# Interagency Committee on Disability Research (ICDR) State of the Science Conference on Disability Statistics

# February 9 and 10, 2023

# Key Findings



## Abbreviations

| ACS | American Community Survey |
| --- | --- |
| ASPE | Office of the Assistant Secretary for Planning and Evaluation |
| BMS | Burn Injury Model System |
| CMS | Centers for Medicare & Medicaid Services |
| CRN | Clinical research network |
| DHDS | Disability and Health Data System |
| HUD | U.S. Department of Housing and Urban Development |
| ICD-10 | International Classification of Diseases, Tenth Revision |
| ICDR | Interagency Committee on Disability Research |
| IDD | Intellectual and developmental disabilities |
| NCBDDD | National Center on Birth Defects and Developmental Disabilities |
| NCHS | National Center for Health Statistics |
| NDSC | National Data and Statistical Center |
| NHANES | National Health and Nutrition Examination Survey |
| NHIS | National Health Interview Survey |
| NIDILRR | National Institute on Disability, Independent Living, and Rehabilitation Research |
| NSDUH | National Survey on Drug Use and Health |
| PCORI | Patient-Centered Outcome Research Institute |
| PCORnet | Patient-Centered Clinical Research Network |
| SCI | Spinal cord injury |
| SCIMS | Spinal Cord Injury Model System |
| SOS | State of the science |
| SSDI | Social Security Disability Insurance |
| SSI | Supplemental Security Income |
| TBI | Traumatic brain injury |
| TBIMS | Traumatic Brain Injury Model System |
| WG-SS | Washington Group Short Set |

## Executive Summary

The ICDR State of the Science (SOS) Conference on Disability Statistics, held on February 9 and 10, 2023, brought together a wide variety of stakeholders, including representatives from over 20 federal agencies, over 50 universities, and over 25 state agencies. Across both days of the conference the following themes emerged from the sessions and discussions:

* Linking datasets can expand the scope of research about people with disabilities.
* In this field, balancing the tension between rigor and relevance of research is important.
* Identifying specific subgroups of disability is critical to ensuring all disability groups are represented.
* Including people with disabilities in every step of the research process is necessary, useful, and expected.
* Communicating the limitations of data and using alternative and inclusive strategies to expand the types of stories that are told can inform improved research methods.
* Having data provides power.
* Making data accessible and user-friendly to a wider range of individuals, especially consumers, is critical.

## SOS Day 1

### Session #1: Disability Research Using Linked Data

#### **Using Linked Data to Understand Disparities Experienced by Adults With Disabilities Who Participate in HUD’s Rental Assistance Programs**

*Debra Brucker, Ph.D., University of New Hampshire and Veronica Helms-Garrison, M.P.H., HUD*

Administrative data from the U.S. Department of Housing and Urban Development (HUD) provide details about housing assistance types and participation in HUD’s other programs. National household surveys provide detailed information about disability, health, health care access, and other outcomes of interest. Linking data from HUD-assisted housing programs with other sources of data can provide information to fill research gaps that cannot be addressed by either of the datasets individually.

HUD can leverage any dataset that already exists in the Census environment and link HUD data to it. They hope to expand their data linkage to include information from Federally Qualified Health Centers, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Generally, about 75% of respondents are eligible for linkage, and about 10% of persons who are eligible link, illustrated by [match rate tables available on the Centers for Disease Control and Prevention (CDC) website](https://www.cdc.gov/nchs/data/datalinkage/NCHS-HUD-Match-Rate-Tables-final.pdf). HUD uses identifiers such as name, date of birth, etc., for linkages.

HUD data have been linked with:

* National Health Interview Survey (NHIS)
* National Health and Nutrition Examination Survey (NHANES)
* National Hospital Care Survey
* Medicare and Medicaid Claims Data
* Medicare Advantage enrollee data (with the Office of the Assistant Secretary for Planning and Evaluation [ASPE] in the U.S. Department of Health and Human Services)
* Cancer registry data (with National Institutes of Health, National Cancer Institute)
* National Crime Victimization Survey (with the Bureau of Justice Statistics)
* Current Population Survey and Food Security Supplement (with the U.S. Department of Agriculture, Economic Research Service)

**Example:** In [a 2021 study](https://doi.org/10.1016/j.dhjo.2021.101098), the presenters used linked HUD–Social Security Administration data to examine health and health care disparities for people with disabilities. They found that SSDI and SSI participants had higher predicted probabilities of fair or poor health, chronic conditions, and obesity than others. They also found that engagement with the health care system was high among SSDI/SSI participants, yet 32% needed but could not afford services in the past year.

