2023, December). *Access to justice is disability access* (Fact sheet). U.S. Department of Justice. https://www.justice.gov/d9/2023-12/access_to_justice_is_disability_access_fact_sheet.pdf

[116]Maruschak, L., Bronson, J. & Alper, M. (2021). *Disabilities Reported by Prisoners: Survey of Prison Inmates, 2016*. Bureau of Justice Statistics. https://bjs.ojp.gov/library/publications/disabilities-reported-prisoners-survey-prison-inmates-2016#.

disability in both state and federal prisoner populations. The most common type of disability reported among both state and federal prisoners was cognitive disability (23%), followed by ambulatory (12%) and vision (11%) disabilities.[117] Beyond incarceration, people with disabilities are overrepresented among the population of adults under community supervision (on parole or probation). Individuals under community supervision were significantly more likely to report having any disability and, as a group, reported a higher total number of disabilities compared to adults without community supervision in the past year.[118]

17. How Can the Federal Government Support the Safety and Security of People with Disabilities?

Illustrative Questions

- To what extent do people with disabilities feel safe in their communities? What factors contribute to their feelings of safety? How does this vary by demographic and other characteristics?
- What factors are associated with disparate rates of victimization for people with disabilities?
- What protective factors may support people with disabilities who are targets of crime?

18. How Can the Federal Government Effectively Address the Needs of Children, Youth, and Parents with Disabilities Who Are Involved with the Child Welfare System?

Illustrative Questions

- How many children and parents involved in the United States child welfare system have a disability? What are their demographic, geographic, and other characteristics, and how have these characteristics changed over time?
- What are the experiences and outcomes of children and parents with disabilities involved in the child welfare system? How does this vary by demographic and other characteristics?
- To what extent do children and parents with disabilities in the child welfare system receive the services they need to address their specific disabilities, as well as overall well-being? What unmet needs do they encounter? How does this vary by demographic and other characteristics?

19. How Can the Federal Government Support Adults Who Experience Abuse or Neglect and Strengthen the Adult Protective Services System?

Illustrative Questions

- How is federal funding for state APS programs impacting the consistency and quality of APS services across the country?
- What are best practices/procedures for recognizing and differentiating abuse and neglect sub-types in the APS client population?

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[117] Ibid.

[118] Winkleman, T., Phelps, M., Mitchell, K. L., Jennings, L., & Shlafer, R. (2020). Physical Health and Disability Among U.S. Adults Recently on Community Supervision. *Journal of Correctional Health Care,*26(2), 129-137. https://doi.org/10.1177/1078345820915920

- What is the effectiveness of specialized/focused interventions (e.g., relationship-based intervention, longer-term interventions, client navigators, peer support services), including impact on different populations and types of clients?
- What are strategies for effective collaboration between APS clients and workers?

20. How Can the Federal Government Expand Access to Justice for People with Disabilities?

Illustrative Questions

- To what extent do federal policies and programs affect people with disabilities' experience in the justice system?
- What role do local, state, and federal laws play in restricting or enhancing access to the justice system for people with disabilities?
- What programs or policies could be leveraged to better support people with disabilities who are in the criminal justice system or on community supervision? To what extent do people with disabilities access responsive services, including the criminal justice system and survivor programs? What are the experiences of people with disabilities with these programs? How do these experiences vary by demographic and other characteristics?

Transportation

For many people with disabilities, lack of access to transportation results in difficulty getting to jobs, school, medical appointments, and recreational and social activities, all of which are critical to their lives, inclusion, and well-being. For example, data from the most recent National Household Travel Survey indicate that in the year 2022, 91% of workers traveled to work in a privately owned vehicle. However, there are nearly 19 million Americans (over 6% of all Americans in that age range) with travel-limiting disabilities. Ten million (54% of Americans with travel-limiting disabilities) are in the working age of 18 to 64, but only a third work full- or part-time compared to over 78% of people in that age range without travel-limiting disabilities.[119] People with travel-limiting disabilities are less likely to own or have access to vehicles than people without disabilities: more than 14% of people ages 18 to 64 with travel-limiting disabilities live in zero-vehicle households, compared to about 5% of people without disabilities.[120]

The Complete Trip concept views the transportation journey holistically, from the time an individual begins to plan the trip, to when the individual leaves the originating location, to the doorstep of the

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[119]Bureau of Transportation Statistics. (2024). *Travel Patterns of Adults with Travel-Limiting Disabilities*. U.S. Department of Transportation. https://www.bts.gov/travel-patterns-with-disabilities#:~:text=NHTS%20estimated%20that%2018.6%20million,persons%20age%2065%20and%20older.

