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## **The 2011 Annual Disability Statistics Compendium and Measuring Disability**

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The New York State Office for the Aging and the Council on Children and Families are two agencies that administer services and support programs, provide education, and monitor services to populations that are particularly vulnerable to health conditions affecting disability. To assist in their program planning, the agencies needed to prepare a review of current literature related to definitions of disability, current trends, and methods of forecasting the size and needs of future populations at risk of disability.

This project was a real education in an area that I was familiar with but no expert. The literature on measuring disability is extensive. There are, as you'll see below, a variety of surveys and other sources of data on disability. There are many varied and overlapping definitions of disability, often contradictory data on trends, and different theories about the course of future trends. One thing is consistent – the call for better data and structuring of programs to serve what all believe to be a rapidly increasing service population.

Measuring trends in disability is complex due to varying operational definitions, different population universes, and different methods of measurement. Most survey data relate to the household population excluding people in group quarters and institutional care. And most are national in scope and do not allow for state and sub-state measurement of disability characteristics and trends. The U.S. Census Bureau has collected data on disability in the traditional decennial census and now the American Community Survey but definitions of disability in those collection instruments have changed over time making comparability difficult.

### The *Annual Disability Statistics Compendium*

(<http://www.disabilitycompendium.org/>) is prepared by the Institute on Disability (<http://www.iod.unh.edu/Home.aspx>) at the University of New Hampshire. The Institute's Rehabilitation Research and Training Center aims to improve knowledge about and access to existing data for decision making by people with disabilities, policy makers, program administrators, and service providers. The 2011 volume is the third annual publication and provides state-level statistics and monthly time-trend statistics published by Federal agencies. The topics cover a wide range of data from population size and prevalence of disability to employment, poverty, education, earnings, and indicators of health status. It also includes a glossary of sources and terminology which is vital to understanding the complex world of disability statistics.

Much of the data in the *Compendium* comes from the Census Bureau's American Community Survey, the Bureau of Labor Statistics' Current Population Survey and administrative reports of the Social Security Administration, the Department of Health and Human Services, the Office of Special Education Programs, and the Rehabilitation Services Administration. Given the complexity of measuring trends in disability, the *Compendium* is designed to serve as a reference guide to government publications, information on how the data is collected, and statistics added each year as new data sources become available.

### **Other Sources of Disability Data**

The American Community Survey provides a measure of disability that is comparable across all geographic areas in the country and provides the basis for comparisons. As a time series measure its use is increasing but is hampered by a change in definition in the 2008 ACS which means the annual data is only comparable from 2008 on. The definition of disability is also restricted to the series of six questions measuring the difficulty persons have in performing specific activities and abilities. It is certainly not the only, nor most robust measure of disability.

The following table presents a brief introduction to various survey sources of data on the disabled.

**Decennial Census ([www.census.gov](http://www.census.gov))**

*Agency Conducting/Sponsor* – U.S. Bureau of the Census.

**Brief Description** - Disability status in the 2000 Census was based on the responses to two questions relating to: long-lasting conditions (such as blindness, deafness, or conditions that limit basic physical activities), or activity limitations as a result of physical, mental, or emotional conditions lasting six months or more.

**American Community Survey**

([www.census.gov/acs/www](http://www.census.gov/acs/www))

*Agency Conducting/Sponsor* – U.S. Bureau of the Census.

**Brief Description** - Disability status is determined from the response to a series of six questions relating to types of difficulty: hearing difficulty; vision difficulty; cognitive difficulty; ambulatory difficulty; self-care difficulty; and independent living difficulty. The questions on hearing and vision difficulty were asked of all persons while the others were only asked of persons 5 and older. This series of questions has changed with the 2008 survey so comparisons with data prior to 2008 are not appropriate. 1-year, 3-year, and 5-year annual estimates are provided for geographic areas nationwide.

**Survey of Income and Program Participation**

([www.census.gov/sipp](http://www.census.gov/sipp))

*Agency Conducting/Sponsor* – U.S. Bureau of the Census.

**Brief Description** - Disability is covered by an extensive set of questions: limitations in functional activities; activities of daily living (ADLs); instrumental activities of daily living (IADLs); use of wheelchairs and other aids; conditions relating to mental functioning; work related disability; and

status of children. National results are based on an annual survey of 15-37,000 households.

