

Disability Data in National Surveys

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Study Sponsorship

- **U.S. Department of Health and Human Services (HHS)/ Assistant Secretary for Planning and Evaluation (ASPE)/ Office of Disability, Aging and Long-Term Care Policy**
- **Disability Data in National Surveys**
 - <http://aspe.hhs.gov/daltcp/reports/2011/DDNatISur.pdf>
- **Assessing the Need for a National Disability Survey**
 - <http://aspe.hhs.gov/daltcp/reports/2011/NatIDS.pdf>

Goals

- **Review existing sources of national survey data on disability**
- **Understand the scope and limitations of existing disability data**

Methods

- Reviewed 40 national surveys
- Survey-selection criteria:
 - Federally sponsored
 - National
 - Fielded in 2000 or later
 - If fielded before 2000, the survey contains significant disability-related content or other relevant information

Existing Disability Data

- **National household surveys**
- **Health, disability, aging, and long-term care surveys**
- **Youth and education surveys**
- **Other surveys**

National Household Surveys

- **Features**
 - Representative of all or most of the U.S. population
 - Collected on a regular basis
 - Core of the government's national data collection efforts
- **17 surveys**

National Household Surveys: Disability-Related Content

Little or No Information

- Census
- Consumer Expenditure Survey
- Survey of Consumer Finance

Some Information

- American Community Survey
- American Housing Survey
- American Time Use Survey
- Current Population Survey

Targeted Information

- National Crime Victimization Survey
- National Household Education Survey
- National Survey on Drug Use and Health
- National Survey of Families and Households

Substantial Information

- Behavioral Risk Factor Surveillance System
- Medical Expenditure Panel Survey
- National Health and Nutrition Examination Survey
- National Health Interview Survey
- Panel Study of Income Dynamics
- Survey of Income and Program Participation