[120]U.S. Department of Transportation. (2024, April 18). *Travel Patterns of Adults with Travel-Limiting Disabilities. Bureau of Transportation Statistics*. https://www.bts.gov/sites/bts.dot.gov/files/2024-04/Travel%20Patterns%20of%20Adults%20with%20Travel-Limiting%20Disabilities_4_18_24.pdf

destination.[121] According to the U.S. Department of Transportation's Accessible Transportation Technologies Research Initiative group:

> The accessibility of a transportation system can be described in terms of the ability of individuals to go from home to a destination without breaks or in terms of a travel chain with various links such as trip planning, travel to station, station/stop use, boarding vehicles, using vehicles, leaving vehicles, using the stop or transferring, and travel to destination after leaving the station or stop. If one link is not accessible, then access to a subsequent link is unattainable and the trip cannot be completed. Thus, the travel chain defines the scope of potential research and development in accessible transportation.[122]

Designing a transportation system with accessible services and inclusive spaces is essential to meet the needs of people with disabilities and has the added benefit of improving access for all travelers.

21. How Can the Federal Government Facilitate and Support Access to and the Accessibility of the U.S. Transportation System and Related Infrastructure for People with Disabilities?

Illustrative Questions

- To what extent do people with disabilities face challenges in accessing the U.S. transportation system? What are those challenges? To what extent do these challenges vary by disability type and demographic, geographic, and other characteristics?
- To what extent do the various modes of transportation in the United States—air travel, passenger rail, public transit and ADA Paratransit, passenger vehicles (i.e., taxis, rideshares, etc.), walking and cycling—meet accessibility standards such as those set forth in the Americans with Disabilities Act and other relevant laws? To what extent do they reflect the current needs of users or differ? To what extent does this vary by geographic area and disability type?
- To what extent are communications around various modes of transportation (i.e., audio and visual announcements during air travel) accessible for people with disabilities?
- To what extent do existing transportation options (i.e., fixed-route public transit, ADA paratransit, demand-responsive, and mobility-on-demand services) meet the travel needs of people with disabilities, across different geographic areas? To what extent does this vary by disability type?
- To what extent do universal design principles (i.e., the design of products and environments to be usable by all people) support people with disabilities to access the U.S. transportation system and increase use of active transportation options?
  To what extent are new and emerging advancements in transportation (i.e., electric vehicles, automated vehicles, accessible vans, or cars/vans with hand controls) accessible for and usable by people with disabilities?

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[121]For more information on the Complete Trip concept, please see: https://its.dot.gov/its4us/htm/overview.htm.

[122]Office of the Assistant Secretary for Research and Technology. (n.d.). *Accessible Transportation Technologies Research Initiative*. U.S. Department of Transportation. https://www.its.dot.gov/research_archives/attri/

Chapter 3: Guidelines for Collecting and Using Disability Data

Following best practices to collect and use disability data are critical to generate the best available evidence to inform federal policies and programs that improve outcomes for people with disabilities. This chapter identifies ten important guidelines for collecting and using federal disability data. Following these guidelines will enable federal agencies to improve and expand their efforts to collect, use, and safeguard disability data.

The guidelines below were developed with input and feedback of members of the DDIWG and the individuals and organizations who participated in the DDIWG's community engagement activities. In addition, many guidelines in this chapter have been adapted from The Federal Committee on Statistical Methodology's Data Protection Toolkit,[123] which provides guidance for federal agencies to use when collecting, sharing, and analyzing data.