**Speakers’ Publications Using Linked Data:**

* Brucker, D. L., & Garrison, V. H. (2021). Health disparities among Social Security Disability Insurance and Supplemental Security Income beneficiaries who participate in federal rental housing assistance. *Disability and Health Journal, 14*(1, 101098)*.* [doi: 10.1016/j.dhjo.2021.101098](https://doi.org/10.1016/j.dhjo.2021.101098)
* Brucker, D. L., & Helms, V. (2019). Health, health behaviors, and health care utilization among adults with serious psychological distress who receive federal housing assistance. *Journal of Behavioral Health Services and Research, 46*(4), 586–606.doi: 10.1007/s11414-018-09647-z
* Brucker, D. L., Helms, V. E., & Souza, T. (2017). Health and health care access among adults with disabilities who receive federal housing assistance. *Housing Policy Debate, 28*(2), 248-266*.* doi: 10.1080/10511482.2017.1357048
* Brucker, D. L., Mitra, S., Chaitoo, N., & Mauro, J. (2015). More likely to be poor whatever the measure: Working-age persons with disabilities in the United States. *Social Science Quarterly, 96*(1), 273–296.doi: 10.1111/ssqu.12098
* Souza, M. T., Collinson, R. A., Martin, M., Steffen, B. L., Vandenbrouke, B. K., & Yao, Y.-G.. D. (2011). *2009 worst case housing needs people with disabilities: Supplemental findings of the worst case housing needs 2009: Report to Congress*. U.S. Department of Housing and Urban Development. <https://www.huduser.gov/portal/publications/worstcasedisabilities03_2011.pdf>

#### **Understanding Social Determinants of Health and TBI Outcomes Using Linked TBI Model System and Geospatial Data**

*Kristen Dams-O’Connor, Ph.D., New York Traumatic Brain Injury Model System at Mount Sinai*

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funds the Traumatic Brain Injury Model System (TBIMS), which has maintained a longitudinal database of people with moderate or severe traumatic brain injury (TBI) for the past 35 years. TBIMS grantees have enrolled people into the study at the time of in-patient rehabilitation and followed them over time. This database includes the largest prospective study of TBI outcomes in the world.

A subset of the TBIMS linked the TBIMS longitudinal data to two types of geospatial data: geo-identification variables that align with an address (GeocodeResults) and socioeconomic status variables that align with Census tracts (GeoSESVariables). Both the GeocodeResults and GeoSESVariables datasets include protected health information, but any investigator can request and gain access to a limited dataset.

**Example**: A current project led by the New York TBIMS, *Associations of Early Life Adversity and Neighborhood Environment on TBI Outcomes in the TBIMS National Database*,will develop theory-driven, empirically based indices of early life adversity and current neighborhood environment and then evaluate their associations with 1-year TBI outcomes. This new study’s data linkage will allow NY TBIMS to disentangle the disability outcomes that are attributable to the injury itself from the disability outcomes that are attributable to the built environment. This distinction is important because some aspects of the built environment are modifiable. NY TBIMS places importance on research that shows how modifiable neighborhood characteristics contribute to disability outcomes after injury, and that thereby informs policy and advocacy efforts to improve modifiable neighborhood characteristics.

#### **Assessing Patterns and Correlates of Mental and Behavioral Health Issues Combing Primary and Secondary Datasets**

*Michael Schoenbaum, Ph.D., National Institute of Mental Health*

Several limitations make mental health research more challenging than physical health research. Among them:

* There are no biomarkers for mental health, making identification of those with a mental health condition cumbersome and raising concerns about the accuracy or validity of the data.
* Mental disorders cannot be listed as the principal cause of death. Therefore, to study mortality associated with mental illness, one needs to study mortality among people with mental illness or in relation to relevant index events, such as emergency department visits or hospitalizations.

There are opportunities to make improvements, especially with respect to tracking survival as an outcome for people with mental health concerns, including psychiatric disability.

Mental health or psychiatric disability is not considered a life-threatening condition, but information for tracking these outcomes should be monitored regularly and routinely. Data needed to track this type of information already exists; the issue is updating policies to make linking data easier.

**Example**: Dr. Schoenbaum and his team linked California emergency department data to California mortality data. They found that, compared to the general population of Californians with similar demographics, Californians who come to the emergency department for a suicide attempt are 56 times as likely to die by suicide in the subsequent year, 16 times as likely to die by accident, and four times as likely to be murdered.

