ICDR TOOLKIT

Surveying the Landscape of Disability Data and Statistics

A Toolkit for Interagency Collaboration

INTERAGENCY COMMITTEE ON
DISABILITY RESEARCH

TABLE OF CONTENTS

Introduction

Complete and accurate data are essential to assessing the needs of a population and designing adequate services to meet those needs. While some estimates suggest that as many as one in four Americans have a disability (Okoro et al., 2018), data on many facets of disability in the United States are still insufficient. As people with disabilities face disparities across multiple areas of daily life (e.g., health, housing, employment) compared to those without disabilities, improved data are needed to provide a more comprehensive picture of these gaps and their underlying causes. Improving data on disability in the United States will provide a strong evidence base on which to make decisions about how to tailor policies and programs to address the equity challenges people with disabilities face.

About the Interagency Committee on Disability Research

The Interagency Committee on Disability Research (ICDR) was authorized by the amended 1973 Rehabilitation Act to coordinate federal research efforts surrounding disability, independent living, and rehabilitation research. The ICDR's vision is to have wide recognition for facilitating and coordinating federal interagency efforts and for promoting collaborative relationships that maximize the best use of federal resources for disability, independent living, and rehabilitation research.

ICDR Subcommittee on Disability Statistics

The ICDR Interagency Subcommittee on Disability Statistics (ISDS) was formed in 1981 and met consistently through 2015. The ISDS served as an integral part of several major disability statistics initiatives during this timeframe. In 1989, the ISDS employed Dr. Inez Storck to compile statistics requested by federal agencies, resulting in the commercial publication *Disability in the United States: A Portrait from National Data*. The ISDS was also closely involved in the development of the 1994–1995 National Early Health Interview Survey on Disability. Another major effort the ISDS participated in was the interagency effort to update the 2000 census, resulting in the addition of two disability questions.

The ICDR has seen recent increased momentum in the federal government and disability research community to improve the collection of disability data and statistics. As a timely contribution, the ICDR is reestablishing the ICDR Subcommittee on Disability Statistics (SDS) to coordinate and collaborate with relevant others to advance the quality and availability of disability statistics. While regularly continuing to grow, the subcommittee currently has membership from the following federal agencies of the United States:

Department of Commerce (DOC)

- Census Bureau

Department of Education (ED)

- Office of Special Education Programs

Department of Health and Human Service (HHS)

- Administration for Community Living (ACL)
    - National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
- Centers for Disease Control and Prevention (CDC)
    - National Center on Birth Defects and Developmental Disabilities
    - National Center for Health Statistics (NCHS)
    - Office of Public Health Data, Surveillance, and Technology
- Centers for Medicare & Medicaid Services (CMS)
    - Office of Minority Health

- National Institutes of Health (NIH)
    - National Institute of Child Health and Human Development (NICHD)
    - National Institute of Mental Health (NIMH)
- Office of the Assistant Secretary for Planning and Evaluation (ASPE)
- Office of the National Coordinator for Health Information Technology

Department of Justice (DOJ)

- Bureau of Justice Statistics (BJS)

Department of Labor (DOL)

- Office of Disability Employment Policy (ODEP)

Social Security Administration (SSA)

- Office of Research, Demonstration, and Employment Support
- Office of Research, Evaluation, and Statistics

The SDS also has plans to invite nonfederal academic members to present and participate in select future meetings to provide their expertise in the field.

The new SDS work group held a roundtable event in April 2022 to discuss priority areas both for the group and for the field of disability data and statistics. Goals of the reinvigorated subcommittee include increasing awareness of the need for gathering disability statistics and capacity to identify people with disabilities in federal datasets, aligning federally funded disability statistics efforts, and promoting the harmonization of questions across instruments federal agencies use to collect disability data. In February 2023, the SDS work group held a 2-day State of the Science Conference on Disability Statistics. Some of the many themes identified during the 2-day conference included the value of data linkages, the tension between rigor and relevance, the importance of keeping data and findings relevant, inclusion of people with disabilities in every step of research, and the importance of accessible public-use data.

Purpose of the Toolkit

The resources in this toolkit outline the current federal landscape of disability data and statistics, with the intention of promoting interagency collaboration at the federal level. These resources can help people with disabilities and those supporting them, disability researchers, and federal agency staff better understand current research and resources on disability data and statistics and places where improvements and additional collaboration are needed. The toolkit offers a wide range of current research as well as resources developed through research conducted by or funded by federal agencies and examples of best practices from across the public and private sectors. This toolkit also discusses current gaps in the field of research on disability data and statistics and highlights areas to guide future research and federal collaboration.

Background

The federal government has recently begun endorsing a mandate for federal agencies to modernize their data capacity to enable them to implement data-driven decision making. The goal of this mandate is to impact the effectiveness and efficiency of their efforts to serve the public (Foundations for Evidence-Based Policymaking Act of 2018, 2019; U.S. Government Accountability Office, n.d; U.S. Office of Management and Budget, n.d.; U.S. Office of Personnel Management [OPM], n.d.). A critical component of these efforts is ensuring the quality and reliability of the data, including the ability to identify population subgroups in order to gather the data required to measure and advance equity (Exec. Order No. 13985, 2021). As the President's Executive Order 13985 states, "A first step to promoting equity in Government action is to gather the data necessary to inform that effort."

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Thus, it is unacceptable that people with disabilities are not identifiable in many national data collection efforts. A recent systemic analysis of disability questions in national censuses and household surveys internationally found that disability questions of any kind are lacking from 65% of questionnaires (Mitra & Yap, 2021). Such a lack of a method to identify people with disabilities in datasets has limited our understanding of their unique needs, especially among the subgroups of people with intellectual and developmental disabilities (IDD) (Krahn & Fox, 2014) and serious mental illness (Olfson et al., 2015; Bahorik et al., 2017) who face the highest amounts of stigmatization from society and even within the disability community (Chan et al., 2009). Due to these compounding systemic effects, these subpopulations are at great risk for experiencing disparities that may affect health outcomes (Krahn et al., 2015). Without data to provide an understanding of the unique needs of these groups, agencies lack the critical information necessary for accurate fiscal projections, policy development, and program planning and evaluation. As a result, crucial resources may be misallocated due to inaccurate and misinformed estimates (Reed et al., 2020).

Experiences during the coronavirus disease 2019 (COVID-19) pandemic further demonstrated how limited data can have far-reaching impacts. For example, an inability to accurately report IDD status (or any disability status) in data collection efforts prevented an assessment of the COVID-19 incidence and mortality rates among this population, drastically hindering an appropriate response to the crisis, and resulting in their excess disease contraction and mortality (Epstein et al., 2021; Gleason et al., 2021).

Several recent federal efforts described below work to address the scarcity of disability data, but much work remains. The President's Executive Order 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,* specifically names people with disabilities as an underserved and at risk population. This inclusion is significant, as people with disabilities have most often not been acknowledged as a vulnerable population needing changes in data collection to inform efforts to achieve equity. However, to fully implement the requirements of this executive order, it is essential that federal agencies create and adopt survey questions to identify people with disabilities fully, accurately, and consistently, and work to streamline such efforts across departments and agencies.

The Importance of Collecting Data on Disability

Federal agencies use data collected on the U.S. population, such as in the census and in the American Community Survey (ACS), to make funding decisions regarding a variety of important government programs. These programs provide access to services related to health care, food and nutrition, education, civil rights and advocacy, housing, education, and employment. Further, the findings of the census affect congressional seats; legislative, school, and voting precincts; and the fair distribution of over $800 billion of annual federal funding across the government programs (Lee et al., 2019). Identifying and counting people with disabilities in federal data collection efforts can provide important information about the population with disabilities that may be relevant to these government programs.

Standardized Sets of Disability Questions

Standardized questions to identify people with disabilities across surveys play a critical role in revealing and documenting the disparities faced by people with disabilities and the barriers and facilitators underlying these disparities. These data are important in informing evidence-based policies for funding and programs serving people with disabilities (Centers for Disease Control and Prevention [CDC], 2020).

Currently, nine national surveys use two main sets of standardized questions on disability:

- **American Community Survey (ACS) six disability-related questions**
- **Washington Group Short Set on Functioning (WG-SS)**

The ACS is a national survey administered by the U.S. Census Bureau. The current disability questions included in the ACS were developed and added in 2008 through an interagency committee under the auspices of the Office of Management and Budget. Participants included the Census Bureau, the National Center for Health Statistics, the ICDR SDS, and several other federal agencies (Brault et al., 2007). These questions use a “yes” or “no” format to assess difficulty with hearing, vision, cognition, ambulation, self-care, and independent living. Additional information about the ACS is available in the toolkit’s section on the U.S. Census Bureau.

The WG-SS questions are used internationally and were developed by the Washington Group on Disability Statistics, using the World Health Organization’s International Classification of Functioning as the framework. The WG-SS questions assess the level of difficulty (i.e., none, some, a lot, cannot do at all) a person experiences in any of six core functional domains: seeing, hearing, walking, cognition, self-care, and communication (Washington Group on Disability Statistics, 2017). Additional information related to the WG-SS questions is available at the end of the toolkit in the "Resources" section.

Current Federal Disability Data Collection Efforts

Several departments and agencies across the federal government collect data on people with disabilities. In addition to the Census Bureau within the Department of Commerce (DOC), other federal entities that collect data on disability are the Administration for Community Living (ACL) and CDC in the Department of Health and Human Services (HHS), Social Security Administration (SSA), Department of Education (ED), Department of Justice (DOJ), and Department of Labor (DOL) (National Disability Rights Network, 2021). Despite the efforts of these departments to collect disability data, comparison of findings across agencies and programs remains challenging or impossible due to differing conceptual and operational definitions and classifications of disability.

To address these challenges, Section 4302 of the Affordable Care Act selected the six ACS disability questions as the standard for all national population health survey data collection efforts across HHS (Office of the Assistant Secretary for Planning and Evaluation [ASPE], 2011). While this streamlined disability data collection within HHS, these questions have known limitations (Hall et al., 2022), and facilitating coordination of data collection efforts across the federal government remains necessary. Additional challenges with federal disability data include difficulty accessing or navigating datasets, gaps in understanding the intersection of disability with other influential characteristics (e.g., criminal justice, racial disparities, etc.), and inadequate involvement of the disability community (National Disability Rights Network [NDRN], 2021).

Centering the voices of people with disabilities in these efforts is vital to improving data collection for disability statistics (NDRN, 2021). People with disabilities bring important perspectives about what additional data should be collected and how to address existing gaps in data collection efforts. Furthermore, as federal agencies work toward these improvements and inclusion of people with disabilities in these efforts, interagency coordination is critical to improving and streamlining disability data collection and analysis.