Guideline 1: Collect disability data when other demographic data are collected

Disability data should be considered essential demographic information that is collected when other demographic characteristics like race, ethnicity, and age are collected for statistical purposes or for the purpose of delivering more effective services. Agencies are responsible for complying with all applicable laws and policies, as they are with collection, use, and publication of other demographic information, though there may be additional, unique considerations when collecting disability data that must be addressed.

Guideline 2: Begin responsible data collection immediately

Just as continued research is necessary to improve the quality of other data collections,[124] the federal government should continuously strive to improve its disability data collection methods. However, in most circumstances, agencies have enough knowledge about appropriate disability questions and data collection approaches to responsibly begin collecting disability data now.

Guideline 3: Ensure data collection efforts are inclusive, accessible, and meaningfully engage people with disabilities throughout the process

It is essential for disability data collection efforts to be accessible and include a range of people with disabilities. This requires intentional and meaningful engagement with people with disabilities throughout the data collection process, including with organizations and disability advocates. Transparency and regular feedback are key for building and maintaining trust. Engaging people with disabilities throughout the process strengthens the quality and accuracy of the resulting data collected and subsequent analyses.

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[123]Federal Committee on Statistical Methodology (2024). *Data Protection Toolkit: Report and Resources on Statistical Disclosure Limitation Methodology and Tiered Data Access* (formerly "Statistical Policy Working Paper #22"), rev. 2024-11-21. Available at: https://nces.ed.gov/fcsm/dpt/versions

[124]For instance, see the updated Statistical Policy Directive No. 15: https://spd15revision.gov/

People with disabilities may face a range of barriers that prevent them from participating in data collection efforts. These include barriers related to communication, mode of delivery, comfort with disclosure, transportation, and others. For instance, members of the deaf and deaf-blind populations who use sign language or tactile signing when taking surveys require access to a sign language interpreter or to braille translations. Strategies that involve phone calls or door-to-door collection may not be accessible.

Data collection tools, including surveys and checklists, should be developed with the involvement of people with disabilities throughout the entire process. To that end, federal agencies should:

- **Incorporate universal design principles to improve the accessibility of data collection tools.** Universal design is a concept in which products and environments are designed to be usable by all people, to the greatest extent possible, without the need for adaption or specialized design. Focus on the accessibility of data collection tools and instruments from the start and make efforts to understand the potential participants and their needs as they may require different types of accommodations or adaptions.[125] Consider developing a range of alternative formats, such as print, audio, and video, to accommodate different preferences. In written formats, use plain language and avoid jargon or technical terms.[126]

- **Ensure that all tools and data collection instruments are Section 508 compliant.** Section 508 requires access for people with physical, sensory, or cognitive disabilities to information and communications technology, which includes websites and electronic documents, that is developed, procured, maintained, or used by federal agencies.[127]

- **Engage with the disability community at all stages of the process.** Involving people with disabilities and their representative organizations in the data collection, analysis, and dissemination processes is important to ensure the data collected and resulting analyses reflects those lived experiences and priorities. An iterative data collection process that includes community engagement and cyclical feedback is needed to accurately collect disability information. Accessibility and usability standards should be strictly adhered to, and all tools should be tested by people with disabilities. Iterate based on feedback from the disability community to refine the approach and the selection of disability questions. It is important to involve people with disabilities in decision-making processes to ensure their voices are heard and respected. Ongoing engagement must genuinely reflect the evolving needs and real-time perspectives of the disability community.

- **Use disability-inclusive language and culturally responsive approaches.** Terminology and language are important to encourage broad participation in data collection efforts. Use neutral

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[125]General Services Administration. (n.d.). *Universal Design and Accessibility*. https://www.section508.gov/develop/universal-design/

[126]General Services Administration. (n.d.). *Federal Plain Language Guidelines*. https://www.plainlanguage.gov/guidelines/

[127]General Services Administration. (n.d.). *Section 508: What is Section 508?*. https://www.section508.gov/

language, emphasize abilities not limitations, and avoid condescending euphemisms such as "physically challenged." While person-first language is often used in more formal writing, many people with disabilities, particularly younger people, are choosing to use identity-first language.[128,129] Consider using both styles, as appropriate, to acknowledge the range of preferences among a diverse group of people with disabilities. Adopt culturally responsive approaches as terminology may not translate or be appropriate for all populations and sub-populations of people with disabilities.