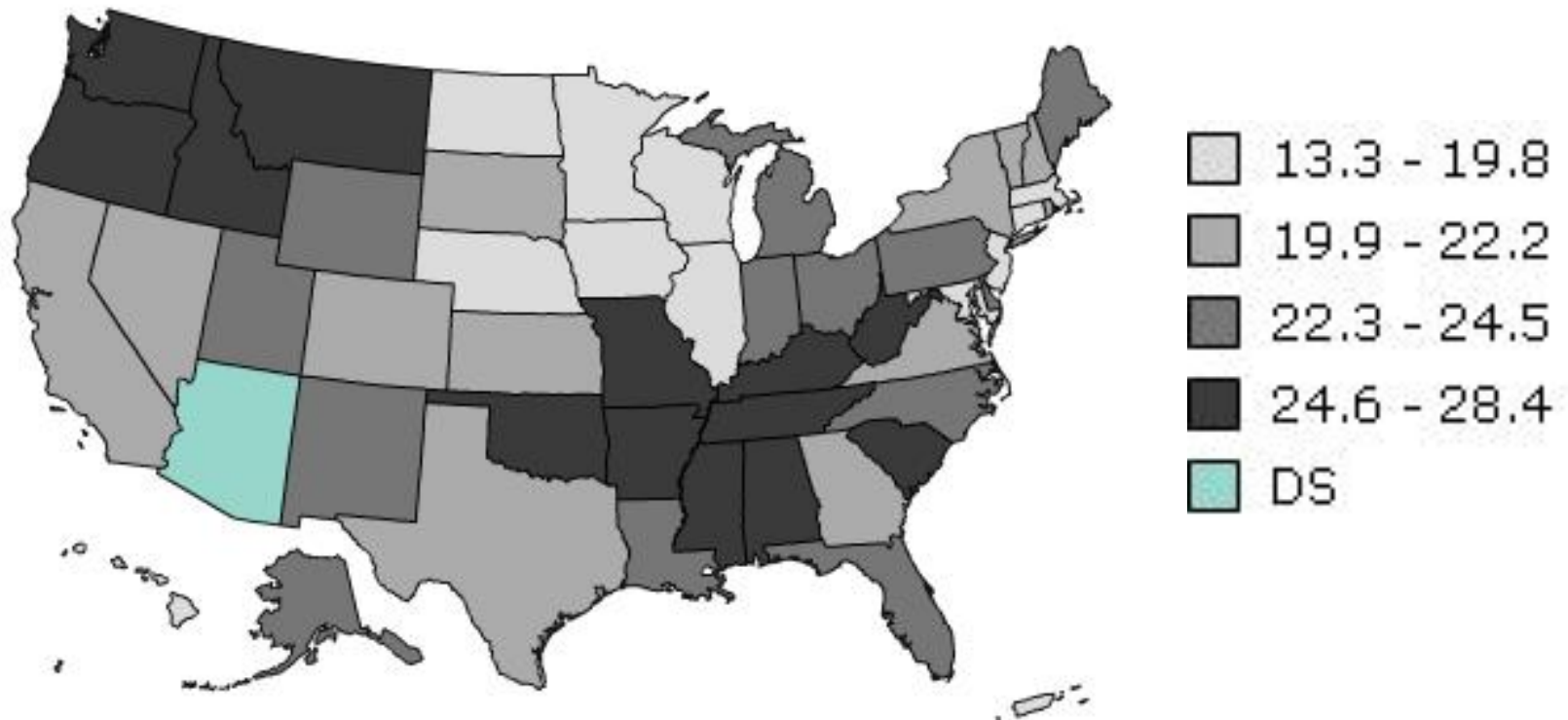
National Household Surveys: Coverage

- **Large samples**
 - American Community Survey, Census
- **Cover certain group quarters and institutional populations**
 - American Community Survey, Census
- **Longitudinal**
 - American Housing Survey, Medical Expenditure Panel Survey, National Health and Nutrition Examination Survey, National Survey of Families & Households, Panel Study of Income Dynamics, Survey of Income and Program Participation (SIPP)

Household Surveys: State Coverage

- **Able to produce state-level estimates**
 - **American Community Survey, Census, Behavioral Risk Factor Surveillance System, Current Population Survey (CPS), National Health Interview Survey (NHIS), National Survey on Drug Use and Health, SIPP**

State-Level Estimates: Behavioral Risk Factor Surveillance System



Health, Disability, Aging, and Long-Term Care Surveys

- **Features**
 - **Restricted to subpopulations**
 - **Older age groups**
 - **Those receiving specific types of benefits or care**
 - **Those eligible based on health status**
 - **Conducted less frequently than national household surveys**
- **11 surveys**

List of Health, Disability, Aging, and Long-Term Care Surveys

- **Older age groups**
 - Health and Retirement Survey
 - Longitudinal Study of Aging
 - National Long-Term Care Survey
- **Those receiving specific benefits or care**
 - Medicare Current Beneficiary Survey
 - Medicare Health Outcomes Study
 - National Beneficiary Survey
 - National Nursing Home Survey
 - National Survey of SSI Children and Families
- **Those eligible based on health status**
 - National Comorbidity Survey
 - National Health Interview Survey on Disability
 - National Survey of Children with Special Health Care Needs

Health, Disability, Aging, and Long-Term Care Surveys: Content

- **All provide information on disability, including:**
 - Functional limitations
 - Limitations in activities of daily living (ADLs)
 - Specific conditions
- **Most provide information on:**
 - General health status
 - Cognitive impairments or developmental disorders
 - Sensory/communication limitations
 - Mental/emotional disorders or symptoms
 - Health insurance
 - Limitations in instrumental activities of daily living (IADLs)
 - Work limitations

Youth and Education Surveys

- **Features**

- **Most sponsored by the Institute of Education Sciences**
- **Restricted by age group**
 - **Young children**
 - **Middle/high school**
 - **College and beyond**
- **Most are longitudinal**

- **Nine surveys**

List of Youth and Education Surveys

- **All children**
 - National Survey of Children’s Health
- **Young**
 - Early Childhood Longitudinal Survey
- **Middle/high school**
 - High School Longitudinal Study
 - National Education Longitudinal Study
 - National Longitudinal Study of Adolescent Health
 - National Longitudinal Survey of Youth
 - National Longitudinal Transition Study 2 (NLTS2)
- **College and beyond**
 - Baccalaureate and Beyond Longitudinal Study
 - Beginning Postsecondary Students Longitudinal Study