Federal Resources and Research on Disability Data and Statistics

There are a variety of important federal efforts working to improve data collection on disability. The following index lists programs, research, initiatives, and resources by agency that will be described in greater depth in later sections of the toolkit:

Interagency Efforts

- *A Vision for Equitable Data: Recommendations from the Equitable Data Working Group*
- *Framework to End Health Disparities of People with Disabilities*
- OPM's *Disability Employment Statistical Reports*
- *The Equal Employment Opportunity (EEO) Status of Workers with Disabilities in the Federal Sector*

National Science Foundation (NSF)

- *Women, Minorities, and Persons with Disabilities in Science and Engineering* report

Social Security Administration (SSA)

- *Disability Analysis File Public Use File*
- *Disability Analysis File Restricted Access File*
- *Disabled Worker Beneficiary Statistics*
- *Fiscal Year Disability Claim Data*
- *National Beneficiary Survey (NBS)*
- *National Survey of SSI Children and Families (NSCF)*
- *Social Security Data Page* and *Open Government Select Datasets*
- Statistics & Data About Disability Insurance

    - *Annual Statistical Report on the Social Security Disability Insurance Program, 2022*
    - *Annual Statistical Supplement, 2023*
    - *SSI Annual Statistical Report, 2022*

U.S. Agency for International Development (USAID)

- *Collecting Data on Disability Prevalence in Education Programs*
- *Disability Identification Tool Selection Guide*
- *Guide on How to Integrate Disability into Gender Assessments and Analyses*
- Included strengthening disability data as a key commitment at the 2022 Global Disability Summit

DOC

- *U.S. Census Bureau*
    - *American Community Survey (ACS)*
    - *Advancing Equity with Data portal*
    - *Disability Data Homepage*
    - *Explore Census Data portal*
    - *National Advisory Committee (NAC) on hard-to-reach populations*
    - *Survey of Income and Program Participation (SIPP)*

ED

- *America's Education Data*
    - *Individuals with Disabilities Education Act (IDEA) Section 618 Data Products: State Level Data Files*
- *Rehabilitation Services Administration (RSA)*
    - Case Service Report (RSA-911)
- *National Center for Education Statistics (NCES)*
    - *DataLab*
    - *Students With Disabilities*
- *Workplace Innovation and Opportunity Act (WIOA) Annual Reports*

HHS

- *HHS Data Council: Introduction*
- *Administration for Children & Families (ACF)*
    - Program Information Report
- *ACL*
    - *AGing, Independence, and Disability (AGID) Program Data Portal*
    - *Data and Research*
    - *Administration on Disabilities*
        - *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*
        - *Advancing a Roadmap for Health and Equity Data for Persons with Intellectual and Developmental Disabilities*
        - *I/DD Counts initiative*
        - *Working Through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys*
    - *National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)*
        - *Americans with Disabilities Act Participation Action Research Consortium (ADA PARC): Advancing Participation Equity for People with Disabilities*
        - *Burn Model System National Data and Statistical Center*
        - *Collaborative on Health Reform and Independent Living*
        - *National Spinal Cord Injury Statistical Center*
        - National Survey on Health and Disability (NSHD)
        - *Rehabilitation Research and Training Center on Disability Statistics and Demographics (StatsRRTC)*
        - *Traumatic Brain Injury Model Systems (TBIMS) National Data and Statistical Center (NDSC)*

        - *Using the National Survey on Health and Disability Panel to Document the COVID-19 Pandemic Experiences of Working-Age Americans with Disabilities*
- *Agency for Healthcare Research and Quality (AHRQ)*
    - *Data Resources*
    - *MEPS: Medical Expenditure Panel Survey*
        - *MEPS Topics: Disability*
        - MEPS Household Component (MEPS-HC) Data Tools
        - MEPS Insurance Component (MEPS-IC) Data Tools
    - *2021 National Healthcare Quality and Disparities Report (NHQDR)*
        - NHQDR Data Tools
    - *Quality Improvement Measurement of Outcomes for People With Disabilities*
- *CDC*
    - *Autism and Developmental Disabilities Monitoring (ADDM) Network*
    - *Autism Data Visualization Tool*
    - *Behavioral Risk Factors Surveillance System (BRFSS)*
        - Behavioral Risk Factors Data Portal
        - BRFSS Video Tutorials
        - BRFSS Prevalence and Trends Data
    - *Data and Statistics on Disability and Health*
        - *Beginner's Guide to Disability and Health Data System Webinar*
        - *Disability and Health Data System: Beyond the Basics Webinar*
        - *Disability Impacts All of Us infographic*

    - NCHS
        - FastStats
        - *Health, United States* Annual Report
    - *National Health Interview Survey (NHIS)*
        - *Interactive Data Query Systems*
- *CMS*
    - *Chronic Conditions Data Warehouse (CCW)*
    - *CMS Fast Facts*
    - *Data.CMS.gov: Data That Helps You Better Understand CMS Programs*
    - *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources*
    - *Mapping Medicare Disparities by Population*
    - *Medicaid Current Beneficiary Survey (MCBS)*
    - Office of Minority Health *Stratified Reporting, Data Snapshots, Data Highlights*, and *Issue Briefs*
    - *The Path Forward: Improving Data to Advance Health Equity Solutions*
- *Human Resources and Services Administration*
    - *Data Resource Center for Child & Adolescent Health*
    - *National Survey of Children's Health (NSCH)*
- *NIH*
    - News Release: *NIH Designates People With Disabilities as a Population With Health Disparities*
    - *Welcome to the NIH Data Book* (includes information on disability status of principal investigators funded by NIH)
    - NICHD
        - *NICHD Data and Specimen Hub (DASH)*
        - *INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) Data Hub*

    - National Center for Medical Rehabilitation Research (NCMRR)
      - *Center for Large Data Research and Data Sharing in Rehabilitation*
  - National Institute on Deafness and Other Communication Disorders (NIDCD)
    - *Statistics and Epidemiology*
  - NIMH
    - *Statistics* homepage
- *Office of Disease Prevention and Health Promotion (ODPHP)*
  - Healthy People Initiative
    - *Healthy People 2030: Data Sources*
    - Objective DH-R01 of Healthy People 2030
- *OMH*
  - *Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability*
- *ASPE*
  - *Dataset on Intellectual and Developmental Disabilities: Linking Data to Enhance Person-Centered Outcomes Research*
  - *Considerations for Building Federal Data Capacity for Patient-Centered Outcomes Research Related to Intellectual and Developmental Disabilities*
  - *Disability Data in National Surveys*
  - *HHS Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*
  - *Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities*
  - Issue Brief: *COVID-29 Data on Individuals with Intellectual and Developmental Disabilities*

    - *Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) Product Library*
    - *Research Agenda: Disability Data*
    - Building Data Capacity for Patient-Centered Outcomes Research (PCOR)
        - Workshop 1 - *Looking Ahead at Data Needs*
        - Workshop 2 - *Data Standards, Methods, and Policy*
        - Workshop 3 - *A Comprehensive Ecosystem for PCOR*
- *Substance Abuse and Mental Health Services Administration (SAMHSA)*
    - Homepage for SAMHSA Data
    - *Data We Collect*
    - *Program Evaluations*
    - *Quick Statistics*
    - Reports and data tables
    - *Substance Abuse and Mental Health Data Archive*

U.S Department of Housing and Urban Development (HUD)

- *A Picture of Disability and Designated Housing*
- *American Housing Survey*
- *Housing Choice Voucher (HCV) Program Data Dashboard*

DOJ

- *Statistics Available from the Department of Justice*
- *BJS*
    - *Crime Against Persons with Disabilities, 2009–2019 – Statistical Tables*
    - *Disabilities Reported by Prisoners*

DOL

- Webpage on DOL disability statistics resources
- *Bureau of Labor Statistics (BLS)*
    - BLS webpage on disability statistics
    - *Current Population Survey (CPS)*
    - *Demographic Data Sources Comparison Matrix*
- *ODEP*
    - *Disability Employment Statistics*
    - *Improving Access to Data for Disability-Related Research*

U.S. Department of Transportation (DOT)

- *Bureau of Transportation Statistics (BTS)*
    - *BTS Data Inventory*
    - *National Household Travel Survey (NHTS)*
    - *Travel Patterns of American Adults with Disabilities*

U.S. Department of Veterans Affairs (VA)

- *Open Data Portal*

U.S. Environmental Protection Agency (EPA)

- *America's Children and the Environment*

Interagency Efforts

A VISION FOR EQUITABLE DATA: RECOMMENDATIONS FROM THE EQUITABLE DATA WORKING GROUP

To address Executive Order 13985, *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government*, in January 2021 the Equitable Data Working Group released the report, *A Vision for Equitable Data: Recommendations from the Equitable Data Working Group*. This report, compiled through consultations with advocates, experts, academic researchers, and community leaders, recommends three overarching priorities for advancing equitable data:

- Generating disaggregated statistical estimates to characterize experiences of historically underserved groups using survey data;
- Increasing nonfederal research and community access to disaggregated data for the evidence building that supports equity efforts; and
- Conducting robust equity assessments of federal programs to identify areas for improvement.

Additionally, the Working Group conducted a series of case studies to identify where existing federal data can be used to address equity-centered questions. The Working Group specifically mentions disability in this report and calls for establishing best practices to measure disability.

FRAMEWORK TO END HEALTH DISPARITIES OF PEOPLE WITH DISABILITIES

In 2022, the National Council on Disability (NCD) released the policy brief titled *Framework to End Health Disparities of People with Disabilities*. This policy framework provides guidance on a cross-government approach to achieving the goal of health equity for all people with disabilities. One major section of this framework discusses ways that data collection about health care for people with disabilities across the lifespan can be improved. Ultimately, NCD recommends that the National Academies of Science, Engineering and Medicine conduct a study and report regarding HHS's data collection systems and practices related to the collection of data on disability. The report also comments on the importance of data linkages between agencies.

OFFICE OF PERSONNEL MANAGEMENT'S DISABILITY EMPLOYMENT STATISTICAL REPORTS

The OPM provides regular reports to the president, the heads of agencies, and the public on the progress of federal employment for people with disabilities in response to Executive Order 13548. The reports can be found on OPM's webpage, and they contain information about the representation of people with disabilities within the federal government and report on best practices agencies are currently using to increase representation.

THE EQUAL EMPLOYMENT OPPORTUNITY STATUS OF WORKERS WITH DISABILITIES IN THE FEDERAL SECTOR

The EEO Commission has a report entitled *The EEO Status of Workers with Disabilities in the Federal Sector* that identifies current trends for workers with disabilities in the federal sector and creates a baseline for measuring the effects of the final rule titled *Affirmative Action for Individuals with Disabilities in the Federal Government*. This report provides information about federal sector participation rates of people with disabilities and persons with targeted disabilities, the federal sector employment stages for both of these groups, and ways federal agencies are improving accessibility.

National Science Foundation

The NSF, an independent federal agency founded in 1950, supports and promotes the field of science to transform the future of the country. In advancing science, NSF also assists with stimulating progress in “the national health, prosperity, and welfare” (NSF, n.d.). Grants from NSF support about 25% of all federally funded basic research in the fields of computer science, mathematics, and the social sciences at U.S. colleges and universities (NSF, n.d.).

The NSF’s report ***Women, Minorities, and Persons with Disabilities in Science and Engineering***, issued every 2 years, provides statistical information about the participation of these three demographic groups in science and engineering education and employment. The website also offers data tables and resources for download.

Social Security Administration

The SSA is a federal agency that provides financial protection for Americans through social insurance, including retirement, disability, and survivor benefits. The SSA provides benefits to around 64 million Americans at various stages of life (SSA, n.d.). Its Social Security Disability Insurance (SSDI) program provides benefits to workers who can no longer work due to disability. The SSA also administers the Supplemental Security Income (SSI) program, a federal assistance program guaranteeing a minimum income for aged, blind, and disabled individuals with limited income and resources. The ***Social Security Data Page*** and SSA's **webpage on open data** provide general information and a complete list of SSA's data.

DISABILITY ANALYSIS FILE

The Disability Analysis File (DAF) is an analytical file that contains SSA administrative data in an easy-to-use format. The DAF includes historical, longitudinal, and one-time data on employment activity, program participation, and benefits for all beneficiaries in the SSI or SSDI programs between 1996 and the date of the file. There is a **full, restricted use version** of the DAF as well as a **public use file** that contains data elements for a random 10% of the sample included in the full DAF.

DISABILITY RESEARCH SURVEYS

The Disability Research Surveys are a new set of surveys currently under development at SSA. The agency has awarded a contract to design, administer, and document the results of three Disability Research Surveys. The first will be an updated version of the NBS which is being fielded in 2023, followed 2 years later by a New Applicant Survey, and a third survey (with a yet-to-be-determined topic) will follow 2 years after that.