- **Conduct proper training for individuals involved in data collection.** All staff and contractors who collect and use disability data on behalf of the federal government from all types of data sources, including surveys, administrative forms, and clinical data, should be properly trained. This helps ensure that disability questions are being asked correctly, appropriately, and consistently. Cultural competency training is also important to create an inclusive data collection process, which can improve accuracy, build trust, reduce bias, and make the process more accessible. Training will also help ensure that staff who collect and use disability data follow confidentiality and privacy rules. Additionally, clear communication materials should be provided to help respondents understand the disability questions, why the data are needed, how the data will be used, and how their privacy will be protected.

- **Follow the FAIR Guiding Principles – Findable, Accessible, Interoperable, and Reusable**.[130] The FAIR principles provide guidelines for improving data management and sharing that emphasize the importance of making data easily discoverable and accessible to humans and machines. The principles advocate for the use of standardized metadata to ensure that data can be integrated and used across different systems. By promoting interoperability and reusability, FAIR principles may enhance the quality, efficiency, and impact of research through better data sharing and collaboration.

- **Expand access and opportunities to scholars with disabilities to use the data and build evidence**. To fully include people with disabilities in the evidence generation and use process, it is necessary to ensure that scholars with disabilities are likewise included in the process. Agencies should actively explore ways to enable scholars who have disabilities to conduct their own analyses and contribute to the body of evidence to inform the design of government policies and programs.

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[128]Person-first language emphasizes the person before the disability, for example, "person who is blind" or "people with spinal cord injuries." Identify-first language puts the disability first in the description, e.g., "disabled person" or "autistic person." See: https://askearn.org

[129]Please see, for example, language from: https://www.cdc.gov/disability-and-health/articles-documents/communicating-with-and-about-people-with-disabilities.html?CDC_AAref_Val=https://www.cdc.gov/ncbddd/disabilityandhealth/materials/factsheets/fs-communicating-with-people.html

[130]FAIR. (n.d.). FAIR Principles. https://www.go-fair.org/fair-principles/

Guideline 4: Use definitions and measures of disability that are most appropriate for agency purposes

Defining and measuring disability in a consistent, harmonized way allows agencies to develop a robust picture for people with disabilities that can be compared to other data sources using the same disability measures. However, given the range of statutory definitions of disability, it is important that agencies use a definition of disability and related measurement approach that is applicable to their programs and services. In practice, this means that agencies should consider their data needs—asking questions like "what information do we need?" and "how will this information be used?"—to identify measures that best fit their purpose and will produce high-quality, accurate data without unnecessarily burdening the individuals providing the information.

Guideline 5: Use disability data to serve people with disabilities

Federal agencies must commit to using the disability data they collect to better serve the disability community. Identifying people with disabilities in data collection efforts is essential to assess experiences with federal programs to ultimately improve outcomes for people with disabilities. For example, disability data on workforce training program participation is important to understand the experiences of people with disabilities, those data may further benefit people with disabilities if they are shared with other programs to streamline eligibility for additional relevant services and used for statistical purposes to assess outcomes.

Guideline 6: Align disability data collection efforts with agency objectives to improve outcomes for people with disabilities

Aligning disability data collection efforts with agency objectives involves a thorough analysis of which administrative forms and surveys should include disability questions, ensuring that the information collected is necessary, relevant, and used appropriately. Agencies must balance the need for detailed and accurate data with minimizing the burden on people providing data. By integrating existing data, harmonizing data across sources, and allowing individuals to routinely access and update their information, agencies can enhance the quality and utility of the disability data they collect. This in turn supports more effective policy development and program delivery to address the needs of the disability community. To accomplish these goals, agencies should:

- **Conduct a robust analysis to determine which data collection instruments should include disability questions.** While this process should ultimately be designed to improve disability data collection, a risk assessment, which is customary for federal data collections,[131] may help in determining where disability data collection should occur. As part of this process, agencies should review existing questions on surveys and forms that solicit a respondent's disability status to understand if the information being collected and used is consistent with the guidelines in this document. In alignment with burden reduction guidance, agencies should

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[131]Please see, for example, Appendix II to OMB Circular No. A-130.

articulate a clear explanation for why this information is needed and how it will be used when determining which disability questions are most appropriate.