### **National Long-Term Care Survey**

([www.nltcs.aas.duke.edu](http://www.nltcs.aas.duke.edu))

*Agency Conducting/Sponsor* – National Institute on the Aging and Duke University. Conducted by the U.S. Bureau of the Census.

**Brief Description** - Provides data on basic and instrumental activities of daily living. The survey began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004. Data derived from a national sample of Medicare enrollees.

### **National Health Interview Survey ([www.cdc.gov/nchs/nhis.htm](http://www.cdc.gov/nchs/nhis.htm))**

*Agency Conducting/Sponsor* - U.S. Centers for Disease Control, conducted by U.S. Bureau of the Census.

**Brief Description** - Disability status of persons determined with a series of three questions: the need for the help of other people with personal care activities (eating, bathing, dressing, getting around); the need for help of other people with routine needs (household chores, necessary business, shopping or getting around); and personal limitations because of impairment or health problems. Data derived from an annual national sample of 40,000 households.

### **Longitudinal Study of Aging ([www.cdc.gov/nchs/isoa.htm](http://www.cdc.gov/nchs/isoa.htm))**

*Agency Conducting/Sponsor* – U.S. National Center for Health Statistics and the National Institute on Aging, conducted by the U.S. Bureau of the Census.

**Brief Description** - Disability status is based on a series of questions to assess respondent's ability to perform activities alone and without using special

equipment. Activities included typical ADL and IADL activities. Conducted between 1984 and 2000, the study surveyed approximately 9,500 civilian non-institutional persons nationwide.

### **Medical Expenditure Panel Survey**

([www.meps.ahrq.gov](http://www.meps.ahrq.gov))

*Agency Conducting/Sponsor* – Agency for Healthcare Research and Quality, conducted by Westat.

**Brief Description** - Adults with disability are defined to be those with a physical, sensory, and/or mental health condition that can be associated with a decrease in functioning in such day-to-day activities as bathing, walking, doing everyday chores, and/or engaging in work or social activities. Data derived from an annual national sub-sample of the National Health Interview Survey.

### **Panel Study of Income Dynamics**

([psidonline.isr.umich.edu](http://psidonline.isr.umich.edu))

*Agency Conducting/Sponsor* – Multiple funding sources led by the National Science Foundation, conducted by the Survey Research Center, University of Michigan.

**Brief Description** - Definition of disability has changed over time with recent expansion in 2003 to include specific medical conditions, ADLs and IADLs. Data derived from an annual national sample of approximately 6,200 families interviewed every two years.

### **National Health and Nutrition Examination Survey**

([www.cdc.gov/nchs/nhanes.htm](http://www.cdc.gov/nchs/nhanes.htm))

*Agency Conducting/Sponsor* – U.S. Centers for Disease Control.

**Brief Description** - Includes a physical functioning section which provides self-reported data on functional limitations caused by long-term

physical, mental, and emotional problems or illness. Data derived from an annual national sample of approximate 5,000 persons age 60 and over.

**Health and Retirement Study ([hrsonline.isr.umich.edu](http://hrsonline.isr.umich.edu))**

*Agency Conducting/Sponsor* – National Institute on Aging and the Social Security Administration. Conducted by the Survey Research Center, University of Michigan.

**Brief Description** – Disability defined as basic and instrumental activities of daily living. Data derived from a national survey conducted every two years since 1998. Approximately 70,000 households are screened for eligibility from a universe of birth cohorts of persons age 50 and over.

**Behavioral Risk Factor Surveillance Survey ([www.cdc.gov/brfss](http://www.cdc.gov/brfss))**

*Agency Conducting/Sponsor* – U.S. Centers for Disease Control.

**Brief Description** - Behavioral Risk Factor Surveillance Survey – time series estimates of obesity

**Medicare Current Beneficiary Survey ([www.cms.gov/MCBS/01\\_overview.asp](http://www.cms.gov/MCBS/01_overview.asp))**

*Agency Conducting/Sponsor* – Centers for Medicare and Medicaid Services, conducted by Westat.

Medicare Beneficiary Survey

**Brief Description** – A multipurpose national survey of the Medicare population to determine expenditures for services, ascertain types of health insurance coverage, and trace changes in health status over time.

While this is certainly not an exhaustive list of sources of data on disability, it should indicate the broad interest and research being

done in the area. Each source is designed with specific research goals in mind and specific population universes so it's critical to understand these characteristics when using the data. That variability is a primary reason why the *Compendium* is such a useful source that provides a comprehensive overview to the nature of disability statistics.

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