DISABLED WORKER BENEFICIARY STATISTICS

The webpage on SSA's disabled worker beneficiary statistics presents unedited data regarding disabled worker beneficiaries paid from Social Security's Disability Insurance Trust Fund.

FISCAL YEAR DISABILITY CLAIM DATA

The website on *SSA Fiscal Year Disability Claim Data* contains information from fiscal year (FY) 2001 onward concerning initial claims for disability benefits. These data can be used to examine disability application filing trends by time and by state, state agency workloads, and disability claims outcomes.

NATIONAL BENEFICIARY SURVEY

The *NBS* collects information about key health, employment, and sociodemographic factors that contribute to SSDI beneficiaries' and SSI recipients' successful or unsuccessful employment efforts. It provides data to support policy analysis for SSA, Congress, other policymakers, and researchers. The NBS collects data on a wide range of variables not available in the agency's administrative systems, including sociodemographic information, health and functional status, health insurance, interest in work, barriers to work, use of services, employment, income, and experience with Social Security programs. There is a full, restricted use version of the NBS as well as a public use file.

NATIONAL SURVEY OF SSI CHILDREN AND FAMILIES

The NSCF includes data on the health status, functional limitations, health care utilization, health insurance coverage, receipt of services, SSI experience, and socioeconomic status of the households of over 8,000 children who were receiving, had received, or were applying for SSI between July 2001 and July 2002. The study was limited to the noninstitutionalized population in the contiguous United States.

The SSA explored options for a second NSCF and posted a link to a survey options report related to the structure and technical aspects of a potential new survey.

STATISTICS & DATA ABOUT DISABILITY INSURANCE

A comprehensive list of data and statistics available at SSA on disability insurance can be found at the SSA webpage titled *Research, Statistics & Policy Analysis*.

Annual Statistical Report on the Social Security Disability Insurance Program

The *Annual Statistical Report on the Social Security Disability Insurance Program* provides important demographic and program statistics on the following six topics: beneficiaries in current-payment status; workers' compensation and public disability benefits; benefits awarded, withheld, and terminated; disabled workers who have returned to work; outcomes of applications for disability benefits; and disabled beneficiaries receiving Social Security, SSI, or both. It contains charts and tables on all of these topic areas that are available for download.

Annual Statistical Supplement

The *Annual Statistical Supplement*, published yearly since 1940, is an important resource for data on SSA programs. It also includes program summaries and legislative histories to help users of these data better understand SSA's programs.

Annual Statistical Report on SSI

The *SSI Annual Statistical Report* provides important demographic and program statistics on federal benefit rates and the number of recipients; the number of recipients in different categories (e.g., children, under age 65, who work); outcomes of applications for SSI; and suspensions and terminations from the program. It contains charts and tables on all of these topic areas that are available for download.

Additional statistics on the Old-Age, Survivors, and Disability Insurance and SSI programs can be downloaded for free at https://www.ssa.gov/policy/index.html.

U.S. Agency for International Development

The USAID is an independent federal agency that leads international development and humanitarian efforts aimed to save lives, reduce poverty, and strengthen democratic governance and help people progress beyond assistance (USAID, 2019).

At the 2022 Global Disability Summit, USAID announced 16 key commitments to achieve change for people with disabilities. One of these commitments was to build on its work promoting disability inclusive education to “strengthen disability data and evidence for education programming.”

Resource Guides from USAID Related to Disability Data

COLLECTING DATA ON DISABILITY PREVALENCE IN EDUCATION PROGRAMS (2020)

This guide presents information about tools and approaches for USAID staff, local actors, and implementing partners on approaches to collecting disability prevalence data in USAID education programming.

DISABILITY IDENTIFICATION TOOL SELECTION GUIDE (2020)

This guide presents information to help determine which data collection tool is most appropriate for collecting data on children and youth with disabilities in USAID education programming.

GUIDE ON HOW TO INTEGRATE DISABILITY INTO GENDER ASSESSMENTS AND ANALYSES (2010)

As all USAID operating units are required to complete a gender assessment prior to developing projects and activities, this guide provides information on how men, women, and children with disabilities should be included in these analyses and assessments.

U.S. Department of Commerce

The DOC aims “to create the conditions for economic growth and opportunity for all communities” (DOC, n.d.). The department consists of 13 different bureaus focused on developing the competitiveness of the U.S. economy, strengthening domestic industry, and growing quality jobs for all communities in the United States. (DOC, n.d.).

CENSUS BUREAU

The U.S. Census Bureau’s mission is to serve as the nation’s leading provider of quality data about its people and economy (U.S. Census Bureau, 2023b). It supports this mission through conducting a variety of federal surveys and data collection efforts. The Census Bureau hosts a portal called ***Explore Census Data*** that offers users the ability to conduct an advanced search, find tables, and build maps. In addition, the Census Bureau has developed a portal for ***Advancing Equity with Data***.

The U.S. Census Bureau recognizes that some people with disabilities may face barriers that make them difficult to contact or interview (U.S. Census Bureau, 2022). When conducting the 2020 census, the Census Bureau partnered with a variety of disability rights organizations to improve outreach to this population and ensure the census included adequate accessibility measures (NDRN, 2021). Another way the Census Bureau addresses hard-to-count populations is through the NAC, which was established in 2012 to consider a variety of hard-to-reach populations as well as data privacy and confidentiality issues. Additional details about how the Census Bureau planned to efficiently and effectively reach hard-to-count communities across the country to ensure the most accurate count during the 2020 census is available in a Census Bureau blog post.

The Census Bureau's disability data homepage contains guidance about its disability data, a disability data library, and publications using these data. The Census Bureau collects data on disability on two of its own nationally representative household surveys: ACS and SIPP.

In addition, the Census Bureau collects data for several other agencies on a reimbursable basis. Some of those surveys also include questions on disability at the discretion of the sponsoring agency.

American Community Survey

The ACS was developed in the late 1990s to reduce the complexity and cost of the decennial census by replacing the long-form sample questionnaire and allowing the decennial count to focus solely on "a basic headcount and minimal demographic data" (U.S. Census Bureau, 2021). As the ACS was being developed, it adopted the six questions being tested for the census 2000 long-form sample questionnaire. After the 2000 census, there were concerns that the six questions were not in line with current models of disability and that the questions focused too heavily on the condition itself rather than the impact those conditions had on functioning (U.S. Census Bureau, 2021). These concerns led to new questions being introduced in 2008, the same ones currently being used. It is important to note, however, that the data on disability from 2008 on cannot be compared to the previous data due to these changes in the questions. Following are the six disability types currently included in the ACS:

- **Hearing difficulty** (deaf or having serious difficulty hearing)
- **Vision difficulty** (blind or having serious difficulty seeing, even when wearing glasses)
- **Cognitive difficulty** (because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions)

- **Ambulatory difficulty** (having serious difficulty walking or climbing stairs)
- **Self-care difficulty** (having difficulty bathing or dressing)
- **Independent living difficulty** (because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping)

ACS Disability Data Tables

View the ACS disability data tables using data.census.gov, such as table *S1810: Disability Characteristics*.

The ACS definition of disability may not capture the full range of disability experiences, yet it allows for estimates to be produced at the state, county, and metropolitan levels (U.S. Census Bureau, 2021). In October 2023, there were proposed changes posted to the Federal Register to the disability questions. In February 2024, it was stated that no changes will be made to the ACS disability questions for collection year 2025. There is continued work with stakeholders in and outside of government to understand the disability data needs and to potentially assess for if any revisions may be needed across the federal statistical system to address these needs.

Survey of Income and Program Participation

The *SIPP* is a nationally representative longitudinal survey that collects comprehensive household-based data on income, employment, household composition, and government program participation. The SIPP contains the same six disability questions asked in the ACS and the CPS, a survey administered by the Census Bureau on behalf of the BLS (discussed in the DOL section). In addition, the SIPP also includes six questions about disability related to children and the working-age population (U.S. Census Bureau, 2023a). Further, beginning in 2021, seven new disability questions sponsored by SSA were added to the SIPP. The SIPP provides data users with two disability recode variables that serve as summary measures of disability. The first summary measure of disability is identical to the measure used in the ACS. The second summary measure of disability is broader in that it also includes data on the six questions about child- and work-related disability. An advantage of the SIPP over the ACS is that it contains more detailed data on household characteristics and well-being, as well as longitudinal data. As a result, the SIPP can be used to investigate associations between disability and many other variables, particularly over time. Users should exercise caution, however, in using the SIPP data for population estimates of disability (particularly SIPP data from 2014 onward). In recent years, national estimates of disability prevalence produced using SIPP data have been higher than estimates from other federal surveys (Jackson et al., 2021).

U.S. Department of Education

The ED is a federal executive department that is responsible for creating policy, administering, and coordinating financial assistance for education, collecting data on schools, and enforcing federal education policy relating to privacy and civil rights.

AMERICA'S EDUCATION DATA

America's Education Data (data.ed.gov) is an open data catalog that brings the ED's data assets together into a single location. Specific to disability, users can search by categories and tag, such as "special education," "Individuals with Disabilities Education Act," or "education of students with disabilities."

CASE SERVICE REPORT

The *Case Service Report (RSA-911)* gathers information about vocational rehabilitation (VR) and supported employment services provided to individuals with disabilities. Collected by state VR agencies and submitted to the RSA on a quarterly basis, the RSA-911 provides comprehensive case-level insights into the demographic characteristics of VR applicants, including their barriers to employment, the types and extent of services they receive, and their employment and educational outcomes. The data collected through the RSA-911 aids in policymaking, program evaluation, and implementation of the WIOA performance accountability system, ensuring the continual improvement of VR services.

DATA PRODUCTS FROM IDEA SECTION 618

Section 618 of the IDEA requires that each state submit data about the infants and toddlers, birth through age 2, who receive early intervention services under Part C of IDEA and children with disabilities, ages 3 through 21, who receive special education and related services under Part B of IDEA. Files containing the submitted data are organized in *State Level Data Files* and Static Data Tables containing summaries of data in Part B and Part C.

NATIONAL CENTER FOR EDUCATION STATISTICS

The NCES is the federal entity responsible for both collecting and analyzing education data in the United States and other nations. The NCES is congressionally mandated to "collect, collate, analyze, and report complete statistics on the condition of American education; conduct and publish reports; and review and report on education activities internationally" (NCES, n.d.). The NCES *DataLab* allows users to sort NCES data by topic, including disability. Additionally, NCES hosts data on students with disabilities who receive services through the IDEA.

WORKFORCE INNOVATION AND OPPORTUNITY ACT

The WIOA of 2014 requires state VR programs to submit an annual statement performance report to the RSA in ED. The *WIOA Annual Reports* contain information on people with disabilities and VR use.

U.S. Department of Health and Human Services

The HHS is a federal executive department with the mission to "enhance the health and well-being of Americans, by providing for effective health and human services by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services" (HHS, 2020). The department's scope is broad. With 11 different operating divisions, HHS includes a variety of contexts in which disability data are being addressed.

The HHS Data Council advises the secretary of HHS on health and human services data policy, strategy, standards, and privacy. The Council works to promote coordination on data issues across HHS and when collaborating with private entities, state and local governments, or other partners.

ADMINISTRATION FOR CHILDREN & FAMILIES

The ACF works to promote the economic and social well-being of children, families, and communities. The ACF Office of Head Start provides a publicly available Program Information Report that offers comprehensive data on Head Start services, staff, children, and families in these programs. This report contains data on the percent of children served by Head Start that have disabilities. Data from the Program Information Report is available upon request.