**Speaker’s Publications Using Linked Data:**

* Harvey, P. D., Heaton, R. K., Carpenter, W. T., Jr., Green, M. F., Gold, J. M., & Schoenbaum, M. (2012). Functional impairment in people with schizophrenia: focus on employability and eligibility for disability compensation. *Schizophrenia Research, 140*(1–3), 1–8. <https://pubmed.ncbi.nlm.nih.gov/22503642/>
* Schoenbaum, M., Sutherland, J. M., Chappel, A., Azrin, S., Goldstein, A. B., Rupp, A., & Heinssen, R. K. (2017). Twelve-month health care use and mortality in commercially insured young people with incident psychosis in the United States. *Schizophrenia Bulletin, 43*(6), 1262–1272. <https://pubmed.ncbi.nlm.nih.gov/28398566/>
* Goldman-Mellor, S., Olfson, M., Lidon-Moyano, C., & Schoenbaum, M. (2019). Association of suicide and other mortality with emergency department presentation *JAMA Network Open, 2*(12), e1917571. <https://pubmed.ncbi.nlm.nih.gov/31834399/>
* Ivey-Stephenson, A. Z., Demissie, Z., Crosby, A. E., Stone, D. M., Gaylor, E., Wilkins, N., Lowry, R., & Brown, M. (2020). Suicidal ideation and behaviors amond high school students — Youth Risk Behavior Survey, United States, 2019. *Morbidity and Mortality Weekly Report Supplement 69*(1),47–55. <https://www.cdc.gov/mmwr/volumes/69/su/su6901a6.htm?s_cid=su6901a6_w>

## Session #2: Data Limitations and Rural Disability Disparity

### Data Limitations and Rural Disability Disparity

*Catherine Ipsen, Ph.D., Lillie Greiman, M.A., and Andrew Myers, M.A., Rural Institute on Disability at the University of Montana*

Rural people are unrepresented or poorly represented in the federal data, so rural residents do not see the data working for them.

Among the challenges with representing rural disability in data:

* People with disabilities in rural areas comprise a small portion of the U.S. population, making the margins of error larger compared to other populations. This situation leads to imperfect prevalence estimates.
* The small size and tightknit nature of rural populations make it easier to identify individuals in rural data than in urban data, violating privacy and anonymity.
* Some of the strategies that help protect privacy can hinder the usefulness of data.
* Data collection in rural areas typically consists of few observations over a large region, making it difficult to accurately assess rural disability prevalence and outcomes.

Although the American Community Survey (ACS) data can be analyzed at the county level, doing so for rural areas has several concerns:

* Rural geographies require 5 years of data for estimates, compared to more populated geographies that can be accessed in 1-year data profiles.
* ACS profiles lack information on outcomes for multiply marginalized groups. For example, people can refer to ACS to find information about female prevalence rates but not across different sociodemographic categories, such as being Black and having a disability.
* ACS compares rates across geography rather than weighting by population, complicating county comparisons.
* Public Use Microdata Areas: When ACS provides person-level files aggregated at 100,000 people within a state, it often merges rural and urban geographies together, interfering with accurate data for comparing the two.
* Any change to the ACS survey, such as a different definition of rural or disability, delays availability of data that must be reported in 5-year estimates, and 10 years for longitudinal comparison.
* Numerous conceptual and operational definitions of rural are used in policies, programs, and surveys, each with its own limitations. Depending on the definition used, rural America is estimated to encompass anywhere from 72% to 97% of the total U.S. landmass and anywhere from 15% to 20% of the total U.S. population. These ranges impact the conclusions that can be accurately drawn.

Some rural classifications are more fine-grained than definitions of the Census Bureau and the Office of Management and Budget—classifications that are more informative when analyzing data based on an urban-to-rural continuum. These classifications include Rural–Urban Continuum Codes, Urban Influence Codes, and Rural–Urban Commuting Area. Participants suggested that having a common set of indicators included with all public use data (such as Rural–Urban Continuum Codes and Urban Influence Codes) would help address the lack of data in rural areas.

## Session #3: Identifying Disability Subgroups Not Identified by Existing Questions on National Surveys

### Who Is Not Being Counted? Respondents With Disabilities Missed by Federal Surveys

*Jean Hall, Ph.D., University of Kansas and Andrew Myers, M.A., Rural Institute on Disability at the University of Montana*

Since the enactment of the Affordable Care Act, most federal surveys use the ACS-6 question set or the Washington Group Short Set (WG-SS). Each of these question sets has limitations. Both sets address functional or activity difficulties but do not identify specific disability types (e.g., intellectual and developmental disability [IDD], mental health). Further, numerous studies have documented that these measure sets undercount some groups and do not differentiate between long-term and transitory disabilities.

Using data from the 2019–2020 administration of the [National Survey on Health and Disability](https://ihdps.ku.edu/nshd) (n = 2,163 adults, ages 18 to 64), the presenters compared respondents’ self-identified disabilities with their responses to the ACS-6 and WG-SS question sets. Many reported disability types did not align with any ACS or WG-SS categories, particularly psychiatric disabilities, autism, chronic pain, or TBI.