- **Assess whether the questions related to disability only solicit information necessary for meeting the instrument's stated purpose**. Consistent with the Paperwork Reduction Act, minimizing data collection burdens on people with disabilities should be taken into consideration. People with disabilities who utilize federal, state, local, and other services already experience a sizeable administrative burden. Leveraging existing data and amending existing data collection systems can help mitigate this burden.

- **Use questions that identify the relevant populations and sub-populations of people with disabilities to assess the outcomes of these groups.** The purpose of the data collection effort and the mode (e.g., full-length survey, in-take forms, disability assessments) should determine the relevant disability questions used. Where possible, data collection efforts need to account for diverse types of disabilities and the various ways people identify with or experience their disabilities. Harmonizing the use of standard questions, where appropriate, and ensuring interoperability across data sets, allows for resulting data sets to be used jointly, which provides a better understanding of the lived experiences of people with disabilities and supports policy and program development.[132]

- **Collect data in as detailed a form as possible.** When releasing tabulations for public use, data may need to be aggregated to protect privacy or to ensure statistical validity. However, the underlying data should be collected with as much detail as possible to facilitate relevant and appropriate internal analyses, particularly those using data from multiple sources. Collecting this level of detail may also enhance efforts to disaggregate data in analyses.

- **Collect disability data from respondents in a way that is clearly separated from information needed to receive services, benefits, funding opportunities, or employment.** Options may include soliciting demographic information on a separate section of a form, on a separate form, or through a separate process. It is important to clarify for respondents that eligibility for programs or benefits does not in any way depend on their responses to disability questions. Absent an explicit statutory or regulatory requirement, disability data should not be used to inform the adjudication of decisions regarding services, benefits, funding opportunities, or employment.

- **Offer ways for individuals to request access to and make corrections to their disability data to the extent feasible**. This approach helps ensure more accurate disability data by creating a pathway for updating information but also gives individuals the opportunity to review and manage the information agencies have about them.

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[132]Mont, D., Madans, J., Weeks, J., & Ullmann, H. (2022). Harmonizing Disability Data to Improve Disability Research and Policy. *Health Affairs, 41*(10), 1442-1448. https://doi.org/10.1377/hlthaff.2022.00479

Guideline 7: Ensure informed consent and make responses voluntary

Informed consent is critical for any federal data collection. While certain circumstances may preclude an individual from providing informed consent, whenever feasible, agencies should do everything possible to ensure that people with disabilities consent to a specific data collection. Respondents to federal collections should have full information about what information will be collected from them, for what purpose, and how it will be used prior to providing their consent. With a thorough informed consent process, a respondent can make an informed decision about whether to provide this information based on its intended uses, potential risks, and their privacy, as well as choose to provide a non-response or otherwise make a case-specific decision not to disclose their status.

In some cases, perceived inability to gather informed consent may mean that some people with disabilities, such as those with intellectual and developmental disabilities, may be presumed incapable of providing the necessary consent, and thus excluded from critical data collections.[133] Agencies must ensure that accommodations are provided to facilitate the consent process and ensure that all people with disabilities are able to provide consent, directly or through a proxy, where feasible.

Processes for obtaining consent should follow consent guidance with respect to Tribal governments. For instance, when pursuing data collection in Indigenous communities, processes for pursuing informed consent should follow "Guidance for Federal Departments and Agencies on Indigenous Knowledge."[134]

At the same time, providing disability data should be voluntary and never required, except when directed by statute or regulation.[135] Disclosing disability status may put respondents at risk in ways that disclosure of other demographic information may not. There is stigma around disability, and some people may not wish to disclose their status.