ADMINISTRATION FOR COMMUNITY LIVING

The ACL aims to help older adults and people of all ages with disabilities to "live where they choose, with the people they choose, and with the ability to fully participate in their communities" (ACL, 2020a). The ACL funds a variety of community-level targeted programs for older adults and people with disabilities, as well as research and education efforts. More information can be found on the *Data and Research* page on the ACL website.

Aging, Independence, and Disability Program Data Portal

ACL hosts the *AGing, Independence, and Disability (AGID) Program Portal*, a query system that includes program data from ACL's Administration on Aging and Administration on Disabilities as well as data from the Census Bureau on aging and disability. Users can search the data, create charts, and look up tables to make comparisons across the datasets. The site has various levels of focus and aggregation, from data-at-a-glance to full access to databases. Resources and data source descriptions are also available in this portal.

Intellectual and Developmental Disabilities Counts Initiative

In 2019, the Administration on Intellectual and Developmental Disabilities in ACL in partnership with the National Health Surveillance for Intellectual and Developmental Disabilities Workgroup released *Working Through the Data Conundrum: Identifying People with Intellectual and Developmental Disabilities in National Population Surveys.* This report describes the need for, availability of, and recommendations for changes in the collection of surveillance data about people with IDD. The same workgroup also partnered with ACL to release a companion report, *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*.

As an outgrowth of this work, ACL's Administration on Disabilities now leads the I/DD Counts initiative in partnership with self-advocates, advocacy organizations, researchers, and the following other agencies within HHS: ASPE, CDC, CMS, and NIH. In this initiative, ACL has worked "with stakeholders to develop a 10-year plan to guide the development of the health surveillance system for people with I/DD." The I/DD Counts initiative held a summit in November of 2022, and recently released the proceedings of it, *Advancing a Roadmap for Health and Equity Data for Persons with Intellectual and Developmental Disabilities*. This summit was organized by the HHS agencies and included people from federal, state, advocacy, academic, and clinical organizations, as well as people with IDD.

National Institute on Disability, Independent Living, and Rehabilitation Research

ACL's NIDILRR is the primary disability research agency in the federal government. Its aim is to produce new knowledge and promote its effective use to improve the abilities of people with disabilities to perform their daily activities (ACL, 2020b). In addition, NIDILRR hopes its research will expand the capacity for society to provide opportunities and accommodations for people with disabilities. NIDILRR examines a wide range of disabilities across the lifespan, including all aspects of a living with a disability. Following are several examples of NIDILRR-funded grants related to disability data and statistics.

Americans with Disabilities Act Participation Action Research Consortium: Advancing Participation Equity for People with Disabilities (2017–2022)

The ADA PARC project expands upon previous collaborative research on how to measure and document participation disparities experienced by people with disabilities. The ADA PARC website hosts a collection of public datasets related to the status of people with disabilities in local communities, encompassing national, state, county, and city data. The disability data included on ADA PARC's website spans three main topic areas: community living, community participation, and work and economics. Data for each of these areas are presented in both map and tabular form, as well as in a summary. The data sources and calculations used for the maps and tables are described on each page.

Burn Model System National Data and Statistical Center

The Burn Model System (BMS) NDSC is an NIDILRR-funded center that serves as a centralized resource for researchers, data collectors, and clinicians. It provides data collection and data management expertise, statistical and methodological assistance and services, access to the BMS National Longitudinal Database, overviews of data contained in this database, and training and technical assistance to BMS Centers. The NDSC website contains webinars about the BMS National Longitudinal Database, information on how to access BMS data, and publications that use the

BMS National Longitudinal Database. Additional information is available on the BMS NDSC website.

Collaborative on Health Reform and Independent Living (2015–2020)

The Collaborative on Health Reform and Independent Living aimed to present disability stakeholders with accurate, current, and actionable information on health policy changes that impacted the community living and participation of working-age people with disabilities. It brought four institutions together to examine how implementation of the Affordable Care Act impacts people with disabilities. As part of this grant, the University of Kansas Institute for Health and Disability Policy Studies developed the NSHD (formerly the National Survey on Health Reform and Disability) in 2018. This survey collects detailed information on experiences with health and health services for a nationally representative group of adults in the United States between ages 18 and 64. The NSHD is now being used in the University of Kansas' current Field-Initiated Project described below.

National Spinal Cord Injury Statistical Center

The National Spinal Cord Injury Statistical Center (NSCISC) is an NIDILRR-funded center that offers knowledge, resources, and services to support the Spinal Cord Injury Model Systems (SCIMS) Program and Database and aims to advance medical rehabilitation through "increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of people with spinal cord injury." The NSCISC website hosts a *Life Expectancy Calculator*, including important information about the statistical methods used to develop this tool. The NSCISC grant funds a web-based system that provides secure and user-friendly features for data management and reporting, website tools for accessing SCIMS data and searching spinal cord injury statistics, resources on SCIMS research, annual statistical reports, and consumer-friendly infographics, presentations, and publications. More information is available on the NSCISC website.

Rehabilitation Research and Training Center on Disability Statistics and Demographics (2018–2023)

The NIDILRR-funded StatsRRTC aimed to address the gap between the producers and the end users of disability statistics by supporting improved data collection that can help inform programs and services for people with disabilities. The center's three research projects generated new survey items and recommendations for improving the collection, relevance, and interpretation of disability statistics; developed techniques to improve the estimation of state/local statistics; and conducted deeper analyses of key demographics, outcomes, and program. Each year the center releases the *Annual Disability Statistics Compendium*, which brings together disability data from a variety of data collections including the ACS and Social Security. In 2021, the center also released a *Compendium of Disability Data Collection Methods*. In addition to the center's research, development, and training projects, it provided technical assistance to end users by assisting with answering questions about a wide range of issues related to disability data and statistics. This funding mechanism was recompeted in FY 2023, and individuals can submit questions for the StatsRRTC on the center's website.

Traumatic Brain Injury Model Systems National Data and Statistical Center

The Traumatic Brain Injury Model Systems National Data and Statistical Center (TBINDSC) is an NIDILRR-funded center that aims to "to advance medical rehabilitation by increasing the rigor and efficiency of scientific efforts to longitudinally assess the experience of individuals with traumatic brain injury" and offers technical assistance, training, and methodological consultation to the TBIMS centers as they collect and analyze longitudinal data, and as they conduct research toward evidence-based traumatic brain injury rehabilitation interventions. The TBINDSC website hosts a variety of resources for researchers, including a data dictionary, publications that use data from the TBIMS National Database, information on how to access TBIMS data, interactive tools, and variety of analytic resources. More information is available on the TBINDSC website.

Using the National Survey on Health and Disability Panel to Document the COVID-19 Pandemic Experiences of Working-Age Americans with Disabilities (2021–2024)

This NIDILRR-funded Field-Initiated Project at the University of Kansas Institute for Health and Disability Policy Studies examined the COVID-19 pandemic-related experiences of working-age adults with disabilities and identified interventions and policy initiatives to support their health and function, employment, and opportunities for community living. This project uses the existing NSHD and partners with other NIDILRR-funded projects to develop survey questions, analyze data, and conduct activities in a rigorous and timely fashion. The project piloted the COVID-19 supplement to the NSHD and uses the findings to develop a variety of resources, including policy briefs, consumer resources, journal articles, and policy and practice recommendations.

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The AHRQ is a federal agency mandated to improve the safety and quality of health care in the United States. The AHRQ develops knowledge, tools, and data necessary to initiate improvements in health care that benefit Americans, health care professionals, and policymakers (AHRQ, 2022).

The agency website offers several research-based tools and a variety of datasets for health care providers and other organizations to make health care safer in all settings. The website hosts a *Data Resources* page where users can filter by topic area. In 2012, AHRQ published a report, *Quality Improvement Measurement of Outcomes for People With Disabilities*, detailing known evidence for health plans, providers, and policymakers to make the necessary changes to close the quality gap for people with disabilities.

Medical Expenditures Panel Survey

The **MEPS** is a large-scale survey administered annually by AHRQ to individuals and families, medical providers, and employers. *The survey* collects data on frequency of use and cost of health care services, as well as the cost, scope, and breadth of health insurance available by employers for U.S. workers. It includes two components: the Household Component, which collects information on individual households, supplemented by medical providers, and the Insurance Component, which surveys U.S. employers to gather data about employer-based health insurance.

The MEPS **page on disability** lists all of the AHRQ publications related to data on disability. Additionally, AHRQ hosts two sets of MEPS data tools: **MEPS–Household Component Data Tools** and **MEPS–Insurance Component Data Tools**. In addition to data tools, these pages provide links to AHRQ updates, chartbooks, technical questions, a list of the survey questions, a glossary, publications, and state tables in spreadsheet format.

National Healthcare Quality and Disparities Report

Each year AHRQ releases the *NHQDR,* which assesses the health care system in the United States on over 250 measures of quality and disparities. While the report does not focus specifically on people with disabilities, it includes a section on beneficiaries dually eligible for Medicare and Medicaid. The *2021* NHQDR is available on the **AHRQ website**. Additionally, the AHRQ website hosts an **NHQDR Data Tools** page that offers a unique set of tools to assist with identifying areas that the health care system in the United States has inefficiently or unevenly distributed services across populations. Users can search by population demographics, including disability status.

CENTERS FOR DISEASE CONTROL AND PREVENTION

The CDC works to protect the health and safety of Americans from diseases both foreign and domestic (CDC, 2022*b*). They support increasing the health security of the country through critical research and health information.

Autism and Developmental Disabilities Monitoring Network

The CDC's ADDM Network collects data to better understand the number and characteristics of children with autism spectrum disorder (ASD), cerebral palsy, and other developmental disabilities throughout the country. It is a collaborative network, and partners are encouraged to use ADDM in their local communities to move initiatives, policies, and research forward for children *with ASD* and their families. Those interested can also access a public, interactive Autism Data Visualization Tool that uses multiple data sources to display ASD prevalence estimates and demographic characteristics at the national, state, and community levels.

Behavioral Risk Factors Surveillance System

The CDC's BRFSS is "the nation's premier system of health-related telephone surveys that collect state data about U.S. residents regarding health-related risk behaviors, chronic conditions, and use of preventive services" (*CDC, 2014*). The BRFSS collects data across all 50 states, the District of Columbia, and three U.S. territories. It is the largest continuously conducted health survey system in the world, and several countries around the world have requested technical assistance to develop similar health surveillance systems. The BRFSS is one of the primary data resources for determining state-level prevalence and characteristics among people with disabilities.

Explore BRFSS Data

BEHAVIORAL RISK FACTORS DATA PORTAL

The Behavioral Risk Factors Data Portal allows users to interact with the BRFSS data directly by filtering the dataset, customizing visualizations, and downloading data. Additionally, the BRFSS team curates resources on relevant facts and trends that are available for use. Video tutorials are also available for users.

BRFSS PREVALENCE AND TRENDS DATA

The *BRFSS Prevalence and Trends Data* page allows users to generate state-level datasets and custom charts and graphs by location or health topic. Users have the option to download prevalence estimates via charts, graphs, or maps.

Disability and Health Data System

The CDC's National Center on Birth Defects and Developmental Disabilities hosts the Disability and Health Data System (DHDS), an online resource that presents analyzed state and national-level health data (collected from the BRFSS) on adults with disabilities. Information is available on six functional disability types: cognitive, hearing, mobility, vision, self-care, and independent living. Data in DHDS cover over 30 different health topics among people with and without disabilities. Users on the DHDS site can organize the data into custom maps, charts, and tables for their state or region as well as identify differences between adults with and without disabilities. Fact sheets that provide an overview of health and disability for each state can be downloaded from the DHDS site. Additionally, DHDS published the

Disability and Health Data System Tutorials

Users can learn more about how to use the DHDS site in the following tutorials:

- *Beginner's Guide to Disability and Health Data System*
- *Disability and Health Data System: Beyond the Basics*

Disability Impacts All of Us infographic that provides an overview of disability and health statistics in the United States.