Youth and Education Surveys: Content

- **All provide the following disability-related information:**
 - Functional limitations
 - Sensory/communication limitations
 - Mental/emotional disorders or symptoms
- **Most provide information on:**
 - Cognitive impairments or developmental disorders
 - Learning disabilities
 - Disability-benefit receipt/program participation

Other Surveys

- **Features**
 - Focus on specific subpopulations
 - Address specific agency needs
 - Conducted infrequently
- **Three surveys**
 - National Survey of Veterans
 - Survey of Inmates in Local Jails
 - Survey of Inmates in State and Federal Correctional Facilities

Other Surveys: Content

- **All provide the following disability-related information:**
 - Functional limitations
 - Sensory/communication limitations
 - Mental/emotional disorders or symptoms
 - Substance use/abuse/dependence
 - Specific conditions
 - Disability-benefit receipt/program participation
- **Other information:**
 - VA disability rating
 - Detailed information on substance use, mental health

Summary of Existing Survey Data

- **Plentiful data on people with disabilities**
 - Nearly all federal surveys include some disability measures
- **Disability measures vary across surveys**
 - Six-question series is becoming more common
 - Few surveys address health conditions causing disability
 - Few surveys contain adequate measures of cognitive and intellectual disabilities
- **Many surveys (22 of the 40 reviewed) contain longitudinal data, but most focus on a specific subgroup**

Key Limitations of Existing Data

- **Inadequate disability measurement**
 - Questions to identify disability vary widely
 - Insufficient detail
 - Inadequate identification of people with cognitive or intellectual disabilities
- **Small sample sizes**
 - Unable to identify particular disability subgroups
 - Unable to analyze small geographic areas
- **Coverage**
 - Certain populations typically excluded from surveys
 - Difficulty responding to survey format

Key Limitations of Existing Data (cont'd.)

- **Inadequately addressed topic areas**
 - Consumption, expenditures, job accommodations, transportation, informal care
- **Lack of longitudinal data for the working-age population**
- **Outdated data**
 - Delays in public-use file releases
 - Infrequent data collection
- **Inconsistent data quality**
 - Possibly due to use of proxy respondents or stigma related to disability
 - Inaccurate self-reports of program participation

Beyond Current Survey Data

- **New survey efforts**
- **Administrative data**

New Survey Efforts

- **Modifications to existing surveys**
 - 2011 NHIS: added questions on disability/functioning
 - 2012 CPS: disability supplement
 - Re-engineered SIPP: disability supplement
- **New data collection efforts**
 - National Longitudinal Transition Survey 2012: expanded sample compared to NLTS2
 - National Health and Aging Trends Study: longitudinal survey of Medicare beneficiaries over age 65

Linking to Administrative Data

- **Advantages**

- Can generate longitudinal data
- Considered the best source of information on program participation

- **Challenges**

- Gaining access to data may be difficult
- Linking data can be time- and resource-intensive
- Information needed to conduct linkages may be limited

Notable Linkages

- **National Center for Health Statistics Linkages**
 - Medicaid, Medicare, Social Security Administration data
 - Linked to NHIS, National Health and Nutrition Examination Study, Longitudinal Study of Aging, National Nursing Home Survey
 - For more information:
http://www.cdc.gov/nchs/data_access/data_linkage_activities.htm
- **School records linked to:**
 - Early Childhood Longitudinal Survey, National Education Longitudinal Study, National Longitudinal Survey of Youth, NLTS2

Conclusions

- **Why do we need disability data?**
 - Monitor the health and well-being of the population
 - Understand the circumstances of people with disabilities
 - Design new programs and policies
- **Disability data are plentiful but could be improved**
 - Improve awareness of data sources
 - Include standard disability measures in all surveys and periodically assess and improve them
 - Enhance access to and use of administrative data

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