One implication of these findings is that many people with disabilities, especially those with mental illness or chronic illness, are missed by ACS-6 and WG-SS measures. As a result, funding for these groups may be inappropriately low, and effects of the pandemic on them may be underestimated. Dr. Hall recommends the addition of specific questions to future federal surveys, including a broad question regarding the presence of a condition affecting life activities, a disability categorization question, and a question to assess age of onset and duration of disability.

### Mental Health Measurement in the National Survey on Drug Use and Health

*P. Mae Cooper, M.P.P., Substance Abuse and Mental Health Services Administration*

The National Survey on Drug Use and Health (NSDUH) is a continuous survey administered by the Substance Abuse and Mental Health Services Administration that covers substance use and mental health in the general population, ages 12 and over. It includes several disability measures, such as the WG-SS, World Health Organization Disability Assessment Schedule, and Kessler Psychological Distress Scale.

* Downloadable public use data (through 2021): <https://www.datafiles.samhsa.gov/node/2>
* NSDUH table creator: <https://pdas.samhsa.gov/>
* Restricted use data at the Research Data Center: <https://www.samhsa.gov/data/data-we-collect/samhsa-rdc>

In 2021, 5,600 respondents, 8% of the those who responded to the NSDUH (n=69,850), reported at least one of the six measured disabilities. Half of the adults with disabilities reported experiencing any mental illness, while one fifth of the people without disabilities reported this. Adults with disabilities were more likely than adults without disabilities to have an illicit drug use disorder (14% vs. 6%). People with communication, self-care, and concentration disabilities were more likely to have an illicit drug use disorder than those with other types of disabilities. Compared to people without disabilities, people with disabilities were more likely to have had major depressive episodes (6% vs. 23%) and more likely to experience serious mental illness (4% vs. 19%).

## SOS Day 2

## Session #4: Current National Disability Statistics Activities

### Disability Data and Activities: National Center for Health Statistics

*Julie Weeks, Ph.D., National Center for Health Statistics*

The National Center for Health Statistics (NCHS) is one of the 13 federal statistical agencies that are part of the executive branch. Three of NCHS’s surveys, the NHANES, the NHIS, and the National Survey of Family Growth, collect disability data using the WG-SS questions. In addition, the NHANES and NHIS include the Washington Group extended set on functioning as well as the Washington Group child functioning modules.

NCHS also conducts a robust data linkage program. Data linkages with NCHS datasets were released in 2022 and include data on veterans from the Department of Veterans Affairs, housing information from HUD, access and utilization data from the Centers for Medicare & Medicaid Services (CMS), and mortality data from the National Vital Statistics Systems. In some cases, these linkages add decades worth of contextual and outcome data. One linkage that may be of particular interest for disability and rehabilitation researchers is the first ever linkage between NCHS survey data and CMS’s Transformed Medicaid Statistics Information System.

NCHS not only collects data but also disseminates statistics and research based on those data. It produces several reports and briefs on a regular basis.

Several current projects at NCHS aim to develop or evaluate new measures:

* NCHS is cognitively testing questions on psychosocial functioning (with the Washington Group).
* NCHS is developing and testing questions that address the barriers and facilitators to education for children with and without disabilities, for use both here and in other countries (with the Washington Group and UNICEF).
* The NCHS cognitive evaluation lab is also working on questions that can be used to identify subpopulations with intellectual or developmental disabilities (with the Administration for Community Living and the National Center on Birth Defects and Developmental Disabilities [NCBDDD]).
* NCHS has an in-house project to evaluate questions and question administration types by quantitative methodologies rather than qualitative methodologies. This project will explore how administering survey items on disability in different formats affects the quality of the data.

### Disability Data & Statistics Activities: Office of the Assistant Secretary for Planning and Evaluation

### *William Marton, Ph.D., ASPE*

Although important strides have been made in collecting disability data in the 30 years since the fielding of the first comprehensive national survey of persons with disabilities, the disability supplement of the 1994–1995 NHIS, these improvements have not addressed the need of policymakers for more specific data, such as linkages to statutory programs or data on specific types of disabilities. With this consideration in mind, ASPE started work to develop a new version of the NHIS disability supplement that will build from the original version’s strengths and weaknesses. For this effort, ASPE strives to enable policymakers, advocates, researchers, and persons with disabilities to understand the prevalence of disability at finer levels, the needs and use of services of different disability subgroups, and the health care and other outcomes of people with disabilities so public programs can better meet their needs.