Disability Measurement Efforts

The CDC is working to expand its surveillance systems to include disability status measures. A single disability question was tested on the National Immunization Survey Adult COVID Module, with results indicating disparities in COVID immunization among adults with disabilities in 2021 (Ryerson et al., 2021). Following this report, the NIS included the full disability standard identification questions (ACS-6 disability questions), as the single question did not allow disaggregation of disability by functional type (e.g., vision, hearing, cognition, etc.). The standard WG-SS set disability questions are also now included on the ongoing U.S. Census Household Pulse Survey.

National Center for Health Statistics

The NCHS is the primary federal health statistics agency aiming to provide accurate, relevant, and timely data to guide actions and policies that improve the health of Americans (CDC, 2022c). This agency offers a variety of resources for researchers interested in performing data analysis. Additionally, NCHS is responsible for tracking progress on the Healthy People Initiative (NCHS, 2020).

FastStats

FastStats is an index facilitated by NCHS that offers quick access to public health statistics in a variety of topic areas. FastStats links to publications, sources, and related webpages. The FastStats page on disability lists summary statistics and tables for selected sensory problems, activity limitations, and difficulties with physical functioning.

Health, United States Annual Report

Each year, NCHS releases the *Health, United States* report, which provides an annual overview of national trends in several key health indicators across many health-related surveys conducted by HHS. The 2019 report is available on the CDC website.

National Health Interview Survey

The NHIS, one of the main data collection programs of the NCHS, gathers information of the health status of noninstitutionalized Americans. Administered since 1957, the NHIS is designed to obtain accurate and current statistical information about the "amount, distribution, and effects of illness and disability in the United States" (CDC, 2022a). The *Interactive Data Query Systems* allow users to view biannual and quarterly estimates as well as navigate interactive summaries of final NHIS data. Users can sort health topics by demographics (including disability status), geographic characteristics, and socioeconomic status.

National Center for Health Statistics Data Linkage Activities

To maximize the scientific value of its population-based surveys, NCHS has developed a record linkage program. Linked data files enable researchers to examine the factors that influence disability, chronic disease, health care utilization, morbidity, and mortality. The *NCHS Data Linkage Activities* web page provides information about available linkages, including summaries of linkage methods.

Currently NCHS surveys are linked with administrative data from the following:

- National Death Index (NDI)
- CMS
    - Medicare
    - Medicaid
- United States Renal Data System
- SSA
- HUD
- VA

CENTERS FOR MEDICARE & MEDICAID SERVICES

The CMS is the federal agency in HHS that administers the Medicare program and partners with states to administer Medicaid, Children's Health Insurance Program, and the Health Insurance Marketplace (CMS, n.d.).

Chronic Conditions Data Warehouse

One main data resource CMS hosts is the *CCW*. The CCW is a research database with Medicare and Medicaid beneficiary claims and assessment data where the preliminary linkage work has already been completed. This research database is designed to make data on Medicare (including Part C data and Part D Prescription Drug Event data) and Medicaid easier for researchers to access and use. The CCW site also contains charts, reports, data dictionaries, and analytic guidance designed for researchers.

Data From Data.CMS.gov

One of the main ways users can access the variety of data on disability CMS collects is on Data.CMS.gov. This site allows users to browse data by category, explore data tools, and conduct searches. The datasets available here are designed so that they can be used in conjunction with external websites and applications. One of the data tools available on the site is the Mapping Medicare Disparities tool, which allows users to better understand disparities in chronic conditions in the United States. For quick reference statistical summaries of CMS data, *CMS Fast Facts* provides downloadable summaries.

Medicare Current Beneficiary Survey

The MCBS is a continuous, multipurpose survey of a nationally representative sample of the Medicare population. It provides important information on health outcomes and social determinants of health for Medicare beneficiaries that is not available in the administrative program data. This survey includes data collection on disability. Annually, the MCBS has three data releases, including an annual *MCBS Chartbook* of key estimates from the survey. The MCBS provides the public use file and accompanying documentation for free to download at the MCBS web page. Limited dataset files are also made available to researchers, and additional information is available at the MCBS web page.

Office of Minority Health

The CMS OMH routinely releases stratified reports, data snapshots, data highlights, and issue briefs on a variety of health services and health outcomes for minority groups, including people with disabilities. The OMH plans to annually release updated reports, including a stratified report on dual eligibility or eligibility for low-income subsidy and disability in 2023.

In several of its recent reports, CMS OMH references the collection of disability data. In 2020, it released the report *Improving Health Care for Adults with Disabilities: An Overview of Federal Data Sources*. This report provides a comprehensive overview of federal data related to the experience of people with disabilities in the health care setting. It also identifies areas where existing data sources can be leveraged to make improvements to data collection efforts on disability. In 2022, CMS OMH published the report *The Path Forward: Improving Data to Advance Health Equity Solutions,* which outlines the current state of enrollee-

The CMS Office of Minority Health Data Highlights on Disability

The CMS Data Highlight products listed below provide data on people with disabilities and health care access. Each document provides an overview of the public health topic, a brief quantitative and or qualitative analysis of the data, descriptions of data sources and methods, and a description of how the findings relate to CMS or other HHS policy or initiatives.

- *How Does Disability Affect Access to Health Care for Dual Eligible Beneficiaries?*
- *Does Disability Affect Receipt of Preventive Care Services among Older Medicare Beneficiaries?*

focused health equity data across CMS programs and discusses CMS's future actions to achieve its mission. This report covers the specific topic of disability data collection.

HUMAN RESOURCES AND SERVICES ADMINISTRATION

The Human Resources and Services Administration Maternal and Child Health Bureau funds the NSCH that provides data on wide-ranging aspects of a child's physical and mental health, access to and quality of health care, and family, neighborhood, school, and social context. The NSCH asks several questions related to disability and chronic illness. The Data Resource Center for Child & Adolescent Health makes data from the NSCH publicly accessible to parents, researchers, community health providers, and others with an interest in maternal and child health.

NATIONAL INSTITUTES OF HEALTH

The NIH is the country's largest biomedical and behavioral research agency (NIH, 2017). Working to turn scientific discoveries into better health for all, the NIH develops and maintains resources to help the nation prevent disease and improve health. Promoting scientific integrity, public accountability, and social responsibility are other integral parts of the NIH's mission.

The NIH has engaged in several recent activities to promote greater inclusion of people with disabilities in research. In September 2023, the NIH announced the **designation of people with disabilities as a population with health disparities**. Additionally, the NIH recently put out a notice of funding opportunity for research applications focused on novel and innovative approaches and interventions that address the intersecting impact of disability, race and ethnicity, and socioeconomic status on health care access and health outcomes. In 2023, the NIH also put out a request for information to solicit feedback on the NIH mission statement. ***The NIH Data Book*** also now contains information related to the **disability status** of principal investigators funded by NIH, and a summary of those data is presented in this **blog post**.

National Institute of Child Health and Human Development

The *Eunice Kennedy Shriver* NICHD began in 1962 to examine human development during the life course, with a focus on understanding disabilities and events that occur during pregnancy. It funds research efforts that work to save lives, improve well-being, and reduce societal costs associated with illness and disability. The mission of NICHD is "to lead research and training to understand human development, improve reproductive health, enhance the lives of children and adolescents, and optimize abilities for all" (NICHD, 2019).

Data Repositories for Enabling Sharing and Reuse

The NICHD has helped establish multiple data repositories that are designed to make data relevant to disability research accessible to the public. They include NICHD's Data and Specimen Hub (DASH), which facilitates data sharing and access to biospecimens for NICHD clinical and population health research, and the INCLUDE Data Hub, a centralized NIH-wide data resource that shares large-scale clinical and multi-omics datasets specific to Down syndrome.

NICHD Data and Specimen Hub (DASH)

The NICHD DASH is an NICHD-funded controlled access data repository established to facilitate data sharing and access to biospecimens for all NICHD clinical research. Researchers funded by or seeking funding from NICHD for clinical and population health research are expected to share data in DASH. Researchers seeking funding from another NIH Institute or Center in a research area relevant to the NICHD mission may also be able to share data through DASH.

INCLUDE Data Hub

The INCLUDE Project is an NIH-wide collaboration that seeks to improve health and quality of life for people with Down syndrome. The INCLUDE Project Data Coordinating Center and partners created the *INCLUDE Data Hub*, a centralized data resource that allows access to large-scale clinical and multi-omics datasets specific to Down syndrome and supports collaborative, cloud-based analysis to accelerate scientific discoveries related to Down syndrome and its co-occurring conditions.

Population Dynamics Branch

The Population Dynamics Branch supports research, data collection, and research training in demography, reproductive health, and population health, including the role of disability. Data collection supported by the Population Dynamics Branch is housed in the *Data Sharing for Demographic Research* archives and the Inter-university Consortium for Political and Social Research at the University of Michigan.

National Center for Medical Rehabilitation Research

The National Center for Medical Rehabilitation Research (NCMRR) was established within NICHD after the passage of the Americans with Disabilities Act and the subsequent Public Law 101-613, NIH Amendments of 1990. The NCMRR seeks to build scientific knowledge to "enhance the health, productivity, independence, and quality of life of people with physical disabilities" (NCMRR, 2021). It supports medical rehabilitation research through grants, training and career development activities, small business and technology grants, and research infrastructure.

Medical Rehabilitation Research Resource Network

The Medical Rehabilitation Research Resource Network (MR3 Network) is made up of six Rehabilitation Research Resource Centers across the nation that provide infrastructure and access to expertise, technologies, and resources to develop medical rehabilitation research. The MR3 Network is supported by NCMRR, the National Institute of Neurological Disorders and Stroke, the National Institute of Biomedical Imaging and Bioengineering, the NIDCD, the National Center for Complementary and Integrative Health, and the National Institute for Nursing Research.

Center for Large Data Research and Data Sharing in Rehabilitation (2010–2022)

The Center for Large Data Research and Data Sharing in Rehabilitation (CLDR) was a previously funded MR3 Network resource center. Its mission was to "build rehabilitation research capacity by increasing the number of investigators conducting rehabilitation and disability outcomes research using large administrative and research datasets" (CLDR, n.d.). This CLDR also conducted important work related to data sharing and archiving information from completed rehabilitation research studies. The CLDR website hosts a variety of useful tools and resources related to disability data, including webinars, a dataset directory, data source user guides, disability status reports, and a disability statistics interactive search tool.

National Center on Deafness and Other Communication Disorders

The NIDCD at NIH "conducts and supports research in the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language" (NIDCD, n.d.). The NIDCD's *Statistics and Epidemiology* page includes statistics, charts and tables, and descriptive explanations of the data for hearing, ear infections, and deafness; taste and smell; and voice, speech, and language.

National Institute of Mental Health

The NIMH aims to understand the scope of mental illnesses and their treatments. The NIMH site has current statistics on the prevalence, treatment, and costs of mental illnesses and disabilities for people in the United States. Additionally, NIMH provides information about potential consequences of mental illness, including suicide and disability. Statistics are sorted and displayed by mental health category.

OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION

The ODPHP in HHS was created in 1976 and assists with setting the nation's public health objectives, programs, services, and education activities to improve the health of all Americans (ODPHP, 2020). The ODPHP hosts information about the Healthy People initiative, discussed below.

Healthy People Initiative

The Healthy People initiative began in 1979 to address the nation's public health priorities. Its goal is to help individuals, organizations, and communities improve overall health and well-being. Progress of this initiative is tracked by the CDC's NCHS, which uses over 80 different data sources to track progress (NCHS, 2020).