In accordance with applicable laws, regulations, and policies,[136] when collecting disability data, agencies should:

- **Be clear about the data collection's purpose and use**. Prior to collecting any data, and consistent with the PRA, an agency should ensure that respondents know what disability and related information will be collected; how that information will be used, stored, protected; how they may be beneficial and supportive to the disability community; and whether and to what

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[133]Horner-Johnson, W., & Bailey, D. (2013). Assessing Understanding and Obtaining Consent from Adults with Intellectual Disabilities for a Health Promotion Study. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(3). https://doi.org/10.1111/jppi.12048

[134]Office of Science and Technology Policy & Council on Environmental Quality. (2022). *OSTP-CEQ Indigenous Knowledge Guidance for Federal Agencies*. https://www.whitehouse.gov/wp-content/uploads/2022/12/OSTP-CEQ-IK-Guidance.pdf

[135]For some statistical agencies, there are mandatory surveys like the U.S. Census Bureau's American Community Survey. To learn more about the U.S. federal statistical system's laws and policies, visit www.statspolicy.gov.

[136]To read more about the U.S. federal statistical system's laws, policies, and guidance, including informed consent, visit the Interagency Council on Statistical Policy's page at www.statspolicy.gov.

extent the data will be shared following its collection, such as part of a de-identified dataset to be used by researchers. Communicate the purpose of the data collection effort in plain language and accessible formats to encourage people to participate and disclose their disability status which in turn helps improve data accuracy.

- **Obtain written informed consent from participants before collecting any data.** Inform participants about their civil protections, and whether they have the right to refuse to participate in the data collection effort or the right to access and correct their data. Ensure that the consent form is written in clear and concise language and provide participants with ample time to review the consent form and ask questions. If an individual is not able to provide consent, determine whether a legal guardian or authorized representative has the authority to consent on their behalf. Verbal assent can enhance the informed consent process as well.

- **Provide respondents with appropriate notice about the protections afforded to the data and how the information might be used or shared in an identifiable manner.** Explain the purpose, procedures, risks, and benefits of the data collection to potential participants in a clear and accessible way. The explanation should describe any potential disclosure to other federal agencies; state, local, Tribal, or territorial governments; third-party organizations; or individuals with a personal or legal relationship to the respondent (such as a family member or a doctor). This will help the respondent make an informed decision about disclosing disability information on a survey or specific administrative form.

- **Consider how disability information is collected or recorded, including potential intermediaries between the respondent and the agency, and how that might impact whether a respondent provides this information or is able to provide their consent.** This includes understanding the role of non-federal actors responsible for collecting disability information for federal purposes, the use of proxies (third parties recording responses on behalf of the respondent or subject), and even the physical environment in which a respondent might provide the information. Where it can be avoided,[137] disability information should not be collected by proxy on administrative forms without the individual's consent. When proxy reporting is required, evidence-based approaches should be used.

- **Explore different modalities to support data collection**. Rely on evidence-based approaches when considering which data collection modalities (e.g., interviews, online, or in-person forms) help individuals to feel comfortable and confident self-identifying their disability status. Respondents may vary in their willingness to provide this information freely, voluntarily, and accurately depending on modality and privacy concerns.

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[137]Examples of situations when proxy reporting cannot be avoided are limited and include collection of form responses for incapacitated individuals and young children. See introduction to this chapter for additional details.

Guideline 8: Rely on self-attestation except for eligibility purposes

In general, no documentation should be required to provide proof of disability information, except in the case of benefit eligibility determinations, eligibility for hiring flexibilities, and to address requests for workplace accommodation.[138] The collection of disability data should not warrant additional documentation or physical examination for verification. Physical examinations are never appropriate for identity documentation. When self-identification about one's disability is made, it should be voluntary and confidential.

In certain instances, agency forms require secondary documentation or evidence to validate a respondent's disability status (e.g., medical letters). Agencies should review their practices and requirements on secondary documentation to eliminate undue burden on respondents, especially since additional verification documentation is rarely required to prove membership in other demographic categories (e.g., race or ethnicity).