They have begun to consider survey questions and data collection strategies, with a focus on identifying subgroups of the population that have strong linkage to programs and policy, including people with Alzheimer’s disease and cognitive impairment, adults with IDD, and the interaction between functioning and severe mental illness. They will examine current survey efforts to assess how adequately existing measures identify populations of interest and to assess their sampling frames and data collection efforts more broadly. After initial review by Mathematica Policy Research, they will begin to discuss developing a set of questions. ASPE looks forward to collaborating with federal partners, such as the Administration for Community Living, NCHS, and others, to improve methods for identifying these groups.

### New Directions for Improving Collection, Use, and Interpretation of Disability Data

*Joe Holbrook, Ph.D., M.P.H., Robyn Cree, Ph.D., Qi Cheng, Ph.D., M.P.H., NCBDDD, CDC*

The CDC NCBDDD aims to promote the health of people with, or at risk for, disability across the lifespan. While the scope of their branch’s work is broad, the common ingredient is a focus on disability statistics.

NCBDDD maintains the [Disability and Health Data System (DHDS)](https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html), a web portal that provides vital information needed to better understand the health needs of adults with disabilities at the state and national levels. The DHDS estimates use Behavioral Risk Factor Surveillance System data to update the DHDS data annually. The uniqueness of the DHDS system is that it is focused not only on the data but also on a wide range of health indicators by disability status and types.[[1]](#footnote-1)

NCBDDD conducted a multistate Medicaid project to improve health for people with IDD. This project funded 10 states to analyze Medicaid administrative claims data to identify patterns of health and health care use for adults with IDD. Several publications have resulted from this work. For example:

* Horner-Johnson, W., Lindner, S., Levy, A., Hall, J., Kurth, N., Garcia, E. Frame, A. Phillips, K., Momany, E., Lurie, M., Shin, Y., Lauer, E. Kunte, P., Silverstein, R., Okoro, C., & McDermott, S. (2022). Time trends in emergency department use among adults with intellectual and developmental disabilities. *Disability and Health Journal, 15*(2), 101225. <https://www.sciencedirect.com/science/article/abs/pii/S1936657421001989>
* Lauer, E., Lindgren, S., Momany, E., Cope, T., Royer, J., Cogan, L., McDermott, S., & Armour, B. (2021). Health service utilization patterns among Medicaid-insured adults with intellectual and developmental disabilities: Implications for access needs in outpatient community-based medical services. *Journal of Ambulatory Care Management, 44*(2), 138–147. <https://stacks.cdc.gov/view/cdc/112659>
* McDermott, S., Royer, J., Cope, T., Lindgren, S., Momany, E., Lee, J. C., McDuffie, M. J., Lauer, E., Kurtz, S., & Armour, B. S. (2018). Using Medicaid data to characterize persons with intellectual and developmental disabilities in five U.S. states. *American Journal on Intellectual and Developmental Disabilities, 123*(4), 371–381. <https://www.cdc.gov/ncbddd/disabilityandhealth/features/kf-medicaid-data-disabilities.html>
* Lu, Z., Cogan, L., McDermott, S., Lauer, E., Lindner, S., Tracy, K., & Momay, E. T. (2020). Disparities in diabetes management among Medicaid recipients with intellectual and developmental disabilities (IDD): Evidence from five U.S. states. *Disability and Health Journal, 13*(2), 100880, <https://pubmed.ncbi.nlm.nih.gov/31870791/>

Building on lessons learned from the 10-state Medicaid project, in October 2022 NCBDDD started the Disability and Health Data Collaborative, a 2-year special interest project to develop a research platform to improve access to disability administrative data. This collaborative will establish a framework for states to use these methods within their capacity, procedures, and data use requirements.

NCBDDD funds two national programs on health promotion for people with IDD and mobility limitations: Special Olympics and the National Center of Health, Physical Activity, and Disability. Both national programs work to strengthen data systems to enhance their capacity for program evaluation.

Additionally, NCBDDD is collaborating with the Association of State and Territorial Health Officials to build public health capacity to monitor the health and well-being of people with disabilities before, during, and after public health emergencies. This effort involves developing, testing, and disseminating syndromic surveillance definitions to identify emergency department visits by disability status and type within [CDC's National Syndromic Surveillance Program](https://www.cdc.gov/nssp/partners/Syndromic-Surveillance-Community-Sets-Clinical-Definition-for-Disability.html).

NCBDDD also funds an emergency preparedness and response project with the Council of State and Territorial Epidemiologists. This project involves the development of a standardized, state-level reporting template that jurisdictions can use for capturing and reporting emergency operations data related to the impacts of public health emergencies on people with disabilities. These data can be used to inform public health interventions, reduce morbidity and mortality, and meet the needs of people.