Healthy People 2020

One of the key findings from the Healthy People 2020 initiative focused on disability data collection, recognizing that it is important to inform policy and program development (ODPHP, n.d.). Healthy People 2020 recommends improving the reliability of disability data by creating standardized questions about disabilities, in the same manner that many federal data collection initiatives have adopted the ACS six questions on disability.

Healthy People 2030

Objective DH-R01 of Healthy People 2030 addresses increasing the proportion of national surveys that include questions to identify people with disabilities. This objective is identified as a "high-priority public health issue." Healthy People 2030 maintains a list of its data sources, all meeting rigorous criteria.

The following are some examples of **Healthy People 2030** data sources specific to disability:

- Residential Information Systems Project Annual Survey of State Developmental Disabilities Agencies
- IDEA Data
- TBIMS National Database

OFFICE OF MINORITY HEALTH

The OMH aims to improve the health of racial and ethnic minority populations through the development of health policies and programs that will help eliminate health disparities. It hosts a webpage *on Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability* that provides the rationale for standards on disability data collection.

OFFICE OF THE ASSISTANT SECRETARY FOR PLANNING AND EVALUATION

The **ASPE** office advises the secretary of HHS on policy development in health, disability, human services, data, and science and provides advice and analysis on economic policy. This office has longstanding work in the area of disability data and statistics, as it identified this topic as an area for further development and improvement in 1995 when it released a **research agenda on disability data**. In 2011, ASPE published **guidelines on disability data collection,** recommending the use of the six disability questions in the ACS. Also in 2011, ASPE released ***Disability Data in National Surveys,*** which provides a review of 40 national surveys that collect data on disability and provides potential uses for each survey in disability research.

Public Workshops on Building Data Capacity for PCOR

In 2021, ASPE sponsored a series of three workshops for the Committee on Building Data Capacity for Patient-Centered Outcomes Research: An Agenda for 2021 to 2030. These workshops brought together stakeholders to examine data needs, discuss the ability of the PCOR data infrastructure to meet those needs, and identify future priorities.

- Workshop 1 - *Looking Ahead at Data Needs*
- Workshop 2 - *Data Standards, Methods, and Policy*
- Workshop 3 - *A Comprehensive Ecosystem for PCOR*

More recently, ASPE released a **2021 report on health insurance coverage among adults with disabilities**. It also released an **issue brief on COVID-19 data on individuals with IDD**, which provides an overview of current local, state, and federal data collection efforts on COVID-19 on individuals with IDD and opportunities to improve these efforts. Two other recent papers describe improvements to disability data collection in patient-centered outcomes research (PCOR) for people with IDD: ***Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities and Considerations for Building Federal Data Capacity for Patient-Centered Outcomes Research Related to Intellectual and Developmental Disabilities***.

Dataset on IDD: Linking Data to Enhance Person-Centered Outcomes Research

This pilot project from ASPE's **Office of Behavioral Health, Disability, and Aging Policy** *f*ocuses on building capacity for person-centered outcomes research on IDD through developing a publicly accessible, de-identified, linked dataset of IDD-relevant state-level data. This project will link the National Core Indicators In-Person Survey, Supports Intensity Scale, Medicaid claims, and other relevant state-level data sources for between four to six states. Doing so will allow disability researchers to examine the relationships between sociodemographic information, need for home- and community-based services, service utilization and expenditures, and person-centered outcomes both before and during the COVID-19 pandemic for this population.

According to ASPE, despite investments in services and supports for this population, "data infrastructure issues limit the ability of researchers to conduct person-centered outcomes research, which limits implementation of evidence-based person-centered practices, programs, and policies" supporting people with IDD. This difficulty also significantly impacts the ability of people with IDD and their families to choose services and supports that match their desired outcomes and goals. Read more about this project on **ASPE's website**.

Office of the Secretary – Patient Centered Outcomes Research Trust Fund Product Library

The OS-PCORTF provides funding for projects that support a wide array of products and services that promote and facilitate developing federal data capacity for PCOR. The OS-PCORTF Product Library hosts all of the products produced by OS-PCORTF projects, including databases and datasets, data elements and information models, health information technology standards, tools and guides, software and analytic services, data governance products, publications, project reports and briefs, vignettes, project spotlights, portfolio reports, and annual and evaluation reports. This library is publicly available as resource for disability researchers.

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

The Substance Abuse and Mental Health Services Administration (SAMHSA) is an agency within HHS that focuses on the behavioral health of the nation. The mission of SAMHSA is “to reduce the impact of substance abuse and mental illness on America’s communities” (SAMHSA, 2022).

Center for Behavioral Health Statistics and Quality

The SAMHSA data and dissemination website provides users with access to reports and data tables, descriptions of what data SAMHSA collects, program evaluations, and quick statistics. The site also offers users the ability to search SAMHSA data or to select a category. In addition, users can find access to state data, analysis tools, and public use files.

The Substance Abuse and Mental Health Data Archive, also hosted by SAMHSA, is designed to provide the public with information on the collection, analysis, and dissemination of SAMHSA’s behavioral health data, including access to datasets for analyses. In addition to data files, the site offers access to codebooks, questionnaires, and a searchable database of bibliographic citations.

U.S. Department of Housing and Urban Development

As the federal executive branch agency that oversees housing and community development assistance programs, HUD strives to promote strong, sustainable, inclusive communities and quality affordable homes for all (HUD, 2022). The department engages in a wide range of housing- and development-related activities, including managing rental assistance programs, conducting housing research, maintaining housing datasets, and facilitating community planning efforts.

A PICTURE OF DISABILITY AND DESIGNATED HOUSING

In 2015, HUD published ***A Picture of Disability and Designated Housing***, a study that uses HUD administrative data, 2009–2013 ACS data, and 2008–2010 Comprehensive Housing Affordability Strategy data to present an overview of households with disabilities and their HUD-assisted housing. Additionally, this study presents policy recommendations, including proposed changes to HUD's administrative data collection on disability to aid in future analyses.

AMERICAN HOUSING SURVEY

The **American Housing Survey** is the most comprehensive national housing survey in the country and is sponsored by HUD and conducted by the U.S. Census Bureau. This survey collects data on disability status.

HOUSING CHOICE VOUCHER DATA DASHBOARD

The ***Housing Choice Voucher Data Dashboard,*** hosted by HUD and available to the public, shows budget and leasing trends, reserve balances, program admissions and attrition, per-unit cost and leasing potential nationally and also at the state and Public Housing Authority level.

United States Department of Justice

The DOJ is the federal executive agency responsible for enforcing the law and defending the interests of the United States based upon the law (DOJ, n.d.). A comprehensive list of DOJ statistics across all topic areas is available on the DOJ website.

BUREAU OF JUSTICE STATISTICS

The BJS is a primary federal statistical agency that focuses on the collection, analysis, publication, and dissemination of information related to crime, criminal offenders, victims of crime, and the operation of justice systems at all levels of government (BJS, n.d.). The BJS website hosts a variety of information on criminal justice statistics, including data analysis tools, information about the data collection process, and publications. Users can search the data by topic or by keyword. Disability is not featured as a topic or variable users can sort by; however, the BJS has recently released two key data products related to disability statistics in the criminal justice system. The first product, ***Disabilities Reported by Prisoners***, is a series of statistical tables using self-reported data from the 2016 Survey of Prison Inmates. These tables highlight the prevalence and types of disabilities that prison inmates reported by demographic groups. The second main product related to disability, ***Crime Against Persons with Disabilities, 2009–2019***, is a series of statistical tables using data from the National Crime Victimization Survey to provide an overview of the prevalence of crime against people with disabilities.

U.S. Department of Labor

The DOL is a federal executive agency that oversees federal labor laws. This responsibility encompasses issues related to occupational health and safety, wage and pay standards, unemployment insurance, economic statistics, and protection from employment discrimination. The mission of DOL is to "foster, promote, and develop the welfare of the wage earners, job seekers, and retirees of the United States; improve working conditions; advance opportunities for profitable employment; and assure work-related benefits and rights" (DOL, n.d.). The department hosts a webpage on disability statistics resources across the department.

BUREAU OF LABOR STATISTICS

The BLS within DOL is the primary federal fact-finding agency in the field of labor economics and statistics. The Census Bureau and BLS jointly sponsor the CPS, the federal government's source of comprehensive statistics on labor force participation, employment, and unemployment. The CPS uses the six questions developed in the Census Bureau's ACS to identify people with disabilities. To find additional information on the disability statistics BLS collects, visit the BLS webpage on disability statistics that provides disability data charts, news releases, tables, and frequently asked questions. Additionally, BLS hosts a Demographic Data Sources Comparison Matrix which can help users identify which data sources to go to for specific demographic characteristics.

OFFICE OF DISABILITY EMPLOYMENT POLICY

The ODEP within DOL promotes policies that foster increased employment opportunities and success for people with disabilities. It accomplishes this mission by coordinating with employers and various levels of the government to increase the use of effective practices and policy to encourage the employment and retention of people with disabilities. This agency offers effective strategies, policy information, and technical assistance for all types of employers.

Recognizing that accurate and complete data are essential to creating change, ODEP hosts a Disability Employment Statistics web page that offers a variety of publicly available resources to promote the use of disability data and statistics to improve employment outcomes for people with disabilities. In 2019, ODEP released the report *Improving Access to Data for Disability-Related Research*. This report details research that was conducted to improve access to data to facilitate research on Stay-at-Work/Return-to-Work topics across four major social insurance disability programs: Workers' Compensation, Temporary Disability Insurance, Paid Family Leave, and SSDI. The report offers recommendations on three main options for developing data sharing agreements and provides information on the feasibility of a web-based resource that will house this data in a format accessible to researchers.

U.S. Department of Transportation

The DOT is a federal executive agency that coordinates safe, efficient, and modern transportation across the United States. It aims to ensure that the nation's transportation system helps improve economic productivity and global competitiveness, enhancing life for all citizens in both rural and urban areas (DOT, 2022).

BUREAU OF TRANSPORTATION STATISTICS

The BTS within DOT organizes, analyses, and distributes transportation statistics collected across the agency. The BTS website hosts a variety of statistical and data products and offers the ability to search data by topic, geographic region, or mode of transportation. The *BTS Data Inventory* page allows users to search all data BTS collects.

The NHTS, conducted by the Federal Highway Administration, provides data on household travel behavior across the country. The NHTS is the primary federal source on the travel behavior of the American public and allows public access to the data to analyze trends in personal and household travel. Its latest version was administered in 2017. This survey determines disability status by asking respondents if they have "a temporary or permanent condition or handicap that makes it difficult to travel outside of the home." Follow-up questions included in the NHTS ask about mobility devices and ways the disability affects travel. Therefore, this survey captures only individuals who have "travel-limiting" disabilities. The *Travel Patterns of American Adults with Disabilities* report presents important key findings related to travel patterns for people with disabilities and provides recommendations for how technological advances can help people with travel-limiting disabilities.

U.S. Department of Veterans Affairs

The VA is a federal executive agency responsible for administering benefits and services earned by veterans of the U.S. military. The VA operates in four main areas: veteran health care; veteran benefits administration; national cemeteries; and preparation for war, emergencies, and disasters (VA, 2021). Because the department serves veterans, many of whom experience injury leading to disability, the VA collects data related to disability experienced by veterans.

The VA hosts an *Open Data Portal* where users can search by keyword. When users search for "disability," they find data and statistics regarding topics such as service-connected disability, disability pension benefits, housing for disabled veterans, and a variety of other topic areas.

U.S. Environmental Protection Agency

The EPA's mission is to protect human health and the environment. The EPA's report *America's Children and the Environment* synthesizes data on children's environmental health from many different national indicators and related information. It provides detailed information on childhood cancer, adverse birth outcomes, respiratory diseases, and other health related topics.