Guideline 9: Ensure privacy protections are properly applied

Assuring and maintaining confidentiality and privacy is essential when collecting any demographic data, particularly data on underserved populations like people with disabilities. Privacy protections are a key component in the federal government's efforts to build and maintain public trust, which are in turn essential for participation in surveys and programs. Disclosure risks and sensitivity have sometimes been used as reasons to not collect disability data. However, these concerns should not be used as an excuse to not collect data. It is possible to collect disability data to inform policy while balancing these protections.

- **Agencies should examine and consider privacy risks, including any that are unique to disability data, when making decisions about collecting and sharing such data.** Agencies should take appropriate steps to deidentify data and consider the privacy risks associated with sharing such data inside and outside the agency. If the safety, health, or well-being of people with disabilities could be negatively impacted, avoid sharing these data. Additionally, agencies should conduct a risk assessment to determine whether to include disability questions on surveys and forms, as they do when considering whether to include other demographic questions on information collections.

- **Ensure privacy protections are followed when publishing and sharing data.** Care must be taken to ensure any data that are made available for public use protects the privacy of the individuals from whom the data was collected. If data cannot be made publicly available but is deemed appropriate for restricted access to approved researchers conducting approved analyses, care must be taken to ensure the data users follow all necessary protocols to protect

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[138]When the disability and/or the need for accommodation is not obvious, the employer may ask the individual for reasonable documentation about his/her disability and functional limitations. Reasonable documentation means that the employer may require only the documentation that is needed to establish that a person has an ADA disability, and that the disability necessitates a reasonable accommodation.

the identity and confidentiality of respondents. Further, Personally Identifiable Information (PII) should generally not be made available to researchers.

Guideline 10: Maximize the utility of disability data and promote open data policies

Underpinning this Federal Evidence Agenda for Disability is the idea that the federal government needs to continue to build evidence to improve outcomes for people with disabilities. The federal government should maximize the utility of disability data currently collected and undertake new disability data collection efforts to inform evidence gaps and support people with disabilities. To promote the more effective use of disability data, agencies should:

- **Highlight the experiences of people with disabilities.** Agencies should highlight the experiences of people with disabilities in analyses using data that are already collected, and when analyzing data from new data collection efforts. While there is more to be done, many agencies already collect disability data in various contexts and programs. Yet, too often, analyses of these data do not break out or otherwise describe people with disabilities as is often done with other demographic groups or subpopulations (e.g., race or age). To the extent that these data collections can look specifically at people with disabilities, including distributional analyses, agencies are encouraged to do so. One-page fact sheets or other infographics that summarize the people with disabilities served by a specific program or receiving a certain benefit is a low-burden opportunity to better use existing data to build evidence on the well-being of and outcomes for people with disabilities.

- **Disaggregate data in analyses whenever possible**. Overall, disability exists across all U.S. populations and subpopulations, although some groups have differential experiences and are more affected than others. Disaggregation is vital to characterizing and meaningfully representing the heterogeneity of the disability community, and in examining differences in disability prevalence between subgroups and/or people with different disability types. Disaggregation facilitates data-informed decision- and policy-making by uncovering disparities and in recognizing that individuals with disabilities might have intersecting identities that could compound existing disparities or barriers, such as additionally identifying as an older adult, racial or ethnic minority, or English language learner. It is also advantageous to examine disaggregated data for longitudinal studies and/or within-group designs as trends and disparities between one or more subgroups within the disability community may become more readily apparent.

  As permitted by applicable privacy laws, best disclosure avoidance practices designed to reduce the risk of disclosing PII, and data stewardship requirements, agencies are encouraged to promote disaggregation when collecting, analyzing, and reporting disability data. In doing so, a clear, meaningful representation of the wide-ranging characteristics of the disability community and its subgroups can be made, along with measuring relevant trends and disparities to improve outcomes and remove barriers to accessing federal programs and services.

- **Consider the benefits of sharing data to support program administration, evaluation, and to reduce data collection burden.** While agencies are bound by specific regulatory or statutory constraints that may limit sharing, to the extent permitted, agencies should make data available for use by other agencies for decision-making and other approved purposes. Chief Data Officers across the federal government are actively working to introduce efficiencies to the data sharing process.