## Session #5: Using NIDILRR Model Systems’ Longitudinal Databases

NIDILRR funds three model systems: the Spinal Cord Injury (SCI) Model System (SCIMS, established in 1970; has 18 centers), the TBIMS (established in 1987; has 17 centers), and the Burn Injury Model System (BMS, established in 1994; has four centers). These model systems conduct research that contributes to evidence-based rehabilitation interventions and clinical impact guidelines that improve the lives of individuals with SCI, TBI, and burn injury. Each of the funded centers conducts at least one center-specific study and participates in at least one multicenter collaborative study. Each of the model systems has a National Data and Statistical Center (NDSC). Each center also collects and submits longitudinal data for inclusion into its national database. All data the model systems collect are publicly available.

### Overview of the Burn Injury Model System National Longitudinal Database: What Is Collected and How to Access the Data

*Dagmar Amtmann, Ph.D., Burn Injury Model System Data and Statistical Center*

The BMS is the only multicenter burn research program in the United States—and, as far as they are aware, in the world—that is dedicated to advancing the long-term recovery of burn survivors. The BMS focuses on the rehabilitation and recovery trajectories of burn injury survivors, and the [BMS NDSC](https://burndata.washington.edu/) tracks how a burn injury is a chronic condition.   
  
The BMS national database is a prospective, longitudinal, multicenter research study that collects data on, and examines functional and psychosocial outcomes following, a burn injury. This database has data on over 4,000 adults and 2,000 children with moderate to severe burn injuries. These data cover a variety of information, including burns of many different etiologies and demographics such as age, sex, pre-injury history of military service, employment, and health conditions. The BMS also collects data on the burn injury characteristics (i.e., size of the burn, burn location, and circumstances of the burn injury), as well as information related to length of stay in the hospital, number of days on a ventilator, and number and nature of burn surgeries. Additionally, the database contains data from standardized measures that assess symptoms such as pain, itch, and sleep, as well as other functional and psychological outcomes (e.g., depression, post-traumatic stress disorder, physical function, and community integration).

Data are collected from self-report and medical records at the time the participant is discharged from the hospital, with follow-up at 6 months, 12 months, and 2 years post injury, and then every 5 years afterwards. All the data collected are available to anyone interested in using the data, for free, and the BMS NDSC provides support to potential data users. See [Access the BMS Data](https://burndata.washington.edu/about-database) for how to request these data.

### Spinal Cord Injury Model Systems National Database

*Yuying Chen, Ph.D., Project Director, SCIMS Data and Statistical Center*

Started in 1970, the SCIMS includes 32 centers across 21 states and the District of Columbia, and 31 centers have contributed to the database. The database is not population based but rather hospital based as they only enroll patients in designated centers. The SCIMS focuses on rehabilitation, following up after initial hospital care at 1 year and 5 year post-injury and then every 5 years until the individual dies, recovers from SCI, or withdraws consent.

As of November 2022, the SCIMS had 6,000 people with SCI enrolled in its database. About one third of those in the database are already deceased, so there is significant opportunity to study the mortality, life expectancy, and cause of death for this population. The database continues to grow by about 1,100 new participants every year.

The SCIMS collects data on variables specific to SCI (i.e., injury characteristics), activities, body functions and structures (e.g., medical complications, physical health conditions), participation (e.g., education, employment), environmental factors (e.g., residence, communication), and personal factors (e.g., background, substance use). The data are geocoded and can also be linked to other datasets. Sources of data include medical record reviews, direct exams, participants’ self-reports (via phone, in-person interview, online, or mail), and death records.

The public use dataset is available for [free download on the SCIMS website](https://www.nscisc.uab.edu/Research/NSCISC_DatabasePublicUse), and currently all the data collected before the last cycle (end of August 2021) are available. There are two versions, the 2021 annual version and the 2016 annual version. Because the variables collected changed over time, there is different information in the two versions.

### The Model Systems National Databases and The Traumatic Brain Injury Model Systems

*Dave Mellick, Ph.D., Co-Director, TBIMS National Data and Statistical Center*

Established in 1987, the TBIMS is the first longitudinal multicenter study ever conducted that examines the course of the recovery and outcomes for people with brain injuries across their lifetime, following the receipt of a coordinated system of acute and inpatient rehabilitation. The study includes large-scale follow-up, up to 30 years post-injury. The TBIMS NDSC also has a contract with the U.S. Department of Veterans Affairs (VA) to follow VA participants who have been admitted to any of five trauma centers.

The TBIMS centers must provide a multidisciplinary system of rehabilitation care specifically designed to meets the needs of individuals with TBI, including emergency medical services at a level I trauma center, acute neural surgical care, comprehensive inpatient rehabilitation services, and long-term interdisciplinary follow-up and rehabilitation services. Requirements for TBIMS centers also include participating in both knowledge generation and knowledge translation. The TBIMS centers must conduct one or two center-specific studies, participate in at least one multicenter (module) study, and collect and submit longitudinal data for inclusion in the national database.