Recommendations From the Field for Next Steps

Collecting and Using Data on Disability to Inform Inclusive Development

A practice note developed by Plan International Australia and CBM Australia-Nossal Institute Partnership for Disability Inclusive Development, *Collecting and using data on disability to inform inclusive development*, provides information on the collection and use of data for disability inclusion. This report provides the following recommendations to ensure data collection methods are disability inclusive:

- Collect data that will inform inclusive practice.
- Use mixed methods to collect data from diverse stakeholders.
- Disaggregate all data at a minimum by sex, age, and disability to allow comparisons and reflect the diverse experiences of disability.
- Use questions on functioning (such as the WG-SS) to identify people with disabilities.
- Use existing data, keeping in mind that it may be incomplete or informed by a particular approach to disability.
- Conduct both household and individual surveys, ensuring surveys ask questions that reveal the different experiences and situations of each individual within the household.
- Use interviews, discussions, and participatory methods to draw out more detailed qualitative information about situations, experiences, and views of people with disabilities.

- Consider child-friendly and participatory data collection methods when collecting data related to children with disabilities.

Health Equity Framework for People with Disabilities

In February 2022, the NCD released the *Health Equity Framework for People with Disabilities*. This framework calls for "improving data collection concerning health care for people with disabilities across the lifespan," including ensuring that indicators of disability status are included in all public health surveillance systems, Medicare and Medicaid data, and the National Health Interview Surveys so that the impact of public health threats or events on people with disabilities can be adequately examined. The NCD recommends that data should be captured "across individuals' lifespans and be inclusive of all ages and times of onset of disability." In the report, the NCD also calls for the National Academies of Science, Engineering, and Medicine to "conduct a comprehensive study and report of HHS's data collection systems and practices, and any data collection or reporting systems required under any of the programs or activities of HHS, relating to the collection of data on disability."

National Disability Status and Program Performance Indicators

In 2008, the NCD released the report *Keeping Track: National Disability Status and Program Performance Indicators*, which outlines a proposed set of statistical indicators to measure the status of working-age adults with disabilities to compare them to working-age adults without disabilities. The report proposes a total of 18 indicators for monitoring by the NCD that were determined by stakeholders to measure "quality of life," spanning the domains of employment, education, health status and health care, financial status and security, leisure and recreation, personal relationships, and crime and safety.

These 18 indicators identified for NCD monitoring are as follows:

Employment

- Indicator 1: Employment rate
- Indicator 2: Employment rate by educational attainment
- Indicator 3: Median annual labor earnings of full-time/full-year workers
- Indicator 4: Median annual labor earnings of full-time/full-year workers by educational status

Education

- Indicator 5: Education less than a high school diploma
- Indicator 6: Education of at least a college degree

Health status and health care

- Indicator 7: Obesity
- Indicator 8: Smoking
- Indicator 9: Health insurance status
- Indicator 10: Failure to get needed care because of cost, by poverty status
- Indicator 11: Doctors or other health providers always show respect for what the patient has to say

Financial status and security

- Indicator 12: Median household income
- Indicator 13: Poverty status

Leisure and recreation

- Indicator 14: Participation in leisure time physical activity

Personal relationships

- Indicator 15: Social and emotional support always available
- Indicator 16: Marital status

Crime and safety

- Indicator 17: Violent crimes per 1,000 people
- Indicator 18: Property crimes per 1,000 people

While these indicators were developed for the purposes of monitoring from NCD, they also may be useful to other federal agencies working to make improvements in the collection of federal data on disability.

This report provided the following key recommendations as well:

- The NCD recommended that NIDILRR (NIDRR at the time) establish and fund a coalition of disability policy makers and advocates to develop a fuller set of indicators that are important to people with disabilities, building on the indicators outlined in the report, and to ensure that disability is included as a subgroup characteristic as the Key National Indicators Initiative is developed.
- A standard set of disability questions should be promoted.
- Disability data should be fully disseminated.
- Administrative records of all means-tested programs should include a disability indicator.
- The Job Training Common Indicators should be expanded.
- Agencies should consider the effects of programs on nonparticipants.

While this report was developed over a decade ago, and progress has been initiated in some of these areas, many of these recommendations are still relevant for priority areas of focus for federal agencies to help move the field of disability statistics forward.

Recommendations for Federal Agencies and the Disability Community to Improve Representation of People with Disabilities in Federal Data

A 2021 report from the NDRN, *Count Everyone, Include Everyone: The Need for Disability Inclusion and Representation in Federal Data*, provides several important recommendations for the disability community and federal agencies to drive improvements in data collection and statistics about people with disability. The recommendations are presented in this order:

1. The NDRN recommends that federal agencies focus on enhanced engagement and equitable access. To facilitate enhanced engagement, federal agencies that collect data should consider
    - providing greater transparency with how data are used and why they are collected (including plain language materials explaining this), and
    - ensuring someone from the disability community is present when discussions are being held related to data collection, methods, outreach, and engagement. (Accuracy, fairness, and accessibility should always be considered.)
2. To work toward equitable access in federal data, federal agencies should consider developing surveys and corresponding materials in various formats and methods of response to encourage full participation by every community.

The NDRN also provides recommendations for how the disability community can assist with improving federal disability data. The disability community can help engage in these improvements through community conversations, participation in the U.S. Census Bureau's NAC and providing public comment, and participation in federal surveys.

3. The disability community should consider participating in community conversations to determine
    - what further data needs to be examined or collected,
    - when aggregated versus disaggregated data are necessary, and
    - who the appropriate collector of the data should be to minimize fear or confusion from participants.
4. The NDRN has participated in the Census Bureau's NAC and encourages other members of the disability community to do the same. Members of the disability community can attend the committee's meetings, held twice each year, to offer public comment and discuss the needs of people with disabilities.
5. Lastly, NDRN recommends that the disability community continue to regularly participate in federal surveys whenever possible, to ensure better representation for people with disabilities.

Resources from the Field

The following include both federal and nonfederal resources related to disability data and statistics to encourage collaboration among federal agency staff, researchers, private organizations, providers, and people with disabilities and those supporting them. The resources are organized by type and include datasets and data tools; organizations; reports, brochures, and research papers; toolkits and compendiums; and webinars.

Datasets and Data Tools

Home of the U.S. government's open data: Data.gov
The website Data.gov, hosted by the U.S. General Services Administration, is the federal hub for government data that is publicly available in open, machine-readable formats. This site hosts data, tools, and resources to conduct research, develop web applications, and design data visualizations.
https://data.gov/

Data for Equity
The Census Bureau is committed to producing data that depict an accurate portrait of America, including its underserved communities. This website provides information about data equity services at the Census Bureau.
https://www.census.gov/about/what/data-equity.html

Directory of HHS Data Resources
The Directory of HHS Data Resources site, with information on all major data collection systems across HHS, was developed with the support of the HHS Data Council.

This directory includes information about each data system, including links to corresponding websites. It is a tool designed for policymakers, administrators, researchers, and the public to be able to access and reference data and statistical resources within HHS.
https://aspe.hhs.gov/collaborations-committees-advisory-groups/hhs-data/hhs-data-council-introduction/dc-archive/directory-health-human-services-data-resources

National Core Indicators®
The National Core Indicators® collects voluntary data from public developmental disabilities agencies to measure and track their performance across several areas, including employment, rights, service planning, community inclusion, choice, and health and safety. The National Core Indicators® hosts state profiles, a chart generator, survey reports, and a variety of other resources.
http://www.nationalcoreindicators.org/

Rehabilitation Dataset Directory
The CLDR also hosts a Rehabilitation Dataset Directory that allows users to search for secondary data on rehabilitation. The search results include a link to a summary dataset description as well as a link to the dataset's primary website. Users can also choose to filter by criteria or browse the included datasets directly.
https://datasetdirectory.disabilitystatistics.org/

State of the States in Intellectual and Developmental Disabilities
The State of the States in IDD is a comparative nationwide longitudinal study that surveys the public financial commitments and programmatic trends across IDD services and supports. This site hosts a variety of tools, including a quick data tool, a chart creator, and state profiles. Additionally, it offers data briefs, reports, and presentations.
https://stateofthestates.ku.edu/

State Data Information on StateData.info Website

The Institute for Community Inclusion hosts StateData.info, a website that collects data from state intellectual and developmental disability agencies, the vocational rehabilitation system, and other agencies (such as SSA, the U.S. Census Bureau, and DOL) on trends in day and employment services for individuals with IDD. Users can build charts, select state snapshots, and download reports and publications.
https://www.statedata.info/

The Disability Data Portal

The Disability Data Portal is a repository for quality quantitative and qualitative data that is globally available. It presents a snapshot of quantitative data from across 79 different national data sources under 16 key development indicators drawn from the United Nations' Sustainable Development Goals framework. The site also hosts qualitative data collected by people with disabilities themselves.
https://www.disabilitydataportal.com/

United Nations Disability Statistics Database

The United Nations Disability Statistics Database hosts a comprehensive international repository of disability statistics. The data and metadata are collected from national population and housing censuses, household surveys, and administrative data. Users can sort the data by country and topic area.
https://unstats.un.org/unsd/demographic-social/sconcerns/disability/statistics/#!/home

Organizations

Center for Large Data Research and Data Sharing in Rehabilitation
The CLDR is funded by NIH and aims "to build rehabilitation research capacity by increasing the number of investigators conducting rehabilitation and disability outcomes research using large administrative and research datasets." The Center is run by a consortium of investigators across several universities, including the University of Texas Medical Branch, Colorado State University, Cornell University, and the University of Michigan. https://www.utmb.edu/cldr

Disability Data Initiative
The Disability Data Initiative is a collaboration of Fordham University, the World Bank, and Wellspring Philanthropic Fund that "provides analyses of disability data to help advance the rights of persons with disabilities and sustainable human development for all." The Disability Data Initiative website hosts annual ***Disability Data Reports*** that review disability questions in national censuses and surveys and disaggregate wellbeing indicators between women with and without disabilities across 35 countries.
https://disabilitydata.ace.fordham.edu/

International Disability Alliance – Disability Data Advocacy Working Group
The International Disability Alliance is an alliance of various disability networks across the globe to "promote the inclusion of people with disabilities across global efforts to advance human rights and sustainable development." The alliance has a Disability Data Advocacy Working Group that aims to facilitate information exchange, learning and dialogue, sharing of good practices, and collaboration related to disability data collection, disaggregation, and analysis.
https://www.internationaldisabilityalliance.org/content/disability-data-advocacy-working-group

K. Lisa Yang and Hock E. Tan Institute on Employment and Disability

The K. Lisa Yang and Hock E. Tan Institute on Employment and Disability conducts research and provides continuing education and technical assistance on many aspects of disability in the workplace. This institute hosts the site *Disability Statistics*, which provides users with easy access to the most current sources of data and statistics on disability and offers a number of user resources, including disability status reports and a variety of research tools. The institute also partners with a consortium of investigators from several universities on the NIH-funded CLDR.

https://www.yti.cornell.edu/

Washington Group on Disability Statistics

The Washington Group on Disability Statistics was commissioned by the United Nations as a Statistical Commission City Group to address the statistical challenges to collect valid, reliable, and cross-nationally comparable data on disabilities and to develop methods to improve collection of statistics on people with disabilities globally. The major goal of the Washington Group is "the promotion and coordination of international cooperation in generating statistics on disability suitable for censuses and national surveys." The Washington Group website hosts resources for data users, as well as the WG-SS that the group developed.