  Agencies may consider combining program participant data with detailed statistical data to better understand the characteristics of the population(s). For instance, a program administering agency may collect detailed administrative data about disabilities but may not collect detailed data about participants' demographic characteristics or household structure. The program agency may want to combine or create a data linkage between its data and data housed at another federal agency to have a greater level of detail about the individuals it serves, which could inform and improve the services the agency provides. In this case, the two agencies could work together to share data in a secure computing environment to produce detailed, anonymized, statistics about the program participants. These types of analyses reduce data collection burden, support detailed evaluation of program operations and outcomes, and inform decision-making about program administration, efficacy, and outcomes.

- **Consider opportunities to link datasets, where feasible and appropriate, to expand what can be learned.** Disability data are more impactful and powerful when combined from multiple sources using PII. Combining data may provide more robust information on outcomes, environmental factors, or other information to enhance analyses that facilitate policymaking to improve outcomes for people with disabilities. Longitudinal, linked data enable federal agencies and external researchers to assess outcomes for people with disabilities, and the need for a broader, cross-government perspective. Consistent with applicable laws and regulations, agencies should seek opportunities to link data they collect with other datasets to facilitate more robust analyses that better inform agencies' approaches to serving people with disabilities.

- **Make data available for research and analysis, as permitted by law.** Data availability refers to both access and ease of use. Agencies should ensure that there is a clear process for making disability data publicly available to external researchers or by providing restricted access to disability data so that users can leverage these data sets to produce more data products about the disabled community.

  Even publicly available data can be underutilized when it is stored in large, complicated data sets that take specialized data skills or resources to analyze. Data sources should be accompanied by interactive data products and infographics that provide summaries and the opportunity to break the data down into subgroups. The Census Bureau's My Community

Explorer interactive tools website[139] and the National Institutes of Health *All of Us* Data Browser website[140] are good examples of interactive data products and infographics that provide non-technical overviews of the data.

Data can be tabulated and released in the form of tables, visualizations, tools, etc. Data can also be made available for record-level analysis (microdata). Options for making non-public (or restricted-use) data available include: (1) development of user licensing agreements where data users agree to abide by a specific set of rules for data access and production of statistical outputs, (2) use of secure virtual data enclaves where data users log in to a secure virtual environment to conduct analysis and receive statistical output electronically after it is cleared for release, or (3) secure physical data enclaves where data users access data in a controlled and monitored physical environment and receive statistical output electronically after it is cleared for release.

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[139]U.S. Census Bureau. (2024). *My Community Explorer*.
https://experience.arcgis.com/experience/13a111e06ad242fba0fb62f25199c7dd/
[140]*All of Us* Research Program. (2022). *Data Browser*. National Institutes of Health.
https://databrowser.researchallofus.org/

Conclusion

The Federal Evidence Agenda on Disability represents a unique opportunity to improve outcomes for people with disabilities. For the first time, the federal government has laid out a roadmap to systematically and strategically further the evidence needed to inform policies and programs that will positively impact the lives of people with disabilities and their families. By identifying those questions that, when answered, will help our government better serve this population, the Evidence Agenda serves as a call to action for federal agencies and the broader external community. Moreover, it provides guidelines for federal agencies as they approach this work to ensure that they are doing so in an effective, inclusive, and responsible way.

Moving forward, the work initiated by this Evidence Agenda will continue on under the purview of the Interagency Committee on Disability Research's (ICDR's) Subcommittee on Disability Statistics[141] within the Department of Health and Human Services. The Subcommittee on Disability Statistics will be responsible for assisting interested federal agencies in addressing the Learning Agenda questions and implementing the guidelines recommended in the Evidence Agenda. It will also develop and publish public disability data resources and hold ongoing community engagement events. We the DDIWG wish the ICDR Subcommittee on Disability Statistics well as they continue this work and look forward to the progress federal agencies will make improving outcomes for people with disabilities.

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[141] Interagency Committee on Disability Research - Subcommittee on Disability Statistics

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