The TBIMS defines brain injury as a traumatic injury, meaning it must have been caused by a mechanical force, as evidenced by lack of consciousness or duration of posttraumatic amnesia or abnormal neurological findings. The TBIMS includes only individuals who have moderate to severe brain injury, were admitted to the hospital’s emergency department within 72 hours after injury, are 16 years and older, receive acute care and comprehensive inpatient rehabilitation within the model systems hospitals, and provide informed consent.

The TBIMS collects two types of information, including Form 1 (inpatient rehabilitation discharge, administered in-person) and Form 2 (follow-up conducted 1, 2, 5, and every 5 years thereafter, administered via phone, in person, or by mail). The TBIMS database consists of over 19,000 people. The TBIMS also collects information on treatment, services received, impairment, disability, and community participation. While they try to collect these data from the primary source, they use proxies when necessary. The [TBIMS National Data and Statistical Center website](http://www.tbindsc.org/) hosts a data dictionary, a PowerPoint presentation about the center that is updated annually, and a list of journal publications.

## Session #6: Late-breaking and Future Activities

### Annual Disability Statistics Collection and Disability Statistics Curriculum

*Andrew Houtenville, Ph.D. University of New Hampshire*

The Rehabilitation Research and Training Center on Disability Statistics (StatsRRTC) has several important disability statistics resources, including the Disability Statistics Curriculum, the Annual Disability Statistics Collection, and various reports.

The Disability Statistics Curriculum is a self-guided curriculum for individuals seeking to learn how to access and analyze disability data; those seeking information about a specific skill or dataset; professors looking for data to support their research ideas or for disability data analysis modules to include in their courses; students looking to propose an independent, for-credit study idea; and anyone interested in learning about disability statistics. The curriculum consists of videos (with closed captioning and transcription), PowerPoint slides, and end-of-module quizzes.

The current modules include Accessibility, Disparities and Program Participation, Disability Measurement and Eligibility Criteria, Models and Concepts of Disability, Available Data Sources, and Accessing Publicly Available Data Sources. Upcoming modules include Software: Importing and Recoding Data, Statistical Significance and Hypothesis Testing, Assessing Accuracy, and Conveying Findings to Others. Each module is independent, so users can choose to focus on specific topics or skills.

The Annual Disability Statistics Collection includes four components:

\* The [Annual Disability Statistics Compendium](https://disabilitycompendium.org/), with data from available federal documents

\* The [Annual Disability Statistics Compendium – Supplement](https://disabilitycompendium.org/sites/default/files/user-uploads/2023_Annual_Disability_Statistics_Supplement_ALL.pdf), which uses public use microdata files to further break down the information

\* The [Annual Disability Statistics Compendium – Standard Errors](https://disabilitycompendium.org/compendium/annual-disability-statistics-standard-errors-companion-2023?page=1), to assist people to generate the margins of error or confidence intervals and t-statistics

\*The [Annual Compendium of Disability Methods](https://www.mathematica.org/publications/2022-compendium-of-disability-data-collection-methods), update of the Annual Compendium methods

The StatsRRTC also produces [annual state reports](https://disabilitycompendium.org/county-reports) with county-level data on prevalence, poverty, and employment and an [Annual Report on People with Disabilities in America](https://disabilitycompendium.org/sites/default/files/user-uploads/Accessible-Annual%20Report%20---%202023%20---%20Accessible.pdf).

### Use of PCORnet® to Inform Research on Intellectual and/or Developmental Disabilities

*Nik Koscielniak, Ph.D., Patient-Centered Outcomes Research Institute*

The mission of the [Patient-Center Outcomes Research Institute](https://www.pcori.org/) (PCORI) is to help people make informed health care decisions and improve health care delivery and outcomes through funding comparative clinical effectiveness research and by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community. One of the ways PCORI supports this work is through funding the [PCORnet](https://pcornet.org/), the National Patient-Centered Clinical Research Network. The purpose of the PCORnet is to harness and harmonize health data from electronic health records, some claims data, patient-reported outcomes, and other sources across many institutions.

The PCORnet includes eight clinical research networks (CRNs) that can help researchers conduct research more efficiently. CRNs serve populations receiving health care within the specified health care delivery systems. Each CRN is composed of two or more health care systems and includes hospitals, Federally Qualified Health Centers, and practice-based networks. ​The CRNs securely collect health information during the routine course of care.