https://www.washingtongroup-disability.com/

Reports, Brochures, and Research Papers

Collecting Data to Ensure Equity in Payment Policy

As part of a two-phase initiative from the Center for Medicare and Medicaid Innovation and the National Academy of Medicine, this discussion proceedings report from an expert panel highlights several priority areas and themes arising during the meeting that related to collecting data to ensure equity. The discussion highlighted disability as a demographic and invited a speaker to discuss data on disability. https://nam.edu/programs/value-science-driven-health-care/collecting-data-to-ensure-equity-in-payment-policy/#:~:text=%20Collecting%20Data%20to%20Ensure%20Equity%20in%20Payment,for%20Action.%20Throughout%20this%20meeting%2C%20the...%20More%20

Count Everyone, Include Everyone: The Need for Disability Inclusion and Representation in Federal Data

This report from NDRN, the membership organization for the federally mandated Protection and Advocacy systems and the Client Assistance Programs for people with disabilities, uses data analysis tools and research methods to explore how the disability community is represented in federal data. The report examines current limitation in how data is collected, explores alternative statistics and data sources, and outlines gaps that should be addressed and examined in federal population data. https://www.ndrn.org/wp-content/uploads/2021/10/NDRN_Count_Everyone_Include_Everyone_2021.pdf

Improving Disability Data to Understand the Effects of Coronavirus (COVID-19) on People with Different Impairment Types

This publication from the United Kingdom's Office of National Statistics explores strategies that can be used to examine administrative health data to explain the impact of COVID-19 on people with disabilities by impairment type. This article provides an overview of the feasibility of each of these strategies. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/improvingdisabilitydatatounderstandtheeffectsofcoronavirus-covid19onpeoplewithdifferentimpairmenttypes/2022-06-07

In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2018

This report provides information on trends from the Residential Information Systems Project, a longitudinal study of long-term supports and services for people with IDD. It is collected through an annual survey to state IDD agencies and provides data and statistics on the settings in which recipients live, federal and state funding sources, residential setting types and sizes, recipient ages, and expenditures. This report, released in December 2021, provides data from the FY 2018 survey.

https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report?preferredLocale=en-US

Inclusive Statistics: Human Development and Disability Indicators in Low- and Middle-Income Countries

This paper, released by the World Bank, examines indicators for persons and households with disabilities across the globe. It disaggregates human development indicators across disability status from 24 censuses and general household surveys from 21 low- and middle-income countries.

https://documents.worldbank.org/en/publication/documents-reports/documentdetail/398321618325378227/inclusive-statistics-human-development-and-disability-indicators-in-low-and-middle-income-countries

Making Visible the Invisible: Why Disability-Disaggregated Data is Vital to "Leave No-One Behind"

This paper highlights the need for comprehensive, high-quality disability data and argues that data can be easily disaggregated. It uses Leonard Cheshire's Disability Data Portal and the Washington Group Question Sets as examples of this. The paper explains how disaggregated data can lead to improvements in planning and budgeting for services for people with disabilities.

https://www.mdpi.com/2071-1050/11/11/3091/htm

Practice Note: Collecting and Using Data on Disability to Inform Inclusive Development

This practice note from Plan International Australia and the CBM Australia-Nossal Institute Partnership for Disability Inclusive Development draws on practical experiences and learning to contribute to the conversation on how disability data can be collected and used within programs to support inclusive development practice and outcomes. This document contains information on why collecting data on disability is important, how to make the data collection process disability inclusive, and how to plan for data collection within a project or program, and it suggests concrete methods and tools for collecting disability data.
https://www.cbmuk.org.uk/wp-content/uploads/2016/05/plan-cbm-nossal_disability-data-collection-practice-note_july2015_1607.pdf

Producing Disability-Inclusive Data: Why It Matters and What it Takes

This brochure from UNICEF details several of the common challenges in collecting disability data. It provides detailed strategies and goals for moving toward inclusive data collection. https://data.unicef.org/resources/producing-disability-inclusive-data-why-it-matters-and-what-it-takes/

Strengthening Collection and Use of Data on Persons with Disabilities for Inclusive Humanitarian Action

This report is the proceedings from a 2-day workshop of 30 participants from the United Nations, international nongovernmental organizations, and organizations of persons with disabilities. During this workshop, participants reflected on disability data-related initiatives and corresponding challenges. As part of the workshop, participants developed 10 global recommendations to maintain momentum in improving collection and use of disability data.
https://centre.humdata.org/wp-content/uploads/2019/07/DisabilityDataWorkshopReport.pdf

Why Disability Data Matters: Review of Leonard Cheshire's Latest Disability Data and the Disability Data Portal

This report from Leonard Cheshire discusses the importance of ensuring high-quality disability data. It highlights new data from the Disability Data Portal and identifies lingering gaps. Additionally, the report spotlights several key data initiatives and the actions and commitments needed to meet the goals for inclusive and disaggregated data at the Global Disability Summit 2022. Lastly, the report provides several best practices in the field of disability data collection across international development programs. https://leonardcheshire.org/sites/default/files/2022-02/why-disabililty-data-matters-report.pdf

Toolkits and Compendiums

2020 Census Disability Community Toolkit

This toolkit from the Disability Rights Education & Defense Fund provides results from important field research in the Los Angeles and Inland Empire area on reasons that people with disabilities do or do not participate in the Census. This toolkit includes factors to consider in conducting outreach to people with disabilities, communicating aspects to consider, and reaching people with disabilities, and it discusses importance of the Census to the disability community and suggests a variety of resources. https://dredf.org/2020-census-disability-community-toolkit/

2021 Compendium of Disability Data Collection Methods

This compendium, compiled by Mathematica for NIDILRR's StatsRRTC, contains research on the methodological issues associated with collecting data from or about people with disabilities. The 2021 compendium contains 441 references across six categories: disability/impairment time; aging and later-life disability; developmental, intellectual, and cognitive impairments; sensory and communication impairments;

physical impairments; and psychiatric impairments and mental health.
https://www.mathematica.org/publications/2021-compendium-of-disability-data-collection-methods

Disability Data Advocacy Toolkit

This toolkit from the International Disability Alliance, CBM Global Disability Inclusion, and the Stakeholder Group of Persons with Disabilities for Sustainable Development discusses the importance of data collection on disability and provides some basic knowledge on data collection and analysis and use of data for evidence-based advocacy.
https://cbm-global.org/wp-content/uploads/2020/11/DisabilityData_advocacy-toolkit_accessible.pdf

Webinars

Webinars from CLDR

The CLDR offers recordings of webinars on its website on a variety of topics related to disability statistics. Webinars cover topics such as how to find disability and rehabilitation data and repositories and tools for identifying and accessing survey and administrative data.
https://www.utmb.edu/cldr/education-training/online-resources

Disability Data Initiative Webinars

The Disability Data Initiative hosts webinars related to global data collection on disability. This link hosts recordings of past webinars and information about future events. Topics center around working towards a global data system that is inclusive of people with disabilities.https://disabilitydata.ace.fordham.edu/events/events/

Mathematica Webinar on *Ensuring the Data System Used for Public Health Centers Equity and Well-Being*

This webinar recording is a virtual discussion of experts who are leading efforts to reimagine public health data in the United States with the goal of becoming more effective at addressing issues of health equity. Speakers presented a range of perspectives across the sectors of philanthropy, local public health agencies, technology, and community-based organizations. This link also includes access to several resources related to improving public health data.

https://www.mathematica.org/events/ensuring-the-data-system-used-for-public-health-centers-equity-and-well-being?utm_source=acoustic&utm_medium=email&utm_campaign=equity&utm_content=Post%20Event%20Public%20Health%20Data%20Equity%20060122%20(1)

nTIDE Monthly Webinar Series

Hosted by the Center for Research on Disability at the University of New Hampshire, the national Trends in Disability Employment (nTIDE) webinars present on data found in the BLS jobs report to discuss the latest statistics and news regarding disability employment. The webinars feature expert panelists in the field who discuss current topics, findings, and events related to disability employment statistics.

https://www.researchondisability.org/ntide

The Washington Group on Disability Statistics Online Trainings and Webinars

This link includes access to several of the Washington Group on Disability Statistics videos, online trainings, and webinars. These resources describe the Washington Group on Disability Statistics and its approach to disability measurement.

https://www.washingtongroup-disability.com/resources/online-trainings-and-webinars/

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Appendix: Abbreviations

ACF	Administration for Children & Families
ACL	Administration for Community Living
ACS	American Community Survey
ADA PARC	Americans with Disabilities Act Participation Action Research Consortium
ADDM	Autism and Developmental Disabilities Monitoring
AHRQ	Agency for Healthcare Research and Quality
ASD	Autism Spectrum Disorder
ASPE	Office of the Assistant Secretary for Planning and Evaluation
BHDAP	Behavioral Health, Disability, and Aging Policy
BJS	Bureau of Justice Statistics
BLS	Bureau of Labor Statistics
BMS	Burn Model System
BRFSS	Behavioral Risk Factor Surveillance System
BTS	Bureau of Transportation Statistics
CCW	Chronic Conditions Data Warehouse
CDC	Centers for Disease Control and Prevention
CLDR	Center for Large Data Research and Data Sharing in Rehabilitation
CMS	Centers for Medicare & Medicaid Services
COVID-19	Coronavirus disease 2019
CPS	Current Population Survey

DAF	Disability Analysis File
DASH	Data and Specimen Hub
DHDS	Disability and Health Data System
DOC	Department of Commerce
DOJ	Department of Justice
DOL	Department of Labor
DOT	Department of Transportation
ED	Department of Education
EEO	Equal Employment Opportunity
EPA	Environmental Protection Agency
FY	Fiscal year
HHS	Department of Health and Human Services
HRSA	Human Resources and Services Administration
HUD	Department of Housing and Urban Development
ICDR	Interagency Committee on Disability Research
IDD and I/DD	Intellectual and developmental disabilities
IDEA	Individuals with Disabilities Education Act
INCLUDE	INvestigation of Co-occurring conditions across the Lifespan to Understand Down Syndrome
ISDS	Interagency Subcommittee on Disability Statistics
MCBS	Medicare Current Beneficiary Survey
MEPS	Medical Expenditure Panel Survey
MR3 Network	Medical Rehabilitation Research Resource Network
NAC	National Advisory Committee

NBS	National Beneficiary Survey
NCD	National Council on Disability
NCES	National Center for Education Statistics
NCHS	National Center for Health Statistics
NCMRR	National Center for Medical Rehabilitation Research
NDRN	National Disability Rights Network
NDSC	National Data and Statistical Center
NHIS	National Early Health Interview Survey
NHQDR	National Healthcare Quality and Disparities Report
NHTS	National Household Travel Survey
NICHD	National Institute of Child Health and Human Development
NIDCD	National Institute on Deafness and Other Communication Disorders
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NSCF	National Survey of SSI Children and Families
NSCH	National Survey of Children’s Health
NSCISC	National Spinal Cord Injury Statistical Center
NSF	National Science Foundation
NSHD	National Survey on Health and Disability
ODEP	Office of Disability Employment Policy
ODPHP	Office of Disease Prevention and Health Promotion
OMH	Office of Minority Health

OS-PCORTF	Office of the Secretary Patient-Centered Outcomes Research Trust Fund
PCOR	Patience-centered outcomes research
RSA	Rehabilitation Services Administration
SAMHSA	Substance Abuse and Mental Health Services Administration
SCIMS	Spinal Cord Injury Model Systems
SDS	Subcommittee on Disability Statistics
SIPP	Survey of Income and Program Participation
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
StatsRRTC	Rehabilitation Research and Training Center on Disability Statistics and Demographics
TBIMS	Traumatic Brain Injury Model Systems
TBINDC	Traumatic Brain Injury Model Systems National Data and Statistical Center
USAID	United States Agency for International Development
VA	Department of Veterans Affairs
VR	Vocational rehabilitation
WG-SS	Washington Group Short Set on Functioning
WIOA	Workplace Innovation and Opportunity Act