The PCORnet Common Data Model standardizes millions of data points from a variety of clinical information systems (primarily electronic health record data) into an innovative common format that can be used for specified research projects, enabling fast insights. The Common Data Model includes a core set of data elements, research-ready data elements, and data elements that are evolving and undergoing work for research.

The [PCORnet Front Door](https://pcornet.org/front-door/) is the access point for investigators, patient groups, health care organizations, clinicians, government, industry, sponsors, and all stakeholders seeking to leverage the PCORnet infrastructure and collaborate on patient-centered research.

In September 2022, the PCORI board of governors approved the following [crosscutting strategies](https://www.pcori.org/resources/strategies-leverage-pcornetr-advance-pcoris-national-priorities-health-and-evaluate-pcornet-performance):

* Funding research that uses the PCORnet infrastructure to conduct definitive studies that advance PCORI's National Priorities for Health
* Investing in PCORnet infrastructure to continuously learn and improve
* Expanding the use of PCORnet
* Increasing use of PCORnet for PCORI’s operational and strategic priorities

There are two main goals of this effort. The first is to strengthen the capacity of the PCORnet infrastructure to facilitate patient-centered outcomes research focused on PCORI’s congressionally mandated research areas, including IDD. The second is public dissemination of the workgroup outputs, including a research agenda relating to IDD and a set of recommendations related to data enhancements and capacity building opportunities to support IDD research across PCORnet. The IDD Work Group currently has eight academic CRN members and four patient stakeholders and works to identify gaps and ways PCORnet can help address the gaps. PCORI has also worked with PCORnet Front Door to develop a descriptive query on the IDD population served by health systems participating in PCORnet, with the goal of demonstrating the utility of PCORnet to support IDD research with broad

cohort identification. International Classification of Diseases, Tenth Revision (ICD-10) codes were used to identify the population cohort, and IDD diagnoses have been grouped into 13 categories. Since 2015, there were over 60 million unique instances of IDD-related ICD-10 codes for patients, not including duplicated patients. PCORI will make the descriptive results of this query publicly available.

### What a Pandemic Taught Us About How to Better Serve People With Disabilities

*Karen Remley, M.D., M.B.A., M.P.H., F.A.A.P., NCBDDD, CDC*

People with disabilities, people of racial and ethnic minorities, and older Americans were at significantly higher risk of developing COVID-19 during the pandemic. The pandemic highlighted three core areas that need to be improved within public health as the nation works toward health equity for people with any type of disability: better data, accessible communication, and more inclusive partnerships and policies. Toward this end, the CDC did three things:

* Added disability status to the National Immunization Survey
* Using the associated data, a [*Morbidity and Mortality Weekly Report* in October 202](https://www.cdc.gov/mmwr/volumes/70/wr/mm7039a2.htm)1 examined the coverage and barriers to vaccination receipt, showing that adults with disabilities were more likely than those without disability to report that it was somewhat or very difficult to get vaccinated.
* Collaborated with CMS to examine COVID-19 related outcomes among disability-eligible Medicare beneficiaries compared to age-eligible Medicare beneficiaries
  + This [*Morbidity and Mortality Weekly Report* study from November 2021](https://www.cdc.gov/mmwr/volumes/71/wr/mm7124a3.htm)showed that rates of both COVID-19 incidence and hospitalization among disability-eligible Medicare beneficiaries (at least 18 years of age) were 50% higher than rates among age-eligible beneficiaries (ages 65 years or older without a disability).
* Worked closely with the CDC Foundation and Georgia Tech Center for Inclusive Design and Innovation to create accessible materials and culturally relevant messages for people with various disabilities

We need to create a paradigm shift from the medical to the social model in disability-related data. This shift is necessary to make the case that disability inclusion is an essential component of any health equity issue. Disability needs to be a demographic variable, not a medical diagnosis. The CDC is incorporating disability into the agency’s health equity framework and encourages everyone to think beyond the ICD-10 codes for identification of people.

The CDC aims to meet the following goals to ensure inclusive practices across the entire agency:

* Standardize disability questions in national surveillance and surveys
* Enhance quality and quantity of disability research
* Translate and disseminate adapted evidence-based and innovative interventions
* Include people with disabilities as focal population in non-research and research notices of funding opportunity
* Regularly engage disability advocates and national organizations
* Collaborate with the Department of Health and Human Services and other federal agencies
* Improve workforce competencies to address health disparities faced by people with disabilities

Helping the CDC get the data they need and turn it into action and improve ways to obtain data that are effective and accurate will allow for greater emergency preparedness if a next disaster occurs.

1. Health indicators in the DHDS include health risks, behaviors, prevention and screenings, barriers and costs of health care, general health conditions, chronic conditions, and mental and emotional health. The number of health indicators in each category changes each year based on the availability of the data. [↑](#footnote-ref-1)